

Dementia Gateway: Working in partnership with carers

This summary highlights key messages from the research on ‘working in partnership with carers of people with dementia’.

Key messages

- Care should be tailored around the person. If such an approach is aimed at both the carer and the person with dementia in parallel, it will be more sustainable than if it was aimed at either one or the other.¹
- There is not much research on ‘working in partnership with carers’ in the context of dementia care. Most research on carers is focused on their views and experiences in the context of their situations and possible ways of helping them.
- Carers and professionals should work together so the person with dementia benefits from their combined expertise and knowledge.⁴
- Professionals should recognise that carers may not know much about dementia and how it changes over time, or what care and support is available or possible.^{4,5} They should give information and support to carers on these issues.^{4,16}
- Carers of people with dementia can suffer from higher levels of burden and depression in comparison with carers of relatives with other chronic diseases.⁷

Introduction

This summary highlights key messages from the research on 'working in partnership with carers of people with dementia' (that is, recognising the expertise that family carers can give). It is not intended to be a comprehensive review of the literature on this topic. The material on which the summary is based was identified through focused searching of the literature published from 2008 to 2012. Some material pre-dating 2008 is also referred to where necessary.

The importance of working in partnership with carers

The term 'family carer' means: 'a person or people identified by the person with dementia (if possible) as important to them, and is intended to cover a spouse, partner, child, other relative or friend and supporter'.²

The support given by a carer to a person with dementia will vary according to the nature of the symptoms and how quickly the disease is progressing,⁵ the health and abilities of the carer to provide care, and the nature and extent of other support that is available.⁴ Carers' tasks include anything from helping with daily living tasks and personal care to supporting the person with meaningful activity and managing their finances and legal issues.^{4, 5}

One of the most powerful ways in which care staff and other workers can make care for people with dementia more helpful and sustainable is by acknowledging and working in partnership with

carers.⁸ This means valuing the experiences of both the person with dementia and their carers.

Working in partnership with carers is a central aim of policy and practice in the United Kingdom.¹⁰ Government policy highlights the need to identify carers at an early stage and value them as expert partners in care.⁹

Personalised care approaches (that is, care that takes into account the person's preferences, likes, dislikes, religion and so on) that are aimed at both the carer and the person with dementia in parallel are more likely to be sustained than those that are aimed at either one or the other.¹

The status of research

There is not much research on working in partnership with carers in the context of dementia care. Research on carers is focused mainly on their views and experiences in the context of their situations and possible ways of helping them.

There is very little research on what is the best way of involving the family in care¹ or interventions in a care home.¹ Also, the research on carers of people with early-stage dementia is inadequate.⁶ But, there is a significant amount of research on the experience of carers of older people with dementia.³ This research takes place over a relatively short period of time though – any study of carers' experiences should take place over a number of years to get a real insight into how the caregiving process changes over time.³

Some principles of working together

Carers as experts

It is essential that both carer and professional work together in partnership so that the person with dementia will benefit from the bringing together of their combined expertise and knowledge.⁴ Carers will usually have firsthand knowledge of the person with dementia, including knowledge of their likes, dislikes, life history and values, and are therefore in a good position to advise professionals⁴. The carer is the expert with knowledge and information about their relative.¹¹ It is important to recognise that the way carers see things will be different from the way people with dementia see things, but both are valid and important.¹¹

Professional support for carers

Being able to act as the voice for a person with dementia if they are not able to communicate, is a strength that carers have but may not realise. Carers need the support and affirmation of professionals to recognise this fact and develop their confidence to work with professionals so that together they can find solutions to care issues.¹¹ Professionals should also recognise that carers may not know much about dementia and how it becomes more advanced over time, or what care and support is available or possible.^{4,5} They should give information and support to carers on these issues.^{4,16}

Staff knowledge and skills needed

Carers think that staff who work with people with dementia need to have certain knowledge and skills. These are: knowledge about dementia; care that is tailored around the person with dementia (taking into account things like their preferences, likes, dislikes, religion and so on); the ability to communicate well with people with dementia; the ability to develop good relationships; the ability to offer support; and the ability to help people with dementia to take part in activities.¹⁷

Caring and the impact on carer health

The impact on carers of supporting a loved one with dementia is profound.^{5,8,10,12} Carers of people with dementia can suffer higher levels of burden and depression in comparison with carers of relatives with other chronic diseases.⁷ Family carers of people with dementia are frequently old¹⁰ and frail themselves, with poor physical and mental health, and a reduced quality of life with limited ability to look after their own health.^{5,12,13} Children or young people under the age of 18 may also find themselves in a caring role if their parent has young onset dementia¹² and may suffer distress and grief for the parent they have lost¹⁴ and anxiety about leaving home because of concern for their parent.¹⁵

Unlike paid care workers, a family carer's responsibilities are ongoing and relentless, and stress, emotional strain and sheer exhaustion can lead to problems in providing the best possible care.^{4,5,16,17} Both the carer and their loved one need advice and support at the right time, and it is important that these are tailored to their situation.^{8,18}

The entwined relationship between carer and relative

The life of the person with dementia and their carer will often be closely entwined, especially if the person with dementia is being cared for by their partner or a relative living in the same house.^{4,19} In these situations, what would be best for the person with dementia and what would be best for their carer cannot be assessed separately. Professionals should think about how best to deal with and balance the different needs and interests of the person with dementia and their carer.⁴

Support needs of carers in their own right

It is important to attend to what carers, in their own right, need in terms of support, including the need for information.^{4,5} But carers often say that information tailored to them as people is rarely supplied to them at the right time.²⁰ Carers also need emotional and practical support, such as support from family and friends,^{3,6} and have a right to an assessment of what they need for support in their own right, such as help in the home, changes that can be made to the house to help them in their caring role and respite care.^{4,9,21}

Black and minority ethnic carers

For black and minority ethnic carers of people with dementia, there may be cultural issues that need to be thought about by services that provide care and support.²² Black and minority ethnic carers, and indeed those from the majority United Kingdom

population, may not be familiar with the term 'carer' and may not see themselves as one because they do not tell the difference between tasks that are related to an illness or disability and those that are rooted in family duties and love.^{22,23} Where giving care to someone is seen as a natural thing to do, this can mean that carers do not ask for professional help as this might be seen as a failure on their part to carry out their caring duties as, for example, in some south Asian communities.²⁴

Carer issues around diagnosis

Information is a very important part of support for carers;¹² and carers need information about the practical and financial support that is available around the time of diagnosis of a relative.⁹ In one study carried out with carers in Wales, the fact that their relative had not got an official diagnosis made them less able to access services in the community as local policy said that a diagnosis is needed for access to services.¹⁶ In the meantime, carers felt confused and concerned and thought that some of the ways their relative was behaving were a result of their relative's age.¹⁶

Caring for the person with dementia at home

Health and social care policy aims to keep people in their own homes for as long as possible.¹⁶ Two-thirds of people with dementia normally live in their own homes or those of their carers, and one-third live in care homes (with both groups possibly spending some time in hospital).¹²

Delaying help seeking

Caring for a person with dementia at home can place enormous strain on the carer, and it is important for them to find help as early as possible.¹²

Psychological support can reduce carers' distress and delay admission to a care home.^{12,16} Carers tend to access services that are provided in the community late in their caregiving experience.^{5,16}

Also, they may not use services because the person they are caring for might be against it; concerns over quality of care; carer guilt; and the inconvenience and costs involved.¹⁶

What carers say about services in the community

Carers say that they need human contact from services that shows empathy and understanding and provides the right information, but carers are often not very assertive.¹⁶ So offering support before it is asked for by carers can have a positive effect.

Awareness and understanding in society

People with dementia and their carers access all types of public and community services, including housing, emergency services, utilities.¹² Employers and people they come into contact with need to understand and support the challenges that they face.¹²

Financial implications

The financial impact of caring can be quite dramatic where the person with dementia, or their main carer, is the main person in the household who brings in income.^{4,5} This is especially so where a carer has to leave their job so that they can continue caring.¹⁴

Supporting carers in the move from home to care home

Involving carers

It is essential that carers feel fully involved and supported if their relative moves into a care home. Carers need to make sure that the identity, role and status of their relative is preserved at this time of transition and make sure that the care home staff are aware of their relative's likes, needs and values.^{25,26}

Carer role beyond care home admission

Many carers still think of themselves as carers even after their loved one has moved into a care home and it is important that the carer's continuing role is acknowledged.^{1,3,4} Carers should be encouraged to contribute to the support of their loved one for as long as they want to and as formal support increases.⁴ There should not be an 'all or nothing' assumption about the carer's desire to be involved or in their ability to cope.⁴

Supporting carers on care home visits

Relationships between staff and carers

Positive relationships between family carers and the care home staff improve quality of life for both residents and carers.²⁵ Families usually want to stay involved in the care of their relative and it is their unique knowledge about them that helps to bring about care that is person-centred (that is, care that is tailored around a person's needs and preferences, values and beliefs, culture, religion, life history and other things that are important to them).²⁵

Giving carers a say

Carers should be informed and encouraged to raise any concerns about the welfare of a relative. An independent route for complaints that is open to everyone is essential.²⁵

Hospital admissions

When a person with dementia goes into hospital, their carer may feel that they have less power, influence or authority and they may feel unsure about their caring role in the future.¹⁷ At the same time, the person with dementia may feel that they have been abandoned by their carer and this may make them feel angry and frustrated. So it is important that hospital staff encourage a therapeutic relationship to develop with the carer and the person with dementia, reassuring the carer that their role is still very important.¹⁷

Advanced dementia and end of life care

Half of carers of people with advanced dementia spend more than ten hours a day caring.²⁷ People with advanced dementia should be seen as having a terminal illness and should therefore be able to access end of life and palliative care regardless of where they live.²

Carers of people who are nearing the end of life need support to help them recognise when their loved one is nearing death and to cope with this, but this may not be available because professionals are not open about a diagnosis of terminal illness.⁹ Family carers go through an extended period of loss, including loss of choice and control, when the person

they care for is moved into institutional care such as a care home or hospice.²⁸ Carers then have mixed emotions when their loved one dies, from a mistaken belief (by other people) that all the grieving is over at death,^{28,29} to relief after a particularly long spell of caregiving.²⁸ Care staff need to be sensitive to these issues.

Implications from the research

There is not much research on the things that encourage partnership working between family carers, people with dementia and care staff. Carers have a valuable part to play as experts in the care of their loved one. Their knowledge should be used more and more to develop training courses and tools for staff who work with people with dementia.

Understanding the needs of carers, their satisfaction with services and use of services is a fundamental aspect of planning how services are provided in the future.¹⁶ But there is not much research on this, especially research that takes a long-term view.

There is a need for better communication, information and emotional support for carers^{4,12,16} and these things need to be built into all dementia-related care and support services.

The person with dementia needs to be treated at all times with patience and respect for their dignity and for who they are as a person³⁰ and this is most likely to be done when professionals work together in partnership with carers.

References

1. Keady, J. and Swarbrick, C. (2011) 'Dementia care: family and significant others', *Nursing and Residential Care*, vol 13, no 11, pp 546-547.
2. Moriarty, J., Rutter, D., Ross, P.D.S. and Holmes, P. (2012) *SCIE Research briefing 40: End of life care for people with dementia living in care homes*, London: Social Care Institute for Excellence.
3. Lin, M.-C., Macmillan M. and Brown, N. (2012) 'A grounded theory longitudinal study of carers' experiences of caring for people with dementia', *Dementia: The International Journal of Social Research and Practice*, vol 11, no 2, pp 181-197.
4. Nuffield Council on Bioethics (2009) *Dementia: Ethical issues*, London: Nuffield Council on Bioethics.
5. World Health Organization (2012) *Dementia: A public health priority*, Geneva: World Health Organization (available at http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf, accessed 5 July 2013).
6. Quinn, C., Clare, L., Pearce, A. and van Dijkhuizen, M. (2008) 'The experience of providing care in the early stages of dementia: an interpretative phenomenological analysis', *Aging and Mental Health*, vol 12, no 6, pp 769-778.
7. Schoenmakers, B., Buntinx, F. and Delepeleire, J. (2010) 'Supporting the dementia family caregiver: the effect of home care intervention on general well-being', *Aging and Mental Health*, vol 14, no 1, pp 44-56.
8. Watkins, J., Stanton, L., Saunders, B., Lasocki, J., Chung, P. and Hibberd, P. (2011) 'Working in partnership with family carers: the importance of learning from carers' experiences', *Quality in Ageing and Older Adults*, vol 12, no 2, pp 103-108.
9. Marie Curie Cancer Care (2012) *Committed to carers: Supporting carers of people at the end of life*, London: Marie Curie Cancer Care.
10. Department of Health (2010) *Recognised, valued and supported: Next steps for the carers strategy*, London: Department of Health.
11. Ghiotti, C. (2009) 'The Dementia End of Life Care Project (DeLCaP): supporting families caring for people with late stage dementia at home', *Dementia: The International Journal of Social Research and Practice*, vol 8, no 3, pp 349-361.
12. Department of Health (2009) *Living well with dementia: A national dementia strategy*, London: Department of Health.
13. Age UK (2010) *Invisible but invaluable: Campaigning for greater support for older carers*, London: Age UK.
14. Armstrong, M. (2003) 'The needs of people with young-onset dementia and their carers',

- Professional Nurse*, vol 18, no 12, pp 681–684.
15. Hunt, D. (2011) ‘Young-onset dementia: a review of the literature and what it means for clinicians’, *Journal of Psychosocial Nursing and Mental Health Services*, vol 49, no 4, pp 28–33.
 16. Cascioli, T.R. and Al-Madfai, H. (2008) ‘An evaluation of the needs and service usage of family carers of people with dementia’, *Quality in Ageing*, vol 9, no 2, pp 18–27.
 17. Douglas-Dunbar, M. and Gardiner, P. (2007) ‘Support for carers of people with dementia during hospital admission’, *Nursing Older People*, vol 19, no 8, pp 27–30.
 18. Fortinsky, R. (2008) ‘Diagnosis and early support’, in M. Downs and B. Bowers (eds) *Excellence in dementia care: Research into practice*, Maidenhead: Open University Press, pp 267–284.
 19. O’Shaughnessy, M., Lee, K. and Lintern, T. (2010) ‘Changes in the couple relationship in dementia care: spouse carers’ experiences’, *Dementia*, vol 9, no 2, pp 237–258.
 20. Manthorpe, J., Samsi, K. and Rapaport, J. (2012) ‘“More of a leg to stand on”: views and usage of the Mental Capacity Act 2005 among staff of local Alzheimer’s Society and carer organisations’, *Ageing and Mental Health*, vol 16, no 1–2, pp 102–109.
 21. National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006) *Dementia: Supporting people with dementia and their carers in health and social care*, CG42, London: National Institute for Health and Clinical Excellence and Social Care Institute for Excellence.
 22. Moriarty, J., Sharif, N. and Robinson, J. (2011) *Black and minority ethnic people with dementia and their access to support and services*, London: Social Care Institute for Excellence.
 23. Townsend, J. and Godfrey, M. (2001) *Asian experiences of caregiving for older relatives with dementia: An exploration of barriers to uptake of support services*, Leeds: Nuffield Institute for Health.
 24. Lawrence, V., Murray, J., Samsi, K. and Banerjee, S. (2008) ‘Attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK’, *British Journal of Psychiatry*, vol 193, no 3, pp 240–246.
 25. Alzheimer’s Society (2007) *Home from home: A report highlighting opportunities for improving standards of dementia care in care homes*, London: Alzheimer’s Society.
 26. Alzheimer’s Society (2010) *My name is not dementia: People with dementia discuss quality of life indicator*, London: Alzheimer’s Society.

27. Alzheimer Europe (2006) *Who cares? The state of dementia care in Europe*, Luxembourg: Alzheimer Europe.
28. Goodman, C., Evans, C., Wilcock, J., Froggatt, K., Drennan, V., Sampson, E., Blanchard, M., Bissett, M. and Iliffe, S. (2010) 'End of life care for community dwelling older people with dementia: an integrated review', *International Journal of Geriatric Psychiatry*, vol 25, no 4, pp 329–337.
29. Adams, K. and Sanders, S. (2004) 'Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: a mixed method analysis', *Dementia*, vol 3, no 2, pp 195–210.
30. Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J.-L., Ferri, C., McCrone, P. Snell, T. and Stewart, R. (2007) *Dementia UK: A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK*, London: King's College London, London School of Economics and Alzheimer's Society.

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