



Federal Ministry for
Family Affairs, Senior Citizens,
Women and Youth

Federal Ministry
of Health

 Nationale
Demenzstrategie



National Dementia Strategy

TEAMGEIST
Für Menschen mit Demenz

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Foreword



Dear readers,

Dementia concerns all of us. In Germany, 1.6 million people are living with dementia. According to the statistics, dementia affects one person in every 25 households. And that number is increasing: an estimated 2.8 million people will have dementia by 2050.

We are still unable to cure dementia. That makes it all the more important to further advance research into the causes and potential treatment strategies. Dementia is a condition that progresses differently in each individual. In many cases it progresses only slowly and gives people living with dementia the chance to remain active members of our society for an extended period of time. Good medical and nursing care is crucial to maintaining autonomy. It is vital that people with dementia remain in the mainstream of society. Anyone who can still go shopping by themselves, who stays a member of a sports team, who carries on singing in their church choir, who travels by public transport or who visits a museum will have a good life for a long time to come.

The National Dementia Strategy commits to ensuring the involved stakeholders take action that will improve the lives of people with dementia and their relatives. Our goal is to enable people with dementia to participate more, to provide more support for relatives, to further improve medical and long-term care health services, and to encourage more research. This strategy represents a major step forward for us all.

The initiatives involved were launched by the German Federal Government. Under the leadership of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) and the Federal Ministry of Health (BMG), under the co-chairmanship of the German Alzheimer Association, and with the intensive participation of the Federal Ministry of Education and Research (BMBF), the federal states, nursing and health care associations, science and civil society, a strategy has been developed for the first time that has the potential to make our society dementia-friendly. We have jointly defined 27 goals and sub-goals, backed up by 162 concrete individual initiatives.

This is a testament to the great commitment of all those involved.

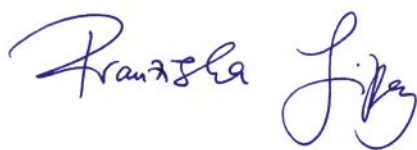
Our aim is to establish local structures in which, for example, voluntary initiatives, welfare organisations, doctors and retirement homes can create a tightly knit solidarity network for people with dementia and their relatives. Our goal is to strengthen prevention, education on dementia, and professional support at every stage of the condition—from home visits at the time of diagnosis, nursing care in severe stages of the condition, medical care, and psychosocial counselling for relatives, to dignified care of the dying. A further element of the strategy is to rebuild local social infrastructure—hospitals need to become more dementia-friendly, public transport staff need to be trained, apartments and houses need to be converted to suit the needs of older people, and the planning of care for older persons needs to be expanded at municipal level. Finally, more research on dementia needs to be promoted and the transfer of research findings into practice facilitated.

The National Dementia Strategy is a great success for all parties involved. For many months, we have been jointly drawing up the strategy. Our thanks goes to all those who have participated in this pro-

cess and have worked hard with us to identify the measures that need to be taken, and above all to the German Alzheimer Society, which as co-chair has actively supported the process. This positive cooperation now serves as the basis for jointly launching the strategy. A great responsibility is borne by the federal states which are responsible at a regional level and can bring about major changes. We look forward to all of us making our country, municipalities and cities noticeably more dementia-friendly over the coming years.

This has become more important than ever before. During the COVID-19 pandemic, older and very old people have needed more support. People with dementia are feeling insecure and find it difficult to get to grips with the measures taken to combat the spread of the disease. Care-giving relatives are under considerable strain due to the changes in support structures, while some older people are avoiding all contact for fear of being infected. It is, therefore, right and proper that the strategy is launched at this time.

Issues that were important before the COVID-19 pandemic have become ever more important. And that's why the present is exactly the right time to launch the strategy.



Franziska Giffey
Federal Minister for Family Affairs,
Senior Citizens, Women and Youth



Jens Spahn
Federal Minister of Health

Summary: the National Dementia Strategy

We are living longer and getting older than ever before, and that is a positive development; the years we gain are often years we enjoy in good health. Nevertheless, the risk of developing dementia increases with age. Life for people living with dementia changes. They become reliant on a wide range of support services. However, the condition has an impact on all areas of life, it affects relatives and the social setting. To this day dementia cannot be cured.

In Germany, approximately 1.6 million people are currently living with dementia. The number of people affected by forms of dementia and the families burdened by this situation is rising sharply. It is therefore the responsibility of all society to support people with dementia in leading a life of self-determination and dignity. Good counselling, support and care for people with dementia in their own homes, in assisted living or in care facilities, require not only specialised knowledge, but, above all, understanding, empathy and respect. Dementia competence must continue to grow, both in everyday life and in the professional health and social care sector. As dementia affects all areas of life, support for those affected and their families needs to be ensured by many stakeholders at different levels of society, public life and the social and healthcare system.

In recent years, Germany has made good progress on its road to a dementia-friendly society, providing a wide range of services for people with dementia and their families. The federal, state and municipal authorities are assuming their responsibilities. Nevertheless, there is a need for more action. For this reason, the Federal Government in

cooperation with the German Alzheimer's Society, representatives of the federal states, municipalities, civil society, social security institutions, health- and long-term care insurance providers, associations of health- and long-term care professionals, the leading welfare organisations, professional and trade associations, and the scientific and research community agreed to draw up a National Dementia Strategy. Improving participation and care of people with dementia as well as the support of their relatives, after all, depends on the coordinated cooperation of many different stakeholders.

The forerunner of the strategy was the Alliance for People with Dementia, which between 2014 and 2018 implemented its agenda 'Together for People with Dementia'. Its further development was anchored in the coalition agreement of the current Federal Government. This agreement has been implemented through the adoption of the National Dementia Strategy by the Federal Cabinet.

The aim of the National Dementia Strategy is to sustainably improve the quality of life of people with dementia and their relatives in Germany. To accomplish this, particular attention should be focused on those measures that are important for daily life and the health- and long-term care of people with dementia at the local level.

The strategy is nationwide in scope, anchored in partnership, binding in its objectives, and conceived for the long term. All stakeholders are to contribute within their own areas of competence and in line with the resources available within their existing budgetary and financial constraints.



The strategy is focused on four fields of action:

1. Developing and establishing dementia-inclusive communities to enable people with dementia to participate in society.
2. Supporting people with dementia and their relatives.
3. Advancing health and long-term care services for people with dementia.
4. Promoting excellent research on dementia.

A total of 27 goals were formulated and 162 measures agreed upon, which will be implemented over the coming years.

The goals and measures are to be seen in the context of current developments in nursing and health policy as well as in research and science. One key component is the introduction and further implementation of the new definition of the need for care, which takes greater account of dementia-related changes. The objectives of the Concerted Action for the care workforce campaign to improve training, working and remuneration conditions of professional nursing staff are also taken into consideration. Last but not least, the goals link up with the efforts of the federal states as well as with existing local structures.

The concrete measures outlined in the National Dementia Strategy were developed before the outbreak of the COVID-19 pandemic. Following the outbreak of the pandemic, specific regulations to provide additional protection for vulnerable and high-risk groups have been implemented at short notice at all levels of responsibility. While these regulations have proven effective, they have also had a major impact on the lives of people with dementia, whose understanding of restrictions to physical contact and social distancing rules in care and social facilities, as well as in the family environment, may be limited. However, it must be assumed that people with dementia and their relatives will be affected by the pandemic for some time to come. This makes it all the more important that the diverse measures specified in the National Dementia Strategy are implemented and, hence, effectively contribute to the support needed by those affected. The stakeholders involved in the National Dementia Strategy are to take this into account when implementing the measures.

The aim of the National Dementia Strategy is to further enable people with dementia to participate in society.

It is the responsibility of the municipalities to ensure a favourable local environment for older people in need of care. The interests of people with dementia and their relatives must also be considered in urban neighbourhood and village development concepts as well as in the planning of provision of care for older people. More dementia-sensitive public meeting places should be created in municipalities to enable people with dementia to maintain their daily lives and participate in social life for as long as possible. Such participation involves improved accessibility of cultural, sports and educational facilities. It is also important that people with dementia are able to navigate safely in public spaces and remain mobile for as long as possible. Hence, more public transport staff, for example, should be trained to become ‘dementia partners’, and complementary mobility services should be extended.

Training courses to become ‘dementia partners’ should also be revised and expanded for other target groups. Broad public awareness is necessary to ensure that people with dementia are not marginalised. To achieve this, improved coexistence will be encouraged by means of outreach campaigns involving outreach ambassadors. Children and young people should also be made aware of the issue. To reduce the risks of dementia, widespread information about the disease and possible risk factors is needed. It is also important to diagnose the condition early. To establish the effectiveness of support methods, home visits are being examined as a standard preventive measure.

In addition, a functioning network of all local participants is needed to guarantee effective supervision, support and health and social care for people with dementia and their family caregivers. To accomplish this, local alliances for people with dementia and other dementia networks are being established and expanded nationwide. The networks are principally sustained by voluntary engagement, which is to be further promoted. In addition, the expansion of regional (dementia)

networks will be encouraged and intensified to facilitate networking between the stakeholders involved in long-term care services. The funds earmarked for this purpose from statutory long-term care insurance are planned to be stepped up significantly.

Remaining at home as long as possible often requires housing adaptation. Consequently, the use of digital aids with a proven benefit should be more strongly supported and housing advice should be expanded.

The aim of the National Dementia Strategy is to provide better support for people with dementia and their relatives.

Anyone diagnosed with the condition should not be left alone. People with dementia, especially those living alone, should receive low-threshold initial counselling from volunteers, and it is currently being examined whether newly diagnosed patients can be provided with professional dementia support for a period of time following diagnosis.

For people with dementia and their relatives, information must be low-threshold and easily accessible. Those affected should be offered comprehensive counselling. Information is available on dementia and support services at care counselling centres, in municipalities, in public places, on the Internet and also at home. The various counselling centres will be linked more effectively and geared to specific target groups. The focus is also on people with early-onset dementia, people with a migration background and relatives living at a distance. Care support centres should cooperate on a supra-regional level and build up intercultural skills. All those providing counselling should ensure high quality standards.

Reconciling care and employment is of central importance for employed family caregivers. Therefore, regulations on family care leave need to be advanced. The awareness of employers in regard to the issue should be raised, and those affected should be supported with appropriate solutions. For this purpose, local networks which focus on the issue of care and employment are to

be set up and expanded. It is also important to establish flexible day care, short-term care and preventive care services in line with needs. It will also be examined whether courses on care might be recognised as continued education.

Relatives play an essential role in ensuring the provision of social and long-term care of people living with dementia. In order to protect their health, opportunities for prevention, health promotion and rehabilitation are being expanded and are being given greater publicity. The spectrum of measures ranges from special telephone counselling and psychosocial counselling in family crises, the development of a special prevention programme for family caregivers, to health care programmes and other preventive measures.

Family carers of people with dementia need good support in end-of-life care. Therefore, information on hospice and palliative care services is to be improved. Collaborative structures in hospice and palliative care services need to be established and expanded. Voluntary work as a mainstay of hospice and palliative care services should be further supported.

The aim of the National Dementia Strategy is to advance health and long-term care services for people with dementia.

To ensure that people with dementia are cared for and given counselling in accordance with their needs, it is essential that enough professional carers are available and that they are qualified at high level. This applies to out-patient care at home as well as to all other health and long-term care services. Hence, dementia-specific further and continuing education for nursing staff in the various healthcare scenarios is to be supported. In addition, other professionals who come into contact with people with dementia during the provision of healthcare, and whose training is insufficient in this respect, should receive training to achieve a basic qualification in dealing with people with dementia.

In particular, in the event of unavoidable periods of acute care in hospitals, dementia-sensitive organisation of work processes and training meas-

ures for the staff involved should aim to prevent an episode of delirium in patients who are affected by dementia. Dementia-sensitive designs of hospitals and care facility places are to be promoted, too.

In addition, effective teamwork between doctors, hospitals and care facilities is vital in providing health and long-term care services for people with dementia. Hence, these stakeholders are being encouraged to network by defining more clearly how they should collaborate in a healthcare services pathway and how best to manage the interfaces of the care they provide. This can help to systematically implement individually tailored multi-disciplinary treatment processes for people with dementia.

In all health service sectors, the impact of regulatory frameworks on the care of people with dementia is to be reviewed, and, if necessary, they are to be advanced and their rigorous implementation in practice is promoted.

The aim of the National Dementia Strategy is to promote excellent research on dementia.

More research is required to better understand the causes and development of dementia and to improve treatment and health services.

Outstanding dementia research requires effective and networked research structures. Improved national and international cooperation in dementia research will allow existing structures and knowledge to be better exploited. Research institutions in Germany are to expand the infrastructure of clinical dementia research as well as conduct more studies on the prevention, diagnosis and therapy of dementia, for example by becoming more involved in certain research fields such as nutrition science.

The availability of anonymised data from health insurers for research purposes should likewise be improved. This should enable researchers to investigate, for example, which health services people with dementia receive. To effectively prevent the development of dementia in the population, the risk factors need to be better understood. These



risk factors are, therefore, to be included in existing long-term health studies. In addition, studies are being conducted specifically on the early stages of dementia. The aim is to research whether and in what ways the course of dementia can be positively influenced. Optimal treatment for people living with dementia depends on health services research, which examines the provision of medical, nursing and therapeutic health services. In the coming years, more concepts for individualised diagnosis, treatment and care will be developed and their effectiveness tested. The quality of health services for people with dementia is also affected by social inequality. This, as well as the effects of the condition on everyday life, of people with dementia, will be considered.

How scientific findings can be better transferred into healthcare practice is to be investigated, too. The aim is to transfer evidence-based prevention and healthcare concepts that have been successfully tested in research projects into standard healthcare. Furthermore, the potential for accelerated authorisation procedures for drugs in the field of dementia should be exploited more effectively. Medicinal products must be authorised before they are placed on the market. The strategy aims to support applicants for marketing authorisation at an early stage of drug development.

Perspective: monitoring and further development of the strategy

The National Dementia Strategy is a long-term initiative. As such, it makes it possible to continuously review the fields of action, goals and measures, to address current issues—for instance the effects of the COVID-19 pandemic—and to set new priorities. A steering group of the central stakeholders in the dementia strategy is being established under the direction of the two leading ministries, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Health. The steering group is to support the implementation of the planned measures through annual monitoring. In addition, all stakeholders involved will meet annually as a National Dementia Strategy Network to exchange experiences. At the end of 2026, the implementation will be reviewed and the strategy developed further.

Stakeholders involved in the National Dementia Strategy

- *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e. V.*
[Association of Scientific Medical Expert Societies]
- The Association of Private Health Insurance
- *Bundesarbeitsgemeinschaft Familienerholung*
[Federal Association for Family Holidays]
- *Bundesarbeitsgemeinschaft der Integrationsämter und Hauptfürsorgestellen*
[Federal Association of Integration Offices and Central Welfare Offices]
- *Bundesverband privater Anbieter sozialer Dienste e. V.*
[Federal Association of Private Providers of Social Services]
- *Bundesarbeitsgemeinschaft der Seniorenorganisationen e. V.*
[German National Association of Senior Citizens' Organisations]
- *Bundesarbeitsgemeinschaft Selbsthilfe von Menschen mit Behinderung, chronischer Erkrankung und ihren Angehörigen e. V.*
[Federal Association of Self-help Organisations of People with Disabilities and Chronically Ill People and their Relatives]
- *Bundesarbeitsgemeinschaft Spezialisierte Ambulante Palliativversorgung*
[Federal Working Group on Specialised Ambulatory Palliative Care Services]
- The Catholic Church in Germany
- The Dementia Support Stuttgart
- The Evangelical Church in Germany
- The Federal Association of Non-statutory Welfare
- The Federal Centre for Health Education
- The Federal Institute for Drugs and Medical Devices
- The Federal Ministry of the Interior, Building and Community
- The Federal Ministry of Labour and Social Affairs
- The Federal Ministry of Education and Research
- The Federal Ministry of Food and Agriculture
- The Federal Ministry for Family Affairs, Senior Citizens, Women and Youth
- The Federal Ministry of Health
- The Federal Ministry of Transport and Digital Infrastructure
- The Federal States (Conference of Ministers for Labour and Social Affairs, Conference of Health Ministers, Conference of the Ministers of Education and Cultural Affairs)
- The German Alzheimer Society—Dementia Self-Help
- The German Association for Psychiatry, Psychotherapy and Psychosomatics
- The German Association for Rehabilitation
- The German Centre of Gerontology

- The German Centre for Neurodegenerative Diseases
- The German College of General Practitioners and Family Physicians
- The German Cultural Council
- The German Disability Council
- The German Episcopal Conference
- *Deutsche Expertengruppe Dementenbetreuung e. V.*
[German Expert Group on Dementia Care]
- The German Home Economics Council
- The German Hospice and Palliative Association
- The German Hospital Federation
- The German Medical Association
- The German Nursing Council
- The German Television Lottery
- The German Society of Geriatrics
- The German Society of Gerontology and Geriatrics
- The German Society for Gerontopsychiatry and Psychotherapy
- The German Society for Nursing Science
- The German Society for Palliative Medicine
- The German Society of Neurology
- *Kuratorium Deutsche Altershilfe e. V.*
[German Foundation for the Care of Older People]
- Local authority associations
- Malteser Germany
- The National Association of Statutory Health Insurance Funds
- The National Association of Statutory Health Insurance Physicians
- The Paul-Ehrlich-Institut
- The Robert Bosch Foundation
- The Robert Koch Institute
- *Spitzenverband ZNS*
[Central CNS Association]
- *Stiftung Gesundheitswissen*
[The Health Knowledge Foundation]
- The Turkish-Islamic Union for Religious Affairs
- The University of Cologne
- *Verband Deutscher Alten- und Behindertenhilfe e. V.*
[Association of German Assistance for the Elderly and Disabled]
- The Centre for Quality in Care

Introduction

A long-lived society

More people in Germany are living longer and with a higher quality of life in old age than ever before. This represents a success of modern societies that has only become reality in recent decades. But, a long-lived society also presents challenges—for older people, for their relatives and for the social environment. Health frequently deteriorates with increasing age, and the need for help and care increases.

Dementia is one of the greatest challenges for a long-lived society. At present, an estimated 1.6 million people in Germany are living with dementia. Demographic trends suggest that this number may rise to around 2.8 million by 2050.¹

Dementia as an individual and social challenge

Dementia has many faces. The cognitive and memory capabilities of people with dementia decline, and their behaviour patterns change. The ability to shape one's own life independently is lost as dementia progresses. Changes in behaviour can lead to lack of understanding and rejection in the community. Improving the acceptance of people with dementia in all areas of society relies on a broad knowledge about the condition. Those who are affected need individual and reliable support in order to carry on pursuing a

self-determined, good life in old age, and participating in social life.

Relatives play a crucial role in everyday life of people with dementia. They frequently assume caring responsibilities and provide loving care for relatives living with dementia. In spite of the associated burden, many of them perceive care as a meaningful, enriching experience in their lives. As family caregivers are often needed around the clock, they, likewise, require support themselves. Counselling and education on dementia, active help, emotional support and the opportunity for recuperation are crucially important. Family caregivers can only assume long-term responsibility if they can count on a reliable support network.

The system of out-patient, partial in-patient and full-time residential long-term care, along with the accompanying counselling, social and support services, provide indispensable resources in this regard. Professional care services are needed to provide effective care for people with dementia from diagnosis through to end of life, to appropriately support care-giving relatives and to network with other organisations or institutions. Volunteers can also provide help with (instrumental) activities of daily living and with the organisation of recreational activities. The quality of life of people with dementia depends on good medical health services. Meticulous diagnosis, comprehensive advice and effective treatment are prerequisites for a good life with dementia. The aetiologies

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1 Alzheimer Europe (2019)

of diseases resulting in dementia have not yet been fully elucidated, and, hence, there is a need for dementia research to provide reliable information on the prevention, development, diagnosis, therapy of dementia and care of dementia patients.

A long-lived society is faced with the task of improving an understanding of people living with dementia and advancing health and long-term care services. The World Health Organization has also highlighted the challenges posed by dementia. In 2012, the World Health Organization declared dementia a global health problem of the highest priority. Since then, national dementia strategies have been launched in 27 of the 194 member states of the World Health Organization. This development has been a valuable source of information in the formulation of a National Dementia Strategy for Germany.

The National Dementia Strategy

In collaboration with a large number of stakeholders, the Federal Government has drawn up a National Dementia Strategy for Germany with the aim of tackling the social challenges of dementia in a sustainable manner. The aim of the strategy is to improve the circumstances of people with dementia and their relatives. People living with dementia should be supported in leading a self-determined and dignified life. This goal can only be achieved through cooperation and collaborative effort of all those involved.

The National Dementia Strategy was developed and agreed upon between January 2019 and April 2020 in a process of partnership and dialogue. Representatives of the federal states, municipalities, civil society, social security agencies, health- and long-term care insurance providers, associations of health- and long-term care professionals, the leading non-governmental welfare organisations, professional associations, and the scientific and research community were involved in the collaboration.

The effort was led by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Health. The German Alzheimer Society—Dementia Self-Help co-

chaired the process. The Federal Ministry of Education and Research coordinated the proceedings in the field of dementia research.

The strategy focuses on the participation of people with dementia in society, their support and that of family carers, their health- and long-term care, as well as basic, clinical and health services related research into dementia.

It also addresses issues of overarching importance, such as digitisation and the use of assistive technologies, cooperation between stakeholders from different health- and social care sectors and support for people with dementia or family caregivers with a migration background.

Basics and initial situation

As the following political initiatives show, in recent years, a broad range of measures has been introduced at all levels of responsibility to improve the quality of life of people with dementia and their relatives.

- In 2009, the German Centre for Neurodegenerative Diseases was founded. It is jointly funded by the Federal Ministry of Education and Research and the federal states where its ten sites are located. Scientists are collaborating across Germany to investigate the causes of disorders of the nervous system and to develop strategies of prevention, treatment and care of dementia. For example, initial clinical intervention studies are being conducted to analyse the therapeutic potential of specific drugs in the development and progression of dementia due to Alzheimer's disease.
- The 'Alliance for People with Dementia', launched by the German government in 2012, has led to the successful implementation of numerous initiatives and projects. The programme 'Local Alliances for People with Dementia', launched by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, aimed to strengthen the integration of and support for people with dementia and their families at their places of residence.

- Regional dementia networks and services to support family caregivers were funded under the Dementia Workshop of the Future programme established by the Federal Ministry of Health.
- Following the Second Long Term Care Act Strengthening Act, which came into effect in 2017, a new definition of care need was introduced. As a result, the legal entitlement to long-term care benefits and the categories of beneficiaries were considerably extended to include persons with dementia or other cognitive and psychosocial impairments. At the same time, the amounts of benefits were also substantially raised.
- The agreements reached in the Concerted Action for the care workforce campaign ('Konzertierte Aktion Pflege' or KAP), presented in 2019, will be implemented swiftly to improve the training, working and remuneration conditions of professional carers in Germany. Many stakeholders in the National Dementia Strategy participated in the KAP campaign. They, therefore, bore in mind the needs of professional carers of people with dementia, when formulating and implementing the measures of the National Dementia Strategy. Implementing the measures from the KAP campaign, in particular the recruitment of skilled workers, is an important prerequisite for the success of many of measures in the National Dementia Strategy.
- In 2019, the Equal Living Conditions commission presented recommendations that are, likewise, significant for people with dementia. These include improving mobility and transport infrastructure, strengthening of voluntary work and ensuring of effective health and long-term care services.
- In all federal states, a large number of initiatives and projects have been implemented for people with dementia and family caregivers, and network and support structures have been established. Bavaria, Rhineland-Palatinate,

Schleswig-Holstein and Saarland have developed their own dementia strategies.

- In addition, there are excellent research stakeholders in all federal states at universities and in non-university research institutions² funded by the federal and state governments. These have been making major contributions to dementia research in epidemiology, prevention, nursing research, health services research, clinical diagnostics and therapy for decades, for example through the acquisition of international, national and regional (research) funding.

The National Dementia Strategy incorporates these activities, consolidates measures and systematically enhances them. The existing structures for counselling, support and care form the basis of the National Dementia Strategy.

The National Dementia Strategy: sustainable and long-term

In July 2020, the Federal Cabinet adopted the National Dementia Strategy for Germany, which was developed jointly with a large number of stakeholders. The concrete measures outlined in the strategy were developed before the outbreak of the COVID-19 pandemic. Following the outbreak of the pandemic, specific regulations to provide additional protection for vulnerable and high-risk groups have been implemented at short notice at all levels of responsibility. While these regulations have proven effective, they have also had a major impact on the lives of people with dementia, whose understanding of, for example, social distancing rules, both in care institutions and in the family environment, may be limited. However, it must be assumed that people with dementia and their relatives will be affected by the pandemic for some time to come. This makes it all the more important that the diverse measures specified in the national strategy are implemented in order to effectively contribute to the support of people with dementia. The stakeholders involved in the National Dementia Strategy are going to consider this when implementing the measures.

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2 Fraunhofer Society, Helmholtz Association, Leibniz Association, Max Planck Society

The National Dementia Strategy is organised into four fields of action with clearly formulated goals, concrete measures and deadlines. The benchmark for all the measures is the needs of people with dementia and their relatives including their diversity and heterogeneity.

The strategy describes the respective starting conditions and the measures that are deemed to be key. The stakeholders are going to implement these measures over the coming years within their own areas of competence, at their own responsibility and in line with the resources available within their existing budgetary and financial constraints. This course of action reflects the responsibility of all societal forces to improve the circumstances of people living with dementia.

The National Dementia Strategy is a long-term initiative. As such, it presents the opportunity to continuously review the goals, to respond to recent developments and to set new priorities. The aim is to take stock after 2026 and further refine the National Dementia Strategy.

To support the implementation of the measures, the Secretariat of the National Dementia Strategy will monitor and report regularly on the progress of implementation. A steering committee will

review these reports and draw on the insights gained to support policy implementation and further develop the National Dementia Strategy. This steering committee will be chaired by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, the Federal Ministry of Health and the German Alzheimer Society—Dementia Self-Help. The tasks of the steering committee in autumn 2020 will include assessing the decisions taken as a result of the COVID-19 pandemic and drawing conclusions from these for the National Dementia Strategy.

In addition, a National Dementia Strategy Network will be established to promote the exchange of information on future developments amongst the stakeholders of the National Dementia Strategy and other experts.

In doing so, the National Dementia Strategy will assist in better supporting those living with dementia at all levels of responsibility. The goal is a long-lived society in whose midst people with dementia can lead a good life.



Fields of action





Field of action 1

Developing and establishing dementia-inclusive communities to enable people with dementia to participate in society

People with dementia have a right to self-determination, freedom from discrimination, equal opportunities and equal participation in society. Inclusion is the declared aim of the UN Convention on the Rights of Persons with Disabilities, which is also binding for Germany. Social participation implies that people can actively participate in social, cultural, economic and political life, regardless of any restrictions. Diseases that cause dementia involve a loss of cognitive abilities. People with dementia experience increasing difficulties in remembering, navigating and coping with daily life. To participate in social life, they depend on a dementia-sensitive environment and the support of others. As a matter of principle, all people with dementia should be enabled to participate in society. However, the prerequisites for this are unequally distributed and depend, amongst other things, on the place of residence, the age of the affected persons and the stage of their dementia. Reducing these differences and developing appropriate provisions for all groups of people with dementia is an ongoing policy challenge.

One means of ensuring participation is to ensure the availability of dementia-sensitive social spaces. Municipalities (communities, cities and rural districts) are responsible for structuring and planning these social spaces, with the aim of providing services of general interest for older people and people with dementia. Older people, especially

those with physical and cognitive impairments, concentrate their lives and their spheres of activity chiefly in their immediate geographical vicinity. Welfare organisations, associations and religious communities also make an important contribution to provision of services of general interest. The municipalities establish the framework for successful cooperation between the locally involved stakeholders.

In 2019, the German government published the results of its Equal Living Conditions commission, and these can, likewise, contribute to supporting people with dementia and their relatives³. In particular in the area of 'integrated socio-spatial planning' a shared objective exists: 'All people, regardless of where they live, should be able to rely on good services of general interest and experience that 'their' local community provides them with a participatory, habitable and attractive environment over the long term.'⁴

An attractive living environment involves appropriate mobility opportunities at local level. Dementia is associated with the risk of isolation of the affected persons as well as of their family caregivers. Demand-oriented provision of mobility services, for instance local public transportation, can help people with dementia to maintain their autonomy.

3 In this context, relatives are understood to be those persons within the close social environment of people with dementia who are responsible for care and support. The focus in this field of action is on relatives within a family. However, in this context, relatives can also refer to people who have a friendly or neighbourly relationship with the person with dementia.

4 Bundesministerium des Innern, für Bau und Heimat (2019): page 123

The aim is to ensure a high quality of life for people with dementia and their relatives regardless of the impact of the condition. Dementia, by its very nature, results in a constant change in the requirements for care as the condition progresses. For this reason, a wide range of interlocking services needs to be made available. To achieve this, networks of all stakeholders in the social and health sectors needs to be established at local level.

People with dementia and their relatives also receive support and relief in the form of informal, voluntary and neighbourly aid. This way, civically engaged citizens contribute to the inclusion of people with dementia and provide relief for family caregivers. Such commitment is a valuable social resource and is to be further strengthened over the coming years.

People with dementia are members of society. However, taboos and stigmatisation of those affected still exist⁵ and uncertainty in how to deal with them is also common. To enable people with dementia to navigate independently in public spaces, the population at large needs to be informed about the condition and the associated disabilities. If citizens are sensitised to the circumstances of people with dementia, they will be able to value contact with those affected.

Spirituality and religion are important aspects of the lives of many people with dementia. Faith communities have a particular responsibility to enable people with dementia and their families to access life in their religious community. They can also provide other stakeholders with information on paths of spiritual counselling for people with dementia.

Protecting those affected and the population at large, represents a key socio-political task. One particularly important aspect is providing them with information on how they can change their lifestyle so as to reduce the risks of dementia. Additionally, they should be provided with infor-

mation on which diseases, for instance hearing loss, can lead to dementia or accelerate its course and, hence, require early treatment.

People with dementia need accommodation matching their needs and the stage of their dementia. Many people with dementia wish to live in their own homes and should be enabled to do so with the necessary support. Alternative forms of accommodation, such as group homes for people with dementia, can be particularly well-suited to for people living alone, and those with an increased need for care. In the later stages of dementia, a move to an inpatient facility can help to improve the quality of life of both the person affected and their relatives.

1.1 Developing social spaces for people with dementia

Social spaces are defined areas within which people interact socially.⁶ From a political perspective, social spaces are given structure by various stakeholders. The challenge is to design social spaces in such a way that people with dementia can participate whilst remaining largely autonomous—as dementia progresses, they lose their ability to orient themselves and adapt to new circumstances. Hence, in recent years, initiatives have been introduced and projects undertaken at numerous locations to respond to such specialised needs.

The diverse lifestyles of people with dementia necessitate differentiated and, simultaneously, precisely-tailored, accessible and non-discriminatory services of general interest for every circumstance in life. The provision of services of general interest is primarily the responsibility of cities, rural districts and municipalities and, therefore, falls within the constitutionally enshrined right of local self-governance (Article 28 II GG). It is at the local level that the best decisions can be made with regard to which services should be provided and how they should be structured. The provision

5 In this context, 'affected persons' refers to people with dementia. People who provide nursing and care for people with dementia are also 'affected' by the condition. However, in this document they are not subsumed under the term 'affected persons'.

6 Bundesministerium für Familie, Senioren, Frauen und Jugend (2016)

of tailored services, oriented to long-term needs, requires integrated, social space-oriented planning that takes the living space of local residents and their particular circumstances as a reference point for various activities and utilises available resources, even across institutions and different legal frameworks. It is thus municipalities that have a special role to play in developing infrastructures for people with dementia as well as for people without dementia. This includes responsibility for the circumstances of older residents. Care of older people, as stated in Section 71 SGB XII, involves social welfare institutions who contribute to care of older people with measures to ‘prevent, overcome or alleviate difficulties arising from old age and to give older people the opportunity to participate in life in the community.’

Fulfilling this task against the background of demographic and social change requires cross-sectoral planning for care of older people at the municipal level. Following the recommendations of the Seventh Ageing Report Commission, planning of care of older people should be established at municipal level.⁷ In the context of integrated social planning, expert planning should be better interlinked and interfaces identified. This is particularly important for people with dementia. They are dependent on functioning local structures and a health service network in which the various services are tailored to local requirements and coordinated with each other.

In line with the concept of developing integrated residential districts, local social space should improve the circumstances of all people living in the residential district. ‘Inclusive residential districts’, as they are termed, are intended to ensure the greatest degree of security of health service provision and social participation for all.⁸ This is an area where urban development funding and village development can play accompanying roles. Urban development funding, as part of an integrated urban development concept, can support these goals by means of construction programmes. Village development can also support these goals

in the context of ‘integrated rural development’. In addition, the *Stiftung Deutsches Hilfswerk* [German Relief Foundation], funded by the German television lottery, promotes social measures to develop residential districts. The target groups are all those living in the residential district and, in particular, people with care needs. The establishment of improved accessibility in Germany is an important step towards an inclusive society. The federal government’s Equal Living Conditions commission took this up in its twelve-point plan of priority measures. The Federal Ministry of Labour and Social Affairs (BMAS) has set the medium-term goal of developing a new *Bundesprogramm Barrierefreiheit verwirklichen* [Federal Programme to Implement Accessibility], financed by the federal government, to bring about concrete improvements for people locally, in particular people with disabilities, older people and young families, and to support municipalities—together with the federal states to complement urban development funding—in creating equal living conditions.

The Inclusive Social Environments Initiative (ISI) of the BMAS, in coordination with the local authority associations, likewise aims to further improve the circumstances of people with disabilities. To promote inclusive residential district development, all these support programmes must incorporate incentives and obligations for cooperation and networking. This way, synergies can be exploited at local level and parallel and duplicate structures avoided. To promote further development of health service concepts and structures for people with dementia, pilot schemes can be funded by social and private long-term care insurance.⁹ This will allow new approaches in the areas of voluntary and self-help care in the sense of Section 45c SGB XI, or the further development of health service structures to be intensified and activated. These funding possibilities should be increasingly utilised to further develop social spaces for people with dementia.

7 Ibid.

8 Kremer-Preiß and Mehnert (2018)

9 Bundesministerium für Familie, Senioren, Frauen und Jugend (2016)

According to Article 29 of the UN Convention on the Rights of Persons with Disabilities, people with dementia should be able to play an active role in shaping public affairs. They should be given the opportunity to review the relevance and appropriateness of local planning processes from their perspective as people living with dementia.¹⁰ This will allow people with dementia to be involved in a participatory way in the planning of social spaces.

A vigorous community depends on public spaces where encounters, discussions and common activities can take place, where relationships can grow, and where neighbourly help and support outside familial structures can develop.¹¹ Thus, neighbourly help should be promoted as an element of a support network for people with dementia.

The participation of people with dementia in cultural public life can counteract isolation and strengthen their own identity and abilities.¹² Cultural programmes must be adapted to the needs, interests and abilities of people with dementia.

More support should be given to social participation in cultural, sporting and educational institutions. For many people, membership in a sports club or sports group is an important part of their personal life story. People with dementia consider it particularly important to be able to continue to be a member of a group, for instance a society that they have belonged to for a lifetime.¹³ Sport provides a space for social interaction, and emotional and cognitive stimulation.¹⁴

Digitisation is increasingly shaping daily life and also offers people with dementia and their families a wide range of support options, for instance, apps that can provide reminders or comprehensive smart home technology. To benefit from

these digital opportunities and promote participation, older people, especially those with dementia, need counselling.¹⁵ Digital assistants should be deployed to provide the necessary skills.

Developing inclusive social spaces for people with dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

1.1.1 Local planning of care and support for older people

Local authority associations are working to ensure that planning for care for older people at municipal level (including the needs-based steering of measures for involvement, participation, preservation of autonomy, and support) is intensified as a reliable policy instrument for older people and especially for people with dementia—potentially as an element in integrated social space planning.

By the end of 2024 the local authority associations will have consolidated their implementation strategies.

1.1.2 Promotion of integrated residential area and village development concepts

Support programmes, launched by the federal states to develop integrated residential area and village development concepts at local level, should address the topic of dementia and issues relating to the planning of generation- and age-appropriate living space, civic involvement and networking and cooperation, including links with the residential and social economy. Municipalities can receive consultation from, for instance, the KDA.

By the end of 2022, the federal states will have reviewed the extent to which support programmes for integrated village and residential area development concepts take into account the

10 Bundesministerium für Arbeit und Soziales (2016)

11 Ibid.

12 Kitwood (2013)

13 Ibid.

14 See also Wolter (2019)

15 Weiß et al. (2017)

needs of people with dementia. The local authority associations will continue to sensitise their members to the fact that they should take the concerns of people with dementia into account in integrated residential area and village planning.

1.1.3 Consideration of concerns of people with dementia in planning processes

The local authority associations will encourage municipalities to ensure that people with dementia and their relatives participate in planning processes and that their interests are taken into account. The municipalities are committed to ensuring that the opportunities for participation by people with dementia and their relatives are explicitly anchored within the residential area development processes.

By the end of 2022, the local authority associations will campaign for such participation at municipal level.

1.1.4 Dementia-sensitive public gathering and recreational spaces

Drawing on participatory needs analyses, the federal states will work towards creating target group appropriate gathering and recreational spaces in the public realm for people with and without dementia. Meeting points and contact points in residential areas are to be adapted to the needs and requirements of people with dementia. Reconnaissance of districts with people with dementia, for example, is recommended to identify suggestions for improving public space from their perspective.

The evangelical and catholic churches in Germany, the leading non-governmental welfare organisations and the bpa are to review their premises to ensure they are suitable for dementia-sensitive public use. Within their means, they will provide premises and staff for providing support, to enable people with dementia and their relatives to continue to meet. The local authority associations will

encourage cities, municipalities and rural districts to make public space accessible to people with dementia by creating welcoming and safe places and green spaces. Sufficient accessible seating and resting facilities and public toilets suitable for the disabled are to be constructed. Together with other stakeholders, the KDA will support the process with its expertise and resources.

By the end of 2022, the evangelical and catholic churches in Germany as well as the leading non-governmental welfare organisations will review their premises and implement changes in this regard. The local authority associations will sensitise the municipalities to the necessity of creating dementia-sensitive areas.

1.1.5 Access of people with dementia to cultural, sporting and educational facilities

Nationwide, the attempt to make local cultural, sporting and educational activities more accessible to people with dementia will be intensified, and the development of specific programmes will be encouraged. Professional and voluntary stakeholders in the fields of culture, education and sport will be supported by schemes to provide information on dementia, to provide appropriate qualifications, and to transfer practical know-how, with the goal of extending existing programmes and developing programmes that target specific groups. They are to work cooperatively and in a network with local dementia networks and will be supported by specialist and coordination offices at the state and regional level.

By the end of 2022, the BMFSFJ will provide its own funding for the establishment and expansion of these programmes. To prepare for such funding programmes and their implementation, stakeholders with relevant academic and practical experience will be consulted in a workshop process. The BMFSFJ is working to ensure that the appropriate federal associations will act as multipliers to support this process and the overall project.



1.1.6 Digital participation

In a pilot scheme known as 'Digital Angel', the BMFSFJ is providing outreach counselling for older people to improve their digital participation. This scheme provides older people with everyday digital skills. A mobile team of advisers visits older people on site and provides them with straightforward advice tailored to their needs. Simultaneously, Digital Angel serves as an in situ signpost on location for existing services being offered.

By the end of 2022, as part of the pilot project, the mobile advisory team will be providing advisory services in 400 municipalities.

1.2 Developing mobility concepts for people with dementia

Freedom of movement is an important factor for autonomy and quality of life. Maintaining mobility is a prerequisite for people with dementia to ensure they can participate in society. As a result

of their condition, people with dementia generally have difficulty navigating and moving independently and safely in public spaces. Due to their physical and cognitive limitations, they are especially dependent on public transport and on support in using it.¹⁶

Travelling alone is often stressful for people with dementia and can lead to dangerous situations. Besides the difficulties involved in orientation and memory, they become increasingly uncertain in how to deal with risks and unforeseen events. People with dementia in such situations need reassurance from those around them. For this to happen, people in their environment need to be made aware of the needs of people with dementia.¹⁷ Sensitisation and training of more public transport employees on the topic of dementia is, therefore, necessary.

Local public transport is not equally well developed throughout Germany. Figures from the German Ageing Survey show that two thirds of 40–85 year-olds in rural areas consider access to

¹⁶ Wißmann et al. (2013)

¹⁷ Jansen et al. (2017)

public transport to be poor.¹⁸ An expansion of adequate services to meet this demand is, therefore, planned for the coming years. Mobility services for people with dementia as one element in the process have been earmarked for particular support. The concept of *Bürgerbusse* [community buses] is one suggestion on how mobility could be improved.¹⁹ These are mostly small and, therefore, easy-to-use buses that facilitate personal contact and thus reduce the stress experienced by people with dementia. Community buses already exist in some federal states. Subsidies for community buses vary from one state to another. Some states provide no funding, while others provide support for advisory services to regional groups or to purchase vehicles. The federal government supports the federal states and municipalities in the provision of public transport with annual subsidies under various legal frameworks. Solely by means of its regionalisation funds and the Municipal Transport Financing Act (GVFG) federal programme, the federal government currently contributes around €9,6 billion annually. In addition, federal funding will continue to increase successively with the implementation of the Climate Action Programme 2030.²⁰ Municipalities, as the ultimate responsible bodies, are required to take into consideration the interests of people with reduced mobility when allocating funds.

Mobility must also be made easier for people with dementia and their relatives using cars. At present, people with an exceptional walking disability, the blind, and those with disabilities caused by thalidomide, or with comparable disabilities (for example, amputation of both arms) can obtain an EU disability parking card. People with dementia are not explicitly included in the scheme. Since dementia can be associated with considerable handicaps, it can be regarded as a severe disability within the meaning of Section 2 SGB IX. Based on Section 46 of the German Road Traffic Regulations, people with dementia may apply for a disabled parking permit and receive an exemption permit if they meet—proved through official medical certification—the requirements of

Section 229 SGB IX. Moreover, people whose mobility is reduced by a disability can apply for an EU disability parking card in their country of residence.²¹ Information on these entitlements should become more widespread among those affected and their relatives.

Developing mobility concepts for people with dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

1.2.1 Expansion of mobility services for people with dementia

Chaperoning and mobility services for people with dementia will be expanded nationwide and extended through existing projects. The federal states are working to ensure that municipalities draw up and implement appropriate mobility concepts for older people and people with dementia. The services offered must be geared to the increased needs of people with dementia for safety and orientation. In addition, there is potential for innovative ideas to be (further) developed by means of competition in the field of mobility in rural areas.

By the end of 2024, all federal states are to present an overview of their existing mobility concepts.

1.2.2 Dementia-sensitive planning of local public transport

The BMVI, the local authority associations and the federal states are working to ensure that more public transport employees working in buses, trams and trains are trained to deal with people with dementia. The aim is to sensitise employees to be able to react appropriately and supportively in challenging situations. In cooperation with the transport companies, the DAzG will offer all employees the opportunity to attend a Dementia Friends training course on dealing with people with dementia as part of the Dementia Friends initiative.

18 Bundesministerium für Familie, Senioren, Frauen und Jugend (2016)

19 Landesinitiative Demenz-Service Nordrhein-Westfalen (2018)

20 Bundesministerium für Verkehr und digitale Infrastruktur (2019); Bundesregierung (2020)

21 Europäische Union (2019)

By the end of 2024, the DALzG will have trained 10,000 public transport employees on the subject of dementia.

1.2.3 Easier parking for people with dementia

The BMFSFJ and the BMAS will provide further information on the website *Wegweiser Demenz* [Dementia Signpost] on the requirements for applying for an orange disabled parking permit for people with dementia and their relatives.

By the end of 2020, the relevant information will have been made available on the website.

1.3 Establishing and expanding networks focusing on dementia

People with dementia and their relatives are dependent on a close network of care and support services to ensure access to individually tailored care and support. Such networks help people with dementia and their families in gaining an overview of available support services and in reaching informed decisions.²² To achieve this, new local forms of cooperation need to be established, and new practices of local joint responsibility brought to life. Funding of pilot schemes within the meaning of Section 45c paragraph 5 SGB XI on trialling new network structures can be used to support this.

Municipalities play a key role in shaping the circumstances of people with dementia. In the context of services of general interest, their task is to regulate direct provision of health services locally. Tasking an employee in the administrations of towns and rural districts with the topic of dementia, can improve the circumstances for people with dementia and their relatives living nearby, as such contact persons can network with local stakeholders, such as specialised offices at state level, care support centres and counselling centres.²³ In addition, centralised contact points at state level

can foster the formation of local network structures or the establishment and expansion of quality standards of local counselling centres. There are currently dementia specialist centres, competence centres or other comparable structures in almost all federal states. These help to improve the circumstances of people with dementia and their relatives, for instance by providing technical and organisational support to local counselling centres, or encourage improvement of health service structures by consulting institutions. For this reason, support structures at state level should be established in all federal states.

Local alliances for people with dementia and their relatives play an important role in improving the daily lives of people with dementia.²⁴ In the scope of this national pilot programme, 500 local support networks have been established or further developed, while their continued development is supported by a networking centre at the German Association of Senior Citizens' Organisations (BAGSO).²⁵ In the coming years, the establishment of further local alliances will be encouraged.

Besides the local alliances, further dementia networks exist. They are extremely heterogeneous in character, as they develop in line with local structures and needs. There are many ways to establish and develop a local dementia network.²⁶ Specific advice from networking stakeholders can help the process. Counselling services of this kind should be promoted. One way of doing this is to showcase good examples of successful networking at district, state or national levels. In addition, the exchange and transfer of knowledge between networkers should be promoted.

Sustainable financing of network structures is a particular challenge.²⁷ Under Section 45c paragraph 9 SGB XI, networks can receive funding from social and private long-term care insurance. Funding conditions vary considerably from one federal state to another. To make better use of

22 See also Ernst-Moritz-Arndt Universität Greifswald (no date)

23 Ministerium für Soziales, Gesundheit, Jugend, Familie und Senioren des Landes Schleswig-Holstein (2017)

24 Mäder (2019)

25 Bundesministerium für Familie, Senioren, Frauen und Jugend (2018b)

26 Ernst-Moritz-Arndt Universität Greifswald (no date)

27 Mäder (2019)

funding to establish and expand local dementia networks, the conditions of funding should be reviewed.

Establishing and expanding networks focusing on dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

1.3.1 Constitution of dementia-specific local support centres

The local authority associations are committed to ensuring that municipalities develop their contact points for dementia and exchange information with specialist centres at state level. The states in which a dementia-specific state specialist centre or a comparable structure have not yet been established are working to ensure that these are established. In addition to their other duties, such state expert centres are supporting the formation of local network structures, the establishment of quality standards for local counselling centres (taking into account the guidelines for care counselling under Section 7a SGB XI), and the expansion of counselling on alternative forms of housing and, in particular, on the subject of group homes. The federal states will continue to support networking of the specialist centres in all federal states. The BAGSO is supporting this process via a networking centre, which organises a regular exchange of expertise and networking opportunities for the state specialist centres. The KDA and the leading non-governmental welfare organisations, together with other stakeholders from science and the field of practice, are supporting the procedure as multipliers through the transfer of knowledge and experience.

The aim is to establish a dementia counselling service by the end of 2024, tailored to the needs of the municipalities. By the end of 2026, all federal states will aim to have established state specialist centres or other structures for nationwide networking and cooperation. Until the end of 2026, the BAGSO networking centre will be providing regular specialist seminars and networking opportunities.

1.3.2 Establishment and expansion of local alliances

The local authority associations and the BMFSFJ are working to promote the establishment of further local alliances successively and in line with demand, at least at district level, from 2020 onwards. Ensuring the establishment of a professional network coordination service is essential in this process. This will involve taking into account and utilising existing structures, such as professional coordination of voluntary work. The BMFSFJ is supporting the expansion with a separate federal programme. The federal states are accompanying and supporting this ongoing development process. The BAGSO and the leading non-governmental welfare organisations are supporting this process via the networking centre by providing counselling, an exchange of experience and supra-regional networking, including with existing local alliances.

By the end of 2026 the BMFSFJ will have completed its national programme.

1.3.3 Guidance on developing network structures

By means of the networking centre, the BAGSO is developing a range of guidance services for local support networks and communities with the aim of establishing and guaranteeing inter-departmental, networked structures to provide information, support and care to people with dementia and their relatives. In addition, the BAGSO organises supra-regional themed networking meetings for participants in local support networks.

The BAGSO and the DZNE will work together and involve the state specialist dementia centres to make resources and examples of good practice available online. Together with other participants, they are drawing up a Development Roadmap for local support networks, based, amongst other things, on the findings of the DemNet-D study, a nationwide study involving the DZNE, the University of Bremen and the Baden-Württemberg Cooperative State University.²⁸

By the end of 2022, the BAGSO will have developed this guidance service and held networking meetings. The BAGSO and the DZNE will make resources, examples of good practice, and the Development Roadmap available online.

1.3.4 Expansion of support for networking according to Section 45c paragraph 9 SGB XI

In its recommendations under Section 45c paragraph 7 SGB XI, the GKV-SV recognises that dementia-specific networks in particular are to be encouraged. With this in mind, a simplification of the funding and the application procedure, taking into account the legal framework under Section 45c paragraph 9 SGB XI, will be examined and implemented if necessary. The DALzG, the BAGSO and the state expert offices also provide additional support to local stakeholders by offering advice and assistance in setting up and developing a network.

By the end of 2024, the number of networks formed as per Section 45c paragraph 9 SGB XI will have increased.

1.3.5 Expansion of support for regional networks according to Section 45c paragraph 9 SGB XI

According to Section 45c paragraph 9 SGB XI, since 1 January 2017, financial resources from statutory long-term care insurance and (pro rata) private compulsory long-term care insurance, amounting to ten million euros per calendar year, can be used to support regional networks. A maximum of 20,000 euros per year is available per district or independent city. The BMG-funded project Future Workshop Dementia has shown that regional, self-organised and structured networking can significantly improve health services for people living with dementia. To support the work of the regional networks, the BMG plans to increase the funds made available by long-term care insurance to promote these networks. Within the framework of the nationwide long-term care network (Pflegenetzwerk Deutschland), initiated by the BMG with the existing networks, it is currently under discussion whether procedures could be simplified to make use of the funding.

By the end of 2022, the BMG will have examined and, if necessary, completed a legal amendment to facilitate funding.

1.4 Encouraging voluntary engagement and informal support for people with dementia

Over the course of their condition, people with dementia increasingly need the support of other people. In general, people with dementia are cared for by family or professional care-givers. In addition, informal, neighbourly support networks and friends can provide support. These forms of aid are a valuable societal resource that needs to be encouraged. It is precisely at the level of neighbourhoods, residential districts and municipalities that people with dementia can be enabled to participate in social and community life. These structures are to be encouraged in the coming years.

Voluntary and informal support for people with dementia is also partly financed by long-term care insurance benefits. This includes assistance in daily life under Section 45a SGB XI, relief benefits under Section 45b SGB XI, and development of care structures and care concepts and for the promotion of voluntary structures under Section 45c SGB XI. In addition, opportunities for funding at the municipal level should be exploited and subsidies by the federal states should be supported.

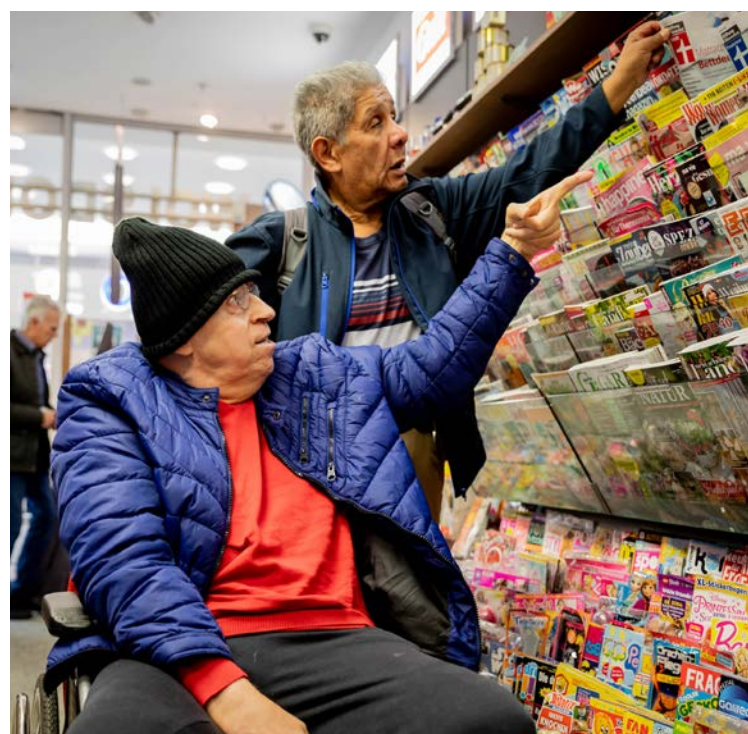
Voluntary work for people with dementia provided over an extended period is a further option. This way, self-help organisations and social and municipal institutions can train volunteers and coordinate their activities to support people with dementia and their families. Representing the churches, this is undertaken by the regional churches and dioceses with their congregations, specialist centres and associations, and by Caritas and Diaconia.

Successful voluntary work for dementia is critically dependent on professional support. The ongoing long-term commitment of volunteers is dependent on the existence of a specific set of conditions. These include the creation of requisite structures for voluntary work and coordination of activities. Such tasks can only be undertaken by professional staff over a longer period of time. For this reason, funding for professional staff is vital for voluntary care.²⁹

Voluntary engagement is particularly pronounced in people aged between 14 and 29 years.³⁰ Many of them are involved in sports and physical recreation and in the spheres of education and culture. To date, however, such volunteers have only rarely been involved in supporting people with dementia.³¹ To encourage engagement with older people, incentives need to be developed for young adults and students.

Visiting and chaperoning services are important services for people with dementia and their families.³² Volunteers who provide visiting and chaperoning services do so in hospitals, in residential care facilities, in the context of ambulatory residential care, and via care in the neighbourhood. To ensure people with dementia have access to such support, these activities are to be expanded in the coming years.

Since 2018, the KDA has been implementing its project *Förderung und Unterstützung des bürgerschaftlichen Engagements von Einzel Helfern durch Servicepunkte* [promotion and support of civic engagement by individual volunteers by means of service points] on behalf of the BMG. In five selected states, service points have been set up thanks to the constant support and training measures provided by the KDA, and implemented at care support centres. These service points exploit the potential of individuals who wish to become involved in care for older people at home in the context of reimbursable services as per Section 45b SGB XI. The project will end in June 2020.



Encouraging voluntary engagement and informal support for people with dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

1.4.1 Promoting neighbourly support

The states recognise that care in the neighbourhood is an important component of age-friendly and dementia-sensitive municipalities, and it should, therefore, be encouraged.

By the end of 2024, the federal states will be providing assistance programmes for support in the neighbourhood.

29 Simonson et al. (2017)

30 Ibid.

31 Hagen and Simonson (2017)

32 Meuter and Zollondz (2016)



1.4.2 Coordination of voluntary work by professionals

The states and local authority associations advocate the establishment of a professional coordinating service for volunteers, including those caring for people with dementia, bringing together existing local and regional initiatives and institutions (for example, volunteer agencies and senior citizens' offices). This is supported by *Hauptamt stärkt Ehrenamt* [professional strengthening of voluntary work], an ongoing project launched by the BMEL and overseen by the German Rural District Association.

An effort is being made to significantly increase the number of professional coordinators for voluntary work at municipal level by the end of 2024.

1.4.3 Encouragement for engagement at universities

The federal states are examining the extent to which voluntary work in the social sphere—in

particular in supporting people with dementia and their relatives—can be encouraged by awarding students credit points at both undergraduate and graduate level for voluntary work, especially in social and care work.

By the end of 2022, the KMK will have examined and drawn conclusions on the feasibility of awarding credit points to encourage voluntary work.

1.4.4 Programmes to recruit volunteers

Within existing programmes to recruit volunteers, the BMFSFJ is focusing on recruiting young people and people between 30 and 40 years of age. The German Voluntary Social Year programme and the Federal Voluntary Service are examples of the numerous ways people can already get involved in voluntary work for people with dementia. Activities of regional voluntary work initiatives in senior citizens' organisations, leading non-governmental welfare organisations and volunteer agencies will be promoted intensely through the programme to recruit volunteers..

The BMFSFJ is focusing on ensuring that, by 2024, the amount of volunteers caring for people with dementia will have increased.

1.4.5 Establishment and expansion of voluntary visiting and chaperoning services in institutions

The BAGSO networking centre is supporting the local alliances and other local aid networks by means of existing schemes. These include the guidelines of the *Pro Alter* [Pro Age] foundation, the expansion of voluntary visiting and chaperoning services and their interlinking with local health service structures, such as hospitals and nursing homes for older people. Institutions seeking to involve volunteers in health services, can receive advice on how to do so from the KDA and the leading non-governmental welfare organisations.

Through to the end of 2024, the BAGSO, the KDA and the independent welfare organisations will be supporting the local alliances and other support networks to expand voluntary visiting and chaperoning services and interlink them with the local health service environment.

1.4.6 Strengthening home support services by volunteers

The BMG is reviewing the results of the project *Förderung und Unterstützung des bürgerschaftlichen Engagements von Einzelhelfern durch Servicepunkte* [promotion and support of civic engagement by individual volunteers by means of service points]; amongst other things it aims to improve health services for people with dementia as well as for their relatives and, if necessary, their incorporation into standard care.

Findings from the review will be available by the end of 2022.

1.5 Raising public awareness of people with dementia

Broad public awareness is required to combat the stigma and preconceptions surrounding dementia. Dementia and the behaviour it entails often make people feel insecure and uncomfortable. This can lead to awkward situations, especially in public. It can lead to people with dementia being excluded from participating in society. Public education to combat this, is a key objective of the National Dementia Strategy.

The Alliance for People with Dementia has already helped to raise awareness of the issue of dementia. The DALzG, for example, has launched its project Dementia Friends. The project organises courses on dementia and how to deal with people with dementia in an appropriate way. Across Germany, there are currently more than 500 course providers, who have trained around 56,400 people to date. Similar courses on the deaf and hard of hearing will soon be offered. Hearing loss is one of the risk factors for developing dementia. Hearing and visual impairments usually occur at an advanced age and are estimated to affect one in three people over the age of 65.³³ Hearing impairment has a negative impact on orientation and social and emotional well-being, as it affects the ability to communicate with other people. Hearing loss is also associated with an increased risk of cognitive deterioration and dementia.³⁴

Since 2014, a targeted public relations event, known as Dementia Week, has been held once a year to roughly coincide with World Alzheimer's Day. During this week, the federal government, the DALzG and numerous other partners provide information on dementia. The National Dementia Strategy aims to raise awareness of Dementia Week through its stakeholders. This will be supported by further awareness-raising measures in the coming years. The focus is on educating the public about the condition and how to treat people with dementia with respect.

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33 World Health Organization (2019b)

34 Kaul et al. (2017); World Health Organization (2019b)

Raising awareness in people in the community is essential for people with dementia.³⁵ This is the prerequisite for them to be able to navigate independently in public and to continue their usual daily activities. This is particularly important for people with dementia living alone. Hence, training people whose job involves a high level of customer interaction can enhance the independence of people with dementia.³⁶ Initiatives and projects are already under way to raise awareness in the community. For instance, the Dementia Friends project trains staff from the police, fire brigade and local public transport. These projects are to be expanded in the future. Generally, children and young people first come into contact with people with dementia in the context of the family. They need age-appropriate information on the issue.³⁷ To more effectively raise awareness in children, adolescents and younger people, communication via social media and social networks is to be expanded. The topic of dementia is also becoming increasingly important for people of working age. Addressing the issue of dementia can reduce anxiety and insecurity and lead to greater respect and tolerance for people with dementia.³⁸

Art and cultural events offer an easily accessible opportunity to inform and educate people about dementia. New target groups can be reached, as information communicated via the arts and culture is communicated and experienced in a different way. These opportunities are to be expanded and supported.

Raising awareness in the general public to the issue of people with dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

1.5.1 Establishing a national Dementia Week

During Dementia Week, which roughly coincides with World Alzheimer's Day, all the stakeholders in the National Dementia Strategy will undertake high-profile initiatives. The intention is to increase public awareness of Dementia Week.

The German Television Lottery, for instance, plans to provide information via its channels about funded projects, to draw attention to the situation of those affected and to educate the public about the condition. During Dementia Week, the issue of dementia will be reported on in the online magazine *Du bist ein Gewinn* [you're a win], on social media and during the ARD lottery winner broadcasts every Sunday. As in previous years, the DAIZG will design a poster and make it available to other stakeholders.

By the end of 2026, all stakeholders will be reporting annually on the initiatives taken.

1.5.2 Support for awareness-raising campaigns

The BMG and the BMFSFJ are examining the feasibility of a joint publicity campaign for the National Dementia Strategy, involving Dementia Week and ambassadors and stakeholders of the National Dementia Strategy. The BMFSFJ is funding an increasing number of projects through the local alliances to raise awareness in the general public to the issue of dementia. A particular focus is on the development and implementation of effective and innovative approaches to public relations. The Dementia Friends initiative can act as an umbrella body for raising awareness amongst the various target groups.

By the end of 2022, the implementation will have commenced. By the end of 2024, local dementia networks will have implemented the first projects to raise awareness and to test and establish new formats of public relations work on the issue of dementia.

1.5.3 Sensitisation and training of multipliers from the social environment

The DAIZG is training multipliers who have contact with people with dementia, who are living alone, to become dementia partners. A similar scheme is also being developed for people who are hard of hearing or deaf. As part of its work to

.....
35 Kitwood (2013)

36 People with dementia can potentially come into contact with employees in pharmacies, the post office and parcel services, taxi drivers, hairdressers, notaries, employees of banks, bakeries and butchers, and employees in the manual trades, retail trade or in the housing industry.

37 Philipp-Metzen (2011)

38 Sekretariat der Ständigen Konferenz der Kultusminister der Länder in der Bundesrepublik Deutschland (2015)

organise networking, the BAGSO is to support such sensitisation measures and will refer interested parties to the DALzG's training courses. The result will be a safer social environment for people with dementia who live alone.

Training courses for multipliers will have commenced by the end of 2026 and information on them will be posted on www.demenz-partner.de.

1.5.4 Expansion of social media work

Public relations work on dementia on social media is to be expanded in a target group-specific manner and with as few barriers as possible. The BMFSFJ, the BMG, the DALzG, the ZQP and the German Television Lottery are working together to coordinate public relations work on dementia in Germany and to exploit synergies.

By the end of 2021 the concept will have been developed and implementation will have commenced.

1.5.5 Schemes for children and young people on the topic of dementia

In cooperation with the DALzG, the BMFSFJ is initiating a nationwide competition for school students. The aim is for students to draft and develop their own ideas for projects, for instance, how to encourage social participation of people with dementia in residential facilities or how to provide better support for people with dementia and their relatives in society. The leading non-governmental welfare organisations are actively supporting this process and, for their part, are developing concepts to provide appropriate support for students during this week. The DALzG will also be updating its handbook *Demenz—Praxis-handbuch für den Unterricht* [dementia—practical handbook for teaching]. The KMK is updating its handout *Handreichung für allgemein- und berufsbildende Schulen, Verständnis für Menschen mit Demenz* [handout for general and vocational schools on understanding people with dementia], which contains tips and resources on how school

students can deal with issues of dementia that affect them. These are designed to be highly accessible.

By the end of 2024, the competition will have been completed and the practical handbook updated. By the end of 2020, the KMK handout will have been updated. By the end of 2022, the teaching resources will be available. By the end of 2024, 250 facilities should be educating children and young people on the subject of dementia. The KMK will investigate whether a corresponding inquiry can be made in the federal states.

1.5.6 Educational and cultural events on the topic of dementia

The German Cultural Council will provide information and raise the awareness of the relevant stakeholders in the fields of culture, art and music on the topic of dementia. Their activities and projects are to explore the topic of dementia from different perspectives to raise its profile in society. The council will encourage them to undertake projects on the topic of dementia.

By the end of 2022, the German Cultural Council will be advocating projects dealing with the topic of dementia.

1.6 Spiritual and religious support for people with dementia

Numerous studies show that spirituality and religion can assist people with dementia and their families in coping with the diagnosis and management of the condition. Both can be central in identity formation and provide comfort for those involved. Spiritual and/or religious anchoring can give people a feeling of support and security, as well as a sense of connection to their own life (path) and to other people. To fully reach out to religious people affected by dementia, it is important to provide them with spiritual and/or religious guidance.³⁹



The German Episcopal Conference and the Evangelical Church in Germany have been jointly supporting the *Woche für das Leben* [Week for Life] event for more than 20 years. During this week, the value and dignity of human life is discussed and celebrated from a variety of key focal perspectives. One such perspective is to be (in the next few years) the issue of dementia.

In addition, the congregations of churches in Germany should further reach out to people with dementia, providing appropriate support and services. These include raising awareness and educating on dementia in the congregations. This can help to reduce preconceptions, while also sending a signal to believers that people with dementia are welcome to participate in church services and activities. Dementia-sensitive worship is particularly valuable for people with advanced dementia. As dementia progresses, the capacity for cognitive assessment of religious beliefs diminishes. Emotional and sensory experiences become more important, for example music, smells and physical contact.⁴⁰

Pastoral care is the central task of churches; this includes accompanying people on physical, psychological, social and spiritual levels. For many people with dementia, this form of support is valuable, especially at the end of life. For this reason, church pastoral workers should be better trained in the subject of dementia. This includes pastoral care for relatives of people with dementia. It can help family members cope with the loss that dementia brings to their own lives.

Religious people need support tailored to their own life history, even in old age. Knowledge about dementia, social integration and religious faith can ease the burden of the condition.⁴¹ More culture- and religion-sensitive support and education is therefore needed. Supporting the spiritual and religious needs of people with dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

40 Kotulek (2016)

41 Küçük (2010)

1.6.1 Inclusion of dementia as a key focal perspective in the ‘Week for Life’

The Evangelical Church in Germany and the German Episcopal Conference will also address the issue of dementia in the coming years as part of their joint Week for Life event.

By the end of 2022, a decision will have been made on when and in what form the topic of dementia will be dealt with in the Week for Life.

1.6.2 Support for dementia-sensitive church services and events

The evangelical and catholic churches in Germany will increasingly provide dementia-sensitive church services and events. They will also provide other resources for holding dementia-sensitive church services.

The DITIB will celebrate dementia-sensitive religious services. The union will ensure that mosques are accessible to believers and provide resources for dementia-sensitive worship. The DITIB is to raise awareness of the issue of dementia through regular (informational) events for all interested parties.

By the end of 2022, religious communities will be producing and disseminating further materials for conducting dementia-sensitive services and events

1.6.3 Pastoral care structures

The pastoral care for older people provided by the evangelical and catholic churches in Germany is increasingly focusing on people with dementia and their relatives at home. The evangelical and catholic churches in Germany are also promoting the training of professional and voluntary pastoral workers to provide appropriate care for people with dementia and their relatives. Their access to pastoral care services will be facilitated by networking of local counselling structures. The evangelical and catholic churches in Germany

will provide other religious associations (such as the Alevi community, the Jewish community and other concerned groups) with a platform to exchange experiences on the topic of voluntary pastoral care for people with dementia. This will include the organisation of a symposium.

By the end of 2022, the pastoral care for older people, offered by the evangelical and catholic churches in Germany, will be networked with other local counselling structures, and further pastoral workers for people with dementia will be trained. A symposium will be held by the end of 2024.

1.6.4 Training of multipliers for people with a migration background

Multipliers for people with a migration background will be trained, with the aim of developing low-threshold support and advisory services. In a cooperative process with Dementia Support Stuttgart and the DALzG, as well as regional stakeholders, the KDA will develop a multiplier training course for professional and voluntary workers.

By the end of 2024, culture- and religion-sensitive support and counselling services for family caregivers will be available. By the end of 2024, employees in migrant support organisations will be trained on the topic of dementia.

1.7 Reducing the risks of dementia

Numerous studies have identified protective factors that can aid in maintaining mental abilities, in delaying the development of dementia and in reducing the risk of developing dementia. A balanced diet, regular physical exercise,⁴² social activities and mental training reduce the likelihood of developing dementia. High blood pressure, obesity, harmful or abusive alcohol consumption and smoking are associated with an increased risk.⁴³ In May 2019, the WHO published a set of recommendations for reducing the risks of cognitive deterioration and dementia in old age

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42 Physical Activity Guidelines Advisory Committee (2018)

43 Livingston et al. (2017); Luck et al. (2018); Scheel et al. (2019)

and highlighted the great potential for prevention.⁴⁴ Numerous measures to promote physical activity and healthy nutrition have already been initiated by the federal government and can help to lower the risk factors for developing dementia. The national action plan IN FORM - Germany's Initiative for Healthy Nutrition and More Physical Activity⁴⁵, for example, has the goal of sustainably improving nutrition and exercise habits in Germany. The prevention campaign Alcohol? Know Your Limit, which has been successfully run by the Federal Centre for Health Education (BZgA) since 2009, also promotes responsible consumption of alcohol.⁴⁶ The GKV-SV has drawn up a set of guidelines on prevention, which form a mandatory foundation for services provided by statutory health insurance (SHI) funds for primary prevention and occupational health promotion.⁴⁷ The BMEL plans to further investigate the link between nutrition and dementia.⁴⁸ In addition, the act to strengthen health promotion and prevention (Prevention Act) has laid an important foundation for the expansion of prevention services.

One study shows that the risk of developing dementia can likely be reduced by a healthy lifestyle, even in cases of marked genetic predisposition.⁴⁹ Good health education is central to strengthening health literacy. Representative studies demonstrate that more than half of the German population has limited health literacy.⁵⁰ Improving health literacy requires, amongst other things, preparation of and access to comprehensible and relevant information for the lay-person.⁵¹ Particularly in the case of dementia, it is evident that many people feel that they have been poorly informed.⁵² Hence, more education is needed and educational programmes must be established.

In the context of 'preventive home visits', it makes sense to link old-age care services offered by local communities per Section 71 SGB XII and health promotion services provided by health insurance

funds as per Section 20a SGB V. This way, older people can be provided with a complex range of counselling and support. Preventive home visits systematically identify the individual needs of older people living in their own homes. The coalition agreement between the CDU, CSU and SPD for the nineteenth legislative period calls for the promotion of preventive home visits by means of the Prevention Act, whose aim it is to prevent as many people as possible from becoming prematurely dependent on nursing care. The BMG is advancing the promotion of preventive home visits in close cooperation with the federal states, the local authority associations and the health insurance funds. This takes into account the available knowledge and experience from pilot projects on outreach counselling for older people. Such projects have been conceptually heterogeneous, and, to date, only very limited evidence has been provided on their effectiveness in preventing and delaying the need for long-term nursing care. As such, questions regarding their nature and target group, as well as their effectiveness and benefit, need to be addressed. The GKV-SV instructed the BZgA to commission an expert report to investigate, in particular, the basic components and access routes for health promotion and prevention in existing home visit programmes for older people. The results of this report have been available since the beginning of 2020 and serve as a basis for discussions between the BMG, the federal states and the GKV-SV. Such discussions are aimed at determining whether and how preventive home visits organised under the aegis of municipal authorities can be promoted by health insurance funds under existing law.⁵³

At the municipal level, the *GKV-Bündnis für Gesundheit* [SHI Alliance for Health] initiative, supported by the BZgA, is providing almost 90 million euros in funding for social situational prevention and health promotion by means of

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44 World Health Organization (2019b)

45 Bundesanstalt für Landwirtschaft und Ernährung (BLE) (no date)

46 Orth and Merkel (2019)

47 GKV-Spitzenverband (2018a)

48 Bundesministerium für Ernährung und Landwirtschaft (2019)

49 Lourida et al. (2019)

50 Schaeffer et al. (2016)

51 Schaeffer et al. (2018)

52 Eggert et al. (2017)

53 Barthelmes et al. (2020)

the GKV. Funding is provided for the establishment and (further) development of functioning municipal cooperation and coordination structures for health promotion and disease prevention, as well as for the implementation of target group-specific measures for particularly vulnerable groups of people. These should, in particular, benefit older people and people with disabilities or impairments. This group can potentially include people with dementia.

Prevention and health promotion for people with dementia and their families is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

1.7.1 Health education to reduce the risks of dementia

In cooperation with the DALzG, the BZgA will produce accessible information resources (leaflet and Internet presence) to showcase ways of reducing lifestyle risk factors and, hence, opportunities for preventing dementia. In addition, the BZgA and DALzG are jointly developing a concept for training courses and workshops on the basis of WHO findings to target risk factors associated with dementia. The objective is to support citizens in realising preventive measures that can reduce risk factors associated with dementia.

By the end of 2022, the resources and training concepts will have been developed and will be available nationwide.

1.7.2 Promotion of preventive home visits

The GKV-SV instructed the BZgA to commission an expert report that examined, in particular, the basic components and access routes for health promotion and disease prevention measures in existing home visit programmes for older people.⁵⁴ Its goal is to support preventive home visits with services for promotion of health and prevention as part of the municipal support programme established by the SHI Alliance for Health.



On this basis, the BMG, with the federal states and the GKV-SV, will clarify by the end of 2022 whether and how health insurance funds can promote preventive home visits organised by municipal authorities.

1.7.3 Utilisation of prevention funds for people with dementia

As municipal health promotion services for older people can also be accessed by people with dementia, the local authority associations are working to ensure that the municipalities, in cooperation with local partners such as sports clubs, counselling centres, neighbourhood facilities and welfare organisations, will also make use of the services available under the SHI Alliance for Health funding programmes to promote the health of people with dementia and their families.

By the end of 2022, extensive collaborations will have been established to create accessible health promotion services at the local level for people with dementia.

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54 Ibid.

1.8 Developing housing concepts for people with dementia

Most people with dementia wish to live in their own homes despite their condition, even if they require care. To make this possible over a longer period of time, their residential circumstances need to be adapted to the changes that come with the condition. The best living arrangements, both for people with dementia and their families, need to be identified. Specialist centres and centres of competence for dementia have an important role to play in advising municipal authorities and relatives of people with dementia on how affected persons can continue to live in their own homes. These and other municipal services are to be expanded.

People with dementia are entitled under long-term care insurance to receive nursing care aids and measures that improve their home environment. Nursing care aids can improve the housing circumstances of people with dementia and their relatives. The *Pflegehilfsmittelverzeichnis* [Nursing Care Aids Directory] provides an overview of which nursing care aids can be made available or loaned out. As part of the KAP campaign, it is currently being examined whether the benefit criteria for nursing care aids under Section 40 SGB XI can be further developed. This should also include dementia-specific aids and examine whether intelligent assistance systems can be provided by long-term care insurance funds.

Providing people with dementia with individualised forms of housing and health services, will require differentiation of the range of housing concepts available in Germany in the coming years. Drawing on the findings of the pilot programme as per Section 45f SGB XI, it can be assumed that expanding alternative housing concepts can contribute to improving the parti-

icipation of people with dementia in their place of residence.

Older people wish to stay in their own homes for as long as possible.⁵⁵ The majority of people with dementia are cared for at home by relatives.⁵⁶ Their housing needs will often need to be adapted over the course of the condition. As people with dementia get older, their housing needs will change. Stairs, narrow doors or bathrooms that make their lives at home challenging can be modified by means of the KfW support programme *Altersgerecht Umbauen* [‘Age-appropriate Conversion’ programme]. Since October 2014, private owners and tenants have been entitled to apply for subsidies for accessibility improvements in their own homes. Housing companies/cooperatives and municipal enterprises can also submit applications under the loan variant of the KfW programme. Improving orientation for people with dementia, for instance concepts utilising colour, is one of the measures that can receive funding.

One of the issues covered by municipal housing counselling is that of alternative forms of housing, such as self-administered nursing group homes. This housing form can constitute a good alternative to living alone, on the one hand, and fully residential care on the other, especially for people with dementia. Amongst other things, group homes linked with out-patient care can be set up in a familiar residential environment and offer people with dementia opportunities for social participation. In addition, life in a group home can be structured to better reflect the established lifestyles of the residents. For people with dementia, this is particularly important and cannot always be achieved in a fully institutional scenario.⁵⁷ Accordingly, this form of care should be supported in line with demand at the state level.

55 Institut für Demoskopie Allensbach und Generali Zukunftsfonds (2012)

56 Hofmann (2019)

57 Klie (2017)



Care facilities should expand further, opening out into residential districts, for older residents to encounter local people in their own living spaces on a daily basis. Such developments can contribute to the networking of parties involved in the residential districts on behalf of people with dementia.

Developing housing policies for people with dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

1.8.1 Housing counselling services for people with dementia

The federal states are working to strengthen existing housing counselling services and to expand them to address the needs of people with dementia. Existing training concepts, such as Ambient Assisted Living (AAL) pilots, are being evaluated and made available. The BMFSFJ is examining whether the Digital Angel pilot project can be extended to provide counselling for people in need of care, especially those with dementia, on how best to exploit digital nursing support tech-

nologies and services. The KDA will introduce the topic of dementia into the dialogue surrounding the *Bundesarbeitsgemeinschaft für Wohnungsanpassung* [Federal Working Group for Housing Adaptation].

By the end of 2024, existing housing counselling services will have been strengthened and reviewed to address the issue of dementia. By the end of 2022, the BMFSFJ will have completed its review of the expansion of the pilot project.

1.8.2 Updating the digital aids listed in the Nursing Care Aids Directory

To fully exploit the latest technical innovations in the field of digital-technical nursing care aids, and in particular by further developing the benefit criteria under Section 40 SGB XI, the GKV-SV is reviewing the inclusion of accessible digital services in the context of updating product group 52, *Hilfsmittel zur selbstständigeren Lebensführung/Mobilität* [aids for more independent living/mobility], of the Nursing Care Aids Directory. In doing so, it will also take into account the findings of the study *Digitale Assistenzsysteme und Pflege-*



bedürftigkeit–Nutzen, Potentiale und Handlungsbedarfe [digital assistance systems and the care for need –benefits, potential and need for action]. The review will focus on the following issues. Consideration of the role of the new definition of care need on the ongoing development of nursing care aids and their classification as objects of daily use, that is, as objects that, rather than merely providing comfort and convenience, specifically fulfil the objectives of Articles 13 and 40 SGB XI.

The ongoing update of product group 52, ‘aids for more independent living/mobility’, will be completed by the first quarter of 2021. The Nursing Care Aids Directory will be continually updated. Accordingly, by the end of 2022, the GKV-SV will take into account the findings of the study on digitisation in long-term care, agreed upon in the KAP campaign and, if necessary, initiate a further update of the Nursing Care Aids Directory.

1.8.3 Support for housing in older age

The programme funds for the KfW programme *Altersgerecht Umbauen* [‘Age-appropriate Conversion’ programme] were increased from 75 million euros to 100 million euros in the 2020 budget, while programme funds of 75 million euros are planned for 2021. In addition, the BMI, the BMFSFJ and the federal states are applying for funding for ‘communal rooms’ through this programme; such communal rooms can also be used for the provision of care. Such funding can also be applied for, in particular, by housing enterprises. In addition, the BMFSFJ will support the development of housing concepts at pilot sites in rural areas as well as in large and small towns. The objective is to develop transferable housing paradigms in residential districts.

The BMFSFJ will provide support for housing concepts and publish the details of successful projects by the end of 2022.

1.8.4 Counselling on living in group homes for people with dementia

The federal states are working to ensure that counselling on living in group homes for people with dementia is provided in line with needs. Whenever possible, they will integrate counselling into the work of the state specialist centres.

By the end of 2024, a demand-oriented service will be available in all states.

1.8.5 Neighbourhood integration of nursing homes

The federal states, the leading non-governmental welfare organisations, the VDAB, the bpa, and the evangelical and catholic churches in Germany are working to ensure that their members will contribute to opening up nursing homes into residential districts. In addition, institutional care facilities will be increasingly integrated as network partners in local alliances or other local support networks. The BAGSO will include this topic in its range of events aimed at establishing and further developing networks and will promote knowledge transfer on how, in concrete terms, nursing homes can be opened out into residential districts. The KDA will follow up on care facilities during the process and evaluate their experiences.

By the end of 2024, nursing homes will be more involved in the life of residential districts and increasingly recruited as partners for local dementia networks.



Field of action 2

Supporting people with dementia and their relatives

Dementia does not just affect the person living with the condition; it also affects their family and social environment. It is relatives⁵⁸ who often assume the responsibility for care and support as the main care-givers.⁵⁹ In 2017, approximately three-quarters (2.59 million or 76 per cent) of all people requiring long-term care in Germany were cared for at home, of which approximately two-thirds were cared for solely by their relatives (1.76 million).⁶⁰ This is in line with the wishes of most people requiring nursing care in Germany.⁶¹ The main care-givers are usually close family members, mostly women.⁶² Family care-givers who decide to take on this task are dependent on suitable support services to provide good care at home. Factors such as changes in familial structure and an increase in the proportion of women in the labour force are necessitating an expansion and adaptation of care services.⁶³ No specific data are available on home-based care for people with dementia. Hence, it must be assumed that their relatives are providing care at home equivalent in scope to the average of family care-givers.

Many families assume the responsibility to support people with dementia out of love and a feeling of care and responsibility. They want their loved one to be able to live in familiar surroundings. Support and care is often also experienced as a meaningful and enriching experience. However, the strain on family care-givers will increase considerably if the person needing care has limited cognitive abilities and diminished ability to cope with daily tasks. Providing care over a long period of time without adequate support is, likewise, stressful.⁶⁴ An extensive personal network can relieve the burden on relatives and help them to maintain care at home in good health for longer.⁶⁵

Family care-givers are dependent on support in the form of comprehensive information. There are various ways of meeting this need: care counselling as per Section 7a SGB XI or other counselling services offered by the municipalities, by the independent social welfare associations and by self-help groups. Nevertheless, many affected persons⁶⁶

58 In this context, relatives are understood to be those persons within the close social environment of people with dementia who are responsible for care and support. The focus in this field of action is on relatives within a family. However, in this context, relatives can also refer to people who have a friendly or neighbourly relationship with the person with dementia.

59 Ehrlich and Kelle (2019)

60 Statistisches Bundesamt (2018)

61 Ehrlich and Kelle (2019)

62 Ibid.; Nowossadeck et al. (2016)

63 Nowossadeck et al. (2016)

64 Thyrian et al. (2017); Zank and Schacke (2007)

65 Schneekloth and Wahl (2005)

66 In this context, 'affected persons' refers to people with dementia. People who provide nursing and care for people with dementia are also 'affected' by the condition. However, in this document they are not subsumed under the term 'affected persons'.

and their relatives feel that they have not had access to adequate information and support. The range of services on offer to provide information, counselling and support for people with dementia and their families should, therefore, be expanded throughout Germany. Existing services should be made better known and access to them should be made easier.

After people have been diagnosed with dementia, they and their relatives often struggle to cope with the situation. General practitioners are often the first to be contacted and asked for support. Solving legal matters is also an issue that frequently needs to be dealt with. Early, needs-based advice is very helpful at this time, for instance on the legal provisions that need to be taken. Legal counsellors, in particular, need to be thoroughly informed on how to meet the needs of people with dementia. Some people with dementia who live alone are neither supported by a family member or by a legal guardian. In such cases, educating people in their immediate environment is particularly important to protect them from financial abuse.

Not all people with dementia share the same circumstances in life and have the same needs. People who develop dementia before the age of 65, for example, have different requirements than older people needing care. They face the challenge of managing the impact of dementia on their family and working lives. To meet this need, existing support networks need to be expanded, and people involved, sensitised.

Sensitisation is also essential for people with a migration background. They feel highly responsible for caring for family members and do so frequently at home, even in the case of dementia. However, their access to the German health and care system is often inadequate. To benefit from counselling and support services, they depend on easily accessible and culturally sensitive services.⁶⁷

To manage daily life and care, family care-givers of people with dementia need information about the nature of the disorder and how to deal with the behaviour of those affected by it.⁶⁸ The long-term care insurance funds are, therefore, obliged by law to offer free care courses to family care-givers and other persons interested in voluntary care work. Access to such training is to be made easier.

Working family care-givers of people with dementia need more support due to the added burden of reconciling work and care. They need the support of their employers to adapt their working hours to the specific demands of care and support, along with access to a local support network.⁶⁹

Overburdening of family care-givers, isolation and the high degree of dependence between people with dementia and their carers can lead to crises in home care situations. To prevent abusive behaviour, it is, therefore, essential that family members are offered both instruction and opportunities to recuperate.⁷⁰

Family care-givers of people with dementia can experience both physical and psychological stress.⁷¹ They are themselves entitled to preventive and rehabilitative support to stimulate, restore or improve their health.⁷² Prevention and rehabilitation services, especially for family carers of people with dementia, are to be expanded.

In particular at the end of life, family care-givers need counselling and support. As far as possible, carers should be able to actively influence the last phase of life. Many hospice and palliative care services are already well-developed in Germany. Special care of this nature should also be made available nationwide to people with dementia and their families.⁷³

67 Tezcan-Güntekin et al. (2015); Tezcan-Güntekin and Razum (2017)

68 Emme von der Ahe et al. (2010)

69 Keck (2012); Unabhängiger Beirat für die Vereinbarkeit von Pflege und Beruf (2019)

70 Huhn (2015); Eggert et al. (2018)

71 Zank and Schacke (2007)

72 Reuter (2019)

73 Deutsche Gesellschaft für Palliativmedizin et al. (2016)

2.1 Improving counselling and support for people with dementia and their families

Dementia poses great challenges both for people with dementia and their families. To cope with these, all those involved need information on the nature of the condition, on possible treatment, and on benefits from and claims that can be made against health and long-term care insurance. In addition, people with dementia and their relatives need information about relevant services offered by the federal states and municipal authorities, and about what their entitlements are in this regard. People with dementia and their relatives also need advice and support during the course of the condition, as care must be continuously adapted as the dementia progresses.

Counselling offers relatives access to the support system; it is the first step in managing the situation at home.⁷⁴ At the same time, qualified counselling reduces the stress experienced by relatives caring for people with dementia. It plays a role in ensuring that people with dementia can be cared for at home for longer, that support services are known about and that the circumstances of the family are addressed.⁷⁵ The intention is to foster a counselling culture in which the first party contacted feels responsible for solving the problems of those affected, accepting their responsibilities and, if necessary, arranging further contacts.

The counselling system for people with dementia and their families is multi-faceted. Due to the varying responsibilities of the federal, state and municipal governments, as well as the welfare associations and independent bodies, the services on offer are extensive, albeit heterogeneous. There is a wide range of counselling services covering all the needs and requirements of people with dementia in both general and specialised forms, and these go far beyond the scope of nursing care. Counselling is provided in person, by telephone or via new modes of communication. A special

mention should be made of the group and individual training courses held within the framework of care courses as per Section 45 SGB XI.

All insured persons receiving benefits from long-term care insurance, as well as persons who have submitted an application for long-term care services and have a recognisable requirement for support and advice, have a legal entitlement to comprehensive individual long-term care counselling as per Section 7a SGB XI. Long-term care insurance funds are responsible for fulfilling this entitlement. Family care-givers or other persons, such as voluntary carers, can also claim this right, provided the person entitled to it wishes them to do so. Care counselling can be provided at home, if desired, or in the institution where the person lives. It includes assessing how much individual assistance is needed, counselling on care aids and social benefits, and drawing up an individual care plan. Care counselling in accordance with Section 7a SGB XI is also provided in almost all federal states at care support centres, which are responsible for facilitate networking among the parties involved in care, support and assistance services. The law provides for individual comprehensive long-term care counselling, that is, case management for those in need of care. Providers of private long-term care insurance offer people they insure counselling on long-term care, specifically in the context of dementia, by the company Compass Private Care Consulting. Counselling is provided via telephone or in the home.

People in need of long-term care above care level 2, who only receive long-term care allowance, are obliged to seek counselling at least once a year (Section 37 paragraph 3 SGB XI). This also applies if the benefits intended for out-patient care services are used solely for services recognised by state law to provide assistance in daily life (within the framework of their entitlement to convert the services they receive). People in need of long-term care at care level 1, and those in need of long-term care receiving benefits in kind, are also entitled to this every six months. Following

74 Pinquart (2016)

75 Emme von der Ahe et al. (2010)



the Care Staff Strengthening Act (Pflegerpersonal-Stärkungsgesetz), which came into effect in January 2019, it was established that the level of remuneration for counselling visits for recipients of long-term care allowance is determined, as per Section 37 paragraph 3 SGB XI, in agreement with the care services. This serves to ensure the provision of good-quality counselling.

People seeking counsel, nevertheless, sometimes feel that they have not received sufficient advice. They often find it difficult navigating the counselling services on offer and sometimes feel hesitant about asserting their current entitlements.⁷⁶ For this reason, relatives need more support in identifying possible support and deciding which services are appropriate for them. The foundations for this should be created.

In addition to good counselling, low-threshold support can be helpful to help people with dementia and their families cope with their new circumstances and to encourage them to seek help. The DelpHi MV study investigated the

effectiveness of counselling and support in the form of dementia care management.⁷⁷ This involves a specially trained care-giver providing dementia-specific support and advice to people with dementia over a longer period of time. The study's findings suggest that a service of this kind improves the quality of life of those affected, relieves the burden on relatives and improves the quality of health and long-term care services.

Since those affected and their relatives often find it difficult to accept assistance and counselling outside their family,⁷⁸ or they do not have time to contact a counselling centre, anonymous telephone or online counselling services are vital. A wide range of telephone counselling services are already available, including those provided by welfare organisations. The DALzG offers a counselling service specifically geared to the needs of people with dementia. It is funded by the BMFSFJ and is the only nationwide counselling hotline on dementia. The Alzheimer's hotline receives between 5,000 and 6,000⁷⁹ calls annually. In addition, the DALzG offers counselling via e-mail.

76 Englert and Büscher (2018); Rothgang and Müller (2018); Schneekloth et al. (2017)

77 Thyrian et al. (2017); Michalowsky et al. (2019); Eichler et al. (2015); Eichler et al. (2014); Thyrian et al. (2012)

78 Statistisches Bundesamt (2018)

79 Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz (no date)

Since ever more young people are also taking on responsibilities as care-givers in their own families, the BMFSFJ has launched an easily accessible advisory service for children and young people entitled *Pausentaste—Wer anderen hilft, braucht manchmal selber Hilfe* [pause button—helpers sometimes need help themselves]⁸⁰. The website and a telephone hotline offer an easily accessible, nationwide counselling service, which aims to help reduce overburdening and overcome isolation. *The echt-unersetzlich* [simply irreplaceable]⁸¹ website of the *Pflege in Not* [Carers in Distress] advice hotline also offers online and personal counselling for under-age care-givers.

Witten/Herdecke University has conducted a project for the Federal Ministry of Health called *Die Situation von Kindern und Jugendlichen als pflegende Angehörige* [the circumstances of children and young people as family care-givers]. Such children go unnoticed in society. The goal of the project was, therefore, to contribute to the development and establishment of needs-based support services for care-giving children and adolescents and to raise public awareness of the issue.⁸²

Awareness of the existence of counselling centres is often insufficient, and aid is usually only sought after a crisis situation has already arisen.⁸³ In particular, people living alone with dementia need support. They tend to live an isolated life, which can reduce social participation and cause them to rarely avail themselves of assistance.⁸⁴ Easily-accessible dementia counselling in public institutions can be helpful in combating this.⁸⁵ First-time support by volunteers represents a further form of support for people with dementia in their daily lives, especially for those who live alone.⁸⁶

The changes to the structures in family life also force relatives to organise care from a distance.⁸⁷ Intensified networking between care support centres and other municipal or local counselling services will support people in such circum-

stances. Crucially, relatives need a contact person at their local care support point and one near to where the person needing care lives. Another way of ensuring that relatives living at a distance receive more appropriate support is to make outpatient services more aware of their needs.

In addition to counselling structures covered by SGB XI, there is a need for counselling services dedicated to old-age care at the municipal level. These can improve integration into social life and enhance the opportunities for shaping (participating in) society. Information on such counselling services, offering support with regard to long-term care and old age as per Section 71 paragraph 2 SGB XII, will be more widely disseminated. Furthermore, it may be useful for municipal authorities to appoint permanent contact persons responsible for the needs of people with dementia.

The aim is to facilitate networking between all those involved in long-term care counselling at state and local level. Section 7a paragraph 7 SGB XI currently requires state long-term care insurance associations and the private health insurance association to draw up joint and standardised framework agreements on cooperation in counselling with the bodies designated under state law for the care of older people close to their place of residence, with the competent social welfare institutions and with the local authority associations at state level. The framework agreements at state level and the supplementary agreements at local level, as per Section 7a SGB XI, are intended to facilitate structured cooperation for the benefit of people seeking counselling, particularly for those with dementia. This legal regulation must be better implemented in practice.

With a view to improving counselling services, the Second Act on Strengthening Long-Term Care regulated the expansion of individual long-term care counselling as well as the evaluation of counselling entitlements, as per Sections 7a and 37

80 www.pausentaste.de/

81 www.echt-unersetzlich.de/

82 Metzging (2018)

83 Reichert et al. (2016)

84 Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz und Trilling (2011)

85 Steiner et al. (2014)

86 Vogel and Romeu Gordo (2019)

87 Nowossadeck et al. (2016)

paragraph 3 SGB XI.⁸⁸ By the middle of 2020, the first research findings on the take-up of the services and the experiences of counsellors and consultees should be available. Furthermore, to increase the quality of long-term care counselling, the GKV-SV adopted guidelines in 2018 on the uniform implementation of long-term care counselling as per Section 7a SGB XI. The long-term care counselling guidelines have, thereby, established quality standards for counselling in line with Section 7a SGB XI. In contrast, the counselling on the care of older people provided by municipalities as per Section 71 SGB XII is not governed by guidelines on procedure, implementation and content. The same applies to counselling centres run by welfare organisations. To ensure that those seeking counselling are guaranteed high-quality counselling at all sites, counselling at municipal level on matters relating to care and old age, and counselling centres run by welfare organisations should set quality standards governing the general scope of counselling.

The GKV-SV has revised the recommendations stipulated in Section 7a paragraph 3 sentence 3 SGB XI of 29 August 2008 on the required number, qualifications and continuing education of nursing care counsellors. The modules defined in Section 4 of the above recommendations contain information on the subject of dementia. By contrast, there are no specific continuing education concepts available nationwide for municipal or private providers.⁸⁹ Due to the complexities involved in caring for people with dementia and providing information for their relatives, and due to the predicted increase in the number of people affected, all long-term care counselling centres need to step up their efforts to address the issue of dementia. To improve access to information, relevant databases and online services should be expanded or established and linked to one another.

Counselling and support for people with dementia and their families is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

2.1.1 Dementia care management

The BMG, in cooperation with the DZNE and other relevant research institutions, the BÄK, the KBV and the GKV-SV will examine whether dementia care management can be introduced within the framework of SGB XI to ensure that people with dementia and their relatives are provided with support and guidance on medical, nursing and psychosocial health service planning and implementation, in line with their needs.

By the end of 2022, the BMG will have completed its assessment on the feasibility of introducing dementia care management within the framework of SGB XI.

2.1.2 Expansion of telephone and e-mail counselling services

With the involvement of the BMFSFJ, the DAzG will expand its independent, anonymous, psychosocial and dementia-specific telephone and e-mail counselling service and raise awareness of it in the general public. It is also targeted at people with rare forms of dementia or at those who do not wish to attend official counselling centres in person.

By the end of 2024, the number of counselling contacts (telephone and e-mail) will have increased by 10 per cent compared to 2018.

2.1.3 Dementia counselling in public institutions⁹⁰

The BMFSFJ, the DAzG, the BAGFW, the federal states and the local authority associations are working to ensure that open meetings or counselling sessions on the topic of dementia are increasingly made available in publicly accessible institutions, for instance during lunchtimes, and in particular for people living alone.

By the end of 2024, the stakeholders concerned will have established dementia counselling

88 GKV-Spitzenverband (no date)

89 Kirchen-Peters and Nock (2016)

90 In this context, a public institution is understood to be an institution that is open for use by the general public, for example, multi-generational houses, community centres and town halls.

services in public institutions, where necessary, and publicised these services.

2.1.4 Initial counselling by volunteers

The BMFSFJ, the BAGSO, the DALzG, the local authority associations, the federal states and Malteser Germany are committed to expanding low-threshold initial counselling by volunteers, especially for people living alone. Such services are to be provided, for example, by local alliances for people with dementia, multi-generational houses and municipal networks or other municipal institutions.

By the end of 2024, more than half of the local alliances, multi-generation houses and networks will have examined whether they are able to offer initial counselling by volunteers and, if so, can establish or expand such a service.

2.1.5 Support for relatives living at a distance

The GKV-SV and the local authority associations are working to ensure that care support centres and other counselling centres to support relatives of people with dementia living at a distance become more closely networked. In addition, the leading non-governmental welfare organisations, the VDAB and the bpa will sensitise their member institutions to the fact that funding organisations of care facilities should systematically adapt their structures to further promote communication and support for relatives living at a distance.

By the end of 2022, all care support centres will, if required, help relatives living at a distance to identify an appropriate contact person geographically close to the person in need of care. Furthermore, the funding organisations will sensitise their member institutions to this need.

2.1.6 Counselling services according to Section 71 paragraph 2 number 3 and 4 SGB XII

The local authority associations are committed to ensuring that people with dementia are better informed about the counselling services available in the context of care for older people under Section 71 paragraph 2 number 3 and 4 SGB XII. They are also working to ensure that, within their financial means, municipalities provide more



human resources for counselling, in particular for people with dementia and their families.

By the end of 2022, the local authority associations be working work towards ensuring that the municipalities enhance the range of counselling services provided under Section 71 paragraph 2 number 3 and 4 SGB XII.

2.1.8 Quality standards for counselling of people with dementia

The GKV-SV will examine the issue of long-term care counselling under Section 7a SGB XI to determine whether supplementing the Long-Term Care Counselling Guidelines and the recommendations under Section 7a paragraph 3 sentence 3 SGB XI are warranted for people with dementia.

The KDA and the DZNE, in cooperation with the bpa, the leading non-governmental welfare organisations, the DPR, the VDAB, the DALzG and the local authority associations will develop a handbook on quality standards for counselling on issues of nursing care and old age for people with dementia and their relatives. This handbook will be made available to counselling centres nationwide. The information provided in the handbook will be taught in multiplier training courses for

counsellors. In the framework of developing a handbook for quality standards, modules for continuing education and training for counsellors will also be developed. Each module will be developed based on the needs for counselling of people with dementia and their families.

By the end of 2022, the Long-Term Care Counselling Guidelines will have been reviewed in the light of the findings of the evaluation and, if necessary, supplemented. By the end of 2024, the handbook will be available, and continued and advanced education modules will be under development.

2.1.9 Addition of dementia-specific topics to existing information platforms

Existing online portals for guidance on entitlements to services, counselling and training will be improved and better interlinked. All stakeholders will utilise the Dementia Signpost website as a central platform for linking their online information resources for people with dementia. The BMFSFJ is also preparing a practical and easily-accessible guide written on all relevant entitlements people with dementia needing care and their relatives have to counselling and training.

By the end of 2022, suitable resources will have been developed or expanded. The practical guide is currently being drawn up.

Expanding existing informational platforms online to incorporate dementia-specific information

The GKV-SV is working with the relevant long-term care insurance funds to ensure that the existing online information platforms (for instance, Pflegenavigator and Pflegelotse) are expanded by their providers to include dementia-specific information and/or search functions. In addition, the federal states are working towards establishing and expanding user-friendly and accessible information resources on dementia-specific services. The databases will also be linked to the BMFSFJ's Dementia Signpost site. The PKV association has

also declared its willingness to continuously develop its relevant information resources.

By the end of 2026, the existing information platforms (for instance, Pflegenavigator, Pflegelotse and www.pflegeberatung.de) will be continuously expanding to incorporate dementia-specific resources. Accessible information resources will exist for all federal states.

2.2 Supporting people with dementia and their family care-givers in legal matters

People with dementia and their relatives require counselling not only with regards, to their entitlement to benefits, but also on other legal matters. Dementia generally restricts the ability of those affected to formulate their own will and make decisions about their own lives. It is, thus, frequently the relatives who must shoulder the responsibility for legal, financial and medical decisions on behalf of the person concerned.

In the case of dementia, it is particularly important that plans are made for medical and long-term care in good time as the condition progresses. Relatives need counselling and support with such decisions. It is also fundamentally important that decisions are made on an advance decision (living will), on the durable power of attorney or on legal guardianship. These decisions often also have an ethical dimension.

As people needing long-term care and family care-givers are often under considerable financial strain,⁹¹ free and easily-accessible legal representation or legal advice is particularly important. People with a low income are already entitled to free legal advice under the Act on Advisory Assistance. People with dementia and their families should be better informed about this recourse.

To further lower the barriers to seeking legal counselling, long-term care counselling and legal counselling⁹² are to be interconnected more

91 Rothgang and Müller (2018); Zank and Schacke (2007)

92 In this chapter, 'long-term care counselling' refers to long-term care counselling as per Section 7a SGB XI, to counselling at municipal level on matters relating to care and old age as per Section 71 SGB XII, and to long-term care counselling provided by welfare organisations.

closely at the local level. Relatives of people with dementia benefit in particular from being able to access long-term care and legal advice from a single source.⁹³ Expansion of local counselling services should, therefore, be promoted, along with interlinking of long-term care and legal counselling centres and associations providing counselling in this context.

General practitioners play a central role in the provision of healthcare for people with dementia and their families, and are often the first to be contacted when problems arise. They should, therefore, be sensitised to legal issues relating to dementia and should also have an overview of local resources for providing legal advice to people with dementia and their families.

When people with dementia are no longer able to manage their own legal affairs due to their condition, a person can be assigned as the legal guardian. In addition to relatives who have been designated as voluntary care-givers, this task can also be entrusted to professional care-givers or other voluntary care-givers who have no close personal relationship with the person involved. Such persons must be sufficiently sensitised to the specific concerns of people with dementia. The same applies to judges at local courts ruling on legal guardianship. The Federal Ministry for Justice and Consumer Protection (BMJV) is preparing an amendment to the German Guardianship Law. Amongst other things, the aim is to further strengthen self-determination for those affected.

Protecting people with dementia from violence and exploitation is also of particular importance. Older people in need of care are particularly at risk of becoming victims of excessive financial charging or exploitation.⁹⁴ Financial abuse of older people can often take the form of putting pressure on an isolated person to distribute his or her assets to third parties, or managing financial assets for personal gain by an authorised person. People with dementia and people who are socially iso-

lated are at an even higher risk of being subject to financial abuse.⁹⁵

Improving the provision of legal advice within the framework of the National Dementia Strategy is one of its objectives. The following measures have been agreed upon to achieve this.

2.2.1 Free legal advice for persons in financial need

People with dementia and their relatives are to be better informed about their entitlement if financially in need to the free⁹⁶ legal advice provided by lawyers and legal advisers under the Act on Advisory Assistance. To this end, the independent social welfare associations, the GKV-SV within the framework of its remit and the local authority associations are collaborating to ensure that nursing care counselling centres provide more information on applying for counselling assistance in particular, and offer assistance with the application process. The BMFSFJ also refers to this free legal advice in its Dementia Signpost site and provides this information for multipliers. The BMG will also supplement its *Ratgeber Demenz* [Guide to Dementia] to this end.

By the end of 2022, long-term care counselling centres will be informed nationwide and will be able to offer support in this respect. In addition, the information will be available on the Dementia Signpost site. The BMG's Guide to Dementia is in the process of being updated.

2.2.2 Networking of long-term care and legal advice centres and care associations

In order to improve legal advice for people with dementia, the local authority associations, the leading non-governmental welfare organisations and the GKV-SV are working within the scope of their remit to ensure that long-term care counselling centres network better with legal advice centres and the care associations.

93 Englert and Büscher (2018)

94 Zank and Schacke (2013); Görgen (2017); Deutscher Bundestag (2019)

95 Görgen (2017)

96 In accordance with Section 44 RVG, persons who are financially in need and who are seeking legal aid are obliged to pay the lawyer a fee of 15 euros.

By the end of 2024, the stakeholders will have provided information on the networking structures that have been established.

2.2.3 Raising awareness among general practitioners and medical specialists on the topic of legal issues related to dementia

General practitioners and medical specialists are to be sensitised to the issues of legal advice for people with dementia via documents published by the KBV and via advanced education courses organised by the DGGPP in cooperation with the German Society for Gerontopsychiatry and Psychotherapy.

By the end of 2022, the topic of legal issues relating to dementia will have been dealt with in documents published by the KBV and in continuing educational courses organised by the DGGPP.

2.2.4 Information for legal advisers and competent judges in local courts

The federal states and the local authority associations will, within the scope of their responsibility in matters relating to the legal power of attorney, continue to work towards ensuring that professional and voluntary persons who have been granted the power of attorney and judges at local courts ruling on law governing the power of attorney are kept well informed about dementia.

By the end of 2022, the federal states will have implemented targeted measures and the local authority associations will have promoted them within the scope of their responsibilities.

2.2.5 Protection of people with dementia living alone from financial abuse

The ZQP is initiating a project together with the German Police University that aims to better protect people with dementia who are living alone from financial abuse. The first step of this project is to collect more research findings on the topic. In a second step, the project will use the findings to draw up recommendations for action and disseminate these with as few barriers as possible. Once a project concept has been submitted, the *Stiftung Deutsches Hilfswerk* [German Relief Foundation] will examine whether funding from the German Television Lottery is possible.

By the end of 2024, recommendations for action will have been developed and disseminated to the public with as few barriers as possible.

2.3 Extending counselling and support structures for people with early-onset dementia and their families

Currently, there are approximately 25,000 people with dementia in Germany who are younger than 65 years of age—and thus of working age.⁹⁷ They are more frequently affected by rare dementias, such as frontotemporal dementia or Lewy body disease.⁹⁸ This also includes people with Down syndrome. These diseases usually differ from Alzheimer's dementia in old age in that other symptoms predominate,⁹⁹ for example, in the case of frontotemporal dementia the symptoms are more psychological and behavioural.¹⁰⁰ Most of those affected are in employment and face the challenge of organising their own professional

97 Bickel (2018)

98 Mendez (2006)

99 Ducharme et al. (2016)

100 Diehl-Schmidt (2017)



activities to accommodate their condition. Currently, in many cases such diseases result in early retirement, often involuntary and not always in accordance with the needs of people with dementia.¹⁰¹ Instead, those affected require a different kind of support in order to be able to perform their usual tasks or to find suitable employment options in their company.

With more information and advice, those affected and their relatives, as well as employers, would be in a better position to take advantage of opportunities of remaining in gainful employment. Continuing education opportunities for the parties involved in companies should, therefore, be created. People should be sensitised to the issue and, for example, empowered to adapt workplaces to the specific needs of people with early-onset dementia. One way to achieve this is to make use of integration offices, which offer resources for disabled people in employment. Integration offices can provide advice and financial support to people with early-onset dementia and their employers, if they are sensitised to the issues faced

by those affected. Alzheimer's societies and regional specialist dementia centres can also play an important advisory role, both for those affected and for integration offices. To facilitate timely support, the various relevant entities need to need to be connected.

In addition, further services need to be established to help people with early-onset dementia cope with the diagnosis. Support groups can help people to feel less isolated and reduce feelings of depression or anxiety.¹⁰² A facilitator can help by taking on organisational and support tasks. As the number of affected persons in this group is small, support services cannot be provided nationwide. Online resources are, hence, particularly beneficial.

Expanding guidance and support service structures for people with early-onset dementia and their families is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

101 Johannessen and Möller (2011)

102 Snyder et al. (2007)

2.3.1 Expansion of information and continuing education resources for relevant bodies/officers in companies

The BMFSFJ is developing a handbook for companies providing information about dementia and outlining the needs of people with early onset dementia. The handbook also identifies opportunities for developing in-house measures to support people with early-onset dementia and employees with dementia. The handbook will be offered free of charge, amongst other ways, via the *Erfolgsfaktor Familie* [success factor family] programme for companies. Furthermore, counselling services provided to companies via the Alzheimer's telephone service provided by the DAzG will be expanded and more information will be provided about the service. In addition, the DAzG's Dementia Friends training programme will allow employees to be addressed via the company health management system.

By the end of 2022, the handbook will have been published in an accessible format and disseminated via the success factor family programme for companies. In addition, by the end of 2024, the Alzheimer's telephone service will have been extended and the effectiveness of calls made via companies evaluated on an annual basis. The Dementia Friends training programme will be supplemented and made use of by employees within the framework of company health management to address the subject of dementia and employment.

2.3.2 Support of local support networks by integration offices

To provide people with dementia in the workplace with support in the form of trained contact persons, integration offices and other counselling and support services will be sensitised to the topic of dementia. To accomplish this, the *Bundesarbeitsgemeinschaft der Integrationsämter und Hauptfürsorgestellen* [federal association of integration offices and central welfare offices] will deploy specialists trained in the subject of dementia to

the specialist integration services and provide information about the available services. In addition, with the support of the DAzG and the BAGSO, the specialist integration services will network more closely with regional dementia networks.

By the end of 2024, network structures between regional dementia networks and integration offices will have been established or expanded.

2.3.3 Moderated online group for people with early-onset dementia

In a pilot project, the DAzG will develop a regularly held, moderated online self-help group for people with early-onset dementia, with the involvement of the advisory body 'Living with Dementia', expanding it if experiences are positive. The group will also address issues relating to rare dementia types.

By the end of 2022, the pilot project will have been implemented and evaluated and, if appropriate, a concept for its expansion will have been drawn up.

2.4 Developing and expanding culturally sensitive counselling services for people with dementia and their relatives

It is estimated that 96,500 people with a migration background aged over 65 years are currently affected by dementia in Germany.¹⁰³ They and their relatives need information about the condition, counselling, support and health and long-term care services. People with a migration background often do not make full use of the benefits to which they are entitled under long-term care insurance. This is due to linguistic, cultural-religious or institutional barriers as well as to the insufficient sensitivity of cultural issues of the services on offer.¹⁰⁴ It is, therefore, crucial that services are adapted to the needs of this target group.

103 Monsees et al. (2018): page 655

104 Ibid.; Tezcan-Güntekin et al. (2015)

To this end, the pilot project *Interkulturelle BrückenbauerInnen in der Pflege* [intercultural bridge builders in care] has trained people originating from various countries on relevant care-related topics. These ‘bridge-builders’ support persons working as counsellors in care, as well as people with a migration background in need of care along with their relatives. The aim is to raise cultural sensitivity in care and counselling institutions and to provide people with a migration background with the necessary information to make use of the benefits provided by long-term care insurance.¹⁰⁵ Such projects can serve as a model for the establishment and development of inter-cultural competence in care support centres and care counselling centres throughout Germany.

The DALzG project ‘Dementia and Migration’,¹⁰⁶ funded by the BMFSFJ, offers, amongst other things, multilingual information on dementia. The Robert Bosch Foundation (RBS) project *DeMigranz—Bundesweite Initiative Demenz und Migration* [DeMigranz—nationwide initiative dementia and migration]¹⁰⁷ was likewise set up to provide better advice to people with dementia with a migration background and thereby facilitate access to support services. The networking of the relevant parties is one aim of this project. These projects should be further developed and new measures implemented to support people with dementia who have a migration background. Such measures involve transparent information about existing culturally sensitive counselling services online. This can facilitate access to appropriate resources.

Expanding and developing culturally sensitive counselling services for people with dementia and their families is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

2.4.1 Intercultural competence at care counselling centres

The GKV-SV (with the involvement of state long-term care and health insurance associations and substitute funds), the federal states and the local authority associations are working to ensure that care support centres and care counselling centres are able to act as language and cultural mediators if required.

By the end of 2022, the states will have established the status quo and the demand for services, and, if necessary, the framework contracts will have been adapted accordingly. By the end of 2024, all care support centres and care counselling centres will be offering a range of needs-tailored services.

2.4.2 Further development and networking of culturally sensitive information services and counselling

The BAGFW, the federal states, the local authority associations and the RBS are working to establish more easily-accessible, culturally sensitive counselling services. To accomplish this, they have made it their goal that counselling centres should network with other culturally sensitive institutions and cooperate with immigrant associations.

By the end of 2022, networks will exist in all federal states. The BAGFW, the federal states and the local authority associations will be in a position to report on the further development of culturally sensitive counselling facilities.

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105 Eifert (2016)

106 www.demenz-und-migration.de

107 www.demenz-support.de/projekte/demigranz



2.4.3 Provision of online information on culturally sensitive counselling services

The federal states will provide sources of information via their dementia and care specialist centres, which will also include information on multilingual counselling services. In addition, the RBS and the DAzG will be expanding the nationwide database of culturally sensitive counselling centres and networking resources on the website www.demenz-und-migration.de. The Dementia Signpost site will link to this database.

By the end of 2022, accessible information services identifying the available multilingual counselling services will be available in all federal states. By the end of 2022, the database at www.demenz-und-migration.de will have been expanded.

2.5 Increasing uptake of training by family care-givers on long-term care and dementia

Family care-givers need access to comprehensive knowledge about the condition, how to deal with dementia-specific behaviour patterns and care-giving expertise. Such knowledge can help people to accept the condition and cope with the changes in their daily lives. As dementia progresses, family members should have the opportunity to develop their skills and adapt to new situations. This will enable them to provide good-quality care over a longer period of time.

Relatives and volunteers can also take advantage of free training courses, even as individuals. Long-term care insurance funds will cover the expenses for these services. The aim of nursing care courses is to enable family care-givers to provide independent care and support at home. Participants generally consider them to have been very helpful and supportive.¹⁰⁸ The recommendations contained under Article 37 paragraph 5 SGB XI for quality assurance of counselling visits under Article 37 paragraph 3 SGB XI of 29 May 2018 already serve to publicise entitlements defined in Article 45 paragraph 1 SGB XI. Taking advantage of this service should be encouraged, especially for relatives of people with dementia.

According to Section 45 SGB XI, long-term care insurance funds can either run care courses themselves or commission other suitable institutions to conduct them. This requires providers of nursing care courses to reach agreements with individual long-term care insurance funds on the reimbursement for their services. It is to be investigated how to make individual home-based training more accessible to relatives of people with dementia.

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108 Schneekloth et al. (2017); Pinguart and Sørensen (2006)

Participation in a nursing care course provides an opportunity for family carers to exchange experiences and knowledge with others, reducing the risk of isolation. To make it easier for them to participate, support services for people with dementia should be supplemented while their relatives are attending care courses.

Attending a nursing care course alongside work is difficult for family care-givers. Educational leave, in principle, gives anyone the opportunity to further their professional or political education. It can be exploited to provide a window of opportunity for those who wish to participate in a nursing care course. The regulations governing educational leave are legally established at state level. These should be extended to facilitate access for family care-givers to nursing care courses.

Increasing the uptake by family care-givers of courses on nursing care and dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

2.5.1 Improving information about nursing care courses and individual training in the home

The GKV-SV, the leading non-governmental welfare organisations, the bpa, the VDAB and the DALzG are working to ensure that more information about nursing care courses is provided on a local level. The PKV association is also willing to participate and will also offer a specialised, individual visitation counselling service (nursing care training at home) via MEDICPROOF. Individuals can be recommended for nursing care training in the context of a care needs assessment or at care counselling. In addition, this facilitates a simple, quick and uncomplicated uptake. On the Dementia Signpost site, the BMFSFJ will provide more detailed information on the options available to support family care-givers in taking advantage of the nursing care courses on offer.

By the end of 2022, the GKV-SV, the leading non-governmental welfare organisations, the bpa, the VDAB, the DALzG and the PKV association will be providing more information about the opportunities to participate in nursing care courses and

support programmes. By the end of 2026, the BMFSFJ will be continuously updating the Dementia Signpost website with information on opportunities for support.

2.5.2 Promoting home-based training as per Section 45 SGB XI

The BMG will review whether there is a need for measures to support wider availability of nursing care courses and home-based training, and whether contracts entered into by communities under Section 45 paragraph 2 SGB can be more widely utilised to provide home-based training.

By the end of 2022, the BMG will report on completion of the review.

2.5.3 Care for the people with dementia whilst their family care-givers are attending a nursing care training course

The GKV-SV, the leading non-governmental welfare organisations, the bpa and the VDAB are working to ensure that entities supplying nursing care courses, as per Section 45 SGB XI, inform family care-givers of people with dementia of their legal entitlement to care for the person in need of nursing care during training courses and, if possible, provide appropriate services or support in finding suitable care.

By the end of 2022, the parties involved will have requested the providers of nursing care courses to implement this measure and will be able to report on developments.

2.5.4 Approval of nursing care training courses as continued education or educational leave

The federal states will review the conditions under which nursing care courses for working family care-givers of people with dementia can be recognised as continuing education or educational leave, and included in the catalogue of approved continuing education measures.

By the end of 2021, the review will have been conducted.

2.6 Reconciling care and employment for women and men

There are currently approximately 2.5 million family care-givers in Germany, of these, approximately 1.65 million are women. One third of all family care-givers are in employment.¹⁰⁹ Family-based care can sometimes be very time consuming. In particular, when care-givers provide care at home, care responsibilities assumed by family care-givers consume a great deal of time: an average of 4.6 hours a day. Women, once again, shoulder more of the burden than men.¹¹⁰ Dementia leads to a limited ability to cope with daily life and requires a high level of commitment from family care-givers to create a safe environment. The extent of the time needed depends, amongst other things, on the stage of the condition. It is often not easy for care-givers with a job to reconcile this with caring for and nursing of a person with dementia.¹¹¹ Overburdening of family care-givers often leads to exhaustion, sickness and absences from work. As a result, companies also have a significant interest themselves in supporting family care-givers and reconciling their work-care needs.¹¹² In addition to its individual and social effects, such reconciliation also has macroeconomic consequences.

The Second Gender Equality Report of the German Federal Government calls for measures to be taken to promote a more equal distribution of care work and to encourage greater participation by men in family-based care.¹¹³ The Seventh Report on Older People also emphasises that reconciliation of care and employment must include both genders.¹¹⁴ In recent years, the federal government has already taken important steps to improve the framework conditions for reconciling care and employment. Amongst other things, the Nursing Care Leave Act and the Family Care Leave Act facilitate the reduction of working hours to

benefit care activities. Long-term care insurance provides compensation for loss of earnings (long-term care allowance) for up to ten working days in the event of a temporary inability to work. The *Unabhängiger Beirat für die Vereinbarkeit von Pflege und Beruf* [independent advisory board on reconciling care and employment] presented its first report in June 2019 with recommendations for action to improve reconciliation of care and employment. Amongst other things, the board was in favour of an entitlement to nursing care leave with wage-replacement compensation, the expansion of options for release from work, the merging of the nursing care leave and family care leave acts, and improving counselling services.¹¹⁵ The federal government is continually examining proposals to improve the reconciliation of care and employment. It will also consider such recommendations from a technical and financial point of view.

For family care-givers of people with dementia, corporate culture and acceptance and support within companies are particularly important. Understanding the circumstances of family care-givers and flexibility in scheduling their working hours can reduce their burden.¹¹⁶ The prerequisite for this is that companies are better informed about the circumstances of employees who care for a person with dementia. This is needed for employers to improve framework conditions, to provide advice on reconciling work and care, and to recommend suitable support services.

Company-appointed *Pflegelotsen* [care pilots] offer further support for family care-givers in the workplace. Care pilots are employees of a company who receive continued training on the topic of reconciliation of work and care, on typical problems and burdens and on the local structures of nursing care support. They represent contact persons for

109 Rothgang and Müller (2018): pages 6, 14

110 Ehrlich and Kelle (2019): page 193

111 Schäufele et al. (2016)

112 Gerlach et al. (2013)

113 Bundesministerium für Familie, Senioren, Frauen und Jugend (2017)

114 Bundesministerium für Familie, Senioren, Frauen und Jugend (2016)

115 Unabhängiger Beirat für die Vereinbarkeit von Pflege und Beruf (2019)

116 Keck (2012)

their colleagues and can refer them to the local support system. Care pilots contribute to a corporate culture in which employees can address the issue of care and are supported in reconciling it with their work. They can, thus, relieve the burden on employees, who can discover a favourable solution to care issues at an early stage and thus ease the burden on themselves.

In addition to the situation at the workplace, a suitable nursing care infrastructure is essential for family care-givers at home. At home, what is important is the right mix of partial in-patient care, out-patient care and other support services. In addition, they need to fit in with their working hours. The key element is the provision of needs-based and sufficient care and support services by the welfare organisations and private sector care providers. In addition, it is helpful if local employers, chambers of industry and commerce, chambers of crafts, care providers, municipal authorities and family care-givers network to identify needs and develop suitable resources. The local alliances for the family, who are working on introducing improvements to reconcile family and career, serve as a model.¹¹⁷

The key element of these solutions is providing sufficient care and support services. They call on welfare organisations and private care providers to create solutions that meet individual needs.

People with dementia have a particularly substantial need for care due to their condition. Depending on the stage of dementia, round-the-clock care may be necessary. Residential accommodation has the potential to provide this, but many people with dementia and their relatives do not wish this. Financing and organising care in one's own home is very time-consuming and resource-intensive, and not all relatives can manage to do so. In addition, the number of relatives living at a distance is increasing. Some of them decide to



employ foreign household and care staff, mainly from Eastern Europe.¹¹⁸ In such employment relationships, health and safety rules are not always respected and in some cases taxes and social security contributions are not paid or not fully paid.¹¹⁹

People with dementia require cares who have at least basic knowledge of the condition and its associated needs. Support and care personnel from abroad are not regulated in terms of their qualifications.¹²⁰ People with dementia are vulnerable due to their cognitive impairment. They are particularly exposed to threat if the care they receive is unregulated.

Improving reconciliation of care and employment for women and men is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

117 www.lokale-buendnisse-fuer-familie.de

118 Horn et al. (2019)

119 Pflegewegeweiser NRW und Verbraucherzentrale NRW e.V. (2018).

120 Ibid.

2.6.1 Advancing of family care leave

On the basis of the first report of the independent advisory board on reconciling care and employment, the BMFSFJ is initiating a broad social discussion and investigation of strengthening family care leave and nursing care leave, so that family care-givers of people with dementia, in particular, are also provided with more support in reconciling care with employment.

By the end of 2021, an appraisal of such further strengthening will have been launched.

2.6.2 Expansion and development of networks for 'care and employment'

The federal states and the local authority associations are working to establish and expand network structures to facilitate reconciliation of care and employment through companies, municipalities, family care-givers and stakeholders in long-term care and social health services at the local level, in particular to support the relatives of people with dementia. The BMFSFJ will commission a study on existing networks and set up a coordinating body at federal level to support the specialist work in the networks.

By the end of 2024, the federal states, the local authority associations and the BMFSFJ will report on the network structures, and the BMFSFJ will make a decision on establishing a coordinating body.

2.6.3 Support for care pilots programmes in companies

The federal states are supporting programmes to qualify employees in companies to become company care pilots with dementia-specific knowledge. The federal states and the BMFSFJ are encouraging voluntary participation in these programmes by companies or associations of micro-companies to appoint care pilots who can guide people with dementia to appropriate community support structures.

By the end of 2024, training for company care pilots will be offered in all federal states. The federal states and the BMFSFJ will report by the

end of 2024 on the establishment of care pilots in companies.

2.6.4 Provision of information for companies and employees on the subject of 'care and employment'

By means of its 'success factor family' programme for companies, the BMFSFJ will work to ensure that employers provide their employees with better information on reconciling care and employment. This takes particular account of the concerns of employees with relatives affected by dementia. The BMFSFJ, with the involvement of the DAzG, will be conducting workshops for chambers of crafts and chambers of industry and commerce to achieve this. The BMFSFJ will also provide more information on ways of improving reconciliation of care and employment on the websites www.wege-zur-pflege.de and www.wegweiserdemenz.de, and via its counselling hotline. In addition, Dementia Friends courses organised by the DAzG and the specific courses offered by associations and care services run by welfare organisations will be adapted to give greater weight to the issue of reconciling care and employment, and such courses will be provided within the framework of occupational health management.

By the end of 2024, the BMFSFJ will have collected information on the situation in companies and corresponding workshops will have commenced. By the end of 2022, the DAzG and the leading non-governmental welfare organisations will be increasingly including the issue of reconciling care and employment in Dementia Friends courses in companies. By the end of 2026, appropriate services will have been expanded nationwide.

2.6.5 Expansion and more flexible opening hours for partial in-patient care services

The leading non-governmental welfare organisations, the VDAB and the bpa are lobbying amongst their member organisations for partial in-patient care services to be expanded in line with demand and for more flexible opening hours to be offered at such care facilities, for instance in the evening and at night, or at weekends and on public holidays.



By the end of 2026, the range of day-care services will be expanded in line with demand, also with flexible opening hours.

2.6.6 Reviewing the framework conditions for care provided by personnel from abroad in private households

The BMG and the BMFSFJ will review which measures are best suited to improve the framework conditions for care provided by personnel from abroad in private households (so-called 24-hour care), as the provision of health services is not always satisfactorily organised and not all private employment relationships are structured in accordance with legal requirements.

By the end of 2022, the review will have been completed.

2.7 Supporting people with dementia and their relatives in coping with family conflicts

It is often the children or spouses of people with dementia who take on the main responsibilities for caring for them.¹²¹ Dementia entails changes in cognitive abilities, communication and behaviour.¹²² Those affected can no longer take on familiar tasks within the family, and instead require help and support. Dementia can also cause depressive moods and behaviour that is difficult and stressful for other family members.¹²³ All this can lead to conflicts. If conflicts arise, relatives need help and support in coping with difficult situations and crises.

Some remedy can be found via the project *Gewaltfreie Pflege—Prävention von Gewalt gegen Ältere in der pflegerischen Langzeitversorgung* [non-violent care—prevention of violence against older people in long-term care] run by the BMG-funded Medical Service of the National Association of Statutory

121 Ehrlich and Kelle (2019)

122 World Health Organization (2019a)

123 Zank and Schacke (2007)

Health Insurance Funds and via the BMFSFJ project 'PURFAM'.¹²⁴ A training module has been developed and tested for out-patient services, which uses check-lists to identify critical care situations and enable interventions.

In addition to education, family care-givers can be provided with effective support in overcoming conflicts by means of crisis counselling and psychological counselling. This relies on the availability of nationwide specialised telephone counselling services and online resources. Crises and conflicts can lead to violence in the care environment. Since violence associated with care remains a taboo subject, anonymous means of counselling are particularly important. Wherever possible, services must be structured or networked in such a way that 24-hour counselling is guaranteed seven days a week.

Support and care at home is often associated with psychological stress for family care-givers.¹²⁵ Stress can be caused by failures of communication between the person with dementia and their relatives.¹²⁶ Psychoeducation can help to reduce the feeling of stress and create a more understanding attitude towards the family member affected by dementia, and this can lead to an improvement in the quality of relationships.¹²⁷ Access to such measures should be facilitated for family care-givers. As a great deal of time is often spent in caring for family members, measures involving visitation should be encouraged.

Dementia is often associated with challenging behaviour that increases the risk of violence from both sides.¹²⁸ Violence includes use of physical restraining measures; physical, psychological, verbal and sexual abuse; neglect; and unauthorised appropriation of property of the person needing care.¹²⁹ To prevent violence, care counselling can improve domestic circumstances by adapting care arrangements to defuse problematic situations. This requires sensitisation and educa-

tion of care counsellors on the issue, in order to arrive at appropriate solutions together with relatives.

If family care-givers find themselves in a difficult situation when caring for people with dementia at home, providing them with easily-accessible information can also be helpful. Amongst other things, such information can help care-givers to reflect on their own actions, avoid escalating behaviour and find suitable contact persons. Online services such as the ZQP website www.pflege-gewalt.de can help to educate care-givers and prevent violence in dementia care. Section 5 SGB XI covers 'prevention of violence' as a field of action in its description of health-promoting and preventive measures in full-care and partial in-patient care facilities (GKV-SV: guideline for prevention in in-patient long-term care facilities under Section 5 SGB XI). Approaches to meet this need are being promoted by the long-term care insurance funds and increasingly implemented in in-patient care facilities.¹³⁰ The measures under consideration are targeted at people with dementia and their families. The GKV-SV publishes annual reports on progress towards implementing health-promotion and prevention measures in the field of action 'prevention of violence' under Section 5 SGB XI.

Supporting people with dementia and their relatives in managing conflicts within the family is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

2.7.1 Telephone counselling and pastoral care for people with dementia and their relatives in crisis situations

The federal states are striving to ensure that telephone counselling is available in crisis situations, specifically for people with dementia and their relatives. In addition, pastoral telephone

124 Zank and Schacke (2013)

125 Kurz and Wilz (2011)

126 Heru et al. (2004)

127 Engel et al. (2016)

128 Zank and Schacke (2007)

129 Görden (2017)

130 Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. und GKV-Spitzenverband (2019)

services for people with dementia and their relatives are being given increased publicity. The DALzG is examining whether cooperating with existing hot-lines, for instance the national crisis hotline, could improve accessibility to telephone counselling to 24 hours a day, seven days a week.

By the end of 2024, existing services will have been reviewed and, if necessary, expanded.

2.7.2 Improving access to psychological counselling for relatives at home

The GKV-SV is assessing the extent to which access to counselling and psychoeducation for relatives of people with dementia can be improved by means of specialists in psychiatry and psychotherapy, specialists in psychosomatic medicine, medical psychotherapists, and specialists in neurology.

By the end of 2022, the assessment will have been completed and conclusions will be drawn on how to improve access to psychological counselling services at home.

2.7.3 Inclusion of the topic of ‘violence in care’ in the guidelines for care counselling issued by the GKV-SV

The GKV-SV will examine the extent to which the guidelines for the uniform implementation of long-term care counselling under Section 7a SGB XI of 7 May 2018 (Long-Term Care Counselling Guidelines) need to be adapted to combat the issue of ‘violence in care’ and, if required, will introduce appropriate supplementary provisions. In addition, if required, the recommendations by the GKV-SV under Section 7a paragraph 3 sentence 3 SGB XI, dated 29 August 2008, in the version of 22 May 2018, concerning the required number, qualifications and advanced education of care counsellors will be amended accordingly.

By the end of 2022, the subject of ‘violence in care’ will have been integrated into the Long-Term Care Counselling Guidelines.

2.7.4 Intensification of educational measures and communication of preventive approaches

Educational measures on the subject of ‘violence in care’ will be expanded, and practical preventive approaches for (partially) informal care scenarios will be taught. To achieve this, the ZQP is supplementing its existing portal on the subject, www.pflege-gewalt.de, with additional dementia-specific content. This will include systematic research into existing online counselling services, supporting people with dementia and their relatives in crisis situations, and linking relevant resources on the portal.

By the end of 2022, the themed portal will have been expanded specifically to cover dementia, and the ZQP will be gathering data on visitor numbers.

2.8 Developing and expanding prevention and rehabilitation services for family care-givers

Assuming the responsibilities of caring for people with dementia can have negative effects on the health, especially the mental health, of family members.¹³¹ Family care-givers of people with dementia are also affected by physical illness more often than other carers.¹³² They can provide care over a longer period if they receive regular support and opportunities to recuperate. Easily-accessible, visiting support that is tailored to individual needs is, therefore, important. Telephone support or online self-help groups can be helpful in preventing psychological overburdening when caring for people with dementia. The BMG is implementing the project *Online Selbsthilfe Initiativen für Pflegende Angehörige* [Online Self-Help Initiatives for Family Care-givers] (OSHI-PA)¹³³. The aim of the project is to develop a self-help portal for online self-help groups. An app, ‘in.kontakt’, has been developed. People needing care and their relatives, as well as interested parties, can exchange experiences and information and mutually support each other with content structured

131 Zank and Schacke (2007)

132 Deutsche Gesellschaft für Psychiatrie und Psychotherapie und Deutsche Gesellschaft für Neurologie (2016)

133 Institut für Teilhabeforschung (2019)

around specific dementia issues, target groups, nationwide information or even local issues.

Beyond this, psychosocial counselling and psychotherapy can support the mental health of family members. Taking a holistic approach to the circumstances of family care-givers, a stance that is generally not common in multidisciplinary counselling, can be very beneficial. This can be achieved by means of systemic approaches.¹³⁴

Improving the health of family care-givers should also be encouraged with a view to prevention. Services to this end find their basis in the GKV guideline on prevention and in the framework of Germany's National Prevention Conference and need to be further developed. It is equally important to provide family care-givers with comprehensive information on ways to avoid overburdening and health problems. Existing online information resources are to be expanded to meet the needs of family care-givers of people with dementia.

The counselling and training measures envisaged in SGB XI (Section 7a, 37 paragraph 3 and Section 45 SGB XI) are also intended to give persons needing long-term care and their relatives the opportunity to gain early access to preventive services. Information on prevention services, especially psychosocial support, is particularly important for family care-givers. They can use them to avoid the burdens on their health that arise from caring for and supporting people in need of care. In addition, reducing the burden on family care-givers can stabilise the circumstances of care at home. Relatives who are under great strain due to their role as care-givers, can particularly benefit from preventive measures.¹³⁵ Hence, the preventive potential of the various counselling formats needs to be more fully exploited.¹³⁶

Family care-givers need time to recuperate and have opportunities to distance themselves from caring at home. For this reason, since the adoption of the Long-term Care Reorientation Act, a

separate entitlement to rehabilitation services for family care-givers has been established.¹³⁷ According to this, family care-givers must be enabled to take advantage of in-patient rehabilitation by ensuring that the person with dementia they usually care for is also provided with care and assistance. Family care-givers who wish to benefit from institutional rehabilitation are, thus, entitled to the person they are caring for also being provided with healthcare in the same institution (Section 40 paragraph 3 SGB V). If the person in need of care cannot be placed in the same institution, long-term care insurers and health insurers are to coordinate care. To enable an increasing uptake of such services, relatives need to be better informed about such entitlements.

Working family care-givers providing care can also claim pension insurance benefits for rehabilitation to preserve or restore their individual earning ability. In such cases, the person with dementia being cared for likewise needs to be looked after during the rehabilitation of the care-giver, and this needs to be coordinated with the long-term care insurer. This is particularly true if the person requiring care is to be admitted to an institution other than the rehabilitation institution of the care-giving relative.

Institutional rehabilitation programmes for family care-givers can also take place in the preventive and rehabilitation centres of the *Müttergenesungswerk* [Mothers' Convalescence Aid Organisation].¹³⁸ Recently, the Care Staff Strengthening Act established the right of family care-givers to institutional rehabilitation, without the requirement that they first have to make use of ambulatory rehabilitation measures. To date, few care-givers have availed themselves of targeted group-specific rehabilitation. Relatives need to be better informed and made aware of this entitlement, amongst other things via the convalescence cure advice centres of the non-governmental welfare organisations.

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134 Schwing and Fryszer (2013)

135 Rothgang and Müller (2018)

136 Angele and Calero (2019)

137 Hertle et al. (2015)

138 Reuter (2019)

Caring for family members is all-encompassing for family care-givers, and opportunities to take holidays together are, therefore, particularly valuable. The costs for care and support of a family member affected by dementia can be covered by long-term care insurance benefits, that is, relief benefits under Section 45b SGB XI or prevention care under Section 39 SGB XI.

Developing and expanding prevention and rehabilitation services for relatives of people with dementia is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

2.8.1 Prevention programme for family care-givers

The GKV-SV views family care-givers as an important group of persons who need to be supported by means of health promotion and prevention measures. To this end, the GKV-SV has already established services within its guideline on prevention and, likewise, within the framework of the National Prevention Conference. Getting people to make use of these is a priority and, if necessary, they should be further developed. In addition, based on past experience and knowledge, the GKV-SV is investigating the possibilities of launching a new programme to support this group of persons once funding for the existing local programme has expired.

By the end of 2023, the GKV-SV will publish the results of its investigation.

2.8.2 Strengthening of psychosocial counselling

The leading non-governmental welfare organisations encourage their family counselling centres to offer more psychosocial counselling for families of people with dementia, and the BMFSFJ provides information on this on the Dementia Signpost site. In addition, Malteser Germany will implement a pilot project aimed at relieving the burden on and providing stabilisation for family care-givers of people with dementia. A specific easily-accessible, systemic programme is being developed and implemented in cooperation with various professions and involving a multi-professional team.



By the end of 2022, psychosocial counselling will be increasingly offered in family counselling centres run by the welfare organisations. By the end of 2024, the pilot project will have been completed along with an accompanying evaluation, and recommendations for action will have been made regarding its implementation.

2.8.3 Addition of dementia-specific topics to the portal www.pflege-praevention.de

The ZQP is further developing its existing prevention portal, www.pflege-praevention.de, to provide information on preventive measures for family care-givers in a manner that is as accessible as possible. Information and tips for family care-givers of people with dementia and for professional healthcare professionals will be expanded. Stakeholders in the National Dementia Strategy will submit their own content and resources and link to the ZQP prevention portal.

By the end of 2022, the prevention portal will have been expanded and the National Dementia Strategy stakeholders will likewise link their sites to the prevention portal. The ZQP will collect visitor figures for the portal.



2.8.4 Entitlement to rehabilitation for family care-givers and simultaneous healthcare for people with dementia according to Section 40 paragraph 3 sentences 2 and 3 SGB V

The GKV-SV will strive to ensure that health insurance funds provide more information about relatives' entitlement to rehabilitation and simultaneous care for people with dementia, which has been in place since 1 January 2019. The local authority associations and the leading non-governmental welfare organisations are working to ensure that counselling centres also provide information on this entitlement. The DALzG will also increase its efforts to publicise the list of rehabilitation programmes. The DKG will remind hospitals' social services that in the context of discharge management (Section 39 SGB V), they should inform family care-givers that they have an entitlement to rehabilitation, if required, and support them in applying for admission to rehabilitation.

By the end of 2022, the GKV-SV, the leading non-governmental welfare associations and the local authority associations will be working to ensure that the recipients of care are provided

with information on their entitlement to such benefits. By the end of 2022, the DALzG will have increased its efforts to publicise the list of rehabilitation programmes. By the end of 2022, the DKG will have informed hospital social services about such programmes. In the context of discharge management, they will document that they have informed family care-givers concerning the rehabilitation programmes on offer.

2.8.5 Coordination of health services for people with dementia during rehabilitation of family care-givers in employment

The BMAS will assess, on behalf of the wider group of providers of medical services for rehabilitation (providers of statutory German pension insurance and accident insurance), how this can be coordinated with health services for people with dementia in line with Section 40 paragraph 3 sentence 3 SGB V, taking into account existing structures.

The assessment will have been carried out by the end of 2022. Changes to legislation will be initiated as required.

2.8.6 Rehabilitation and provision of care for family care-givers in facilities of the Mothers' Convalescence Aid Organisation

The leading non-governmental welfare organisations will increasingly promote rehabilitation and preventive care for family care-givers of people with dementia in facilities run by the Mothers' Convalescence Aid Organisation, and the BMFSFJ will disseminate information on this.

By the end of 2022, measures to disseminate information will have been taken.

2.8.7 Joint holidays for people with dementia and their family care-givers

The BMFSFJ will collaborate with the *Bundesarbeitsgemeinschaft Familienerholung* [Federal Association for Family Holidays] to further develop and publicise opportunities for care-givers to go on joint holidays with relatives who have dementia.

By the end of 2022, the opportunities will have been further developed and publicised.

2.8.8 Prevention counselling at home according to Section 7a SGB XI

The PKV association has announced that its subsidiary company, compass *private pflegeberatung*, will, in future, be providing specific visiting prevention counselling services nationwide for family care-givers. This specialised counselling is to be provided at an early stage of care, so as to identify stresses caused by care early on and to mitigate these by means of individualised interventions.

By the end of 2022, a report will have been published on the findings on and effects of prevention counselling for family care-givers.

2.9 Supporting relatives of people with dementia in end-of-life care

People with dementia need adequate hospice and palliative care, regardless of whether they live at home or in a residential care facility. As defined by the WHO,¹³⁹ hospice and palliative care involves measures to improve the quality of life of people living with incurable diseases. The most important of these are measures to prevent further diseases and measures to control symptoms, in particular to treat pain and other complaints of a physical, psychological and spiritual nature. However, palliative care, as defined by the WHO, must also include measures to improve the quality of life of relatives. In the last phase of the life of a loved one, they also face particular burdens and challenges. This is especially true when relatives are involved in care. At the end of life, the burden of care generally increases. Relatives need additional counselling and support to cope themselves with parting from the dying, to accompany them on their last journey and to guarantee good palliative care.¹⁴⁰ Caring for terminally ill dementia patients is associated with very particular needs. In addition to cognitive deficits, the ability of patients to communicate changes;¹⁴¹ for example, they often have difficulty communicating pain.

Relatives are often required to take decisions about medical care that can have particularly far-reaching consequences at the end of life. They have the challenging task of respecting the wishes of the person concerned and shaping the end of life to suit their wishes, even if these are not necessarily in line with their own ideas and wishes. Ethical and legal questions may arise, and relatives need to be given advice to resolve these. Under the Hospice and Palliative Care Act, insured persons are entitled to receive private consultation on palliative and hospice care services. This also comprises information on legal provisions for the end of life.

139 World Health Organization (no date)

140 Ferrar and Voltz (2018); Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz (2017);

141 World Health Organization (2012)

People with dementia who are cared for at home are entitled not only to general medical care by their family doctor and nursing care, but also to ambulatory palliative care. This can relieve the burden on family care-givers and help people to die with dignity. Relatives of people with dementia should be better informed about the support available and about further palliative and hospice services.

The objectives of the Charter for the Care of the Critically Ill and the Dying in Germany are to ensure high-quality hospice and palliative care that meets the needs of all those affected and is accessible to all, providing the best possible quality of life for those receiving care and support at the end of life.¹⁴² The charter's national strategy has called for health and care institutions to raise awareness of the special needs of people with dementia.¹⁴³ To raise awareness amongst hospice and palliative care providers of the special needs of people with dementia and their relatives, examples of good practice in the field should be highlighted and local cooperation promoted. Additionally, in the context of providing medical and nursing care, more attention should be paid to the needs of the relatives of people with dementia, as they play a central role in hospice and palliative care for people with dementia.

Voluntary engagement is still a mainstay of hospice and palliative care. Accompanying people with dementia and their relatives on a voluntary basis is also becoming increasingly important. Volunteers accompanying the terminally ill need specialised knowledge and experience in working with people with dementia at the end of their lives. Communication is a case in point. Training resources¹⁴⁴ on the subject are available and should be regularly utilised. Volunteers accompanying the terminally ill should continue to be supported and valued for their work.

Supporting relatives of people with dementia in caring for the terminally ill is one objective of the National Dementia Strategy. The following measures have been agreed upon to achieve this.

2.9.1 Advice and information on hospice and palliative care

The BMFSFJ, along with the local authority associations, the leading non-governmental welfare organisations, the DHPV and the DGP are working to ensure that local stakeholders, such as senior citizens' offices, local alliances and multi-generational houses, work with out-patient hospice services throughout Germany to raise awareness amongst the relatives of people with dementia of the options open to them for hospice and palliative care and support at an early stage. Online information on hospice and palliative care will also be improved. To accomplish this, the BMFSFJ will update the Dementia Signpost site to include these issues, incorporating a 'Hospice and Palliative Care in Germany' guide.

By the end of 2024, the local stakeholders will be taking on this responsibility. By the end of 2024, concepts for sensitisation will have been drawn up and the Dementia Signpost site will have been updated to include hospice and palliative care.

2.9.2 Dissemination of examples of good practice from hospice work and palliative care

With a view to supporting people with dementia and integrating their relatives, examples of good practice in hospice work and palliative care will be effectively disseminated nationwide. The DHPV, the DGP, the BMFSFJ, the BMG, the DAIZG, the leading non-governmental welfare organisations and the federal states will endeavour to raise awareness of the results of good hospice and palliative care work involving people with dementia and the integration of their relatives. The DGP will prepare informational material for the multipliers on this issue.

By the end of 2022, the stakeholders, in particular the DGP and DHPV, will have published examples of good practice in an accessible format. By the end of 2024, the DGP will have presented accessible informational material and made it available to stakeholders.

142 Deutsche Gesellschaft für Palliativmedizin et al. (2016)

143 Ibid.

144 Deutscher Hospiz- und Palliativverband e.V. und Deutsche Alzheimer Gesellschaft (2012); Schmidt et al. (2015)



2.9.3 Establishment and expansion of cooperative structures in hospice and palliative care

The DALzG, the leading non-governmental welfare organisations, the VDAB, the bpa and the DKG will raise awareness amongst their members to the special needs of relatives of people with dementia with regard to hospice work and palliative care and will encourage local cooperation. To this end, the BAGFW will publish a paper on coordinating regional hospice and palliative care networks. Furthermore, Malteser Germany in collaboration with the DHPV and the DGP will prepare a handbook. The BAGSO is raising awareness of cooperation with hospice associations via its networking centre 'Local Alliances for People with Dementia'. In addition, good examples of cooperation between local networks and hospice associations will be listed on the website of the networking centre.

By the end of 2024, a handbook will have been prepared and distributed. By the end of 2024, the stakeholders will have established cooperative structures with hospice services at various levels.

2.9.4 Attracting volunteers to accompany people with dementia in the last phase of life

The DHPV and the leading non-governmental welfare organisations, with the participation of the DALzG, are committed to providing nationwide training for volunteers to accompany terminally ill persons with dementia in hospice services and facilities. The BMFSFJ, the leading non-governmental welfare organisations, the DHPV, the DGP and the BÄK, as charter signatories, will support training initiatives in hospice work aimed, in particular, at recruiting and specifically training volunteers, as well as at providing information to those persons involved, with the objective of relieving the burden on family care-givers of terminally ill dementia patients. They will foster the expansion of hospice-palliative networks in local and regional dementia networks.

By the end of 2024, the DHPV will have updated its curriculum *Mit-Gefühl* [with empathy] together with the DALzG. By the end of 2024, the leading non-governmental welfare organisations and other stakeholders will have taken steps to support the training and deployment of voluntary hospice companions, particularly in the area of public relations.



Field of action 3

Advancing health and long-term care services for people with dementia

People with dementia require medical and nursing care that is tailored to their individual health-related needs. This requires not only the expansion of appropriate services and adequate staffing, but also a low-threshold and barrier-free structure that enables access for those affected¹⁴⁵ and their families¹⁴⁶. In addition, effective networking of the various services is crucial. Hence, efficient cooperation between stakeholders providing cross-sectoral health services for people with dementia is a central objective of the National Dementia Strategy.

In recent years, numerous endeavours have been made to improve the medical treatment and care of people with dementia by the federal government, the federal states, municipal authorities and all those involved in health services. Such efforts have included the reform of long-term care insurance and *Hilfe zur Pflege* [help for care], as per SGB XII within the framework of the Long-Term Care Strengthening Acts. The impact of the Long-Term Care Strengthening Acts II and III was evaluated on the basis of Section 18c SGB XI. The findings of the evaluation were published in January 2020.¹⁴⁷ One of the key issues was the introduction of the new definition of care need: With its introduction, capabilities and impair-

ments due to gerontopsychiatric diseases are systematically taken into consideration in assessing dependency on long-term care. This has made it possible to better assess the individual circumstances and care needs of people with dementia today. Since the reform, a greater number of people with dementia have been receiving more substantial benefits from long-term care insurance.¹⁴⁸ The new definition of care need is also the basis for assessing care in the context of long-term care insurance and 'help for care'. It is, consequently, also a reference point for ongoing developments, issues and processes in long-term care insurance (for example, quality improvements, personnel assessment procedures, long-term care counselling). This approach to long-term care involves a change of perspective, moving away from a deficit-oriented view of the person requiring care and adopting a resource-oriented approach instead. The effect is to focus on the person in need of care with their individual needs and to support them in leading a life that is as self-determined and as independent as possible. In this context, long-term care aims to 'support a person with dementia in accomplishing everyday activities and pursuits by identifying opportunities for needs-based occupation and anchoring these in daily life'.¹⁴⁹

145 In this context, affected persons refer to people with dementia. People who provide nursing and care for people with dementia are also 'affected' by the condition. However, in this document they are not subsumed under the term 'affected persons'.

146 In this context, relatives are understood to be those persons within the close social environment of people with dementia who are responsible for care and support. The focus in this field of action is on relatives within a family. However, in this context, relatives can also refer to people who have a friendly or neighbourly relationship with the person with dementia.

147 Bundesministerium für Gesundheit (2020)

148 Rothgang (2018)

149 Wingenfeld et al. (2017): page 8

The further development and promotion of long-term care and the support infrastructure provided by the federal states (under Section 9 SGB XI) also contributes to this goal. In particular, the federal states can take measures aimed at improving the circumstances of people with dementia and their relatives.¹⁵⁰

As advocated by the KAP campaign, a large number of measures were introduced to improve the working conditions of nursing staff in Germany. These measures, which are currently being implemented, will also benefit professional care-givers of people with dementia and help to empower those affected.

To ensure that people with dementia are cared for and supported in accordance with their needs, it is essential that care and support staff are appropriately qualified. This applies not only to support at home but also to all other areas of nursing care provision. People with dementia engage in individual and complex patterns of behaviour that are not always compatible with the structures and work-flows of an institution or hospital. Nursing staff need to be better equipped to independently cope with such challenges in practice.¹⁵¹ This will allow them to provide individualised support to people with dementia, and will result in targeted employment of staff.

Most people with dementia would, despite their condition, prefer to continue living in their own homes and to be looked after and cared for there. This task is primarily assumed by family care-givers. Support of care at home, measures to alleviate the associated burden, and quality assurance of care are also dependent on the availability of professional care, nursing, therapy and rehabilitation services. These services need to be adapted and coordinated to the special needs of people with dementia. It is only on this basis that individually tailored care at home can be successful over a long period of time.

Fully residential long-term care is another important health service available to people with

dementia. High-quality, fully residential long-term care for people with dementia is dependent on implementing comprehensive dementia-specific strategies in nursing homes. This is especially important when people with dementia engage in behaviour that is likely to lead to conflict when cohabiting with others. Dementia-sensitive structuring of fully residential long-term care requires continuous development of the relevant framework conditions.

Since the number of people with dementia will continue to rise in coming years, hospitals must also continually adapt to caring for patients with dementia. Dementia-sensitive structuring of care processes in acute care in hospitals is a major challenge in view of the short lengths of stay of dementia patients and given the fact that, in contrast to geriatric care facilities, the care provided by hospitals is not focused on structuring daily life and living. In addition to the levels of staffing required, it is, therefore, essential to adapt work processes and the environment to the needs of people with dementia.

In the context of medical care, contact with general practitioners and medical specialists plays a particularly important role for people with dementia and their relatives. These doctors provide medical advice and treatment and, in many cases, coordinate medical care. Strengthening and developing these services in the interests of people with dementia, is one of the objectives of the National Dementia Strategy. In addition, medical health-care services for people with dementia need to be expanded.

Effective medical, therapeutic and nursing health-care services for people with dementia is dependent on a functioning network between all those involved and on good interface management. Dementia is associated with a complex range of care needs, and it is imperative that different health and social care professionals collaborate in the interests of those affected. At the same time, people with dementia are particularly dependent on coordination of health services and safeguard-

150 For instance, since 2018, partial in-patient and full-care facilities as well as short-term care facilities in Bavaria have been eligible for funding for projects aimed at designing indoor and outdoor spaces for dementia-sensitive care in line with funding guidelines for long-term care.

151 Erpenbeck and Sauter (2013); Dewing and Pritchard (2009)

ing of their interests by others. Low-threshold structures for cooperation are, therefore, required.

Prevention and rehabilitation measures can prevent dementia from developing, make it easier to cope with the condition, preserve functional ability, slow down chronic progression of the condition and, in doing so, increase social participation. Rehabilitation services can also help to improve the quality of life of people with dementia, provided they are adapted to the specific needs of persons with dementia. This is especially true for people who are undergoing rehabilitation not primarily for dementia, but for other disorders. This is the rationale for expanding dementia-sensitive rehabilitation services. It remains to be seen whether rehabilitation can also improve dementia symptomatology and, hence, should be prescribed more extensively.

Medical and nursing care for people with dementia can be divided into the following four areas:

- Capacities and staffing—dementia care is dependent on sufficient health services capacities and adequate levels of staffing.
- Training and quality—staff must be qualified for the tasks they perform in caring for people with dementia. The quality of health services needs to be assured and further developed.
- Cooperation, networking and coordination—all those involved in health services¹⁵² need to work together within the fragmented dementia care and health system.
- Dementia-sensitive design—all facilities and healthcare sites should be adapted to the special needs of people with dementia. This encompasses not only the physical design of facilities but also the organisational structure of healthcare services and how to meet the needs of those affected.

3.1 Strengthening out-patient care, partial in-patient care and short-term care

In 2017, about three quarters (2.59 million or 76 per cent) of all people requiring long-term care in Germany were cared for at home, about two thirds of them solely by their relatives.¹⁵³ The figures for people with dementia are probably comparable. No separate statistical data are available on care for people with dementia at home.

As dementia progresses, those affected usually require more support and care. Even if family caregivers carry on assuming a portion of these tasks, professional care-givers' support is important in relieving the burden on family care-givers and in ensuring quality of care at home. Hence, the out-patient and partial in-patient care under Sections 36 and 41 SGB XI, the psychiatric home nursing care under Section 37 SGB V and short-term care services under Section 42 SGB XI should be structured in such a way that people with dementia can live at home for as long as possible, if this corresponds with their wishes. This also applies to accompanying support at the end of life and palliative care. The new definition of care need, which was introduced in 2017, forms the essential basis for the structuring of long-term care assistance. The above-mentioned expert report *Strukturierung und Beschreibung pflegerischer Aufgaben auf der Grundlage des neuen Pflegebedürftigkeitsbegriffs* [Structuring and describing long-term care tasks on the basis of the new definition of care need] and the document *Leitfaden: Das neue Pflegeverständnis in der Praxis* [Guideline—the novel approach to long-term care in practice], which was prepared following the academic study on the introduction of the new definition of care need, provide an important introduction to implementing the new definition of care need in practice and adapting the concepts and procedures in out-patient and in-patient care facilities.

152 Field of action 3 focuses on the professional stakeholders in health services. Family care-givers and volunteers contribute most significantly in fields of action 1 and 2.

153 Statistisches Bundesamt (2018): page 8

The new definition of care need has led to a change of perspective in long-term care that takes the needs of people with dementia into account to a greater extent, not only in the process of assessment, but also with regard to the tasks of long-term care and the structuring of long-term care assistance. This new approach to long-term care also needs to be applied to the services and procedures provided in out-patient care, partial in-patient care and short-term care. As part of the KAP campaign, the associations of long-term care facilities, the GKV-SV, the PKV association and the Federal Ministry of Health have agreed to develop an implementation strategy to support long-term care facilities in implementing, both conceptually and practically, the diverse yet closely related measures.

In the framework of the Long-Term Care Strengthening Acts, the services provided for short-term care and for preventive, day and night care were significantly expanded.¹⁵⁴ Nevertheless, health service structures need to be continuously developed in line with demand, and the coordination of services across the entirety of out-patient care needs to be enhanced.

In the Appointment Service and Care Provision Act, which came into force in May 2019, domiciliary care providers were introduced as approved service providers under long-term care insurance. Ambulatory domiciliary care institutions provide long-term care and assistance with domestic tasks for people needing care.¹⁵⁵ Ambulatory domiciliary care services can ease the burden, in particular, on people with dementia and their family caregivers, as these groups are particularly in need of support and care. The domestic support and household assistance provided by ambulatory domiciliary care was evaluated within the framework of the pilot project conducted under Section 125 SGB XI (former version). The academic findings of the pilot project demonstrated domiciliary care services were beneficial to the quality

of life and to the perceived burden of those using the services and to their relatives.¹⁵⁶ The GKV-SV has issued guidelines for quality assurance in domiciliary care as per Section 112a SGB XI. Based on these, domiciliary care services are to be expanded within the existing structures.

Short-term care represents an important way of providing relief for people with dementia living at home and for their relatives. Short-term care under Section 42 SGB XI can be provided in transitional and relief phases or in crisis situations, if care at home or in a day-care facility is not available for some reason. A principal care-giver, for example, may have recently been treated in hospital or have fallen ill. Short-term care can help to stabilise care at home in such cases. People with dementia often experience changes in their familiar surroundings as stressful, and this is one reason why short-term care needs to be provided in a dementia-sensitive manner.¹⁵⁷ Short-term care assignments are usually offered either as occasional assignments in fully residential long-term care facilities or via purely short-term care facilities. In spite of high demand, the number of purely short-term care facilities in Germany has declined over the past 20 years.¹⁵⁸ One of the main reasons why the supply of short-term care has not matched demand is that it is economically difficult to provide both purely and occasional assignments. In contrast, in the short term they are made use of at a constant rate: in 2018, approximately 524,000 people needing care took advantage of short-term care services. This is approximately equivalent to the figure from 2017.¹⁵⁹ To enable people with dementia to make use of the relevant services on offer, the framework conditions need to be correspondingly attractive for short-term care to be developed and expanded throughout Germany, both in the form of long-term care institutions providing occasional short-term care and that of purely short-term care institutions.

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154 PSG I Erstes Pflegestärkungsgesetz; PSG II Zweites Pflegestärkungsgesetz; PSG III Drittes Pflegestärkungsgesetz

155 These services include engaging older people in conversations, providing them with activities that stimulate their memory and accompanying them on walks.

156 Rellecke et al. (2018)

157 Wächtershäuser (2016)

158 In 1999: 245; in 2005: 280, in 2017: 148 institutions providing short-term care. The number of short-term care institutions in Germany can be obtained from the Federal Health Reporting website at www.gbe-bund.de. Last reviewed on 11 February 2020.

159 Bundesministerium für Gesundheit (2019)



Home nursing under Section 37 SGB V regulates psychiatric care at home (pHKP), and people with dementia are one group who are entitled to the services covered. In the framework of home nursing, they are entitled to ongoing specialist medical and nursing support. This can include providing assistance in periods of crisis, training in skills and abilities to deal autonomously with their condition, or developing compensatory aids in the event of condition-related impediments (incapacities). In an effort to uniformly regulate the structural requirements for nursing care services providing pHKP, it is currently being deliberated whether the framework recommendations under Section 132a (1) SGB V should be supplemented. In the first quarter of 2020, these deliberations will have been concluded.

Domestic workers, for instance those who work in group homes for people with dementia, undertake basic household tasks, such as preparing meals. The training required of these workers and their tasks are regulated differently depending on the federal state and the health services scenario. How these requirements and qualifications can be aligned needs to be examined.

‘Sociotherapy’ under Section 37a SGB V is intended to support patients in making use of out-patient services rather than hospital treatment. Sociotherapeutic support covers, among other things, coordinating and accompanying people to appointments and supporting them in structuring their daily lives.¹⁶⁰ This service is, fundamentally, also relevant to people with dementia. Hence, an investigation will be conducted to determine whether people with dementia living at home might benefit from sociotherapy.

The last phase of life and care at the end of life poses a particular challenge in caring for people with dementia at home, one example being how to identify pain. During this phase, home nursing care in the context of general out-patient palliative care (AAPV) can be provided. This allows people with dementia to receive palliative care that focuses on improving their quality of life, for example by controlling pain. In addition, specialised out-patient palliative care (SAPV) can be provided as a specialized service by doctors and qualified nurses with specialist qualifications and experience,¹⁶¹ as well as by psychosocial specialists if the patient’s symptoms are particularly

160 Gemeinsamer Bundesausschuss (2017)

161 In this context, qualified nurses are considered to be those who have completed a three-year professional training course in nursing or have studied nursing.

complex.¹⁶² People with dementia at the end of life have special needs and demands that require qualified handling by nursing professionals. Hence, specialist advanced and continued courses should be examined and adapted, and supervisory resources for nursing staff¹⁶³ should be established.

The Charter for the Care of the Critically Ill and the Dying in Germany also plays a role in improving the circumstances of people with dementia in the last phase of life. Its aim is to provide high-quality hospice and palliative care that meets the needs of all those affected and is accessible to all, ensuring the best possible quality of life during care and support at the end of life.¹⁶⁴ It details measures that need to be implemented to improve access to hospice and palliative care for people with dementia.

Counselling of people with dementia and their family care-givers is an important task. The comprehensive counselling offered by long-term care consultants from long-term care insurers under Section 7a SGB XI, represents one of the options available. Such counselling can also take place under Section 7c SGB XI in cooperation with municipal authorities in nursing care support centres. In addition, municipal authorities also offer counselling on questions of care and old age under Section 71 SGB XII. The welfare organisations also offer counselling. People needing care and their relatives can also make use of counselling on specific issues relating to care at home under Section 37 paragraph 3 SGB XI. This allows regular monitoring and, if required, adaptation of care to the changing care needs of people cared for at home. The changed legal framework for this form of counselling, which permits more time for and thus better quality of counselling, can contribute to improving the circumstances of care for people with dementia in their own domestic environment (for example flat/house, residential group). This development is to be encouraged.

With a view to improving the care of people with dementia, the German Network for Quality Development in Nursing Care has developed an expert standard entitled Sustaining and Fostering Relationships with People with Dementia. This standard focuses on the quality of life of people with dementia and identifies ways to promote it through fostering relationships. Once the expert standard has been implemented, it will help, amongst other things, to avoid the use of physical restraining measures. Implementing the expert standard over all long-term care services is a central objective of the National Dementia Strategy.

Providing effective treatment and care for people with dementia in out-patient, partly in-patient and short-term care is crucially dependent on treating people with dementia appropriately and setting up work processes to achieve this. Such efforts require appropriately qualified, multi-professional teams that can jointly formulate a customised care programme. This requires all occupational groups involved in care to be appropriately trained. A wide range of training and continued education programmes specific to the needs of people with dementia are already available.¹⁶⁵ In addition to various continuing educational courses, such as the Gerontopsychiatrische *Basisqualifikation* [foundational qualification in gerontopsychiatry] offered by various institutions, some federal states offer state-regulated continued education to become specialists in gerontopsychiatric nursing and care. The task of such specialists in gerontopsychiatric nursing and care involves, in particular, providing professional gerontopsychiatric care and nursing that incorporates modern nursing and care models. Alongside qualified nurses, care and support for people with dementia always involves other groups of professionals who have no nursing or medical training. This applies to care at home, in fully residential long-term care facilities, in day-care and short-

162 Gemeinsamer Bundesausschuss (2019)

163 In this context, nursing staff are considered to be those who have either completed a three-year professional training course in nursing, have studied nursing or have trained as nursing assistants.

164 Deutsche Gesellschaft für Palliativmedizin et al. (2016)

165 Advanced training should be viewed as life-long learning, with the goal of constantly refreshing and updating the knowledge, skills and abilities acquired through training and professional activity in line with the latest scientific and technological developments. Advanced training involves participation in advanced training courses and studying the specialist literature. Continued education, in contrast, requires resumption of organised study at state-recognised continued educational institutions after completion of vocational training and employment in the profession in question, with the aim of furthering professional qualifications and qualifying participants to work in specialist areas. Continued education teaches participants subject-related theoretical knowledge and practical skills and culminates in gaining a continued education professional title.

term care facilities and in hospitals. These groups of professionals include specialists in home economics. They are generally not trained to deal with people with dementia, but have contact with them in their daily work. A basic knowledge of dementia, amongst other things, is indispensable in successfully shaping such contact. Since 2017, as part of the Third Long-Term Care Strengthening Act, cross-sectoral state care committees can be established to improve care in the home and in residential areas. These committees jointly develop recommendations for structuring care planning in federal states. The complex care setting of people with dementia, in particular, requires cross-sectoral coordination of out-patient health services. To this end, the joint recommendations on long-term care under Section 8a paragraph 2 SGB XI, and in particular those regarding people with dementia, need to be examined.

Promoting out-patient, partial in-patient and short-term care for people with dementia is one objective of the National Dementia Strategy.

The following measures will be taken to bring about improvements in the area of capacities and personnel.

3.1.1 Alignment of long-term care services to the new definition of care need

Service funders and providers under Section 75 SGB XI are working to ensure that the new definition of care need and the approach to long-term care based on the academic understanding of this definition are implemented in the state framework agreements for out-patient, partial in-patient care and short-term care. This will establish a structural framework for implementing long-term care tasks specific to people with dementia. The leading non-governmental welfare organisations, the bpa and the VDAB are supporting their members within the framework of the implementation strategy to implement this academically-founded approach to nursing care in out-patient, partial in-patient and short-term care facilities for people with dementia.

By the end of 2022, the first steps of the implementation strategy will have been taken.



3.1.2 Expansion of domiciliary care for people with dementia

The local authority associations, the federal states, the BMFSFJ, the BMG, the GKV-SV, the PKV association and the VDAB are supporting the domiciliary services introduced under the Appointment Service and Care Provision Act to expand, and are disseminating the guidelines for quality assurance in domiciliary care as per Section 112a SGB XI. The GKV-SV is developing and publishing a supplementary guide on this subject.

Service provider and funding associations will work to ensure that the framework-agreement regulations at state level under Section 75 SGB XI will be correspondingly amended by the end of 2022 to reflect the introduction of domiciliary care services.



3.1.3 Further development of short-term care for people with dementia

The bpa, the BAGFW, the GKV-SV, the PKV association and the VDAB are committed to enhancing the quality of short-term care services and expand them to include people with dementia. The stakeholders are working to ensure that the parties to the agreement at state level examine the corresponding federal framework agreement regulations to this end, in accordance with Sections 75, 85 and 86 SGB XI. In sum, framework conditions must be created that enable short-term care assignments to be operated economically, including those involving people with dementia.

The stakeholders will work to ensure that the regulations have been adapted by the end of 2022.

3.1.4 Uniform implementation of psychiatric care at home into the provision of ambulatory care

The GKV-SV, the BAGFW, the bpa and the VDAB, as contractual partners are striving to establish—with the framework recommendations under Section 132a paragraph 1 SGB V—nationwide uniform framework conditions for regional health services supply contracts as per Section 132a paragraph 4 SGB V.

They plan to present the revised nationwide uniform framework recommendations by the end of 2022, and corresponding health services supply contracts at state level by the end of 2024.

3.1.5 Inclusion of skilled domestic workers into health services

Together with the associations of professional home economics services (the umbrella organisation for whom is the German Home Economics Council), and with the participation of the societal partners and the relevant organisations, the BMG is holding a workshop to examine the feasibility of involving home economics specialists more closely in the provision of home economics services for people in need of long-term care and, in particular, for people with dementia. The aim is to expand the pool of specialists in the provision of health services for people in need of long-term care and to relieve the burden on professional care-givers.

By the end of 2022, the workshop will have been held and recommendations for action will have been formulated.

3.1.6 ‘Sociotherapy’ as per Section 37a SGB V

As members of the G-BA, the DKG, the GKV-SV and the KBV are committed to examining whether and how patients with dementia could benefit more from prescribed sociotherapy. Once they have completed their examination, they will, if necessary, endeavour to adapt the directive accordingly.

By the end of 2022, the G-BA will have submitted its report on the issue.

3.1.7 Implementation of universal ambulatory palliative care

The local authority associations, the GKV-SV, the KBV and the service providers (bpa, BAGFW, VDAB) are working within the remit of their responsibilities to ensure that the special concerns of people with dementia are taken into account when implementing the AAPV in the federal states.

By the end of 2022, the stakeholders will have reported on developments in the federal states.

3.1.8 Implementation of specialist ambulatory palliative care on a uniform basis

The GKV-SV, the bpa, the leading non-governmental welfare organisations and the VDAB, with the involvement of the Federal Working Group for SAPV, will establish a nationwide common basis for SAPV by concluding a framework agreement as per Section 132d paragraph 1 SGB V. The GKV-SV will work to ensure that health insurance funds and substitute funds—after submission of a federal framework contract under Section 132d paragraph 1 SGB V—quickly conclude supply contracts with service providers who meet the requirements of the framework contract. Existing contracts will be revised if necessary. This will be done with due consideration of the needs of people with dementia.

The framework agreement will be concluded by 2020. By the end of 2023, the GKV-SV will be working on implementing the framework agreement.

3.1.9 Training of care staff on the topic of ‘dementia and the end of life’

As stipulated by state law, the federal states will examine existing curricula in further and continued education in nursing care, to determine whether the topic of ‘dementia and the end of life’ has been addressed in sufficient depth; if required, supplementary material will be suggested. Within the framework of existing support programmes for continued education, the states will also promote relevant advanced education of nursing professionals. The VDAB, the BAGFW and the bpa are committed to ensuring that ambulatory services and in-patient nursing facilities provide their staff with sufficient resources for advanced education in this specialist area, and that they provide support and supervision for qualified nurses in hospice and palliative care.

By the end of 2026, the federal states will have gained an overview of how the topic of ‘dementia and the end of life’ is anchored in the curricula for advanced training and for continued education in nursing care. The funding associations will be in a position to provide information on the qualification levels of their institutions on the topic of ‘dementia and the end of life’ and on strategies to supervise nursing staff working in hospice and palliative care.

The following measures have been agreed upon to bring about improvements in the area of qualifications and quality.

3.1.10 Improvement of counselling as per Section 37 paragraph 3 SGB XI

The leading non-governmental welfare organisations, the bpa, the GKV-SV, the PKV association, the local authority organisations and the VDAB are working to ensure that the improved legal framework for counselling visits under Section 37 paragraph 3 (et seq.) SGB XI is exploited to also accommodate the specific needs for counselling of people with dementia and their relatives. To this end, the leading non-governmental welfare organisations, the bpa, the GKV-SV, the PKV association, the local authority organisations and the VDAB, as members of the committee for quality



assurance in nursing care, will examine whether there is any need to adapt the recommendations under Section 37 paragraph 5 SGB XI relating to counselling standards, to the requisite qualifications of counsellors and to measures that may need to be introduced in individual cases. Furthermore, the GKV-SV and the PKV association will review the guidelines under Section 37 paragraph 5a SGB XI with regard to the preparation, evaluation and standardised documentation of findings from individual consultations by long-term care insurance companies or private insurance companies. They will also examine whether a counselling guide would be effective for counselling people with dementia and their relatives.

By the end of 2022, the review will have been completed. By the end of 2024, the counselling guideline will have been examined and, if appropriate, introduced.

3.1.11 Implementation of the expert standard in out-patient and partially in-patient nursing practice

After completion of the model project implementing the expert standard entitled Sustaining and Fostering Relationship with People with Dementia,¹⁶⁶ this will provide a consensual and recognised basis for appropriate care of people with dementia. The stakeholders (primarily the BAGFW, bpa and DPR) are supporting the implementation and application of the expert standard in nursing practice. This standard applies to out-patient, partial in-patient and short-term care. The BMG is considering funding a specialist event on its implementation.

By the end of 2022, a specialist event on the subject will have been held.

3.1.12 Dementia-specific training qualifications of nursing staff in out-patient and partial in-patient care

The BAGFW, the bpa and the VDAB are supporting the state-approved continued education programme for specialists in gerontopsychiatric care and support, as well as qualifications and advanced training in gerontopsychiatric skills.

By the end of 2022, the above-mentioned stakeholders will be supporting relevant services offered to this end.

3.1.13 Foundational qualification for all staff coming into contact with people with dementia

The BAGFW, the bpa and the VDAB are committed to ensuring that all staff who come into contact with people with dementia, and whose training did not cover issues related to dementia, receive foundational training, for instance Dementia Friends training.

By the end of 2024, the associations will have reported on the current status.

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166 Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (2019)

The following measures have been agreed upon to bring about improvements in the area of cooperation, networking and coordination.

3.1.14 Improved coordination of ambulatory nursing services for dementia

The DKG, the KBV and the GKV-SV are working to ensure that the partners mentioned in Section 8a paragraph 2 SGB XI are involved in the development of joint recommendations on long-term care services within the framework of existing cross-sectoral state long-term care committees, with the aim of improving coordination within the ambulatory care service structure as regards the specific situation of people with dementia.

By the end of 2024, the (cross-sectoral) state long-term care committees in the federal states will have addressed this issue.

3.2 Promotion of dementia-sensitive design and organisation of fully residential long-term care facilities

In 2017, 3.4 million people were in need of long-term care in Germany, 24 per cent of whom were cared for on a fully residential basis in nursing homes in accordance with Section 71 paragraph 2 SGB XI.¹⁶⁷ Dementia is one of the most common reasons for admittance into fully residential long-term care facilities. In many fully residential long-term care facilities, more than two thirds of the residents have dementia. This trend is likely to intensify as the number of people with dementia in the population is expected to increase further. Measures need to be formulated to promote the quality of health services for people with dementia in fully residential long-term facilities.

Dementia, and the associated behaviour of those affected, can lead to a high need for support and care in long-term care. This is the case, for example, when the behaviour of a resident is challeng-

ing, that is, when their behaviour is particularly conspicuous, restless, aggressive or disinhibited.¹⁶⁸ Ensuring that this group of people requiring care is also properly cared for, necessitates adequate staffing to meet this increased need for care and support. Within the framework of the Second Long-Term Care Strengthening Act, the bodies responsible for self-administration of long-term care (Pflegerelbstverwaltung) were commissioned to develop and test an evidence-based procedure for uniformly assessing personnel requirements in long-term care facilities on the basis of qualitative and quantitative standards (Section 113c SGB XI). The specific needs of people with dementia and challenging behaviour were also taken into account. In the practice of long-term care, it is important, under consideration of the new definition of care need, that long-term care assistance directly or indirectly supports people requiring care in coping with the effects of health impairments in various areas of life. It is, nevertheless, also important to enable and encourage people requiring long-term care—and possibly also relatives—to independently cope—as far as still possible—with the challenges of their own circumstances in life.

Institutions should be supported by their associations in implementing the personnel assessment procedure under Section 113c SGB XI. One way to ensure good provision of care for people with dementia with appropriate staffing levels, might be to establish a staffing office providing staff with specialist gerontopsychiatric skills. Given its dementia-specific expertise, such an office would be able to structure care together with all the staff involved in caring and nursing.¹⁶⁹ This possible method of developing quality in the care of people with dementia will, therefore, be investigated in a pilot project.

The work of professional care-givers is particularly demanding. Both the objective workloads and the subjective stress experienced, are above average compared to other professions in the healthcare sector.¹⁷⁰ This is particularly true for caring for people with dementia, in which the

167 Statistisches Bundesamt (2018)

168 Bartholomeyczik et al. (2006)

169 McCormack et al. (2009)

170 Höhmann et al. (2016)



psychosocial aspects of care and support play a crucial role.¹⁷¹ As advocated by the KAP campaign, support services for nursing staff also need to be promoted to prevent overburdening of nursing staff who care for people with dementia.

Since the introduction of the new definition of care need, cognitive and gerontopsychiatric impairments are now being included more systematically in assessing the need for care. This is beneficial for people with dementia as they can receive benefits from long-term care insurance early on.

The contractual partners under Section 75 SGB XI have the option, via state framework agreements, to establish forms of care specifically for people with dementia. One example of this is the project Special Inpatient Dementia Care in Hamburg,¹⁷² which resulted in improved health services for people with dementia with challenging behavioural patterns.¹⁷³ In light of this finding, special forms of care for people with dementia at state level should be given greater support.

Implementing the expert standard Sustaining and Fostering Relationships with People with Dementia, can improve care in fully residential long-term care facilities by contributing, amongst other things, to an improvement in managing people with dementia on the basis of appropriate training.

Working Group 2 of the KAP campaign agreed upon measures to step up advanced training and continued education for nursing staff. Amongst other things, the funding bodies of institutions have committed themselves to ensuring that qualified nurses and other professional care-givers are equipped with the knowledge necessary for their tasks.¹⁷⁴ This approach should also be implemented in the care of people with dementia in fully residential long-term care facilities.

Effective treatment and care of people with dementia in fully residential care requires multi-professional teams that can jointly structure appropriate care and support. Skilled staff with

171 Kostrzewa and Kocks-Kostrzewa (2018)

172 Behörde für Gesundheit und Verbraucherschutz Hamburg (2016)

173 Weyerer et al. (2004)

174 Bundesministerium für Gesundheit et al. (2019)

dementia-specific qualifications can make a significant contribution to this. They should, therefore, be given greater support in acquiring the relevant qualifications. Alongside qualified nurses, care and support for people with dementia always involves other groups of professionals. Some of these are not provided with basic knowledge on the topic of dementia as part of their training, and they would, therefore, benefit from a foundational qualification on the topic (see also Chapter 3.1).

Non-medicinal forms of therapy are particularly meaningful for people with dementia. Occupational and physical therapy (amongst other things) can alleviate the symptoms of the condition and slow down the deterioration in functional ability.¹⁷⁵ Psychiatric and psychotherapeutic treatment can make it easier to cope with the diagnosis and the consequences of the condition.¹⁷⁶ Therefore, dementia-sensitive utilisation of these forms of therapy in fully residential long-term care facilities should continue to be supported.

The functional nature of fully residential long-term care facilities is one reason why they cannot be automatically regarded as dementia-sensitive places; instead, they must be deliberately designed to be so. To achieve this, what is needed is not only adaptation of the design and equipment of a facility but also of the entire environment (milieu) of a person affected by dementia. Due to the cognitive impairments of people with dementia, this milieu should be made as manageable and safe as possible. People with dementia experience an environment that is characterised by comfort, a familiar and comprehensible pattern of daily life, and a degree of flexibility as especially reassuring.¹⁷⁷ People with dementia also benefit when processes are geared to their biographical habits and when a respectful and permissive approach is possible. Fully residential long-term care facilities throughout Germany should be structured along these lines.

Promoting dementia-sensitive organisation and design of fully residential long-term care facilities is, therefore, one objective of the National Dementia Strategy.

The following measures will be taken to bring about improvements in the area of capacities and personnel.

3.2.1 Implementation of the personnel assessment procedure according to Section 113c SGB XI

As part of the project to develop and evaluate a personnel assessment procedure for care facilities as per Section 113c SGB XI, the BMG and the BMFSFJ are assessing whether the personnel assessment procedure is sufficiently well founded to provide an appropriate method of allocating personnel (*Personalschlüssel*) for the care and support of people requiring long-term care with gerontopsychiatric disorders and highly challenging patterns of behaviour. The results of the project will be taken into account during implementation of the personnel assessment procedure. The leading non-governmental welfare organisations, the bpa and the VDAB are supporting the implementation of these measures by promoting organisational and personnel development in their member institutions.

By the end of 2022, the BMG and the BMFSFJ will have completed their assessment. By the end of 2024, appropriate measures will have been taken by the associations of service providers to implement the personnel assessment procedure.

3.2.2 Employment of staff with specialist gerontopsychiatric expertise

The pilot project on the introduction of the personnel assessment procedure under Section 113c SGB XI will also examine the effect of employing staff with specialist expertise in the care of people with dementia. Such staff are also responsible for supervising their colleagues and for ensuring that the structures and processes of an institution are dementia-sensitive.

By the end of 2022, the assessment will have been completed.

175 See also Holthoff-Detto (2018)

176 Gutzmann et al. (2017)

177 Dietz (2018)

3.2.3 Provision of support services for nursing and care staff

The BMG will be funding a pilot project from 2020 to 2022 to provide support services for professional care-givers, care staff and other personnel who are under particular physical or mental stress. The aim of the pilot project is to optimise support, based on a holistic approach, for occupational health promotion in nursing care; to encourage professional qualification of professional care-givers, especially in the case of care of people with gerontological psychiatric disorders and with regards to managing challenging behaviour and practising de-escalation approaches; and to expand individual and universal prevention measures as well as counselling and supervision services for professional care-givers, support staff and other employees. The project will also investigate in more detail the effects of approaches to prevent violence and ensure a healthy working environment.

By the end of 2022, the pilot project will have been evaluated.

3.2.4 Reliable design of the assessment instrument for gerontopsychiatric disorders

The BMG will review the findings of the evaluation of the new definition of care need under Section 18c SGB XI, along with those of other studies, to determine whether the assessment instrument introduced on 1 January 2017 takes appropriate account of limitations in the independence or in the abilities of people requiring long-term care with gerontopsychiatric disorders and highly challenging behavioural patterns.

By the end of 2022, the evaluation and the review will have been completed.

3.2.5 Development of framework agreements for the provision of long-term care of people with dementia

The local authority associations, the leading non-governmental welfare associations, the bpa, the GKV-SV, the PKV association and the VDAB are working to ensure that the contractual partners review the development of special agreements on the provision of long-term care for people with dementia at state level under Section 75 SGB XI.

By the end of 2022, the stakeholders at state level will have conducted a review, and the stakeholders at federal level will have been informed of its findings.

The following measures have been agreed upon to bring about improvements in the area of qualifications and quality.

3.2.6 Implementation of the expert standard in fully residential long-term care facilities

After completion of the model project implementing of the expert standard entitled 'Sustaining and Fostering Relationships with People with Dementia',¹⁷⁸ this will provide a consensual and recognised basis for appropriate care of people with dementia. The relevant stakeholders (BAG-FW, bpa and DPR) are supporting the implementation and application of the expert standard in nursing practice. The BMG is considering funding a specialist event on its implementation.

By the end of 2022, a specialist event on the subject will have been held.

3.2.7 Dementia-specific training for care staff in in-patient care

The BAGFW, the bpa and the VDAB are supporting the state-approved continued education programme for specialists in gerontopsychiatric support and care, as well as qualifications and advanced training in gerontopsychiatric skills.

By the end of 2022, the above-mentioned stakeholders will be supporting relevant services offered to this end.

3.2.8 Provision of foundational qualification for all staff coming into contact with people with dementia

The BAGFW, the bpa and the VDAB are committed to ensuring that all staff who come into contact with people with dementia, and whose training did not cover issues related to dementia, receive foundational training, for instance Dementia Friends training.

By the end of 2024, the associations will have reported on the current status.

3.2.9 Therapeutic care in fully residential long-term care facilities

Together with the DGPPN, DGGPP, DEGAM and with the participation of other relevant stakeholders, the KBV is developing a proposal on how to better take into account the special requirements of therapeutic care for dementia patients in fully residential long-term care facilities. The proposal incorporates occupational therapy, physiotherapy, speech therapy, psychotherapy and other proven non-drug treatments. They will involve the DVfR and the funding associations of the care facilities in the deliberations. The KBV and the DGPPN will make their findings available, if necessary with the involvement of other expert societies, to the associations of service providers (BAGFW, bpa, VDAB). The service providers will ensure the proposal is disseminated amongst their members.

By the end of 2022, the proposal will have been developed and, if positively evaluated by the associations of service providers, will be disseminated amongst their members.

The following measures have been agreed upon to bring about improvements in the area of dementia-sensitivity.



3.2.10 Development of dementia-sensitive long-term care facilities

The KDA, with the participation of the BAGFW, the bpa, the DALzG, the VDAB and other appropriate stakeholders, is developing recommendations for the introduction of favourable milieus for people with dementia in care institutions. These will include the design of rooms, work organisation and ways to manage people with dementia. The recommendations should be suitable both for existing and new facilities. The federal states will support these recommendations after they have been appropriately evaluated. The BAGFW, bpa and VDAB will inform their member institutions about the recommendations.

By the end of 2022, the recommendations will have been developed, and the BAGFW, bpa and VDAB will have informed their member institutions.

3.3 Dementia-sensitive healthcare in hospitals

People with dementia experience a high degree of stress when admitted to or staying in hospitals, which can lead to increased cognitive difficulties and behavioural changes.¹⁷⁹ Working Group 2 of the KAP campaign agreed that the bodies in self-administration of personnel, with the participation of the BMG and other relevant stakeholders, should develop an evidence-based instrument for assessing care personnel, which, after testing, should be proposed for implementation. The instrument is to take into account the specific needs of people with dementia, with a view to providing appropriate care and support for this important group of patients in hospitals providing acute care.

In particular, the aim is to promote treatment options that avoid unnecessary hospital admissions. In the field of psychiatric care, these include treatment in the patient's own residential environment (for example flat/house, nursing home, residential group) equivalent to treatment in a ward in accordance with Section 115d SGB V. Treatment of this kind can, in certain cases, be of great benefit to people with dementia and should, therefore, be expanded nationwide and developed further where necessary.

People with dementia may also require admission to a hospital for emergency and acute treatment. Approximately 40 per cent of all patients over the age of 65 who are admitted to general hospitals are affected by cognitive impairment, dementia and/or delirium.¹⁸⁰ For this reason, hospitals providing acute care need to continue to adapt to the needs of this group of patients.¹⁸¹ This applies to all hospital departments, including accident and emergency departments. Patients with dementia are particularly reliant on adaptation of processes in accident and emergency departments to meet their needs.¹⁸²

A general prerequisite for effective medical and nursing care for people with dementia in hospital is recognition of their cognitive limitations and adaptation of healthcare to address them. Screening techniques to ascertain possible dementia in patients at the time of admission have proven to be effective.¹⁸³ One particularly important criterion is being able to differentiate whether a patient is suffering an episode of delirium.¹⁸⁴ Such techniques should, therefore, be encouraged throughout hospitals.

People with dementia have an increased risk of developing delirium if admitted into hospital.¹⁸⁵ Measures to prevent delirium rely heavily on systematic cooperation of the various professional groups involved in healthcare. Training in the use of such screening procedures will enable staff to employ them at an early stage, evaluate the results and implement prevention strategies.

Implementing the expert standard Sustaining and Fostering Relationship with People with Dementia also has the potential to improve care for people with dementia in hospitals. The particular challenge lies in implementing the expert standard not only in gerontological psychiatric or geriatric wards, but also in other areas, for instance in an accident and emergency department or a surgical ward.

Adaptation of the workflow of medical and nursing care to the special needs of people with dementia is particularly important. A loss of mobility and cognitive abilities can be counteracted by coordinated structuring of daily activities combined with stimulatory care, for instance, by physical and occupational therapists and voluntary helpers. A practical guide, funded by the RBS, summarises these and other key elements required for developing dementia-sensitive hospitals.¹⁸⁶

179 Hofmann (2016); Kirchen-Peters and Krupp (2019)

180 Bickel et al. (2018); Reynish et al. (2017)

181 Motzek et al. (2017)

182 Holthoff-Detto and Technische Universität Dresden (2019)

183 Carpenter et al. (2019); Hessler et al. (2017)

184 Hower et al. (2016)

185 Frühwald et al. (2014)

186 Kirchen-Peters and Krupp (2019)

Effective treatment and care of people with dementia in hospitals requires multi-professional teams that can jointly structure appropriate health services. Skilled staff with dementia-specific qualifications can make a significant contribution to this. They should, therefore, be given greater support in acquiring the relevant qualifications. Alongside qualified nurses, care and support for people with dementia always involves other groups of professionals. Some of these are not provided with basic knowledge on the topic of dementia as part of their training, and they would, therefore, benefit from a foundational qualification on the topic (see also Chapter 3.1).

To ensure that people with dementia receive the same standard of medical treatment in hospital as other patients, it is essential that sufficient staff are available, that they are appropriately qualified, that hospital processes are adapted and that hospitals are designed in a dementia-sensitive manner.¹⁸⁷ Hospitals should be supported in achieving such developments. These include, for instance, designing hospitals to be easily navigable to facilitate the independence of people with dementia while at the same time offering them security. In this regard, hospitals have the challenging task of meeting various requirements. Investment cost financing provided by the federal states is one of the possible means for adapting or refurbishing regional hospitals.

An objective of the National Dementia Strategy is to reduce hospital admissions of people with dementia, if at all possible, and to ensure that, if treatment in a hospital is unavoidable, it should be conducted in a dementia-sensitive manner.

The following measures have been agreed upon to bring about improvements in the area of capacities and personnel.

3.3.1 Home-based psychiatric treatment equivalent to that in a hospital ward

The DKG is calling on its members to establish, expand and, if necessary, further develop the nationwide provision of home-based psychiatric treatment equivalent to that in a hospital ward as per Section 115d SGB V for people with dementia as an alternative to fully in-patient treatment.

By the end of 2022, all its member institutions will have been informed. By the end of 2024, implementation of such provision will have been reviewed.

The following measures have been agreed upon to bring about improvements in the area of qualifications and quality.

3.3.2 Development of recommendations for emergency care of people with dementia in hospitals

The DGGPP and the DGPPN are developing recommendations for emergency care of people with dementia in hospital. The DALzG, the DKG and other relevant bodies are also involved in developing these recommendations. After they have been developed, implementation of the recommendations will be encouraged by making training programmes available and by ensuring the relevant parties in hospitals optimise their workflows.

By the end of 2022, the recommendations will have been developed. Thereafter, their implementation will be supported until the end of 2024.

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 187 Pöschel and Spannhorst (2018); Bundesministerium für Familie, Senioren, Frauen und Jugend (2018a); Büter and Marquardt (2019); Ingenium-Stiftung und Bayerisches Institut für alters- und demenzsensible Architektur (2018)



3.3.3 Dementia and delirium procedures in hospitals

The DKG is working to ensure that validated screening procedures for dementia and delirium are implemented in hospitals and that they are carried out by trained staff. The DGPPN and the DGGPP are developing appropriate recommendations for hospitals and involving the DGG, the DGGG and the DGN in the process. The DKG is committed to establishing and implementing the recommendations of the delirium network aimed at preventing and treating delirium in somatic and psychiatric treatment units. The DGGPP and DGPPN expert societies are drawing up recommendations on relevant continued education programmes.

By the end of 2022, the procedures will have been developed. By the end of 2024, the implementation of the procedures will have been reviewed by the regional hospital associations. By the end of 2022, the recommendations of the expert societies will have been drawn up.

3.3.4 Implementation of the expert standard in nursing practice in hospitals

After completion of the model project implementation of the expert standard entitled 'Sustaining and Fostering Relationship with People with Dementia',¹⁸⁸ this will provide a consensual and recognised basis for appropriate care of people with dementia. The DKG is supporting the implementation and application of the expert standard in nursing practice. The BMG is considering funding a specialist event on its implementation.

By the end of 2022, a specialist event on the subject will have been held.

3.3.5 Dementia-sensitive care provision in hospitals

The DKG is working to ensure that the organisational processes of medical and nursing care in hospitals are adapted to the special needs of patients affected by dementia. Such adapted processes include examinations without the need of

.....
188 Deutsches Netzwerk für Qualitätsentwicklung in der Pflege (2019)

relocation (on the ward), striving to reduce food and fluid restriction periods as far as possible when planning surgical treatment, accompaniment on routes within the hospital, and avoiding waiting times. The DKG is supporting hospitals in providing stimulatory care for people with dementia during hospital stays by introducing adapted personnel and room strategies. The DKG is encouraging hospitals to recruit, qualify and deploy volunteers to accompany patients with dementia.

By the end of 2024, the DKG will be supporting hospitals in ensuring that, if required, treatment planning is dementia-sensitive.

3.3.6 Dementia-specific training of nursing staff in hospitals

The DKG, the federal states and the boards of nursing are evaluating recommendations or regulations on continued education in specialist gerontopsychiatric nursing and care.

By the end of 2022, the DKG, the federal states and the boards of nursing care will have drawn up appropriate recommendations and regulations.

3.3.7 Provision of foundational qualification for all staff coming into contact with people with dementia

The BAGFW and the DKG are working to ensure that all occupational groups involved in the care of people with dementia, whose training does not provide appropriate dementia-specific content, should receive foundational qualifications that are as accessible as possible, as well as refresher courses at appropriate intervals. A Dementia Friends course can serve as initial training.

By the end of 2024, the DKG and BAGFW will have reported on the current status.

The following measures have been agreed upon to bring about improvements in the area of dementia-sensitivity.

3.3.8 Dementia-sensitive design and architectural construction of hospital environments

The DKG is providing its member associations with information on dementia-sensitive design and architectural construction of hospital environments. This information is based on the findings of the RBS's¹⁸⁹ funded projects on the subject. The federal states will take dementia-sensitive constructional design into account in their investment cost financing.

By the end of 2022, the DKG will have provided information to its members and by the end of 2026, it will have requested feedback from its member associations on the progress of implementation.

3.4 Improving medical care for people with dementia

People with dementia are entitled to informed diagnosis and appropriate treatment of their dementia-associated disease. Their continued care must also be appropriately structured to address the problem of dementia.

Medical care by general practitioners and specialists is centrally important in caring for people with dementia. This is true not only in diagnosing conditions involving dementia in accordance with guidelines, but also in providing information about the disease, and, if necessary, transferring patients to neurological clinics, other medical specialists and counselling centres. General practice clinics are, therefore, often the first point of contact between those affected and the professional medical health services network, and they are crucial to the further course of the condition. In Germany, treatment of people with dementia by general practitioners and medical specialists is supplemented, amongst other things, by out-patient gerontological psychiatric clinics.¹⁹⁰ Patients in these clinics receive care based on a multi-professional approach.

189 Büter and Marquardt (2019); Ingenium-Stiftung und Bayerisches Institut für alters- und demenzsensible Architektur (2018)

190 In out-patient gerontological psychiatric clinics, older patients with complex diseases and an increased risk of acute relapse receive highly regular treatment (occasionally ambulatory) by multi-professional teams (management by medical specialists, nursing, psychological counselling, social work and occupational therapy).

Telemedicine represents another way of providing medical care for people with dementia. Telemedicine encompasses elements of medical care such as diagnosis, therapy, rehabilitation and advice by doctors on medical choices. It is independent of geographical location and time restrictions.¹⁹¹ The potential of telemedicine in providing medical care for people with dementia is to be examined.

If dementia is suspected, general practitioners are an important point of contact for those affected and their relatives. They can make a diagnosis and provide initial counselling. People in the early stages of dementia often do not (yet) need practical care or assistance, and instead need a great deal of advice.¹⁹² At the early stages of the condition, personal counselling can be particularly valuable in supporting the affected person, but, nevertheless, it should also be provided at later stages as well. Appropriate strategies for such counselling based on the needs of general practitioners are to be adapted and made available.

Diagnosing and counselling people with a migration background is particularly challenging. Cultural and language barriers are major factors. Standard diagnostic procedures rely on the recipient being proficient in German and familiar with German culture, and they are, therefore, not appropriate for all people with dementia. Doctors may need to adapt how they diagnose patients to suit differing linguistic abilities and cultural backgrounds.¹⁹³

In addition to general practitioners, a wide range of other professional healthcare professionals are also involved in structuring effective medical treatment for people with dementia. Treatment is informed by appropriate guidelines, such as the S3 'Dementia' guideline, which covers diagnosis and treatment of dementia. Utilising such guidelines needs to be encouraged in practice.

Medical dementia consultants at state level can assist doctors in basing the care they provide to dementia patients on the relevant guidelines.

They serve as contact persons for questions about treatment and can also strengthen networking within health services structures. State medical associations should, therefore, be encouraged to have their own dementia consultants. For people with dementia, medical examinations and treatment can be stressful. Long journeys and waiting times are contributory factors. Consequently, if possible, patients should be treated in their own domestic environment (such as an flat/house, nursing home, residential group) or in a familiar medical practice. Novel approaches need to be explored to also widen medical care in this context to include specialist medical care. Home visits and mobile consultation services are particularly promising ways to provide low stress consultation by medical specialists, as is telemedicine.

Improving medical care for people with dementia is one objective of the National Dementia Strategy.

The following measures have been agreed upon to bring about improvements in the area of capacities and personnel.

3.4.1 Ambulatory neuropsychiatric care in multidisciplinary centres (Komplexzentren)

In cooperation with the KBV, the SPIZ ZNS is developing a multi-professional approach to ambulatory neuropsychiatric healthcare at multidisciplinary centres staffed by statutory healthcare practitioners. In multidisciplinary centres, patients with neurological and/or psychiatric diseases, including those with dementia, are to be treated by interdisciplinary, multi-professional teams on an ambulatory basis close to where the patients live.

By the end of 2022, this concept will have been drafted and an evaluation of its integration into existing health services will have been conducted.

191 Bundesärztekammer (no date)

192 Hauser (2017)

193 Flüh (2014); Tillmann et al. (2018)

3.4.2 Digital health services tools for people with dementia

The GKV-SV, KBV and SPIZ ZNS, in cooperation with the DEGAM, DGPPN and DGGPP, are investigating whether digital healthcare tools can improve the provision of healthcare for people with dementia. The BAGFW, the bpa and the VDAB are also participating.

By the end of 2022, the investigation will have reached a conclusion.

The following measures have been agreed upon to bring about improvements in the area of qualifications and quality.

3.4.3 Psychosocial counselling for people with dementia in the early stages

The KBV and the GKV-SV as funding agencies of the assessment committee are investigating whether standard care can be improved by developing an approach to psychosocial counselling that better reflects the needs of patients diagnosed with dementia and their relatives. The approach would encompass extensive information on prognosis and treatment options as well as regional consulting services. The competence of expert societies such as the DEGAM and SPIZ ZNS could also be integrated into this approach.

By the end of 2022, the investigation will have come to a conclusion.

3.4.4 Multilingual, culturally sensitive assessment instrument for diagnosing dementia

The medical expert societies DGGPP and DGPPN are developing a proposal on the use of multilingual, culturally sensitive assessment instruments based on the current status of research for dementia diagnosis. The DALzG and DEGAM are also participating. When the proposal has been finalised, a recommendation on how such instruments should be applied will be prepared and disseminated to the relevant bodies.

By the end of 2022, an assessment instrument will have been recommended.



3.4.5 Guidelines for medical practitioners on how to treat people with dementia

The DEGAM, DGGPP, DGPPN, SPIZ ZNS, KBV and BÄK, together with the *Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e. V.* [Association of Scientific Medical Expert Societies], are committed to promulgating guidelines recognised by the relevant expert societies on how to treat people with dementia in a more targeted manner. To achieve this, they are drawing on established sources of information and methods of exchanging experience (for instance, KBV practice news and specialist forums) and promoting tailored advanced training and continued educational measures for medical practitioners. By means of guideline-based inter-professional cooperation and networking, regional supply chains for people with dementia can be developed.

By the end of 2022, the involved bodies will have provided information on this initiative.

3.4.6 Dementia consultants in state medical associations

The BÄK will recommend that state medical associations appoint medical dementia consultants, who can provide members with information on health services for patients with dementia and on advanced training for dementia.

By the end of 2022, the BÄK will have submitted its recommendation to the state medical associations.

3.4.7 Ensuring access to specialist medical services for people with a secondary diagnosis of dementia

The GKV-SV, the PKV association and the KBV are examining how people with dementia can receive specialist medical care both at home and in statutory healthcare practices. Funding is to be provided for both home visits and for mobile services. The professional associations and expert societies are involved in the process.

By the end of 2022, a workshop on the subject will have been held.

3.5 Support of cooperation in the health services network

Improving medical care for people with dementia is dependent on a functioning network between the involved participants. An exemplary case in point is the work of the Local Alliance in Hildesheim, which provides advanced training courses and networking meetings with family practices.

For people with dementia, emergencies are a major challenge owing to their altered state of perception, and can quickly overwhelm them. Dealing with people with dementia is also challenging for emergency personnel and requires knowledge about the condition and the distinctive

methods needed to communicate and treat these patients. For this reason, recommendations on how to provide emergency care for people with dementia will be developed jointly with the partners mentioned in Section 8a paragraph 2 SGB XI.

Cooperation at the interface between medical and nursing care for people with dementia is key to the quality of health services in residential long-term care facilities.¹⁹⁴ Since the introduction of the Care Staff Strengthening Act at the beginning of 2019, under Section 119b paragraph 1 SGB V entering into agreement of cooperation contracts has been mandatory.¹⁹⁵ Effective application of these contracts to benefit people with dementia is to be promoted.

For networking to be effective, the tasks of all those involved needs to be defined, in compliance with legal or contractual provisions, and the interfaces between health services revealed. A 'health services pathway' for people with dementia should, therefore, be developed. Healthcare services pathways can help to systematically implement individually tailored treatment processes for people with dementia.

Because dementia entails complex care needs, the task of coordinating care is crucial. General practitioners are often the first point of contact for people with dementia and their relatives. For them to be able to assume responsibility for care coordination, appropriate framework conditions need to be established. To reflect this, an adjustment of the remuneration system for statutory health insurance medical practitioners and psychotherapists needs to be examined.

In addition, networking among medical professionals on the subject of care for people with dementia is, specifically, to be intensified. The KBV is promoting improvements to the standard of health services provided by statutory health insurance medical practitioners by means of 'quality circles'. This concept¹⁹⁶ is to be expanded to improve networking and professional develop-

.....
194 Balzer et al. (2013); Snowden (2010)

195 According to a survey by the KBV, over 22,000 cooperation contracts had been signed by 31 December 2018.

196 Siebolds and Quasdor (2018)



ment of medical practitioners in the field of dementia. Improving cooperation between general practitioners and medical specialists is of particular importance here. Developing quality criteria for such networking should help to improve the situation.

The cross-sectoral state care committees, established under the Third Long-Term Care Strengthening Act in accordance with Section 8a paragraph 2 SGB XI, are discussing the need for cross-sectoral cooperation between health services and drawing up appropriate recommendations. Effective cross-sectoral cooperation is particularly important in medical and nursing care of people with dementia.

Improving cooperation in the health services, network is one objective of the National Dementia Strategy.

The following measures have been agreed upon to bring about improvements in the area of qualifications and quality.

3.5.1 Recommendations on out-patient emergency care for people with dementia

The DKG, GKV-SV, KBV and the PKV association are working to ensure that recommendations on emergency care for people with dementia are adopted in the federal states.

By the end of 2024, the (cross-sectoral) state long-term care committees in the federal states will have addressed this issue.

3.5.2 Medical care by general practitioners and medical specialists in fully residential long-term care facilities

The KBV and the GKV-SV are further developing the agreement under Section 119b paragraph 2 SGB V, with the participation of the SPIZ ZNS, DEGAM, DGPPN and DGGPP, bpa, BAGFW and VDAB, to better address the special requirements for medical care of dementia patients in fully residential long-term care facilities. This agreement will give due consideration to funding telemedicine.

By the end of 2022, the extended agreement will have been reached.

The following measures have been agreed upon to bring about improvements in the area of cooperation, networking and coordination.

3.5.3 A health services pathway for people with dementia

In the context of the National Dementia Strategy, a health services pathway for people with dementia is being developed. The following stakeholders are involved: BAGFW, BÄK, bpa, DALzG, BAGSO, DED, DGG, DGGG, DGGPP, DGPPN, DZNE, DKG, DVfR, DEGAM, DPR, GKV-SV, KBV, KDA, SPIZ ZNS and VDAB. They will define the respective tasks within the pathway and describe the required interfaces between the sectors. Other relevant stakeholders, such as the German Disability Council and the Federal Association of Self-help Organisations, will be involved. The BMG and the BMFSFJ are setting up an independent project to achieve this. Once a health services pathway has been developed, all involved stakeholders will encourage its implementation into practice.

By the end of 2024, the health services pathway will have been developed.

3.5.4 Reflection of cooperation in the standard schedule of fees (Bewertungsmaßstab)

The GKV-SV and the KBV, as funding agencies of the assessment committee, are reviewing whether coordination and cooperation of health services for patients with dementia might be improved by modifying how these are reflected in the standard schedule of fees.

By the end of 2022, the assessment committee will have completed its review.

3.5.5 Development of a quality circle module

In cooperation with the BÄK, DGPPN, DGGPP, DEGAM and SPIZ ZNS, the KBV is developing working materials (a quality circle module) for utilisation of interdisciplinary quality circles in the care of patients with dementia.

By the end of 2022, a manual on the module will have been published.

3.5.6 Quality criteria for networking between general practitioners and medical specialists

In cooperation with the BÄK, DGPPN, DGGPP, DEGAM and SPIZ ZNS, the KBV and GKV-SV are developing quality criteria for networking of general practitioners and medical specialists.

By the end of 2022, the quality criteria will have been developed.

3.6 Strengthening of preventive and rehabilitation services for people with dementia

People with dementia are fundamentally entitled to prevention and rehabilitation services. Access to medical rehabilitation is covered by Section 40 SGB V. In addition, early rehabilitation services can be provided during hospital treatment under Section 39 SGB V. Furthermore, under Section 5 paragraph 4 SGB XI, long-term care insurance funds are to encourage implementation of all relevant services for prevention, medical treatment and medical rehabilitation to prevent the onset of need for care.

It is assumed that people with dementia are fundamentally entitled to benefit from (early) rehabilitative treatment programmes—regardless of whether these are related to the dementia itself or to another disease. The S3 'Dementia' guideline, for instance, specifies that specific treatment programmes for persons with a mild to moderate dementia are similarly, or only slightly less, successful in improving mobility and autonomy than in cognitively healthy individuals.¹⁹⁷

In assessing the rehabilitative capacity of people with dementia, lower expectations are justified in view of their diminished cognitive abilities and capacity for physical exertion. This is taken into account in the framework recommendations for

out-patient geriatric rehabilitation, and lower-threshold requirements are expected regarding the rehabilitative capacity of patients.¹⁹⁸ For people with dementia who have received medical rehabilitation and have a secondary diagnosis of dementia, there is strong scientific evidence for the effectiveness of rehabilitation. In contrast, the scientific evidence is inadequate for the effectiveness and benefit of rehabilitation in patients diagnosed with a primary performance-based dementia.¹⁹⁹

The various stakeholders in the National Dementia Strategy hold different views on rehabilitation of people with a primary diagnosis of dementia. Hence, an independent project to clarify these positions has been instigated to examine whether and how rehabilitative capacity in people with dementia can, in principle, be assessed. Regardless of this, the justification for prescribing rehabilitative sport for people with dementia is to be assessed separately.

Assessment and instigation of a rehabilitative measure after a hospital stay falls within the scope of discharge management. People with a secondary diagnosis of dementia should, similar to other patients, be enabled to benefit from follow-up rehabilitation. To support this, information and awareness-raising within hospitals and health insurance funds is to be stepped up to promote prescription of rehabilitation. Consequently, rehabilitation indicators are to be recorded more systematically in the process of discharge and health services management.

Mobile rehabilitation for people with dementia encompasses the provision of rehabilitative measures in the patient's own familiar surroundings. Mobile rehabilitation is particularly recommended for geriatric patients with multiple illnesses, whose rehabilitative capacity increases if they receive rehabilitation in familiar surroundings. Such rehabilitation can involve using house-

hold objects as training aids, and can involve the support of relatives.²⁰⁰ This approach is, hence, particularly apposite for people with dementia. At present, however, there are too few mobile geriatric rehabilitation services available in Germany, and, as a consequence, demand for them nationwide cannot be fully met.²⁰¹

In the context of determining the need for care, a comprehensive separate set of prevention and rehabilitation guidelines has been drawn up to identify whether, beyond the need for rehabilitation, a patient would also benefit from preventive services. The long-term care insurance funds are required by law to comprehensively assess, providing reasons, the effectiveness of a measure for prevention or medical rehabilitation on the basis of an expert opinion (see Section 18a paragraph 1 SGB XI). The preventive measures recommended in assessing long-term care needs were, likewise, scientifically evaluated as per Section 18c paragraph 2 SGB XI. Amongst other things, this evaluation focused on how the recommendations employed to determine needs for prevention have developed. Health-promoting and preventive services are defined both under Section 20 paragraph 2 SGB V and Section 5 SGB XI. Approaches to meet these needs are promoted by long-term care insurance funds and are increasingly being implemented in fully residential long-term care facilities.²⁰² On the basis of this evaluation, adapting the guidelines on prevention under Article 20 paragraph 2 SGB V and Article 5 SGB XI may be appropriate.

The DAzG has prepared an information sheet detailing information on the various rehabilitative and preventive measures available and clarifying the preconditions for their use.²⁰³ To ensure that people with dementia and their relatives are better informed about the available range of specialist rehabilitation facilities, this overview is to be further developed and supplemented. It should continue to be the basis for recommendations on

198 GKV-Spitzenverband (2018b)

199 The reasons invoked by the GKV-SV can be found at Meinck and Preuß (2015)

200 GKV-Spitzenverband et al. (2007)

201 Bundesarbeitsgemeinschaft Mobile Rehabilitation e.V. (no date); Schmidt-Ohlemann (2017)

202 See also Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen e.V. and GKV-Spitzenverband (2019)

203 Reuter (2019)

nationwide adaptation of rehabilitative health services.

Improving rehabilitative and preventive care for people with dementia is one objective of the National Dementia Strategy.

The following measures have been agreed upon to bring about improvements in the area of capacities and personnel.

3.6.1 Rehabilitation for people with a primary diagnosis of dementia

The BMG is reviewing whether to fund a project on rehabilitation for people with a primary diagnosis of dementia. The aim of the project is to clarify how much potential rehabilitation has for people with a primary diagnosis of dementia, what form such services should take, whether legal regulations need to be adapted and how to appraise the merit of a recommendation for rehabilitation.

By the end of 2022, the review of the proposed project will have been completed and a decision taken on its possible implementation.

3.6.2 Rehabilitative sport for people with dementia

The GKV-SV and the KBV are working to ensure that the partners in the framework agreement on rehabilitative sport and functional training investigate how patients with dementia can better benefit from rehabilitative sport. Once they have completed their investigation, they will, if necessary, endeavour to adapt the framework agreement.

By the end of 2022, the investigation will have been completed.

3.6.3 Thorough review of rehabilitation indicators in discharge management

The DKG and the GKV-SV will update hospitals and/or health insurance companies on the available findings relating to the rehabilitative capacity of people diagnosed with secondary dementia. The objective is to ensure that, within the framework of discharge management or the existing procedure for instigating follow-up rehabilitation as well as within the framework of the health services management under Section 11 paragraph 4 SGB V, people diagnosed with secondary dementia are, similar to other patients, systematically and universally assessed on whether they would benefit from rehabilitation.

By the end of 2022, the DKG will have updated hospitals and the GKV-SV, health insurers on the findings.

3.6.4 Mobile rehabilitation for people diagnosed with secondary dementia

The BAGFW, the bpa and the GKV-SV are committed to expanding the available range of mobile rehabilitation services to meet the special needs of people diagnosed with secondary dementia. The GKV-SV will report on developments in the field of mobile rehabilitation.

By the end of 2024, the GKV-SV will have reported on measures that have been undertaken to develop mobile rehabilitation.

3.6.5 Improvements to preventive services for people with dementia

The BMG will systematically evaluate the findings of the evaluation (Section 18c paragraph 2 SGB XI), both with regard to its conclusions on the topic of 'prevention' and with regard to recommendations based on these conclusions. On this basis, the BMG will assess whether legal amendments are

warranted and/or possible with a view to improving preventive care. The GKV-SV will review whether the guideline on prevention under Section 20 paragraph 2 SGB V and the guideline on prevention under Section 5 SGB XI need to be supplemented.

By the end of 2022 the evaluation and the reviews will have been completed. By the end of 2024, legislative measures will have been implemented if required.

The following measure has been agreed upon to bring about improvements in the area of qualifications and quality.

3.6.6 Overview of available rehabilitation services for people with dementia

Together with its members and in cooperation with the DAzG, the DVfR is developing an accessible overview of rehabilitation services available for people with dementia and their relatives. The overview will take into account the various stages of dementia as well as the appropriate forms of accommodation for those affected. Based on this, the DVfR will develop recommendations for further development of facilities to provide rehabilitative care for people with dementia. It will make these recommendations available to the associations of service providers.

By the end of 2022, the overview will have been drawn up and recommendations developed on how to develop facilities to meet the needs of people with dementia.



Field of action 4

Promoting excellent research on dementia

Excellent and networked research into dementia is crucial to understanding the development and course of the diseases underlying the condition. At present, the root causes of demential diseases have not been conclusively identified. Research (for instance basic research, clinical research and population research) provides important insights into their causes and molecular mechanisms. Based on such research, improved preventive and diagnostic strategies can be developed, as well as novel therapies. Research also makes an important contribution to improving the care of people with dementia. Applied health services research on dementia needs to define the care demands and needs of people with dementia and examine the effectiveness and efficiency of medical, nursing and therapeutic measures.²⁰⁴ These diverse research fields need to be coordinated with each other.

Dementia research needs to consider not only the specific needs of people with dementia, but also those of their relatives.²⁰⁵ Furthermore, the population of people with dementia is very heterogeneous. It includes people living alone or in relationships, older and very old people, (very) young people, people of working age, people from varying socio-economic backgrounds, people with a migration background and people developing dementia as a co-morbidity, for instance, individuals with trisomy 21. Combinations of different

characteristics are also possible. Such people represent particularly vulnerable groups and should not be excluded from research projects.

Research infrastructures and national and international networking in dementia research need to be strengthened. The same applies to cooperation between research and healthcare provision, where additional efforts are needed to introduce and, hence, translate scientific findings more quickly into health services for people with dementia. Research findings are not only meaningful for professionals, such as doctors, therapists and qualified nurses, but also for people with dementia, their relatives and the interested general public. Research results need to be accessible and comprehensible to the general public so that all people in society can access information on them. The BMBF is supporting and engaging in dialogue-oriented communication of scientific findings in a manner comprehensible to the general public, with the aim of reaching out to society at large. In November 2019, the BMBF published its *Grundsatzpapier des BMBF zur Wissenschaftskommunikation* [BMBF policy paper on science communication], outlining key ways of improving science communication. For the general population, information on ways to reduce the risk of dementia is particularly relevant. People with dementia and their relatives can profit, in particular, from information on the available support

204 Livingston et al. (2017)

205 In this context, relatives are understood to be those persons within the close social environment of people with dementia who are responsible for care and support. The focus in this field of action is on relatives within a family. However, in this context, relatives can also refer to people who have a friendly or neighbourly relationship with the person with dementia.

options open to them and on the latest developments in treatment approaches for dementia.

Better cooperation between different research fields is crucial for the success of the National Dementia Strategy. The first steps in achieving this objective are being taken in the form of a proposed series of joint measures. The overall goal is to network the different research fields within dementia research; basic research needs to be more closely linked with population research, clinical research, health services research and other research fields.

Excellent research into dementia depends on people with dementia having the opportunity to participate in the design phase of research projects.²⁰⁶ This way, projects will genuinely reflect the actual needs of those affected.²⁰⁷ And research findings can, thus, contribute to improving the quality of life and health services for people with dementia. More support needs to be provided to encourage participation in research studies in the case of representative studies on the causes of dementia or on new therapeutic approaches.

The National Dementia Strategy is targeting all research institutions in Germany that perform outstanding dementia research internationally. This includes stakeholders named in the implementation measures, who can cooperate with other expert partners. Research findings thus obtained on novel approaches to prevention, diagnostics, therapy, and health and long-term care services will be implemented in health and long-term care throughout Germany to improve the circumstances of life for people with dementia. This nationally coordinated strategy involves research networks at different levels as well as scientists involved in basic research, clinical research and health services research, with the objective of bringing together the various disciplines.

The federal government is currently already providing ongoing support for research into dementia. The BMBF regularly publishes funding guidelines for research projects. Applications for funding for dementia research projects can, likewise, be submitted within the framework of these funding guidelines. Scientists are invited to apply for funding for outstanding research projects focusing on demential diseases. The success of such applications is decided in a competitive process. The BMEL is also planning to make a contribution to dementia research. The federal states are also continuing to support a wide range of research activities. Germany is home to a broad and excellent research landscape in the field of dementia research.

The DZNE has been researching demential diseases since 2009 and is exploring means of prevention, diagnostics, therapy and the provision of healthcare. The DZNE is funded by the BMBF and the eight states in which it is situated. In addition, outstanding research partners in all federal states are to be found at universities and in Leibniz and Fraunhofer Institutes financed by the federal and state governments. Some of these have been making significant contributions into dementia for decades in epidemiological and prevention research, nursing research, health services research, clinical diagnostics and therapy, and have done so in part by obtaining competitive international, national and regional funding. Since 2018, the DZNE's German Dementia Aid foundation has also been responsible for collecting private donations from the general public to support research and innovation at the DZNE. In addition, the Dementia Competence Network has been operating since 2002; an initiative of the BMBF within its Competence Networks in Medicine. This network is a research association of fourteen university hospitals, whose objectives include achieving the earliest possible diagnosis, and developing therapeutic measures and health services structures for people with dementia.

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206 Alzheimer Europe (2017)

207 In this context, 'affected persons' refers to people with dementia. People who provide nursing and care for people with dementia are also 'affected' by the condition. However, in this document they are not subsumed under the term 'affected persons'.

Additionally, the German Innovation Fund represents an important means of optimising medical and nursing health services for people with dementia in Germany. Finally, various foundations and societies, such as the DALzG, support research in the field. By means of programmes of this kind, the social challenge of dementia is already being addressed.

As the causes and onset of demential diseases have not yet been fully understood, special emphasis needs to be placed on research into issues of prevention, diagnostics, healthcare provision, health services structures, nursing interventions and support, as well as into achieving a good quality of life for people with dementia.

4.1 Strengthening national and international infrastructure in dementia research

Excellent dementia research requires effective research structures. These need to be continuously funded and expanded. By improving national and international cooperation in dementia research, existing structures and existing knowledge can also be better exploited.

In light of this, clinical research units need to be integrated into a national network. Such a network²⁰⁸ was proposed²⁰⁹ by, amongst others, the Forum for Health Research. To date, specialist research units capable of conducting early clinical studies, have only existed at a limited number of sites in Germany. As no effective treatment for demential diseases has yet been found, reducing the risks of developing the condition and exploring new therapeutic approaches are a major priority. These require close ties to basic research. Strengthening clinical research should also help to ensure that findings from basic research are better integrated into the standard care of people with dementia.

The structures of health services research, including research into science-based care provision and support strategies, also need to be strengthened. Here, too, national networks need to be established to conduct interdisciplinary and inter-sectoral research on dementia. This will allow health services research to be further developed with regard to its substance, methods and institutions. The aim is to promote cooperation between scientific research and the practice of health services.

The ongoing expansion of biobanks is also essential for generating valuable research data. Biobanks are repositories of samples of blood, other bodily fluids and tissues that can be analysed by researchers. They are essential, for example, for the identification and continued research into molecular mechanisms, biomarkers and genetic risk and protective factors. Germany has a number of such biobanks at its disposal.²¹⁰ In addition, in 2015 the BMBF published a guideline on support measures for ‘upgrading German biobank sites in order to link them to the BBMRI’, with the aim of promoting a network of German biobank sites (German Biobank Alliance). The aim of this alliance, which is coordinated by a contact and mediation office (national nodes), is to facilitate access to biological samples and data, and promote their utility for research. The linkage with the European research infrastructure BBMRI-ERIC will facilitate coordinated international action to develop, test and apply comprehensive genetic standards, products and solutions.

The provision of routine data from the healthcare system for research purposes is also to be improved. This data can be exploited to investigate, for example, which health services are used by people with dementia. Under Section 75 SGB X, data records of individual health insurance funds may be transferred from health insurance funds to researchers. In addition, GKV accounting data can be evaluated by designated institutions for defined purposes. The Digital Health Care Act furthers

208 Further information can be found at www.gesundheitsforschung-bmbf.de/de/forum-gesundheitsforschung-5787.php

209 Deutsches Ärzteblatt (2018)

210 The network includes, amongst others, the centralised biomaterial bank of the Charité, the biobank of the LIFE Health Study, the centralised biobank of the NAKO Health Study, and the DZNE’s Brain Bank and clinical research biobank.

development of the information system (DaTraV data), originally located at the German Institute for Medical Documentation and Information (DIMDI), which enabled nationwide regulated access to cross-insurance fund data from the database of the morbidity-adjusted risk compensation scheme. This development involved, in particular, revising the data flow procedure and introducing a data collection point at the GKV-SV, which should significantly speed up the procedure. Before this development, the accessibility of the data depended on the completion of the risk compensation scheme, which meant that authorised users had to wait for up to four years after the survey before they had access to the data. The act also expands the range of data provided. Nevertheless, the data is still only a portion of the total accounting data set. Statutory long-term care insurance and social pension insurance benefits, for example, are not included.

The federal government has already taken measures in recent years to strengthen cooperation at national and international level. The EU Joint Programme—Neurodegenerative Disease Research (JPND)—is one successful example of just such a measure. The BMBF is a partner in the JPND and supports the establishment of interdisciplinary and multi-professional collaborative structures at European level. Supporting this programme in the future on a long-term basis will be important, as will be ensuring German participation. Project funding is also available through the Network of Centres of Excellence in Neurodegeneration (COEN). This initiative aims to establish transnational collaborative research into neurodegeneration. Furthermore, collaborative research projects that involve German research, such as the pan-European network Interdem, should also be integrated into funding and research initiatives.

Scientists have the responsibility to communicate their findings to the general public.²¹¹ There is a broad public interest in the findings of dementia research. A study by the ZQP, for example, showed

that 58 per cent of respondents were interested in information on the subject of preventing dementia.²¹² Scientific papers on new advances in dementia research frequently cannot be accessed by patients, relatives and the interested public and are difficult to understand. Many people are reliant on third parties to interpret findings. In 2014, the Alzheimer Society, Munich launched the *EinBlickDemenz* [InsightDementia] project under the Local Alliances for People with Dementia. In cooperation with the Munich Cluster for Systems Neurology (SyNergy) and the DZNE, InsightDementia presents findings from scientific research into dementia in a comprehensible form and provides access to them for the public. In addition, the BMFSFJ's Dementia Signpost site, the DALzG and the Public Health Foundation, amongst other bodies, provide comprehensible information on research online. These are important initiatives, which should be complemented by further measures.

The National Dementia Strategy aims to strengthen the national and international infrastructure of dementia research and collaboration. To accomplish this, the following measures, in which the stakeholders named in the measures are to cooperate with other competent research institutions, will be implemented.

4.1.1 Expansion of a national clinical dementia research network

The DZNE, jointly with researchers from academic teaching hospitals, is expanding the infrastructure of regional clinical research centres working in dementia research. The sole purpose of these research centres is to perform clinical research. They are closely coordinated with basic research. Their focus is research into prevention, diagnosis and treatment measures. The clinical research network, for example, is increasingly conducting clinical trials; it is in close contact with, amongst others, the pharmaceutical industry and the regulatory authorities. The research centres will be

211 Deutsches Netzwerk Evidenzbasierte Medizin e.V. (2016)

212 Zentrum für Qualität in der Pflege (2017)



recruiting their own staff, including study investigators, study nursing staff, technical staff, nurse scientists, psychologists, therapists and gerontologists. The research centres are to be coordinated via a centralised clinical research platform (project management, quality control, data management and centralised biobanking). The centralised clinical research platform also organises access to further education and training programmes. A conference of all clinical researchers working in the research centres will specify the activities grouped under the central clinical research platform. This expansion will be chiefly financed by the BMBF. The BMG will also be monitoring the expansion. The planning and implementation of this measure will involve expert societies such as the German Society of Nursing Science, the DGN and the DGPPN.

By the end of 2024, a national clinical dementia research network will be established and continuously developed. At least five different regional clinical research centres will be established. Furthermore, by 2024 construction of an interdisciplinary, coordinating clinical research platform will have commenced.

4.1.2 Expansion of a national network for dementia health services research

In cooperation with relevant research institutions, both affiliated and non-affiliated with universities, the DZNE is developing a national network for dementia health services research. It will also be integrating nationally active groups into this network. This measure is being funded by the BMBF. The BMG is also providing additional funding for individual research projects. The BMFSFJ is supporting this measure by contributing its own expertise. This network will bundle resources and expertise in dementia health services research. It will facilitate a systematic exchange of findings and methods in health services research, and specific expertise will be shared within the German Network for Health Services Research. Competencies are being identified and regional health services research centres are being incorporated into a research platform. The DKG will be involved in defining the nature of programmes incorporated into the expansion of the network. This will potentially involve the BMBF's recently established research practice networks in general medicine. Expert societies such as the German Society for Nursing Science, the DEGAM and the DGPPN



will also participate in expanding infrastructure for health services research into dementia.

By the end of 2024, a national network on health services research for people with dementia will have been established and will be continuously developed. As a consequence of the work within the network, at least one multi-site healthcare provision study will have been successfully implemented by the end of 2024.

4.1.3 Expansion and networking of biobanks

The BMBF is supporting the expansion and networking of existing biobanks under the funding initiative *Ertüchtigung deutscher Biobank-Standorte zur Anbindung an BBMRI* [upgrading German biobank sites in order to link them to the BBMRI]. The German Biobank Alliance funded by the BMBF will also incorporate further suitable biobank locations. In establishing this biobank, the DZNE is aiming to establish a better data basis for research into demential diseases. The NAKO Health Study with its biobank can, likewise, supply valuable information for future research projects in the field.

By the end of 2024, additional research institutions will be extending mutual access to their biomaterial repositories, allowing scientists to study and understand the causes and mechanisms leading to dementia and identify the genetic risk and protective factors contributing to it.

4.1.4 Access to comprehensive routine data for research purposes

The BMG is laying the groundwork and advocating better access for researchers to research-relevant routine data. The Digital Healthcare Act establishes the framework for expanding the BMG's Data Preparation Centre, for instance, into a Research Data Centre. The dispersed accounting data held by the health insurance companies is to be pseudonymised by the GKV-SV, which will serve as a data collection point, and then collected in the Research Data Centre. If requested, the Research Data Centre will analyse the data and, following verification, transmit the aggregated and anonymised results to authorised users. Details, in particular concerning the type and scope of the data and the tasks of the Research Data Centre, are to be regulated in a statutory ordinance issued by the BMG.

The technical details on how data is to be transmitted will be clarified by the GKV-SV by the end of 2022. By the end of 2022, implementation will have commenced.

4.1.5 Support for dementia research under the EU Joint Programme—Neurodegenerative Disease Research

The BMBF is participating in the JPND and is funding transnational networks, which, amongst other things, are conducting research into dementia-specific issues. National funding of this programme will be extended and successful applicants will receive funding on the basis of future communiqués, for example, in 2021 funding will be provided for the planned thematic focus of developing methodologies and technologies. In addition, the BMBF is actively advocating that research on demential diseases remains a priority and is encouraging other countries to participate in the JPND, for instance within the framework of the G20.

National funding of the JPND will be maintained at least until the end of 2024, and the focus on research into dementia will remain unchanged. The BMBF will encourage other countries to participate in the JPND. It aims to extend funding for the programme beyond 2024.

4.1.6 Development of an evidence-based online information platform

The ZQP is developing a concept for a multimedia online platform aimed at sharing knowledge and information from findings in research into dementia with the general public. The platform will, in particular, present ground-breaking research findings—from basic research to health services research—in a layperson-friendly manner and additionally group these findings into categories. The key partners cooperating to develop the platform, and in particular during the subsequent implementation of the concept, comprise relevant research institutions such as the DZNE, BMG, BMBF, BMFSFJ and DAzG. Beyond members of the general public interested in the subject of dementia, the platform will target groups, such as people with incipient dementia and relatives of people with dementia. The platform will also serve as an information resource for researchers and practising healthcare professionals. The platform will be designed to integrate and network with existing psychosocial, medical and nursing information sites and provide them with greater visibility. The concept will be developed around existing scientific research findings; the evidence it presents may—jointly with other third parties such as the Health Knowledge Foundation—be systematically broadened into relevant associated research fields.

By the end of 2022, the concept for the online platform will have been submitted. Subsequently, with the supporting expertise of its key partners, the ZQP will implement the concept step by step in a first development stage until the end of 2024, and then in a budget-conscious manner in a second development stage until the end of 2026. The BMG will review whether funding can be

provided for the implementation of the concept's individual components after its submission. The BMFSFJ will link its contents on its Dementia Signpost site, with a view to increasing awareness.

4.2 Support for research into prevention and treatment of dementia

The causes of dementia in Alzheimer's disease and in other demential diseases have not yet been fully established. No effective treatment for dementia has yet been developed.²¹³ Further work is, therefore, needed over the coming years in basic research, clinical research and population research. This will require new partnerships between research and industry and the early involvement of regulatory authorities. In addition, a special focus is to be placed on cooperation with scientific start-up companies and small and medium-sized life science companies.

This type of research can contribute to a better understanding of the development and course of demential diseases and of the potential for prevention, diagnosis, therapy, care interventions and rehabilitation.

Nutrition may also play an important role in preventing dementia. There is evidence that specific diets can reduce the risk of dementia. However, more in-depth insights into the interaction between diet and dementia will require further studies to support the preliminary evidence.

Crucially, this will entail research involving patients. This can provide clues on mechanisms that may have therapeutic potential. Such findings may lead to therapies that improve the course of dementia.²¹⁴ Research on animal models has yielded many important findings, but therapeutic approaches in animal models have not yet been successfully translated into treatment for humans.²¹⁵ Hence, the focus should be placed on research into dementia in humans.

213 Livingston et al. (2017); Laschet (2018)

214 Tacik (2018); Laschet (2018)

215 Laschet (2018)

In order to assess the risk factors of dementia and their potential for prevention, as mentioned above, there is a need not only for clinical research, but also for research into the development of dementia at the population level, as the Lancet Commission on Dementia Prevention, Intervention, and Care has noted. To facilitate such research, the expertise existing at large epidemiological university and non-university research institutions needs to be pooled, and cooperation between these institutions strengthened.

Representative cohort studies are essential to identify the possible causes of dementia and understand its course. The Rhineland Study, launched by the DZNE in 2016, is one example. Over a period of at least 30 years, this study will involve approximately 30,000 participants from a region of North Rhine-Westphalia. The Rhineland Study is a life-long longitudinal study to develop an understanding of the causes and mechanisms of dementia and includes people aged 30 years and older, including individuals over 85 years of age, who are invited to an unprecedentedly deep phenotypic examination every three to five years. In addition, since 2014 the NAKO Health Study in Germany has been expanding a cohort of people aged between 20 and 69 years on entry into the study. Over a period of 20 to 30 years, 200,000 people throughout Germany will be repeatedly examined. The information collected includes details of cognitive functions and cognitive performance disorders. It, therefore, constitutes a valuable foundation on which research projects into dementia can build. The aim of these two long-term studies is to investigate the interaction of hereditary factors, lifestyle and environmental influences as causes of healthy ageing in order to shed light on the causes of widespread diseases, to identify risk factors, to establish ways of effective prevention and to discover methods to detect diseases at an early stage. Similar studies include the DELCODE, AgeCoDe, AgeQualiDe and LIFE health studies. To identify factors that can prevent dementia or that are therapeutically relevant, cohorts consisting of healthy older and very old

people²¹⁶ are needed. In light of this, further development of representative cohort studies is warranted.

Ongoing health monitoring studies at the RKI, such as the DEGS and GEDA health studies, can provide insights into the general distribution of risk and protective factors, the prevalence of chronic diseases and the general state of health-care provision in the overall population.²¹⁷ To make use of findings from health monitoring in dementia research, monitoring needs to incorporate dementia-relevant indicators. Since January 2019, the RKI, with financial support from the BMG, has been conducting the national MonAge study on people aged 65 and over. This study includes very old (80+) and health-impaired older people who to date have not been sufficiently represented in the federal government's health monitoring system, as they were difficult to recruit using the previous methods for participation in surveys and studies. MonAge also includes dementia risk factor monitoring, which, in addition to selected cardiometabolic risk factors, includes a brief assessment of cognitive functioning and self-reported memory impairment.

Studies on early stages of dementia should also be undertaken. The aim is to improve dementia prevention, diagnosis, treatment and care interventions. Studies on people at risk or studies on people with the first symptoms of dementia are of particular interest.²¹⁸ A population-representative study has indicated that 69 per cent of people would be willing to be tested for early diagnosis of dementia.²¹⁹ In addition, numerous studies have identified protective factors that are associated with maintaining mental ability and that could potentially delay the development of dementia. Such findings were demonstrated, amongst others, by the Finnish Geriatric Intervention Study (FINGER) and the Multidomain Alzheimer Preventive Trial (MAPT). They showed that regular physical activity, a balanced diet and social activities are likely to reduce the probability of developing dementia. High blood pressure, obesity,

216 People who are 80 years old or older.

217 Fehr et al. (2017)

218 Jessen (2018); Laschet (2018)

219 Luck et al. (2012)



nicotine and excessive alcohol consumption, on the other hand, are associated with an increased risk.²²⁰ In May 2019, the WHO published recommendations on reducing the risks of cognitive deterioration and dementia in old age and highlighted the potential for risk reduction, as well as the considerable shortfalls in evidence that still exist. The first international prevention studies have yielded encouraging results (for instance FINGER and MAPT). In 2018, the first German multi-modal lifestyle-based intervention study on dementia prevention was launched, involving over 1,000 high-risk individuals.²²¹ Broad-based monitoring and intervention studies are clearly needed.

Clinical research enables, amongst other things, new biomarkers to be developed based on detailed examination of persons at risk and of patients. These biomarkers facilitate timely diagnosis and can be used to identify subgroups of specific diseases. Biomarkers and genetic tests can, for example, be used to predict how dementia will

develop in a particular patient population several years before the onset of symptoms. Biomarkers will potentially be used in the future to test therapeutic approaches in the early stages of diseases and to individually tailor treatment of patients.²²² In 2018, the BÄK published a statement on the use of tests to predict whether a person is at risk of developing Alzheimer's disease.²²³ This statement represents an important step in the societal discourse on the subject of dementia. The BMBF has initiated a further step by funding the discourse procedure *Konfliktfall Demenzvorhersage* [Conflict Dementia Prediction], in which the likely effects of dementia prediction were discussed by a wide range of interdisciplinary protagonists.²²⁴ Systematic, long-term access to digital databases is essential for new scientific knowledge and innovation. These incorporate data on validation of biomarkers. They need to be easily locatable and well-ordered for third parties and to be analysed and cross-referenced with other databases from different disciplines and countries. To transform research data into scientific, wide-ranging, useful

220 Livingston et al. (2017); Hussenoeder and Riedel-Heller (2018); Luck et al. (2018)

221 Zülke et al. (2019)

222 Grimmer and Kurz (2018); Strech and Götzelmann (2018)

223 Bundesärztekammer (2018)

224 Bartholomeyczik et al. (2018)



datasets of societal value, the federal and state governments have agreed to establish and jointly fund a National Research Data Infrastructure (NFDI). Within the NFDI, providers and users of research data are to work together in consortia, merge existing data sets and services, and establish new, cross-disciplinary services and ensuing solutions for research data management in Germany.

The debate in society on how to deal with the issue of dementia is shaped by the attitudes of the general public to people with dementia. So far, however, little is known about the attitudes members of the public have towards people with dementia. Findings from the German Ageing Survey (DEAS)²²⁵ will be pertinent both for social reporting and for research in the social and behavioural sciences. Future surveys should, therefore, take into account attitudes towards people with dementia among the general public. Findings on the circumstances of older people with dementia are to be documented for the first

time by the survey Old Age in Germany (D80+).²²⁶ These surveys constitute an information resource for political decision-makers, the public and scientific research.

The National Dementia Strategy aims to support research into the prevention and treatment of dementia. In particular, research into prevention strategies for healthy ageing and preventing demential diseases is being conducted by large epidemiological research institutes, for example the Leibniz Institute for Prevention Research and Epidemiology (BIPS) as an element, on the one hand, of its primary and third-party funded research focus Life Course Epidemiology and, on the other, of its participation in the Leibniz Research Alliance Healthy Ageing alongside 18 other Leibniz institutes. In addition, the following measures will be agreed upon, in which the stakeholders named in the measures can, or are to, cooperate with other competent research institutions.

225 The DEAS is a nationwide representative cross-sectional and longitudinal survey of people in the second half of life (40 years and older); see also www.deutscher-alterssurvey.de

226 The D80+ survey of old age is a representative population survey, which interviews people aged 80 years and older (or their representatives) in private households and institutions; see also www.dza.de/forschung/hochaltrigenstudie-d80.html.

4.2.1 Support for basic research on dementia in humans

The BMBF will continue to fund basic research on dementia in humans. For the DZNE such institutional research funding enables it, amongst other activities, to perform advanced research into the causes, mechanisms, and risk and protective factors underlying dementia.

The BMBF will continue to fund basic research focusing on dementia in humans until at least the end of 2026. The funding level from 2019 will serve as a benchmark for future funding. The BMBF aims to extend this funding beyond 2026.

4.2.2 Representative cohort studies focusing on dementia

The DZNE is conducting cohort studies to analyse the possible causes of dementia and to assess the resilience, risk and protective factors associated with dementia. These representative cohort studies, which are focused on dementia, are primarily funded by the BMBF. When forming cohorts, healthy older and very old persons are also included to investigate resilience factors.

The DZNE will conduct the Rhineland Study into dementia until the end of 2026 and will assess whether extending it is appropriate. The DZNE and the BMG will work to ensure that the results of existing cohort studies at the end of 2026 are incorporated into the development of new potential interventions aimed at preventing and treating dementia.

4.2.3 Dementia-related indicators in health monitoring

The BMG has commissioned the RKI to investigate the extent to which established indicators of dementia risk can be practicably supplemented by broadening ongoing, long-term health monitoring studies to include older people. Its investigation will evaluate the RKI's MonAge study to

identify additional indicators relevant to dementia. One of the focuses of MonAge is describing the frequency and distribution of established dementia risk factors or combinations of risk factors in the general population. Collectively, the findings from MonAge will provide information on the practicability and benefits of population-based dementia risk factor monitoring. This will be periodically repeated in future nationwide representative health monitoring studies of older and very old people in Germany.

The RKI will be conducting the MonAge study until the end of 2022.²²⁷ The data from MonAge will be used to test the extent to which known relationships, for instance between cardiometabolic risk factors, cognitive function and self-reported memory impairment, can also be demonstrated in a nationwide population study.

4.2.4 Conduction of studies into the early stages of dementia

The DZNE is conducting observational and intervention studies into the early stages of dementia.²²⁸ These studies are primarily funded by the BMBF. They are investigating the effectiveness of target-group specific, lifestyle-based interventions, including exercise, nutrition, cognitive training and therapy monitoring. It is currently being reviewed whether long-term funding can be provided for ongoing intervention studies. Additionally, the DZNE is conducting observational and intervention studies into the early stages of dementia to investigate diagnostic procedures and the efficacy of drugs. The higher federal authorities (the BfArM and the Paul Ehrlich Institute (PEI)) can provide scientific advisory services, including advice to applicants prior to the approval of a clinical trial.

By the end of 2024, the DZNE will have committed itself to planning at least two clinical studies drawing on existing national expertise to investigate diagnostic procedures and the efficacy of drugs.²²⁹ By the end of 2026, the DZNE will have

227 The MonAge study will run until 30 September 2022.

228 These studies involve people who either have a high genetic risk of dementia but no symptoms, or who are at a very early stage of dementia and displaying initial symptoms.

229 Subject to the approval of the relevant regulatory authorities.

launched studies to investigate the effectiveness of secondary prevention measures for people with dementia.

4.2.5 Expansion of research on clinical validation of biomarkers

The BMBF is funding studies on clinical validation of biomarkers and therapies for dementia. The DZNE will be conducting these studies. The BfArM will provide expert advice in advance, if required, and will approve these studies after appropriate review.

The DZNE will plan studies to clinically validate biomarkers and related potential therapies up until the end of 2024, incorporating existing expertise beyond the DZNE. These studies will take into account developments in the National Research Data Infrastructure and exploit potential avenues of cooperation.

4.2.6 Representative survey on attitudes towards people with dementia in the general population

The BMFSFJ is funding the DEAS, which is conducted by the DZA. In 2020, the DEAS will, for the first time, also examine attitudes towards people with dementia in the general population. Findings from the DEAS are made available to political decision-makers, the public and researchers.

The DZA will conduct research via the DEAS into attitudes towards people with dementia in the general population until the end of 2024.

4.2.7 Collection of information on dementia in a representative survey of the very old

The BMFSFJ is funding the survey Old Age in Germany (D80+) conducted by the University of Cologne and the DZA. The D80+ study examines the circumstances and quality of life of people over 80 years of age. It is collecting, for the first time, population-representative information on

older and very old people living in private households and in nursing homes. This approach makes it possible to also gather information on people aged 80 years and older who are affected by dementia. The findings from the D80+ study will be made available to political decision-makers, the public and researchers.

The University of Cologne and the DZA will be investigating the circumstances and quality of life of people aged 80 and over until the end of 2024.

4.3 Funding health services research into dementia

Optimal treatment for people with dementia depends on health services research, which examines the provision of medical, nursing and therapeutic health services. It examines existing structures to identify overuse, underuse and misuse and develops suitable measures to prevent them. To achieve this, new health services concepts are also being developed, implemented and evaluated in a practice-oriented manner, taking into account, in particular, the perspective of people with dementia and their relatives.²³⁰ With the accumulation of evidence on risk reduction, health services research is becoming ever more important.²³¹

In recent years, numerous research projects of this kind have received funding and been conducted, for example supported by the German Innovation Fund.²³² Hence, the German Innovation Fund represents an important means of optimising medical, nursing and therapeutic health services for people with dementia in Germany. Nevertheless, further measures are necessary. The BMBF is currently supporting the development of and research into new nursing technologies.

The National Dementia Strategy has also identified a number of subjects and issues in health services research that have not yet been adequately covered.

230 Scheel et al. (2019); Thyrian (2017)

231 Zülke et al. (2019)

232 Blettner et al. (2018)

Amongst other things, evidence-based approaches to individual diagnosis, therapy, nursing intervention, and healthcare of people with dementia are to be researched and their effectiveness and cost-effectiveness reviewed. One aspect being researched is individual counselling and support for people with dementia and their relatives in the context of case management, as well as the support, structural development and networking provided via care management.²³³ The DelpHi-MV study, which is coordinated by the DZNE, has already positively evaluated the process of dementia care management. The current aim is to investigate ways to better establish dementia care management into care services for people with dementia.

In addition, strategies for secondary and tertiary prevention are to be developed and evaluated. They aim to avoid complications and concomitant diseases (secondary prevention) and to rehabilitate people's functional skills (tertiary prevention). To develop such strategies, studies need to be conducted investigating the effectiveness of secondary preventive and rehabilitative measures in real-life scenarios. Such measures are focused on how to maintain the autonomy of people with dementia and how to encourage them to participate in their social environment.

Research is also to be conducted into how evidence-based prevention and healthcare strategies can be transferred into standard care. People with dementia can engage in challenging behaviour, which can be accompanied by restlessness, aggressive behaviour or apathy. This behaviour can be stressful for healthcare providers of people with dementia.²³⁴ Challenging behaviour and other stresses, such as cognitive difficulties in people with dementia, are often aggravated by hospitalisation.²³⁵ Hence, if possible, hospitalisation of people with dementia should be avoided. Hospitalisation cannot always be avoided, however, and this adds weight to ensuring hospitals are designed to be dementia-sensitive, including



medical, nursing and therapeutic processes, patient management, the involvement of relatives, and the physical architecture and environment of hospitals. In addition, discharge management needs to be made dementia-sensitive.²³⁶ Furthermore, people with dementia are at a higher risk of developing delirium if hospitalised,²³⁷ and, additionally, delirium can exacerbate the development of dementia. However, identifying delirium in patients with pre-existing dementia can be challenging, as the symptoms of delirium and dementia can resemble each other. This complicates differentiating between the two syndromes.²³⁸ In view of this, dementia-sensitive delirium management is vital. Evidence-based strategies to address these issues need to be considered.

Proprietary medicinal products may only be placed on the market if they have been authorised by the respective competent federal higher authority (either the BfArM or the PEI), or by the European Commission under a centralised

233 Riedel-Heller (2018b); Thyrian et al. (2017); Thyrian et al. (2018)

234 Kastner and Löbach (2018); Alltag et al. (2019); Riedel-Heller (2018a); Conrad et al. (2018)

235 Hofmann (2016)

236 Büter and Marquardt (2019); Pöschel and Spannhorst (2018)

237 Frühwald et al. (2014)

238 Hewer (2018)



procedure. At a European level, conditional marketing authorisation, and marketing authorisation under special circumstances represent different ways of ensuring innovative medicines are made available to patients as soon as possible. In addition, applicants are entitled to obtain information on regulatory and procedural issues relating to the development and authorisation of medicinal products by means of scientific consultation by the higher federal authorities or by the European Medicines Agency (EMA). The goal of such consultation is to offer applicants guidance at a very early stage of development on any regulatory procedural steps they may need to take. To this end, the higher federal authorities can provide general information on ways to accelerate proceedings and specific advice on the substance and procedures of a planned authorisation procedure.

Investigating cross-sectoral networking in the context of health services represents a further key area of research. Numerous inter- and intrasectoral interfaces exist in the provision of healthcare for people with dementia, and these can result in discontinuities. Health services research can

contribute to improving cross-sectoral cooperation between all involved parties.

Digitalisation offers major opportunities for improving dementia prevention and health services for people with dementia. However, the inherent possibilities and limitations associated with digital systems have not been adequately explored. A wide range of issues relating to digitalisation will be investigated in the coming years. These include the use of telemedicine and telecare, robotics and artificial intelligence. In principle, these have the potential to relieve the burden on nursing staff and family care-givers and thus improve long-term care for people with dementia.²³⁹ In addition, interactive assistance systems can support people with dementia in remaining independent and, as a result, enable them to cope better with their daily life at home and be less reliant on assistance. Beyond this, more research is needed into user acceptance and the effectiveness of digital systems for people with dementia and their relatives.²⁴⁰ Such research should also take issues relating to social inequality into account. Participation of people with demen-

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239 Livingston et al. (2017); Nordheim et al. (2015); Kramer (2016)

240 Bossen et al. (2015);

tia is a key component of the funded research and development projects. Only by enabling people with dementia to participate, can the opportunities and limitations of new digital healthcare technologies for people with dementia—and for relatives, doctors and qualified nurses—be assessed and considered from ethical, social and legal perspectives. Launched by the BMBF in 2017, the Future of Nursing cluster is already trialling—under clinical, in-patient and out-patient settings—nursing care technologies that can be used, amongst other ways, for social care, design of therapies and increasing the security of people with dementia. Findings from these trials are to be incorporated into future research projects. The digital opportunities for prevention and the associated potential to exploit digital innovations for preventive interventions is to be explored in appropriately designed research projects. It is apposite that such research be conducted in cooperation with an institution such as the Leibniz Science Campus Digital Public Health, which is jointly funded by the State of Bremen, the Leibniz Association and the Leibniz Institute for Prevention Research and Epidemiology (BIPS).

Another key focus of research will be the circumstances of family care-givers and the status of long-term care in the home. People with dementia who live at home are predominantly cared for by close relatives. This responsibility involves a high degree of psychological stress and physical exertion for family care-givers, including a high risk of exhaustion.²⁴¹ Without appropriate support, the high degree of stress experienced by family care-givers can incur the risk of seriously compromising their quality of life, and may even lead to themselves falling ill. Intervention programmes to support highly stressed family care-givers have already been established, but their implementation in daily care remains too rare. Hence, further development and evaluation of staged strategies tailored to the individual needs of family care-givers is an important objective of research. Care by relatives who live remotely and the care mix provided are further focal points. Thus, diverse health service scenario combinations are

to be investigated. Such research can identify ways of improving care.

Many family care-givers need to combine family and career. However, there is currently no conclusive research into the framework conditions that would be required to provide optimal support to family care-givers in their daily lives. Family care-givers of people with dementia face particular challenges, as the further dementia progresses, the more intensive care needs to be.²⁴²

Legal impact studies relating to dementia also needs to be intensified. Whenever laws are passed to improve the circumstances of people with dementia, research is needed to monitor the impact of these laws. Such studies examine whether the envisaged improvements have genuinely come to fruition. For instance, the Second Long Term Care Strengthening Act introduced the new definition of care need, as well as a new assessment instrument.²⁴³ With these developments in mind, the BMG in accordance with Article 18c paragraph 2 SGB XI commissioned a study to evaluate, in particular, the measures and outcomes arising from the preparation and implementation of the transition to the new procedure for establishing the care for need. In principle, the study should yield insights into the success, in particular, of the Second and Third Long Term Care Strengthening Acts in achieving their goals. A report on this evaluative study was submitted on 1 January 2020. Based on the findings of the evaluation, the report considers whether statutory regulations or subordinate regulations need to be adapted. Further legislative processes are to be examined accordingly.

One study examined differing care coping strategies employed by relatives who care for people with high dependency needs. It considered the influence of various factors, such as socio-economic status, sex, ethnicity and employment status.²⁴⁴ Other studies—‘Avoiding physical restraining measures’ (ReduFix) and ‘Implementation of a multicomponent intervention to prevent physical restraints in nursing homes’ (IMPRINT)—have examined how to avoid imposing restrain-

241 Pantel (2018); Thyrian et al. (2017)

242 Zentrum für Qualität in der Pflege (2016)

243 PSG II Zweites Pflegestärkungsgesetz

244 Auth et al. (2018)

ing measures. These examples provide valuable points of reference for improving the quality of care at home. Nevertheless, further research with a focus on dementia is needed. The quality of healthcare for people with dementia is influenced, amongst others, by psycho-social factors and social and socio-economic inequalities. For instance, a low level of education is associated, on average, with higher risks of more serious somatic disorders, including certain forms of dementia.²⁴⁵ These relationships are to be researched in greater depth. Similarly, more research is needed into the interconnected ways people with dementia experience the world (Lebenswelt).

Another important aspect of health services research is addressing the ethical questions raised by dementia research. More debate is needed, for example, on research into biomarker-based early diagnosis and the capacity of people with dementia to provide informed consent.

The National Dementia Strategy aims to support health services research involving the broadest possible involvement of relevant dementia stakeholders. This topic is also currently, and will continue to be, the focus of numerous third-party funded projects, such as at the Institute for Public Health and Care Research at the University of Bremen. In addition, the following measures will be implemented, in which the stakeholders named in the measures can or are to cooperate with other competent research institutions.

4.3.1 Development of evidence-based strategies for healthcare provision for people with dementia

The DZNE is developing evidence-based strategies for personalised diagnosis, treatment and healthcare and is testing them for their effectiveness. The focus is on the cost-effectiveness of healthcare and the potential benefits of qualifying academic or specially trained qualified nurses to responsibly manage dementia care. The BMG is funding a measure to investigate the issue. As one of its pilot programmes to further develop long-

term care insurance, the GKV-SV will be supporting projects on how to improve health services for people with dementia. One focus of these is on non-medicinal interventions—their development and proof of their effectiveness. The DALzG, DEGAM and the German Society for Nursing Science are also contributing their expertise in implementing this measure.

By the end of 2024, the insights gained will be instrumental in further developing treatment and care guidelines.

4.3.2 Development and evaluation of strategies for secondary and tertiary prevention

The DZNE is developing and evaluating strategies for secondary and tertiary prevention (rehabilitation), to ensure that people with dementia can maintain as much autonomy as possible. The BMFSFJ is involved in an advisory capacity. Expert societies such as the German Society of Nursing Science, the DALzG, BÄK, KBV, DEGAM and the GKV-SV are contributing their expertise to developing the strategies. To ensure a holistic approach, the development and evaluation of the strategies will be guided by the problems people with dementia face in managing daily life and in integrating into their social environment. The strategies will be based on analyses of which factors impede and which enhance autonomy. This will lead to recommendations on how to design social spaces for people with dementia. Research is being conducted to determine how counselling for people with dementia needs to be structured to promote autonomy at every stage of the dementia. The participants are committed to ensuring that secondary and tertiary preventive measures are an integral part of treatment for people with dementia.

By the end of 2024, strategies for secondary and tertiary prevention will have been developed and evaluated, and recommendations on how to design social spaces and on counselling for people with dementia will have been developed.

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245 Kämpers (2012); Müller (2018)



4.3.3 Transfer of evidence-based prevention and healthcare strategies into standard care practice

In cooperation with the German Network for Health Services Research, the DZNE and other health services research institutions are working to launch more research projects on the prerequisites and conditions for sustainable transfer of evidence-based prevention and healthcare provision strategies into standard care practice of people with dementia. The work will focus, in particular, on how to transfer evidence-based findings on dealing with challenging behaviour, managing dementia-sensitive delirium and adapting discharge management in various healthcare scenarios. In addition, further dementia care strategies will be systematically monitored and investigated to identify factors that might promote or inhibit models of standard healthcare provision. The BMG is funding a measure to this end. Expert societies, such as the German Society of Nursing Science and the DALzG, will contribute their expertise to implementing this measure.

By the end of 2024, the prerequisites and conditions for sustainable transfer of evidence-based health services strategies into standard care practice will have been established and solutions will have been developed in the form of a strategy for implementing effective and cost-efficient health service models into practice.

4.3.4 Accelerated procedures for authorisation of medicines for people with dementia

In addition to the EMA, the BfArM and the PEI provide orientation guidance on any regulatory procedural steps that may be required at very early stages in the development of drugs. This guidance also includes general information on potential ways to accelerate the procedural steps as well as scientific advice on the specific details and procedures of a proposed authorisation procedure via the innovation offices of the higher federal authorities. The DZNE is already making use of such guidance from its cooperation partner, the BfArM, to speed up authorisation procedures for drugs for people with dementia by ensuring that regulatory requirements are addressed at the earliest possible date. This will enable research

findings from clinical trials to be more promptly incorporated into the care of dementia patients.

Taking into account the regulatory requirements, the DZNE will work towards initiating at least one accelerated authorisation procedure for drugs related to dementia by the end of 2026.

4.3.5 Investigation of the cross-sectoral networking of forms of health services

The DZNE is investigating which factors promote or inhibit cooperation between the various forms of health services and healthcare system sectors, how existing hurdles can be surmounted and whether legal measures can be taken to address them.

By the end of 2024, factors promoting or inhibiting cooperation will have been identified and recommendations for action will have been formulated to initiate updated forms of health services. In addition, proposals for legislative measures to improve cross-sectoral networking of forms of health service (including improved reimbursement options) are being developed.

4.3.6 Research into digitalisation in prevention and healthcare

The BMBF intends to continue its support for research and development projects on how digitalisation can improve the daily life of people, in general and in particular the lives of people with dementia who live autonomously at home. Participation of people with dementia is a key component of the funded research and development projects. To enable this, research is concentrating, in particular, on interactive assistance systems, telemedicine and telenursing, robotics and artificial intelligence. The BMBF's efforts here are based on findings from ongoing funded measures, for instance *Pflegeinnovationen für Menschen mit Demenz* [care innovations for people with dementia], medical technology, the Future of Nursing cluster and the Leibniz Science Campus. Medical technology research focuses on therapy support (including digital support) and diagnostics. The

DZNE will likewise be participating in research related to dementia. In the DZNE's DigiCare project, for example, it will work together with universities, long-term care facilities and companies to develop online courses in nursing science in the state of Mecklenburg-Western Pomerania. Within the framework of the pilot programmes to further develop long-term care insurance and the newly established funding focus 'digitisation in long-term care', the GKV-SV is funding projects that address, in particular, the concrete benefits of digital assistance technologies for people requiring long-term care, including those with dementia. One focus of these projects is on the independence and autonomy of people with dementia with a view to enable them to live in their familiar domestic environment for as long as possible. Expert societies, such as the German Society of Nursing Science and the DALzG, will also contribute their expertise to developing and implementing this measure. The BMBF and the DZNE will also involve members of the German Ethics Council to ensure that ethical framework conditions are developed and adhered to. Other parties, such as small and medium-sized companies and foundations, can contribute within their own means to implementing this measure.

By the end of 2026 at the latest, the research findings will be contributing to the further development of potential technical and digital tools for prevention, diagnosis and therapy for people with dementia. The BMBF aims to extend funding for this research beyond 2026.

4.3.7 Research to support overburdened family care-givers

The BMBF-funded joint project ReDiCare is testing the use of a combined, staged assistance strategy to support overburdened family care-givers. A three-month long consultation, based on a structured problem-solving approach, will be followed by a six-month long telephonic behavioural therapy intervention. The project's aim is to obtain important information on how to translate the findings into daily healthcare in the future.

After the study has concluded, the available findings will be reviewed until the end of 2024 to determine the legal basis on which they can be incorporated into standard care.

4.3.8 Health services research into relatives of people with dementia

The DZNE is reviewing available health services to support relatives in caring for people with dementia. The DZNE's review will examine which forms of health services are currently available, which skills relatives need to provide optimal care and support for people with dementia, and what effects home care has on affected families, especially on care-giving women (personal burden, financial circumstances and social environment). The review will also consider the situation of foreign assistance and care staff, care provided by relatives living remotely, and issues relating to social inequality (such as gender and migration background). This measure is supported by the BMFSFJ. Expert societies, such as the German Society of Nursing Science and the DEGAM and the DAzG, will contribute their expertise to implementing this measure.

By the end of 2024, the DZNE will have prepared a comprehensive overview of various scenarios for the care of people with dementia in Germany, drawn up recommendations for action to overcome barriers to accessing support services and developed healthcare strategies to sustain the health of relatives.

4.3.9 Study on the compatibility of care and employment

The BMFSFJ is commissioning a study on the circumstances of family care-givers who care for a person with dementia and are simultaneously employed. Specifically, special consideration will be given to issues of gender.

By the end of 2024, the study will have been submitted to the BMFSFJ.

4.3.10 Support for legal impact studies on dementia

The DZNE is conducting research into the effects of individual laws (for example SGB V, SGB XI) on people with dementia, their relatives and service providers. Such research will take the ongoing or planned evaluations of SGB V and SGB XI into account. The BMBF is funding this measure as part of its support for the DZNE. Expert societies, such as the German Society for Nursing Science, will be contributing their expertise to implementing the measure.

On the basis of the findings, the DZNE will have developed recommendations for legislative amendments by the end of 2024.

4.3.11 Research on the interconnected ways people with dementia experience the world

The BMFSFJ and DZNE are cooperating in researching the interconnected ways people with dementia experience the world (Lebenswelt). This research will consider various factors relevant to the development of dementia and the treatment and care of people with dementia: psychosocial factors, social inequality, socioeconomic inequality and demographic patterns of ageing. Furthermore, it will examine the experience of dementia over the course of the condition from the perspective of those affected and from that of people in their immediate social environment. It will consider the effect that manifestation of the condition's symptoms has on the organisation and management of daily life in various scenarios (informal care, out-patient care, in-patient care and a care mix) and circumstances in life (people living alone and people with a migration background), as well as on interpersonal relationships (relatives, care-givers and support providers). This measure is funded by the BMFSFJ. Expert societies, such as the German Society of Nursing Science and the DEGAM, the DAzG, and research institutions, such as the DZNE and the DAzG, will contribute their expertise to implementing this measure.



By the end of 2024, four projects on these issues will have been conducted and corresponding recommendations for action will have been prepared and made available to academics in the field.

4.3.12 Research on ethical issues in predictive dementia diagnostics

The BMBF is planning a specific, international funding guideline for ELSA research within the framework of ERA-NET NEURON research networks in neuroscience. Funding can also be provided to projects in the field of predictive diagnostics for dementia. The projects can examine and address bioethical issues related to early diagnosis of dementia, for instance into the acceptance and reliability of (biomarker-supported²⁴⁶) early diagnosis, the disclosure of

accidental diagnoses (right not to know) and into treating symptom-free patients.

By the end of 2022, the BMBF will have funded measures to research ethical, legal and social issues in the field of neuroscience.

4.4 Improving participation in dementia research

To improve health services and the quality of life of people with dementia in line with their needs and requirements, people with dementia and their relatives must be actively included in participating in dementia research from the outset. Alzheimer Europe recommends that people with dementia become involved on an equal footing with researchers over the entire research process. If

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246 In the future, increasingly involving blood-based markers

required, such participation can be supported by commensurate and appropriate funding.²⁴⁷

Participation of people with dementia is also dependent on examining ethical issues. Participation in a study is based on the informed consent of people with dementia. However, the current consent procedures are not always appropriate for people with cognitive disabilities. For example, consent texts tend to be demanding in order to accurately describe the objectives of studies and the rights of study participants.²⁴⁸ Once dementia has progressed, a patient's ability to provide consent is also often reduced. Hence, research needs to be conducted on how suitable patient information documentation and consent procedures for people with dementia should be formulated.

New forms of participation are likewise to be given greater consideration. The BMBF, for example, intends to increasingly support 'makers'²⁴⁹—people who independently improve products, either as appliers or actual users of the products. Their activities can lead to the development of application-oriented solutions to the challenges that people with dementia and their relatives face in daily life.

The National Dementia Strategy aims to improve the participation of people with dementia in research at all levels. The following measures have been agreed upon to achieve this.

4.4.1 Research projects on patient information documentation and informed consent procedures

Within the framework of ELSA research, the BMBF is funding innovative projects in accordance with national and international funding guidelines to investigate socially relevant issues in the field of neurodegenerative diseases. These may include specific projects on the ability of dementia patients to provide informed consent. Funding can potentially be obtained under a specific, international funding guideline for ELSA research

within the framework of ERA-NET NEURON (in the field of neuroscience and planned for 2020). The findings will be used to analyse and continuously develop the scientific, political and regulatory framework conditions and foster social discourse.

By the end of 2022, the BMBF will have funded measures to research ethical, legal and social issues in the field of neuroscience.

4.4.2 System to involve people with dementia in research projects

The DALzG and the DZNE are jointly developing a system for involving people with dementia and their families in participatory dementia research. Self-help and patient organisations along with general practitioners will be involved in developing the design of studies to fit into this system. Researchers will also receive training on how to communicate with people with dementia and their relatives in an appropriate and comprehensible manner. Participatory research with people with dementia is supported by the BMG. In addition, the DZNE will establish a new patient advisory panel and bear its costs. Together with the medical ethics department of the University of Göttingen and corporate partners, the DZNE is conducting the EIDEC project to investigate the ethical and social issues engendered by the use of digital technologies in diagnosing and caring for dementia patients. People with dementia and their relatives will be systematically involved from an early stage in the medical-ethical research of this project.

By the end of 2024, a system to integrate people with dementia in an accessible manner into research will have been developed, the patient advisory panel will have been established and self-help and patient organisations will be better networked.

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247 Alzheimer Europe (2017)

248 Hoffmann et al. (2017); Sturma (2018)

249 Makers, in the strictest sense, are hobbyists belonging to a DIY subculture that make their own products, and increasingly make their own technical aids. In a broader sense, makers are appliers or users of products who independently improve existing ones or create alternatives. Their essential characteristic is that making new products is not their actual principal activity. In the broadest sense, makers can be employees who develop products at work, facilitating their smooth transition into traditional, corporate innovation structures.

Appendix

List of acronyms

AAL	Ambient Assisted Living
AAPV	General out-patient palliative care
AgeCoDe	German Study on Ageing, Cognition and Dementia in Primary Care Patients
AgeQualiDe	AgeQualiDe study: Needs, health services use, costs and health-related quality of life in a large sample of oldest-old primary care patients (85+)
ARD	Working group of public broadcasters of the Federal Republic of Germany
BAGFW	The Federal Association of Non-statutory Welfare e.V.
BAGSO	German National Association of Senior Citizens' Organisations e.V.
BÄK	The German Medical Association
BBMRI-ERIC	Biobanking and Biomolecular Resources Research Infrastructure—European Research Infrastructure Consortium
BfArM	Federal Institute for Drugs and Medical Devices
BIPS	Leibniz Institute for Prevention Research and Epidemiology
BMAS	Federal Ministry of Labour and Social Affairs
BMBF	Federal Ministry of Education and Research
BMEL	Federal Ministry of Food and Agriculture
BMFSFJ	Federal Ministry for Family Affairs, Senior Citizens, Women and Youth
BMG	Federal Ministry of Health
BMI	Federal Ministry of the Interior, Building and Community
BMJV	Federal Ministry of Justice and Consumer Protection
BMVI	Federal Ministry of Transport and Digital Infrastructure
bpa	<i>Bundesverband privater Anbieter sozialer Dienste e.V.</i> [Federal Association of Private Providers of Social Services]
BZgA	Federal Centre for Health Education
CDU	Christian Democratic Union of Germany
COEN	Centres of Excellence in Neurodegeneration
CSU	Christian Social Union in Bavaria
DAIzG	German Alzheimer Society e.V.—Dementia Self-Help
DaTraV	Regulation on the implementation of data transparency requirements (Data Transparency Regulation)
DEAS	The German Ageing Survey
DED	<i>Deutsche Expertengruppe Dementenbetreuung e.V.</i> [German Expert Group on Dementia Care]
DEGAM	German College of General Practitioners and Family Physicians
DEGS	German Health Interview and Examination Survey for Adults
DELCODE	DZNE-Longitudinal Cognitive Impairment and Dementia Study
DelpHi-MV	Dementia: Life- and Person-Centred Help in Mecklenburg-Western Pomerania
DemNet-D	Dementia Networks in Germany
DGG	German Society of Geriatrics e.V.
DGGG	German Society of Gerontology and Geriatrics e.V.
DGGPP	German Society of Geronto-Psychiatry and Psychotherapy e.V.
DGN	German Society of Neurology e.V.
DGP	German Society for Palliative Medicine e.V.
DGPPN	German Association for Psychiatry, Psychotherapy and Psychosomatics e.V.
DHPV	German Hospice and Palliative Care Association e.V.
DIMDI	German Institute for Medical Documentation and Information
DITIB	Turkish-Islamic Union for Religious Affairs e.V.
DKG	German Hospital Federation e.V.
DPR	German Nursing Council e.V.

DVfR	German Association for Rehabilitation e.V.
DZA	German Centre of Gerontology e.V.
DZNE	German Centre for Neurodegenerative Diseases e.V.
EIDEC	Ethical and Social Issues of Co-intelligent Sensory Dementia Care
ELSA research	BMBF funding focal area: Ethical, Legal and Social Issues in the Life Sciences
EMA	European Medicines Agency
ERA-NET	European Research Area Networks
EU	European Union
FDP	Free Democratic Party
FINGER	Finnish Geriatric Intervention Study
G-BA	Federal Joint Committee
GEDA	German Health Update
GG	Basic Law for Germany
GKV	Statutory Health Insurance
GKV-SV	National Association of Statutory Health Insurance Funds
GVFG	Municipal Transport Financing Act
IMPRINT	Implementation of a Multicomponent Intervention to Prevent Physical Restraints in Nursing Homes
JPND	EU Joint Programme—Neurodegenerative Disease Research
KAP	Concerted Action for the care workforce
KBV	National Association of Statutory Health Insurance Physicians
KDA	Foundation for the Care of Older People e.V.
KfW	KfW Banking Group
KMK	Standing Conference of the Ministers of Education and Cultural Affairs
LIFE	Leipzig Research Centre for Civilization Diseases
MAPT	Multidomain Alzheimer Preventive Trial
MonAge	Study on the health of the elderly (over 65 years) in the German healthcare system
NAKO	German National Cohort e.V.
NEURON	Network of European Funding for Neuroscience Research
NFDI	National Research Data Infrastructure
ÖPNV	Local public transport
OSHI-PA	Online Self-Help Initiatives for Family Care-givers
PEI	Paul Ehrlich Institute
pHKP	Psychiatric Care at Home
PKV-Verband	Association of Private Health Insurance e.V.
PURFAM	Potentials and Risk Factors of Family Caregiving for Older People
RBS	Robert Bosch Foundation
ReDiCare	Relieving Distressed Caregivers A pragmatic study to investigate the effectiveness of a staged counselling approach consisting of care counselling and telephonic short-term psychotherapy
ReduFix	Avoiding Physical Restraining Measures
RKI	Robert Koch Institute
RVG	Act on the Remuneration of Lawyers
SAPV	Specialised out-patient palliative care
SGB	German Social Code
SHI	Statutory health insurance
SPD	Social Democratic Party of Germany
SPIZ ZNS	<i>Spitzenverband ZNS</i> [Central CNS Association]
SyNergy	Munich Cluster for Systems Neurology
UN	United Nations
VDAB	<i>Verband Deutscher Alten- und Behindertenhilfe e.V.</i> [Association of German Assistance for the Elderly and Disabled]
WHO	World Health Organisation
ZQP	Centre for Quality in Care

Participants in the working groups

Field of action 1—Developing and establishing dementia-inclusive communities to enable people with dementia to participate in society

Aktion Demenz e. V. [Dementia Action Campaign]
 Conference of Ministers for Labour and Social Affairs (ASMK)—Hesse
 Federal Association of Non-statutory Welfare e. V. (BAGFW)
 German National Association of Senior Citizens' Organisations e. V. (BAGSO)
 Networking Centre of the Local Alliances for People with Dementia of the BMFSFJ
 Federal Ministry of the Interior, Building and Community (BMI)
 Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ)
 German Alzheimer Society e. V.—Dementia Self-Help (DAIzG)
 German Episcopal Conference (DBK)
 German Television Lottery
 German Association of Towns and Municipalities (DStGB)
 German Association for Public and Private Welfare e. V.
 Evangelical Church in Germany (EKD)
Kuratorium Deutsche Altershilfe e. V. [German Foundation for the Care of Older People] (KDA)
 Ministry of Social Affairs, Labour, Health and Demography of Rhineland-Palatinate
 (Dementia Strategy Rhineland-Palatinate)
 Prof. Dr. Adelheid Kuhlmei

Field of action 2—Supporting people with dementia and their relatives

Action Group for the Mentally Ill e. V. (APK)
 Bavarian State Ministry of Health and Care (Bavarian Dementia Strategy)
Beirat für die Vereinbarkeit von Pflege und Beruf [Advisory Board on the Compatibility of Care and Work]
 Federal Association of Non-statutory Welfare e. V. (BAGFW)
 Federal Ministry of Justice and Consumer Protection (BMJV)
 Federal Ministry of Labour and Social Affairs (BMAS)
 Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ)
 Federal Ministry of Health (BMG)
Bundesverband privater Anbieter sozialer Dienste e. V. [Federal Association of Private Providers of Social Services] (bpa)
 German Alzheimer Society e. V.—Dementia Self-Help (DAIzG)
 German Society for Palliative Medicine e. V. (DGP)
 German Hospice and Palliative Care Association e. V. (DHPV)
 German Sport University Cologne (DSHS)
 German County Association (DLT)
 Conference of Health Ministers (GMK)—Lower Saxony
 National Association of Statutory Health Insurance Funds (GKV-SV)
 German Malteser—Dementia Specialist Centre
 Robert Bosch Foundation (RBS)
Verband Deutscher Alten- und Behindertenhilfe e. V. [Association of German Assistance for the Elderly and Disabled] (VDAB)
 Centre for Quality in Care (ZQP)

Field of action 3—Advancing health and long-term care services for people with dementia

Conference of Ministers for Labour and Social Affairs (ASMK)—Bremen
 Federal Association of Non-statutory Welfare (BAGFW)
 German Medical Association (BÄK)
 Federal Ministry of Health (BMG)
Bundesverband privater Anbieter sozialer Dienste e.V. [Federal Association of Private Providers of Social Services] (bpa)
 Federal Centre for Health Education (BZgA)
Der Pflegebevollmächtigte der Bundesregierung [The Federal Government Plenipotentiary for Long-Term Care]
 German Alzheimer Society e.V.—Dementia Self-Help (DALzG)
Deutsche Expertengruppe Dementenbetreuung e.V. [German Expert Group on Dementia Care]
 German College of General Practitioners and Family Physicians (DEGAM)
 German Society of Geronto-Psychiatry and Psychotherapy e.V. (DGGPP)
 German Association for Psychiatry, Psychotherapy and Psychosomatics e.V. (DGPPN)
 German Hospital Federation e.V. (DKG)
 German Association for Rehabilitation e.V. (DVfR)
 German Nursing Council e.V. (DPR)
 Association of German Cities (DST)
 Conference of Health Ministers (GMK)—Hamburg
 National Association of Statutory Health Insurance Funds (GKV-SV)
 National Association of Statutory Health Insurance Physicians (KBV)
 Standing Conference of the Ministers of Education and Cultural Affairs (KMK)—Vocational Education and Training
Kuratorium Deutsche Altershilfe e.V. [German Foundation for the Care of Older People] (KDA)
 Ministry of Social Affairs, Health, Women and Family (Dementia Strategy Saarland)
Spitzenverband ZNS [Central CNS Association]
 Association of Private Health Insurance e.V. (PKV Association)
Verband Deutscher Alten- und Behindertenhilfe e.V. [Association of German Assistance for the Elderly and Disabled] (VDAB)

Fields of action 4—Promoting excellent research on dementia

Federal Institute for Drugs and Medical Devices (BfArM)
 Federal Ministry of Education and Research (BMBF)
 Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ)
 Federal Ministry of Health (BMG)
 German Alzheimer Society—Dementia Self-Help (DALzG)
 German Association for Palliative Medicine
 German Sport University Cologne (DSHS)
 German Centre for Neurodegenerative Diseases (DZNE)
 National Association of Statutory Health Insurance Funds (GKV-SV)
 Institute of Social Medicine, Occupational Medicine and Public Health, University of Leipzig
 Standing Conference of the Ministers of Education and Cultural Affairs (KMK)—Higher Education and Science
 Ministry of Social Affairs, Health, Youth, Family and Senior Citizens of Schleswig-Holstein (Dementia Strategy Schleswig-Holstein)
 Centre for Quality in Care (ZQP)
 Prof. Dr. Adelheid Kuhlmei

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