

Hear Our Voice: Improving dementia and memory loss services and support in Cornwall through carer experience

Appendix 2: Contextual literature review

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Introduction

This contextual review aims to equip the reader with a lens of background information and expected standards through which they can view the outcome of this current survey and contrast what they see with reported experiences of Carers and in particular Carers of people living dementia from previous reports.

A fair question may be asked by both lay and professional readers as to why there is the need for this survey to be conducted in 2022.

Anyone asking this question has a fair point, as the experiences of carers of people living with dementia, their importance and the risks to their health and well-being are documented extensively. Between 1998 to 2020, 2,376 papers have been published relating to the impact of dementia on informal care givers¹.

Government Guidance, Standards and Research

It may be helpful to acknowledge the plethora of guidance issued by HM Government in respect to carers in a similar time frame. The National Service Framework for Older People² in 2001 (quick reality check 21 years ago) set the standard (Standard 7) that "Older people who have mental health problems have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support, for them and for their carers" (p96). Further specifying that:

¹ Lindeza P., Rodrigues M., Costa J. 2020. "Impact of dementia on informal care: a systematic review of family caregivers' perceptions". (BMJ Supportive & Palliative Care, 2020).

² "National service framework for all the people" (Department of Health, 2001).

“Specialist mental health services should be available to be consulted about and treat the most common mental health disorders in old age (depression, **dementia**, schizophrenia, mania and confusional states) and the other less common disorders including anxiety, delirium, and dependency problems. The emphasis should be on promoting the independence of older people with mental health problems and supporting them, **and their carers**, in the community wherever possible and practical’ (p99).

The National Institution for Health and Care Excellence published its guidance³ on “Dementia: supporting people with dementia and their carers in health and social care Clinical guideline [CG42]” in November 2006 (quick reality check 16 years ago) making recommendations for the identification, treatment and care of people with dementia and the support of carers. The guideline listed a range of interventions to support carers emphasising:

“Those carrying out carers assessment should seek to identify any psychological distress and the psychosocial impact on the carer. This should be an ongoing process and should include any period after the person with dementia has entered residential care” (p44).

In England, Living Well with Dementia – A National Dementia Strategy⁴ was launched in 2009. Scotland’s National Dementia Strategy⁵ was published in 2010, with strategies for Wales⁶ (National Dementia Vision for Wales) and Northern Ireland⁷ (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.

In England, Living Well with Dementia identified 17 clear objectives of which number 7 stated:

“Family carers are the most important resource available for people with dementia. ...Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks....”

The apparent absence of change experienced by Carers of People Living with Dementia was emphasised in a report commissioned from the University of York by the Carers

³ [“Dementia: Supporting people with dementia and their carers in health and social care” \(NICE, 2006\).](#)

⁴ [“Living well with dementia: A National Dementia Strategy” \(Department of Health, 2009\).](#)

⁵ [Scotland’s National Dementia Strategy June 2010](#)

⁶ [National Dementia Vision for Wales 2011](#)

⁷ [Improving dementia services in Northern Ireland – a regional strategy](#)

Trust⁸. Entitled “A Road Less Rocky – supporting carers of people with dementia” the research based report was informed by a national survey which collected responses from 325 carers (287 online and 38 on paper).

The research considered the anticipated improvement in carers experiences following the policy changes in the National Dementia Strategies of England, Wales and Scotland, along with the implementation of the “NHS Outcomes Framework⁹ for 2013” which placed specific emphasis on the provision of carers breaks and support, personal budgets for carers as well as for people with dementia.

The researchers identified that the extent to which changes were implemented locally was very variable identifying that many carers were still finding themselves under-informed and over-burdened, with the provision of information, support and services lagging behind their needs. The researchers identified 10 critical points during the caring journey (page 65), 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.

Best practice recommendations are made around these 10 critical points. The research concludes by describing in detail the 4 key characteristics that Carers emphasised the need for professionals:

1. To have a good knowledge of dementia.
2. To have an understanding of carers’ needs and issues.
3. To know both the person with dementia and the carer.
4. To take a proactive approach.

The report ends stressing “these recommendations call for a clear recognition of the long-term and changing experience of caring for someone with dementia” (page 69).






⁸ [Newbronner L, Chamberlain R., Borthwick R., Baxter M., Glendinning C. 2013. “A Road Less Rocky – Supporting Carers of People with Dementia” \(Carers Trust\).](#)

⁹ [NHS Outcomes Framework 2013 to 2014](#)

As a follow up to the National Dementia Strategy Prime Ministers Challenge's on Dementia have been published¹⁰. First in 2013 and then in 2018. Prime Ministers Challenge 2020 contains over 50 commitments focused on making England the best country for dementia care and support for people with dementia to live. This document introduces The 'well pathway' which sets an overarching framework to align and co-ordinate the contribution of health and social care partners to meet key commitments on:

- Improving diagnosis
- Support and care after diagnosis
- Enabling people to live well in their own homes for longer
- End-of-life care
- Education training and workforce

This is often described in an infographic which has an addition of Preventing Well.

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA				
PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	"I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	"I know that those around me and looking after me are supported" "I feel included as part of society"	"I am confident my end of life wishes will be respected" "I can expect a good death"
STANDARDS: Prevention ⁽¹⁾ Risk Reduction ⁽⁵⁾ Health Information ⁽⁴⁾ Supporting research ⁽⁵⁾	STANDARDS: Diagnosis ⁽¹⁾⁽⁵⁾ Memory Assessment ⁽¹⁾⁽²⁾ Concerns Discussed ⁽³⁾ Investigation ⁽⁴⁾ Provide Information ⁽⁴⁾ Integrated & Advanced Care Planning ⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾	STANDARDS: Choice ⁽²⁾⁽³⁾⁽⁴⁾ , BPSD ⁽⁶⁾⁽²⁾ Liaison ⁽²⁾ , Advocates ⁽³⁾ Housing ⁽³⁾ Hospital Treatments ⁽⁴⁾ Technology ⁽⁵⁾ Health & Social Services ⁽⁵⁾ Hard to Reach Groups ⁽³⁾⁽⁵⁾	STANDARDS: Integrated Services ⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers ⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite ⁽²⁾ Co-ordinated Care ⁽¹⁾⁽⁵⁾ Promote independence ⁽¹⁾⁽⁴⁾ Relationships ⁽³⁾ , Leisure ⁽³⁾ Safe Communities ⁽³⁾⁽⁵⁾	STANDARDS: Palliative care and pain ⁽¹⁾⁽²⁾ End of Life ⁽⁴⁾ Preferred Place of Death ⁽⁵⁾
<small>References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.</small>				

(NHS England undated). Elaboration is provided in relation to Supporting Well that emphasises the importance of support following diagnosis for people with dementia and their carers with the urgent need for information, advice and support both immediately after diagnosis and to help them throughout the stages of their experience.

The impact of the national situation on the economy is well spelt out in current information and guidance published for healthcare professionals¹¹:

“An estimated 540,000 people in England act as primary carers for people with dementia; half of these are employed. 112,540 have needed to leave employment to meet their caring roles and 66,000 carers have cut their working hours. This results in a

¹⁰ [“Prime Ministers Dementia Challenge 2020” \(Department of Health, 2016\).](#)

¹¹ [Dementia: applying All our Health. Guidance from Office for Health Improvement and Disparities, 2022](#)

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lower standard of living for those carers and significant costs to society in general” going on to say that the contribution of unpaid carers of people with dementia in the UK totals £13.9 billion a year, making the point that these costs would otherwise have to be met up by the government.”

In a report by The Health and Social Care Committee¹² (appointed by the House of Commons to examine the expenditure, administration, and policy of the Department of Health & Social Care) the current situation relating to carers of people living with dementia is described in the following terms:

“Instead of receiving integrated care across the health and social care system, those living with dementia and their carers are required to navigate complex and uncoordinated care pathways. The most vulnerable in our society are left at risk of falling through the gaps after receiving a diagnosis of dementia and their families and carers are left to grapple with burdensome bureaucracy in the system “set up to ration”. (House of Commons 2021)

Independent Reports

This year has seen a number of reports published by independent organisations focused on the needs of carers. Three are considered here produced by Carers UK¹³, Age Concern¹⁴ and Dementia Carers Count¹⁵.

Carers UK released their “State of Caring in the UK – 2022” report in early November 2022. It is described as the largest and most comprehensive survey of unpaid carers, with over 12,400 current carers conducted between 12 July and 11 September 2022. The survey covered many other aspects of caring, from the impact of caring on health, to experiences of using support services, and the challenges of juggling work and care. It headlines the consequences of the pressures on the NHS, and the record levels of demand for social care services:

- “Many carers are facing serious difficulties in getting NHS treatment – of those waiting for specialist treatment or assessment a third (34%) have been waiting for over a year.
- Two thirds of those (67%) waiting for treatment said that waiting is having a negative impact on their physical or mental health.
- 41% of carers haven’t taken a break from their caring role in the last year.
- Half of all carers (51%) took over a year to recognise their caring role, with over a third (36%) taking over three years to recognise themselves as a carer.

¹² [“Health and Social Care Committee Supporting people with dementia and their carers, Seventh Report of Session 2021–22” \(House of Commons, 2021\).](#)

¹³ [“State of Caring 2022 Report – A snapshot of unpaid care in the UK” \(Carers UK, 2022\).](#)

¹⁴ [“Why can’t I get care? Older people’s experiences of care and support” \(Age UK, 2022\).](#)

¹⁵ [“Dementia Carers Count Survey 2022” \(Dementia Carers Count, 2022\).](#)

- 75% of carers worry about continuing to juggle work and care going forward.
- With many services being reduced or cut completely, carers are extremely worried about the future: 61% said they were uncertain about what practical support they might be able to access in the next 12 months.
- There are opportunities to support carers through digital means and using data creatively, but approaches need to be tailored and digital exclusion combatted”.

Recommendations included a call for:

- A funded National Carers Strategy for England.
- A review and reform of carers’ benefits.
- Investment in social care to support carers with adequate breaks.
- Better access to NHS and support services for unpaid carers.

The survey responses flagged that the UK wide cost-of-living crisis has added to pressures for carers, which has not only affected their finances but their health and wellbeing prompting a further report ‘Heading for crisis: caught between caring and rising costs’ based on these findings. Highlights from the report are:

- Those who have been caring for more than five years are struggling most, with one in five (19%) in debt compared to 9% of people caring for less than five years.
- Those receiving Carer’s Allowance – just £69.70 a week for people providing 35 hours or more of unpaid care each week – are worst affected. Two in five (40%) of carers receiving Carer’s Allowance are in debt as they try to manage their costs. More than a third (35%) are cutting back on food and heating, with four in ten (39%) saying they are struggling to make ends meet. (Carers UK 2022 B).

Age Concern published “Why can’t I get care? Older people’s experiences of care and support” in November 2022. Seeking to answer the question posed in the title the report identified that:

- 22% of older people with a long-term condition were concerned about their ability to access local authority services.
- 70% of care home residents have dementia or severe memory problems, but the average proportion of care home beds dedicated to dementia in each region is only 21% – a 4.2% decline from 2019.
- 50,000 fewer care worker posts are filled now than in 2021.
- 36% decrease in registered nurse filled posts since 2012/13.

Concluding that “In most cases, the answer to the question this report poses – ‘why can’t I get care?’ – is that there simply isn’t the care to get. The severe shortages in staff

and the lack of funding to pay for more or better services to provide care or respite provision have left a gaping hole in support, and often services just aren't available.

"Dementia Carers Count" carried out its first nationwide survey over the summer of 2022. 435 family carers participated. The survey asked participants about their experiences of caring for someone with dementia and what they thought could make the greatest difference to daily life. The report described specifics about the caring experience identifying 5 key areas:

1. No choice.
2. Lack of support.
3. Reaching Crisis.
4. Working and caring.
5. Carers assessments;

The majority of participating carers reported that they had not chosen their caring roles, that the experience is intense and most carers lack support. It reports that this results in many carers reaching crisis points, some on a regular basis: finding that over 80% of family and friends caring for people with dementia are reaching crisis points and not getting the support they need stating that one in five family dementia carers are reaching crisis point on a regular basis. They report that many find it impossible to continue with work. Family carers shared that they feel *alone, trapped* in a life they have not chosen and *broken*. The survey further identified that nearly 60% of participants had not had a Carer's Assessment and that of those who had 70% say that they have not received the support they need. More than half of those who received a Carer's Assessment felt that it did not highlight useful options.

The report ended with a description of the support carers are asking for:

1. Having a single point of contact.
2. Support for the emotional toll of caring.
3. Clearer information about a dementia diagnosis treatment and care.
4. More respite care.
Feeling included and heard.

Postscript

The reader may have noticed a trend in the documents reviewed here, that guidance is consistent in describing the approaches that are helpful to carers, that Government directives make reference to shortcomings and set strategies for improvement whilst independent reports highlight the value of carers and the gaps between expectations and lived experience.

This short contextual review may leave the reader with a sense that the needs of carers of people living with dementia have been researched, understood, and verified resulting

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in standards of support being defined and published. It may be fair for the reader to assume that this body of understanding, available to commissioners, managers of health and social care organisations as well as practitioners will have impacted positively on carers of people living with dementia in Cornwall. The reality will become clear to the reader as they progress through the report.