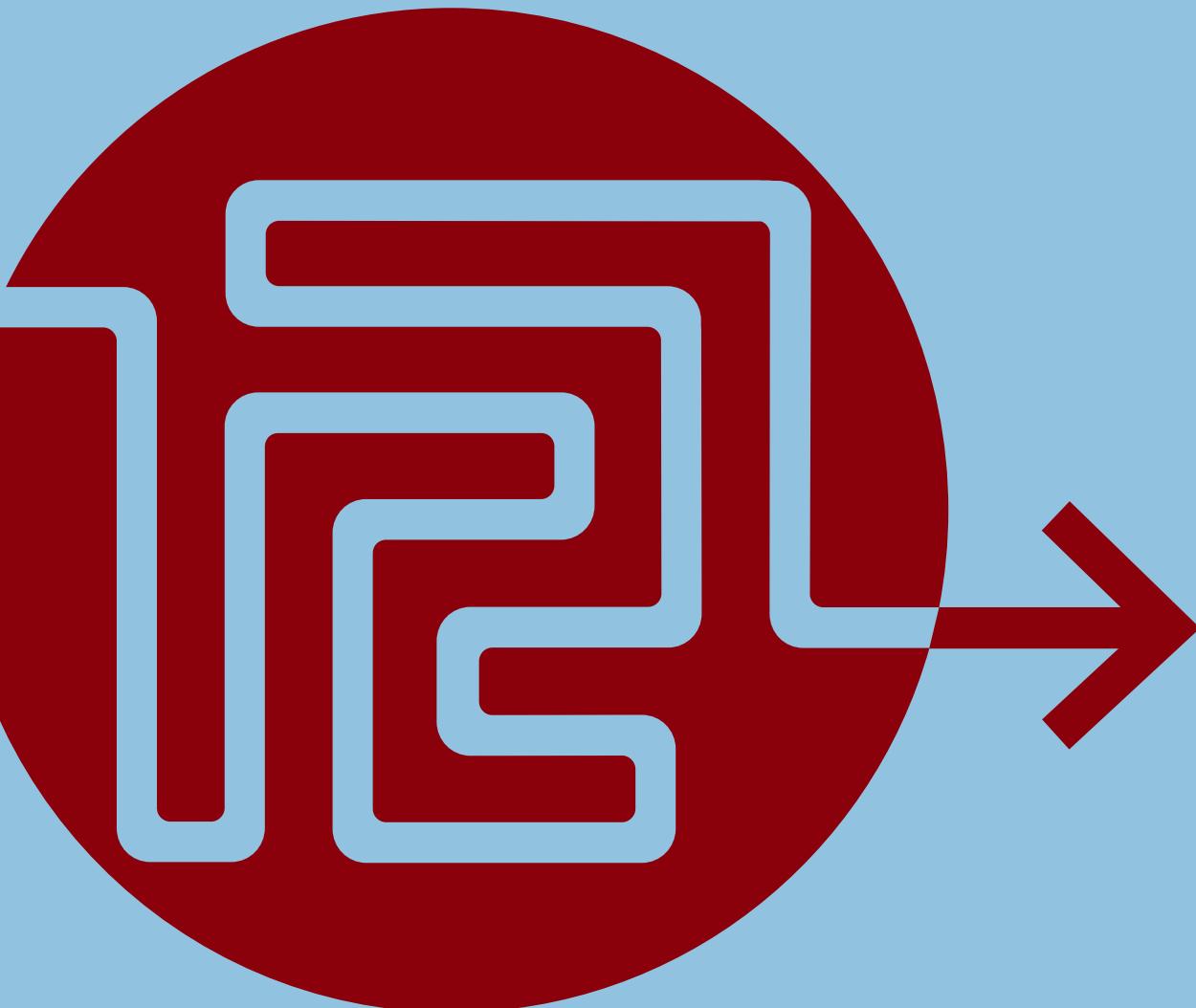




Federal Ministry for  
Family Affairs, Senior Citizens,  
Women and Youth



Federal Ministry  
of Health



# Alliance for people with dementia

The fields of action

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## Introduction

The Alliance for People with Dementia (Allianz für Menschen mit Demenz) is an initiative of the German Federal Government and, as a Working Group, is part of the Demographic Strategy. At the inaugural meeting on 19 September 2012, on the occasion of World Alzheimer's Day, the partners adopted a joint declaration, on which basis this agenda was elaborated with specific resolutions and measures.

The objective of the German Federal Government's Demographic Strategy is to give all individuals, in accordance with their situation in life and age, the opportunity to develop their full potential and skills, and to live life as they envision it. A special and overarching need for action exists with regard to the situation of people with dementia and their families. The German Federal Government therefore established the Alliance for Dementia as one field of action in the Demographic Strategy. The Alliance focuses on the questions of aging with dignity, as well as high-quality health services and care.

In a society characterized by longevity, the number of people who will contract dementia is on the rise. An increasing number of people with dementia live in our families, neighbourhoods and communities. The media also are taking up the issue more frequently. Nevertheless, dementia is associated with feelings of shame and is often tabooed. Patients and their family members feel isolated; the help and support they need are not forthcoming.

For these reasons, there is a need for action, especially since no chance of a cure exists at present. We must improve the quality of life of patients and their families, and preserve their prospects for the future.

This is the goal of the Alliance for People with Dementia. It brings together public agencies and civil society organisations, including self-help groups, who work to support people with dementia on a federal, state and municipal level, and pools the forces of all responsible stakeholders.

The partners active in the Alliance want chiefly to make a contribution to improving the living situation of people with dementia and their families. They respect the wishes of most people to remain in their accustomed environment despite dementia.

The Agenda is shaped by the principle of inclusion. The self-determination and participation of people with dementia stand at the forefront of all deliberations. The German Alzheimer's Association (Deutsche Alzheimer Gesellschaft), as the representative of people with dementia and their families, is therefore an important partner to the Alliance. Furthermore, people with dementia who are organized in self-help groups have formulated their own visions and expectations of the Alliance. To ensure their continued inclusion in the work, all results will be made available in plain language.

Inclusion requires a new understanding of living life together with people with and without impairments. The partners want to advance the social debate that is needed in this connection. To do so, they need realistic profiles of people with dementia, which clearly demonstrate their existing potential. This standpoint requires a participation-oriented view of support, health services and care. The partners want to contribute to such a principle through this Agenda. It also is a first step towards a national dementia strategy.

The Agenda is to be implemented with various combinations of funding and management over the next few years and will be supported by the Office of the Alliance in the Federal Office for Family Affairs and Civil Society Functions. The Alliance will present its first progress report in early 2016.

# I.

## Field of action: Science and research

Scientific studies and the communication of their results are of central importance for providing qualified treatment and health care services for people with dementia and for ensuring their participation in life in society.

### 1. Research

Efforts must be stepped up in all areas of research to better understand the development of dementia diseases and identify potentials for prevention, diagnosis, therapy and rehabilitation. The support, health services and care provided to dementia patients can be optimized in this way, and the benefits to all concerned documented.

Therefore, the responsibility of research is to:

- Identify the causes of dementia diseases and improve diagnosis and therapy,
- Take advantage of findings in all fields of research that support prevention and rehabilitation measures,
- Better coordinate the various areas of research,
- Analyse health care and health care structures, and introduce and implement recommendations for their development,
- Inform the general public about the results of research in timely and comprehensible fashion.

#### 1.1 Biomedical and clinical research

The task of basic biomedical research is to understand molecular mechanisms in the brain and nervous system and, based on these findings, to identify the causes of neurodegenerative diseases. This is the fundamental prerequisite for developing new and efficient diagnostic and therapeutic methods for neurodegenerative diseases like dementia.

The objective of clinical research is to explain the emergence and course of a disease. The approach is patient-centred. The findings of clinical research are combined with the results of basic biomedical research to develop specific therapeutic approaches and new drugs. Subsequently, these are subjected to scientific testing, primarily in the framework of clinical studies. Above all, the aim of biomedical and clinical research is to detect dementia diseases as early as possible in their development and treat them successfully.

## 1.2 Health care research

The task of health care research is to examine the demand for support and assistance among patients and their family members as a function of the stage of the disease and additional illnesses, as well as the individual and combined benefit of diagnostic and therapeutic measures, and to develop corresponding health care concepts. Health care-based studies make it possible to research the demand for, as well the utilization and costs of diagnosis and treatment.

The different care concepts, places of residence and styles of living, including technical assistance systems and possibly building modifications or design measures must be taken into account in this connection. Comprehensive accompanying concepts must be developed with regard to the possibilities of existing and still-developing diagnostic approaches in the early stages of the disease.

Studies on the influence of health economic framework conditions and health care epidemiology are likewise a part of health care research. Applying study findings to health care services in practice, as well as introducing and disseminating them region-wide, can help to improve health care services for people with dementia.

## 1.3 Gerontology research in the social and behavioural sciences

Gerontology research focuses on aging processes in adulthood in all their diversity, in particular physical and emotional aspects, as well as social and societal implications. In view of dementia diseases, gerontology research in the social and behavioural sciences should more strongly incorporate the following perspectives: the quality of life of patients, the stress experienced by family and friends, how society deals with the issue of dementia and social inclusion and participation. Suitable instruments must be developed for this purpose.

## 1.4 Nursing research

The task of nursing research is to develop and evaluate overarching concepts for nursing services, and to develop innovative ideas for increasing the efficiency and quality of nursing care in the support of people with dementia and their families.

It is of particular importance that research findings be incorporated in vocational education and training. This can be supported by professional diagnostic and therapy teams, which incorporate the respective medical, nursing and therapeutic methods.

## 1.5 Empirical principles and epidemiological research

The goal of epidemiological research is to gain insight into the relationships between the cause, progression, frequency and distribution of diseases.

Fundamental methods for epidemiological research in the field of dementia must be further developed. This includes the validation and evaluation of (early) diagnosis and the improvement of estimates of the total number of new cases per year. Extensive studies are required to document risk factors, such as genetic predisposition and lifestyle, and their interaction. They should help to better understand the onset of dementia, derive prevention potentials as a result and improve or develop treatment options for health services and nursing care.

Scientific questions also depend on biomaterial banks, which enable comparisons to be made between different patients with regard to genetic information, biological markers for disease, the progression of disease, and the influence of environmental factors and lifestyles.

## 2. Research structures

The different fields of research need interdisciplinary research structures designed for the long term. The goal of such structures is to efficiently link the individual phases of the research process, from biomedical basic research and clinical studies, to population studies: New findings should be made useful to patients as quickly as possible – in the fields of prevention, diagnostics and treatment.

The German Centre for Neurodegenerative Diseases, financed jointly by the German Federal Government and the Länder (DZNE) brings universities, university hospitals and non-university research together at nine locations. The work of the DZNE focuses on studying neurodegenerative diseases and accelerating the transfer of basic research results to the hospital and health care sectors. The aim is to improve early diagnosis, treatment and thus health services for people with dementia.

All the major research organizations, such as the Leibniz Association, the Max Planck Society, the Helmholtz Association and the German Research Foundation, likewise place great emphasis on dementia research. Furthermore, numerous colleges and university hospitals, private research institutions, companies, non-profit foundations and associations participate in discovering new findings, above all in the fields of clinical and health care research.

### Resolution

The partners commit to the goal of:

- Giving dementia research high priority and including all fields of research,
- Preserving and further expanding productive research structures,
- Intensifying the international scientific exchange,
- Increasing the effectiveness of dementia research through interdisciplinary cooperations,
- Strengthening geriatric, gerontopsychiatric, and gerontological methods development and research in Germany,
- Further developing epidemiological research and health care research as essential parts of modern dementia research,
- Putting in place processes and measures through which the general public can be informed quickly and comprehensively about new and well-founded developments and findings in dementia research,
- Ensuring sufficient access to routine data from the health care sector.

### Contributions of the partners

- The **Federal Government** supervises, supports and funds projects in various fields of research on dementias with universities, non-university and industrial partners, among other things by:
  - Continuing and continuously developing nationwide health monitoring via the Robert Koch Institute,

- Promoting Era-Net NEURON and the EU Joint Programme – Neurodegenerative Disease Research (JPND)
  - Maintaining an international, scientific exchange on the study of dementia diseases,
  - Improving the availability of routine data from the statutory health insurance system for use in health care research.
- The **Federal Government and Länder** support research on the medical, health, ethical, legal and social aspects of dementia, on improving quality of life and health services and on preserving the independence and human dignity of people with dementia, among other things by:
- Supporting the German Centre for Neurodegenerative Diseases,
  - Establishing a National Cohort, together with the Helmholtz Association, with 200,000 people between the ages of 20 and 69.
- The **Federal Government and Länder** support the continued development of specialized health professions, and ensure that the subject of dementia is reinforced in the curricula of training and education courses. They examine the expansion and establishment of courses of study in specialized health professions.
- The **Länder** and their institutions of higher learning strengthen epidemiological and health care research in the field of dementia.
- The **national associations of local authorities** work to ensure that municipalities (towns, counties and boroughs) inform their citizens of projects in the region, and participate within the framework of their capabilities in model projects on caring for people with dementia in their home environment.
- The **sponsoring associations of care facilities** support the implementation of research projects on the subject of dementia by putting them in contact with care facilities.
- The **National Association of Statutory Health Insurance Funds (GKV-SV)**, within the framework of its model programmes, funds projects aimed at improving the health and care situation of people with dementia, and disseminates the results.
- The **Association of Private Health Insurers (PKV-Verband)**, as founder of the Centre for Quality in Care (Zentrum für Qualität in der Pflege - ZQP), contributes to optimizing the quality and improvement of health care in practice.
- The **long-term care insurance providers**, together with the respective Länder or municipalities, will initiate model projects for testing new health care concepts and structures, particularly for dementia patients requiring care.
- The **German Alzheimer's Association (Deutsche Alzheimer Gesellschaft)** will constructively participate in research projects and ensure that they include the issue of people with dementia and their families.
- The **partners**, with regard to implementing inclusion, resolve to strengthen collaborations with scientific, economic, social and patient groups.
- The **partners** will intensify the scientific technical discourse through suitable event formats, and inform the general public of well-founded results in dementia research, for instance through events, brochures and Internet portals.

## II.

### Field of action: Social responsibility

People with dementia are dependent above all on competent contacts and a dementia-friendly environment. Only in this way can they participate, with self-determination, in life in society. Being able to treat patients with respect and as equals requires knowledge of the disease and understanding for sufferers. Consequently, social integration of all those involved continues to be a challenge. Local community support can alleviate the situation to some extent. In addition, new forms of cooperation must be developed and civic/volunteer participation further expanded.

### 3. Participation in society

Inclusion is the declared objective of the UN Convention on the Rights of Persons with Disabilities, which also was ratified by Germany and thus is binding. People with disabilities, including those with dementia, have a right to self-determination, non-discrimination, equal opportunity and equal participation in society. Establishing and developing the necessary framework conditions is a task for society as a whole. It also includes destigmatising the disease, raising awareness of its different forms and bringing about a change in how we interact with people suffering from the disease.

#### 3.1 Creating community

To ensure the participation in society of people with dementia, greater success must be achieved than before in encouraging people to offer - or accept - spontaneous, neighbourly assistance. Furthermore, life in town neighbourhoods and in villages must be set up in such a way that people with dementia, with their existing resources, are valued and respected. This presupposes that they are included in planning and decision-making processes. The development of caring communities, characterised by participation and assistance, counteracts marginalization and is a task for society as a whole.

#### **Resolution**

The partners commit to the goal of:

- Helping to achieve a lasting change in the social perspective and to destigmatise the disease,
- Increasingly shaping the living environments of dementia patients such that they are open to social encounters, exchange and participation, and developing them towards the concept of caring communities,
- Encouraging patients and their families to continue participating in social and community life.

### Contributions of the partners

- The **Länder** will promote understanding for people with dementia by supplying suitable materials to teachers at general and vocational education schools.
- The **national associations of local authorities** commit to ensuring that municipalities promote a dementia-friendly climate, in part via targeted information and counselling programmes.
- The **national associations of local authorities** commit to ensuring that municipalities preserve and if necessary expand programmes for inclusion (e.g. in the areas of culture, sports) and household-oriented services.
- **Aktion Demenz e.V.** will contribute and communicate the experiences and findings it acquired from its “Dementia-Friendly Local Communities” programme.
- The **partners** commit to preserving places and occasions for group activities and to creating new meeting places.
- The **partners** will disseminate successful models for assisting people with dementia.
- The **partners**, within the framework of their capabilities, will help via targeted public relations work to continue raising awareness of the various forms of dementia and the needs of people with dementia.

### 3.2 Accessibility

Accessibility is defined in the context of the UN Convention on the Rights of Persons with Disabilities. For people suffering from dementia, it is a critical requirement for continuing to lead a self-determined and independent life. Eliminating barriers enables people with dementia to act independently, on their own initiative, without constantly coming up against their own limitations.

In their social relationships and day-to-day lives, they mainly encounter the following barriers:

#### ■ Cognitive abilities

Decreasing cognitive ability, as a core symptom of dementia, requires information to be provided in a more comprehensible form.

#### ■ Orientation

Many people with dementia need very clear information in order to navigate in different places and situations. On account of their restricted memory, previously familiar routes can become strange and lead to a feeling of insecurity. Due to their altered perception, they may even view coloured markings or brightness differences as barriers blocking their path.

#### ■ Communication

People with dementia sometimes have an incomprehensible, contradictory or inadequate way of expressing themselves from the viewpoint of people they are speaking with. However, with patience, sensitivity and good powers of observation, the desires and needs of people with dementia usually can be identified. A lack of esteem from others can shake a patient's feeling of self-worth. In communicating with people with dementia, it must be kept in mind that they can better understand clear, simple and short sentences.

#### ■ Behaviours

Because of their mode of behaviour, people with dementia sometimes are viewed as vulnerable, disturbing or even threatening. This can lead to marginalisation and social isolation. Real risks should be minimized without restricting a sufferer's participation in society.

**I Need for time**

Cognitive limitations, lack of motivation, anxiety, etc. may slow activities, decisions, making contact and the cultivation of relationships. If the time needed is not available, this also is a kind of barrier to activities and relationships.

**Resolution**

The **partners** commit to the goal of:

- I Helping to facilitate the everyday lives of people with dementia by specifically shaping their environment for this purpose,
- I Facilitating the adaptation of home and living environments to the needs of people with dementia via consulting services and funding,
- I Advocating the consistent avoidance of structural barriers in new buildings and improving accessibility in the course of building conversions,
- I Eliminating barriers that block access to participation in society and promoting possibilities for personal interaction,
- I Establishing accessibility/barrier-reduced access to information systems, including barrier-free Internet sites,
- I Ensuring accessibility/barrier-reduced access to health care facilities,
- I More actively promoting the use of assistive technologies to enhance competence in daily activities, ensure mobility at home and in the neighbourhood, and avoid dangerous situations, and working towards the advancement of such technologies.

**Contributions of the partners**

- I The **Federal Government** is drawing up guidelines on specific accessibility and safety requirements for dementia patients, with the collaboration of people affected by the disease.
- I The **Federal Government** supports the development of integrated and assisted mobility solutions that can also be used by people with cognitive and physical limitations to achieve self-determined mobility in both urban and rural environments.
- I The **Federal Government** will expand the existing home conversion loan programme of the KfW Group Bank to include an “Age-Oriented Conversion” subsidy component.
- I The **Federal Government** is examining the establishment of a KfW Group Bank programme for an “accessible health care system.”
- I The **Federal Government** will also disseminate information on the agenda in plain language.
- I The **Länder** are examining their funding guidelines for housing construction to determine how they give consideration to the needs of people with dementia.
- I The **national associations of local authorities** are working to ensure that municipalities give consideration to the special needs of people suffering from dementia in designing residential environments. This includes making local public transportation safe, particularly in rural areas, and campaigning for its use.
- I The **national medical and dental associations** will disseminate information on the various dimensions of medical and dental care, and will further intensify the exchange of experiences and initiatives in the profession.
- I The **National Association of Statutory Health Insurance Physicians (KBV)** targetedly disseminates ideas and recommendations for eliminating barriers to physicians’ private practices and physical therapists’

- The **GKV-SV** and **PKV-Verband** work towards ensuring that long-term care insurers make their correspondence easily comprehensible, review the use of plain language and name representatives for telephone inquiries.
- The **partners** are working to inform people with dementia and their families about the possibility of home conversion and the use of corresponding technologies, and to make their own offers in the area of accessibility.
- The **partners** actively support the use of plain language to overcome language barriers.

## 4. Networking

For people with dementia, combining and closely networking health care and support programmes is of critical importance. The objective should be to make the different support and funding offers transparent. To this end, new forms of collaboration and shared responsibility among all stakeholders must be developed and put into action, beyond the scope of local competencies. Just as important is the networking of stakeholders in civil society. Networking in rural regions poses special challenges.

### Resolution

The partners commit to the goal of:

- Continuously promoting the establishment of networks within the framework of their capabilities,
- Pooling offers for educating and informing interested citizens and better coordinating existing offers,
- Achieving better availability and accessibility of offers in rural regions.

### Contributions of the partners

- The **Federal Government**, in collaboration with the Länder, is promoting the establishment of up to 500 local groups of the Alliance for People with Dementia.
- The **Federal Government** disseminates the results of the “Future Workshop on Dementia” (Zukunftswerkstatt Demenz), as a contribution to establishing new networks.
- The **Federal Government, Länder and municipalities** support the establishment of new networks and promote an exchange of experience.
- The **Federal Government, Länder and municipalities** evaluate good networking examples and disseminate information on local initiatives for the participation of patients and their families.
- The **Federal Government and Länder** are setting up a working group to strengthen the role of municipalities in managing and planning regional care structures. It also is to elaborate a recommendation on how municipalities can be more involved in, among other things, care counselling services, care training courses, the ongoing counselling of care allowance recipients and the granting of assistance for infrastructure-promoting measures.
- The **partners** support other municipal stakeholders, such as the police and fire departments, in initiating networks.
- The **partners** work to facilitate the formation of networks, especially in rural regions, through suitable programmes, such as mobile counselling centres or information offers on the Internet.

## 5. Legal questions

Over the course of a dementia illness, a patient's ability to think, act and make decisions is increasingly restricted. The cognitive abilities of dementia patients and the progression of the disease differ greatly from one case to the next. This can lead to legal problems and legal uncertainty for those affected. Furthermore, tensions may arise between the justified desire of a patient for self-determination and participation, and the simultaneous necessity of providing him or her with legal protection.

Even patients with the same functional disorder can have different resources. Therefore, the measure of independence and self-determination must be re-evaluated in every phase of the disease. It further must be ensured that assistance and care are commensurate with the current abilities and needs of dementia patients, and that they are protected against violence, abuse and a lack of health care.

### 5.1 Legal capacity

A great deal of uncertainty exists, above all among family members, about the legal capacity of people with dementia. Contrary to popular belief, a diagnosis of dementia does not automatically limit or suspend a person's legal capacity. In case of dispute, legal capacity must be determined by a court of law.

### 5.2 Traffic and administrative law

Scientific studies show that already in an early stage of dementia, patients can be so restricted in their abilities that they react more slowly than normal and, for example, incorrectly judge distances and speeds. Performance tests can provide information on whether safe driving still is possible. Under the Driving License Ordinance, diseases do not automatically lead to a suspended driving license. Only in the case of severe dementia does the Driving License Ordinance mention definite driving license suspension. Physicians, within the framework of their duty to provide care, must inform patients that they will become unable to drive as dementia progresses. If patients are resistant, it may be justified for a physician – after reviewing his obligations to maintain confidentiality – to inform the Driver and Vehicle Licensing Agency.

#### Resolution

The partners commit to the goal of:

- Intensifying education on legal issues.

#### Contributions of the partners

- The **Federal Government** will cover legal questions in greater depth on its website at [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de).
- The **partners** will set up a working group to elaborate recommendations as to how greater certainty with regard to legal transactions and road use can be achieved in practice, and how the independence of people with dementia can be preserved as long as possible.

### 5.3 Legal planning

It generally is possible to plan ahead for future legal incapacity. With a **health care power of attorney**, any person of legal age and capacity (principal) can name another person he trusts as an agent, giving that agent the right to make decisions and act in his name, if he should become incapable of doing so. To protect the principal individual, any steps that represent extreme intervention by the agent are only effective if approved by a court of protection. For people with dementia who are no longer capable of giving their consent or communicating their wishes, it is particularly difficult to make decisions for or against what are often very invasive medical measures, especially when they serve to prolong life.

With a **living will**, a person can give instructions beforehand concerning whether or not medical measures should be taken under certain circumstances in the event that the person becomes incapable of making decisions.

An **adult guardianship directive** (Betreuungsverfügung) can influence which persons are appointed by a district court to manage legal matters and how a patient's own affairs should be settled if he can no longer make decisions himself. Conversely, this document can also state who should not, under any circumstances, be named as a guardian to provide this kind of service. Furthermore, in this document, dementia patients can specify wishes and habits they want to have considered, such as which care facility they prefer. In contrast to the health care power of attorney, dementia patients can still draw up or amend an adult guardianship directive even if they are no longer fully legally competent.

#### Resolution

The partners commit to the goal of:

- | Widely disseminating information on the various options for legal planning,
- | Encouraging citizens to plan ahead,
- | Emphasizing the importance of including family members, neighbours, friends, counselling centres and physicians,
- | Supporting professional adult guardians, volunteer guardians and legal agents in assisting dementia patients in an appropriate and understanding manner, in line with their capabilities.

#### Contributions of the partners

- | The **Federal Government** will improve adult guardianship law in structural terms, thereby strengthening the right to self-determination without neglecting the protection of people with dementia.
- | The **Federal Government, Länder and municipalities** will intensify their information offers on legal planning for health care.
- | The **Länder** will review their regulations to determine if the advisory and support services provided for volunteer guardians and legal agents are reliably financed by care associations, and that the successful fulfilment of this interfacing task receives targeted funding.
- | The **national associations of local authorities** work towards ensuring that issues relating to legal health care planning are addressed by municipalities. They support municipalities in providing information and advice on all general questions surrounding health care powers of attorney and adult guardianship directives, and in referring patients to assistance programmes that help to avoid the need for guardianship. They work to ensure that government agencies responsible for adult guardianship are properly equipped to fulfil their tasks.

- **Health and long-term care insurance providers**, as part of their advisory services, provide information on living wills, e.g. on their websites.
- The **partners** work to ensure the formation of local working groups, comprising district courts, adult guardians, government guardianship agencies and care associations, and in the process work with local self-help groups, service-providers and nursing care counsellors.
- The **partners** will make more information available, also in plain language, and if necessary in the relevant native languages.

#### 5.4 Compulsory measures

People with dementia frequently are affected by compulsory measures. These are interventions in a person's basic rights, which are only permitted after approval by a judge in a court of law. In this connection, cooperation between adult guardians, legal agents, guardians ad litem, judges and case experts is of critical importance. Using their expertise, they prepare compulsory measures and decided if and which measures will be taken. In the case of dementia patients, this most commonly involves measures that restrict a patient's liberties or deprive him of them entirely. In most cases they limit the independence of people with dementia to a tremendous degree. However, concerns that these measures are required to protect people with dementia, prove to be unjustified in many cases. Much more preferable are measures that activate and preserve mobility, which can be combined with suitable, technical protective measures. Examples of best practices in care facilities show that such steps can be successful and can lead to almost a complete reduction in measures that deprive a person of such freedoms. These examples must be implemented on a widespread basis.

#### **Resolution**

The partners commit to the goal of:

- Achieving greater transparency about measures that deprive a person of liberties,
- Educating the public on alternative protective measures and options for conflict avoidance and conflict management,
- Further reducing significantly the number of applications, approvals and implementations of measures for deprivation of liberty.

#### **Contributions of the partners**

- The **Federal Government** supports the elaboration of a criterion list to assist in the decision-making processes relating to applying for, deciding on, and the duration of compulsory measures.
- The **Federal Government** develops online training programmes for alternatives to compulsory measures and makes it available on the website: "Wegweiser Demenz".
- The **Federal Government** provides more in-depth information on adult guardianship law, the health care power of attorney and the living will.
- The **Federal Government** will publish a hand-out of recommendations for avoiding conflicts, conflict management and alternatives to compulsory measures.
- The **Länder** will make the hand-out available to the responsible courts and guardians.
- The **German Medical Association** informs all physicians about steps for avoiding compulsory measures.
- The **partners** increasingly provide information in plain language on alternatives to compulsory measures.

## 6. Information and public relations work

Awareness of dementia must be significantly increased among the general public. The disease and its effects must be the focus of information and health education measures. Apart from situations that are a stress factor, emphasis must be given to the resources that patients have and to existing crisis management aids. What is necessary is far-reaching and considerably intensified information and public relations work. This includes training central persons involved in everyday life, such as salespeople, bus drivers and police officers, in how to interact with people with dementia. Not least, the goal is to better inform dementia patients themselves about available assistance programmes.

### Resolution

The partners commit to the goal of:

- | Promoting education about the disease and contributing to destigmatising dementia,
- | Expanding information and public relations programmes, coordinating them more closely and designing them to be more effective,
- | Improving information on diagnostic options as well as drug and non-drug treatments, and offering the right support and assistance especially in the early phase of the disease.

### Contributions of the partners

- | The **Federal Government** will expand the “Wegweiser Demenz”.
- | The **Federal Government** will publish information on the results of the “Future Workshop on Dementia,” expected in 2015.
- | The **partners** will network their information offers and point towards existing offers, such as the “Wegweiser Demenz” ([www.wegweiser-demenz.de](http://www.wegweiser-demenz.de)) or the nationwide Alzheimer’s hotline (01803-171017).
- | The **partners** will form a working group to review existing information offers and determine what needs for information exist, with the goal of joining forces on public relations work.
- | The **partners** advertise the information offers they develop and make them available to the other partners wherever possible.
- | To stabilize public relations work, the **partners** will make use of the World Alzheimer’s Day on 21 September, introduced around the globe in 1994 by Alzheimer’s Disease International (the world Alzheimer’s federation) and the WHO, for joint actions with complete media coverage. At the same time, this will be the kick-off for a Dementia Week, in which information about the disease is spread nationwide and “Information Days” are offered in suitable facilities.
- | The **partners**, in their respective spheres of responsibility and if not already in existence, will develop group-specific training concepts (e.g. for young people, police, local public transportation, retail trade, schools, companies, etc.) and advertise them along with existing concepts.
- | The **partners** will provide information on all legal rights to statutory benefits for patients. They also therefore work towards ensuring that low-threshold care offers are used to a greater extent than before.

## III.

### Field of action:

### Support for people with dementia and their families

At present, roughly two-thirds of all people with dementia live in their accustomed social environment, most with their families, others in living communities with mobile nursing care or inpatient care facilities. Supporting and caring for a dementia patient is a tremendous challenge for many families, but also for friends and neighbours, particularly when it extends over a long period of time. Ensuring health care and supporting patients in their home environment can completely overwhelm family members, putting them at risk of falling ill themselves. To avoid jeopardising the quality of care and life for both patients and family members, they need assistance and support.

## 7. People with dementia

For people with dementia, preserving competencies, self-determination and a feeling of self-worth is of special importance. Despite the cognitive limitations associated with the disease, they are aware for a long time of the irreversible nature of their disease. As the disease progresses, they are more and more dependent on support and assistance. Offers of support and assistance must be designed to acknowledge and strengthen a dementia patient's resources and to preserve their self-determination.

### 7.1 Counselling and support

Shame, inhibitions, fear of entering a new place, fear of a diagnosis but also a lack of knowledge of suitable help programmes are barriers preventing many people with dementia from accepting counselling and assistance. Reaching and supporting these people hinges on trust-based, proactive, early and continuous counselling. Long-term care insurers, as part of their long-term care advice offers and associated case management activities, are a committed point of contact for people with dementia and their care-givers. Counselling and training for family care-givers are also offered by care facilities, other institutions, municipalities and physicians.

#### **Resolution**

The partners commit to the goal of:

- I Improving the quality of programmes and collaboration between the various counselling centres, as well as more closely networking and coordinating such programmes,

- Launching offers for counselling, support and assistance in the early phase of the disease, adapting these offers locally to the needs of patients requiring care and their families, and ensuring continuity as the situation progresses,
- Better networking reliable, individual counselling more towards local case/health care management,
- Implementing the objective of the law to provide local, outreach-type information/counselling across all funding institutions such that access to offers is facilitated,
- Tangibly improving collaboration with general practitioners in particular,
- Providing need-based offers for inpatient and semi-inpatient health care services,
- Supporting existing offers, such as information and training for care-giving relatives, under Art. 45 SGB XI (German Social Security Code), and making them more known.

#### **Contributions of the partners**

- The **partners** strive for binding agreements on coordinating tasks and exchanging information with one another, e.g. in the form of framework recommendations on the **Länder** level. Apart from existing long-term care support centres or comparable structures managed by the long-term care insurance funds, municipalities and self-help groups should also be included in the process.
- The long-term care counselling centres and long-term care support centres established in the **Länder**, and the long-term care insurers deliberate on assistance benefits.
- The **national associations of local authorities** work towards developing locally networked and transparent information structures, drawing up an overview of existing information structures and making them easily accessible. Addressees/distributors of this overview are general practitioners and specialist physicians, nursing services, care facilities, local health and long-term care insurance representatives, care counsellors, pharmacies, social workers in hospitals, employers, associations, housing associations and housing information centres.
- The **national associations of local authorities** work towards ensuring that people with dementia and their families in the municipalities receive neighbourhood-based, community support.
- The **providers of services** declare their willingness to communicate their programmes to the municipalities and to continuously update them.
- The **German Alzheimer's Association**, with its member associations, works towards the more widespread establishment of self-help groups for people with dementia.

## 7.2 Participation

The access of people with dementia to various social offers must be preserved. They are dependent on those around them understanding their situation and need social contacts. Important for them are encounters with people, feeling like they belong and the opportunity to get involved.

#### **Resolution**

The partners commit to the goal of:

- Enabling dementia patients in all situations to lead a self-determined life in the midst of society,
- Strengthening the autonomy of people with dementia,
- Acknowledging their competencies in a suitable manner,
- Urging the most extensive possible social participation of people with dementia,
- Giving people with dementia the possibility to help shape social processes.

### **Contributions of the partners**

- The **partners** review the procedures they have used up to now with regard to the participation of people with dementia, and if necessary adapt them in line with the motto applied in the work of associations for people with disabilities: "Not about us, without us".
- The **partners** will pay closer attention to actively including people with dementia in implementing programmes.
- The **partners** work towards ensuring that societies and associations provide appropriately designed offers in which people with dementia can also participate.
- The **partners** underline their support of the self-help movement, encourage groups to apply for funds provided for this purpose and continue to expand self-help within this framework.

### 7.3 Structuring the home and living environment

For people suffering from dementia, preserving their independence, regardless of their respective living situation, is of particular importance. All the more important it is to facilitate navigation at home and in the local community and to provide low-threshold care offers. The key factors in this area are to raise awareness in the neighbourhood, promote interaction between people with and without dementia in local neighbourhoods and appropriately structure the living environment. Other important aspects include developing creative access to social participation and integrated space and social planning. In this connection, rural areas require concepts different from those in urban areas.

#### **Resolution**

The partners commit to the goal of:

- Improving the conditions in defined social environments for dementia patients by means of appropriate measures, such as neighbourhood management,
- Promoting the adaption of housing and living environments, giving consideration to the special situation prevailing in rural regions.

### **Contributions of the partners**

- The **Federal Government** promotes a "Neighbourhood Contact Centres for the Elderly" programme with the objective of encouraging communication and enabling participation and assistance.
- The **Federal Government and Länder** are examining whether the options of housing and urban development can be targeted more to the needs of people with dementia.
- The **national associations of local authorities** work towards ensuring that municipalities, with the support of the Länder, initiate processes for the age-oriented structuring of social environments, giving consideration in particular to the health care needs of people with dementia. Available data and findings relating to local health care services are used for this purpose.
- The **Federal Government** supports this process by contributing experiences from the "Future Workshop on Dementia".
- The **municipalities, sponsoring associations of care facilities and long-term care insurers** promote diversity in local residential, care and support programmes, so that dementia patients can remain integrated in their familiar environment. Other relevant stakeholders, such as housing associations, can also make a significant contribution in this area.

- The **municipal counselling centres** funded by the Federal Government and called "Technology for a Better Life in Old Age", offer a comprehensive range of information, tailored to individual needs and requirements, on technical assistance systems for the elderly, which is particularly useful also in the context of dementia.
- **Long-term care insurance** supports the founding of maximum 3,000 living communities with mobile nursing care and grants an allowance for people in need of care who live in communities with mobile nursing care.
- **Inpatient care facilities** give consideration to the habits of people with dementia in designing housing and living environments.

## 7.4 Freedom of mobility and protection for people with dementia

Freedom of mobility is the most fundamental form of freedom and an important expression of self-determination. Furthermore, preserving mobility is one of the most important steps for avoiding falls. Nevertheless, in interacting with dementia patients, the people providing them with health care or general care can repeatedly encounter situations in which a risk to the person or a third party exists. Particularly in advanced stages of the disease, one symptom can be an unspecific urge to move that is difficult to control and can lead to self-endangerment. It is handled in some cases by restraining measures. Strict criteria must be applied for determining the necessity of such measures. Any kind of bodily restraint must therefore be reviewed on a regular basis for possible alternatives. The process of evaluating this need must be improved, because these measures severely restrict a patient's freedom of mobility. They reduce their individual motion coordination abilities and therefore increase the risk of falls; they cause stress, intensify emotional problems and thus the risk of self-harm. Using these measures creates the very conditions that make them necessary in the first place.

Interventions in freedom of mobility in a person's own home can also be viewed as a restriction of liberty. Various studies show that physical or pharmacological restraining measures are used in some cases in which they are either not at all necessary, or not for the planned length of time, because other methods would have been just as effective.

### Resolution

The partners commit to the goal of:

- Reducing the frequency and duration of restraining measures,
- Extensively avoiding physical restraining measures,
- Providing information on suitable intervention options for avoiding restraining measures,
- Gathering data on restraining measures also in view of the recommendation of the German Ethics Council (Deutscher Ethikrat).<sup>1</sup>

### Contributions of the partners

The **Federal Government** will fund a research project with the goal of determining the possibilities for reducing pharmacological restraining measures.

- The **Länder** and **long-term care insurers** analyse the judicial statistics data sources available to them on the level of the district courts, the supervisory authority for care facilities and quality evaluations with the goal of regular reporting on restraining measures.

<sup>1</sup> Excerpt from a recommendation of the German Ethics Council on "Dementia and Self-Determination" (Demenz und Selbstbestimmung - 2012): "The Länder of the Federal Republic of Germany should at least every two years prepare a joint report on the number of placements and restrictions of liberty under Section 1906 of the Civil Code and under the statutes of the Länder on protection and help for mentally ill people (Psychisch-Kranken-Gesetze) and the reservations of consent (Section 1903 of the Civil Code). The report should be the basis for an evaluation of practice, since the measures set out above must remain restricted to cases of absolute necessity".

- The **Länder** review how reliable information can be obtained in the outpatient sector, particularly on pharmacological restraining measures.
- The **sponsoring associations of inpatient care facilities**, within the framework of their capabilities and together with the health and long-term care insurers and others, work towards rapidly implementing the findings of the ReduFix project on avoiding physical restraining measures.<sup>2</sup>
- The **sponsoring associations of inpatient care facilities and mobile nursing services** will step up their work towards avoiding restraining measures in inpatient and home care situations by changing structures and organisational procedures, avoiding overwork, training personnel and providing appropriate support.<sup>3</sup>
- The **national medical associations** provide information on options for avoiding pharmacological restraining measures.

## 7.5 Violence

The subject of protection as it relates to providing health care services to people with dementia also includes the effective prevention of any and all forms of violence (verbal, physical, physiological, sexual), which often are an expression of overwork and helplessness on the part of the people supporting, caring for and nursing dementia patients, and which occasionally are facilitated by the inability of dementia patients to see reason. In many cases, care-givers lack knowledge of alternative ways to handle situations and relieve their burden. The use of such violence is not acceptable under any circumstances.

### **Resolution**

The partners commit to the goal of:

- Increasing focus on the problem of the use of violence in the care sector and implementing suitable measures of prevention and intervention.

### **Contributions of the partners**

- The **Federal Government** will make the results of the study "Potentials and Risks of the In-Family Care of the Elderly" in suitable form.
- The **municipalities and long-term care insurers** work together with and support local centres for violence prevention and for help against violence in nursing care.
- The **sponsoring associations of care facilities** offer professional support, e.g. supervision/coaching for employees.

## 8. Help and support network particularly for family care-givers

Not only people with dementia, but also family members and people otherwise involved in a patient's life are dependent on support. This group can include neighbours, friends and volunteers. They, too, need information about strategies for interacting with dementia patients on a daily basis, about treatment options and about support and health care offers.

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2/3 bpa: "The sponsoring associations must be provided with the economic and personnel resources needed for this purpose. Corresponding funds have been earmarked for this within the framework of the pending long-term care/health care reform". VDAB: "The sponsoring associations must be provided with the economic and personnel resources needed for this purpose".

## 8.1 Supportive counselling and promoting competencies

Ensuring appropriate assistance and reliable support for people with dementia requires a basic attitude of acceptance, empathy, experience, knowledge and competencies. Exchanging experiences with other people in similar situations also is very helpful. Therefore, there is a demand for targeted and easily accessible information on the disease, its progression, on interacting with patients in everyday life and on concrete support and assistance offers.

Anyone caring for a person with dementia frequently has very little free time and is dependent on offers that take his or her situation into account. For family care-givers, comprehensive information and education about support offers and financing options are extremely important especially early on, when a care/support/nursing situation often arises unexpectedly. They help to more clearly define the new and difficult life situation for all those involved, and to structure the process of support and care.

### Resolution

The partners commit to the goal of:

- Evaluating and further developing the quality of counselling offers for all those involved in care-giving,
- Further improving support and assistance for family care-givers,
- Getting people involved as volunteers and specifically training them, for instance as care-giver assistants, dementia mentors or lay assistants,
- Supporting local forums and networks that give (care-giving) family members the opportunity to exchange and reflect on experiences and that provide information,
- Providing information on the special programmes offered by long-term care insurers, nursing services and other institutions for training family care-givers and volunteers, and encouraging care-givers to take advantage of these offers,
- Examining training programmes to determine the degree to which issues are covered such as care-giver exhaustion and self-neglect.

### Contributions of the partners

- The **Federal Government** will merge the possibilities of the Act on Care-Giving Leave and the Act on Family Care-Giving Leave with legal entitlement and further develop them, in order to better support the reconcilability of care-giving and work.
- The **Länder** support the further expansion of low-threshold care offers by providing corresponding funding within the framework of their capabilities.
- The **Federal Government, Länder, municipalities and long-term care insurers** provide information on additional assistance benefits and the associated, diverse support offers, and improve the degree to which people apply for these benefits.
- The **national associations of local authorities** work towards ensuring that municipalities support local dementia forums and networks of those responsible for the concerns of people with dementia, in order to further develop and coordinate offers, and to promote an exchange of experience among the occupational groups involved.
- The **long-term care insurers** develop their care counselling services also for special target groups like dementia patients and their family members, in order to facilitate access to benefits.

- The Working Group (Vertragswerkstatt) of the **National Association of Statutory Health Insurance Physicians (KBV)** will disseminate its check-up concept for family care-givers, which was developed in 2013.
- The **German Alzheimer's Association**, with its member associations, offers independent counselling and support according to the concept of self-help.

## 9. Volunteer work and active citizenship

People with dementia can live at home all the longer, the stronger their social network is, despite the advancing severity of the disease and their growing dependence. Neighbourhood action will continue to gain importance in these networks. Volunteer work also plays a priority role in inpatient care facilities and old-age assistance institutions.<sup>4</sup>

For dementia patients, active citizenship gives them access to additional, personal interactions adapted to their needs, offers new possibilities for organizing daily life, contributes to opening institutions more and supports employees and family members.

One area for volunteers is the often time-consuming, continuous and familiar attention needed by patients or family care-givers. The commitment of volunteers often helps to maintain the social and cultural participation of dementia patients and supports a lively exchange and encounters in public settings. That benefits both patients and non-patients. Society can learn from role models of active citizenship how to interact with dementia patients openly and without fear.

Successful projects, like the care-giver assistant programme, have proven that active citizenship benefits helpers, patients and family care-givers alike. Getting people involved in volunteer work requires facilitating structures, support and a culture of recognition.

### **Resolution**

The partners commit to the goal of:

- Stepping up the promotion of different forms of active citizenship,
- Acknowledging active citizenship as a special asset in the support/care of people with dementia and in supporting and relieving the burden on family members, and its importance for the development of a positive social climate,
- Providing more training for volunteers and the corresponding resources,
- Motivating groups previously underrepresented in volunteer work (men, people with a migrant background, young people),
- Expanding low-threshold volunteer programmes for these target groups.

### **Contributions of the partners**

- The **partners** in acknowledging the importance of a well-coordinated “mix of help” comprising full-time nursing and care provided by family members or volunteers work towards joint learning between active citizens and professional nurses.
- The **Federal Government** places special focus on this collaboration in developing and implementing the new nursing training programme with specialization.

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<sup>4</sup> bpa and VDAB support equal taxation for volunteers working for non-profit, municipal and private service providers.

- The **Länder** develop implementation strategies for promoting and integrating active citizenship and contribute to promoting low-threshold care offers and active citizenship through long-term care insurance.
- The **national associations of local authorities** support municipalities in increasingly promoting active citizenship with a view to ensuring the social and cultural participation of people with dementia.
- **Outpatient and inpatient care facilities** work towards winning citizens to do volunteer work. They cooperate actively with local structures, e.g. church parishes, senior citizen offices, volunteering agencies, long-term care support centres, initiatives such as the care-giver assistant or senior citizen assistant programmes, and ensure that their volunteers receive training, instruction and support.
- The **associations of the care facilities**, within the framework of their capabilities, work towards ensuring that care-givers and suitable structures are provided to actively integrate active citizenship in patient care.
- The **partners** will compile their programmes for acknowledging active citizenship and make them available as examples of Good Practice.

## IV.

### Field of action: Structuring the support and health care system

Dementia patients and their relatives need a holistic, cross-sectoral system of support and health care that takes into account not only the various clinical pictures and phases of the illness, but also the individual needs and the support required to permit participation in community life. The health care system thus needs to be geared to the individual and must provide coordinated offers of support for all phases and forms of the illness, i.e. for young and old persons, for people with an immigrant background, for patients living alone and in family networks. In rural areas, bottlenecks in medical and nursing care must be avoided, and access to benefits of the health system, including rehabilitation and prevention, must be guaranteed, as well as access to medical care at home.

To be able to individualise existing offers of assistance and to address the specific requirements of the patients and their families in the respective phases of the illness, there is a need for forms of accommodation and assistance tailored to the respective requirements, for more intensive networking of outpatient and inpatient health care, for qualification of everyone involved, and for quality assurance in both the inpatient and home sectors.

## 10. Health care structures

### 10.1 Accommodation and living in neighbourhoods

The clinical picture of dementia includes not only the increasing deterioration of memory, but also disorientation as regards time, space and location, as well as symptoms that make it increasingly difficult or even impossible for patients to remain in their accustomed home environment. As the clinical picture progresses, most people with dementia therefore need a living environment with networked assistance structures and forms of accommodation designed to suit their capabilities. This includes a low-stress living environment that provides orientation, conveys a sense of calm and security, and facilitates access to health facilities. The service providers in the health system are called upon to adapt their offers to the requirements of people with dementia, and thus to contribute to maintaining their health and that of their relatives.

#### **Resolution**

The partners commit to the goal of:

- I Further developing the range of different forms of accommodation, including group homes and living communities, in accordance with requirements,

- | Forming social networks in the spirit of caring communities,
- | Expanding outpatient assistance structures aimed at "living at home until the end of life", including semi-inpatient care, in accordance with requirements,
- | Involving in particular the local, private and municipal housing sector in discussing and further developing instruments for support,
- | Eliminating barriers impeding access to benefits of the health system, including sociotherapy, psychotherapy and rehabilitation, and guaranteeing the benefits necessary for this purpose and access to them, also for people with dementia,
- | Creating framework conditions ensuring that case management can be effectively applied.

### Contributions of the partners

The **Federal Government** funds

- the establishment of up to 500 Local Alliances as help networks throughout Germany by the end of 2016,
- 450 multi-generational centre as the starting point for a Caring Community,
- 300 contact points for older people in neighbourhoods, in order to enable independent living, even in cases requiring assistance and nursing care.
- | The **Federal Government** funds the support of care-giving relatives and regional networks in the "Future Workshop on Dementia" until 2015.
- | The **Federal Government** will simplify the start-up financing of living communities with mobile nursing care and expand the grants for measures to improve the residential environment.
- | The **Federal Government** further develops the KfW programme "Age-Oriented Conversion", which can currently already be used to fund Ambient Assisted Living and precautionary structural measures.
- | The **Federal Government** reviews the principles for ascertaining a degree of disability for people with dementia, given the diverse effects on participation in life in society. This is done in the framework of the current general revision of the Social Security system's Medical Impairment Assessment Guidelines (Versorgungsmedizinische Grundsätze).
- | The **Länder** facilitate the establishment of living communities with mobile nursing care in the framework of their legislation and eliminate bureaucratic obstacles in administrative enforcement, without neglecting the quality of living communities with mobile nursing care.
- | The **national associations of local authorities** work towards ensuring that the residential environment, which can be structured by the municipalities, is adapted even more extensively to the needs of people suffering from dementia.
- | The **national associations** of local authorities support the municipalities in promoting the options for people in need of long-term care to remain in their own domestic surroundings through collaboration with the responsible stakeholders in the region. Within the framework of their capabilities, the municipalities provide advice and support regarding other forms of accommodation and assistance as alternatives to inpatient care, e.g. group homes, living communities with mobile nursing care, assisted living in host families, or the new living groups with mobile nursing care.
- | The **long-term care insurance** system funds the establishment of up to 3,000 living communities with mobile nursing care with up to 30 million Euros in total, provides grants for measures for improving the residential environment and towards the care costs for persons in need of long-term care in living groups with mobile nursing care, and ensures an unbureaucratic application procedure.

- The **GKV-SV** elaborates a programme with a volume of 10 million Euros for funding and further developing new forms of accommodation for people in need of long-term care.
- The **inpatient care facilities** and **outpatient services** gear themselves more extensively to the requirements of dementia patients in the framework of statutory and contractual regulations.

## 10.2 Rehabilitation

The statutory priority given to rehabilitation over long-term care also applies to dementia patients. The long-term care insurers examine all applications as to whether medical rehabilitation benefits are open to consideration. In the framework of their contracting policy, the health insurance funds ensure that sufficient rehabilitation offers for dementia patients are available, this also including mobile rehabilitation offers. The latter are of decisive importance for ensuring that multimorbid patients can also avail themselves of rehabilitation benefits without their dementia being aggravated by a change in environment. The aim is to maintain and/or improve skills through the complex benefit of rehabilitation by applying rehabilitation concepts suitable for this group of persons. This can also include mobile rehabilitation offers.

### **Resolution**

The partners commit to the goal of:

- Expanding rehabilitation benefits, particularly for people with dementia and their relatives,
- Providing suitable medical and psychosocial offers, expanding these offers and taking the respective research findings into account in this context.

### **Contributions of the partners**

- The **Central Association of Long-Term Care Insurance Funds, the Health Insurance Medical Service and Medicproof** further develop the criteria and procedures for identifying the rehabilitation requirements of dementia patients when assessing the need for long-term care, in accordance with the latest scientific findings.
- The **health insurers** support the need-oriented expansion of offers, also of close-to-home, mobile rehabilitation for dementia patients.
- The **health insurers** support the access of dementia patients, in accordance with the medical necessity, to facilities whose structure and treatment concepts do justice to their special rehabilitation requirements and needs.
- The **rehabilitation providers** expand their offers of rehabilitation for care-giving relatives and develop them further, also in order to cater to the possible need to provide simultaneous assistance for dementia patients and their relatives.

## 10.3 Medical/nursing care

The majority of dementia patients present not only the symptoms accompanying dementia, but also a wide range of other illnesses requiring intensive medical and nursing care. Moreover, as the illness progresses, the affected persons can become increasingly immobile and are dependent on outreach medical care and nursing, be it in the domestic environment or in an inpatient care facility. As patients increasingly lose their ability to give information, and the relatives are

often overtaxed by the situation, interaction between the different service providers in medical treatment and nursing is of key importance. One significant aspect in this context is the coordination of the multimedication involved, the side-effects of which can lead to a deterioration in the symptoms. In this respect, particular attention must be paid to treatment with psychotropic drugs.

### Resolution

The partners commit to the goal of:

- | Implementing standards for diagnosis and therapy in the spirit of guideline-oriented medicine,
- | Expanding collaboration in the provision of health care for dementia patients and working towards structured collaboration of general practitioners and specialists with the hospitals, long-term care facilities and institutions offering specific counselling services,
- | Improving the provision of outpatient GP, specialist and dental care for people suffering from dementia,
- | Working towards the indication-oriented provision of medication for dementia patients, in order to avoid excessive use of psychotropic drugs,
- | Examining the introduction of models for accompanying patients in the first year following diagnosis,
- | Further supporting volunteer-related structures, especially in the home environment, and making available offers of assistance with daily activities and the household,
- | Further developing or providing offers of palliative care at home, and also in inpatient facilities, paying particular attention to dementia,
- | Intensifying volunteer hospice support at home, and also in inpatient facilities,
- | Improving the benefits offered by the long-term care insurance system, particularly with an eye to people with dementia, and appropriately acknowledging the need for long-term care.

### Contributions of the partners

- | The **Federal Government** further develops the long-term care insurance system. It will initially introduce benefit improvements taking effect in the short term, adjust the benefit amounts and launch a Long-Term Care Provident Fund (Pflege-Vorsorgefond) in order to create demographic reserves. The new definition of the need for long-term care will be introduced as soon as possible during the current legislative term, on the basis of the recommendations of the Expert Advisory Committee and following prior testing. The provisions of benefits law will also be implemented on this basis. People with dementia, in particular, are intended to receive better and more fitting benefits in this way.
- | The **national associations of local authorities** aim to achieve greater involvement of the municipalities in the provision of health care, especially in rural areas and particularly for people with dementia. They offer support, particularly by networking and coordinating the region-wide provision of health care services for the population, which must always also give consideration to the provision of nursing services.
- | The **national associations of local authorities** commit themselves to a modern, sustainably efficient and effective public health service, which particularly also looks after people suffering from dementia. They work towards ensuring that the necessary framework conditions exist.

- The **national associations of local authorities** work towards nursing care not being restricted to the benefits of the long-term care insurance system. The municipalities gear their diverse health promotion services even more to the needs of people with dementia.
- The competent **medical bodies** endeavour to advance the development of Dementia Health care Guidelines.
- The **KBV** promotes the further development of standards for diagnosis and therapy. It provides physicians in private practice with information on counselling centres, training programmes and self-help groups, so that they can already offer corresponding information when first explaining the diagnosis.
- The **KBV** develops a staged health care concept, including new, quality-assured services, for the establishment of specialist geriatric practices for providing health care for dementia patients. The authorised outpatient departments of geriatric institutes provide need-oriented support of the outpatient geriatric care offered by general practitioners.
- The **outpatient departments of gerontopsychiatric institutes** further develop their programmes for improving the provision of health care and cooperation with SHI-accredited physicians.
- In the framework of the model of the Federal Union of German Associations of Pharmacists (ABDA) and the KBV, the **KBV** supports medication management to reduce the risks of poly-medication, and further develops the specific medication catalogue for Alzheimer's disease.
- The **KBV** supports the nationally standardised medication plan, developed by the Drug Commission of the German Medical Profession (AkdÄ), which makes it easier for physicians and nursing staff involved in caring for dementia patients to rapidly obtain information on current medication.
- The **KBV** elaborates a concept for care-giving relatives regarding the prevention of health risks resulting from the mental and physical strain of care-giving. The representatives responsible for nursing, and any existing offers, are involved in the elaboration and implementation of the health care concepts of the KBV, as is already customary in the framework of its Working Group (Vertragswerkstatt).
- The **GKV-SV**, the **KBV**, the **German Hospital Federation (DKG)** and the **associations of long-term care providers** review existing cooperation agreements with the intention of identifying opportunities and typical problem situations, the aim being to develop joint recommendations for cooperation between general practitioners and specialists, hospitals and care facilities.
- The **GKV-SV** supports efforts of the health insurance funds to incorporate special regulations regarding care for dementia patients in its agreements on GP-centred care. If necessary, these regulations also include treatment at home.
- The **GKV-SV** promptly starts the testing of home assistance benefits provided by assistance services and endeavours to exhaust the available financial volume of 5 million Euros.
- The **National Associations of SHI-Accredited Physicians and Dentists (KBV and KZBV)** make the necessary preparations for prompt mediation of cooperation between SHI-accredited physicians/dentists and inpatient care facilities. Based on the agreements at the national level, they develop regionally adapted, flexible solutions for the provision of health care services by SHI-accredited physicians/dentists in inpatient care facilities and recruit SHI-accredited physicians and dentists to participate.
- The **GKV-SV** and the **KBV/KZBV** provide the public with information on the concluded cooperation agreements, based on reports from their regional members.

- The **associations of the providers of care facilities** support inpatient care facilities in concluding any necessary cooperation agreements and in complying with their statutory duty to provide information regarding the organisation of medical and dental care in the care facilities.
- The **associations of long-term care insurers** and the **service providers at the national and Länder level** work towards the speedy and region-wide conclusion of contracts with licensed outpatient nursing services for home assistance services, particularly for insureds with dementia.
- The **long-term care insurance system** will, by providing long-term care counselling, comprehensively support insureds in compiling assistance benefits in accordance with their individual requirements, and advise them on the selection of suitable providers.

## 10.4 Health care in acute-care hospitals

For people with dementia, every acute illness, and every resultant switch of their environment to an acute-care hospital, is a major strain and a risk factor for deterioration of their overall condition, their cognitive impairment, all the way to a threat of delirium. An unfamiliar and unstructured environment, changed daily routines, limited options for occupying themselves, frightening activities and a lack of continuity in assistance additionally lead to the more frequent occurrence of problematic behaviour and the danger of increased use of sedating medication.

Particularly for people with dementia, the principle of "outpatient is better than inpatient" and "inpatient as briefly as possible" is therefore very important. Geriatric and gerontopsychiatric departments have in recent years developed particular competence in providing health care for patients with this diagnosis, and have also devised their own concepts, incorporating the pre- and post-inpatient health care systems.

### Resolution

The partners commit to the goal of:

- Avoiding hospitalisation of dementia patients and keeping necessary periods of hospitalisation as short as possible,
- Identifying and giving consideration to existing dementia as soon as possible upon admission to hospital, especially in emergency situations, and promptly informing patients and relatives about specific offers of the hospital for dementia patients,
- Hospitals already being informed in writing of the presence of dementia by the referring physicians and care facilities involved at the time of referral/transfer,
- Patients with dementia, undergoing inpatient treatment for other illnesses, being given medical care and support appropriate to their dementia in hospitals and rehabilitation facilities,
- Hospitals providing special offers for patients with dementia for structuring their day, for individual therapy and occupation, as well as rooms that are as homely as possible and specially designed,
- Offering relatives the option of rooming-in, if so requested,
- Training hospital staff in how to deal with dementia patients,
- Improving structures for the use of volunteers and cooperation with the professionals,
- Working towards better interaction between physicians in private practice, hospitals, rehabilitation and care facilities, also as regards discharge management,

- Testing and further developing the creation of in-house, multidisciplinary wards, based on the model of Special Care Units, or integrative geriatric departments for people diagnosed with dementia,
- Reviewing the sector of pre- and post-inpatient treatment in hospital, and of day clinics, as therapeutic options.

#### **Contributions of the partners**

- The **DKG** supports the hospital operators in elaborating a concept enabling more rapid identification of patients with major cognitive limitations upon admission to hospital, even in emergency situations.
- The **DKG** cooperates with physicians, outpatient and inpatient care facilities and health insurers to elaborate recommendations on the discharge management of hospitals for people with dementia, with the aim of ensuring uninterrupted medical and nursing care following discharge.
- The **DKG** supports hospital operators in developing training and continuing education concepts for staff, especially physicians and nursing staff, regarding the appropriate care of, and interaction with, dementia patients, also regarding the frequency, identification and avoidance of delirium, and regarding the coordination of care and assistance in interdisciplinary teams.
- The **DKG** supports hospital operators in developing professional concepts for designing rooms in hospitals that are suitable for the needs of people with dementia, as well as for appropriate assistance, support and structuring of the day by trained staff and volunteers.
- The **GKV-SV**, the **KBV** and the **DKG** elaborate recommendations on dealing with dementia patients in an appropriate, sensitive manner, and on the question of how the hospitalisation of dementia patients can be avoided or its duration reduced.
- The **German Alzheimer's Association** and the **DKG** develop information brochures for dementia patients and their relatives/care-givers to inform them of the challenges and possibilities associated with hospitalisation.

#### **10.5 Qualified personnel**

The individual support and care of people with dementia presupposes human and time resources that permit need-oriented, high-quality care. Appropriate consideration must be given to the growing importance of dementia in nursing training. In view of demographic developments, there is a need to increasingly recruit qualified personnel for nursing. In this context, attention must be paid to culture-sensitive old-age care that takes into account the different cultures of the people providing and requiring the care. The knowledge existing in the fields of special-needs education and services for the elderly must be better combined in the field of care for ageing persons with mental impairments. The attractiveness of occupations in old-age care needs to be improved at all events.

#### **Resolution**

The partners commit to the goal of:

- Counteracting the shortage of professionals,
- Improving the framework conditions in old-age care, and thus its attractiveness,

- Putting continuing education and specialist training on a broad footing across all occupational groups involved,
- Promoting multi-professionalism,
- Examining the use of technical aids in order to make work easier and also gain more time for personal attention.

#### Contributions of the partners

- The **Federal Government** will reform nursing training and, through an Act on Nursing Professions, establish a standardised occupational profile with common basic training and, based on it, specialisation in geriatric, medical and paediatric nursing.<sup>5</sup>
- The **Federal Government and the Länder** aim to create an Expert Commission that, on the basis of the Training and Examination Regulations of the planned Act on Nursing Professions, is to develop nationally applicable recommendations for a framework curriculum for instruction and practical training.
- The **Länder** support schools of geriatric nursing in combining the field of learning "Care of the elderly with dementia and gerontopsychiatric conditions", provided for in the Training and Examination Regulations for the occupation of geriatric nurse, with other fields of learning – in the spirit of a spiral curriculum – in such a way that the topics of counselling (of patients and care-givers) and inclusion – particularly also in the sense of intercultural nursing – are implemented.
- The **Länder** encourage the parties responsible for training in health care professions to structure and, if appropriate, expand the curricula for basic training, continuing education and specialist training to include the subject of "Interacting with people with dementia", modelled on the training in geriatric nursing.
- The **Länder** work towards institutions of higher education developing and testing appropriate qualification modules.
- The **Länder** support the development and testing of working aids for improving the provision of care for immigrants with dementia.
- The **German Medical Association** develops specialist training measures for physicians regarding the treatment of dementia patients.
- The **partners in the Training and Skills Development Offensive** already agreed in December 2012 on a host of concrete measures for securing the professional base in old-age care. Their implementation is in progress.
- The **partners in the Training and Skills Development Offensive** will, in the framework of their competence, step up efforts to qualitatively and quantitatively improve the assessment of personnel requirements in care facilities according to standardised principles and on a scientifically sound basis – starting from the professionals quota, Land-wide personnel assessment procedures or Land-wide personnel guide figures.

## 10.6 Quality of health care

The quality of life of people with dementia is decisively dependent on the quality of the support and care they receive, and on the effectiveness of the concepts applied. These, in turn, are dependent on human resources, qualified staff, appropriate time management and effective, qualification-oriented personnel deployment.

<sup>5</sup> bpa and VDAB: "We reject a generalised system geared to a common training certificate in the fields of medical, paediatric and geriatric nursing."

### Resolution

The partners commit to the goal of:

- █ Promoting assistance and care that utilises people's resources and is geared to their needs,
- █ Limiting documentation duties and bureaucracy to the absolutely necessary,
- █ Improving the efficiency of care documentation,
- █ Implementing new findings faster and taking them into account in the concepts applied.

### Contributions of the partners

- █ The **contract partners of funding agencies** and **service providers** agree to implement the greatest possible degree of self-determination of persons in need of long-term care.<sup>6</sup>
- █ The **contracting parties according to Section 113 SGB XI** further develop quality reporting in long-term care with the aim of making the nursing quality of facilities more transparent for the consumer. To this end, they agree on regulations regarding the demands on an indicator-based procedure for the comparative measurement and presentation of outcome quality in the inpatient sector.<sup>7</sup>
- █ The **authorities** responsible under the respective Länder laws, the **Health Insurance Medical Services** and the **Inspection Service of the Association of German Private Health Insurers** coordinate and simplify their examinations.
- █ The **associations of care facilities** support care facilities in implementing the findings from the practical test on improving the efficiency of care documentation. The contracting parties according to Section 113 SGB XI supplement their agreement on care documentation accordingly.

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6 bpa: "The funding agencies must be equipped with financial and human resources to this end. Corresponding funds for this purpose are provided for in the framework of the forthcoming nursing/health care reform." VDAB: "wThe funding agencies must be equipped with financial and human resources to this end."

7 VDAB: "To this end, valid indicators still need to be developed for outpatient care, short-term care and semi-inpatient care."



## External and internal partners

### External

- Aktion Demenz e.V.  
(Campaign for People with Dementia)
- Aktion Psychisch Kranke e.V.  
(Campaign for the Mentally Ill)
- Arbeits- und Sozialministerkonferenz  
(Conference of the Ministers of Labour and Social Affairs)
- Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege e.V. (Federal Association of Non-Statutory Welfare)
- Bundesärztekammer (German Medical Association)
- Bundesverband privater Anbieter sozialer Dienste e.V. (Federal Association of Private Providers of Social Services)
- Deutsche Alzheimer Gesellschaft e.V.  
(German Alzheimer's Association)
- Deutsche Gesellschaft für Gerontopsychiatrie und -psychotherapie e.V.  
(German Association for Gerontopsychiatry and Gerontopsychotherapy)
- Deutsche Krankenhaus Gesellschaft e.V.  
(German Hospital Federation)
- Deutscher Landkreistag  
(Association of German Counties)
- Deutscher Pflegerat e.V.  
(German Council of Nursing)
- Deutscher Städtetag  
(Association of German Cities)
- Deutscher Städte- und Gemeindebund  
(German Association of Towns and Municipalities)
- Deutscher Verein für öffentliche und private Fürsorge e.V. (German Association for Public and Private Welfare)
- Deutsches Zentrum für Neurodegenerative Erkrankungen e.V. (German Centre for Neurodegenerative Diseases)
- Gesundheitsministerkonferenz (Conference of the Ministers Responsible for Health)
- GKV-Spitzenverband (National Association of Statutory Health Insurance Funds)
- Kassenärztliche Bundesvereinigung  
(National Association of Statutory Health Insurance Physicians)
- Kuratorium Deutsche Altershilfe (German Foundation for the Care of Older People)
- Kultusministerkonferenz  
(Conference of the Ministers of Education and Cultural Affairs)
- Verband der Privaten Krankenversicherung e.V. (Association of German Private Health Care Insurers)
- Verband Deutscher Alten- und Behindertenhilfe e.V. (Association of German Assistance for the Elderly and Disabled)

## Internal

- Bundesministerium für Familie, Senioren, Frauen und Jugend (Federal Ministry for Family Affairs, Senior Citizens, Women and Youth)
- Bundesministerium für Gesundheit (Federal Ministry of Health)
- Bundesministerium für Bildung und Forschung (Federal Ministry of Education and Research)
- Bundesministerium für Arbeit und Soziales (Federal Ministry of Labour and Social Affairs)
- Bundesministerium des Innern (Federal Ministry of the Interior)
- Bundesministerium der Justiz und für Verbraucherschutz (Federal Ministry of Justice and Consumer Protection)
- Bundesministerium für Ernährung und Landwirtschaft (Federal Ministry of Food and Agriculture)
- Bundesministerium für Umwelt, Natur- schutz, Bau und Reaktorsicherheit (Federal Ministry for the Environment, Nature Con- servation, Building and Nuclear Safety)
- Bundeskanzleramt (Federal Chancellery)

## Signatures of the partners

**Manuela Schwesig**

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

**Hermann Gröhe**

Federal Minister of Health

**Heike von Lützau-Hohlbein**

Chairwoman of the Executive Committee,  
German Alzheimer's Association, Dementia  
Self-Help

**Minister Sylvia Löhrmann**

President, Conference of the Ministers of  
Education and Cultural Affairs (KMK)

**Senator Cornelia Prüfer-Storcks**

Chairwoman, Conference of the Ministers  
Responsible for Health (GMK)

**Minister Alexander Schweitzer**

Chairman, Conference of the Ministers of  
Labour and Social Affairs (ASMK)

**Lord Mayor Dr. Ulrich Maly**

President, Association of German Cities

**County District Commissioner Reinhard Sager**

President, Association of German Counties

**Lord Mayor Christian Schramm**

President, German Association of Towns and  
Municipalities

**Stephan Baumann**

National Chairman, Association of German  
Assistance for the Elderly and Disabled  
(VDAB)

**Alfred Dänzer**

President, German Hospital Federation  
(DKG)

**Dr. Andreas Gassen**

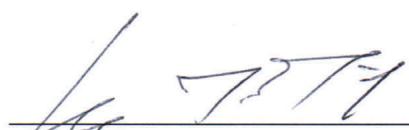
Chairman of the Executive Committee, National  
Association of Statutory Health Insurance  
Physicians (KBV)

Berlin, 15. September 2014



**Dr. h.c. Jürgen Gohde**

Chairman, German Foundation for the Care  
of Older People (KDA)

  
**Prof. Dr. med. Hans Gutzmann**

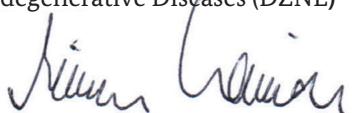
President, German Association for Gerontopsychiatry and Gerontopsychotherapy  
(DGGPP)

  
**Bernd Meurer**

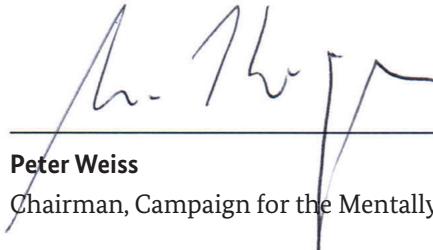
President, Federal Association of Private  
Providers of Social Services (bpa)

  
**Prof. Dr. Dr. Pierluigi Nicotera**

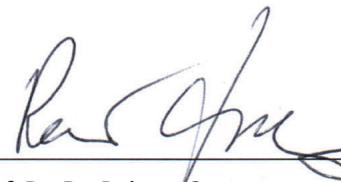
Member of the Executive Committee responsible  
for Scientific Affairs, German Centre for  
Neurodegenerative Diseases (DZNE)

  
**Wilhelm Schmidt**

President, German Association for Public and  
Private Welfare

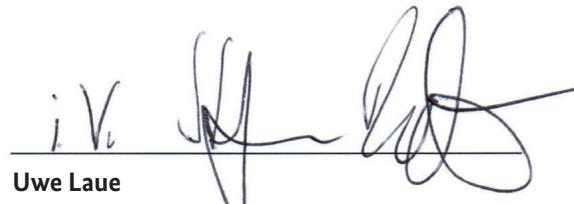
  
**Peter Weiss**

Chairman, Campaign for the Mentally Ill



**Prof. Dr. Dr. Reimer Gronemeyer**

Chairman of the Executive Committee, Cam-  
paign for People with Dementia

  
**Uwe Laue**

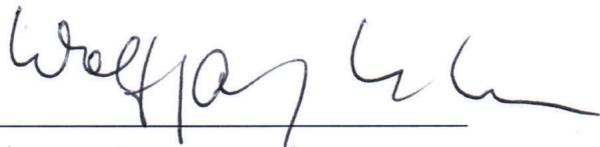
Chairman of the Executive Committee,  
Association of German Private Health care  
Insurers (PKV-Verband)

  
**Prof. Dr. med. Frank Ulrich Montgomery**

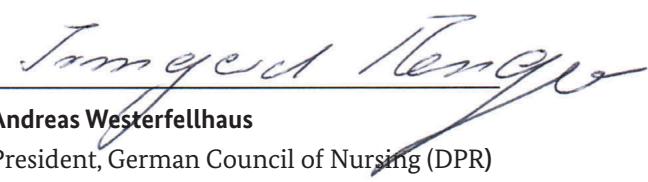
President, German Medical Association (BÄK)

  
**Dr. Doris Pfeiffer**

Chairwoman, National Association of Statu-  
tory Health Insurance Funds

  
**Wolfgang Stadler**

President, Federal Association of Non-Statu-  
tory Welfare (BAGFW)

  
**Andreas Westerfellhaus**

President, German Council of Nursing (DPR)

## Glossary

### ABDA

The Federal Union of German Associations of Pharmacists. ([www.abda.de](http://www.abda.de))

### AkdÄ

The Drug Commission of the German Medical Profession. ([www.akdae.de](http://www.akdae.de))

### "Age-Oriented Conversion"

KfW funding measure: granting of loans for measures that improve accessibility or for the purchase of converted accommodation. ([www.kfw.de/inlandsfoerderung/Privatpersonen/Bestandsimmobilien/Finanzierungsangebote/Altersgerecht-umbauen-%28159%29/index-2.html](http://www.kfw.de/inlandsfoerderung/Privatpersonen/Bestandsimmobilien/Finanzierungsangebote/Altersgerecht-umbauen-%28159%29/index-2.html))

### Ambient Assisted Living (AAL)

Ambient Assisted Living, based on microsystem and communication technology, increasingly supports the elderly in their personal environment. Intelligent systems and services permit a self-determined life at home and improve communication with the social environment.

### Alzheimer's Disease International

The international federation of Alzheimer associations. ([www.alz.co.uk](http://www.alz.co.uk))

### "Technology for a Better Life in Old Age"

BMBF funding programme: Establishment of municipal counselling centres (Module 1), Development of a sustainable, networked knowledge base (Module 2). ([www.bmbf.de/foerderungen/21452.php](http://www.bmbf.de/foerderungen/21452.php))

### Guardianship-avoiding assistance

The Act for Strengthening the Functions of Guardianship Authorities particularly aims to illustrate and mediate other forms of assistance for affected persons not involving the appointment of a guardian. Outreach social services of the Social Services Offices, joint service centres of the rehabilitation providers and long-term care support centres could provide guardianship-avoiding assistance of this kind.

### German Research Foundation (DFG)

The German Research Foundation is the self-government organisation of the scientific community in Germany. The core task of the DFG consists in the competition-based selection of the best research projects of scientists at institutions of higher education and research institutes, and in their funding. ([www.dfg.de](http://www.dfg.de))

### Case management

Case management organises, controls and secures the provision of made-to-measure health care for a client or patient across system boundaries in the framework of continuous, possibly longer-term support, paying attention to aspects of effectiveness and efficiency.

**Act on Family Care-Giving Leave**

Family care-giving leave makes it possible to care for close relatives while continuing to be employed. During family care-giving leave, employees caring for close relatives can reduce their working time to a minimum weekly working time of 15 hours over a maximum period of two years. The Act on Family Care-Giving Leave came into effect on 1 January 2012. ([www.gesetze-im-internet.de/fpfzg/index.html](http://www.gesetze-im-internet.de/fpfzg/index.html))

**Office of the Alliance**

Office of the Alliance for People with Dementia at the Federal Office for Family Affairs and Civil Society Functions (BAFzA), Sibille-Hartmann-Strasse 2-8, D-50969 Köln. ([gst-demenz@bafza.bund.de](mailto:gst-demenz@bafza.bund.de))

**GP-centred health care**

GP-centred health care is a form of medical care in Germany where a general practitioner acts as the first point of contact for a patient and coordinates all treatment steps (Section 73b SGB V GP-centred health care).

**Helmholtz Association**

The Helmholtz Association is an association of 18 scientific-technical and medical-biological research centres, whose task is to pursue long-term research goals of the state and society, and to preserve and improve the basis of human existence. ([www.helmholtz.de](http://www.helmholtz.de))

**Integrative Geriatric Department**

Integrative geriatrics is a special treatment concept for dementia patients with acute illnesses. It is based on the concept of Silviahemmet. The primary goal is to re-integrate elderly patients into their domestic and social environment as quickly as possible. Beyond this, individual independence is to be preserved and satisfaction increased. One key element of the care concept of integrative geriatrics is early and regular activation. ([www.malteser-stjohannesstift.de/medizin-pflege/geriatrie-und-fruehrehabilitation/leistungsspektrum/integrative-geriatrie.html](http://www.malteser-stjohannesstift.de/medizin-pflege/geriatrie-und-fruehrehabilitation/leistungsspektrum/integrative-geriatrie.html))

**KfW**

The Kreditanstalt für Wiederaufbau (Reconstruction Loan Corporation), the national funding bank.

**Leibniz Association**

As a registered society, the Leibniz Association pursues exclusively non-profit objectives: it promotes science and research at its member institutions, whilst safeguarding their scientific, legal and economic independence. The institutions in the Leibniz Association cooperate intensively with one another, as well as with universities, institutes belonging to other research organisations, business enterprises, state institutions and social organisations, at the national and international level. ([www.leibniz-gemeinschaft.de](http://www.leibniz-gemeinschaft.de))

**Local Alliances**

A funding programme of the BMFSFJ, launched in 2012. Up to 500 "Local Alliances for People with Dementia" are to be established throughout Germany by 2016. The aim is to pool and network the potential of citizens, societies, industry and trade, educational institutions, politics and municipal administration, thereby catering better locally to the needs of dementia patients and their relatives. ([www.lokale-allianzen.de](http://www.lokale-allianzen.de))

**Max Planck Society**

The current 82 Max Planck Institutes engage in basic research in the natural sciences, life sciences, the humanities and social sciences in service of society. Max Planck Institutes are active in research fields that are particularly innovative or involve special demands in terms of financing or time. ([www.mpg.de](http://www.mpg.de))

Medicproof

The medical review service of the private health and long-term care insurers

## Low-threshold care offers

Low-threshold care offers are offers in which, with professional guidance, volunteers in particular not only take on the care of persons in need of long-term care within the meaning of Section 45a SGB XI who have a substantial need for general supervision and care in groups or at home, but also relieve the burden on care-giving relatives and provide advice and support. The care can also be offered by commercial providers, insofar as they are approved under the Länder laws. (See SGB XI Section 45c Further development of health care structures ([www.gesetze-im-internet.de/sgb\\_11/\\_45c.html](http://www.gesetze-im-internet.de/sgb_11/_45c.html)))  
The level of cost reimbursement for the utilisation of low-threshold care services for insureds fulfilling the prerequisites of Section 45a SGB XI is governed by Section 45b SGB XI. (See SGB XI Section 45b Additional care services ([www.gesetze-im-internet.de/sgb\\_11/\\_45b.html](http://www.gesetze-im-internet.de/sgb_11/_45b.html)))

## Partners of the Training Offensive

Federal Ministry for Family Affairs, Senior Citizens, Women and Youth | Federal Ministry of Labour and Social Affairs | Federal Ministry of Health | Federal Ministry of Education and Research | Federal Employment Agency | Conference of the Ministers of Labour and Social Affairs | Conference of the Ministers for Youth and Family Affairs | Conference of the Ministers Responsible for Health | Conference of the Ministers of Education and Cultural Affairs | Association of German Counties | Association of German Cities | German Association of Towns and Municipalities | National Association of Statutory Health Insurance Funds | Association of German Private Health care Insurers | Arbeiterwohlfahrt Bundesverband e.V. (National Workers' Welfare Association) | German Caritas Association | Diakonie Deutschland – Evangelischer Bundesverband (Social Welfare Service of the Protestant Churches in Germany) | Deutscher Paritätischer Wohlfahrtsverband – Gesamtverband e.V. (National Association of Social Movements in Germany) | German Red Cross | Zentralwohlfahrtsstelle der Juden in Deutschland e.V. (Central Welfare Agency for Jews in Germany) | Bundesverband privater Anbieter sozialer Dienste e.V. (Federal Association of Private Providers of Social Services) | Verband Deutscher Alten- und Behindertenhilfe e.V. (Association of German Assistance for the Elderly and Disabled) | Arbeitgeberverband Pflege e.V. (Association of Employers in Nursing) | ver.di (Trade Union for the Services Sector) | Arbeitskreis Ausbildungsstätten für Altenpflege (Working Group on Training Facilities for Old-Age Care) | Deutscher Berufsverband für Altenpflege e.V. (German Professional Association for Old-Age Care) | German Council of Nursing | Deutscher Verband der Leitungskräfte von Alten- und Behinderteneinrichtungen e.V. (German Association of Managers of Facilities for the Elderly and Disabled) | Berufsgenossenschaft für Gesundheitsdienst und Wohlfahrtspflege (Employers' Liability Insurance Association for the Health Service and Welfare)

## Long-Term Care Reorientation Act

The Long-Term Care Reorientation Act (PNG) was adopted by the German Bundestag in its second and third reading on 29 June 2012, and essential parts of it came into effect on 30 October 2012. Further regulations entered into force on 1 January 2013, meaning that all the regulations of the PNG are now prevailing law. ([www.bgblericht.de/banxaver/bgblericht/start.xav?startbk=Bundesanzeiger\\_BGBI&jumpTo=bgblericht112s2246.pdf](http://www.bgblericht.de/banxaver/bgblericht/start.xav?startbk=Bundesanzeiger_BGBI&jumpTo=bgblericht112s2246.pdf))

Long-Term Care Provident Fund (Pflege-Vorsorgefonds)

The first stage of the Long-Term Care Reform is already scheduled to come into effect on 1 January 2015, offering more benefits for persons in need of long-term care and their relatives. The contribution rate in long-term care insurance will rise by 0.3 percentage points with effect from 1 January 2015. On the one hand, this will finance the planned benefit improvements, for which 2.4 billion Euros per year are available. On the other hand, an annual 1.2 billion Euros will be put into a Long-Term Care Provident Fund. Its purpose is to cushion a future increase in contributions when the baby boom years reach the age of long-term care – starting in about the year 2035. ([www.bmg.bund.de/pflege/verbesserungen-in-der-pflege.html](http://www.bmg.bund.de/pflege/verbesserungen-in-der-pflege.html))

### Act on Care-Giving Leave

The Act on Care-Giving Leave entered into effect on 1 July 2008 as Article 3 of the Long-Term Care Further Development Act. The aim of care-giving leave is to enable employees to be released from work for a limited period of time, without continuation of wage payments, or to work part-time, in order to care for relatives in need of long-term care. The employment contract is not jeopardised by care-giving leave, since the employee has special protection against dismissal. The maximum duration of care-giving leave is six months. ([www.bmfsfj.de/BMFSFJ/gesetze,did=140564.html](http://www.bmfsfj.de/BMFSFJ/gesetze,did=140564.html))

### Potentials and risks in the family-based care of old people (PURFAM)

A practical research project funded by the BMFSFJ at two universities (1.12.2009 to 30.11.2012), focusing on the prevention of violence against, and neglect of, old people in family-based care through early detection and strengthening of resources, as well as integration of international examples of Best Practice for optimising practical action. ([www.bmfsfj.de/BMFSFJ/aeltere-menschen,did=164686.html](http://www.bmfsfj.de/BMFSFJ/aeltere-menschen,did=164686.html))

### Neighbourhood management

Neighbourhoods are small, cohesive social and residential settings. Neighbourhood management is designed to help the formation and strengthening of social networks. These networks consist of various stakeholders from administration, local politics, the private sector, local clubs and societies, parishes and non-organised residents, this giving rise to a lively, mutually supportive neighbourhood.

### ReduFix

Projects, funded by the BMFSFJ and the BMBF, for reducing the use of restraining measures in old-age care. ([www.redufix.com](http://www.redufix.com))

### Rehabilitation providers

According to Section 6 Para. 1 SGB IX, the providers of benefits for participation (rehabilitation providers) can be:

1. The statutory health insurance funds, for benefits according to Section 5 Nos. 1 and 3,
2. The Federal Employment Agency, for benefits according to Section 5 Nos. 2 and 3,
3. The providers of statutory accident insurance, for benefits according to Section 5 Nos. 1 to 4,
4. The providers of statutory pension insurance, for benefits according to Section 5 Nos. 1 to 3, the provider of farmers' old-age security, for benefits according to Section 5 Nos. 1 and 3,
5. The providers of war victims' pensions and the providers of war victims' welfare in the framework of the right to social compensation for health-related damage, for benefits according to Section 5 Nos. 1 to 4,
6. The providers of public youth welfare, for benefits according to Section 5 Nos. 1, 2 and 4,
7. The providers of social welfare, for benefits according to Section 5 Nos. 1, 2 and 4.

### Special Care Unit

Specialised care departments with multiprofessional teams and (in this case, dementia-specific) orientation.

### Spiral curriculum

The spiral curriculum is an educational concept for arranging instructional content.

A curriculum that does not exclusively follow the internal logic of the subject, but also gives consideration to aspects of developmental and teaching psychology, arranges the material not in linear fashion, but in the form of a spiral, such that individual topics recur several times in the course of the school years, at a higher level each time.

### UN Convention on the Rights of Persons with Disabilities (UNCRPD)

The human rights convention concerning the rights of persons with disabilities.

The United Nations Convention on the Rights of Persons with Disabilities came into effect on 3 May 2008. The aim of the Convention, and of the Additional Protocol, is to promote, protect and guarantee equal enjoyment of human rights and basic liberties by persons with disabilities. Following signing of the ratifying act, the Convention has been binding in Germany since 26.03.2009. ([www.bmas.de/DE/Themen/Teilhabe-behinderter-Menschen/Politik-fuer-behinderte-Menschen/Uebereinkommen-der-Vereinten-Nationen/rechte-von-menschen-mit-behaenderungen-langtext.html](http://www.bmas.de/DE/Themen/Teilhabe-behinderter-Menschen/Politik-fuer-behinderte-Menschen/Uebereinkommen-der-Vereinten-Nationen/rechte-von-menschen-mit-behaenderungen-langtext.html))

### Health care management

Health care management pursues the goal of introducing concrete health care structures in a field and optimising complex health care processes, on an interdisciplinary basis where necessary. In this context, there is a particular focus on interface management between individual health care fields. The aim is to achieve the provision of need-oriented, resource-conserving health care, avoiding underprovision, misprovision and overprovision, through networked, related analyses and interventions. The personal health care preferences of a client are the focus in this context and must be taken into account in health care management. According to Section 11 Para. 4 SGB V, persons with statutory health insurance have a legal claim to health care management, particularly for solving problems relating to transitioning between the different health care sectors, e.g. when transitioning from inpatient treatment in hospital to outpatient treatment by a specialist.

### Contracting parties according to Section 113 SGB XI

The contracting parties according to Section 113 SGB XI ("self-government in care at the national level") are:

The National Association Federation of Long-Term Care Insurance Funds,  
 The Federal Working Group of Regional Providers of Social Welfare,  
 The Federal Association of the Associations of Local Authorities, and  
 The associations of providers of care facilities at the national level.

The associations of providers of care facilities at the national level include both provider associations in the non-statutory welfare sector and associations of private care facilities. According to Section 118 SGB XI, the key organisations at the national level for safeguarding the interests of persons requiring long-term care and persons with disabilities, and their self-help organisations, cooperate in an advisory capacity in the development or amendment of the agreements of the self-governing partners.

### World Alzheimer's Day

Since 1994, diverse activities have been organised around the world on 21 September each year, in order to draw public attention to the situation of Alzheimer patients and their relatives.

### WHO

The World Health Organization. ([www.who.int/en](http://www.who.int/en))

### Living communities/Living groups

In organisational terms, a living group is directly affiliated to a home or a provider, but is located in a normal residential environment. People live there in a group that is not freely determined and does not require round-the-clock assistance. The nursing and assistance services cannot be selected by the residents, but are controlled by the home. The individual persons providing assistance cannot be chosen. In the case of a living community with mobile nursing care, external nursing and assistance services are offered to a common household in return for payment. Self-determination must be guaranteed, also as regards the choice of the nursing and assistance service (not the individual assistants) and the scope. The accommodation must be structurally, organisationally and economically independent and not part of an inpatient facility.

### Future Workshop on Dementia

A funding programme of the BMG. Twenty-nine projects were funded in 2008 - 2009 in the framework of the "Lighthouse Project on Dementia", the results of which were presented at a public event in September 2010 and discussed with the Federal Minister of Health and the parliamentary state secretary regarding their importance for the health care situation of people with dementia. The "Future Workshop on Dementia" funding programme of the Federal Ministry of Health is geared to supplementing the knowledge gained to date from the "Lighthouse Project on Dementia", where necessary, and to appropriately implementing the available knowledge in routine health care. ([www.bmg.bund.de/pflege/demenz/zukunftswerkstatt-demenz.html](http://www.bmg.bund.de/pflege/demenz/zukunftswerkstatt-demenz.html))

### Centre for Quality in Care (ZQP)

The Centre for Quality in Care was established by the Association of German Private Health Care Insurers in 2009 in the form of a non-profit, incorporated foundation. ([www.zqp.de](http://www.zqp.de))



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