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Newbronner, L., Chamberlain, R, Borthwick, R et al. (2 more authors) (2013) *A road less rocky:supporting carers of people with dementia*. Research Report. Carers Trust , London.

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A Road Less Rocky

– Supporting Carers of People
with Dementia

Executive Summary

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Executive summary

In May 2012, Carers Trust commissioned the Social Policy Research Unit at the University of York, and Firefly Research & Evaluation, to undertake research to ‘understand more about the caring journey undertaken by carers of people with dementia and the challenges they face, from initial concerns that there may be something wrong to experiences at the end of life and afterwards’. Specifically, it wanted to know:

- What are the key stress points in the caring journey when support or advice is most needed?
- What are the key types of advice and support needed at what times, in relation to caring for the person with dementia?
- What are the key types of advice and support needed at what times, in relation to the carer’s own life and wellbeing?

The report brings together the findings from the research, which had three stages:

- A limited literature review of recent research with carers of people with dementia.
- Interviews and focus groups with a total of 46 carers in four locations across the UK (two in England, one in Scotland and one in Wales).
- A national survey of carers of people with dementia, which elicited 325 responses.

The literature review found a reasonable number of papers that examined the experiences of carers of people with dementia, but there was a dearth of empirical research which examined interventions developed to support carers of people with dementia.

A distinctive aspect of this research is that it explored (through the interviews, focus groups and the survey) the information and support needs of carers along their caring journey. Every carer’s journey is unique and carers’ preferences will differ. However, the study has shown that there are a number of critical points along the journey where carers most value information and where support is most needed. It is important to note that while critical points for carers are

often linked to the progression of the illness, they may be different to the critical points experienced by the person with dementia. Furthermore, they are not necessarily neatly sequential, and may be affected by many other factors, including carers' own health and circumstances. Together, the evidence from the literature review and the information provided by the carers involved in the study have highlighted a range of information, advice, support and services which can help carers at each of the critical points:

When dementia is diagnosed

- All professionals, but particularly GPs, listening to and taking account of carers concerns.
- Timely diagnosis (including access to diagnostic tests and information about them).
- Access to specialist multi-disciplinary teams (for example, in memory clinics, early onset dementia services, regional services for rare dementias).
- Advice and information about dementia-related medication (and, where appropriate, interactions with other medications).

When the carer takes on an 'active' caring role

- Information about dementia and its possible impact and progression.
- An information 'checklist' for professionals involved in supporting people with dementia and their carers around the time of diagnosis of dementia, to ensure that core information is given consistently.
- Signposting to local and national information sources about dementia.
- Advice about legal issues (for example, lasting power of attorney), managing money and benefits/financial support for people with dementia and carers.
- Information about support available and key contacts for the future.
- A timely carer's assessment.

When the capacity of the person with dementia declines

- Repeated or topped up core information and advice at later points along the caring journey and by all the different professionals who come into contact with carers and people with dementia.
- Ongoing (but not necessarily frequent) support or contact with a mental health worker and (where appropriate) support and advice from a social worker.

- Information about, and easy access to, an assessment of the person with dementia's eligibility for social care support and regular reviews thereafter; these should always include questions about the carer's willingness and ability to continue caring and any support the carer needs to do so.
- Personal care at home provided by a small group of care workers who are trained to care for people with dementia.
- Practical support in the home, and recognition in assessments of social care eligibility and carers' assessments that practical support in the home can be very important in managing a caring situation.
- Positive advice about coping with dementia.

The three critical points – diagnosis, taking on an 'active' caring role and the decline of the person with dementia's capacity – which occur early in the caring journey, will arise for the majority of carers. They are extremely important opportunities for professionals and services to provide carers with initial information, advice and signposting.

When the carer needs emotional support and/or a break from caring

- Support from informal networks and local communities, and formal services which complement these.
- Carer support groups, 'buddying' and groups/activities for both the carer and the person with dementia (for example, dementia cafes).
- Active signposting by professionals to national and local carers support services.
- Professionals recognising when carers need emotional support.
- Professionals working with carers to plan time off from caring, rather than waiting for carers to reach a crisis point.
- Information about, and the availability of, different (and flexible) respite care options, including in-home, day and residential respite.
- Support for carers to continue working and carrying out other family/community roles.

When the person with dementia loses their mobility

- Professionals anticipating the person with dementia losing their mobility and working with the carer to put things in place to deal with this.

- Timely and appropriate provision of equipment and adaptations, or advice about these if carers are paying for them themselves.
- Advice and training for carers in lifting and handling.

When the person with dementia has other health problems

- Recognition of the role carers play in undertaking day-to-day healthcare tasks, and advice and training in undertaking these.
- Good routine healthcare for the person with dementia and a more holistic approach to assessment and treatment which take account of both their physical health needs and their dementia.
- Information, advice and advocacy for carers who think the person with dementia may be eligible for NHS Continuing Care funding.

When the carer has to cope with behaviour problems

- Information about common behaviour problems and positive strategies for dealing with them.
- Advice and support for carers in managing behaviour problems, including support from a mental health professional who knows both the person with dementia and their carer.
- Information about, and the availability of, night sitting and night care services.

When the carer's own circumstances change

- Regular carers' assessments and reviews.
- Supporting carers to maintain their own health, including time away from caring to attend for example, appointments or screening services.
- Support to maintain/obtain employment and advice about balancing work and caring (including alternative care options and financial issues).

When the person with dementia becomes incontinent

- Professionals anticipating when the person with dementia's incontinence is becoming a problem and working with the carer to plan ahead for how to deal with it.
- Adequate and appropriate incontinence supplies.
- Information and advice about dealing with incontinence and where necessary, support from a specialist continence advisor who understands dementia.
- Practical help with laundry, either by providing washing and drying equipment in the home or through laundry services.

When decisions about residential care and end of life care have to be made

- Advice and support from a trusted professional when making decisions about continuing to care at home, residential care and end of life care, and recognition that this may involve helping carers, family members and the person with dementia work through conflicting views and wishes.
- Clear information about different care options and where appropriate, quality information about residential care, including specialist providers for people with rare forms of dementia or early onset dementia.
- Active involvement of carers in decisions about end of life, in particular decisions about active intervention to prolong life and whether the person with dementia should be transferred to hospital at the very end of their life.

What is important at all these critical points is that carers know who to contact in order to get advice and support or be referred to someone else who can provide it. In particular, carers emphasised the need for professionals who have a good knowledge of dementia; an understanding of carers' needs and issues; know both the person with dementia and the carer; and are able to take a proactive approach.

The evidence from this study has highlighted a number of critical points when carers' needs for information, advice and help are particularly acute – and these are also points at which they are likely to encounter professionals and service providers. This means that all professionals and service providers will need to check that carers have the information and advice appropriate for the challenges they are currently experiencing and that they know where to go for further information and advice when future difficulties arise. Failure to recognise carers' needs at these points risks the breakdown of care-giving and the carer's health and other costs for carers and wider society.



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