



BEST PRACTICE RECOMMENDATIONS

From the Actifcare Study

Access to Community Care Services

For Home-Dwelling People with Dementia and Their Carers

Home-dwelling people with mild to moderate dementia and their informal carers are found to use community services, such as home support, day care, respite care and counselling less frequently than medical services, despite the fact that these services may be highly beneficial in their situations (Weber et al., 2011). Studies have found that people with dementia and their informal carers often do not receive services of the type and quality that they need, and that they also experience difficulty accessing home- and community-based services (Phillipson, Jones, & Magee, 2014).

The Actifcare Project

These Best Practice Recommendations are a result of the work of the Actifcare project (ACcess to Timely Formal Care, (<https://www.alzheimercentrumlimburg.nl/actifcare>), an EU Joint Neurodegenerative Programme Disease Research (JPND) project. The participating countries were the Netherlands, Germany, Sweden, the United Kingdom, Norway, Ireland, Portugal, and Italy.

The Best Practice Recommendations concern how barriers regarding access to and use of community care services can be overcome. This is described in the Actifcare study via multiple methods, including literature reviews, focus group interviews, expert interviews, in-depth interviews with people with dementia and their carers, and a cohort study encompassing a total of more than 1000 participants in eight countries. The barriers regarding access to care services that were identified include:

- A lack of services and support in general, especially for people with young onset dementia;
- Poor organization or functioning of existing services;
- A lack of knowledge among people with dementia, carers and health care professionals, including general practitioners (GPs), regarding available services, who to turn to for help, and the benefits of using services;
- A lack of focus on social needs and financial support (the focus is mainly on medication and physical needs);
- Stigma related to receiving services and the experience of services or care as a threat to independence among carers and/or people with dementia; and
- Inequitable access related to financial status, being members of ethnicity/minority groups, educational level, the gender of the person with dementia, and the gender of the carer.

Delphi process

A Delphi process was a central part of the development of the Actifcare Best Practice Recommendations. The primary investigators of the Actifcare national research teams provided the statements for rating in the Delphi process.



The participants of the Actifcare Delphi process were experts from the eight Actifcare countries and included professional scientific, clinical and administrative experts, as well as experts by experience, i.e. people with dementia and informal carers and members of the European Working Group for People with Dementia. Special measures were taken to safeguard the perspectives of the experts by experience.

The Actifcare Best Practice Recommendations are based on the statements that reached consensus in the Delphi process and were supported by findings from the following Actifcare research deliverables:

- a) Actifcare literature review regarding structural aspects of access (Bieber, Broda, & Stephan, 2014);
- b) Actifcare focus group interviews with people with dementia, their informal carers and health care professionals regarding experiences of access to services (Stephan, Bieber, Broda, & Meyer, 2016);
- c) Actifcare in-depth interviews with national policy and decision makers regarding their perspectives on barriers and facilitators (Broda, Stephan, Bieber, Bartoszek, & Meyer, 2016);
- d) Actifcare scoping review regarding measures to enhance access (Røsvik, Michelet, & Selbaek, 2016);
- e) Actifcare cohort study, in-depth interviews with people with dementia and their informal carers regarding access to care (Kerpershoek, 2017a); and
- f) Actifcare one-year cohort study focusing on the needs and quality of life of people with dementia and their informal carers (Kerpershoek, 2017b).

The supporting findings are provided following each recommendation/set of recommendations and identified according to their letters above.

The recommendations are categorised as follows:

- A. Recommendations to enhance access;
- B. Recommendations to enhance use; and
- C. Recommendations that can facilitate access or use indirectly, i.e. enabling factors.

Implementation

To accommodate different health care systems, the implementation of the Best Practice Recommendations will be discussed, and actions will be formulated in each of the Actifcare countries.

Acknowledgements

The Actifcare project is grateful to the European Working Group for People with Dementia for its valuable input in the preparation of the Delphi process and for taking part as experts by experience in the process. We also thank the national experts; professional experts and people with dementia and informal carers who took part. In addition, we wish to extend our gratitude to the scientific advisory board and to the consumer board for their contributions to these recommendations.

A. RECOMMENDATIONS TO ENHANCE ACCESS

Recommendations that can enhance access to services directly

1. People with dementia and their carer/family should have a named contact person

The contact person may be the general practitioner, a case manager, or someone working inside the care system. The contact person may also be part of a team specialising in dementia

The contact person should:

- 1.1. be trained in dementia and person-centred care, which implies focusing on the perspective, needs and wishes of the person with dementia
- 1.2. have sound knowledge of the available dementia services
- 1.3. be easy to reach
- 1.4. cooperate closely with the primary care clinics and hospitals (inpatient and outpatient units) in their area to arrange the services people need at home

Supporting findings

The letter in front of each supporting finding refers to the deliverables listed in the introduction. Not all recommendations have supporting findings from all deliverables (a-f).

b) Actifcare focus group interviews with people with dementia, informal carers and health care professionals: A key contact person available to the people with dementia and their families was considered a good practice approach.

Social competences, commitment and knowledge regarding dementia and regarding available services influence whether services are accessed and used (Stephan et al., 2016).

c) Actifcare in-depth interviews with experts: Regarding the complexity and continuity of care, generally, the experts in all countries could understand that complexity and continuity of the dementia-care system were problems for those with dementia and their carers. In terms of ideas, strategies or suggestions to deal with complexity and continuity, the need for a coordinating role was stressed (Broda et al., 2016).

d) Actifcare scoping review: The positive effects of care-management interventions in regard to access to services were identified (Røsvik et al., 2016).

Other evidence: Professional care required establishing a trusting relationship, tailor-made interventions and a single person or organization to contact. These were the findings of the RightTimePlaceCare project (<https://www.ncbi.nlm.nih.gov/pubmed/25430690>) (Karlsson et al., 2015).

A study using qualitative and quantitative data to investigate German dementia networks and their role in providing information about dementia-support services to carers found that more formalized knowledge-management processes in dementia-care networks can lead to a higher level of knowledge among family carers (Heinrich, Uribe, Wubbeler, Hoffmann, & Roes, 2016).

2. The contact person or other personnel delivering services should:

2.1. establish contact with the person with dementia and the carer/family at a timely point in the disease process, that is, at the right moment in accordance with the wishes of the person with dementia and the informal carer

2.2. establish and continuously maintain contact proactively

Supporting findings

b) Actifcare focus group interviews with people with dementia, informal carers and health care professionals: Carers stated how helpful they found proactive professionals to be (Stephan et al., 2016).

c) Actifcare in-depth interviews with experts: Services that are client- or patient-centred, multidisciplinary, proactive, and flexible and that can provide counselling, 24/7 access, and can involve the voluntary sector are preferred (Broda et al., 2016).

Other evidence: A priority should be the establishment of a core of community-based case managers who are involved from the time of diagnosis throughout the dementia continuum as a resource for those with dementia and/or their carers/family members (Nolan, McCarron, McCallion, & Murphy-Lawless, 2006)(p.12–13).

2.3. regularly assess the needs of the person with dementia and his/her carer/family, including psychosocial needs

Supporting findings

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers: Several carers indicated that professionals should consider individual needs when finding the right type of care. The information received focused on medication and physical needs but was lacking in regard to social needs and financial support (Kerpershoek, 2017a).

2.4. provide individualised information about dementia and available services to people with dementia and their carer/family

Supporting findings

a) Actifcare literature review: It was mentioned repeatedly that there should be more knowledge about available services (Bieber et al., 2014).

c) Actifcare in-depth interviews with experts: The need for information about available services and the necessity of networking, cooperation and communication among all persons involved in care were highlighted (Broda et al., 2016).

d) Actifcare scoping review: The positive effects of awareness and information-focused interventions were identified (Røsvik et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers:

Several participants highlighted that information from the municipality/town or local area was important. More information about dementia and the services that are available is needed at the time of diagnosis. The information should be clear, too much at one time is overwhelming (Kerpershoek, 2017a).

2.5. provide continuous support and advice to the people with dementia and their carer/family

Supporting findings

b) Actifcare focus group interviews with people with dementia, informal carers and health care professionals: An important strategy is to remain approachable and be ready to provide support as soon as the situation changes (Stephan et al., 2016).

2.6. encourage people with dementia and their carers/families to consider referral to services that may be relevant to them and facilitate referral, if wanted

2.7. discuss decisions about service use with the person with dementia and his/her carer/family

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care professionals: The decision to use professional dementia care may not be merely a rational decision but rather one influenced by a complex interplay of psychological and social aspects, attitudes and beliefs towards dementia and formal care and features of every health care professional and organisational aspect of the health care system.

As revealed within the focus groups across the countries, health care professionals apply a range of strategies to support people with dementia and, in particular, informal carers in the decision-making process regarding the use of professional support. An example of a strategy is to identify and suggest services that address the specific social, psychological and emotional needs of the person with dementia. Discussions about attitudes and beliefs are important in the decision-making process, as they can facilitate the process (Stephan et al., 2016).

3. Services should be affordable and monetary support should be offered when needed

Supporting findings

a) Actifcare literature review: Private out-of-pocket payments may further contribute to low utilisation of services (Bieber et al., 2014).

d) Actifcare scoping review: The positive effects of monetary support interventions were identified (Røsvik et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers: In several countries, finances are identified as barriers. Financial concerns are mentioned as a reason to postpone the use of formal services or may lead to non-use of such services (Kerpershoek, 2017a).

4. Information about dementia and dementia services should be accessible

4.1. Information about dementia and dementia services should be available to people with dementia and carers/families in a way that is easily understood and accessed

4.2. An online information platform should be established with updated information about available care services in all communities. This platform should:

- i. be easy for people with dementia and carers/families to access**
- ii. provide health care personnel with updated information**

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care professionals: Information regarding dementia emerged as an important theme on both individual and system levels (Stephan et al., 2016).

c) Actifcare in-depth interviews with experts: The need for information about available services and the necessity of networking, cooperation and communication among all persons involved in care were highlighted.

An important theme that emerged in almost all countries was “information”, which refers to creating transparency about available services and the benefits of these services. People with dementia and their carers need to have access to information as a prerequisite of access to the service itself. Collecting information about the services that are available and disseminating it in an adequate manner is crucial to accessing and utilising them. Experts from some countries suggested setting up online platforms or websites that contain various existing services (Broda et al., 2016).

d) Actifcare scoping review: The positive effects of awareness and information-focused interventions were identified (Røsvik et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers: The identification of overarching aspects that seemed to be of importance on both levels (individual and system), such as information regarding dementia throughout the whole course of the dementia disease, was emphasised by some participants (Kerpershoek, 2017a).

5. Other parties of the health care system should have knowledge and provide information about available community services as well as ensuring referrals

Memory clinics/specialised outpatient services, general practitioners and other health care professionals assigned to work in dementia services should have knowledge and provide information about available community care services. They should also refer to services or to the contact person/other relevant health care personnel in the community who can refer to services

Supporting findings

a) Actifcare literature review:

General practitioners (GPs) have a defined function that includes detecting and diagnosing dementia (and excluding other diagnoses) and referrals to other services or specialised physicians. The GP is regarded as a continuous reference person in the United Kingdom, Sweden, Ireland and Italy (Bieber et al., 2014).

b) Actifcare focus groups with people with dementia, informal carers and health care professionals:

A GP often serves as a gatekeeper, initiating the clinical process of getting the diagnosis and obtaining help from the appropriate community services (Stephan et al., 2016).

d) Actifcare scoping review: The positive effects of referral-focused interventions were identified (Røsvik et al., 2016).

e) Actifcare cohort study: In-depth interviews with people with dementia and informal carers:

A couple of participants reported that it facilitates finding access to care if health care professionals make referrals to the correct type of services/other professionals (Kerpershoek, 2017a).

Other Evidence: Most people with dementia and carers are not aware of the treatment options available to them. Health care professionals should play an important role in their empowerment (Wolfs, de Vugt, Verkaaik, Verkade, & Verhey, 2010).

6. There should be appointed personnel, well-defined pathways* for referral to services, and coordination of advice

**A pathway is a set stepwise procedure to be applied in a certain situation, e.g. when someone has been diagnosed with dementia.*

6.1. In each country, there should be a well-defined pathway to community care services, that includes admission to and discharge from acute care hospitals

6.2. In all hospital units where older people are commonly admitted, there should be an appointed health care professional who cooperates with the community to arrange the services needed at home

6.3. In each country/state, there should be a well-defined pathway for general practitioners' referrals for treatment of persons with dementia who have severe psychological distress and other urgent cases

6.4. When services are provided by both communities and private health and social care providers, advice regarding the services should be coordinated

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care

professionals: Having a single pathway to gain access was generally considered a facilitator of service use; however, diverse possibilities to access services may also have advantages in that the individual's needs may be better met (Stephan et al., 2016).

7. Psychoeducation should be provided following a diagnostic disclosure

The diagnostic disclosure should always include psychoeducation about what dementia entails and practical advice on how services can help people with dementia and their family/carers cope with dementia

Supporting findings

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers:

More information at the time of diagnosis about dementia and the services that are available is needed. The information should be clear and should not include so much at once that it is overwhelming (Kerpershoek, 2017a).

B. RECOMMENDATIONS TO ENHANCE USE

Recommendations that can enhance use of services

8. Transportation to and from dementia services and help to get ready for transportation should be available to people with dementia if they need it

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care

professionals: Transportation and an easy way to access services such as day care centres were mentioned as quite simple but important facilitators (Stephan et al., 2016).

9. Coordination of services should be ensured, and cooperation between people with dementia, their families, professionals, and volunteers should be enhanced

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care

professionals: A key contact connecting different health care professionals was considered a good practice approach. Moreover, good cooperation between care providers (e.g. between municipality and specialists) is described as important, including the exchange of information among providers (Stephan et al., 2016).

c) Actifcare in-depth interviews with experts: The necessity of information about available services and the necessity of networking, cooperation and communication among all persons involved in care were highlighted. A coordinating role to help people navigate the system of available services is needed (Broda et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers:

Some participants highlighted that there were often several people (sometimes too many) involved in information and planning of dementia services and that information and care plans were often not communicated and/or agreed upon between different professionals and clients (Kerpershoek, 2017a).

10. Use of services should begin with a social introduction between staff and the person with dementia/family, and the use may be gradually built up over time

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care

professionals: Professionals described seeking to overcome resistance by building up the use of services gradually, hoping to avoid crises in the future (Stephan et al., 2016).

e) Actifcare cohort study in-depth interviews with people with dementia and their informal

carers: An early start and gradual increase of formal care was reported by some to be helpful, and the formal care would be easier to incorporate into people's routines. For instance, the first step could be meal support (e.g. meals on wheels) or home help (e.g. household chores), and then health care personnel could introduce themselves through these services before more help was introduced (Kerpershoek, 2017a).

11. Services assigned to people with dementia should be flexible rather than set and detailed regarding setting, type, and amount of services granted. For instance, respite should be provided at home as well as in institutions

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care

professionals: Services should be flexible since the needs of those with dementia may change from day to day (Stephan et al., 2016).

c) Actifcare in-depth interviews with experts: Services should be client- or patient-centred, multidisciplinary, proactive, flexible, providing counselling, providing 24/7 access, and involving the voluntary sector (Broda et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers:

In some countries, participants reported feeling that the available services were poorly organised and inflexible. It was also pointed out that professionals could be more flexible (Kerpershoek, 2017a).

12. There should be continuity of staff and a timetable should be provided and adjusted to the person's routine, indicating when staff from home services are coming and which staff should be expected

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care

professionals: Ensuring that the same staff care for the person with dementia (thereby building trust and ensuring security) and establishing ongoing contact with the person with dementia and their family not only during a crisis was something that would contribute to continuity (Stephan et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers:

Using formal care can be seen as a limitation for the independence of both the carer and the person with dementia, as one has to adjust to the schedules of personnel. Personal care provided in the home is also often rejected, as it is seen as an infringement on one's privacy.

People with dementia experience formal care as disruptive due to irregular times of visits and changing faces. Some participants expressed a reluctance to use home health care since they believed that it would interrupt their daily routines. They imagined that they would have to wait a lot, and there would be many different persons; they also worried about losing their freedom. Having a sense of control over the nature of service received was seen as important (Kerpershoek, 2017a).

13. People with dementia should have access to dementia-specific services provided by specially trained personnel appointed to these services

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care

professionals: The focus of formal care should be widened beyond physical care, and community-based support, in particular, should address the social and psychological aspects of care. People

with dementia should be engaged in meaningful activities that relate to their personal interests. Overall, dementia-specific services are deemed more appropriate (Stephan et al., 2016).

14. Services should aim at enhancing independence in people with dementia and in carers

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care professionals: Services should aim at supporting the independence of those with dementia by including them in decision-making (also about daily activities), maintaining functioning and supporting them in continued community involvement or participation in social clubs.

People with dementia perceive and experience professional support and care as being a threat to their independence instead of being a way to maintain their independence. To the best of our knowledge, this aspect has not been described in previous studies. Therefore, accepting professional support might be a process of carefully balancing the expected and the actual benefits and losses – for those with dementia *and* the informal carers (Stephan et al., 2016).

C. ENABLING FACTORS

Recommendations that can facilitate access or use indirectly

15. Access to services should be equitable and needs driven

Supporting findings

f) Actifcare cohort study: There seems to be inequitable access to care for some types of services: Major drivers for dementia-related service use in general are reporting more needs, having a greater disease severity and living alone. For personal care at home, older and more highly educated people with dementia and younger carers find access to care more easily. For care-home admission, less formal education of carers is associated with greater risk of admission to a care home. There are some variables that predict whether any formal care is used after 6 and/or 12 months. *Characteristics of persons with dementia:* living alone, lower functioning in activities of daily life, instrumental activities of daily life. *Characteristics of informal carer:* higher education, participating in a support group.

A higher amount of need leads to a lower quality of life, both for the person with dementia and for the carer (Kerpershoek, 2017b).

16. Support groups for people with dementia and their carers/families should be facilitated locally

Supporting findings

f) Actifcare cohort study: When informal carers visit a support group, they are more likely to use formal care services (Kerpershoek, 2017b).

17. Service providers should ensure that proper training for health care professionals is provided

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care professionals: Health care professionals should also be targeted with training and educational programmes since they play a major role in the process of accessing and using services. They should be made aware that their behaviours, their social competences and their ability to establish a trusting relationship may serve either as a barrier or a facilitator to the use of services (Stephan et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and their informal carers: Some participants emphasised the need for care workers to have participated in dementia-specific training (Kerpershoek, 2017a).

18. Health care personnel should undertake training in safeguarding dignity and showing empathy and respect for people with dementia

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care professionals: Health care professionals should provide tailored and personalised help and demonstrate social competencies such as trustworthiness and respect for the person with dementia (Stephan et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and informal carers: Some countries report that people with dementia and carers experience a lack of empathy from health care personnel. Meeting empathetic and open-minded professionals helped in accessing and positively evaluating the service. Health care personnel should value the perspectives of the person with dementia and the carer with dignity, and be more empathetic, collaborative and communicative with the family (Kerpershoek, 2017a).

19. Health care personnel should receive training in how to deal with conflict regarding care decisions between people with dementia and their significant others

Supporting findings

f) Actifcare cohort study: Of those who are not receiving care, 18% indicate that the reason is that the person with dementia refuses care (Kerpershoek, 2017b).

20. General practitioners (GPs) should have specific dementia training to enable them to diagnose dementia at the right time for the person and the family, and to recognize when an advanced diagnostic assessment of dementia is required

Supporting findings

c) Actifcare in-depth interviews with experts: GPs should have access to instruments and training in order to refer people with dementia more adequately and timely to specialist assessment (e.g. memory clinics, neurology or psychiatry outpatients clinics); this would allow faster and more adequate answers from specialised care (Broda et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and their informal carers: Several countries reported that health care personnel and GP's need more training, skills and confidence in diagnostic expertise; this would prevent a delay in the receipt of information and access to services. Several participants also reported that there should be more support and guidance, and it was pointed out that health care personnel has to be trustworthy and organised (Kerpershoek, 2017a).

21. General practitioners (GPs) should have an overview of the situation of the person with dementia

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care professionals: The GP is considered the first contact for people with dementia and their families, making a diagnosis or referring to specialists, providing first information and also taking over an initial gatekeeping function (in order to ensure care within the community). However, as revealed, for example, in Germany, Ireland and Portugal, it is not the case that all GPs fulfil their role, and there seems to be great variance among individual GPs (Stephan et al., 2016).

22. The provision of care should build on the principles of person-centred care*

22.1. Services should focus on the perspective, needs and wishes of the person with dementia

22.2. Services for people with young onset dementia should fit their specific needs

* Person-centred care as described in 1.1 and 22.1 also encompasses ethnic and cultural factors.

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care professionals:

Increased public awareness and particularly a better understanding of the needs of younger people with dementia could facilitate the use of professional support, prevent social isolation among people with dementia, and promote understanding and normality (Stephan et al., 2016).

c) Actifcare in-depth interviews with experts: Experts across countries agreed that services should be client- or person-centred, individualised, proactive, and multidisciplinary (Broda et al., 2016).

e) Actifcare cohort study, in-depth interviews with people with dementia and their informal carers: Cooperation with professionals is experienced by some as insufficient or inappropriate with regard to the individual needs of people with dementia and carers. If the services offered are not tailored to the individual, this can lead to rejection of further use of formal care (Kerpershoek, 2017a).

23. Awareness about dementia should be increased

23.1. Education about dementia should be provided at all levels of the educational system

23.2. Mass media should be used to disseminate information about dementia to the general public in order to combat stigma

Supporting findings

b) Actifcare focus groups with people with dementia, informal carers and health care professionals: Some of the focus groups consider that improved public awareness of dementia would lead to increased sensitivity towards the symptoms of the disease. This may generally support people to use formal care if the social environment also encourages them to do so. Furthermore, normalising dementia within society would be destigmatising and would thus facilitate access to formal care.

c) Actifcare in-depth interviews with experts: Public awareness; experts referred to various means of raising awareness, e.g. education, using mass media or campaigns such as “Dementia Friends”, and involving celebrities (Broda et al., 2016).

d) Actifcare scoping review: The positive effects of awareness and information-focused interventions were identified (Røsvik et al., 2016).



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