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A Road Less Rocky

– Supporting Carers of People
with Dementia

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Rachel Borthwick, Martin Baxter,
Caroline Glendinning



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Please note identities of carers have been changed in the interest of privacy.

Contents

Foreword	5
Executive summary	6
Chapter 1 Introduction	11
1.1 Background	12
1.2 Policy context	13
1.3 Methods	14
1.4 Profile of the carers who took part in the research	16
Chapter 2 Recent research on carers of people with dementia: findings from the literature review	19
2.1 Situations where support is required	19
2.1.1 Different groups of carers	19
2.1.2 Dealing with the emotional/psychological effects of caring	20
2.1.3 Carers' experiences in relation to the dementia journey	21
2.1.4 Varying needs for information and education	21
2.1.5 Dealing with difficult behaviours of the person with dementia	22
2.1.6 Making decisions for the person with dementia	22
2.2 Support and services useful at different stages in providing care	22
2.2.1 Obtaining a diagnosis	22
2.2.2 Local communities and support networks	22

2.2.3	Getting a break from caring	23
2.2.4	Support groups	23
2.2.5	Practical help	24
2.2.6	Tailored support	24
2.2.7	Support for decision making	25
2.2.8	Other support and services that were useful at different stages	25
2.3	Unmet need for services and support	26
2.3.1	Information and advice	26
2.3.2	Awareness of the needs of different groups of carers	27
2.3.3	Flexibility in service provision	27
2.3.4	Access to services	28
2.3.5	Emotional support	28
2.3.6	Recognition of the carer's 'expert' role	28
2.3.7	Carers' assessments	29
2.3.8	Help with changing/difficult behaviours	29
2.3.9	Other areas of unmet need	29
2.3.10	Barriers to taking up service provision	30

Chapter 3 Information and support needs along the caring journey **31**

3.1	Initial problems and diagnosis	32
3.1.2	Medication	34
3.2	Taking on a caring role	34
3.2.1	Information about dementia	34
3.2.2	Information about support available	36
3.2.3	Carers' assessments	36
3.2.4	Legal issues and managing money	37

3.2.5	Benefits and financial support	37
3.3	Changing capacity of the person with dementia	38
3.3.1	Ongoing monitoring by health services	38
3.3.2	Social care assessment and review	40
3.3.3	Personal care at home	43
3.3.4	Practical help in the home	45
3.3.5	Positive advice about coping with dementia	45
3.4	Emotional support and a break from caring	46
3.4.1	Emotional support for carers	46
3.4.2	Time off from caring	48
3.5	Loss of mobility	51
3.5.1	Lifting and physical care	51
3.5.2	Aids and adaptations	52
3.6	Co-morbidities and general health care	52
3.6.1	General health care	53
3.6.2	Holistic approach to assessment and treatment	53
3.6.3	Advice/training in undertaking healthcare tasks	54
3.6.4	Hospitalisation and discharge planning	54
3.6.5	NHS continuing healthcare	55
3.7	Behaviour changes and problems	55
3.7.1	Managing challenging behaviours	55
3.7.2	‘Sundowning’ and night time disturbance	57
3.8	Changes in carers’ own circumstances	58
3.9	Dealing with incontinence	60
3.10	Decisions about residential care and end of life care	62

Chapter 4	Conclusions and key messages	65
Appendix A	Methods	71
	Literature review	71
	Interviews and focus groups with carers	73
	National survey of carers	74
Appendix B	Example of a caring journey	76
Appendix C	Additional data from the survey	78
	References	85
	General references	85
	References from the literature review	86

Foreword



It is estimated that one in three people will care for a person with dementia in their lifetime. Dementia is a degenerative condition that has a wide reaching effect on the lives of those with the condition and those that care for them.

Carers Trust was delighted to receive the support of Ecclesiastical Insurance so that we were able to undertake this comprehensive research into the needs of carers of people with dementia from the point of concern that a family member or friend may have dementia to the end of life. The research has long been needed to highlight exactly what the key points of intervention for carers are and what types of information, advice and support they require at these junctures.

This research sets out simply what is needed and why, to make what is a difficult journey just a bit easier. The evidence is clear, straightforward and compelling. It shouldn't be hard to put in place the information, advice and guidance carers of those with dementia are asking for and need and yet we know they frequently don't receive it.

Carers Trust hopes that this valuable research will enable policy makers, commissioners and practitioners to develop the right types of support that carers desperately need, as well as ensuring that they are seen as walking hand-in-hand with the person with dementia. In this way, by supporting, including and recognising them, everyone can benefit.

Thea Stein
Chief Executive

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 takes 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.

1 Introduction

About Carers Trust

Carers Trust is a major new charity for, with and about carers, formed by the merger of The Princess Royal Trust for Carers and Crossroads Care. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with our Network Partners – a unique network of 118 independent carers centres, 63 Crossroads Care schemes and 96 young carers services. Together we are united by a shared vision for carers – to make sure that information, advice and practical support are available to all carers across the UK.

Over the past two years, Carers Trust (and the former The Princess Royal Trust for Carers) (in partnership with Network Partners) has been building a programme of work focusing on the needs of older carers. Through this work, Carers Trust identified that it needed to understand the needs of carers of people with dementia more fully if it was to successfully raise awareness of the difficulties they face and promote more effective support for them. 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?

This report brings together the findings from the research. In this first chapter we set out the background to the study and the current policy context. The methods used to conduct the research are also briefly described, with a more detailed presentation of methods in Appendix A. Chapter 2 sets out the main

findings from the literature review and Chapter 3 – the caring journey – highlights the critical points along the journey where carers most need information, advice and support. Lastly, Chapter 4 draws together the main conclusions and key messages from the research.

In Chapter 3 we use a number of personal stories to illustrate key issues. Some of these are taken from the interviews and focus groups, while others are drawn from information provided by survey respondents (some of whom provided very detailed information). To make them more accessible we have given the carers and the person they care for names but it is important to note that while the facts of the stories are real, the names have been changed.

1.1 Background

There are around 800,000 people with dementia in the UK and an estimated 670,000 family and friends acting as primary carers to someone with dementia. The current financial cost of dementia to the NHS, local authorities and families is £23bn a year; this is expected to grow to £27bn by 2018 (Alzheimer's Society, 2012).

The majority of people with dementia are cared for at home by a relative or friend. The average age of (unpaid) family carers is between 60 and 65 years, and many are much older. Caring for someone with dementia can be different from caring for people affected by other types of illness or disability, because of the complex, unpredictable and progressive nature of the illness. Carers of people with dementia are likely to have higher than normal levels of stress, and report higher levels of depression than carers of other older people (Wills and Soliman, 2001; Moise et al, 2004). Consequently, carers' needs for practical and emotional support to relieve the emotional stress of caring are especially high. Recent research by The Princess Royal Trust for Carers and others (The Princess Royal Trust for Carers and Crossroads Care, 2009; Alzheimer's Society, 2012) confirms that carers (especially older carers) of people with dementia face particular difficulties. Almost half the respondents to a recent survey of people with early onset dementia felt their carer was not, or was only sometimes, getting the support they needed in their caring role (Alzheimer's Society, 2012).

Carers of people with dementia are often in their 50s or 60s and are balancing work and caring for parents and others (Arksey et al, 2005) or they are older people caring for a partner. Research (over more than 20 years) has clearly shown that caring has an adverse effect on carers' own physical and emotional health (for example, Hirst, 2003, 2005; Glendinning et al, 2009). Yet the more demanding the care is, the less likely it is that carers will have time to look after, or seek help in relation to, their own health (Arksey et al 2002); female carers in particular are less likely to see their GP than would be expected (Arksey and Hirst, 2005). The Princess Royal Trust for Carers survey of older carers (The Princess Royal Trust for Carers, 2011) also supports these research findings.

1.2 Policy context

In the light of this research, there have been a number of important policy developments in relation to dementia and support for carers. In England, Living Well with Dementia - A National Dementia Strategy was launched in 2009. Scotland's National Dementia Strategy was published in 2010, with strategies for Wales (National Dementia Vision for Wales) and Northern Ireland (Improving Dementia Services in Northern Ireland) following in 2011. They outlined a wide range of objectives for health, social care and wider society, including improving public and professional awareness and understanding of dementia. Timely diagnosis and intervention for all and good quality information for those diagnosed with dementia and their carers were highlighted, as well as the importance of, in England, the implementation of the Carers Strategy.

Since the launch of the English National Dementia Strategy, the Government has identified a number of areas of progress in dementia care in England, including: 94% of (then) primary care trusts (PCTs) having a dedicated memory service for dementia; more than 90 leading organisations joining the Dementia Action Alliance, and the launch of a Dementia Commissioning Pack in July 2011.

Building on this progress, The Prime Minister's Challenge on Dementia, launched in 2012 (with a progress report in 2013), focuses on three areas:

- Driving improvements in health and care.
- Creating dementia friendly communities that understand how to help.
- Better research.

The improvements in health and social care aim to: increase diagnosis rates through regular checks for over 65s; provide financial rewards for hospitals offering quality dementia care; develop a Dementia Care and Support Compact signed by leading care home and home care providers; and promote local information on dementia services.

Alongside these dementia policy initiatives, the refreshed Carers Strategy of 2010 set out the Government's priorities for carers and identified the actions to be taken to ensure best outcomes for carers, including:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage.
- Recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual packages of care.
- Enabling those with caring responsibilities to fulfil their educational and employment potential.
- Personalised support both for carers and those they support, enabling them to have a family and community life.
- Supporting carers to remain mentally and physically well.

Local authorities and clinical commissioning groups are required to have local carers strategies and plans, and budgets for supporting carers. The NHS Outcomes Framework for 2013 placed specific emphasis on the provision of carers breaks and support. In social care, personal budgets for carers as well as for people with dementia should create increased choice and independence.

Together, these policy developments could, if they work as intended, have a significant impact on the caring journey of those people who care for someone with dementia. However, the extent to which they are being implemented locally is very variable, and the research described in Chapter 2 suggests that many carers are still finding themselves under-informed and over-burdened, with the provision of information, support and services lagging behind their needs.

1.3 Methods

The three stages of the study are briefly described here. A full description of the methods used in each stage is contained in Appendix A.

Literature review

A limited literature review was conducted between July and October 2012 in order to identify the most relevant recent research into supporting carers of people with dementia. The aim of the literature review was to identify recent empirical research conducted on, or with, carers of people with dementia and reporting their experiences of caring; the support and services they found useful at different stages in providing care; and their unmet needs for services and support.

Interviews and focus groups with carers

All Carers Trust Network Partners across the UK were invited, by Carers Trust, to be involved in this stage of the research. From these, 20 Network Partners volunteered to take part. Four were purposefully selected to ensure a spread across England (two), Scotland and Wales, urban and rural areas, and communities with different ethnic and socio economic make-up. Network Partners were asked to distribute information about the research to carers they were in contact with and through other local organisations and networks, with the aim of each recruiting five carers to participate in individual face-to-face interviews, and up to eight carers to participate in a focus group.

The individual interviews were conducted using an approach which enabled the 'carer's journey' to be captured, through the researcher putting together a timeline with the carer to track separately the services, support and information for the person with dementia and for the carer themselves (illustrated in an example in Appendix B). The timeline was completed by the researcher together with the carer. Researchers used semi-structured topic guides for both the individual interviews and focus groups. The focus groups discussed and refined the ideas that began to emerge from early analysis of the individual interviews.

Overall, 22 carers were involved in individual interviews and 24 were involved through focus groups, totalling 46.

National survey of carers

A national survey of carers of people with dementia was carried out in spring 2013. The content of the survey was informed by the literature review and the findings from the interviews and focus groups. It gathered biographical information about the carer and the person with dementia and then had four main sections: diagnosis; assessment; information and advice; services and support.

The survey was available in both online and paper versions and was conducted across the UK. All Carers Trust Network Partners were asked to recruit a minimum of four carers to complete the survey either online by themselves, online with support from Network Partner staff or on paper. 12 ‘volunteer’ Network Partners who were willing to be more actively involved in the research, took extra steps to support carers who might be regarded as ‘hard to reach’ to complete the survey. The survey was also publicised through other organisations working with carers and/or people with dementia, including the Alzheimer’s Society, Alzheimer’s Scotland, Dementia UK and Carers UK, and directly to carers via Twitter, Facebook and Carers Trust’s website. Responses were received from 325 carers (287 online and 38 on paper). Table 1 below shows the number of responses by the regions of the UK.

The quantitative data from the survey was analysed using Excel and the free text responses were analysed thematically alongside the data from interviews and focus groups. Key data from the survey has been incorporated into Chapter 3, with additional data being presented in Appendix C.

Table 1 Survey responses by UK region

Country/region	Survey returns	Proportion of total returns (n=290)	Population 2011	Proportion of population
East England	11	3.8%	5,847,000	9.3%
East Midlands	10	3.4%	4,533,000	7.2%
Greater London	48	16.6%	8,173,000	12.9%
North East England	1	0.3%	2,597,000	4.1%
North West England	28	9.7%	7,052,000	11.2%
Northern Ireland	1	0.3%	1,811,000	2.9%
Scotland	37	12.8%	5,295,400	8.4%
South East England	61	21.0%	8,635,000	13.7%
South West England	34	11.7%	5,289,000	8.4%
Wales	22	7.6%	3,063,000	4.8%
West Midland	23	7.9%	5,602,000	8.9%
Yorkshire and the Humber	14	4.8%	5,284,000	8.4%
			63,182,000	
Not stated	35			
Total	325			

1. 4 Profile of the carers who took part in the research

This section provides a brief profile of the carers who took part in the study, either by participating in the interviews and focus groups, or through the survey. Table 2 gives an overview of the gender, ethnicity, age of participants, and their relationship to the person with dementia.

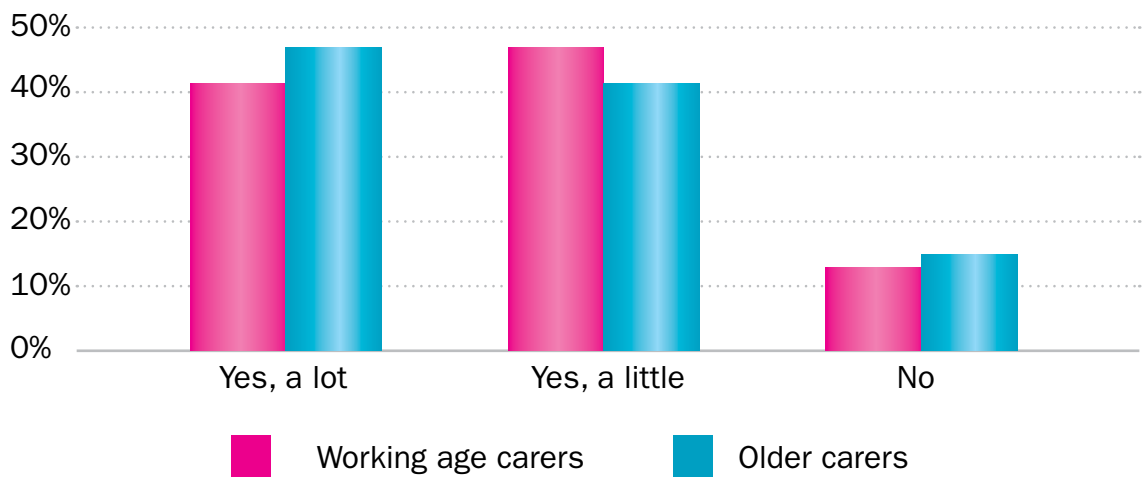
Table 2 Overview of carers participating in the study

	Interviewees (n=22)	Focus group participants (n=24)	Survey participants (n=325)
Gender			
Males	6	3	62
Females	16	21	235
Ethnicity			
White	20	22	283
Asian or Asian British	2	0	4
Black or Black British	0	1	4
Mixed heritage	0	1	4
Other ethnic group	0	0	2
Age			
16–34	0	0	10
35–64	16	10	188
65+	6	14	95
Caring for			
Spouse/Partner	7	14	118
Parent/Parent-in-law/Grandparent	14	10	171
Other family member/friend/neighbour	1	0	10

Sections 1 and 2 of the survey asked carers to provide background information about themselves and the person they care for. 23% (n=75) of respondents either chose not to complete section 1 at all or did not answer one or more questions. The percentages given here are based on the totals of those who did answer each question.

Carers' health: The survey asked carers whether they considered themselves to have a disability or long-term health problem. 33% (n=66) of working age carers said they did, with the percentage increasing to 47% (n=45) for older carers. When asked if their caring role affected their physical or mental health 40% (n=80) of working age carers said 'Yes, a lot' and a further 46% (n=92) said 'Yes, a little'. As Figure 1 shows, the figures for older carers were very similar.

Figure 1 Responses to the question ‘Has your physical and/or mental health been affected by your caring role?’



Employment status: 40% (n=116) of respondents were retired or early retired. Full-time working, part-time working and not in paid employment each accounted for around 15%. In responses to the question ‘Does your caring role affect your ability to work?’ 82% (n=162) of working age carers said that it did.

Length of time caring: Overall, over 50% of carers responding to the survey had been looking after the person with dementia for between one and five years, with around a quarter caring for five to ten years.

Caring situation: 50% of working age carers lived with the person they cared for while 84% of older carers did so. Of those who did not live with the person they cared for, nearly 60% lived under five miles away; 25% lived between five and 30 miles away; and 18% lived over 30 miles from the person they cared for. Nearly 20% of the carers completing the survey cared for more than one person, with a few (n=11) caring for two other people.

Profile of people being cared for: Overall, 92% of people being cared for were aged 65 years or over and 70% had other health problems in addition to their dementia. These included sensory impairments and mobility problems, common long-term conditions such as diabetes and arthritis, as well as a range of other conditions such as stroke, cancer and heart failure.

2 Recent research on carers of people with dementia: findings from the literature review

A focused literature review was undertaken to inform the fieldwork for the study. The aim of the review was to identify recent empirical research conducted on, or with, carers of people with dementia reporting their experiences of caring, the support and services they found useful at different stages in providing care, and their unmet needs for services and support. Search parameters were set in line with the aims of the study and the resources available; hence only empirical research involving carers of people with dementia that had been published in the UK since 2005 was included. Discussion papers, policy documents and ‘think pieces’ were excluded. Titles that were not from refereed academic journals were also excluded – inclusion in a refereed academic journal acting as a proxy indicator of quality. The total number of papers included in the final review was 44. Appendix A describes the inclusion/exclusion criteria and the search strategy in more detail. Although a reasonable number of papers were located that examined the experiences of carers of people with dementia, there was a dearth of empirical research which examined interventions developed to support carers of people with dementia. The findings of the literature review are described below.

2.1 Situations where support is required

In this section, findings are discussed which relate to carers’ experiences of caring for someone with dementia and the specific circumstances in which support is required.

2.1.1 Different groups of carers

A number of papers focused on the needs of different groups of carers of people with dementia, including male carers, those from black, Asian and minority ethnic communities and gay/lesbian carers. There was some evidence that different groups of carers may respond to offers of support in different ways or may need different kinds of support. Some men may find it difficult to adapt to the caring role and so may be reluctant to access services (Baker and Robertson, 2008; Baker et al, 2010).

Juttla and Moreland's (2009) qualitative research with Sikh carers highlights the fact that minority ethnic groups are not homogenous and assumptions should not be made about apparent cultural sameness. Lawrence and colleagues (2008) also found that there were differences in experiences of caring between and within different ethnic groups of carers. Different ideologies (which crossed ethnic boundaries) appeared to affect the carer's ability to accommodate change and sustain continuity in their relationship with the person with dementia. Some cultural traits (including fear of stigmatisation), however, can influence how much carers choose to reveal about their caring situation and can lead to a reluctance to access services and increasing isolation for carers as the dementia of the person they care for progresses (Mackenzie, 2006).

For gay and lesbian carers of people with dementia, the caring situation can be the catalyst by which their sexuality is made public through their contact with service providers (Price, 2010). Price found that carers responded in different ways to service providers in relation to their sexuality and knowing when/if to disclose their sexuality was a source of stress to carers.

Differing circumstances of carers may also affect their ability to care and their need for support. Parveen and colleagues (2011) reported that people who had multiple roles (for example, parent and employee) as well as caring for someone with dementia, found adopting the caring role more difficult. Carers of people with dementia living in rural areas also had varying needs and wanted 'flexible, joined-up services that were responsive to subtle changes in need' (McDonald and Heath, 2008, p 13).

2.1.2 Dealing with the emotional/psychological effects of caring

The emotional effects of caring for someone with dementia were explored in several papers and findings highlighted carers' need for support to deal with these effects. In Benbow and colleagues' (2009) narrative accounts of carers' experiences, people described a range of emotions related to being a carer of someone with dementia, including guilt, confusion, resentment, helplessness, grief and sadness. Carers in Callaby and colleagues' (2012) research also cited a number of these emotions as well as fear. In Cascioli and colleagues' (2008) evaluation of the needs and service usage of carers of people with dementia, carers stressed their need for support to deal with the emotional aspects of caring. All the carers in the study 'found the emotional strain of caring very difficult to deal with' (p 21). Hirst (2005) – whose prospective research did not only involve carers of people with dementia – found that carers who provided long hours of care over extended time periods had raised levels of distress (women more so than men). For spouse carers in O'Shaughnessy and colleagues' (2010) exploration of the effect of dementia on couples' relationships, uncertainty about the future led some carers to experience fear which in turn led to denial, as a way of coping. Some people said that their sense of self had been subsumed by the role of the carer and they found it difficult to balance their own needs against those of their spouse. Carers in the study expressed a need to develop emotional and practical strategies to give them a sense of control over their situation.

There was some evidence that the emotional impact of caring can have psychological consequences for carers of people with dementia and this in turn can have an impact on the carer's behaviour towards the person they are caring for. Cooper and colleagues (2010b) found that carers who exhibited more symptoms of anxiety and depression were more likely to report abusive behaviour towards the person with dementia that they were caring for. A large proportion of carers in Nurock and Wojciechowska's (2007) study into the outcomes that matter for carers of people with dementia placed high importance on the provision of psychological therapies for carers.

2.1.3 Carers' experiences in relation to the dementia journey

A number of studies reported that carers of people with dementia relate varying experiences at different stages in their caring journey. These changing experiences may require different kinds of support at different times. Downs and colleagues (2006) found that in the early stages of dementia, carers delayed contacting their GP with their concerns about the person they cared for and by the time they did, they were experiencing mounting worries and increased daily difficulties. The spouse/partner carers looking after people in the early stages of dementia in Quinn and colleagues' (2008) research went through a number of different experiences in relation to dealing with their new situation. These included changes in the balance of their relationship with their spouse/partner, restrictions in their lifestyles, learning to cope with and understand their spouse's/partner's dementia and dealing with the emotional strains of being a carer. Nurock and Wojciechowska (2007) found that the priorities of the carers in their study changed over time. Carers of people in the early stages of dementia were concerned with better diagnosis, pre- and post-diagnosis support, and help with cognitive difficulties in the person with dementia. Towards the later stages of dementia, carers were more concerned with palliative care and end of life support issues. Chung and colleagues (2008) also found that carers experienced different emotional responses along the dementia 'continuum'. Hirst (2005) found that adverse effects on the psychological wellbeing of heavily involved carers (not just carers of people with dementia) were most pronounced at the beginning and at the end of the caring journey.

In the later stages of dementia, carer burden may increase. Georges and colleagues' (2008) survey found that half of those caring for someone with severe dementia spent in excess of ten hours per day in caring tasks. McLaughlin and Jones (2011) found that carers of people with Down's syndrome and dementia became increasingly isolated as the severity of the dementia increased and existing services became unable to cope. Carers in Capus' (2005) study also described experiencing social isolation as a result of worsening dementia.

2.1.4 Varying needs for information and education

Findings from studies which examined carers' information and education needs suggest that these needs vary depending on the stage the carer is at in the caring journey (McDonald and Heath, 2008; McLaughlin and Jones, 2011). McDonald and Heath (2008) found that, in relation to development of

services for carers of people with dementia, carers' most pressing need was for information and education, given at the right time and at the right pace. Although McLaughlin and Jones' (2011) study focused on the experiences of carers of people with Down's syndrome and dementia, its findings will have some resonance for all carers of people with dementia. The research found that carers' need for information varied depending on the stage of the dementia; the authors suggest that information needs are high each time the person with dementia progresses to a new phase of their illness. It is important for support services to be aware of these varying needs and be flexible in order to respond appropriately.

2.1.5 Dealing with difficult behaviours of the person with dementia

The carers involved in Capus' (2005) study described difficulties in dealing with certain challenging behaviours by the person they were caring for, for example, repetitiveness, restlessness and difficulty in decision making. In Cooper and colleagues' (2010a) research into abusive behaviour by people with dementia, over one third of carers reported significant abuse from the person they cared for.

2.1.6 Making decisions for the person with dementia

There is some evidence that carers of people with dementia have difficulty making decisions for the person they care for when that person lacks capacity; this was found to be the case at all stages of the caring journey (Livingston et al, 2010). Carers cited resistance from the person they cared for and alterations in their family role as reasons for this difficulty. Problems with decision making were sometimes exacerbated by feelings of guilt and role conflict.

2.2 Support and services useful at different stages in providing care

Although there was very little literature found which formally evaluated the effectiveness of particular interventions for carers of people with dementia, many of the studies examined carers' views on the support that they received and what they found useful. This section highlights these positive aspects of service provision.

2.2.1 Obtaining a diagnosis

An evaluation of the needs and service usage of carers of people with dementia in Wales found that carers had valued receiving a diagnosis for the person they cared for as it gave them an opportunity to plan for the future (Cascioli et al, 2008). Mukadam and colleagues, however, found that the majority of minority ethnic carers in their study did not seek help early on and only sought services when a crisis point was reached. These carers did not see receiving a diagnosis as helpful, whereas the white British carers in the study did. The stigma of mental illness and negative experiences of psychiatric services were mentioned as barriers to seeking help by minority ethnic carers (Mukadam et al, 2011).

2.2.2 Local communities and support networks

A number of studies highlighted the value carers of people with dementia placed on the support provided by informal networks and local communities

(Blackstock et al, 2006; Egdell et al, 2010; McLaughlin and Jones, 2011; Price, 2011; Quinn et al, 2008). For the carers in Blackstock and colleagues' study (2006), who lived in remote areas of Scotland, having a supportive local community was considered invaluable. Carers in both Price's (2011) and Quinn and colleagues' (2008) studies highlighted the importance of their informal networks. For those in Price's study of lesbian carers, the support they received from friends was more helpful than that which they received from statutory or voluntary sector services. Carers of people with Down's syndrome and dementia in McLaughlin and Jones' research (2011) talked about the benefits of knowing other people who were caring for people with dementia and some also benefited, both practically and emotionally, from sharing the care. Practical support from informal networks was also of value to carers in Egdell and colleagues' study (2010) who mobilised friends and neighbours to help monitor the person they cared for, for example when they wandered. Carers reported that their informal networks affected their experiences of caring and that they either used pre-existing networks or developed new ones to respond to their needs. The study also found that the configuration of support networks altered over the caring journey (Egdell et al, 2010).

2.2.3 Getting a break from caring

There was some evidence that, unsurprisingly, carers valued getting a break from caring (Hampson, 2009; Parveen et al, 2011; Tommis et al, 2007) but Tommis and colleagues highlighted that the carers in their study seemed to value a few hours sitting service per week more than longer, but less frequent, respite breaks. Their research, which looked at rural/urban differences between carers of people with dementia and stroke, found that rural carers received less day care/sitting services than urban carers but rural carers received higher levels of respite care breaks. Urban male carers were more likely to receive day care/sitting services than rural male carers, which the authors think may explain why the urban male carers had more positive scores on the SF12 health status survey (Tommis et al, 2007). The carers of people with dementia in Hampson's study (2009) benefited from the person they cared for attending a wellbeing group because not only was it a break for the carer but the person they cared for also had improved mood and behaviour afterwards. Parveen and colleagues (2011) found that the carers in their study used activities – including work – away from the caring environment as a method of coping with the stresses of being a carer.

2.2.4 Support groups

Carers support groups were found to be of value to carers of people with dementia according to several studies. In their systematic review of information and support interventions for carers of people with dementia, Thompson and colleagues (2007) found statistically significant evidence that group-based supportive interventions impacted positively on the psychological morbidity of carers of people with dementia (but they did not find any evidence for positive impact of any other form of intervention) (Thompson et al, 2007). A weekly facilitated focus group provided for carers of people with dementia in Callaby and colleagues' (2012) research was considered successful by carers because

it involved social contact with others in the same situation and also provided physical activity. Members of therapeutic support groups in Manslow and Vandenberghe's (2010) study valued these groups because they enabled them to acknowledge their feelings and experiences. Carers also received support and validation from other members of the group. Specialist groups for black, Asian and minority ethnic carers of people with dementia gave members the opportunity to socialise without the stigma of dementia putting constraints on their enjoyment (Mackenzie, 2006). The groups also gave carers the opportunity to share their thoughts and feelings and enabled them to realise that they were not alone. Spouse carers in O'Shaughnessy and colleagues' (2010) research also benefited from being with other carers of people with dementia; they gained a sense of belonging and emotional validation from attending carers support groups. Support groups were also seen as being useful for getting information/advice and for providing learning opportunities (O'Shaughnessy et al, 2010; Quinn et al, 2008).

Groups which are provided for both the carer and the person with dementia may be helpful for some carers. A dementia cafe was felt by carers to be a safe place to share experiences and provided a basis for new social networks (Capus, 2005). Carers in Chaudhry's (2008) study found the groups useful as a place to learn about dementia and local services, and they had reduced levels of stress following the programme of seven weekly groups than they had had prior to the groups starting.

2.2.5 Practical help

A Carers UK survey of carers (including carers of people with dementia) found that the availability of practical help (such as equipment and help with maintaining the independence of the person they cared for) was very important in relation to reducing carers' stress and improving their emotional and physical health. In some cases, getting some practical help enabled the carer to continue to work but those who did not receive the right help were sometimes forced to give up work; 'a heavy penalty to pay because they did not get the ... right support at the time' (Carers UK, 2006, p 4). Lawrence and colleagues (2008) also suggested that service providers needed to promote carers' non-caregiving roles and offer practical support for them to maintain these roles.

2.2.6 Tailored support

A few studies highlighted the value of offering a range of support to different types of carers or those at different points on the caring journey. Carers of people with dementia in Innes and colleagues' evaluation of service provision in rural Scotland thought that some services may be inappropriate early on in the dementia journey (Innes et al, 2005). Lawrence and colleagues (2008) suggest that there is a need to support carers with different outlooks in different ways. If carers have a more 'traditional' view of caring (that is, they believe that caring is 'natural, expected and virtuous') then the support offered may be better utilised if the benefit to the person being cared for is emphasised. Those who could be considered to have a 'non-traditional' view of caring (that is, they believe that caring is 'unnatural', 'conflicts with expectations' and is 'lacking in virtue')

should be offered services which reinforce the value of the caring role and help to enhance the rewards of caregiving (Lawrence et al, 2008).

2.2.7 **Support for decision making**

There is some evidence that carers of people with dementia value support when they are put in the position of having to make decisions for the person they care for. Participants in Livingston and colleagues' (2010) study of carers' decision making emphasised the importance of professionals, voluntary organisations and other family members giving practical and emotional support when carers had to make decisions on behalf of the person with dementia. It was felt that doctors had an important role to play as either barriers or facilitators and they should actively encourage the person with dementia to allow sharing of information with carers. A communication tool called Talking Mats was found to assist in decision making concerning daily living when used by carers and the people with dementia that they cared for. It was felt that the relationship between the carer and the person with dementia could benefit if everyone involved felt that the views of the carer and the person with dementia had clearly been acknowledged (Murphy et al, 2010).

2.2.8 **Other support and services that were useful at different stages**

- **Information:** Information at the right time is valuable to carers as it helps them to plan their lives and make important decisions (Carers UK, 2006). Particularly in the case of new carers, the difficulties of their caring situations can be eased when they are well-informed (Yeandle et al, 2007). Carers can become informed by looking for information on the internet and in books and through watching relevant television programmes (McLaughlin and Jones, 2011). Carers in Livingston and colleagues' (2010) study indicated that carers want information but not necessarily all at once.
- **Effective communication with professionals:** Carers value effective communication with health and social care professionals, such as GPs, according to the findings from Downs and colleagues' (2006) study: 'Carers value GPs who listen to them, hear what they say, show understanding of their experiences and concerns as carers, offer help, including timely referral to other services' (p 368). Use of carer held records, which enable communication between carers and professionals, can help to reduce carer strain and enable carers of people with dementia to feel more in control (Simpson et al, 2006).
- **Training for carers:** An evaluation of a training programme for carers (not just carers of people with dementia) found that carers gained confidence, felt a sense of empowerment and became more assertive after undergoing the training programme (Yeandle and Wigfield [eds], 2011). Two thirds of the carers who did the training reported being more confident in practical caring skills. The outcomes were found to be good in relation to carers carrying out their caring role more effectively and having better access to support and services.

- **Professional support:** Support from health and social care professionals was shown to be of value in a few studies. Participants in Blackstock and colleagues' (2006) research praised service providers for giving emotional and practical support and peace of mind to carers. Innes and colleagues also found that carers of people with dementia in their study reported that positive aspects of the service provided included professional support for carers and peace of mind. The support provided was both emotional and practical – having a sympathetic yet informed listener was very important to carers (Innes et al, 2005).
- **Buddying:** McDonald and Heath (2008) reported that mutual support from other carers was seen as very important by the carers in their study. A carers' buddying scheme, where people were matched with other carers with similar backgrounds and interests, benefited participants through its informality and respect for shared experience.


2.3 Unmet need for services and support

Studies outlined a range of ways in which carers of people with dementia had unmet needs for services and support; these are outlined below.

2.3.1 Information and advice

The literature reviewed seems to indicate that there is a lack of information available to carers of people with dementia at all stages of the caring journey (Blackstock et al, 2006; Carers UK, 2006; Cascioli et al, 2008; Georges et al, 2008; Lawrence et al, 2008; Powell et al, 2010; Quinn et al, 2008; Yeandle et al, 2007). Cascioli and colleagues found that at diagnosis, carers had unmet needs for information about the nature of dementia and the causes and progression of the disease (that is, what might happen at different stages). Carers said that they wanted more information about services that were available (for example, a directory); about the legal and financial aspects of caring; and about the disease itself (Cascioli et al, 2008). Other authors also identified a lack of information being provided to carers of people with dementia at the time of diagnosis and early on in the caring journey (Georges et al, 2008; Lawrence et al, 2008; Yeandle et al, 2007). Early information about a range of subjects such as benefits, assessment, services, respite care and breaks, and rights and options at work had not been given to carers in Yeandle and colleagues' study and/or carers had not found this information easy to find. 41% of participants did not know what services for carers were available locally (Yeandle et al, 2007). Carers in Lawrence and colleagues' research who had a 'non-traditional' view of caring (see above, section 2.2.6) emphasised the importance of early provision of information. There was evidence in Powell and colleagues' (2010) study that carers had unmet information needs concerning the availability, roles and efficacy of potentially helpful technology. Quinn and colleagues recommend that carers are assisted in developing an understanding of dementia in the early stages and that this should form an integral part of the care provided from initial diagnosis and assessment onwards (Quinn et al,

2008). A Carers UK study, however, pointed out that information for carers was not enough on its own and needed to be followed up with some more concrete action in the form of support:

 Carers also say that information is not an end in itself, that for there to be real meaning, there had to be something tangible at the end of it. In other words, if a carer providing substantial care, whose health is at risk and who needs support does not get it, the information that led them to ask for support is instantly devalued in the eyes of the carer.'

(Carers UK, 2006, p 3)

2.3.2 Awareness of the needs of different groups of carers

A number of studies highlighted a lack of awareness on the part of services and professionals of the needs of different groups of carers (Blackstock et al, 2006; Jutilla and Moreland, 2009; Lawrence et al, 2008; Parveen et al, 2011; Price, 2010). British South Asian carers in Parveen and colleagues' (2011) qualitative study were unhappy with formal support services – they felt that there was a lack of awareness of their culture and that service providers used language barriers as an excuse for not providing services. All the carers in Lawrence and colleagues' (2008) research wanted services that listened to them and responded to their individual needs. Some participants in Price's research into gay and lesbian carers' experiences said that they had experienced overtly homophobic behaviour by service providers but others described mostly heterocentric and heterosexist practices by service providers (Price, 2010). Blackstock and colleagues (2006) highlighted the need for services for carers to be not only 'condition-specific' but also 'area-specific', in order that rural carers could receive services that were tailored to their needs.

Carers of people with Down's syndrome and dementia in McLaughlin and Jones' (2011) study did not always get the support they needed, either around the time of diagnosis or post-diagnosis. One carer in the study was told the diagnosis of her sibling over the phone, rather than face to face. Post-diagnosis, carers seemed to lack knowledge about what support was available to them, for example, respite care. The authors recommended that thought should be given to ways in which carers of people with Down's syndrome can be made aware of the signs of dementia as they may not be in day-to-day contact with services. Getting a timely diagnosis would allow carers more time to plan for any changes that might need to be made.

2.3.3 Flexibility in service provision

There was some evidence of a lack of flexibility in service provision/support which does not take account of the different needs of carers and their different stages in the caring journey (Blackstock et al, 2006; Innes et al, 2005; Yeandle et al, 2007). Both new and longer term carers in Yeandle and colleagues' study

reported that services were not flexible and sensitive enough for their specific needs, especially (for the longer term carers) in combining work and care (Yeandle et al, 2007). There were problems for the rural carers in Innes and colleagues' (2005) research because of services being delivered in unsuitable ways, for example, respite care being provided at the wrong time or not for long enough. The authors highlighted the need for services to be relevant to individual preferences and circumstances.

2.3.4 Access to services

Some studies suggested that a proportion of carers may have problems getting access to services for a variety of reasons, including rurality and the lack of a diagnosis for the person with dementia (Benbow et al, 2009; Blackstock et al, 2006; Cascioli et al, 2008; Egdell et al, 2010; Innes et al, 2005; Yeandle et al, 2007). The rural carers in Blackstock and colleagues' (2006) study had problems of access due to a lack of available transport to and from services that were provided, as did the rural carers in Innes and colleagues' (2005) study. The majority of carers in Innes and colleagues' study also reported other gaps in service provision, the main ones being respite care, support for carers, home care and day care. 41% of carers of people with dementia in Cascioli and colleagues' evaluation had not received a specific diagnosis of dementia for the person they cared for, which led to difficulties in accessing appropriate services.

2.3.5 Emotional support

Participants in a few of the studies felt that they did not get enough emotional support in their role as carers of people with dementia. Over one third of the carers in Cascioli and colleagues' (2008) evaluation said that they did not get enough emotional support from service providers. For them, the most important thing was human contact; they wanted visits from people who could empathise and also provide advice and assistance. Longer term carers in Yeandle and colleagues' (2007) study felt poorly supported by service providers and often reported reaching a 'crisis point'. Chung and colleagues (2008) suggested that carers need to be emotionally supported by allowing them to talk through and share their experiences and for professionals to be non-judgemental in all interactions, allowing validation of the carer's experience. However, a randomised controlled trial designed to evaluate an intervention which provided emotional support to carers of people with dementia in the form of befriending found that there was limited uptake of the offer to be part of a befriender scheme and, in addition, no benefits to having contact with a volunteer befriender were found (Charlesworth et al, 2008).

2.3.6 Recognition of the carer's 'expert' role

Chung and colleagues suggested that carers in their study did not get proper recognition of the 'expert' role they played in caring for the person with dementia. Many participants felt that their needs were marginalised and their voices were often unheard. The authors suggested that services need to recognise that carers have often been making complex decisions for several years and should seek to understand the strategies that carers already use. Carers' crucial role in the home situation needs to be recognised and

acknowledged (Chung et al, 2008). Carers in Yeandle and colleagues' (2007) study also felt that they had become 'experts' over their years of caring but this was not always recognised by the agencies that they dealt with.

2.3.7 Carers' assessments

Some difficulties in relation to carers' assessments were highlighted by Seddon and colleagues in their study into carers' experiences of carers' assessments. The authors found that a proportion of carers perceived the carer's assessment to be a test of their ability to care not their willingness to care. They were unsure about the aims of the assessment and how it might help them. Carers reported a lack of opportunity to discuss issues that were important to them, such as continuing to work, and there also appeared to be minimal recording of unmet needs on the part of the carer. Some carers in the study did not know if they had had an assessment or not. The findings suggested that carers perceived the onus to be on them to request an assessment. Carers who had had an assessment were not confident that changes in their circumstances would prompt a review of their needs (Seddon et al, 2007).

2.3.8 Help with changing/difficult behaviours

There was no empirical research that evaluated interventions to help carers with the changing/difficult behaviour of the person with dementia. However, some unmet need was identified. Quinn and colleagues (2008) found that spouse/partner carers of people with dementia felt that they lacked help in dealing with their partner's/spouse's altered behaviour. They felt they needed professional support to help them cope with these changes and their caring responsibilities in general. Carers in Georges and colleagues' (2008) study identified dealing with activities of daily living and behavioural symptoms in the person with dementia as being the most problematic areas for them to cope with. Cooper and colleagues (2010a) suggested that interventions to change carers' coping styles might alleviate the impact of abusive behaviour directed at the carer by the person with dementia.

2.3.9 Other areas of unmet need

- **Communication:** Cascioli and colleagues (2008) found that the carers in their study thought that communication with health and social care services, including communication with GPs and hospital consultants, was poor; they did not feel that they were 'kept in the loop'. Carers in Downs and colleagues' (2006) study gave low ratings for GPs in relation to their contacts with them in the early stages of the dementia of the person they cared for. These low ratings were associated with an absence of interpersonal skills, empathy, acknowledgement and action.
- **Training:** The majority of female carers in Cascioli and colleagues' study indicated that they would have liked proper training before taking on the role of carer. They also felt that nursing and medical staff should have more training (Cascioli et al, 2008). Nurock and Wojciechowska (2007) also found that a majority of carers wanted interventions that would lead to the provision of a better trained workforce in the community and in acute settings. Carers saw this as the single most important factor that could improve their situation.

- **Joint support for carer and person with dementia:** Carers in Cascioli and colleagues' (2008) study reported a lack of services for the carer and the person with dementia together; they wanted support groups that were provided for both.
- **Support to continue working:** Many of the carers in Yeandle and colleagues' (2007) study felt that they did not have adequate services in place to enable them to continue working. This was the case for almost two thirds of those who worked part time and for nearly half of those who worked full time.

2.3.10 **Barriers to taking up service provision**

Some studies highlighted a number of barriers to carers taking up the service offered. In Cascioli and colleagues' (2008) study, barriers to taking up services provided by social services cited included resistance from the person with dementia, reluctance due to guilt on the part of carers, the hassle involved, costs, and concerns over quality of care. Carers in Innes and colleagues' study also said they did not always take up services offered to them because of distress/reluctance on the part of the person with dementia and feelings of guilt. Other barriers included a desire to remain at home, perceptions of coping and a desire to protect their privacy (Innes et al, 2005). Many carers in Yeandle and colleagues' (2007) research reported that the person they cared for did not want to use the services available which placed carers under considerable pressure.

3 Information and support needs along the caring journey

A distinctive aspect of this research is that it explored the information and support needs of carers along their caring journey. Obviously every carer's journey is unique – carers' own circumstances will vary and the speed and way in which the person with dementia's illness progresses will be different. Moreover, carers will have differing preferences for the types of information and support they want, the ways in which these are given, when they are offered, and who should provide them. However, the in-depth discussions with carers in the individual interviews and focus groups about their journeys, and the feedback from a wider group of carers in the survey, has shown that there are a number of critical points along the journey where carers most value information, or where support is most needed. Professionals and organisations working with carers and people with dementia should be able to recognise these and use them as opportunities to reduce the physical, emotional, and even financial burdens on carers and, where they wish to, enable them to care for longer.

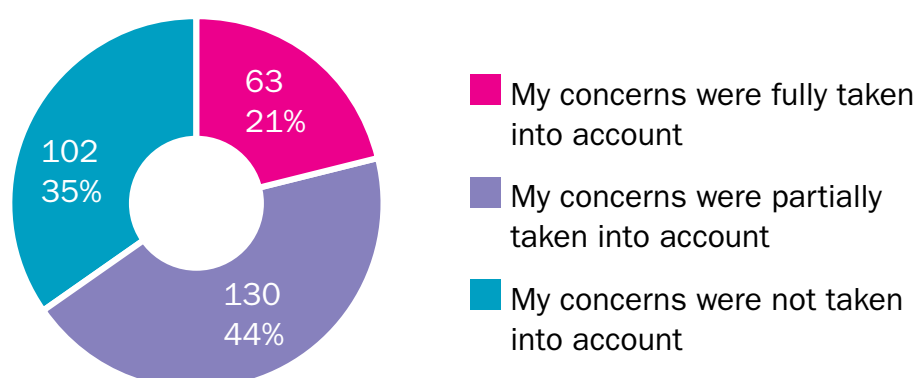
This chapter describes these critical points and explores the information and support needs that are likely to arise at these points. It is important to note that while critical points for carers are often linked to the progression of the illness, they may be different to the critical points experienced 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. The chapter also discusses the services carers valued in meeting their needs. Some of these services are primarily provided for the person with dementia but are of immense benefit to carers. Conversely, services which are intended to support carers can have benefits for the person with dementia. For this reason, we have not drawn a sharp distinction between services for carers and those for the person with dementia.

3.1 Initial problems and diagnosis

Over half (52%) of the carers in the survey reported difficulties in obtaining a diagnosis of dementia for the person they cared for. These difficulties included: doctors (GPs in particular) minimising the problem or not taking carers' concerns seriously; the condition being misdiagnosed or not recognised; doctors/health professionals focusing on other health issues; denial on the part of the person with dementia or other family members; the person with dementia 'passing' memory tests; and delays in getting appointments and tests. Some survey respondents said that they had had to pay privately for tests and/or appointments with specialists in order to get a diagnosis more quickly, and a number believed that the biggest gap in services/support for them had been the lack of, or delays in, getting a diagnosis of dementia.

The survey also asked carers if, during the process of getting a diagnosis, they felt their concerns had been taken into account. As Figure 2 shows, only 21% of respondents felt their concerns were fully taken into account. Not surprisingly, there was a close relationship between carers' perceptions that there were problems getting a diagnosis and feeling that their concerns had not been taken into account.

Figure 2 Did you feel your concerns as a carer were taken into account?



The majority of carers who completed the survey (66%) said that they had received a diagnosis of dementia for the person they cared for within a year of first seeing a health professional about the person's symptoms. However, for nearly a quarter (23%) it had taken between one and three years, and 10% had had to wait over three years. A few carers said that they were only able to get a diagnosis when the caring situation broke down because they could no longer cope and referrals to mental health services/social services were made.

Carers participating in the interviews and focus groups acknowledged that it was sometimes hard to pinpoint when the person with dementia's problems first started. Many of those being cared for had multiple health problems and in some cases carers said it was difficult to know what was causing the memory loss. They understood that this could make the process of diagnosis more complicated. However, they also emphasised how crucial timely diagnosis was for getting access to services and enabling carers and people with dementia to plan

ahead while the latter still have capacity. This was particularly the case for carers of people with early onset dementia, where the person with dementia was still working and the financial implications of loss of employment were significant.

The health professionals most commonly involved in the process of diagnosis were GPs. Almost half (48%) of the carers who responded to the survey said that the mental health team had been involved in the diagnosis and 45% said that the person they cared for had attended a memory clinic. Among the carers who were interviewed, GPs were often the first step on the road to getting a diagnosis. In some cases the carer had noticed problems but the person they cared for did not want to acknowledge these and was therefore reluctant to see their GP. Satisfaction with responses from GPs was variable; while some carers said that they had been extremely helpful and had immediately referred the person they cared for to mental health services and/or for further tests or scans, several people described how they had repeatedly raised concerns with their GP but had not been taken seriously. Some carers felt that the memory tests conducted by their GP were inadequate or at least should have been considered alongside the information they were providing. A carer of Pakistani origin was also concerned that the memory tests used were not culturally meaningful – she said her mother would not have been able to answer many of the questions even before she had dementia. However, there were also examples, like Penny's story below, where the GP played a pivotal role both in getting a diagnosis and in providing ongoing care.

Penny's story

Penny cares for her husband David who was diagnosed with dementia in his late 50s. His problems first showed up at work where issues were raised about performance but they soon became apparent at home too. David saw his GP who referred him for an MRI scan and for an appointment with a psychiatrist (who carried out the Addenbrookes Cognitive Examination¹). David was diagnosed with Pick's disease and prescribed Aricept. Initially this appeared to help but the side-effects were a problem. In addition, David was being treated for stomach ulcers and the interaction of the medicines caused problems. After two years of taking a number of medicines, David's GP did a full review and suggested that they should stop them all and then gradually build them up again, as needed.

Penny explained that David has a really good relationship with his GP and this has made a huge difference, not just in relation to the diagnosis and medication, but also in getting access to other services (for example, regular community psychiatric nurse support) and making difficult decisions such as persuading David to give up driving.

¹ The Addenbrookes Cognitive Examination III is one of the cognitive impairment tests recommended by the Alzheimer's Society. See Ballard, C et al (2013), *Helping you to Assess Cognition: A Practical Toolkit for Clinicians* (London, Alzheimer's Society).

While it is difficult to generalise from the small numbers involved in the interviews and focus groups, carers involved in this part of the study appeared to be more positive about the process of obtaining a diagnosis where the person they cared for was referred to a local memory clinic (or equivalent), with specialist multi-disciplinary support and a designated key worker.

3.1.2 Medication

Among the carers who were interviewed, there were no problems reported in relation to getting medication for dementia prescribed but a number felt the information they had been given about the medication and its side effects was inadequate. This was confirmed by the survey responses, with more than half the carers saying that they had not received information about managing the medication of those they cared for. Of those who had received information about managing medicines, nearly two thirds had received this from the GP. Although a number of carers in the survey felt that they had received information about managing medications at the right time, others said that they would have preferred to receive the information when the dementia was diagnosed or at least early on in the caring journey. Some carers said that they had never had any information about medication and had been left to 'get on with it' themselves.


Some of the carers who were interviewed said they were not always informed about what different drugs were for and about possible side effects. Carers wanted medication to be reviewed regularly by those most closely involved in the person's medical care and the personal story above illustrates the very positive approach taken by one person's GP. Some carers (in both the survey and the interviews) said their local pharmacist had been the best person to help explain drugs, when this information had not been forthcoming from elsewhere.

3.2 Taking on a caring role


Many people had already taken on a caring role before having any contact with health professionals, but the contact they had with professionals during the process of diagnosis was an important opportunity for a range of information to be conveyed to them and soon after. At this early stage, many carers had limited knowledge of dementia, and so giving carers information about the illness, its likely progression and its implications (for example, for the person's ability to look after themselves, or manage their money) was vital. Furthermore, there is much research evidence that carers often do not regard themselves as 'carers' and are not aware of their rights to assessment or of the types of carer support available.


3.2.1 Information about dementia

Among the carers in the survey, nearly a third said that they had not been given general information about dementia. This finding reflects a number of other studies which have found that carers perceive there to be a lack of available information about dementia (for example, Blackstock et al, 2006; Cascioli et al, 2008; Lawrence et al, 2008 – see section 2.3.2. Almost 10% (n=30) said that the biggest gap in services/support for them had been the lack of information about dementia.

 Information about the condition and what to expect all the way through – a roadmap of sorts – would have been helpful in making the right decisions about my husband’s care. Instead, I have muddled through and provided his care by instinct rather than with informed help. That has caused a great deal of stress on me and inevitably on him.’


Where information about dementia was provided, community psychiatric nurses/mental health workers and voluntary sector organisations (for example, Dementia UK, Alzheimer’s Society, Alzheimer’s Scotland) were commonly cited. Two carers mentioned how valuable the information from Admiral Nurses had been, towards the later stage of the illness, but they regretted not having this information much earlier. Several people said they were very unhappy about the level of information provided by medical staff, where they would have expected more. This was especially the case for people who had less common forms of dementia. However, there were a small number of positive experiences which illustrate the kind of information (and the approach to providing it) that carers valued at this early stage:

 The community mental health nurse allocated to my father was excellent. I was given plenty of information about dementia from the very beginning and advice about applying for Attendance Allowance and referred to my local carer organisation to assist me complete the Attendance Allowance form. The nurse also asked if I required any emotional support such as counselling.’

 The psychiatrist was very helpful during appointments and explained things clearly and spoke to my father and me separately as well as with my mother. I went to some carers education sessions and found the medical session particularly helpful in understanding dementia and its progress.’

In many cases, carers said they found out about dementia themselves through the internet and found this very valuable – particularly where people had less common forms of dementia. However, some people noted that searching for this information could be very time consuming and they could not always trust the quality of information available. Some suggested that signposting to certain websites would be valued.

The majority of carers interviewed said they really would have valued much more information about dementia and its possible impact and progress at this early stage so that they could be more prepared:


 If right from the start they had said, look, this is the pathway. It might not happen for, you know, it could happen in ten months, it could happen in ten years but this is it, these are the signposts and she may go backwards and forwards.'


However, a small number of carers said they would have had difficulties taking on board more detailed information about dementia because they could not absorb it at this early stage and stressed the need for more personalised or staged information giving, enabling carers to find out more when they needed to and felt able to.

3.2.2 Information about support available

Carers varied somewhat in the level of information they wanted about the types of support available at this early stage of their journey; some stressed that they could not take everything in at the beginning or preferred to find out more as problems emerged, rather than worrying about future deterioration. However, carers thought that a core of information about available support/key contacts should be routinely provided as early as possible, by whichever clinicians are involved, whether at the hospital or the GP surgery:

 We needed a 'what now' pack of essential information.'

 After Mum's assessment I'd have liked to have received a file containing info that I might have needed then or in the future, all in one place, so that I can refer to it as when needs arise. As it is I have to go digging, researching, chasing people.'

 [If we had known] earlier in her diagnosis, we could have explored support networks and taken advantage of them.'

Carers organisations were also seen as an important gateway to further information, but many people interviewed said they were not routinely given information about these organisations by statutory services. For some carers this had huge implications as they had not known about support services for several years.

3.2.3 Carers' assessments




Carers will not typically be offered a carer's assessment when first taking on a caring role or prior to the person with dementia having an assessment of their eligibility for social care support, and many of the carers interviewed were unaware of their rights to a carer's assessment, regardless of whether the person with dementia had had contact with social services. However, among many of those interviewed there had been little or no contact with social

services for several years following a diagnosis of dementia and this meant that the carer had not had the opportunity to be offered an assessment to address their own support needs. There were many examples where carers had struggled to carry on caring or taken important decisions, such as giving up work to care, without knowing that other options might have been available. Some carers complained that they had had no choice about taking on a caring role and that professionals often made assumptions about this.

3.2.4 **Legal issues and managing money**

Carers said that they would have valued early advice about how to plan ahead for when the person with dementia was no longer able to manage their own affairs, particularly their money. There were a number of examples of difficulties around managing money: one carer had discovered financial abuse by a family member; another described how her mother had accumulated masses of items through mail order shopping; and another carer explained that her husband had given hundreds of pounds away (including setting up direct debits), in response to charity marketing letters. Several carers said that they would have valued early advice about how to spot and deal with money management problems.

Of the carers responding to the survey, less than half had been given information on legal issues and managing money, for example lasting power of attorney, up-dating wills and having joint signatories on bank accounts. Many had learned about lasting power of attorney too late, when the person had lost capacity to give their permission. Several survey respondents stressed how important this information was, right from the start:


-  **This should be a priority right at the start. Without lasting power of attorney you cannot do anything.'**
-  **Everyone should be informed about powers of attorney, financial and health, from 40th birthday.'**
-  **It was too late to get power of attorney by the time diagnosis given, which caused problems and financial hardship as we were unable to access Dad's savings account when he needed a ramp to get outside, and had to use credit card for expenses which obviously cost more.'**

Where this information was provided, respondents said it was generally through a social worker or voluntary organisation, but interestingly over 40% of people said they had sought this information themselves, for example, through internet searches or their solicitor.

3.2.5 **Benefits and financial support**

Nearly two thirds of carers completing the survey had been given information and advice about benefits and financial support, generally by social workers or voluntary sector organisations. Some people were very impressed with the

comprehensive information and help to fill in forms they had received and there were examples where this extended to both the carer and the person with dementia. However, some carers felt that the information they received was partial, and they found out much later about certain benefits (such as Council Tax rebates). Others said that they received information on benefits far too late and had lost out financially as a result. One carer noted that as their GP was the only professional her husband had had any contact with in the early stages of his dementia (which was not at all unusual), primary care providers should be much more proactive in providing information and signposting about this issue.

 As a carer of a husband with young onset Alzheimer's, most of the stress that has been caused to me has been trying to cope on my own with finances – it would have helped immensely if someone could have given me help and information at the beginning of my husband's diagnosis instead of leaving me to cope on my own – finding my way around the benefit system nearly caused me to have a breakdown, help should have been forthcoming. Unfortunately, society on the whole believes that the only people who get Alzheimer's disease are people in the twilight years of their life who have no mortgage and are drawing their pensions, unfortunately for me and my family, this is not the case.'

3.3 Changing capacity of the person with dementia


Inevitably, over time, the person with dementia's capacity to look after themselves and manage at home declined. For all carers, but particularly those who did not live with the person they cared for, such changes were further critical points at which information and help were needed.

3.3.1 Ongoing monitoring by health services

Just under a half the carers who completed the survey said they had had some support from a community psychiatric nurse or mental health worker. For some, the contact had been a one-off brief meeting, or a small number of meetings in the early stages, but for others, support had been regular and ongoing. Memory clinics were generally valued, because they tended to offer a consistent point of contact, with some offering regular reviews. However, several carer interviewees said that after initial assessment there had been no review or contact with health services for months or even years, until a crisis such as a fall triggered some involvement. In those areas where there were Admiral Nurses, between 6–18% of survey respondents made reference to the support they had had from them.

Many carers stressed how much they wanted regular ongoing contact with, and support from, health services, to monitor the progress of the disease, review

medication, highlight emerging support needs, and monitor the ability of the person with dementia to manage safely at home (as well as the carers' desire/ability to provide care). A number of carers in the survey said that not having one individual who knew what was going on and was a point of contact was the biggest gap in services/support that they had experienced.

 Having one person from the beginning who understood what I was going through and how I could deal with it all. To be referred to as the carer when my life had suddenly been torn up, was being shattered, and I didn't feel any security in any role that I was doing, couldn't make any sense out of what was going on – this was the hardest and is still the hardest thing to cope with. It is not enough when someone feels they are whizzing off the rails pretty fast to make comments such as – 'This phase will soon pass' or 'Don't worry about that' when all you can think about is what is the next disaster round the corner. Someone to help me steer through all those sickening peaks and troughs in the early days would have been invaluable.'

However, establishing a clear link with a named professional at an early stage was a positive step for many carers, with some explaining how reassuring it was to have this point of contact, even if they did not use it:

Christine's story


Christine has provided care for her widowed mother, who lives alone, since 2009. She explained that when she started to get really concerned about her mother, the GP undertook initial tests, informed the family about power of attorney, and referred her mother to a psychiatrist for further tests. This took place within three weeks and following this she was prescribed medication and referred to a community psychiatric nurse. The community psychiatric nurse explained the medication, offered equipment (such as a commode), made a referral to the continence nurse, and provided information about the local Network Partner where staff helped her apply for benefits for herself and her mother and provided information on carer support groups/services. Christine said she found this input invaluable. She does not have much ongoing contact with the community psychiatric nurse, but she said: 'I know that there is an open door if I need to contact her, she is very approachable.'

3.3.2 Social care assessment and review


Not all of the carers involved in the research had had contact with social services. Of those who completed the survey, 75% said that the person with dementia had received an assessment for adult social care services but 15% had not sought one. Both the survey and the interview/focus group participants suggested that sometimes carers did not try to obtain an assessment for reasons that were unrelated to whether or not they needed support:

- Some were unaware of the range of information and support that might be made available through adult social care services, or that it might be an access point for carer's assessment/support.
- The person with dementia had refused to have an assessment or was rejecting external support.
- There were negative perceptions about the support that might be provided via the local authority and/or independent care agencies.

There were also two examples where people said they did not wish to seek help because of fear and denial about what was happening:


 I was frightened of what I was getting into, and as long as I didn't seek help and get 'into the system' as it were, I could go on kidding myself that this wasn't happening and things might not deteriorate.'

Around 5% (n=15) of survey respondents said that the biggest gap for them had been not getting any support from adult social services. One carer commented:

 [The biggest gap was the] lack of a personal social worker. We had one for a while, and it was very useful to be visited once in a while to discuss the current situation and get useful info from someone who knew us and our situation. The team that looked after us has been disbanded, and there are too few social workers looking after too many clients, so we are now just a file and a yearly review. I now feel quite isolated.'

Where an adult social care assessment had been requested for the person with dementia, some carers said there had been problems obtaining this. 9% of the survey carers said that they had had difficulties obtaining an assessment, regardless of the amount of time that the person had been affected by dementia – for example, five of the 31 carers who had been caring for more than ten years said that they were having such difficulties. There were examples of poor communication, with 'front door' local authority services that put some carers off contacting them for considerable periods of time (for example, phone calls were not always returned) and several carers said that they could not get


past customer services. Others were frustrated that the needs of people with dementia could be neglected if there was a strong focus in eligibility guidance (or its interpretation by staff) on physical and personal care needs. A number of carers commented that eligibility thresholds were very high; for example one carer said she was informed that personal care would only be provided if her mother (who lived alone) was incontinent. In many cases, assessments of the person with dementia had only been initiated following support and advocacy from a local carers organisation or when triggered by a crisis:

 **We tried to access help on many occasions. It was not until my father was sectioned under the Mental Health Act that we received better help and communication from social services.'**

Geraldine's story


Geraldine has been caring for her widowed father since 2008. He came to live with Geraldine and her husband following a heart operation, which at first masked the symptoms of dementia. Some self-funded support was available locally in the form of lunch groups and someone driving him around the local area, perhaps stopping for a drink, which he really enjoyed; as well as being a positive interaction for him, it was an invaluable short break for Geraldine. However, as time went on he found groups of people more difficult to cope with and was 'disruptive, because he always wanted to be the centre of attention', so Geraldine organised privately funded home support.

In 2011 her father deteriorated abruptly, but even though Geraldine had previous experience of working within social care services, she had difficulty obtaining a social care assessment for her father or for her own needs as a carer; she felt this was because he did not have high personal care support needs.


 **I just thought I was going to fall apart to be honest. I thought I'd have a breakdown. After about the fourth or fifth call I spoke to a duty social worker who said: 'Quite frankly you could be waiting forever'.'**

At the time of the interview the only way forward for Geraldine appeared to be for her to purchase more self-funded support. She was worried that her relationship with her husband was suffering and she may have to give up work.

Some carers did not know what different professionals could provide and spent a lot of time tracking down who to phone:

 **You have to research everything and ring from one place to another to actually get an assessment.'**

There were some positive examples of support from social workers where, for example, information had been provided, further referrals (for example, to occupational therapists) had been made and care services put in place. However, several carers were unhappy about what they saw as undue bureaucracy and paperwork, or the lack of any tangible outcomes in terms of information given or services provided. Where the person with dementia was paying for services themselves, some carers commented that there was no support for them:

 **There is enough money to pay for things privately – however, this seems to mean that there is no advice available either and that we desperately do need.'**

Carers suggested that statutory agencies should be much more proactive in identifying needs and exploring support options with the person with dementia and their caring network, regardless of who funded the support. Carers also valued having consistency of social worker, as this provided continuity for them and the person with dementia.

A significant number of the carers interviewed did not appear to have had a separate carer's assessment and were not familiar with the term 'carer's assessment' (cf Seddon et al, 2007 – see section 2.3.7). In other areas, carers' assessments were carried out by carers organisations on behalf of the local authority. However, most carers said they had been involved in assessments and reviews of the person with dementia; not surprisingly, some complained that the focus was entirely on the person with dementia and/or they were not given adequate time to discuss their own support needs. Among those completing the survey, 67% said that their needs as a carer were discussed/considered during the social care assessment of the person with dementia, but only 51% said they were given an opportunity to talk separately about their needs and how much care they felt able to provide.

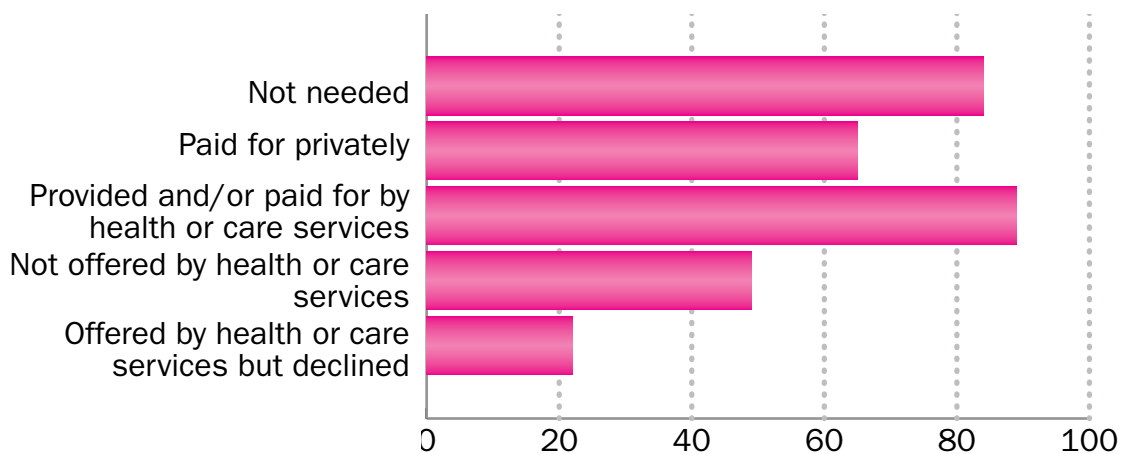
Moreover, many carers said that professionals conducting assessments of the person with dementia did not check whether they were willing and able to provide care/continue caring. Some made comments that suggested carers felt these questions were intentionally not asked in order to save the state money. However, in many cases carers believed that care provide by anyone else – or by too many people or by inadequately trained people – would just make matters worse. Pressure also came from some people with dementia who did not want support to be provided by anyone other than the carer, or who were oblivious to the impact caring was having:

4 The problem is as always that my aunt has her rights but I as a carer have none so when needs are being assessed my aunt would say ‘No, I don’t need anything, I’m fine with my niece here’.

3.3.3 Personal care at home

Carers who completed the survey were asked about the personal care support provided (for example, help with bathing, dressing or toileting) for the person with dementia; Figure 3 shows the responses:

Figure 3 Provision of personal care (n = 309)



Where personal care was funded by health or care services, over 75% of respondents considered that they had been able to get this support in a timely way. However, significant numbers of people were paying for this care privately or managing without support; and over 20% did not feel that they were able to get this support for the person with dementia from statutory agencies when required.

There were a number of concerns about the quality of personal care services, particularly where these were provided by independent sector services. Where the person with dementia needed several visits each day, carers emphasised how unhelpful it was having several different care workers visiting. It not only compromised continuity of care and getting to know people’s needs, but frequent changes of staff could confuse and upset the person with dementia: ‘If someone else comes in, it’s: ‘Who are you? What are you doing?’. For this reason some carers had cut down on the number of hours of personal care they received – two carers said they had refused evening visits because it was better to manage the care themselves rather than have even more people in their home. There were also concerns about the quality of staff training. Some carers interviewed in one area had experience of different types of personal care providers, and one described their very different experiences of them:

Alison's story

Alison has been caring for her mother since 2004 and, with some support from siblings, provided sole care until 2011 when her mother was hospitalised following a fall. Before she was discharged from hospital a package of care was put together, which was made up of a mix of ongoing family support and personal care from two different agencies. One is a (voluntary sector) specialist dementia service and provides a consistent team of three care workers; Alison said they are always on time and communicate even the slightest change in her mother's behaviour/health and she has great confidence in the service.

By contrast, Alison said that the other (independent sector) service, which is generic, has been 'dreadful', with seven different care workers in a week and a lack of training/awareness of the needs of people with dementia among the care workers. She described how workers would accept at face value, what her mother said, for example about having eaten or taking medication, not realising that her perception or recollection may be affected by the dementia. She also described how workers came in late when her mother had already gone to bed with her clothes on and dentures still in, so they would then wake her up to prepare her for bed and give medication, thoroughly confusing her. Alison would prefer all of the formal care to be provided by the specialist agency, but not enough capacity was available at the time.

Despite these concerns, many carers said that they wished that they had had access to personal care services sooner or had made the decision to start using these services earlier. In some cases carers said the amount provided was inadequate and where it could be afforded they were topping up the personal care provided via the local authority by paying privately for extra care. Two of the carers interviewed said they were using a personal budget for the person with dementia to purchase personal care and they appreciated the flexibility and control that this offered. However, overall very few of those interviewed were aware of personal budgets as a way of having more choice and control over the care and support provided.

Some carers did not explore options for personal care support because of the issues outlined in 3.3.2. As a result, many people were providing personal care themselves or making their own arrangements by employing care workers directly (where this could be afforded):

 I followed the lead of other carers who were also employing individuals themselves. Far more empowering and much better care/terms and conditions, both ways.'

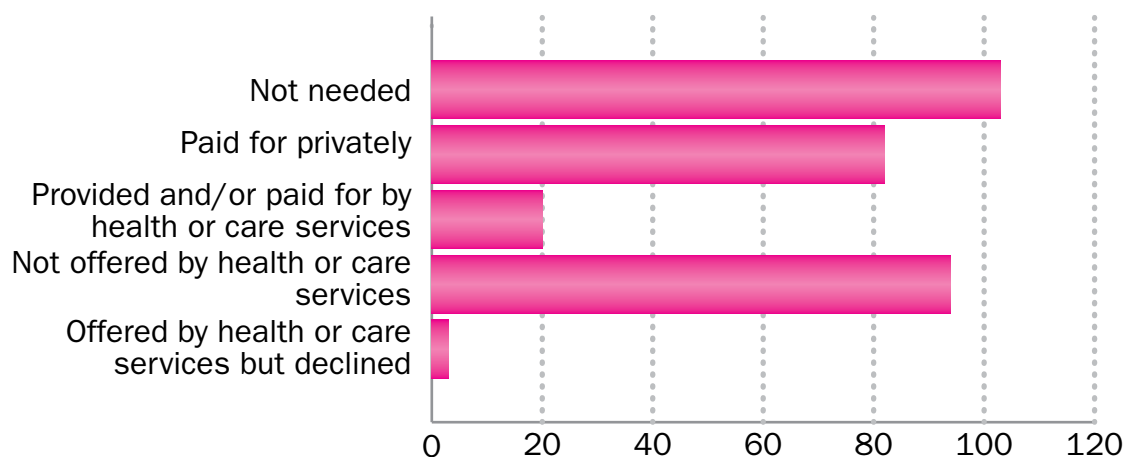
Carers said they wanted more choice of providers and more specialist providers. A carer of Pakistani origin who was interviewed said that (even privately) she had had difficulty finding home care workers from the same culture who could speak her parents' language.

3.3.4 Practical help in the home

Many carers interviewed explained that routine practical tasks around the home could be really exhausting and time consuming. Carers who did not live with the person with dementia in effect managed two households, with all the administrative and maintenance tasks that came with that. Housework, cooking and gardening could be hard to keep on top of, and/or expensive to purchase privately, especially where the person with dementia was not eligible for adult social care support. Where people were in receipt of social care services, often these did not extend to household tasks. Furthermore, many people with dementia who only required help with practical tasks (and had no personal care needs) were generally not deemed to have needs that met substantial/critical eligibility thresholds for adult social care. Laundry was particularly challenging for carers where the person with dementia was incontinent. Many carers wanted the importance of their practical support needs to be more fully recognised and taken account of when services are provided.

The survey of carers served to highlight the low level of practical support available at home, with a number saying that this had been the biggest gap in services/support for them. Many were paying privately for this type of support (see Figure 4).

Figure 4 Provision of domestic help (n = 302)



Although very few carers said that practical support was provided by statutory services, 90% of those who did get it in this way said that it had been provided in a timely way.

3.3.5 Positive advice about coping with dementia

Some of the comments from carers involved in both the interviews and the survey revealed how important it was that information and advice should extend beyond the 'bare essentials' of personal and practical support. Carers clearly valued positive advice about strategies for coping with dementia and maintaining

the quality of life of the person with dementia. In particular they highlighted:

- How the person with dementia could be stimulated in positive ways (for example, singing for the brain groups, art and music therapy).
- How communication could be aided (for example, using notice boards and pictorial reminders, learning effective responses).
- How the organisation of the household could be changed to help calm the person (for example, de-cluttering, avoiding patterned surfaces).
- How setting up routines could help to limit confusion.

Often they had picked up this information from other carers, through peer support groups and online forums/websites.


Two of the carers interviewed described the benefits of creating (with the help of the local Network Partner) a Life Story Book outlining the person with dementia's life, their likes and preferences. This provided a useful talking point with the person with dementia and was also valuable for professionals working with the individual, enabling them to be seen as a whole person and facilitating interaction. One carer said she had taken the book into the hospital when her mother had been admitted and the nurses had found it very useful to help communication and calm her when she was agitated.

3.4 Emotional support and a break from caring


Emotional support and having a break from caring are both extremely important in enabling carers to maintain their emotional and physical wellbeing. As was noted in section 2.2.2 of the literature review, the support provided by informal networks (including family members) and local communities was highly valued by carers of people with dementia. However, many carers who took part in the interviews or completed the survey had eventually reached a point where they needed emotional support from outside their informal networks, or more formal services to enable them to have a break from caring. Their comments suggested that often they did not have the necessary information to know what support might be available.

3.4.1 Emotional support for carers


Many of the carers involved in the research talked about the difficulties of coming to terms with dementia and the practical challenges in dealing with changed behaviours, managing households and finances and maintaining jobs. However, among those completing the survey, only a third of carers said they had used some kind of formal emotional support service (for example, counselling or carers groups). Some had made their own arrangements for emotional support, in some cases even paying for this themselves:

 ... provision of ten sessions have been made over a nine year period at critical points by the [local Network Partner]; but critical points occur frequently. I pay to see the same counsellor occasionally. He has been the only constant figure for five years.'

However, as was noted in Chapter 2, a number of studies have reported a lack of or inadequate emotional support for carers (for example, Cascioli et al, 2008; Yeandle et al, 2007 – see section 2.3.5). A small number (n=20) of carers who responded to the survey also said that the biggest gap in services for them had been in the area of emotional support:

 I really need to be able to talk at length to someone about the problems I face. I feel isolated and so very tired. I heard a programme about post-natal depression and I realised that I feel pretty much the same sort of helplessness and despair.'

Several carer interviewees said that their local carers organisation had been their main source of emotional support and they wished they had known about the various support services (for example, carers groups or social support activities) they could offer, much earlier. One survey respondent commented on how hard it can be for some carers to accept support, and professionals could play a more active role in facilitating this:

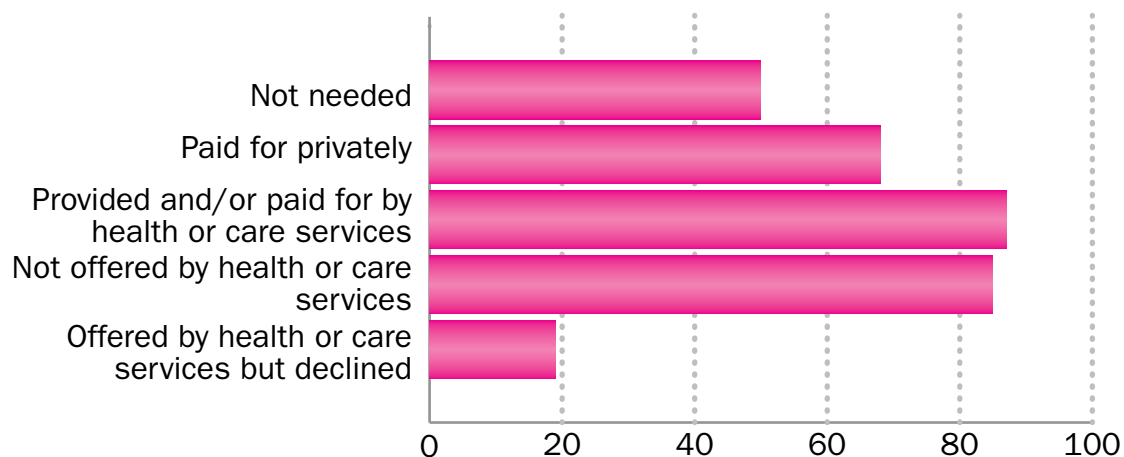
 Although I had contact details for Carers Trust it took me a long time to finally admit that I was not coping as well as I thought I was. My feeling is that a more proactive attitude from my GP would have been useful. Carers do not think that we are carers until we are in over our heads.'

While it was not for everybody, some carers had attended a carer support group and one person described how this had been invaluable: 'If you listen to carers it can help you think. And sometimes we have a laugh and that makes it all right. A bit of empathy can go a long way'. There were also examples of carers organisations providing training sessions for carers to help them to feel more in control. These forms of support were not always accessible to working carers: 'The carers groups suggested to me all take place at times when I am working', and some carers commented that it was 'hard to take time out' from caring to attend such meetings. However, online forums or support groups were valued sources of support for other carers, particularly those caring for someone with a less common form of dementia.

3.4.2 Time off from caring

Figure 5 shows that about a fifth of those responding to the survey said that they did not require time off from caring or had declined it. This was generally because they had concerns about the quality of the respite care or the person with dementia would not accept the service.

Figure 5 Provision of respite/ time off from caring (n = 309)




Almost 10% of the carers who completed the survey said that the biggest gap in service provision for them had been not being able to get a break from caring:


⚡ Respite. Vital for a Carer. Asking for this is extremely frustrating. The local authority never seems to have the money even though my dad contributes towards respite. Carers can lead a very stressful life, and a break is absolutely essential for their wellbeing. Their aim is to support the carer, on paper maybe but not in reality.'

⚡ It is mentally exhausting, and I am stuck in 'Groundhog Day' as every day is the same, draining grind, with no change in sight for the future. I feel my life is over. Time out is what I need.'

Time off from caring can take many forms, including residential care, day care and in-home respite. In many cases, the option of residential respite was not available through statutory services because the person with dementia or their carer were not deemed eligible or a priority. One person said that she desperately wanted a proper break, but as she did not live in the same household she was not regarded as the main carer:


 At various points I was exhausted. It was never offered as my dad was seen as the original carer and the social work department did not recognise me as the main carer as I did not live with them ... they did give my dad some respite care but I got none at all.'


Consequently, a significant number were privately funding residential respite, where they could afford to, though many stressed that the high cost limited the frequency or duration of their break. Many carers also said that where residential respite care was provided through the local authority, they had had to wait a long time for it– over a year in some cases. Some also expressed concern that because local provision was so limited there was no choice and they had to reserve places months in advance:


 We had to book time off a year in advance each year which is hard when you have two small children and things happen in family life.'

Some carers described poor experiences in relation to the quality of residential care homes, such as inadequately trained staff. Residential respite could also risk additional stress for the carer, where the person with dementia had become even more confused because of the unfamiliar environment.


For many carers, day services were a valuable form of respite. One carer described how her husband understood things better in his first language (Welsh) as his dementia progressed; she was really impressed that a member of staff at the specialist dementia day service made the effort to learn a few Welsh words and a Welsh song to sing with him – she said this had really helped to calm her husband, who had been behaving in an agitated way. However, experiences of the quality and availability of day services described in the research varied – for some carers, facilities to enable the person with dementia to have a bath or shower at a day service was very important (especially if s/he was incontinent); for others there were concerns that people were 'lumped together' with poorly trained staff and inadequate provision for different age groups and people with early onset dementia. A few carers also had concerns that day services were not sufficiently stimulating or culturally sensitive, or that they were not able to deal with certain behaviours:

 My husband paid towards care but stopped going to the day care centre as he was bored having to sit and do nothing all day.'


 Our experience shows that individual personalities are not always catered for – assumptions about common cultures.’

 Yes [respite was provided], but every time I tried to leave her for respite I received a call within the hour to come and collect her because they couldnot cope with her.’

In some cases, it was not the quality of the day care, but the fact that the transport to get there (often picking up others along the way) would have resulted in journeys that were too long and unsettling, or that appropriate support for the journey was not put in place:

 At that time Dad was too physically/emotionally fragile to take her and I physically could not. A taxi was offered without support staff?? Vulnerable adult alone? I wrote to my parents’ MP to ensure a positive outcome. It took forever, was a bad experience, but in the end correct procedures were put in place.’

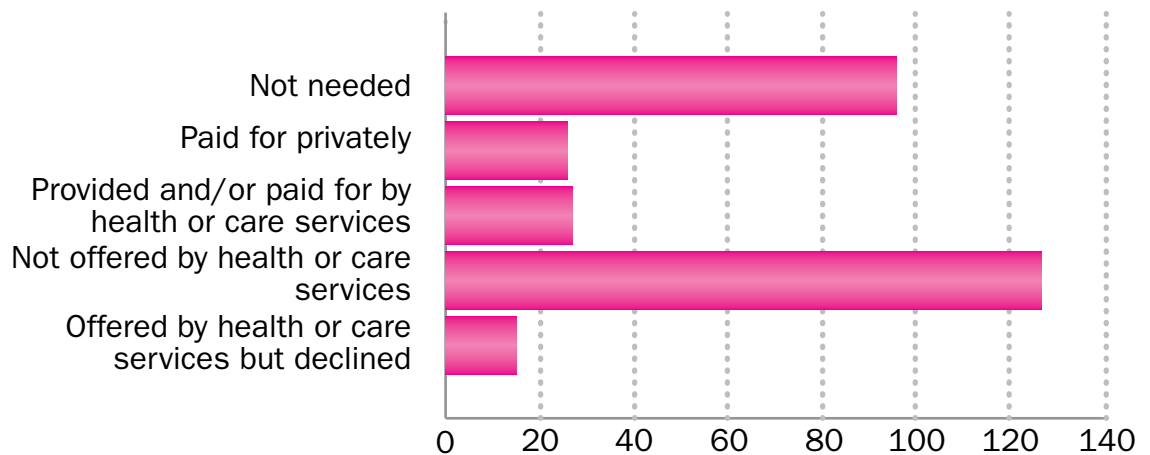
For some carers, it was care in the home that provided a degree of respite, but here the quality of that care was key, as described by this survey respondent:

 Previously I had carers to help me three times per day but because the carers changed so often and it caused Mum distress I started to act as the double-up at all visits. I had trusted carers who could come and check on Mum if I wanted to go out for half a day but not anymore – it is still very much needed but no longer provided.’

Where they could afford it, carers had often set up home-based care arrangements with a combination of family members and paid care workers who the person with dementia knew; several carers said that the best type of respite would be someone coming and looking after the person with dementia in their own home so that the carer could be at home but just free to do other things (cf Tommis et al, 2007 – see section 2.2.3). Some carers were using the person with dementia’s personal budget for this purpose. Others said that they would have liked somewhere where they could go for a break together with the person they cared for – this would have been especially valuable where the person with dementia would not accept residential respite.

Befriending services were also valued by some carers because these enabled them to have a short amount of time to themselves – though a few people said these services were suffering from cutbacks. However, as Figure 6 below shows, very few people used this type of support and comments from those completing the survey suggest that some carers were unfamiliar with this type of service:

Figure 6 Provision of befriending services (n = 286)




A few carers who had experience of befriending services said the timing of this kind of support was critical – it needed to be provided to the person with dementia in the early stages when a relationship could be formed, otherwise carers felt it could just cause more confusion.


3.5 Loss of mobility


An important critical point in terms of both the physical care the carer has to provide, and the scope for services to support them, is when the person with dementia loses their mobility. A number of the carers interviewed felt that health services did not pay enough attention to maintaining the mobility of people with dementia and failed to appreciate the implications for the carer of the former's loss of mobility. For example, some said that they had had difficulty getting physiotherapy for the person they cared for after a physical illness or operation, or the physiotherapy was less effective because the carer was not included in the sessions and the person with dementia could not remember the exercises they had been given. Training, advice and equipment to enable carers to lift safely was also a key concern.


3.5.1 Lifting and physical care

Support to safely move/transfer people is key to ensure the health and safety of carers (and the person with dementia), but some people interviewed said they had had to push very hard to get funding and the installation of a hoist in the home. Among those completing the survey, very few carers said that they had received information and advice on lifting and physical care, and where they did get it, it most often came from other professionals such as occupational therapists, or voluntary sector organisations. Many comments suggested that carers would have liked to have advice on lifting and moving much earlier. Without this kind of advice, they were struggling and putting their own health at risk:

 I hurt my back lifting him when I should have said no but he was shouting that I didn't care and he needed help so I gave in!

 I got no help with showering him even though I asked his doctor. He had TIAs [transient ischaemic attacks] – when he would fall I would cover him up, wait for him to recover and edge him to a chair and then use a pole between my feet to lever him off the floor.'

 Very late, I had been asking over and over again for a course to teach me how to lift, I was told to find and pay for my own. By chance, I saw a mention of a one off course run by Crossroads. It is a bit late for my health.'

 'Lifting and handling would be really useful to learn about. Still don't know how to do it properly, and we've had some really difficult lifting situations.'

3.5.2 Aids and adaptations

More than half (59%) of the carers who completed the survey said that they had received information on aids and adaptations, and this was mainly through social workers or other professionals such as occupational therapists. Comments from both those responding to the survey and interviewees suggest that it was generally through a social care or hospital discharge assessment that carers had access to independent information and expert advice on this issue and many said they would have welcomed it sooner, before things had deteriorated or reached a crisis. Attention to health and safety issues was also a concern for some people, and a couple of carers suggested that more information should be available in the early stages of dementia about things like telecare services, gas safety devices, fire sensors, and access to the home in cases of emergency.

3.6 Co-morbidities and general health care


Survey respondents were asked about any health problems other than dementia experienced by the person they cared for. The most common conditions mentioned were: problems with mobility (23%); heart problems (20%); arthritis (18%); blood pressure problems (14%); diabetes (12%) and various cancers (11%). Deafness and sight loss were mentioned by 9% of respondents each and Parkinson's disease and osteoporosis by 8% each. Nearly one third (32%) of carers who gave details about the health conditions of the person they cared for said that they had one other health condition, 26% said they had two other conditions and 19% said the person they cared for had three health conditions

in addition to dementia. Three people noted seven different conditions in addition to dementia.


The interviews and focus groups were opportunities to discuss with carers any examples of co-morbidities and the impact these had on the person with dementia and their caring journey. Co-morbidities emerged and changed over time and could really complicate the ways in which support needed to be provided. Carers described how these multiple health problems could be so much more complicated where a person has dementia – for example, cataracts cause sight impairment which can add to a person with dementia’s sense of confusion, or where the person with dementia has diabetes it may be much more difficult for the carer to control what they are eating. There was also an example of alcohol misuse by a person with dementia which caused a fall.

3.6.1 **General health care**

Some carers who were interviewed commented on how routine health issues, such as nutrition and hydration were really important things to keep abreast of. This was not always easy for some carers, especially where they were not living in the same household, and they needed confidence that care providers were monitoring and addressing these issues. The risks and implications of dehydration were usefully summarised by one carer:


 It is often difficult to get the dementia sufferer to drink enough and if they are double incontinent that further increases the risk of UTIs [urinary tract infections] too. UTIs increase the difficulty of caring for someone with dementia and puts them at even greater risk of accidents. They become far worse in terms of confusion than when not suffering with an infection and it makes the care far more difficult – whether that is dealing with their general behaviour, getting them to eat and drink, washing them and dealing with toileting, taking medication or their sleep patterns and general anxiety.’

One survey respondent commented:

 I might have been able to stay employed if I knew that Dad was being checked on and his medication and nutrition requirements were being met whilst I was away.’

3.6.2 **Holistic approach to assessment and treatment**

It was clear from the interviews that it was often health issues unrelated to the dementia which triggered reassessment, unscheduled reviews, hospitalisation, or new or changed services. Where the people they cared for had multiple health problems, many carers were concerned that medical assessments were not always sufficiently holistic – they said clinicians just looked at the conditions separately and not how they interacted. One survey respondent commented:

 [I would have liked] someone to support me and advise on how to deal with certain situations – particularly with cancer diagnosis and not knowing how to speak to Mum about or at all as she would soon forget anyway. Found myself having to speak to any medical staff before any appointments to ensure they knew she had dementia – lack of communication between hospitals/GP/health visitors (at the end) was, I'd say, one of the biggest problems and one that caused me the most anxiety.'


Carers also had worries about the potential 'cocktail' of drugs related to different conditions, and wanted more information about how they might interact and possible side effects.

3.6.3 **Advice/training in undertaking healthcare tasks**

The health problems of the person with dementia had huge implications for carers both in terms of the demands placed on them and the nature of the tasks they had to undertake (for example, administering a range of medication, dealing with catheters, pressure sore management, feeding and administering insulin for diabetes). Additional challenges arose when these interventions could not be easily explained or understood by the person with dementia. Few carers interviewed had been given much or any training in undertaking healthcare tasks. There was also a mixed picture among those who completed the survey, with some saying they had been guided on things such as catheter care by, for example, the district nurse or hospital staff prior to discharge, while others said they had had to 'figure it out' for themselves.

3.6.4 **Hospitalisation and discharge planning**

Through the interviews and focus groups there was an opportunity to explore with carers their experiences in relation to any hospital care and discharge planning of the person with dementia. Hospital admissions were generally not related to the dementia, but to a fall or other condition. While a small minority said the experiences were positive, many carers expressed concern about the quality of hospital care. In a couple of examples, hospitalisation had resulted in dehydration, sores and a lack of nutrition because the impact of the dementia had not been taken into account by staff. Several carers also raised concerns that they were not properly involved in discharge planning, with appropriate support in place, for example:

 It all should have been properly arranged as the rehab unit knew she was doubly incontinent and everything should have been put in place and proper arrangements made with the continence service prior to discharge. It was a nightmare for me. I had the commode but no pads or other means of preventing her and all her bedding becoming saturated.'

3.6.5 NHS continuing healthcare

Some carers noted that they had tried to get NHS Continuing Care funding for the person they cared for, but in most cases this had been refused. The interviews and focus groups suggested that for the majority, their experiences of the process had not been good. The whole process seemed bureaucratic and opaque, with a lack of clarity about how long it would take to get a decision (ten months in one case) and dismay at the way the criteria were applied. As one survey respondent put it:

 I would most have valued support on the issue of Continuing Health Care – something which has remained a criminal mystery to most.'


3.7 Behaviour changes and problems

In both the interviews and the survey, carers highlighted the difficulties of both coming to terms with and managing behaviour changes in the person with dementia. Where the changes in behaviour were more gradual or less difficult, carers had often learned from experience and had put in place strategies to deal with them or generally create a more helpful environment. However, where the person with dementia's behaviour became aggressive or unsafe or highly disruptive, carers often struggled and wanted advice and support (cf Quinn et al, 2008; Georges et al, 2008 – see section 2.3.8).


3.7.1 Managing challenging behaviours

Many carers, particularly those caring for someone in the later stages of the illness, felt ill equipped to deal with more agitated or aggressive behaviours that might develop, including difficult sexual behaviours. These kinds of behaviour changes were also emotionally very upsetting and many of the carers interviewed said that they would have liked someone outside the family to talk to about it. More than two thirds of those surveyed said they had not received any training or advice on this issue. A few people said that they had found information/advice online, from both professionals and other carers, and some had found this very valuable. Some people had also been provided with information and leaflets or attended courses run by voluntary organisations, but some felt these were too general and they really needed advice about the specific behaviour problems they were having to deal with.

There were however, a few examples of good advice and support, although again carers wished they had had it sooner. Most often it had come from community psychiatric nurses, mental health workers or Admiral Nurses but one carer described the exceptional help they had had from a music therapist:

 [We] received excellent advice from a very skilled music therapist who helped us to explore ways of communicating with my dad when he was very distressed and anxious.'


There were a great many additional comments in the survey about this issue. While the majority of carers said that information about managing challenging behaviours should be provided in the very early stages, several suggested that it should be ongoing, as and when behaviour starts to change:

 I would have liked info much earlier – always reacting to new stages and problems – if I'd had info before new phase began I could have been ready to adapt to it and would have caused less upset for Dad.'


One carer's story threw a spotlight on the practical and emotional challenges of coping with some behaviours, which can have a far reaching impact:

Ian's story

Ian cared for his mother, who came to live with him and his partner. About 18 months after this move, a specialist dementia nurse visited, and invited them to attend a carers course that ran for one afternoon per week for six weeks.

 I could have done with information a lot sooner because prior to this I hadn't appreciated that much of Mum's contrary and difficult behaviour was due to dementia. Once I understood that I could to some degree make sense of it and cope with most of it.'

When the behaviour became more problematic the nurse provided some further advice but the coping strategies suggested did not always work or didn't work for long.

 Mum had a wonderful way of circumnavigating them after a few weeks. For example, she would walk into our bedroom in the middle of the night and switch the light on. [The nurse] suggested we put a lock on the bedroom door – which we duly did. This deterred Mum for a few weeks until she started knocking on the door, or hammering on it and shouting for attention ... So eventually we left the door open and took the light bulb out. Sad to say that most of the suggestions from [the nurse] invariably boiled down to talking to Mum calmly and rationally and making her a cup of tea ... When you care for someone 24/7 and they go through a spate of waking you up in the wee small hours, you don't feel much like rationally making them a cup of tea every time ... I loved my mum more than words can ever express but dementia could turn her and me into monsters that I did not recognise.'

3.7.2 'Sundowning' and night time disturbance

Several carers said that frequent night time disturbance and providing care at night could be very difficult and demanding. Loss of sleep often left carers feeling exhausted and some of those interviewed said this made it more difficult to cope generally. It also made it harder to concentrate and retain information when advice and information was provided by professionals.

Among those completing the survey, as the figure below shows, very few people had any support to manage night time disturbance, and most help was paid for privately. In most cases people were managing this alone or with family members because funding external help was prohibitively expensive:


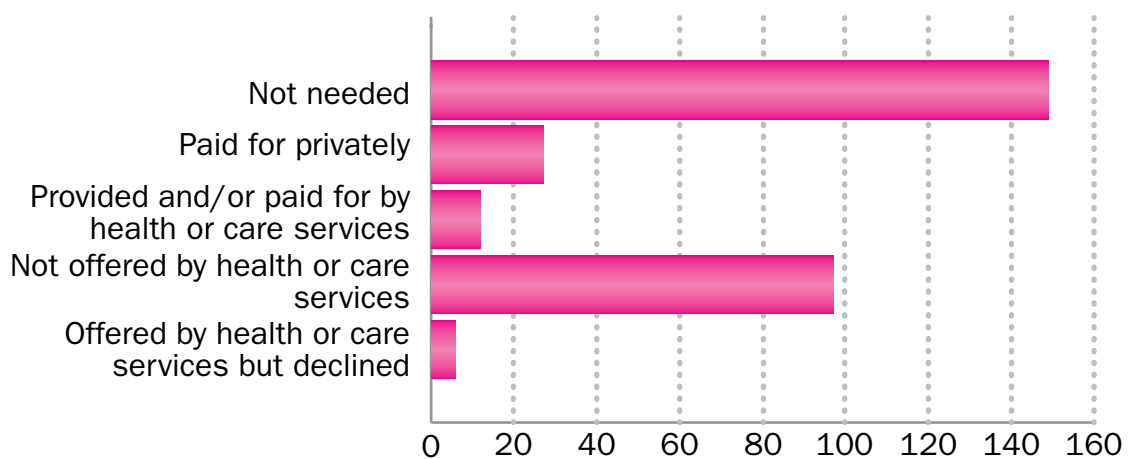

 Not offered so my family had to take turns staying overnight at my dad's. My dad was up all night. We then had to go to work as usual, this continued for a year and social work were aware.'

Figure 7 Provision of night sitting/night care (n = 291)



Another survey respondent commented that more information should be made available on ‘sundowning’² (a term to describe behavioural problems that begin to occur in the evening or while the sun is setting) which would have been helpful:

 There was no information from experts at all on the important area of sundowning – this was the most difficult behaviour to understand and to manage – had to do all research myself – reinventing the wheel because most social workers/care assistants hadn’t got a clue what it was. Seems a big area of omission.’

3.8 Changes in carers’ own circumstances

Carers of people with dementia are often in a caring role for a number of years – a quarter of those responding to the survey had been caring for five years or more. It is highly likely therefore that many carers will experience some change in their circumstances during their caring journey. In particular their employment situation may change, they may have their own health problems or their housing/home circumstances may change (sometimes because of their caring role). These changes provide opportunities for agencies to review support, provide information and/or advise carers on key decisions. The quality of this support and advice can make a significant difference to both carers’ quality of life and their ability to continue caring.

The ability to obtain or maintain employment was a very important issue for many carers. As well as being an important source of income, some carers commented on how valuable it was to keep working to maintain a sense of ‘normality’ and that work could be a form of ‘respite’. As was noted in Chapter

² Alzheimer’s Association (2011), *Sleeplessness and Sundowning* (www.alz.org), Accessed 14 May 2012.

1, of the working age carers who responded to the survey, 82% said that caring had adversely affected their ability to work.

Among those interviewed, there were a few positive examples of support which took account of carers' working lives, as the story below illustrates:


Peter's story

Peter has provided support for his wife since 2003. She has early onset dementia linked to Pick's disease. Prior to that he spent many years caring for her as she has had ongoing mental health problems. He said that the hospital team (specialist elderly mental ill) had been extremely supportive to her with a review every three months, in which he felt fully involved, with treatments focused on improving what memory she had, which he was able to support. He was also able to see the psychiatrist alone to discuss her changes/needs.

When her condition rapidly deteriorated in 2009 there was a swift response from the community psychiatric nurse, resulting in a social care assessment and further care services, where she would accept these. Peter works full time (including some evenings) and care services were provided as much as possible to enable him to carry on working; some medical assessments were fast tracked to enable his wife to access support more swiftly; and Peter was also able to speak directly to the hospital team on the telephone about issues such as dehydration.

While Peter is still worried that his work is at risk because of the challenges of supporting his wife, he felt that the support services have really taken on board his needs as a working carer.

However, several carers said they had reduced their working hours, given up work completely or taken early retirement in order to be able to care. There were also examples of people being signed off work on long-term sick leave due to the stress of caring. In some cases carers had made the decision to stop working or reduce their hours because they did not feel confident about the care alternatives; the care alternatives were just not sufficient to enable them to juggle work and caring; or the person with dementia rejected alternative care and was very reliant on the carer alone. A few carers said that the lack of support to enable them to continue working had been the biggest gap in service provision for them (cf Yeandle et al, 2007 – section 2.3.10).

 [The biggest gap has been] organisation of daily care for me as I am working full-time. Now giving up work because I can't manage any longer.'

Carers' capacity to maintain/obtain employment should be taken into account in carers' assessments (Carers (Equal Opportunities) Act 2004), but many of the carers interviewed who had taken decisions to reduce their hours or give up work because of their caring responsibilities had had no contact with social services.

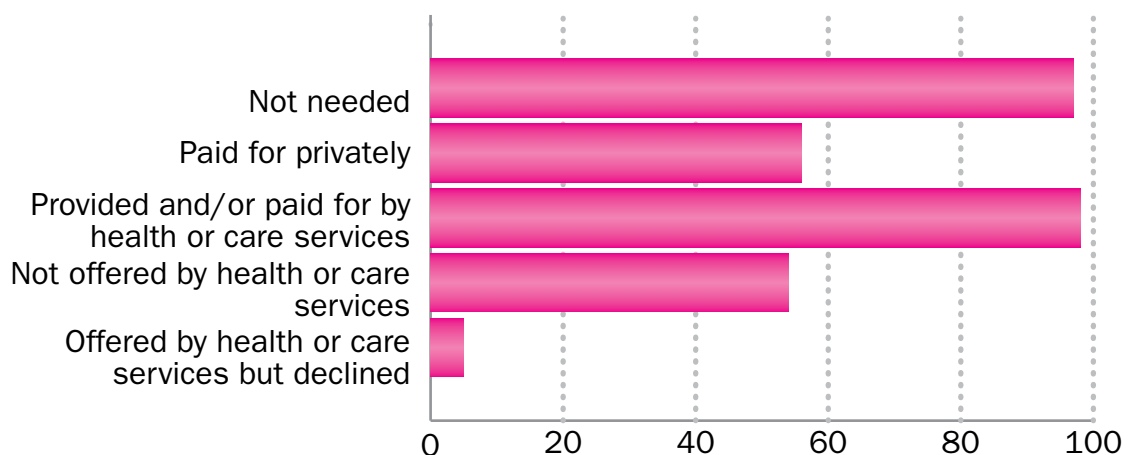
More generally, changes in carers' own health could also be an important opportunity to review the support provided to both the person with dementia and the carer. There were some positive examples of health and social care professionals using these opportunities but also examples of inflexible and inadequate service provision. Many carers worried about what would happen to the person they care for if they become ill suddenly or had an accident. One positive way to address this was the use of emergency plans. A small number of carers said that with the help of staff from local carers organisations, they had put together a plan in case they fell ill and could not care for a period. In one area this also included an emergency card which was kept in a prominent place in the house.

3.9 Dealing with incontinence


The interviews highlighted that for many carers the point at which the person with dementia became incontinent, particularly faecal incontinence, was a really critical point in terms of their caring role and one where they needed substantial advice and support. The survey asked carers if they had received any information about dealing with incontinence. More than half (52%) said that they had not been given any information and 6% said they had done their own research.

The survey also asked if carers had been given any advice or incontinence products by health or social care services. The responses outlined in Figure 8 below show that while around a third were receiving such advice and/or products, a third were also funding/dealing with this issue privately.


Figure 8 Provision of continence advice/products (n = 310)




Even where carers were getting statutory supplies, many said that they were topping up these because they appeared to be tightly rationed and insufficient – for example, one carer said they had just been offered four large pads for the year and was told that if any more were required the family would have to purchase them. Several carers also said that the products supplied were unsuitable, particularly where products were hard to secure and the person with dementia would try and remove them. As a result of this they were purchasing their own, and this was at some expense:

 [We were] only offered string pants with pad from community nurse/GP. Not adequate for Dad, cost of incontinence pants, wipes, disposal bags, laundry bags, laundry products and washing very expensive – SS [social services] income assessment allows £11 per week for it but in fact it's more like £25.'

The responses to the survey showed that around 60% of those who had received advice or support from health and social care services about managing incontinence did not consider that it had been delivered on time. Additional comments from survey respondents suggested that there is some confusion about what people can expect and where to get accurate information:

 We were buying products privately for over a year before we were informed that the local Community Nursing Team could help out.'


 We did not realise we could get more on prescription were never told despite asking Older Age Nurse who said we'd had our quota!'

Several carers who participated in both the interviews and survey also said that there were significant delays (in some cases months) between the need for help with incontinence being identified and pads being supplied – one carer said '[It] needs an emergency response team'.

In the interviews, carers highlighted just how much of a turning point dealing with incontinence could be. In some cases it had precipitated the person with dementia entering residential care, at great financial and emotional cost:

Elaine's story

Elaine had been caring for her husband since 2005, with social services support in the form of respite from 2010. In 2011 he became doubly incontinent and Elaine found this very difficult to cope with. She was frustrated that it was local policy not to provide incontinence pants (as they were more expensive), and her husband was constantly pulling off the pads that were provided:

 Incontinence was a problem, I feel I didn't have any help with it even though we had a Continence Nurse. They used to provide pants, but they just stopped. ... It was all the issues around the incontinence that were the final straw ... it would be all over the carpet and he had walked in it, and I thought 'I just can't cope with this'.'

She explained that she was also having to wash soiled clothes every day and nobody had given her any information about laundry services or other support options. Elaine was also exhausted by lack of sleep; getting up constantly at night to deal with soiled bedding. These problems and the lack of support were significant factors in her deciding she could not cope any more, and her husband has now gone into residential care.


3.10 Decisions about residential care and end of life care


As the preceding sections have highlighted, there are a number of factors which may precipitate a move to residential care, particularly when the person with dementia is no longer safe at home, behaviour difficulties, incontinence, or, more usually, a combination of these. It is important to stress that many carers involved in the study chose to continue caring for the person with dementia at home or would have chosen to do so if the appropriate level and type of home support had been available. However, when the caring situation began to approach this crisis point, carers again felt it was important to be able to obtain advice and support. Above all, carers wanted quality information about the range of options available to them – be that continuing to care at home or a move to residential care – and support to help them make what could be very difficult decisions.

While decisions about suitable accommodation will be informed by personal preferences, it is clear that decisions were also influenced by perceptions of what was available locally and the quality of that provision. Some carers were happy with the standards of local residential care homes, while others explained that they had rejected this option after visiting local homes or because of


previous poor experiences of residential respite care. Many carers were unhappy about the lack of local choice of provision.

Of the carers completing the survey, the majority of people who required information on residential care had been provided with this by their local social services department. However, some carers expressed concerns about the quality of this information:

 Given a badly photocopied sheet of nursing homes in the area, no indication of vacancies or any suggestions as to which were potentially suitable for my dad's needs.'

 Although given a booklet of local care homes, no one wanted to highlight the most applicable or the best. So left alone fishing in the dark, with disastrous consequences, seriously disastrous. No social worker accompanied me to look at care homes and the Alzheimer's Society were not in a position to highlight best practice either. The CQC [Care Quality Commission] reports at the time seemed grossly inadequate.'

Some carers of people with rare forms of dementia or early onset dementia said the information from statutory services about residential care options was poor or non-existent. Some felt that because there are so few specialist providers, national information is required, not just local. A few carers also explained they had had very little time to undertake research or visit homes, as the information they needed was provided much too late:

 My husband was considered to be 'bed-blocking' and the consultant told me there was no choice, he had to go. The social worker told me about four different places that might be suitable for my husband but each one I looked at seemed even more unsuitable than the last. This sort of information should be linked in to when the person gets the diagnosis and what the likely course of the dementia might be, considerations of moving, financial aspects, possibilities of staying together, problems of living apart – all has to go into the melting pot and the solution gradually reached – not: 'You have one month to secure somewhere else for your husband' – result panic!'

However, there were examples of positive support from professionals. One carer said how much she valued the social worker explaining to her mother why she needed to go into residential care – she felt she would be blamed by her mother and this was a huge load off her – 'it was tremendously helpful'. Other carers

described how invaluable their local Network Partner had been in helping them make decisions about residential care. Several people described how difficult making this decision could be – especially when there were disagreements within the wider family about courses of action – and they wanted more support to help deal with this.

Where the person with dementia had gone into residential care it was very clear that this was *not* the end of the caring role, though it changed in its form. Many carers (especially spouse carers) were visiting the person daily, and providing for example, social support and help with eating. There could also be complex emotions to deal with, such as feeling guilt and/or relief, a new sense of loss, and problematic family dynamics. Some carers commented on how helpful it was to be supported through these transitions.

The majority of the carers who contributed to the study were still actively caring and so relatively little information was obtained about carers' experiences of end of life care and bereavement support. However, a few important points were raised. Carers stressed that health care professionals should not make assumptions about whether or not there should be active intervention to prolong the life of the person with dementia. Carers also wanted to be actively involved in decisions about end of life care, in particular whether the person they care for should be transferred from their home or care home to hospital at the very end of their life.

A few carers involved in the study had been given emotional support following bereavement and they had clearly found it very valuable. This support had often been provided by carers organisations or specialist bereavement organisations such as Cruise. Conversely, some carers spoke about how some professionals failed to acknowledge or appreciate the impact on the carer of the death of the person they cared for.

4 Conclusions and key messages

For carers of people with dementia there is no such thing as a ‘typical’ caring journey, either for the person with dementia or for the carer themselves. The way in which the person with dementia’s illness affects them will vary, as will carers’ capacity to cope, both physical and emotionally. However, the findings from the research suggest that there are a number of critical points during the caring journey, which are:

1. When dementia is diagnosed.
2. When the carer takes on an ‘active’ caring role.
3. When the capacity of the person with dementia declines.
4. When the carer needs emotional support and/or a break from caring.
5. When the person with dementia loses their mobility.
6. When the person with dementia has other health problems.
7. When the carer has to cope with behaviour problems.
8. When the carer’s own circumstances change.
9. When the person with dementia becomes incontinent.
10. When decisions about residential care and end of life care have to be made.

Most carers will experience some of these critical points but when they occur and in what order will be different for each carer. The critical points which occur early in the caring journey, in particular when the diagnosis of dementia is made, when the carer takes on an active caring role, and when the capacity of the person with dementia begins to decline, will arise for the majority of carers. These early critical points are extremely important opportunities for professionals and services to provide carers with initial information, advice and signposting.

The extent to which carers experience those critical points which are more likely to occur as the person with dementia’s illness progresses, will vary. At these points, it is impossible to define any ‘common core’ of advice and support, because the needs and preferences of carers (and people with dementia) will be different. However, as the findings set out in Chapter 3 show, at some critical points the advice and support needed is obvious and fundamental. For example,

when the person with dementia becomes incontinent carers need clear advice about managing incontinence, a reasonable supply of appropriate incontinence products and possibly help with laundry. At other critical points, a range of advice and support needs can be identified. For example, most carers will need a break from caring, either on a regular basis or intermittently, but beyond this, individual preferences are likely to differ. For some carers, residential respite will be the answer but others will prefer home-based respite; some will want to be able to have a holiday with the person with dementia, while others will want an afternoon out with friends.

However, this study has 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 maintaining a caring situation.
- Positive advice about coping with dementia.

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 carry 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 carers 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 takes 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 homes, 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. Many carers highlighted the benefits of having regular (but not necessarily frequent) contact with one, or a small number of, health and social care professionals, with whom they can establish a relationship and who are familiar with their situation and that of the person with dementia. Carers emphasised the need for professionals who:

- **Have a good knowledge of dementia:** Having easy access to a professional who is able to offer sound advice about dementia (including different types of dementia), and how it might affect a person, was essential. Carers also wanted professionals supporting them and the person they cared for to know about services available locally for people with dementia, and to be able to refer or direct them to these services if necessary.
- **Have an understanding of carers' needs and issues:** Importantly, carers wanted professionals who not only had an understanding of carers' needs but listened to them as individuals. For some carers this included helping them make important decisions or negotiating difficult or risky situations with the person they cared for, for example persuading the person with dementia to stop driving, accept outside help, or move to residential care. Carers also expected professionals to be able to signpost them to carers advice and support services.
- **Know both the person with dementia and the carer:** Feeling that professional(s) knew both the person with dementia and the carer, and had an appreciation of their circumstances/preferences was hugely reassuring for carers. As the person with dementia's illness progressed, carers valued being able to ask for guidance from someone who knew the person they cared for. This was especially important for carers who had been caring for many years, as they felt it was easy to 'lose perspective' – a knowledgeable professional who knew the person with dementia could help them keep things in perspective and develop strategies for dealing with changes.

- **Are able to take a proactive approach:** The nature of dementia means that the condition of the person being cared for will deteriorate. Some changes may be very gradual but others may be more rapid. Carers wanted professionals to help them anticipate (and plan for) significant changes and put advice and support in place early, rather than waiting for a crisis to occur. They highlighted four critical points where a proactive approach was particularly important – behaviour problems, incontinence, losing mobility and the carer reaching the point where they needed a break from caring.

These recommendations are based on interviews and survey responses from carers across the UK; despite the different health and social care systems of the four countries, there were remarkable similarities in carers' accounts of the help they had found, or would find, useful. Taken together, these recommendations call for a clear recognition of the long-term and changing experience of caring for someone with dementia. In contrast, many encounters with health and social care professionals and services are short-term and episodic. 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 health and other costs for carers and the wider society.

Appendix A

Methods

Literature review

A limited literature review was conducted between July and October 2012 in order to identify the most relevant recent research into supporting carers of people with dementia. The aim of the literature review was to identify recent empirical research conducted on, or with, carers of people with dementia reporting their experiences of caring, the support and services they found useful at different stages in providing care and their unmet needs for services and support. The inclusion and exclusion criteria were as follows:

Include:

- Empirical research involving carers of people with dementia reporting:
 - Experiences of caring.
 - Support and services that they found useful at different stages in providing care.
 - Unmet needs for services and support.
 - Interventions to help carers manage problematic behaviours by people with dementia.
- Research involving carers of people with Down's syndrome and dementia.
- Published since 2005.
- UK publications only.

Exclude:

- Studies concerning psychological/clinical wellbeing of carers or which test psychological or clinical interventions.
- Studies which only examine interventions for people with dementia.
- Studies examining the quality of the relationship between the carer and the person with dementia.
- Discussion papers.
- 'Think pieces'.
- Policy updates and analyses.
- Practice guidelines.

The search used the following bibliographic databases which were most likely to contain empirical research relevant to the review:

- Applied Social Sciences Index and Abstracts (ASSIA).
- Social Services Abstracts.
- Psychinfo.
- ISI Web of Knowledge (Social Sciences Citation Index).

Search terms were developed to facilitate a highly focused search restricted to outputs since 2005 in order to enable studies conducted since the implementation of the National Service Framework for Older People and the recent Carers and Dementia Strategies to be included.

Search strategies are outlined below:

Social Services Abstracts

Searched for: su(dementia) AND subject("Caregivers") AND yr(2005-2012)

105 results

20th July 2012

Applied Social Sciences Index and Abstracts (ASSIA)

Searched for: (SU.exact("CARERS") AND SU.exact("DEMENTIA")) AND YR(>2005)

207 results

11 July 2012

Psychinfo – pared down subject search

1. exp Dementia/

2. exp Caregivers/ or exp Caregiver Burden/ or exp Family Members/

3. 1 and 2

4. limit 3 to (English language and abstracts and yr="2005 -Current")

5. limit 4 to journal article

6. limit 5 to (2900 social processes & social issues or 2910 social structure & organisation or 2930 culture & ethnology or 3000 social psychology or 3020 group & interpersonal processes or 3040 social perception & cognition or 3373 community & social services or 3375 home care & hospice or 3377 nursing homes & residential care)

7. (England or United kingdom or Wales or Scotland or Northern Ireland or UK). mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

8. 6 and 7

22 results

20th July 2012

Psychinfo – phrase search

1. carers of people with dementia.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
 2. limit 1 to (English language and abstracts and journal article and yr="2005-Current")
- 36 results
20th July 2012

ISI Web of Knowledge

Subject search on the two main terms (carers and dementia) filtered by UK and social sciences.

A total of 193 titles were collected. All titles and abstracts/summaries were reviewed and those that appeared to fall within the scope of the review were identified and retrieved. Titles that were not from refereed academic journals were excluded at this stage – inclusion in a refereed academic journal acting as a proxy indicator of quality. The total number of papers retrieved was 85.

Each retrieved report was read in full and a further decision was made as to whether it definitely fell within the scope of the review. The main priority was to identify relevant issues relating to carers' experiences that would shape the subsequent fieldwork. A significant number of papers (41) were excluded at this stage when it became clear that they had no relevant findings. Hence, the total number of papers included in the final review was 44. The applicable findings of each of these papers were summarised on an Excel database.

Interviews and focus groups with carers

The individual interviews and focus groups took place in four locations across the UK. Carers Trust contacted all its Network Partners to invite them to assist in this stage of the study. 20 carer organisations volunteered and from these four localities – two in England (Eden Carers in Cumbria and Carers Support Merton in Greater London), one in Scotland (Greater Pollok Carers Centre in Glasgow) and one in Wales (Crossroads Care in the Vale, in the Vale of Glamorgan) – were selected which together covered communities with different socio-economic, ethnic and urban/rural make-up. In each locality we would work through Carers Trust Network Partners to recruit carers willing to contribute to the study. Carers were recruited through a range of methods, including telling carers attending groups and activities about the research, invitation letters sent to individual carers and more general invitations posted on websites and in newsletters. Carers were given the choice of participating in either a focus group or an individual interview.

In each locality we began by undertaking between five and eight individual interviews with carers (22 interviews in total). Written consent was obtained before the start of each interview. The interviews were undertaken face-to-face, either in the carers own home or at the Network Partner's offices. A 'timeline' approach was used in the interviews, after being piloted with four volunteer

carers in the York area. This is a visual, exploratory technique which helps draw out people's perceptions and experiences within a specific timeframe (see Berends, 2011). The graphic form of this approach helped carers to reflect and enabled them to identify the stress points along their journey in a creative, tangible way. It also helped them (and the researchers conducting the interviews) distinguish between the journey of the person with dementia and the carer's own caring journey. The findings from the literature formulate appropriate questions and prompts about the types of advice and support needed at different points along the journey.

One focus group was held in each locality and in total 24 carers took part in the groups. The focus groups were facilitated by a researcher, using a semi-structured topic guide, which was shaped using the findings from the interviews. Written consent was obtained from all participants before each focus group commenced.

Both the interviews and focus groups were digitally recorded (with participants' consent) and written up as detailed notes and quotes rather than fully transcribed. They were then analysed thematically and the results were used to shape the national survey and to inform the overall findings presented in this report.

National survey of carers

A national survey of carers of people with dementia was carried out in spring 2013. The content of the survey was informed by the literature review and the findings from the interviews and focus groups. It was piloted with a small number of carers and carers workers from two Carers Trust Network Partners. It gathered biographical information about the carer and the person with dementia and then had four main sections: diagnosis; assessment; information and advice; services and support.

The survey was available in both online (via Smart Survey) and paper versions and was conducted across the UK. All Carers Trust Network Partners were asked to recruit a minimum of four carers to complete the survey either online by themselves, online with support from Network Partner staff or on paper. 12 'volunteer' Network Partners who were willing to be more actively involved in the research took extra steps to support carers who might be regarded as 'hard to reach', to complete the survey. The survey was also publicised through other organisations working with carers and/or people with dementia, including the Alzheimer's Society, Dementia UK, and Carers UK, and directly to carers via Twitter, Facebook and Carers Trust's website.

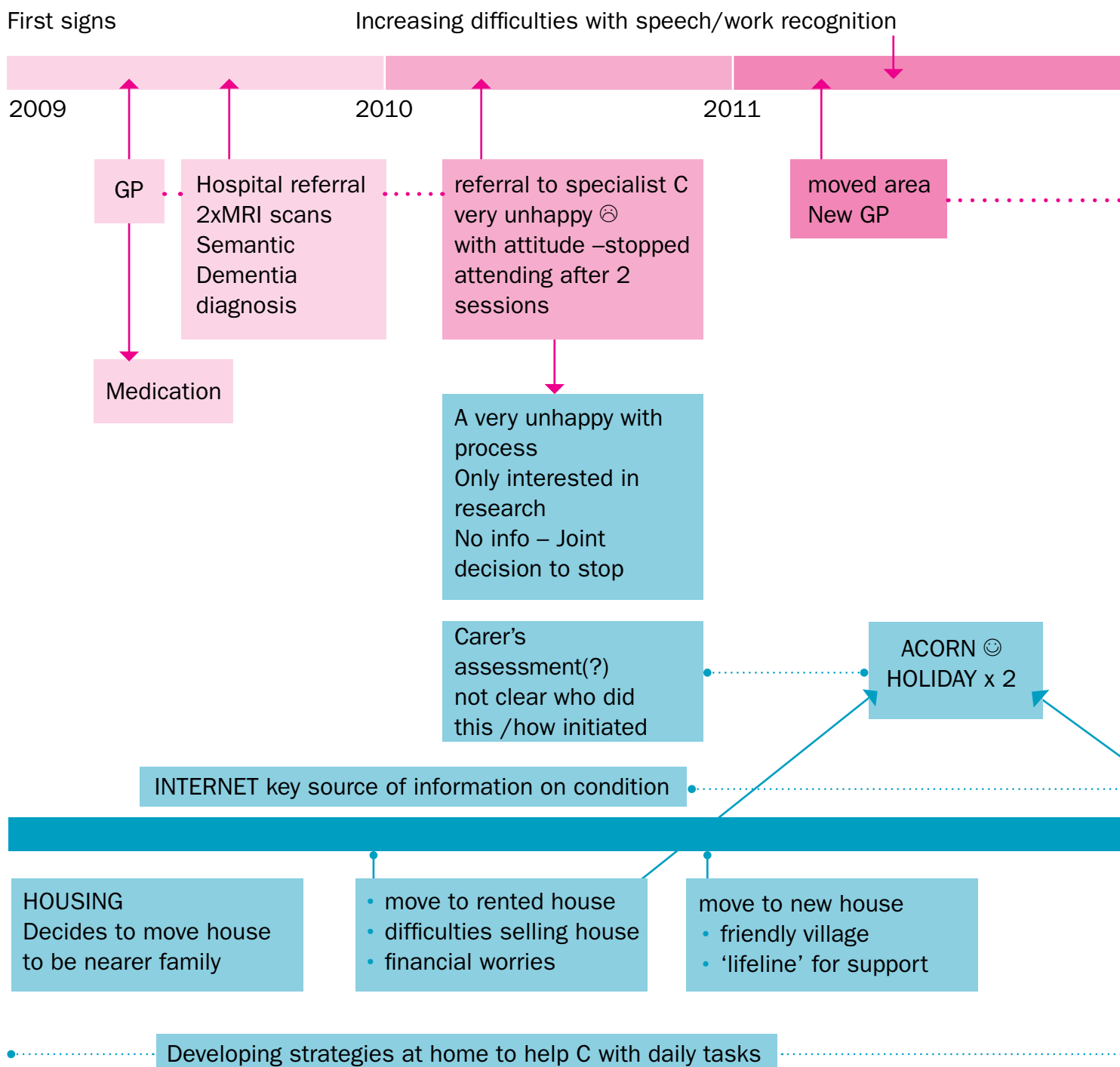
The survey went live on 7 March and was initially due to close on 15 April. However, to improve the response rate the survey was kept open for a further three weeks and Carers Trust Network Partners and national partners were asked to publicise and promote it once again. In total 325 carers responded to the survey – 287 on line and 38 on paper.

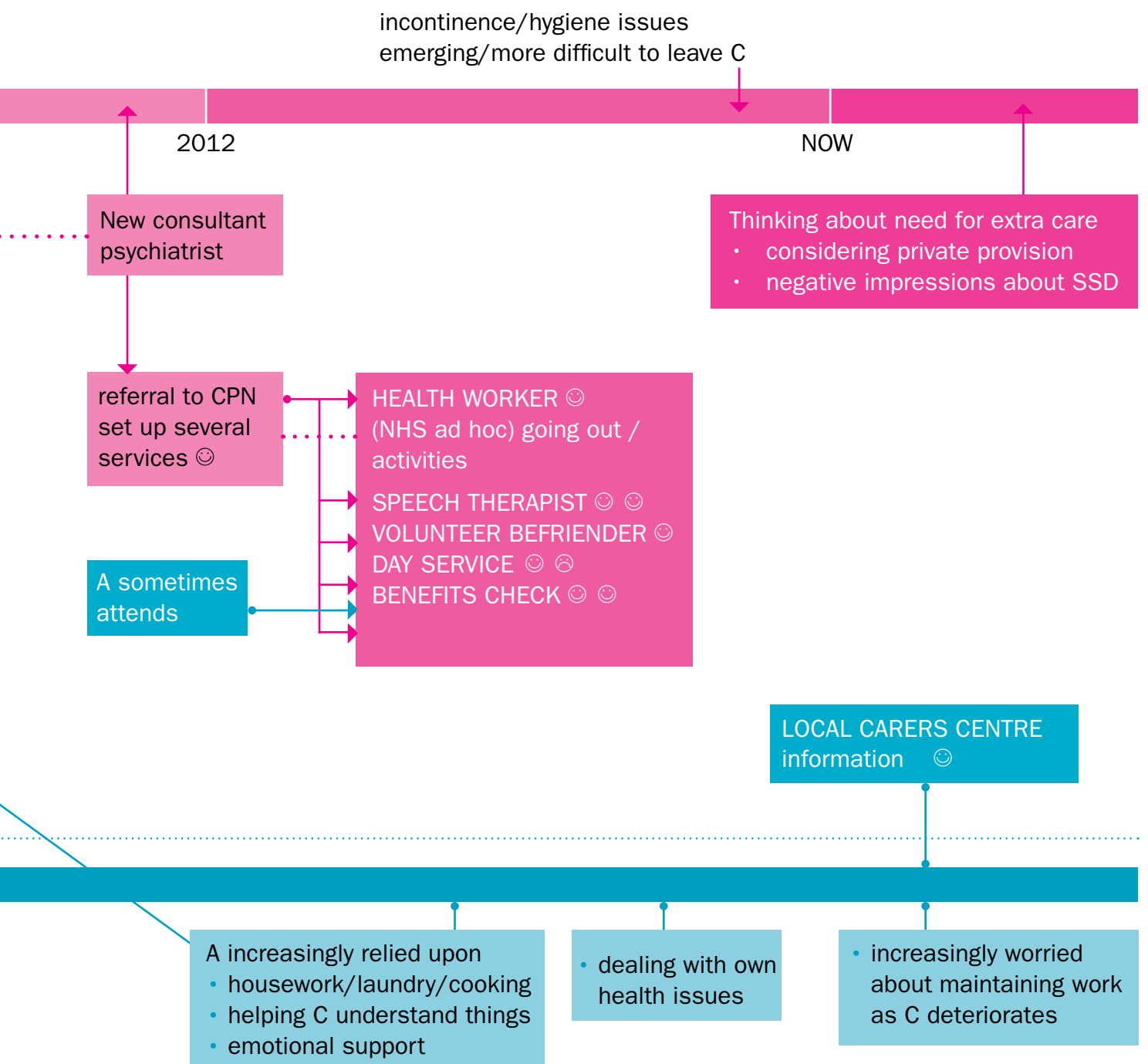
Responses to the online questionnaire were automatically collated by Smart Survey. When the survey closed, the data from the online version was downloaded and transferred into Excel. The paper responses to the survey were entered directly onto Excel to create one dataset for data management and analysis. The quantitative data was analysed using descriptive statistics and the narrative from the questions was analysed alongside the data from interviews and focus groups.

Appendix B

Example of a caring journey

A cares for his wife C – the top line represents A's timeline and the bottom, C's timeline





Appendix C

Additional data from the survey

Diagnosis

Table C1 When the person you care for started to have symptoms of dementia, were there any problems getting a diagnosis?

	N=294	
Yes	152	52%
No	142	48%

Table C2 Which agencies were involved in getting a diagnosis?

	N=293	
GP	248	85%
Mental health team	141	48%
General hospital	101	34%
Memory clinic	131	45%
Other	20	7%

Table C3 Time to getting a diagnosis of dementia from first seeing someone (for example, GP or other health professional)

	N=276	
Less than 6 months	105	38%
6–12 months	78	28%
1–2 years	40	14%
2–3 years	26	9%
More than 3 years	27	10%

Assessment

Table C4 Has the person you care for had their needs assessed by social services (that is, someone coming to talk to them and you about the help they need)?

	N=297	
Yes	224	75%
No – have had difficulties getting an assessment	29	10%
No have not sought assessment	44	15%

Where the person with dementia had had their needs assessed by social services (See Table C4 – ‘Yes’ responses) two further questions were asked:

Table C5 During the social services assessment were your needs as a carer discussed/considered?

	N=224	
Yes	150	67%
No	72	32%
Not stated	2	1%

Table C6 During the social services assessment did you have an opportunity to talk separately about your needs and how much care you felt able to provide?

	N=224	
Yes	114	51%
No	108	48%
Not stated	2	1%

Information and advice

Figure C1 Proportion of respondents who said they had been provided with:

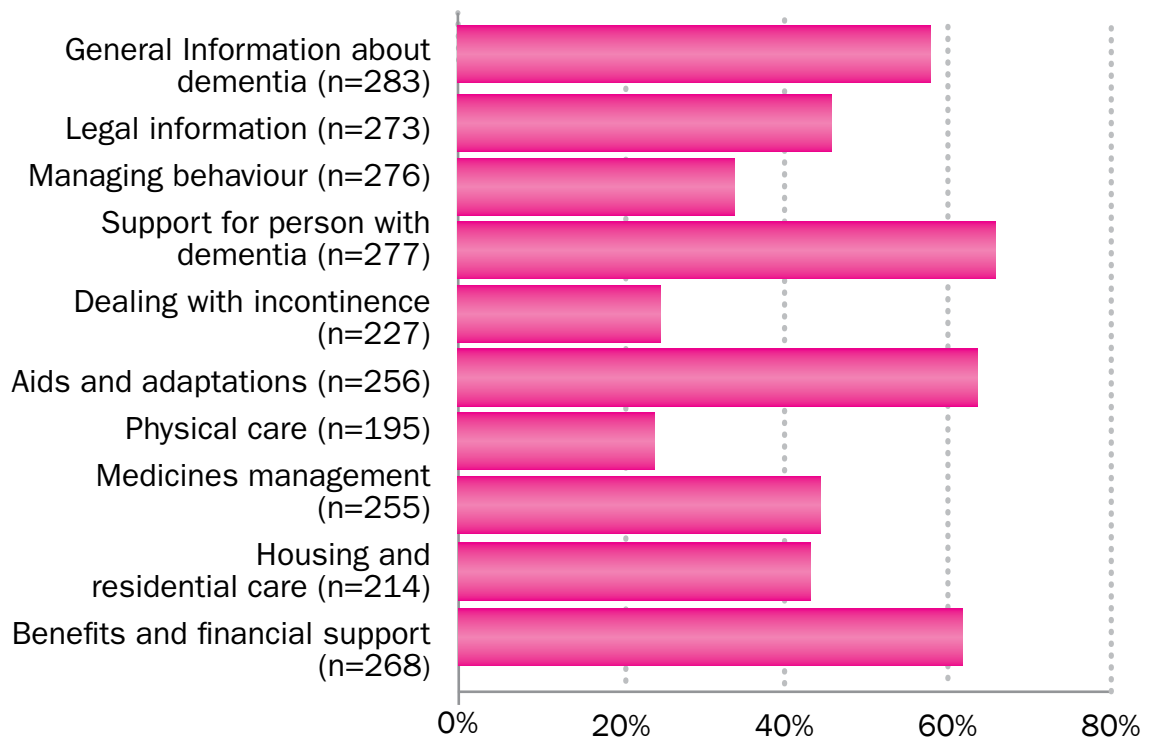
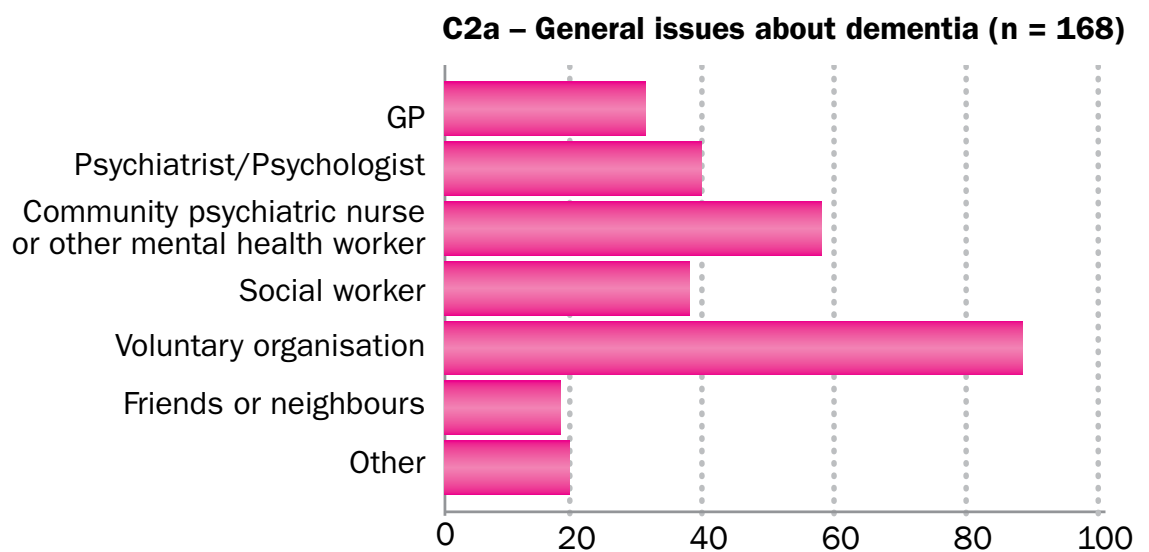
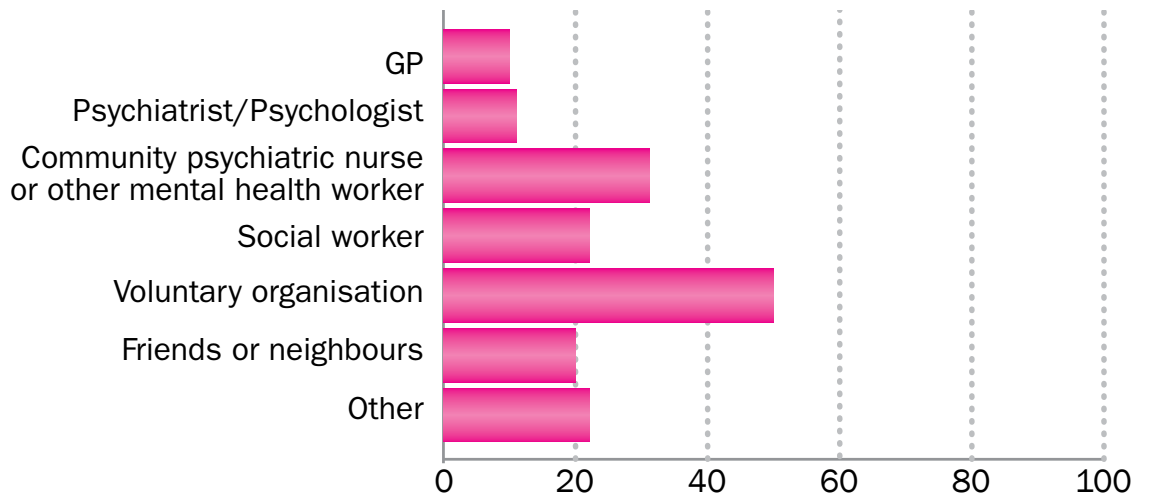


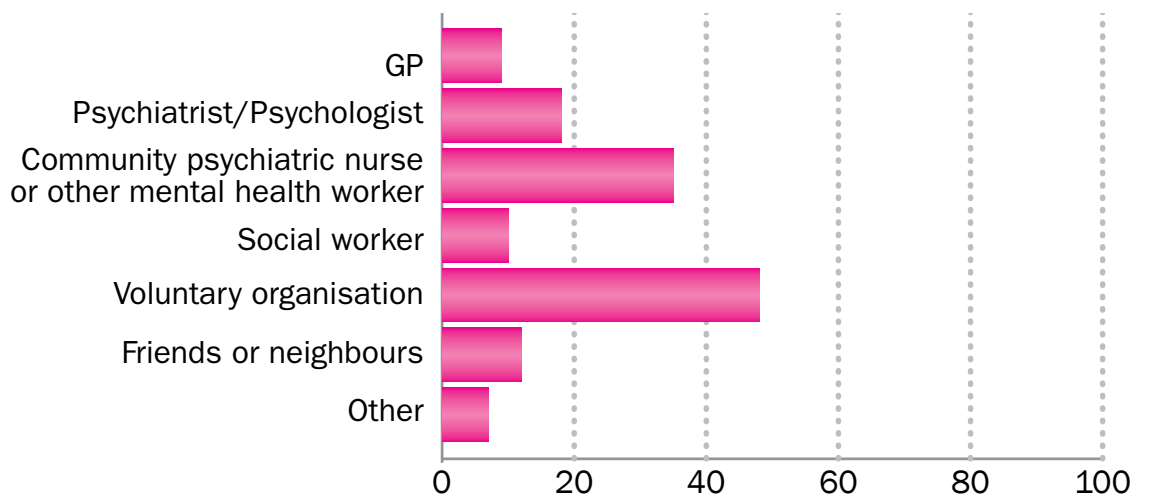
Figure C2 Who provided the information on the following topics?



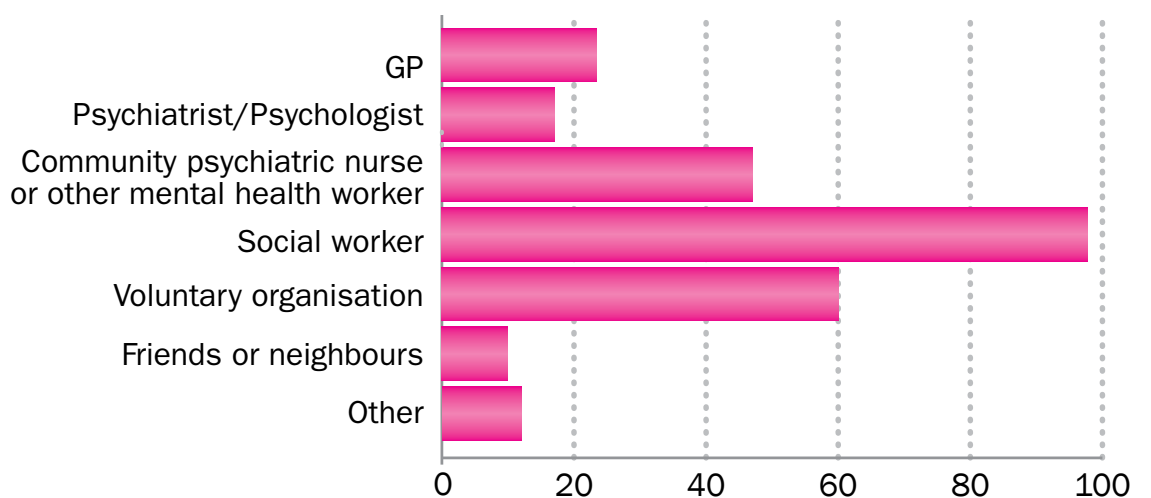
C2b – Legal issues (n = 124)



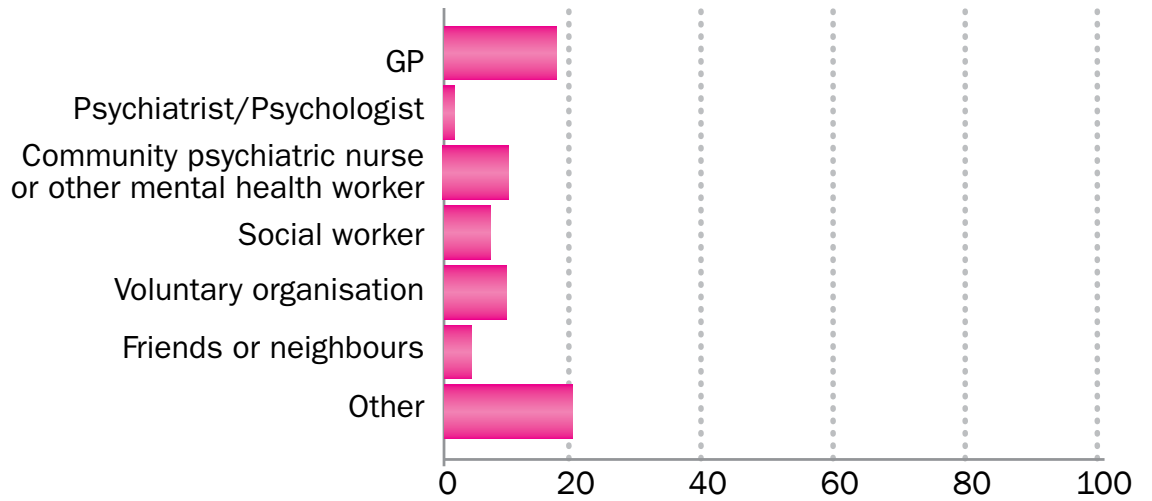
C2c – Managing behaviour (n = 87)



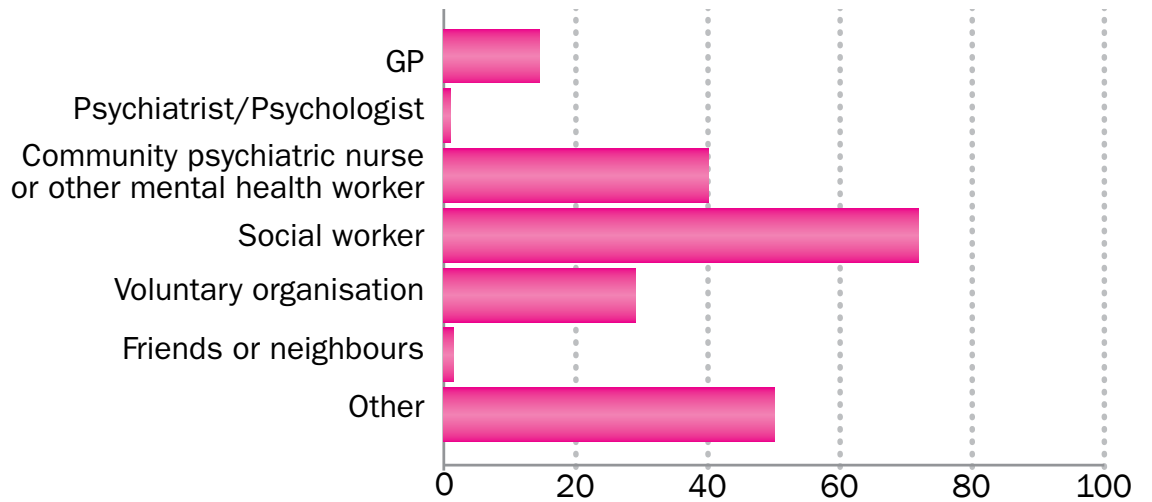
C2d – Support for person with dementia (n = 179)



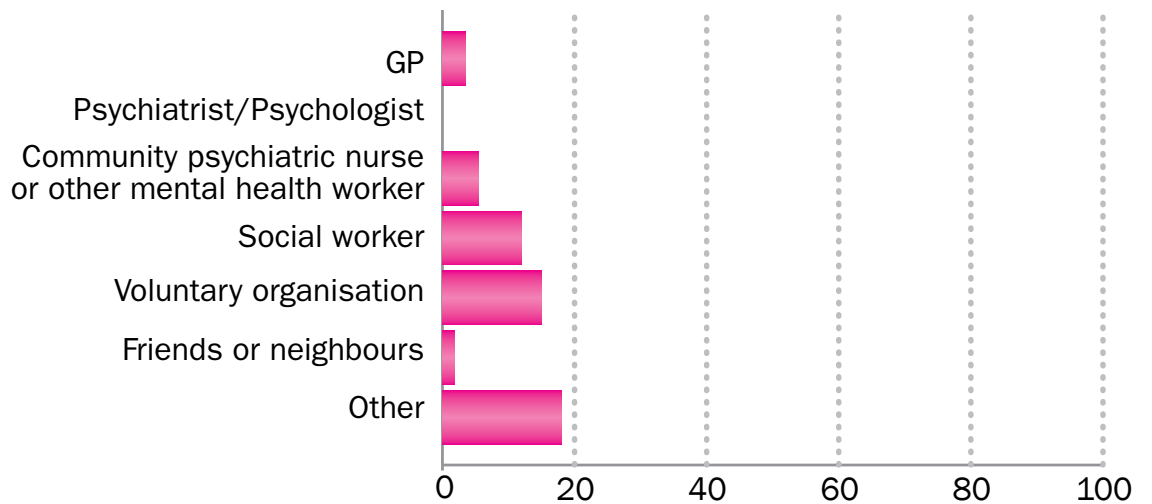
C2e – Dealing with incontinence (n = 62)



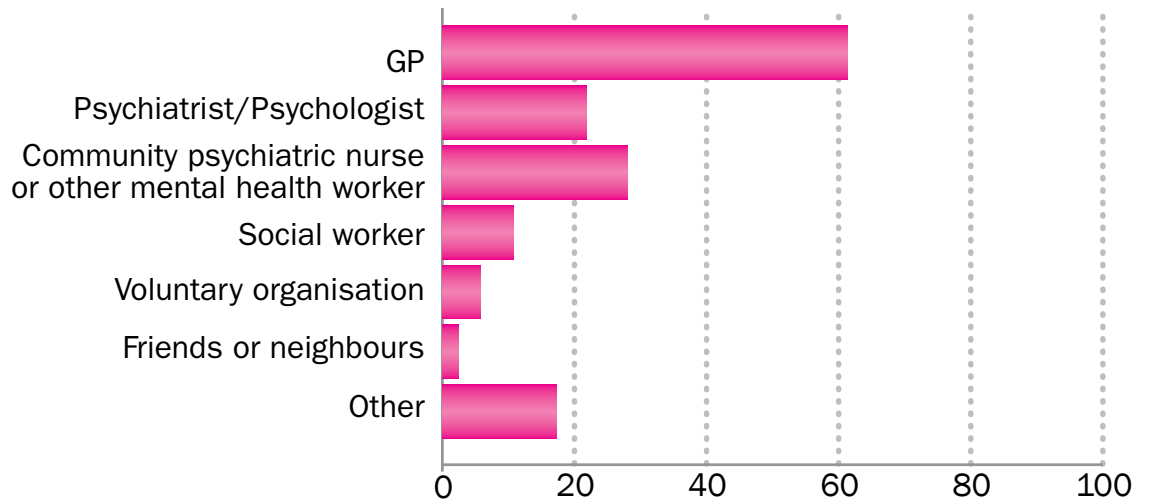
C2f – Aids and adaptations (n = 159)



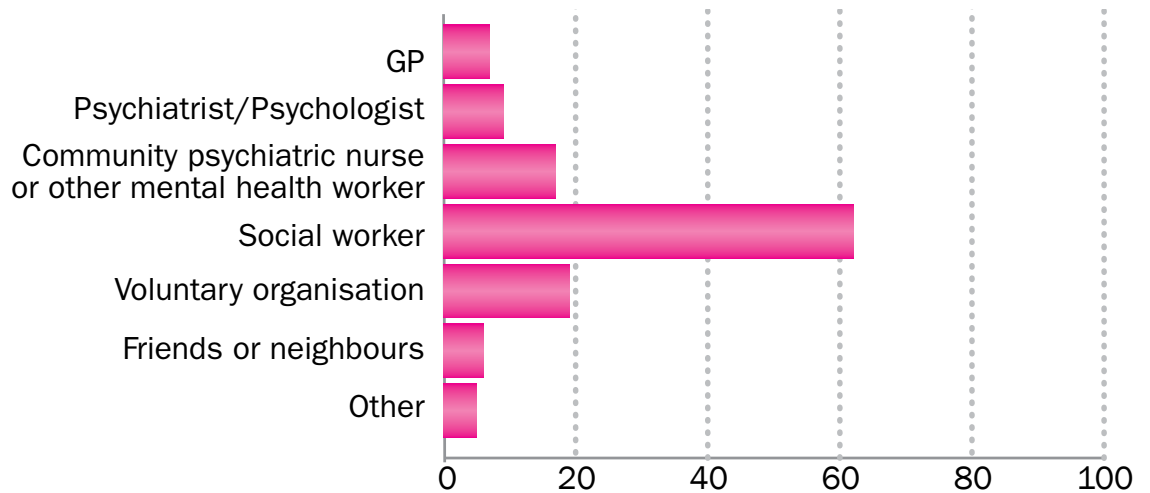
C2g – Physical care (n = 45)



C2h – Medicines management (n = 111)



C2i – Housing and residential care (n = 94)



C2j – Benefits and financial support (n = 168)

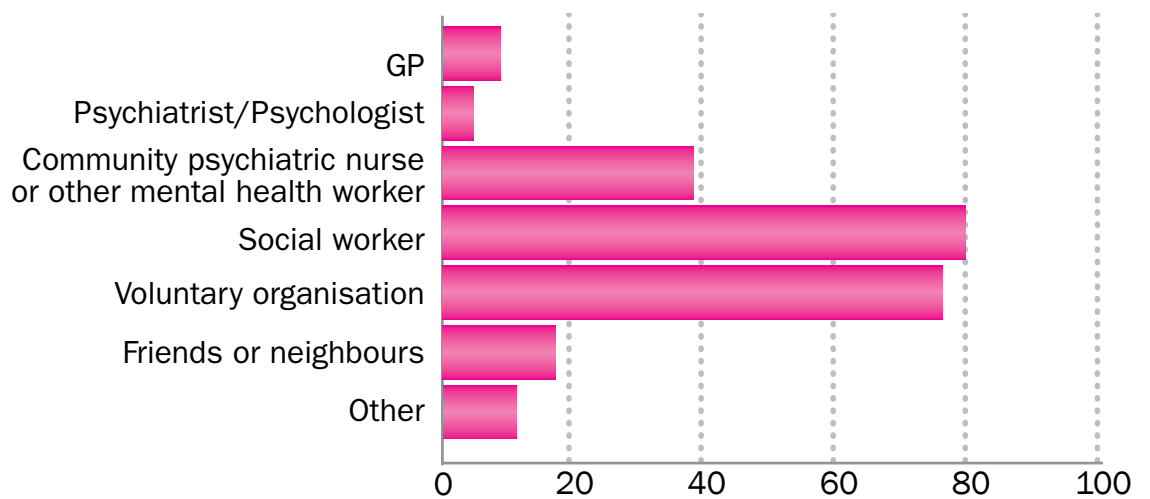


Figure C3 Service provision

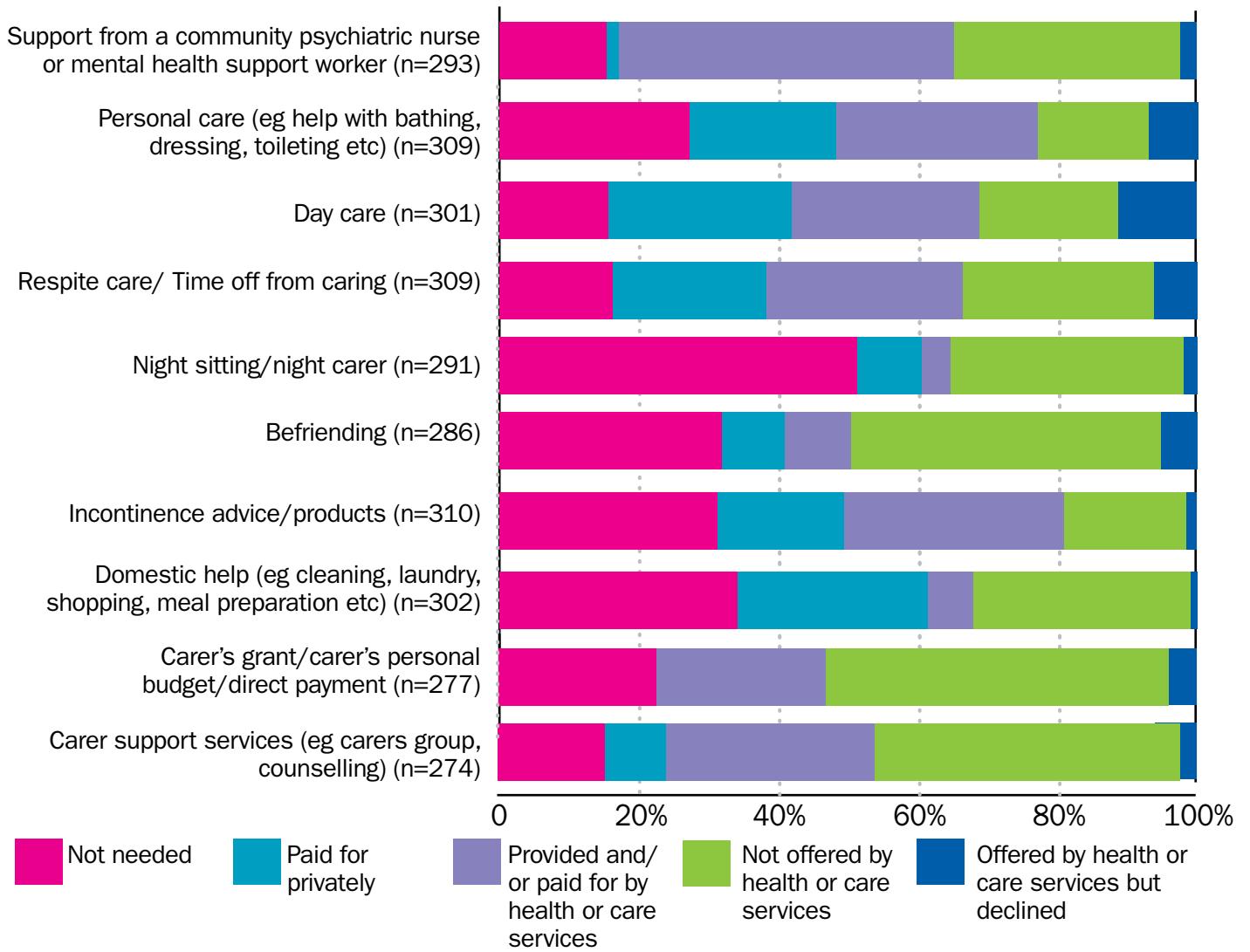
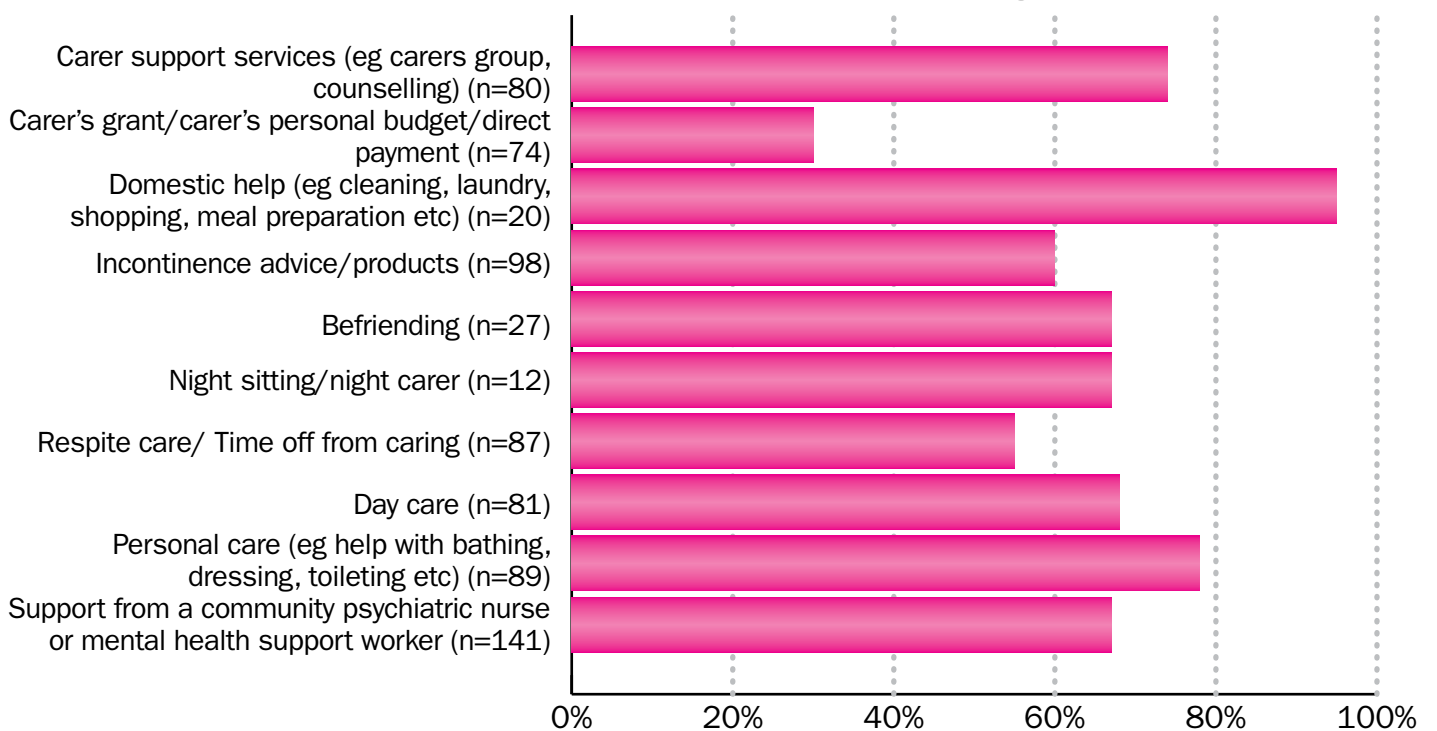


Figure C4 For those carers who had a service provided by health or care services – proportion who considered they got the service on time



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Please note identities of carers have been changed in the interest of privacy.

A Road Less Rocky – Supporting Carers of People with Dementia