

Dementia strategy

Living well with dementia



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Executive Summary (german)

Die für Österreich entwickelte Demenzstrategie „Gut leben mit Demenz“ soll einen **Rahmen von partizipativ und konsensuell erarbeiteten Wirkungszielen bilden, deren Erreichen die Lebenssituation von Menschen mit Demenz verbessert**. In Folge und auch durch die entsprechende Anerkennung und Wertschätzung der Arbeit ihrer An- und Zugehörigen soll auch deren Lebenssituation verbessert werden.

Daher wurden Wirkungsziele (WZ) und Handlungsempfehlungen (HE) mit Betroffenen, Entscheidungsträgern/Entscheidungsträgerinnen und Umsetzern/Umsetzerinnen und Experten/ Expertinnen in einem Prozess gemeinsam entwickelt. Arbeitsgruppen diskutierten in 18 Sitzungen Maßnahmen und Vorschläge, die auf unterschiedlichen Ebenen umgesetzt werden können.

Die präzisierten Handlungsempfehlungen ermöglichen den Entscheidungsträgern/-trägerinnen (auf den Ebenen Bund, Länder und Gemeinden) in ihren jeweiligen Wirkungsbereichen konkrete Maßnahmen zu planen und umzusetzen, um so gemeinsam die definierten Wirkungsziele zu erreichen.

Was soll die Demenzstrategie bewirken?

Für Menschen mit demenziellen Beeinträchtigungen:

In einem Lebensumfeld wohnen zu können, das Teilhabe sicherstellt und weitest gehende Selbstbestimmung fördert	HE 1b, 1c, 1d
Über Unterstützungsangebote Bescheid zu wissen und diese auch nutzen zu können	HE 2d, 2e
Darauf vertrauen zu können, von optimal geschulten und qualifizierten Menschen professionell betreut und unterstützt zu werden	HE 3a
Bestmögliche mobile, teilstationäre und stationäre Betreuungsformen vorzufinden, die eine integrierte Versorgung flächendeckend ermöglichen und aus einer Vielfalt von Angeboten wählen zu können	HE 5a
Im Krankenhaus darauf vertrauen zu können, dass auf die eigenen Bedürfnisse (im Zusammenhang mit Demenz) eingegangen wird	HE 5b
Flächendeckend und wohnortnah niederschwellige Anlaufstellen zur Information, Beratung, Früherkennung, Diagnose und Begleitung vorzufinden,	HE 6a

in denen multiprofessionelle Teams gemeinsam mit den Menschen individuelle Maßnahmen planen und notwendige Leistungen koordinieren

Für An- und Zugehörige:

In einem Lebensumfeld wohnen zu können, das Unterstützung und Betreuung von Angehörigen mit Demenz möglich und leichter macht

HE
1b, 1c,
1d

Über Unterstützungsangebote Bescheid zu wissen

HE
2d, 2e

Ausreichend zur Unterstützung und Betreuung von Angehörigen mit Demenz geschult, beraten und unterstützt zu werden

HE 3b

Aus einer Vielfalt von Angeboten für den Angehörigen mit Demenz wählen zu können, um so in der Betreuung unterstützt zu werden

HE 5a

Flächendeckend und wohnortnah niederschwellige Anlaufstellen zur Information, Beratung, Früherkennung, Diagnose und Begleitung vorzufinden, in denen multiprofessionelle Teams gemeinsam mit den Menschen individuelle Maßnahmen planen und notwendige Leistungen koordinieren

HE 6a

Für die Bevölkerung:

Mehr Bewusstsein für die Bedürfnisse von Menschen mit Demenz zu entwickeln und in einem Gemeinwesen zu leben, in dem Teilhabe von allen gelebte Wirklichkeit ist

HE 1a

Informationen zum Thema Demenz zu erhalten, die die Angst vor der Krankheit nehmen und den Umgang damit erleichtern

HE
2a, 2b

Sensibilität für einen positiven Zugang zur Krankheit Demenz zu entwickeln

HE 2f

Für spezifische Berufsgruppen, z. B. für kommunale Dienstleister, Behörden, Exekutive, Einsatzorganisationen oder Apotheken:

Spezifische Informationen zur jeweils eigenen (beruflichen) Tätigkeit zu erhalten, um Menschen mit Demenz besser zu verstehen und auf ihre Bedürfnisse eingehen zu können

HE 2c

Für Gesundheits- und Sozialberufe und Anbieter/innen von Gesundheits- und sozialen Dienstleistungen:

Ausreichend im Umgang mit Menschen mit Demenz geschult zu sein und sich laufend aus- und weiterbilden zu können

HE 3a

Im Weiterentwickeln der Angebote auf ausreichende und qualitätsgesicherte Daten und Forschungsergebnisse zugreifen zu können

HE 7a,
7b, 7c

Für (politische) Entscheidungsträger/-trägerinnen:

In einem laufenden Austausch mit Experten/Expertinnen und anderen Entscheidungsträgern/Entscheidungsträgerinnen zu stehen, um auf Bundes und Landesebene aufeinander abgestimmte Strukturen und Rahmenbedingungen für Menschen mit Demenz schaffen und weiterentwickeln zu können

HE 4a,
4b, 4c,
7a, 7b,
7c

Executive Summary (English)

The Austrian dementia strategy **Living well with dementia** provides a framework of objectives and recommendations for taking action to improve the lives of people with dementia as well as their families and friends.

In six working groups, persons with dementia, (political) decision makers as well as experts developed objectives and recommendations for action. The work process took place between March and October 2015 and comprised 18 workshops (three per working group). Results were presented in a report which underwent a comprehensive online consultation process. About 600 responses from all relevant stakeholders contributed to the further development of the strategy.

The dementia strategy concerns:

- people with dementia;
- informal and formal carers;
- health care and social care professionals and service providers;
- the public;
- and (political) decision makers at national and regional levels.

Objectives and recommendations

The strategy aims to create a system in which people affected by dementia and their families and friends

- live in a community that promotes participation and autonomy to the greatest possible extent;
- get the information they need as early as possible;
- know where to go for help and which services are available;
- get high-quality care irrespectively of their place of residence;
- and are actively involved in decisions about their care.

The strategy intends to assist everyone in the community to develop a better understanding of dementia and to break down the stigma attached to it.

Another key message of the strategy is the need for better education and training of professionals.

The success of the strategy will depend on the commitment of (political (decision) makers as well as service providers to work together to coordinate and provide (specific) services tailored to the needs of people with dementia and their caregivers.

The Austrian dementia strategy lists seven objectives:

Objectives	Outcomes and recommendations
<p>1. Promote participation and self-determination/independence for people with dementia and their caregivers</p>	<p>The public and professionals should become more aware of dementia and should better understand dementia, which can be achieved by</p> <ul style="list-style-type: none"> – removing the stigma of dementia – creating a dementia-sensitive living environment (e.g. check-list for communities, improving technology and closer-to-home services), <p>People with dementia should be able to participate in social and community life, which can be achieved by</p> <ul style="list-style-type: none"> – improving community support services, – improving and promoting self-determination by supporting self-help groups and support networks in the community, by involving people with dementia in planning their care (advance care planning) and by ensuring legal representation - if necessary, – involving people with dementia in applied research.
<p>2. Ensure high-quality knowledge of and raise awareness of dementia in the public but also in special target groups</p>	<p>People with dementia, their families and caregivers and the public should have access to good-quality information on dementia and relevant services through</p> <ul style="list-style-type: none"> – broad information and media campaigns, – supplementary information for special target groups, – easily accessible information on diagnosis and care services, – the development of a code of good practice for media information.

- 3. Improve the knowledge, skills and expertise of formal and informal caregivers**

All health care and social care staff as well as informal caregivers should acquire the necessary skills to give the best care to people with dementia. This can be achieved by

 - providing the appropriate training and
 - supporting the caregivers to keep on learning about dementia.
- 4. Create consistent framework conditions for coordinated care**

(Political) decision makers as well as health care and social care service providers should cooperate in developing systems of coordinated services, by

 - establishing cooperation between the health and the social sectors at national and regional levels,
 - developing quality standards,
 - creating a platform for all stakeholders to plan and work together in a coordinated way.
- 5. Ensure and improve health care and social care services**

All people with dementia should have access to the support and care they need. This can be achieved by

 - ensuring integrated care by multi-professional teams on a local basis with treatment, care, and support as needed after the diagnosis, especially mobile support services for people living at home, intermediate care, and residents with dementia in nursing homes,
 - improving the quality of care for people with dementia in general hospitals.
- 6. Improve cooperation and coordination between different care services**

All people with dementia and their families should have access to closer-to-home contact points and drop-in centres where multi-professional teams give information, provide services for early diagnosis and support, and coordinate care according to the specific needs of the person affected.
- 7. Improve and ensure quality of care by research on dementia**

A clear picture of the research on the causes of dementia and the needs of people with dementia will be provided by

 - communicating the recent state of research on dementia,
 - identifying the gaps in information and data,
 - undertaking coordinated research to close the gaps, and
 - disseminating the findings to (political) decision makers, the public and people with dementia.

Demographic change and the related increase in the prevalence of dementia as well as the rising cost of providing support and care led the Austrian government to include the development of a dementia strategy in its current programme for 2013-2018. Alongside the people receiving care, it also focuses on their families and friends.

Introduction

Gesundheit Österreich GmbH (Austrian Health Institute) was commissioned to accompany the process of drawing up an Austrian dementia strategy. This was launched with an opening event in February 2015 at which important stakeholders with a decisive influence on the realisation of the strategy were represented in the plenary. Within the framework of this plenary, six working groups were formed which in the period from March to October 2015 drew up objectives and recommendations for action. This paper presents the results from a total of 18 workshops involving the working groups.

Goals of the Austrian dementia strategy

The dementia strategy is intended to form a **joint orientation framework** for **targeted cooperation** between the stakeholders. The federal government, local authorities and the social insurance system as well as numerous institutions and organisations have already taken measures to promote health, prevent dementia and care for those who are suffering from it. If this commitment is orientated towards a dementia strategy which has been jointly drawn up by stakeholders from all areas of policy, funding and efforts can be pooled.

The objectives and recommendations for action form a **joint basis** for the specification of goals and measures by the organisations involved. In subsequent processes, the respective parties should stipulate further steps to specify the goals and their implementation.

The issue of dementia **cannot be fully covered** in the recommendations for action which have been drawn up, but the recommendations do illustrate the **key areas where there is the greatest need for action** in the field of dementia care.

Principles for drawing up objectives and recommendations for action

The working groups develop objectives and recommendations for action on the basis of the following principles:

- The needs of the affected persons and their family members are the main focus
 - taking particular notice of the varying needs of different social groups
 - and the inequality of access to offers of help (for minorities, the homeless, people with migrant backgrounds, people with disabilities...)
- Resource orientation, e.g. the strengths and potential of people with dementia-related impairments as well as those of their family and friends, is the crux of measures
- Health promotion measures are meaningful at all ages and for every degree of impairment
- The promotion of equal opportunities – i.e. the reduction of health- and socially related inequality should be taken into account throughout the strategy
- The inclusion of and openness towards people suffering from dementia-related impairments
- Outcome orientation and relevance; e.g. evidence of the meaningfulness and relevance of goals and recommendations using data and facts
- Practicability – in other words recommendations for action which appear realistic with regard to their actual feasibility under the given conditions
- Taking into account and using existing structures as a basis, thus avoiding the creation of parallel structures.

Prevention

The topic of the prevention of dementia has been left aside for the time being. The latest research findings will – as soon as they are available – be included in the implementation of the dementia strategy.

Main focuses

Overall, seven objectives and 21 recommendations for action were drawn up in the working groups.

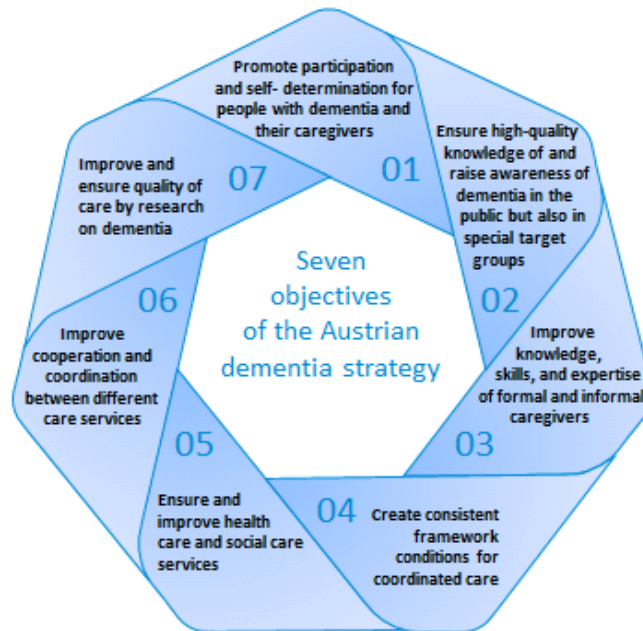


Abbildung 1: 7 objectives of the Austrian dementia strategy

7 objectives of the Austrian dementia strategy

01 Ensuring the participation and self-determination of those affected

02 Extending the provision of information in a broad and target-specific way

03 Strengthening knowledge and competence

04 Creating standard framework conditions

05 Designing and ensuring the provision of care offers suited to people with dementia

06 Extending coordination and cooperation which is focused on those affected

07 Quality assurance and quality improvement via research

The focus is on people with dementia-related impairments and their families and friends: the goal is to ensure that in spite of the existing impairments the participation of these people in social processes is guaranteed as far as possible. One of the ways in which this can be achieved is by breaking down fears and prejudices in society. As the UN Convention on the Rights of Persons with Disabilities describes, disabilities arise from the interaction between people with disabilities and barriers in the form of attitudes and the physical environment

These barriers can act as obstacles towards full, effective and equal participation in society. The breaking down of such barriers also forms one of the goals of the dementia strategy.

The realisation of the recommendations for action in the strategy has advantages for all sectors of the population: appreciation and respect for other individuals forms the basis for a coexistence based on understanding which is independent of disabilities, age or illness.

Definitions of terms

Dementia – people with dementia-related impairments

In this report, dementia is understood as a condition which involves health impairments as well as social disadvantages and is therefore more than just an illness or medical diagnosis. We will therefore use the term *people with dementia-related impairments* here rather than *dementia sufferers*. For reasons of readability, however, the term **people with dementia** will be used at some points.

Family members and friends

Other persons addressed by the dementia strategy are family members, friends and neighbours as well as other people who are important to the person with dementia-related impairments. For reasons of readability, these people are referred to here as **family and friends**.

Orientation towards resources and needs through multi-professional teams.

The plan is for people with dementia-related impairments as well as their families and friends to receive support and help according to their needs. Everyone has specific individual resources and potential which should be taken into account and promoted. Not least, the respective social environment should be taken into account, as it constitutes a highly relevant factor for the individual person.

Resources- and needs orientation includes coordinated support, care and help. The individual situation of the person involved is decisive for the selection of the professional group deployed. In order to give sufficient attention to this aspect, we use the term **multi-professional teams** here to describe all of the necessary occupational groups.

Overview of the objectives and recommendations for action

“People have to be encouraged to believe that getting old can also be wonderful. [...] I also wrote down that one has to have the courage to be out of the ordinary. You can be different without dementia too, but it’s easier with it. And I think that’s not bad at all. Being out of the ordinary also means leaving your own prison a bit. People should be made aware of the fact that being out of the ordinary can also be viewed positively.”

(interview with a person with dementia-related impairments as part of the consultation process for the dementia strategy)

Objective 1 – Ensuring the participation and self-determination of those affected

- Recommendation for action 1a – Taking measures to promote increased awareness
- Recommendation for action 1b – Ensuring participation in the communities where those affected live
- Recommendation for action 1c – Enabling the self-determination of the people affected
- Recommendation for action 1d: Participatory science – the realisation of research with the involvement of all those affected

Recommendation for action 2 – Extending the provision of information in a broad and target group-specific way

- Recommendation for action 2a – Development of comprehensive information and communication concepts
- Recommendation for action 2b – Broadly-based public relations work and (media) campaigns
- Recommendation for action 2c – Target group-specific information
- Recommendation for action 2d – Low-threshold information offers
- Recommendation for action 2e – Web-based information and offers
- Recommendation for action 2f – Development of a code of good practice for media reporting

Objective 3 – Strengthening knowledge and competence

- Recommendation for action 3a – Raising awareness and the development of competences and skills training for medical and non-medical personnel in facilities of the health care and social systems
- Recommendation for action 3b – Strengthening of expertise for families and friends

Objective 4 – Uniform design of the framework conditions

- Recommendation for action 4a – Creation of coordinated and integrated care for people with dementia and a cross-sectoral structure through cooperation between the system partners in the health and social sectors
- Recommendation for action 4b – Development of quality standards in the fields of health, social affairs, care and support
- Recommendation for action 4c – Establishment of a Dementia Strategy Platform

Objective 5 – The design and guarantee of suitable dementia care offers

- Recommendation for action 5a – The best possible long-term care for people with dementia
- Recommendation for action 5b – Adaptation of the structures, processes and environmental factors in hospitals to the needs of people with dementia

Objective 6 – The extension of coordination and cooperation focused on those affected

- Recommendation for action 6a – The nationwide expansion and integration into existing systems of low-threshold contact points for people with dementia and their families and friends. The contact points act regionally, and if necessary visit people on the basis of a coordinated concept

Objective 7 – Quality assurance and quality improvement through research

- Recommendation for action 7a – Development of a nationwide data pool on epidemiology and care offers, an evidence base for care offers related to people with dementia, and the evaluation of existing offers as a basis for the further development of the structure of offers
- Recommendation for action 7b – Development of a national research agenda for the care of people with dementia
- Recommendation for action 7c – Research findings should be communicated to all relevant target groups and be reflected on and considered in society, politics and professional practice

Objective 1 – Ensuring the participation and self-determination of those affected

Two factors enable people with dementia and their families and friends to participate in the life of society: structuring the living environment in a way which is sensitive to dementia, but also appreciation and self-determination. In this way, an important contribution is made towards a greater quality of life for those affected.

Explanation and challenges

Challenges

People with dementia-related impairments are frequently excluded from the life of society. This can also result in their families and friends suffering from social isolation. The opportunity to be outside and move around in a familiar environment is of great significance for the quality of life of people with dementia-related impairments.

The fundamental human need to experience respect does not end in old age, nor due to health impairments, and is a key element of quality of life.

A further challenge lies in weighing up the greatest possible self-determination of people with dementia-related impairments against the possibility that they might endanger themselves. Designing living environments in a way which is sensitive to dementia is thus an important precondition for a considerable degree of self-determination.

The needs of family and friends and their ideas regarding the quality of life do not always coincide with the needs of people with dementia-related impairments. The resulting conflicts are not always recognised or spoken about, but should always be taken into account.

The desired effects

Above all, living well with dementia means participation in society and appreciation for those affected. It means enabling people with dementia-related impairments and their families and friends to articulate their own wishes and needs and to make them visible. This too must be reflected in research practices.

Supporting people with dementia-related impairments, the recognition of their resources and abilities, and their participation in public life are important tasks for society as a whole. The living conditions of people with dementia-related impairments should – particularly through dialogue in civil society – be improved and stigmatisation counteracted.

The different requirements and needs of differing ways of life should be recognised and facilitated. The general conditions prevalent in society should be structured in such a way that a self-determined life is enabled. This can be achieved via the realisation of dementia-friendly communities/local authorities: This means a community in which those affected and their families can live well and where participation in the life of the community is a reality. Real improvements can only succeed when forms of the joint assumption of responsibility are developed and lived.

Ideas of an affected person on the successful realisation of the strategy:

“I live a happy and active life wherever I want, and dementia does not stress me and my friends.” -

“I’m ok: I forget and am not alone; I live with dementia in public; I am seen and heard”.

(Dementia strategy working group)

Recommendations for action<0}

Recommendation for action 1a – Increasing awareness and taking measures to this end

Living spaces should be designed in such a way that all people are able to participate in the life of society and to exercise their rights. To this end, it is necessary first of all to raise awareness in all sectors of society in order to achieve quality of life and resource orientation, and to make the public receptive towards the need for respectful and caring coexistence.

At a **community and local authority level**, measures to increase awareness and provide information should be taken which promote the design of dementia-sensitive living environments (e.g. people with dementia-related impairments are active members of sports and singing clubs; going to the hairdresser's/barber's and to pubs and restaurants are a normal occurrence; nursery schools and schools are places of intergenerational exchange).

In communities and local authorities, members of the public and political decision-makers as well as other local actors will – to some extent – have to reinvent their areas of activity: for example via supporting structures, awareness raising and information work with targeted campaigns and events, opportunities for encounters in everyday life, exchanges between the generations and professions, neighbourly help and civic engagement.

National information campaigns as well as target group-specific information support these awareness-raising efforts (see recommendations for action 2b and 2c).

Target groups:

- The entire population as well as specific target groups in the environment in which those affected live.

Levels of realisation:

- Local authorities, local community networks
- Provincial government level (health care, social affairs and social insurance)
- The competent ministries
- Occupational and political interest groups
- Self-help groups

Recommendation for action 1b – Ensuring participation in the communities where those affected live

During the entire course of dementia, the residential environment – in an institutional (i.e. in the field of nursing homes and assisted living) or domestic context – plays an important role for those affected. The goal is the needs-oriented design of a person's living situation by means of the inclusion of those affected and their families and friends.

Designing the community environment in a dementia-sensitive way means (in villages/local authority areas, in urban districts) the creation of opportunities to increase the well-being of people with dementia-related impairments. Mobility and activity are key health

factors for those affected. Remaining in one's own home and in familiar surroundings has positive cognitive, physical and emotional effects. Outdoor activities increase the self-esteem and independence of people with dementia-related impairments; this is also true for those in nursing homes or other facilities. A dementia-sensitive environment includes the larger part of a community: clearly demarcated pavements with dropped kerbs, visible points of reference or landmarks such as churches, a bakery or post office. Inclusion is connected to a large number of social aspects – the aim is to raise the awareness of society as a whole, because a dementia-friendly environment is pleasant for everyone.

This development is to be supported by the **creation of checklists** which specify how people's living environment (whether it is at home or in a nursing home, etc.) can be designed in a dementia-sensitive way, and also via **information/training events** for mayors and local councillors (e.g. in the context of seminars for mayors sponsored by the Healthy Austrian Fund) as well as for people who run nursing homes or assisted living schemes.

Participation improves with **structures which facilitate more social involvement in local communities**. This refers to aspects of urban and rural planning, traffic and transport and mobility planning, the construction of accessible social housing, and the establishment of dementia-sensitive facilities and businesses such as the local council office, pharmacies etc.

Technologies which support the autonomy of those affected should be offered and further developed accordingly.

Target groups:

- People with dementia-related impairments, their families and friends

Levels of realisation:

- Local authority areas, towns and cities
- With the involvement of
 - Urban planners and landscapers, builders of residential housing, architects, political decision-makers in urban districts
 - Provinces (health care and social affairs) and the social insurance system
 - Occupational and political interest groups (e.g. Chamber of Pharmacies, Economic Chamber)
 - Police, ambulance, fire service and public transport providers
 - NGOs, volunteers and the general public in local authority areas or urban districts

Recommendation for action 1c – Enabling the self-determination of the people affected

Strengthening self-help groups and the creation of opportunities for encounters (e.g. making venues available for meetings organised by the participants themselves) can encourage the participation of people with dementia-related impairments, and support their self-advocacy and self-organisation. People can lead a largely independent life over a longer period in spite of dementia. Involving them in **decisions and the recognition of their individual competences** by society facilitate participation and self-determination and contribute towards the breaking down of stigma. As Helga Rohra, chair of the European working group of people with dementia says: *“Nothing about us, without us”*.

Facilitating and supporting the self-determination of people with dementia-related impairments also means listening to them in order to strengthen them, and giving them space and time to formulate their own wishes. Among other things, this can be achieved with appropriate **advance care planning**. Advance care planning means initiating a communication process between people with dementia-related impairments and their support team in which worries, wishes, ideals and preferences for future support and care are discussed and planned and which refer to a time when the person is no longer in a position to make their own decisions. Advance care planning means professional care and support options and cooperating with family and friends and other important persons of the respective person. A necessary element is informing the sectors/institutions involved and documenting wishes and ideas.

Suitable framework conditions are a key precondition and also include adequate legal protection. In order to support the self-determination of people with dementia-related impairments, existing models of legal representation (guardianship) should be further developed and simplified. Instruments of advance planning such as a power of attorney for health care, living wills and supported decision-making must be affordable. Complaints bodies should be established.

Statement of an affected person: “It is important not to delude yourself – face what will happen and make plans with regard to the future, such as the question of who I want to be looked after by, family or professional carers” (Interview with people with dementia-related impairments within the framework of the consultation process for the dementia strategy)

Target groups:

- People with dementia-related impairments, their families and friends

Levels of realisation:

- Federal government level (e.g. for legal aspects)
- Provincial government level (health care, social affairs and social insurance)
- Local authority level
- Self-help groups
- Providers of health care services and social services
- Patients' Ombudsman's Office

Recommendation for action 1d: Participatory science – carrying out research with the involvement of those affected

Participative science works methodically with all those who are affected and interested. By involving members of the public (and particularly people with dementia-related impairments and their families and friends) in the research process at any early stage, questions and problems from the lives of those affected are taken up. At the same time, the public is systematically involved in research and thus in the solution of social problems.

Research findings can help to clarify what constitutes quality of life and how it is influenced. Dementia-oriented research which takes the special situation of people with dementia-related impairments and their families and friends into account in its ethical practices is to receive increased funding (see also target no. 7). A dementia-sensitive research culture is necessary in the interests of the quality of life of those affected.

The key issue here is to create understanding for this in the research community, and to implement recommendations for action and **guidelines for research institutions** as well as for funding bodies and **ethics commissions**. People with dementia-related impairments, their families and friends as well as representatives from interest groups should be actively involved in this process using appropriate methods.

Target groups:

- Research and educational institutions
- Funding bodies
- Ethics commissions
- People with dementia-related impairments, their families and friends

Levels of realisation:

- Research institutions
- Educational institutions
- Funding bodies

Objective 2 – Extending the provision of information in a broadly-based and target group-specific way

People with dementia, their families and friends as well as the entire population have access to low-threshold, nationwide information about dementia

Explanation and challenges

Challenges

People with dementia-related impairments and their families and friends need a great deal of information, particularly on questions such as: What is dementia, and what can a good life with dementia look like? Is that already dementia or 'normal' forgetfulness in old age? What course does dementia take? Can I/ my mother/ my father still live alone, or do I/ he/ she need to be looked after on an ongoing basis, or even go into a home? Can I still look after my grandchild alone? Which options are available for treatment/funding, and is it possible to obtain financial support?

Persons who are familiar with those affected (neighbours, supermarket staff...) are sometimes perturbed when they cannot interpret some aspects of people's behaviour. A lack of information on dementia therefore often leads to misunderstandings, prejudices, taboos and the exclusion of people with dementia-related impairments and their families and friends. Information deficits of this kind can even be found in health care and social professions.

The desired effects

Public relations work on dementia should therefore be as broadly-based as possible and as target group-specific as necessary in order to achieve the following objectives:

- Understanding people with dementia-related impairments and their behaviour (target group: general public, but also specific target groups such as bus drivers, shop assistants, the police)

- Counteracting people's fears and showing them that a great deal is still possible with these people (work, fun, creativity)
- Recognising early signs of dementia and making people aware of the possibilities, opportunities and risks of an early diagnosis
- Informing people about the technical possibilities with regard to support in everyday life
- Knowing about offers in one's own environment

Early recognition and understanding in a person's surroundings can lead to a timely diagnosis and thus contribute to an early or earlier start of preventive and therapeutic measures. A decisive factor here is also to make people aware of the opportunities and risks of an early diagnosis. The intention is to reduce the fear of dementia, to show that a lot of things are (still) possible, and to establish a normal, neutral way of interacting with people with dementia-related impairments and their environment.

The advantages of an early diagnosis are that those affected can adapt themselves to the possible course of the condition, that the use of medication and non-medication therapy can begin, and that preventive measures can be taken. However, this can also be accompanied by mental strain and anxiety about the future. In addition, clear diagnoses are difficult to make, particularly in the early stages (e.g. difficult to differentiate from depression).

The following recommendations for action aim to ensure that people with dementia-related impairments and their families and friends as well as society in general are well-informed and know who they can turn to close to their homes if the need arises.

All of the media should be involved, and at the same time, the necessary structures need to be created for nationwide, low-threshold information and advisory work.

Statement of a person suffering from dementia-related impairments:

“That's the key point for me too: that people (family members) often talk about what is good for me instead of talking to me. Then I get the feeling that I as a person am being shrunk a bit”

(interview as part of the consultations on the dementia strategy)

For all of the following recommendations for action, it is understood that people with dementia-related impairments and their friends and families have to be involved in the conception of information work.

Recommendations for action

Recommendation for action 2a – Development of comprehensive information and communication concepts

Before the beginning of information and campaign work, the following issues have be clarified and described: which issues are to be prepared for which target group (positive images conveying quality of life, appreciation...), which contents are core messages, and through which channels can/should which information be disseminated (ideally).

Detailed measures could be, for example, a joint logo for all activities, brochures (information for those affected, information from affected persons, research involves affected people), a newsletter, a series of events, conferences, passing on outreach information, awareness programmes, a magazine for caregiving family members and friends.

The following factors should be taken into account in the realisation:

- Ensuring a low-threshold approach
- A solution and resource-oriented approach (positive/appreciative)
- Participative design of content with the involvement of those affected as well as their families and friends
- A staged and phase-specific structure (based on the dementia strategy in terms of content)
- Information and education are provided as part of initial and further training (for key groups) in addition to other contexts

Target group and levels of implementation:

- Federal government, the provinces and the social insurance system
- With the involvement of
 - providers of health care services and social services

Recommendation for action 2b – Broadly-based public relations and (media) campaigns

Public relations work is intended to broadly initiate the societal discourse on the topic of dementia and a change in social values.

The following are to be addressed

- diagnosis and its consequences; i.e. on the one hand what it means, and on the other what it (above all) does not mean;
- which offers exist for people with dementia-related impairments, their families and friends;
- what everyone can do in their own environment and how an (ageing) society can learn to deal with dementia in a way which is positive overall.

Alongside series of information material in a wide range of media, high-profile activities and benefit events such as regular balls, solidarity concerts etc. can be organised in order to support positive images of getting older and to thus contribute towards the breaking down of stigma and taboos.

Target groups:

- The general public

Levels of realisation:

- Federal government, the provinces and the social insurance system
- With the involvement of
 - Providers of health care services and social services
 - Occupational and political interest groups
 - The advisory council on health in the Austrian Broadcasting Corporation (ORF) and in other media
 - Self-help groups, educational institutions, affected persons

Recommendation for action 2c – Target group-specific information

Alongside broadly-based public relations work, providing target group-specific information is necessary to reach specific occupational groups with information which is relevant to them and to raise their level of awareness (see also Recommendation for action 1a).

Target groups:

- All occupational groups in the health care, nursing and social systems
- Authorities, the police, emergency services (e.g. fire service, ambulance, transport services for the sick)
- Service providers, retailers, trades (public transport, banks, etc.)

Levels of realisation:

- Federal government, provinces and the social insurance institutions with the involvement of providers of health care services and social services
- Occupational and political interest groups, educational institutions
- With the involvement of
 - Self-help groups and those affected

Recommendation for action 2d – Low-threshold information offers

Whereas in the previous recommendations for action (2b and 2c) a broader public is reached with general information and at the same time certain occupational groups are addressed in a target group-specific way, in this recommendation those affected are the focus (people with dementia-related impairments and their families and friends), whereby these persons are addressed in a low-threshold way.

Measures for low-threshold information offers are, for example:

- Information events using accessible language; multilingual)
- Outreach information work, particularly for rural areas (e.g. Memory Bus)
- The extension of events related to dementia, such as the MiniMed degree

Target groups:

- People with dementia-related impairments, their families and friends as well as carers

Levels of realisation:

- Communities and local authorities
- General practitioners
- Specialists
- Primary care providers and their partners (e.g. pharmacies)
- Providers of health care services and social services
- Senior citizens' organisations
- Advice points
- Occupational and political interest groups
- Self-help groups
- Teachers, pre-school and nursery school teachers

Recommendation for action 2e – Web-based information and offers

The objective is, based on existing information/websites, to maintain a **quality-assured** information hub with an overview of existing offers. At federal government level, basic information (e.g. www.gesundheit.gv.at; www.pflegedaheim.at) and international examples should be provided and links made available to information and offers from the provinces. Ideally, federal government and provincial websites should be structured using a uniform system so that affected persons can find their way more easily.

The opportunities offered by new media (active networking, exchange and training) should be explored and used. It is important that these websites are manageable for those affected, which means they should be designed to be easy to read, simple and clear.

Target groups:

- People with dementia-related impairments (if they are still able to use the internet), their families and friends, the general public

Levels of realisation:

- Federal government, the provinces and the social insurance system
- With the involvement of
 - Providers of health care services and social services
 - Occupational and political interest groups
 - Occupational groups
 - Science

Recommendation for action 2f – Development of a code of good practice for media reporting

The media and publications influence society's image of old age. Given their opinion-forming function, media writers bear a great deal of responsibility. Headlines such as "THE SCOURGE OF DEMENTIA" do not help to reduce the taboos and stigma connected with dementia. To underline this significance, a special code of good practice is to be developed. This code of good practice should be integrated into the relevant media prizes and awards as a fundamental basis, and thus have a positive effect on reporting.

Target groups:

- Media

Levels of realisation:

- Federal government, the provinces and the social insurance system
- The trade union of Austrian journalists, the Austrian Broadcasting Corporation and other media
- With the involvement of
 - Providers of health care services and social services
 - People with dementia-related impairments, their families and friends

Objective 3 – Strengthening knowledge and competence

Information and skills training for occupational groups in the health care and social sectors as well as for families and friends enable all those involved to act in a competent, cooperative and reciprocally binding way.

Explanation and challenges

Challenges

Dealing professionally with people with dementia-related impairments requires special knowledge and forms of interaction. Neither of these are sufficiently well-developed in the respective occupational groups. Specialist knowledge and the corresponding competence therefore have to be deepened, extended and strengthened in order to improve the quality of support.

Families and friends provide key care and support work for people with dementia. This fact leads to the following problem: family members and friends often do not possess sufficient knowledge and competence in dealing with people with dementia-related impairments, thus leading to adverse consequences for safety aspects and strategies to reduce the burden on individuals. This leads to stress and strain and thus to withdrawal, irritation, aggression, escalation and subsequently to all kinds of violence. In addition, there is a lack of systematic cooperation between families and friends and professional service providers and of corresponding specialist support.

Dementia-specific programmes in initial, further and continuing training are only offered to a limited extent or piecemeal for health and social professions, caregiving family members and friends, and for 24-hour carers.

The desired effects

Suitable training and education measures facilitate the equal involvement of those affected, families and friends, and experts.

The first educational measures are awareness-raising ones which equally include all those involved in a system (e.g. in hospital from the reception to hospital beds and transport services).

In the professional sector, dementia-specific issues should already be included in initial training and extended in further training and continuing education. Specially trained professionals support people with dementia-related impairments. General practitioners are competent persons of trust.

Initial training and training programmes for families and friends or volunteers create dementia-specific competence with the goal of recognising and reducing individual burdens and challenges and achieving a higher quality of support in the informal sector.

Statements of those affected:

“I went up the wall and now I can’t get back down. Can you help me?”

Recommendation for action 3a – Raising awareness and the development and strengthening of competences, and skills training for medical and non-medical personnel in facilities of the health care and social systems

The goal is the gradual development of competence in dealing with people with dementia-related impairments, by (among other things):

- The clarification of roles, particularly in multi-professional teams, and defining the interfaces between the health care and social sectors.
- The development of staged competence profiles
- The inclusion of specialist aspects and the implementation of dementia-specific contents in initial and further training and continuing education, such as
 - Raising awareness (and increasing knowledge) of the needs and rights of people with dementia, and communication and interaction based on the former, particularly person-centred concepts in interaction and communication (verbal, non-verbal)
 - The prevention of challenging behaviour, and how to deal with it when it occurs
 - Strategies to recognise, prevent and react to crises and violence
 - The pathologies of dementia including symptoms, differential diagnosis, resources and processes
 - Structured medication management, particularly to prevent undesired side effects and interactions as well as the risk of polypharmacy and potentially inappropriate medication (PIM)

- Needs- and situation oriented¹ multi-professional care (including biography work, day structuring, activation, and work with families and friends)
- Ensuring the transfer between theory and practice through suitably qualified personnel with scientific, practical and educational competence
- Networking opportunities for multi-professional exchange are to be created

Target groups:

- Multi-professional teams
- Legal representatives (guardians)
- Actors in various public institutions in the health care and social systems

Levels of realisation:

- Training institutions
- Regional administrative bodies
- Providers of health care services and social services with the involvement of multi-professional teams.

Recommendation for action 3b – Strengthening of the competences of families and friends

The development and expansion of a nationwide programme of low-threshold, affordable information and training offers on the following themes:

- Basic knowledge about dementia and dealing with people with dementia-related impairments
- Person-centred interaction and communication training
- Internet-based learning and information offers (see also recommendation for action 2e)
- Coaching for family members and friends, for example on strategies and programmes to reduce workloads and strain
- The prevention and recognition of violence, and combatting violence
- Information on the compatibility of caregiving and paid work
- Advice for family members and friends on the legal, social, occupational and financial situation

¹ Situation-oriented means orientation towards the specific needs of people with dementia-related impairments at a certain moment in time

Target groups:

- Family members and friends of persons suffering from dementia-related impairments:
- Volunteers who provide neighbourly help

Levels of realisation:

- Communities/ local authority level
- Social and health professions
- Providers of health care services and social services
- With the involvement of
 - Occupational and political interest groups as well as self-help groups
 - Federal government, the provinces and the social insurance system

Objective 4 – Uniform design of the framework conditions

Needs-oriented services which are coordinated across all areas of care provision and are continuously available to people with dementia-related impairments and their family members and friends require the cooperation of all decision-makers in the health and social sectors. This cooperation facilitates the design of a nationwide structure of comparable offers.

Explanation and challenges

Challenges

Low-threshold offers of support and care for people with dementia-related impairments and their families and friends are to be made at a regional level in order to enable an individualised and – as far as possible – needs-oriented approach (see also objectives 5 and 6). This requires the cooperation of system partners in the health and social sectors.

Synergies are to be used in the planning, realisation and further development of measures in order to minimise differences in quality and parallel structures.

The areas covered by the ongoing health reform (target-based health governance) are already implementing the measures for the required coordinated service structures in some fields. However, within and/or between the different system levels (e.g. social and health care systems) there can still be inefficiencies at the interfaces.

The desired effects

At both federal government and provincial levels there are coordinated structures and framework conditions which take into account the needs of people with dementia-related impairments and ensure that in the entire country services are available with the same quality and with comparable conditions, and which can be taken advantage of by people. These services can subsequently be established and implemented at regional and organisational levels.

Statements of those affected:

“You haven’t got the right light – I see things differently.”

Poster series of the Dementia Campaign in Vorarlberg)

Recommendations for action

Recommendation for action 4a – Creation of coordinated and integrated care provision for people with dementia and of a cross-sectoral structure through cooperation between the system partners in the health and social sectors

Through the nationwide establishment of a cross-sectoral structure, particularly by means of the definition of system partners, interfaces and processes, the cooperation of all system partners in the health and social sectors will be facilitated. Existing concepts and regional structures will be taken into account in this process. One of the goals is to optimise the services provided by general practitioners and specialists in private practice and to coordinate the processes at the interfaces between the health and social sectors. This ensures needs-oriented continuous and individually coordinated service provision for people with dementia-related impairments and their families and friends.

Target group:

- Providers of health care services and social services

Levels of realisation:

- Federal government and provincial partners in target-based health governance, with the inclusion of the social sector at federal and provincial levels

Recommendation for action 4b – Development of quality standards in the fields of health, social affairs, care and support

Priority will be given to taking the following actions:

- Development of quality standards for diagnosis, treatment, care and support
- Developing and the mandatory deployment of quality assurance instruments (quality assurance cycle) (see target 7)

- Definition of minimum contents in relation to the support/treatment of people with people with dementia-related impairments in the curricula of initial and further training and continuous education (see recommendation for action 3a)
- Development, adaptation, updating and implementation of evidence-based guidelines for treatment with and without medication (taking into account the already existing guidelines)
- Drawing up guidelines in which the needs of people with dementia-related impairments are taken into account (e.g. for the structure of care organisations, operational concepts and the realisation of buildings in all areas of care).

Target groups:

- Providers of health care services and social services
- Support staff and carers
- People with dementia-related impairments, their families and friends
- Courts, guardianships, the representatives of the residents of homes

Levels of realisation:

- Federal government, the provinces and the social insurance system
- With the involvement of
 - Research institutions
 - Providers of health care services and social services
 - Professional associations

Recommendation for action 4c – Establishment of a Dementia Strategy Platform

The platform is intended to facilitate coordinated action and the realisation of joint framework conditions and recommendations. To this end, political decision-makers, those realising the actions, researchers and those affected form a joint platform, whereby existing structures are taken into account. It is recommended that similar platforms should be established at a provincial level (particularly in order to involve local authorities).

Possible tasks:

- Providing impulses for the implementation of the dementia strategy
- Coordination between the federal government and the provinces
- Annual conferences to evaluate the realisation of the strategy
- Coordination and transfer of knowledge via offers, new projects and research results

- Advice on realisation on the basis of research findings
- Support in the development of recommendations and framework specifications – e.g. the main points of specific care concepts
- Knowledge transfer

Target groups:

- Responsible persons in the health and social sectors
- Health and social professions
- Affected persons, self-help groups
- Providers of health care services and social services
- Research institutions

Levels of realisation:

- Federal government
- Provinces
- With the involvement of
 - relevant stakeholders

Objective 5 – The design and guaranteed provision of suitable dementia care offers

The offers of the care chain from health promotion to palliative care are low-threshold, affordable, multi-professional, coordinated, continuous and individualised.

Explanation and challenges

Challenges

Supporting and looking after people with dementia-related impairments – from health promotion measures to palliative care – requires a wide-ranging and coordinated programme.

The majority of people with dementia-related impairments live alone at home and/or are cared for and supported by family and friends. Care and support in a domestic setting is mostly provided by women – according to a survey from 2014 just under 80 percent (Dementia Report 2014). Greater awareness and a changing understanding of roles among men and women can lead to more men taking on the work of caregiving and providing support in the future. Offers of support should correspond to the needs of people with dementia-related impairments as well as those of their families and friends.

A need for action – particularly with regard to a coordinated approach – can be seen in all parts of the care chain: regarding doctors in private practice (general practitioners, specialists), in acute care in hospitals, in the field of mobile services (such as home helps and nursing care at home) and in semi-inpatient and inpatient long-term care (such as day centres, nursing homes and assisted living for people with dementia-related impairments), but also in the field of psychosocial and therapeutic offers.

A growing number of patients in acute hospitals have a secondary diagnosis of dementia alongside an acute condition. In addition, there are patients who may also be suffering from non-diagnosed dementia/delirium or depression. Staff of acute hospitals are facing increasing challenges in caring for patients. Currently, everyday life in clinics is hardly attuned to people

with dementia-related impairments, which can have negative consequences for patients as well as staff.

Specialist skills are needed to judge which measures would benefit these patients and which of them might even damage them. Acting in a competent, coordinated and networked way in all settings contributes towards fitting care for people with dementia-related impairments and thus also to cost savings.

The desired effects

Nationwide, close-to-home and coordinated care of people with dementia-related impairments is made available in accordance with the course of the condition and in all areas of the health care and social systems. Support is provided on the basis of individual-centred surveys of needs.

In long-term support and care (e.g. mobile services, semi-inpatient offers such as day centres, or assisted living), people with dementia-related impairments and their families and friends can choose from a range of offers, whereby those affected are provided with support to enable them to live independently for as long as possible. Family members and friends are supported in a professional and needs-oriented way. Existing gaps in care provision are closed.

Statements of those affected:

“I want to go home, but not to that home – I mean the other home”

(Poster series of the Dementia Campaign, Vorarlberg)

Recommendations for action

Recommendation for action 5a – Best possible long-term care for people with dementia

Long-term care covers mobile, semi-inpatient and inpatient care forms (such as home helps, nursing care at home, day centres, nursing homes, assisted living, and shared flats and houses).

In order to facilitate the coordinated care of people with dementia-related impairments, offers of specialised care need to be made available nationwide. In addition, dementia-specific aspects must be taken into consideration in standard care provision (such as recognising special needs and reacting to them, particular needs with regard to nutrition, and communication).

The following areas will be developed in a targeted way and on the basis of regional needs and development plans:

- (mobile) interdisciplinary, multi-professional teams specialised in old-age psychiatry with a focus on dementia and clearly agreed responsibilities. In order to ensure needs-oriented support in all regions, the offers range from initial screening to care at home in the case of advanced dementia
- Mobile multi-professional advisory and therapeutic offers including on-site instruction
- Replacement care offers on an hourly basis, from professionals and also volunteers
- Flexible support opportunities for several hours or more (e.g. occasionally, evenings, weekends)
- Mobile de-escalation management with qualified staff, particularly for the prevention of violence
- Qualified care of dementia sufferers in the field of palliative care and hospices
- The extension of short-term care and day and night support and care (including transport services) for people with dementia-related impairments, also as replacement care to relieve the burden on families and friends
- Ensuring the provision of offers of transitional (rehabilitation) care for people with dementia-related impairments
- The further development of alternative forms of living and inpatient long-term care facilities in order to deal with the anticipated demand and the needs of people with dementia-related impairments (personnel, workflow organisation, structure, spatial concepts)

Target groups:

- People with dementia-related impairments, their families and friends

Levels of realisation:

- The provinces and the social insurance system
- With the involvement of
 - all relevant providers (professional offers and self-help groups), primary care facilities

Recommendation for action 5b – Adaptation of the structures, processes and environmental factors in hospitals to the needs of people with dementia

In order to recognise and take into account the needs of people with dementia-related impairments in hospitals, framework conditions will be created and guidelines developed in order to ensure coordinated support in hospitals (e.g. accompanying persons, procedures). Primary nursing is an integral element of care.

Target groups:

- People with dementia-related impairments, their families and friends, hospital staff

Levels of realisation:

- Hospital operators with the involvement of staff, professional associations and self-help groups
- The provinces and the social insurance system

Objective 6 – Extension of coordination and cooperation focused on those affected

Throughout Austria, people with dementia and their families and friends receive low-threshold offers on early recognition as well as advice and support which is appropriate to the stage of the condition of the respective person. Multi-professional teams plan individual measures together with the affected persons and their families and friends, and coordinate them with other service providers if necessary.

Explanation and challenges

Challenges

There are a large number of Information as well as advisory and support offers available in Austria for people with dementia-related impairments and their families and friends. However, they are often fragmented and somewhat obscure. Particularly in stressful situations, it is often difficult for people to obtain relevant information, not least because dementia is often not diagnosed, or not early enough. Fear and embarrassment about the condition lead to withdrawal, and support is often not accepted. This leads to the illness being recognised late and diagnosed even later.

In addition, throughout the course of the illness different occupational groups, institutions, facilities and care levels are involved in providing care for people with dementia-related impairments. This results in numerous interfaces where information losses can occur.

Specific measures for people with dementia-related impairments are currently being planned in various ways and are dependent on the respective regional situation and persons. Due to a lack of a systematically coordinated approach, (planned) measures are hardly communicated at all and existing needs-oriented offers are not found by those who enquire about them.

The health care and social systems are only coordinated to a small extent, which increases the fragmentation of service offers.

The desired effects

Low-threshold, barrier-free and close-to-home contact points for information, advice, early recognition and support have been established nationwide and provide competent and holistic advice and support for those affected. Cooperation across occupational groups and sectors has been realised in a structured process and is oriented towards the needs of people with dementia-related impairments and towards those of their families and friends.

The affected persons know exactly who they should turn to when they require medical care and various forms of advice and information about dementia, and make use of these low-threshold offers.

Statements of affected persons:

“There are weeds on my head, I need an appointment with a gardener”

(poster series of the Dementia Campaign, Vorarlberg)

Recommendation for action

Recommendation for action 6a – Nationwide expansion of low-threshold contact points for people with dementia and their families and friends and their integration into existing systems. The contact points deploy a coordinated concept to act regionally and if necessary on an outreach basis.

Low threshold regional contact points should be developed and extended accordingly – and connected to existing facilities or the creation of new offers.

The task of these contact points is to provide people with dementia-related impairments and their families and friends with low-threshold advice, support and treatment throughout the different stages of the condition. Multi-professional teams plan individual measures together with all affected persons, and coordinate the measures with service providers. Working methods such as case and care management can be applied here.

The following principles should be observed during implementation:

- Low-threshold, outreach if necessary, resource oriented, affordable and multi-professional

- Information work on experiences in the existing projects
- Development is carried out on the basis of previous experiences and concepts in order to support a coordinated approach
- The development of regional implementation plans takes place with the consideration of regional circumstances and using connections to existing facilities

Offers are established nationwide according to concepts and plans – by linking them to existing facilities or creating new offers.

The offers will be announced and made available to those affected free of charge.

Target groups:

- People with dementia-related impairments, their families and friends

Levels of realisation:

- The provinces in cooperation with local authorities and the associations of local authorities
- Social insurance system
- With the involvement of
 - already existing contact points

Objective 7 – Quality assurance and quality improvement through research

From prevention to palliative care, all professionals diagnose, treat and provide care on the basis of scientific/quality-oriented criteria and take the individual needs of people with dementia into account.

Explanation and challenges

Challenges

A specific challenge is to obtain concrete data on the number of persons affected and their living situations. Regional surveying and evaluation models have not yet been coordinated throughout Austria, and surveys are carried out according to different criteria, thus the data and the results of the evaluation are not comparable. Universal empirical research on the way therapeutic and nursing interventions work as well as research on the scientific foundations of various types and offers of care is necessary.

For long-term planning of needs-oriented service offers, it is necessary to carry out surveys to obtain prevalence data on dementia and to strengthen research into the provision of care.

The desired effects

High-quality data is available and is – taking data protection into account – accessible for affected persons as well as for researchers and public decision-makers.

The offers for people with dementia-related impairments and their families and friends are science-based and designed using a multi-professional approach. They are continuously evaluated and further developed.

Those responsible for the planning and financing of care (federal government, provinces, local authorities, hospital operators, the social insurance system, etc.) have sufficient data and information for the further development of care offers.

A new culture of the communication of science has been introduced – those affected and broad sections of society are informed in a timely and comprehensible way about research findings and insights. This is also an important condition for the emergence of new, practically-relevant social initiatives

Statements of affected persons:

“I’m fine. It’s just other people who don’t see it that way.” “Take me with you into your world”

(poster series of the Dementia Campaign, Vorarlberg)

Recommendations for action

Recommendation for action 7a – Development of a nationwide data pool on epidemiology and care offers, an evidence base for care offers related to people with dementia, and the evaluation of existing offers as a basis for the further development of the structure of offers

Realisation will be carried out in stages:

- Starting out from a target definition for a data pool, a catalogue of dementia-specific data types will be drawn up, whereby the data provides demographic, clinical and care-relevant information and is used as a basis for ongoing monitoring processes.
- Determination of the status quo with regard to existing data on dementia (which data is already available on a cross-provincial basis) and the definition of a minimum data set on the basis of the previously developed catalogue and with the inclusion of existing data (which data should be available at regional level / provincial level), as well as the establishment of criteria for the standardised recording of data
- Establishment and further development of continuous monitoring with the involvement of all system partners as the basis for a regular dementia report and a nationwide documentation system
- The promotion of an evidence base with regard to the setting up and further development of care offers
- The definition of care quality in connection with dementia, whereby the focus will be on quality of life as a global outcome and the development of indicators for the measurement of the quality of results. The perspectives and needs of those affected shall

be taken into account in the definition of the criteria and methods for evaluation (self-evaluation and/or external evaluation).

Target groups:

- Health and social planning authorities of the provinces, funding bodies, and the providers of health care services and social services
- People with dementia-related impairments, their families and friends

Levels of realisation:

- Federal government and provinces (health and social planning), the social insurance system
- With the involvement of
 - Research institutions, experts

Recommendation for action 7b – Development of a national research agenda on the care of people with dementia

A national research agenda (particularly taking account of research into care) will be developed in a systematic and methodologically sound way on the basis of leading international examples. This will involve experts from all of the fields of science and practice which are relevant to this topic as well as affected persons.

The research agenda forms the basis for the main focuses of the targeted promotion of research (e.g. from existing funds), and the setting of priorities for university and non-university research institutions as well as developing a profile within the framework of the Austrian universities' strategy.

Target groups:

- Research institutions and bodies responsible for the promotion of research and the economy

Levels of realisation:

- Federal government, the provinces and the social insurance system (taking into account the structures according to HE 4a, 4c)

- Research institutions and bodies responsible for the promotion of research and promotion of the economy

Recommendation for action 7c – Research findings should be communicated quickly and in their entirety to all relevant target groups and be reflected and considered in society, politics and professional practice

A new culture of research communication must be developed in Austria in order to convey research results directly (whereby they are presented in a way which is suited to the target group) to those in practice, to those affected, but also to the relevant decision-makers. To this end, it is not only necessary to generally introduce a new publication culture in science, but to also design and develop other forms of publication which are very close to the target groups in cooperation between researchers/scientists

Knowledge transfer is never one-sided. Alongside the classical transfer of research findings to those affected, spaces also have to be created in order to communicate key practical experience from affected persons and professionals to those working in research, so that a circulation of knowledge can take place instead of a one-sided knowledge transfer. The corresponding networking activities at the interface between research and practice are being further developed (e.g. in the form of competence centres and service points).

Target groups:

- People with dementia-related impairments, their families and friends
- Experts from the field
- Providers of health care services and social services
- Occupational and political interest groups
- Research institutions, decision-makers, media, etc.

Levels of realisation:

- Research institutions
- Federal government, the provinces and the social insurance system
- Representatives of the media, self-help groups, educational institutions

Members of the working groups

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