



BEST PRACTICE RECOMMENDATIONS

From the Actifcare Study

Access to Community Care Services

For Home-Dwelling People with Dementia and Their Carers

Short version

Home-dwelling people with mild and 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 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, (<http://www.actifcare.eu/>), 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 recommendations are based on the research findings of the Actifcare work packages, marked as letters in raised font following each recommendation/ set of recommendations. For details regarding how the supporting findings are related to each recommendation, please see the full version of the recommendations (<http://www.actifcare.eu/>). The findings include:

- 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);
- f) Actifcare one-year cohort study focusing on the needs and quality of life of people with dementia and their informal carers (Kerpershoek, 2017b); and
- g) Other supporting findings.



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^{b,c,d,g}

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**

2. The contact person or other personnel delivering services should: ^{a,b,c,d,e,g}

- 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**
- 2.3. regularly assess the needs of the person with dementia and his/her carer/family, including psychosocial needs**
- 2.4. provide individualised information about dementia and available services to people with dementia and their carer/family**
- 2.5. provide continuous support and advice to the people with dementia and their carer/family**

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

3. Services should be affordable and monetary support should be offered when needed ^{a,d,e}

4. Information about dementia and dementia services should be accessible ^{b,c,d,e}

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**

5. Other parties of the health care system should have knowledge and provide information about available community services as well as ensuring referrals ^{a,b,d,e,g}

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

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

**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

7. Psychoeducation should be provided following a diagnostic disclosure ^e

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.

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 ^b

9. Coordination of services should be ensured, and cooperation between people with dementia, their families, professionals, and volunteers should be enhanced ^{b,c,e}

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 ^{b,e}

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 ^{b,c,e}

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 ^{b,e}

13. People with dementia should have access to dementia-specific services provided by specially trained personnel appointed to these services ^b
14. Services should aim at enhancing independence in people with dementia and in carers ^b

C. ENABLING FACTORS

Recommendations that can facilitate access or use indirectly

15. Access to services should be equitable and needs driven ^f
16. Support groups for people with dementia and their carers/families should be facilitated locally ^f
17. Service providers should ensure that proper training for health care professionals is provided ^{b,e}
18. Health care personnel should undertake training in safeguarding dignity and showing empathy and respect for people with dementia ^{b,e}
19. Health care personnel should receive training in how to deal with conflict regarding care decisions between people with dementia and their significant others ^f
20. General practitioners 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 ^{c,e}
21. General practitioners (GPs) should have an overview of the situation of the person with dementia ^b

22. The provision of care should build on the principles of person-centred care* b,c,e

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.*

23. Awareness about dementia should be increased b,c,d

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

References

- Bieber, A., Broda, A., & Stephan, A. (2014). Structural aspects of access to formal dementia care services across the European countries. *ActifCare, JPND research, Work Package 2 Deliverable D2.1*
- Broda, A., Stephan, A., Bieber, A., Bartoszek, G., & Meyer, G. (2016). Perspective of decision makers on barriers and facilitators of timely access to formal dementia care. *ActifCare, JPND research, Work Package 2 Deliverable D2.3.*
- Heinrich, S., Uribe, F. L., Wubbeler, M., Hoffmann, W., & Roes, M. (2016). Knowledge evaluation in dementia care networks: a mixed-methods analysis of knowledge evaluation strategies and the success of informing family caregivers about dementia support services. *Int J Ment Health Syst, 10*, 69. doi:10.1186/s13033-016-0100-8
- Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M. S., Stephan, A., . . . Hallberg, I. R. (2015). Dementia care in European countries, from the perspective of people with dementia and their caregivers. *J Adv Nurs, 71*(6), 1405-1416. doi:10.1111/jan.12581
- Kerpershoek, L. (2017a). Access to care. In-depth interviews with persons with dementia and their informal carers *ActifCare, JPND research, Work Package 3 Deliverable D3.2.*
- Kerpershoek, L. (2017b). Factors associated with the (non)-use of formal care services. *ActifCare, JPND research, Work Package 3 Deliverable D3.1.*
- Nolan, L., McCarron, M., McCallion, P., & Murphy-Lawless, J. (2006). Perceptions of Stigma in Dementia: An Exploratory Study *The School of Nursing and Midwifery. Trinity College Dublin.*



- Phillipson, L., Jones, S. C., & Magee, C. (2014). A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. *Health Soc Care Community, 22*(1), 1-12. doi:10.1111/hsc.12036
- Røsvik, J., Michelet, M., & Selbaek, G. (2016). Enhancing timely access to and utilisation of formal community care services for home dwelling persons with dementia and their informal carers. Interventions, policies and recommendations. A scoping review *ActifCare, JPND research, Work Package 5 Deliverable D5.1*.
- Stephan, A., Bieber, A., Broda, A., & Meyer, G. (2016). Experiences of people with dementia, informal carers and healthcare professionals with access to formal care. *ActifCare, JPND research, Work Package 2 Deliverable D2.2*.
- Wolfs, C. A., de Vugt, M. E., Verkaaik, M., Verkade, P. J., & Verhey, F. R. (2010). Empowered or overpowered? Service use, needs, wants and demands in elderly patients with cognitive impairments. *Int J Geriatr Psychiatry, 25*(10), 1006-1012. doi:10.1002/gps.2451