

## National Dementia Strategyshort version









## Content

Foreword	5
Joint action for people with dementia in Germany	9
Goals and measures of the National Dementia Strategy	15
Implementation and monitoring of the National Dementia Strategy	31
National Dementia Strategy Network	33
Stakeholders involved in the National Dementia Strategy	35
Further information	38

## Foreword





### Dear readers,

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

We are still unable to treat or cure the cause of dementia. That makes it all the more important to further advance research into the causes and potential treatment strategies. Dementia is a condition that progresses differently in each individual. In many cases it progresses only slowly and gives people living with dementia the chance to remain active members of our society for an extended period of time. Good medical and nursing care is crucial to maintaining autonomy. It is vital that people with dementia remain in the

It is important that people with dementia continue to live in the middle of society. mainstream of society. Anyone who can still go shopping by themself, who stays a member of a sports club team, who carries on singing in their church choir, who travels by public transport or who visits a museum will have a good life for a long time to come.

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

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

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

The National Dementia Strategy is a great success for all parties involved. For many months, we have been jointly drawing up the strategy. Our thanks goes to all those who have participated in this process and have wrestled with us to identify the measures that need to be taken, and above all to the German Alzheimer Society, which as co-chair has actively supported the process. This positive cooperation now serves as the basis for jointly launching the strategy. A great responsibility is borne by the federal states which are responsible at the regional level and can bring about major changes. We look forward to all of us making our country, municipalities and cities noticeably more dementia-friendly over the coming years.

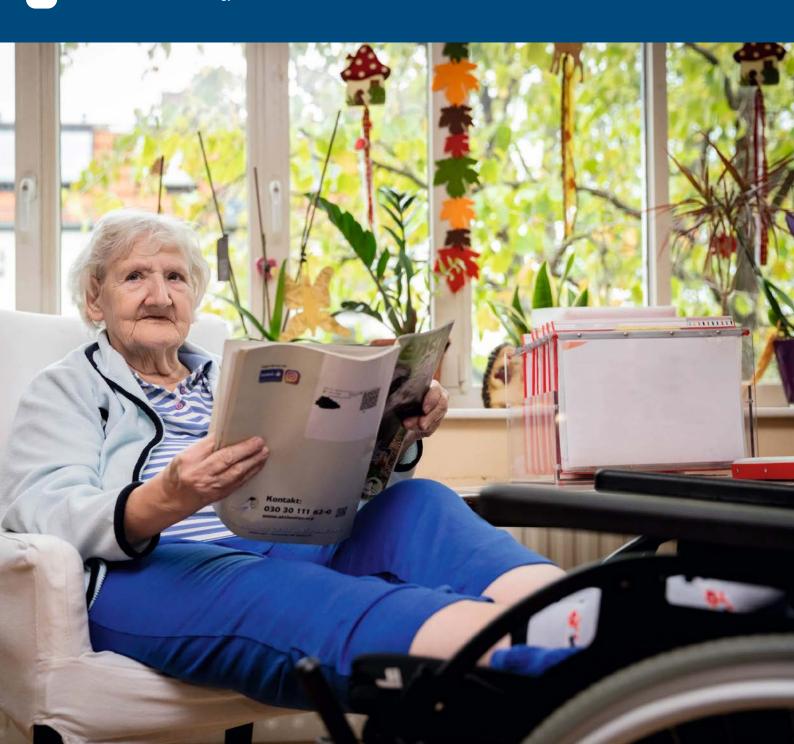
Effective cooperation serves as the basis for jointly launching the strategy.

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

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Franziska Giffey

Federal Minister for Family Affairs, Senior Citizens, Women and Youth **Jens Spahn** Federal Minister of Health



## Joint action for people with dementia in Germany

Dementia wholly transforms people's lives. People with dementia and their families need to be supported in many areas of life. In Germany alone, 1.6 million people are currently living with dementia. Their number is increasing every year. Urgent action is essential. To ensure people with dementia can lead a good life, changes need to be introduced in many different areas. In particular, social awareness of dementia and support for people with dementia and their families is crucial. Dementia-sensitive medical and long-term care services are crucial, as is excellent research into dementia to better understand its causes and improve therapeutic options. The Federal Government along with numerous partners from politics, society and research have, therefore, developed the National Dementia Strategy for Germany.

Dementia is a challenge for the whole of society. The National Dementia Strategy aims to significantly improve the circumstances of people with dementia and was cooperatively drawn up by 74 stakeholders from relevant fields, who will all jointly implement it. Changing society will require commitment at all levels: committed individuals, municipalities working to become dementia-friendly, a new focus for healthcare provision and new advances in science. A dementia-friendly society requires the concerted action of everyone concerned.

The National
Dementia Strategy
was developed
jointly with 74 stake-

#### Dementia facts and figures

#### Potential risk factors<sup>4</sup>

- Physical inactivity
- Smoking
- Imbalanced diet
- Alcohol consumption
- Low level of education

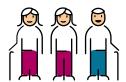
absolute number of

people with dementia

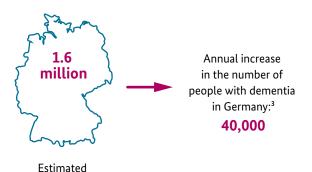
in Germany<sup>2</sup>

Social isolation

- Obesity
- High blood pressure
- Diabetes
- Depression
- Hearing impairment



Two thirds of older people with dementia are women and one third are men<sup>3</sup>





Globally, a new case of dementia is diagnosed every 3 seconds<sup>1</sup>

Approximately

2.8 million
people will be
affected in Germany
Prognosis for 2050<sup>2</sup>



- 1 Patterson C. 2018. World Alzheimer Report 2018 The state of the art of dementia research: New frontiers. London: Alzheimer's Disease International
- 2 Alzheimer Europe. 2019. Dementia in Europe Yearbook 2018. Comparison of national dementia strategies in Europe. Luxembourg: Alzheimer Europe
- 3 Bickel, Horst. 2020. Die Häufigkeit von Demenzerkrankungen, Informationsblatt 1. Berlin: Deutsche Alzheimer Gesellschaft e. V. Selbsthilfe Demenz
- 4 World Health Organization. 2019. Risk Reduction of Cognitive Decline and Dementia, WHO Guidelines. Geneva: World Health Organization

Since March 2020, the COVID-19 pandemic has had a major impact on the lives of people living with dementia. Social distancing and personal contact restrictions have often limited the support available to people with dementia and their families. The repercussions will continue to be felt for some time to come. Implementing the strategy is therefore, all the more important, with targeted support to improve the lives of those affected.

#### Development of the National Dementia Strategy

The National Dementia Strategy was developed under the co-ordination of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) and the Federal Ministry of Health (BMG) and with the significant participation of the Federal Ministry of Education and Research (BMBF). Other federal ministries and representatives of the federal states and local authorities were also involved. The German Alzheimer Society—Dementia Self-Help co-chaired the process. Representatives of civil society, social security agencies, health- and long-term care insurance providers, associations of health- and long-term care professionals, the leading non-governmental welfare organisations, professional and trade associations, and the scientific and research community were also involved in the collaboration. The strategy is nationwide in scope, anchored in partner-ship, binding in its goals and conceived for the long term. All the stakeholders are united in their shared objective to improve the circumstances of people with dementia and their families throughout Germany and to establish viable structures for the future.

The strategy is nationwide in scope, anchored in partnership, binding in its goals and conceived for the long term.



The National Dementia Strategy is to be implemented by 2026. The process of developing the strategy started in January 2019. Four key fields of action were agreed upon and each was addressed in working groups under the leadership of one federal ministry and one partner:

- Developing and establishing dementia-inclusive communities to enable people with dementia to participate in society (leadership: BMFSFJ and the German Association of Towns and Municipalities)
- Supporting people with dementia and their relatives (leadership: BMFSFJ and the German Alzheimer Society)

- Advancing health- and long-term care services for people with dementia (leadership: BMG and the Federal Association of Non-statutory Welfare)
- Promoting excellent research on dementia (leadership: BMBF and the German Centre for Neurodegenerative Diseases)

The starting point in the development of the strategy were the needs of people with dementia and their circumstances in life.

Within the four fields of action, 27 goals and 162 concrete measures were drawn up to be implemented between 2020 and 2026. The National Dementia Strategy was agreed upon by all stakeholders and adopted by the German government on 1 July 2020.





## Goals and measures of the National Dementia Strategy

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

Older people often wish to live in their familiar domestic environment for as long as possible—as do people with dementia. A dementia-sensitive environment is needed to achieve this. The ability to shape one's own life independently decreases as dementia progresses. Changes in behaviour can lead to lack of understanding and rejection by others. Improving public awareness and understanding of people with dementia in all areas of society relies on a broad knowledge of the condition. Those who are affected need individual and reliable help in order to carry on pursuing a self-determined, good life in old age and to be able to continue to participate in social life.

The stakeholders have, therefore, set themselves the goal of designing social spaces and mobility concepts for people with dementia, establishing and expanding networks, encouraging voluntary engagement and informal support for people with dementia, and raising awareness in the general public of the issue of people with dementia. The stakeholders also agreed to expand spiritual and religious services on offer, reduce dementia risks and draw up dementia-sensitive housing policies.

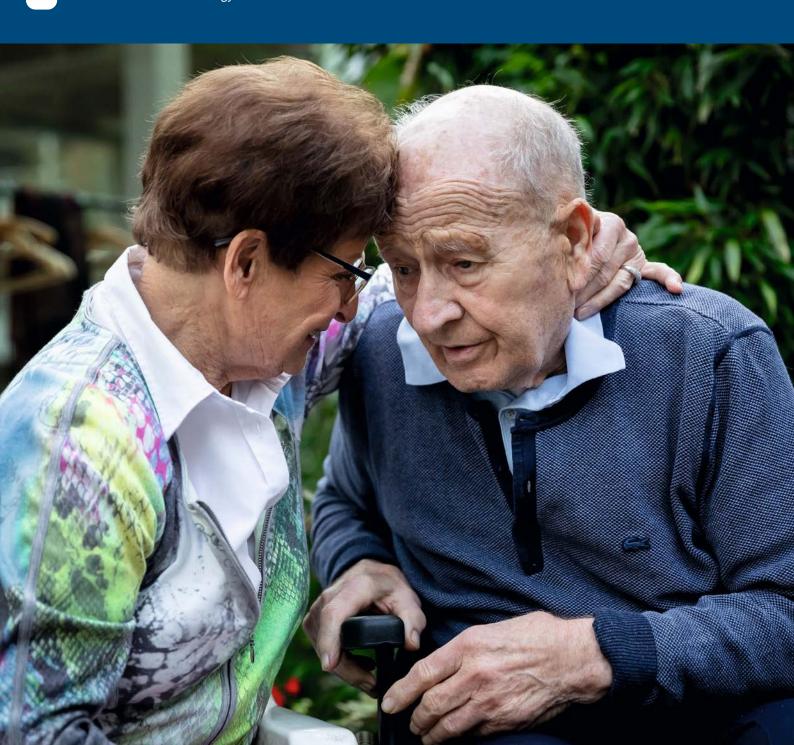
Improving public awareness and understanding of people with dementia relies on a broad knowledge of the condition.

## To achieve these goals, the following measures, among others, will be implemented over the coming years:

- The interests of people with dementia and their family carers will be targeted in residential area and village development concepts as well as in the local planning of care and support for older people.
- → Measures<sup>5</sup> 1.1.1, 1.1.2
- Local authorities will provide more dementia-sensitive public meeting places.
   Such participation involves increased accessibility of cultural, sports and educational facilities.
- → Measures 1.1.4, 1.1.5
- More public transport staff are to be trained to become 'Dementia Friends' and complementary mobility services should be extended.
- → Measures 1.2.1. 1.2.2
- Networks are to be fostered that provide effective local counselling, support and healthcare for people with dementia and their families. To achieve this, on the one hand, more money than hitherto is to be provided from long-term care insurance to foster regional networks, while on the other hand, 'Local Alliances for People with Dementia' are to be established and expanded nationwide.
- → Measures 1.3.2, 1.3.5

<sup>5</sup> The comprehensive formulation of these measures can be found in the long version of the National Dementia Strategy. It can be downloaded at www.nationale-demenzstrategie.de.

- Voluntary engagement and support for people with dementia is to be further strengthened. This will focus, in particular, on visiting and chaperoning services.
- → Measures 1.4.5, 1.4.6
- The Federal Government is launching a campaign to raise public awareness of dementia. Information and training courses to become 'Dementia Friends' within various occupational groups are intended to contribute towards establishing a dementia-friendly environment. Children and young people are also to be made more aware of the needs of people with dementia.
- → Measures 1.5.2, 1.5.3, 1.5.5
- The introduction of preventive home visits as a regular preventive measure is being considered.
- → Measure 1.7.2
- Housing counselling services and funding for adaptation of housing for older people will be expanded, as will funding for digital aids with a proven benefit.
- → Measures 1.8.1, 1.8.2, 1.8.3



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

Most people with dementia are cared for at home, primarily by relatives. The amount of care and support required for people with dementia varies from person to person and, in particular, is dependent on the stage and form of the condition. However, the cognitive changes that accompany dementia mean that care is generally more demanding and stressful than that of people who do not have dementia. Family care-givers require information about the clinical situation and about counselling and support options in order to cope well with everyday life and care.

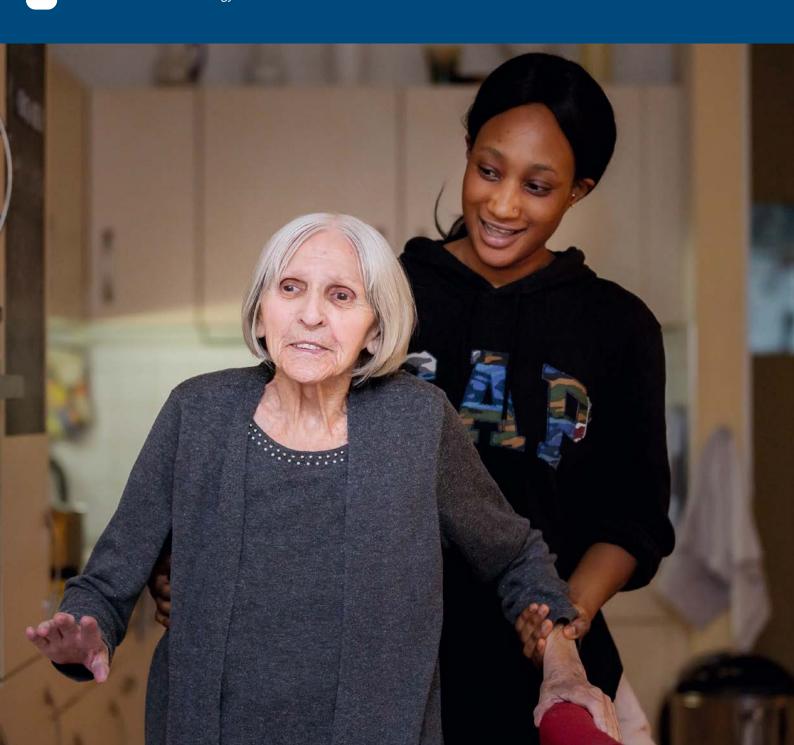
The stakeholders have, therefore, set themselves the goal of improving counselling and support for people with dementia and their relatives. They also agreed to expand counselling and support services for people in employment who have dementia, to develop culturally sensitive counselling services and to increase the uptake of training on care and dementia by relatives. They also agreed that reconciling care and work should be made easier for women and men and that people with dementia and their families should be supported in coping with family conflicts. Preventive and rehabilitative services for relatives are to be established and expanded. Relatives who provide end-of-life care for people with dementia should receive appropriate support.

Family care-givers of people with dementia require comprehensive advice and support.

## To achieve these goals, the following measures, among others, will be implemented over the coming years:

- An assessment is to be carried out as to whether dementia patients can be provided with dementia support directly after being diagnosed with it and whether this can be regulated in line with SGB XI.
- → Measure 2.1.1
- People with dementia, especially those living alone, should receive lowthreshold initial counselling and support by volunteers after being diagnosed with dementia.
- → Measure 2.1.4
- Low-threshold information services as well as comprehensive and highquality counselling services for people with dementia will be made available and expanded. The focus, in particular, is on people with early-onset dementia, people with a mogration background and relatives living at a distance. Networking of the relevant parties will be fostered.
- → Measures 2.1.5, 2.1.6, 2.1.7, 2.3.1, 2.3.3, 2.4.1 and others
- It is being considered whether courses on long-term care might be recognised as advanced education qualifications.
- → Measure 2.5.4
- Local networks to address the issue of long-term care and employment should be established and expanded. These will be targeted at helping family care-givers of people with dementia to reconcile work and care. In addition, employers are to be made more aware of the issues of family care-givers.
- → Measures 2.6.2, 2.6.3, 2.6.4

- Flexible support services will be provided for people with dementia via day care or partial in-patient care services.
- → Measure 2.6.5
- Opportunities for prevention, health promotion and rehabilitation for family care-givers will be expanded. These will include special telephone counselling and psychosocial counselling in family crisis situations as well as special prevention programmes for family care-givers, including health cures and preventive healthcare measures.
- → Measures 2.7.1, 2.8.1, 2.8.5 and others
- Information on hospice and palliative health services is to be improved, and cooperative structures in hospice and palliative care, expanded. In addition, voluntary work in hospice and palliative care will be strengthened.
- → Measures 2.9.1, 2.9.3, 2.9.4 and others



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

People with dementia require medical and nursing care that is tailored to their individual health-related needs. This requires not only the expansion of appropriate services and adequate staffing, but also a low-threshold structure that facilitates access for those affected and their families. A functioning network of services is also of central importance. Hence, efficient cooperation between stakeholders providing cross-sectoral health services for people with dementia is a central objective of the National Dementia Strategy.

The stakeholders have, therefore, set themselves the goals of promoting out-patient, partial in-patient and short-term care for people with dementia, strengthening dementiasensitive design and organisation of fully residential care facilities, expanding dementiasensitive healthcare in hospitals and improving healthcare provision for people with dementia. In addition, cooperation in the health services network is to be fostered, and preventive and rehabilitative services for people with dementia expanded.

People with dementia need individually adapted long-term care and healthcare provision.

## To achieve these goals, the following measures, among others, will be implemented over the coming years:

- The Federal Government will examine whether residential long-term care facilities are adequately staffed to provide appropriate care for people with dementia.
- → Measure 3.2.1
- Dementia-specific advanced training and continued education for nursing staff in the various health services sectors will be promoted.
- → Measures 3.1.9, 3.1.12, 3.2.2, 3.2.7, 3.3.6
- Foundational qualifications will be offered for all occupational groups involved in the provision of healthcare for people with dementia whose training did not provide appropriate dementia-specific content.
- → Measures 3.1.13, 3.2.8, 3.3.7
- Long-term care facilities will be designed to more specifically meet the needs
  of people with dementia. This will incorporate architecture and the facilities
  of long-term care homes as well as work organisation in long-term care.
- → Measure 3.2.10
- Validated screening procedures for dementia and delirium in hospitals will be implemented and conducted by trained personnel.
- → Measure 3.3.3

- A health services pathway will be developed to improve collaboration in accompanying, counselling, treating and caring for people with dementia.
- → Measure 3.5.3
- An assessment will be conducted as to whether and how preventive services for people with dementia can be strengthened.
- → Measure 3.6.5
- In all health services sectors, the impact of regulatory frameworks on the care of people with dementia is to be reviewed, and, if necessary, further developed.
- → Measures 3.1.3, 3.1.7, 3.1.14, 3.2.5, 3.3.1, 3.5.2 and others



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

Comprehensive research into dementia is important for the understanding of the development of demential diseases and identifying the potential for prevention, diagnosis, therapy and rehabilitation. The Federal Ministry of Education and Research is, therefore, contributing significantly to the measures in field of action 4. In addition, the findings from the latest research should be made available to people with dementia, their families and the general public.

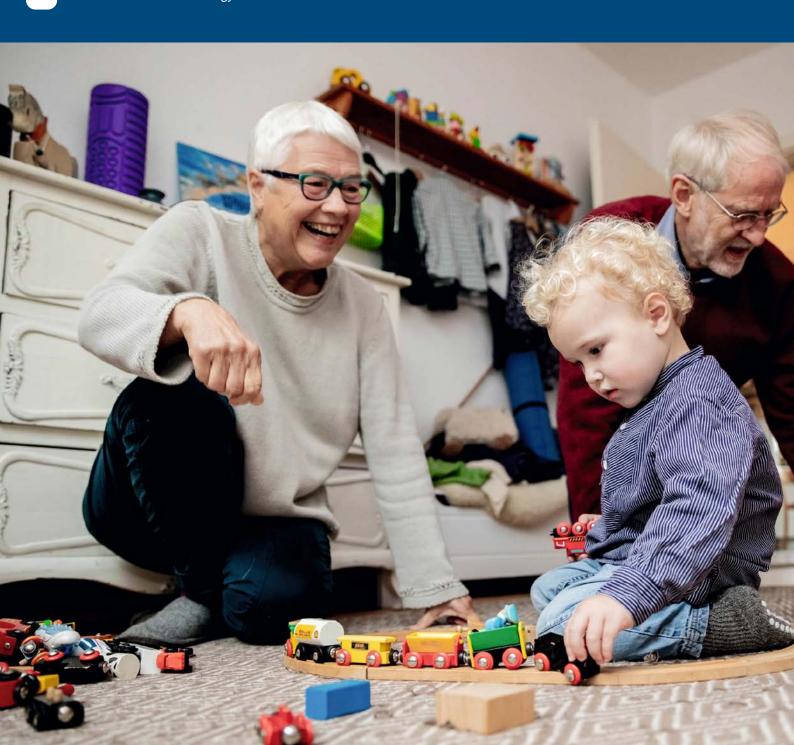
The stakeholders have, thus, set themselves the goal of strengthening national and international infrastructure in dementia research, promoting research into the prevention and treatment of dementia, supporting health services research in dementia and improving participation in dementia research.

Outstanding dementia research in the areas of prevention, therapy and healthcare provision is to be expanded.

## To achieve these goals, the following measures, among others, will be implemented over the coming years:

- Research institutions in Germany will cooperate more closely and undertake more studies on the prevention, diagnosis and treatment of dementia.
- → Measure 4.1.1
- A national network is being established to pool resources and expertise in dementia health services research.
- → Measure 4.1.2
- Researchers will be provided with improved access to anonymised data from the healthcare insurance system, which are relevant for research on dementia.
- → Measure 4.1.4
- Scientific research and cooperation on dementia at a European level will be supported.
- → Measure 4.1.5
- Dementia risk factors will be included in existing long-term health studies in Germany to establish a better basis for research into such factors.
- → Measure 4.2.3
- More studies are to be conducted during the early stages of dementia to investigate whether and how the course of dementia can be positively influenced.
- → Measure 4.2.4
- More strategies for diagnosis, treatment and healthcare provision are to be developed and tested for their effectiveness.
- → Measure 4.3.1

- Research projects that investigate the transfer of scientific findings into clinical practice are to be launched.
- → Measure 4.3.3
- The potential for accelerated authorisation procedures for drugs in the field of dementia is to be exploited more effectively.
- → Measure 4.3.4
- The circumstances of family care-givers of people with dementia are to be examined. Special emphasis will be placed on support services.
- → Measure 4.3.8
- Research on the interconnected ways people with dementia experience the world will be funded.
- → Measure 4.3.11



# Implementation and monitoring of the National Dementia Strategy

In the National Dementia Strategy, 162 concrete measures were agreed upon to improve the living circumstances of people with dementia and their families. All stakeholders are responsible for implementing the measures they have committed to over the coming years. Each measure will be assessed on the basis of a benchmark and an evaluation date.

Implementation of the strategy is to be monitored by a steering group under the leadership of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Health.

The Secretariat of the National Dementia Strategy will be responsible for monitoring and submitting an annual report to the steering group.

The aim is to take stock after 2026 and further refine the strategy.



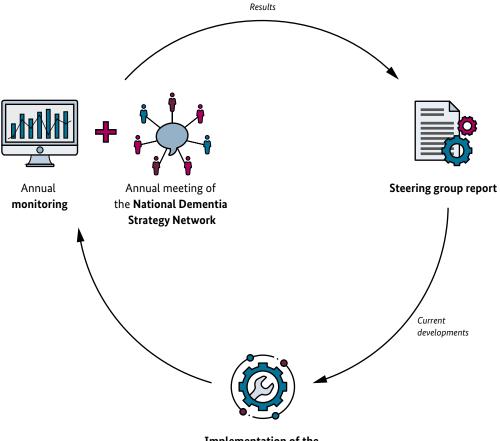
## National Dementia Strategy Network

Implementing the National Dementia Strategy effectively calls for close cooperation between all its stakeholders. They offer differing approaches, opportunities and expertise to support people with dementia and their families. Networking and collaboration can also help to transcend challenges involving the participation of more than one stakeholder. As a result, cooperation is actively encouraged during the implementation phase.

The National Dementia Strategy Network is expected to expand in the coming years. We invite all partners who are engaged in supporting people with dementia throughout Germany to participate in the network.

Networking and cooperation between the stakeholders are a prerequisite for successful implementation.

### Implementation process



Implementation of the National Dementia Strategy 2020–2026

## Stakeholders involved in the National Dementia Strategy

- · Aktion Demenz e. V. [Dementia Action Campaign]
- Action Group for the Mentally Ill
- Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e.V. [Association of Scientific Medical Expert Societies]
- BAGSO—Bundesarbeitsgemeinschaft der Seniorenorganisationen e.V. [German National Association of Senior Citizens' Organisations]
- Networking Centre of the Local Alliances for People with Dementia of the BMFSFJ
- Bavarian State Ministry of Health and Care (Bavarian Dementia Strategy)
- Beirat f
  ür die Vereinbarkeit von Beruf und Pflege
  [Advisory Board on the Compatibility of Work and Care]
- Federal Association of Non-statutory Welfare
- Bundesarbeitsgemeinschaft der Integrationsämter und Hauptfürsorgestellen [Federal Association of Integration Offices and Central Welfare Offices]
- Bundesarbeitsgemeinschaft Familienerholung [Federal Association for Family Holidays]
- Bundesarbeitsgemeinschaft Selbsthilfe von Menschen mit Behinderung, chronischer Erkrankung und ihren Angehörigen e. V. [Federal Association of Self-help Organisations of People with Disabilities and Chronically Ill People and their Relatives]
- Bundesarbeitsgemeinschaft Spezialisierte Ambulante Palliativversorgung [Federal Working Group on Specialised Ambulatory Palliative Health Services]
- German Medical Association
- Federal Institute for Drugs and Medical Devices
- Federal Ministry of Justice and Consumer Protection

- The Federal Ministry of the Interior, Building and Community
- The Federal Ministry of Labour and Social Affairs
- The Federal Ministry of Education and Research
- The Federal Ministry of Food and Agriculture
- The Federal Ministry for Family Affairs, Senior Citizens, Women and Youth
- The Federal Ministry of Health
- The Federal Ministry of Transport and Digital Infrastructure
- Bundesverband privater Anbieter sozialer Dienste e.V.
   [Federal Association of Private Providers of Social Services]
- The Federal Centre for Health Education
- Dementia Support Stuttgart
- Der Pflegebevollmächtigte der Bundesregierung
   [The Federal Government Plenipotentiary for Long-Term Care]
- The German Alzheimer Society—Dementia Self-Help
- The German Episcopal Conference
- Deutsche Expertengruppe Dementenbetreuung e.V. [German Expert Group on Dementia Care]
- The German Television Lottery
- The German College of General Practitioners and Family Physicians
- The German Society of Geriatrics
- The German Society of Gerontology and Geriatrics
- The German Society for Gerontopsychiatry and Psychotherapy
- The German Society of Neurology
- The German Association for Palliative Medicine
- The German Society for Nursing Science
- The German Association for Psychiatry, Psychotherapy and Psychosomatics
- The German Hospital Federation
- The German Sport University Cologne
- The German Association for Rehabilitation
- The German Disability Council
- The German Home Economics Council
- The German Hospice and Palliative Association
- The German Cultural Council
- The German Nursing Council

- The German Association for Public and Private Welfare
- The German Centre of Gerontology
- The German Centre for Neurodegenerative Diseases
- The Evangelical Church in Germany
- The National Association of Statutory Health Insurance Funds
- The Institute of Social Medicine, Occupational Medicine and Public Health, University of Leipzig
- The National Association of Statutory Health Insurance Physicians
- The Catholic Church in Germany
- The local authority associations (the Association of German Cities, the German County Association, the German Association of Towns and Municipalities)
- The Foundation for the Care of of Older People
- The Federal States (Conference of Ministers for Labour and Social Affairs, Conference of Health Ministers, Conference of the Ministers of Education and Cultural Affairs)
- Malteser Germany
- The Ministry of Social Affairs, Labour, Health and Demography of Rhineland-Palatinate (Dementia Strategy Rhineland-Palatinate)
- The Ministry of Social Affairs, Health, Youth, Family and Senior Citizens of Schleswig-Holstein (Dementia Strategy Schleswig-Holstein)
- The Ministry of Social Affairs, Health, Women and Family (Dementia Strategy Saarland)
- The Paul Ehrlich Institute
- Prof. Dr Adelheid Kuhlmey
- The Robert Bosch Foundation
- The Robert Koch Institute
- Spitzenverband ZNS [Central CNS Association]
- The Public Health Foundation
- The Turkish-Islamic Union for Religious Affairs
- The University of Cologne
- The Association of Private Health Insurance
- Verband Deutscher Alten- und Behindertenhilfe e.V.
   [Association of German Assistance for the Elderly and Disabled]
- The Centre for Quality in Care

## Further information

### Further information on the National Dementia Strategy:

The Secretariat of the National Dementia Strategy
The German Centre of Gerontology
Manfred-von-Richthofen-Str. 2
12101 Berlin

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www.nationale-demenzstrategie.de

#### Telephone advice line on nursing care and dementia

Care-line of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth:

+49 30 201 791 31 (Monday to Thursday, 9 a.m. - 6 p.m.)

#### The Federal Ministry of Health citizens' nursing care hotline:

+49 30 340 606 602 (Monday to Thursday, 8 a.m.-6 p.m., Friday, 8 a.m.-12 a.m.)

#### Alzheimer advice line of the German Alzheimer Society— Dementia Self-Help:

+49 30 259 379 514 (Monday to Thursday, 8 a.m.-6 p.m., Friday, 8 a.m.-3 p.m.)

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Commitment Family Older Persons Equality Children and Youth