



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



Federal Ministry
of Health



The Alliance for People with Dementia

Results of the 2014-2018 Common Efforts - Short Report

Download detailed report

This brochure presents the summarised report on the 2014-2018 implementation of the Agenda of the Alliance for People with Dementia. The report provides more detailed descriptions of all projects and measures implemented under the Agenda and can be downloaded from the Alliance for People with Dementia website:

www.allianz-fuer-demenz.de/report-agenda

Preamble

Living with Dementia

Dementia is one of the greatest challenges facing our society. Around 1.7 million people in Germany already suffer from it, to which 300,000 people are diagnosed with dementia every year. These figures also reflect the fates of those affected and their families. People with dementia can be parents, close family members, friends, neighbours, former work colleagues or simply people we meet in the supermarket. We all therefore need to learn what dementia is and how to deal with it. This includes accepting dementia: People with dementia belong to us.

To promote a greater understanding of people with dementia and their relatives and to further expand support opportunities, the federal government has launched the “Alliance for People with Dementia” - a broad alliance between politicians and civil society that supports the interests of dementia patients and their relatives in all areas of life.

After four years of working together, we would now like to take a look at what we have achieved together. Every partner in the Alliance has made a contribution to supporting people with dementia and their relatives with their ideas and projects. We will not stop there. The Alliance is continuing its work because it has not yet reached its goal. Improving the living conditions for people with dementia and their relatives and anchoring awareness of dementia throughout society still remain our major concerns.



A handwritten signature in black ink, reading "Dr. Franziska Giffey".

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

A handwritten signature in black ink, reading "Jens Spahn".

Jens Spahn
Federal Minister
of Health

Preface: Dementia concerns us all

Whether in the family, the neighbourhood or the local area: we can encounter dementia anywhere. As life expectancy increases, so does the number of people suffering from dementia. There are currently about 1.7 million of them in Germany and according to forecasts, there will be 3 million people with dementia by 2050.

Ensuring a self-determined life

Even with dementia, most of these people wish to be able to remain in their usual home environment. Characterised by inclusion as a guiding principle, in which self-determination and participation of those affected are at the focus, the Alliance for People with Dementia - initiated by the federal government - wants to contribute to this. In this way, the federal government is implementing the objective of the United Nations Convention on the Rights of Persons with Disabilities.

With regard to enabling people with dementia to lead a self-determined life, there is a particular need to support caregiving relatives in the best possible way and, in a straightforward manner, to provide help in meeting their needs. This includes improving knowledge about the disease, establishing new forms of cooperation, making towns and villages dementia-friendly and barrier-free, and networking care and support services more closely.

A joint effort for everyone

For this to succeed, everyone must assume responsibility: in politics, administration, research as well as civil society. This is exactly the path that the federal government is taking.

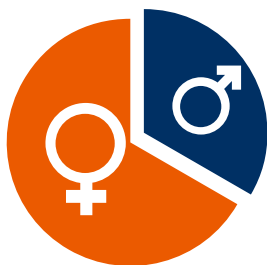
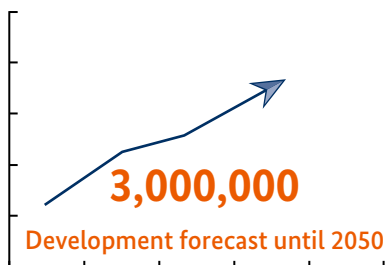
Facts and Figures on Dementia



Every **3** seconds, one person in the world is afflicted with dementia

Possible risk factors

- old age
- lack of exercise
- high blood pressure
- depression
- diabetes
- obesity
- low education
- smoking
- hearing loss
- social isolation



People with dementia by gender:
1/3 males, 2/3 females

Estimated absolute number of people in Germany suffering from dementia aged over **65**

New cases every year:

300,000
people over 65 years of age

By involving a large number of stakeholders within the Alliance, it utilises existing expert knowledge and, at the same time, ensures social mobilisation. The experience of the last four years has shown that real improvements have been achieved for people with dementia and their relatives.



A timeline of the work of the Alliance for People with Dementia

The Alliance for People with Dementia: what is it and what does it do?

The Alliance for People with Dementia is an initiative of the federal government. It was constituted as part of World Alzheimer's Day 2012.

The Alliance is partnered with representatives of the federal government, the federal states, central associations of local authorities, associations and organisations in the fields of health and care, science and civil society bearing responsibility for people with dementia. The common concern of all those involved is to ensure the quality of life of people suffering from dementia and their families and to promote understanding and sensitivity in society.

Now the Alliance is taking stock of what has been achieved over the last four years. To this end, the partners examined the most important thematic areas and described the need for action.

A common Agenda to achieve the goals

The Alliance's partners have set out their specific goals in the "Together for people with dementia" Agenda. Nearly 100 target agreements and over 150 contributions with around 450 measures have been reached, with which the partners aim to implement four fields of action:



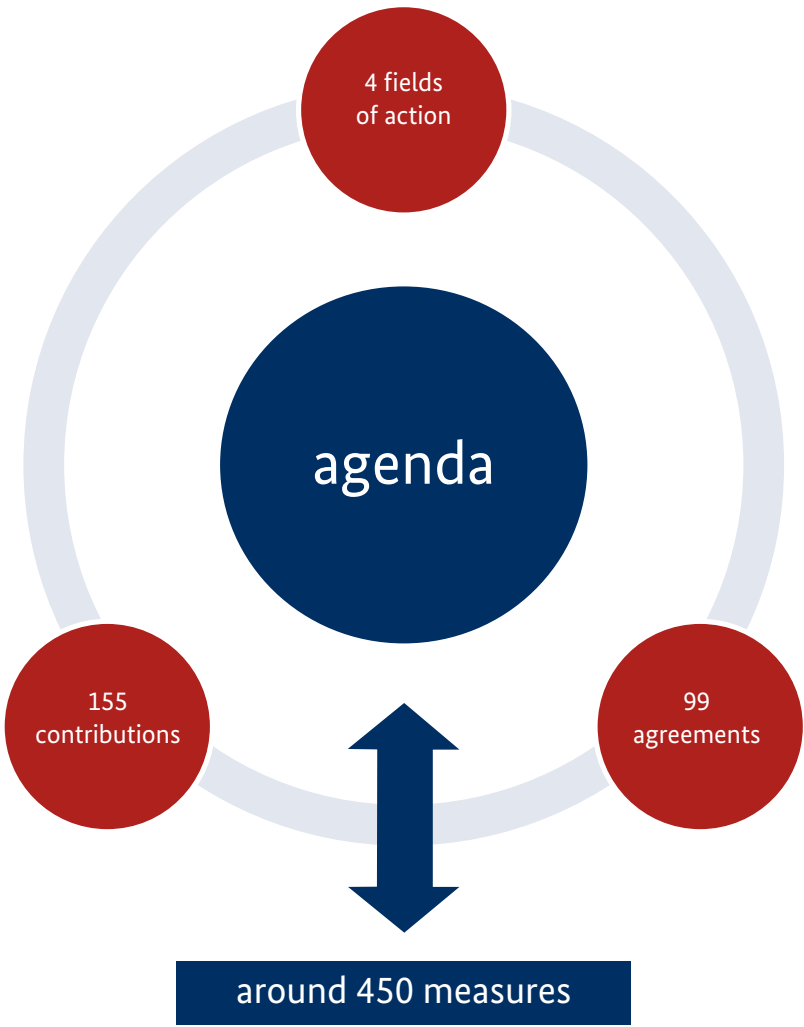
- **Science and research:** various types of dementia should be researched and the results communicated to the general public.
- **Social responsibility:** people with dementia should find competent contact persons and a dementia-friendly environment.
- **Support for people with dementia and their families:** people suffering from dementia should be able to live independently in their living environment and the skills of caregiving relatives should be enhanced.
- **Structuring the support and care system:** the aim is to ensure good individual care for those affected, whether at home or in hospital.

The official signing of the agenda by the partners in September 2014 marked the start of the implementation of the agreed contributions. To this end, the partners have developed, coordinated and implemented concrete measures, initiatives and projects.



Organisational partners and cooperation partners

The Alliance consists of a smaller and a wider circle. The organisational partners are the founding members of the Alliance for People with Dementia, who jointly developed the “Together for People with Dementia” Agenda. To strengthen the Alliance, cooperation partnerships were



Structure of the Agenda of the Alliance for People with Dementia

concluded. The cooperation partners have committed themselves to the Alliance's objectives. With their own activities and measures, they are involved in the implementation process and support the organisational partners' networking initiatives. A list of all partners can be found at the end of the brochure.

Constant support

Upon signing the Agenda, the partners made a voluntary commitment to implement the agreed measures and projects. The Agenda's implementation process was coordinated and accompanied by the Office of the Alliance for People with Dementia at the Bundesamt für Familie und zivilgesellschaftliche Aufgaben (Federal Office of Family Affairs and Civil Society Functions, BAFzA).

Understanding dementia: expanding research, sharing knowledge

Further development of scientific research on dementia, its prevention and treatment as well as the dissemination of knowledge play an important role in improving the lives of those affected and their families. It therefore forms the Agenda's **Field of Action I**.

Understanding dementia means, above all, raising the potential for prevention, diagnosis, therapy and rehabilitation. With the aim of clarifying the causes of dementia, further developing care structures, better coordinating research and informing the public about current research results, the partners had agreed to intensify efforts in all research areas. The partners' research questions included, inter alia, the following aspects:

- risk factors and risk groups for dementia,
- gender differences in dementia,

- particularities in younger people with dementia,
- prevention and early diagnosis,
- technical assistance systems and care innovations that help people with dementia to better manage their lives at home,
- independent orientation in the living environment,
- support in decision-making processes after diagnosis,
- reaching excluded or underrepresented groups,
- further development in the health and nursing professions.

At eye level: creating dementia-friendly environments

People with dementia need understanding and competent contact persons in addition to a dementia-friendly environment to be able to participate in society in a self-determined way. An appreciative encounter with affected people requires sufficient knowledge of the clinical picture and understanding of their needs and concerns. Local support structures ensure that people with dementia can continue to live their daily lives.



Field of Action II is therefore dedicated to social responsibility. The subject areas are divided into social participation, networking, legal issues as well as information and public relations.

The partners are inter alia involved in the following areas:

- creating age-appropriate and intergenerational neighbourhoods,
- managing needs of deaf people with dementia,
- dealing with people with dementia from migrant backgrounds,
- accessibility in the home and living environment,
- using easy language,
- developing and expanding networked aid structures (for example, by establishing 500 Local Alliances for People with Dementia),
- conducting educational projects, campaigns, events, guides and information portals (for example, the “Wegweiser Demenz” and “Online-Ratgeber Demenz” online portals),
- handling legal issues, such as pension schemes, or how do deal with restraining measures involving people with dementia.



Living a self-determined life: supporting people with dementia and their relatives

Most elderly people, including those in need of care and assistance, want to live as long as possible in their familiar environment. Approximately three quarters of all people in need of care are cared for at home. Nursing them, however, often poses great challenges for relatives, friends and neighbours. To avoid being overburdened and to maintain the quality of life of those affected, people with dementia are dependent on help tailored to their needs.

Field of Action III therefore includes the topics of counselling and support, inclusion and participation, designing the living environment as well as freedom of mobility and protection for people suffering from dementia. Enhancing the skills of caregiving relatives and the possibilities of voluntary work also play a role. These and other aspects have been expedited by the partners:

- early, continuous and networked counselling services (for example, through improved care counselling),
- strengthening the autonomy of people in need of care,
- adapting living space and funding new accessible buildings,
- a quality seal for dementia-friendly living,
- information on technical assistance systems and aids,
- preventing violence and deprivation of liberty (for example, through fixations),
- behavioural strategies, offers of assistance and financing options for caregiving relatives,
- supporting volunteer work and associations of neighbours that provide help,
- promoting the reconcilability of caregiving and work (for example, by legal regulations on care time and family care time).

Secure structures: good care for people with dementia

People with dementia and their relatives need a regional, functioning support and care system which is tailored to the various clinical pictures, phases of the disease and the individual needs of those affected. It must include and reach people of all ages, origins and in all living situations, whether living alone or in the family, in the city or in rural areas.

For this reason, **Field of Action IV** covers the areas of housing and living in the neighbourhood, rehabilitation, medical and nursing care, care in the acute hospital, the recruitment of qualified personnel and quality assurance in both inpatient and domestic areas.

The partners are inter alia active in the following areas:

- possibilities of remaining in the living environment (for example, through shared flats and multi-generational houses),
- further development of the long-term care insurance (for example, by expanding the “need for care” concept to support people with dementia),





- expanding cooperation in cross-provider care (for example, between doctors and nursing homes),
- information on palliative care options,
- dealing with dementia patients in acute care in hospitals,
- discharge management and transitional care between hospital and home care,
- making the nursing professions more attractive and developing them further,
- cutting down the red tape in care documentation.

Outlook

What happens next?

The work of the Alliance for People with Dementia over the last four years has shown that important successes have been achieved together. At home and abroad, the Alliance is considered a remarkable cooperation between the federal government and civil society.

The final report summarises the steps taken by the Alliance's partners. These have, however, also both initiated and implemented a large number of initiatives, projects and strategies that will continue to pursue the goals formulated in the Agenda in the future. To this day, the Alliance has accomplished a great deal of work, but it has not finished yet. For a good life for people with dementia in the middle of society and for better support for their relatives, there is still much to be done.

From the Alliance to the National Dementia Strategy

That's why, together with all stakeholders, the federal government will further develop the Alliance for People with Dementia into the National Dementia Strategy. To this end, new goals are to be formulated and binding measures defined. This requires good medical and nursing care, more information about the clinical picture, competent handling of different types of dementia and reliable networks at municipal level.

The development of the National Dementia Strategy shall begin in 2018, immediately after completion of the Agenda's implementation phase.



The Alliance's Partners

Organisational partners

- Aktion Demenz e. V. (Action Dementia e. V.)
- 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)
- Bundeskanzleramt (Federal Chancellery)
- Bundesministerium für Arbeit und Soziales (Federal Ministry of Labour and Social Affairs)
- Bundesministerium für Bildung und Forschung (Federal Ministry of Education and Research)
- 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 des Innern, für Bau und Heimat (Federal Ministry of the Interior, Building and Community)
- Bundesministerium der Justiz und für Verbraucherschutz (Federal Ministry of Justice and Consumer Protection)
- Bundesministerium für Umwelt, Naturschutz und nukleare Sicherheit (Federal Ministry for the Environment, Nature Conservation and Nuclear Safety)
- Bundesverband privater Anbieter sozialer Dienste e. V. (Federal Association of Private Providers of Social Services)
- Deutsche Alzheimer Gesellschaft e. V. (German Alzheimer Society - Dementia Self-Help)

- Deutsche Gesellschaft für Gerontopsychiatrie und -psychotherapie e. V. (German Association for Gerontopsychiatry and Gerontopsychotherapy)
- Deutsche Krankenhausgesellschaft e. V. (German Hospital Federation)
- Deutscher Pflegerat e. V. (German Nursing Council)
- 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 Federal Health Ministers)
- GKV-Spitzenverband (National Association of Statutory Health Insurance Funds umbrella organisation)
- Kassenärztliche Bundesvereinigung (National Association of Statutory Health Insurance Physicians)
- Kuratorium Deutsche Altershilfe (German Foundation for the Care of Older People)
- Kultusministerkonferenz (Standing Conference of the Ministers of Education and Cultural Affairs)
- Kommunale Spitzenverbände (Deutscher Landkreistag, Deutscher Städtetag, Deutscher Städte- und Gemeindebund (Central municipal associations))
- Verband der Privaten Krankenversicherung e. V. (Association of German Private Health Care Insurers)
- Verband Deutsche Alten- und Behindertenhilfe e. V. (German Association for the Elderly and Disabled)

Cooperation Partners

- Bundeszentrale für gesundheitliche Aufklärung (Federal Centre for Health Education)
- Charta zur Betreuung schwerstkranker und sterbender Menschen (Charter for the care of seriously ill and dying people)
- Deutsche Fernsehlotterie gGmbH (German Television Lottery)
- Deutsche Gesellschaft für Pflegewissenschaft e. V. (German Society for Nursing Science)
- Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde e. V. (German Society for Psychiatry and Psychotherapy, Psychosomatics and Neurology)
- Deutsche Sporthochschule Köln (German Sports University Cologne)
- Robert Bosch Stiftung GmbH (Robert Bosch Foundation)
- Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen (German Council of Experts for the Assessment of Developments in the Health Care Sector)
- Spitzenverband ZNS (Central Association of the CNS)
- Zentrum für Qualität in der Pflege (Centre for Quality in Nursing)

Further information and contact persons

Agenda „Alliance for people with dementia - The fields of action“

Detailed description of the four fields of action with a total of 27 thematic focuses

www.allianz-fuer-demenz.de

Direct link to the Agenda: <https://bit.ly/2zRMdEZ>

“Interim report on the implementation of the Agenda“

Interim report of the implementation status of September 2016 (in German language)

www.allianz-fuer-demenz.de/service/meldungen/zwischenbericht-zur-umsetzung-der-agenda.html

Report on the Implementation of the Agenda of the Alliance for People with Dementia 2014-2018

www.allianz-fuer-demenz.de/report-agenda

Advice by telephone

- Telephone hotline of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth: + 49 30 20197130 (Monday to Thursday from 9am - 6pm)
- Citizen's telephone hotline of the Federal Ministry of Health on the subject of care: +49 30 3406066-02 (Monday to Thursday from 8am - 6pm, Friday from 8am - 12pm)
- Alzheimer-telephone of the German Alzheimer Society
030 259379514 (Monday to Thursday from 9am to 6pm, Friday from 9am bis 3pm)

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