DEMENTIA
CARERS COUNT
Supporting Family Carers

Invisible

2023 Dementia Carers Count Survey Findings

Foreword

"There are nearly one million families caring for someone with dementia, part of a larger group of over five million unpaid carers, who provide irreplaceable care and support to individuals with a range of different needs. This number is growing.

Caring for someone with dementia is a journey filled with both moments of profound connection and unique challenges. It requires strength and resilience. Carers provide invaluable support and comfort to those facing the complexities of dementia.

It should be impossible not to notice, not to see these carers who do so much day in day out. They are the glue holding our society together, especially as our population ages, and dementia prevalence increases. Not least as funding and resources for adult social care services are far from keeping pace with what is needed. Yet, despite all these carers do, ask, and they will tell you that they feel invisible.

They feel unseen, unheard and unsupported. To make matters worse, carers caring for someone living with dementia can feel invisible to that person too. Relationships change in unimaginable ways. An all too familiar aspect of dementia is that there comes a time when the person being cared for is unable to recognise the person caring for them.

Is it no wonder that nine in ten carers are reaching crisis. Feeling forgotten, scared of what is to come, carers are struggling to cope.

We believe dementia carers count. This report is dedicated to all carers who feel invisible.

We see you. We hear you. You are not alone."

Trevor Salomon, Chair Carers' Advisory Panel

Acknowledgements

This report has been produced with thanks to:

- The 1,314 respondents who took part in the survey. We greatly value you sharing your experiences and recommendations for what would make a difference.
- The many organisations, community groups, dementia support groups and individuals across the UK who helped us share this survey with family carers.

DEMENTIA CARERS COUNT
Supporting Family Carers

Who are dementia carers?

58%

did not choose to be a carer and one in ten prefer not to think of themselves as a carer

39%

are caring 24/7

31%

of carers felt negative about their caring experience

89%

have reached crisis point at least once with over a quarter trying to manage crises often

24%

have poor or very poor physical health

51%

have had a carer's assessment and one in three carers who have had an assessment have not received a support plan

36%

have a disability

29%

have provided care for over 5 years

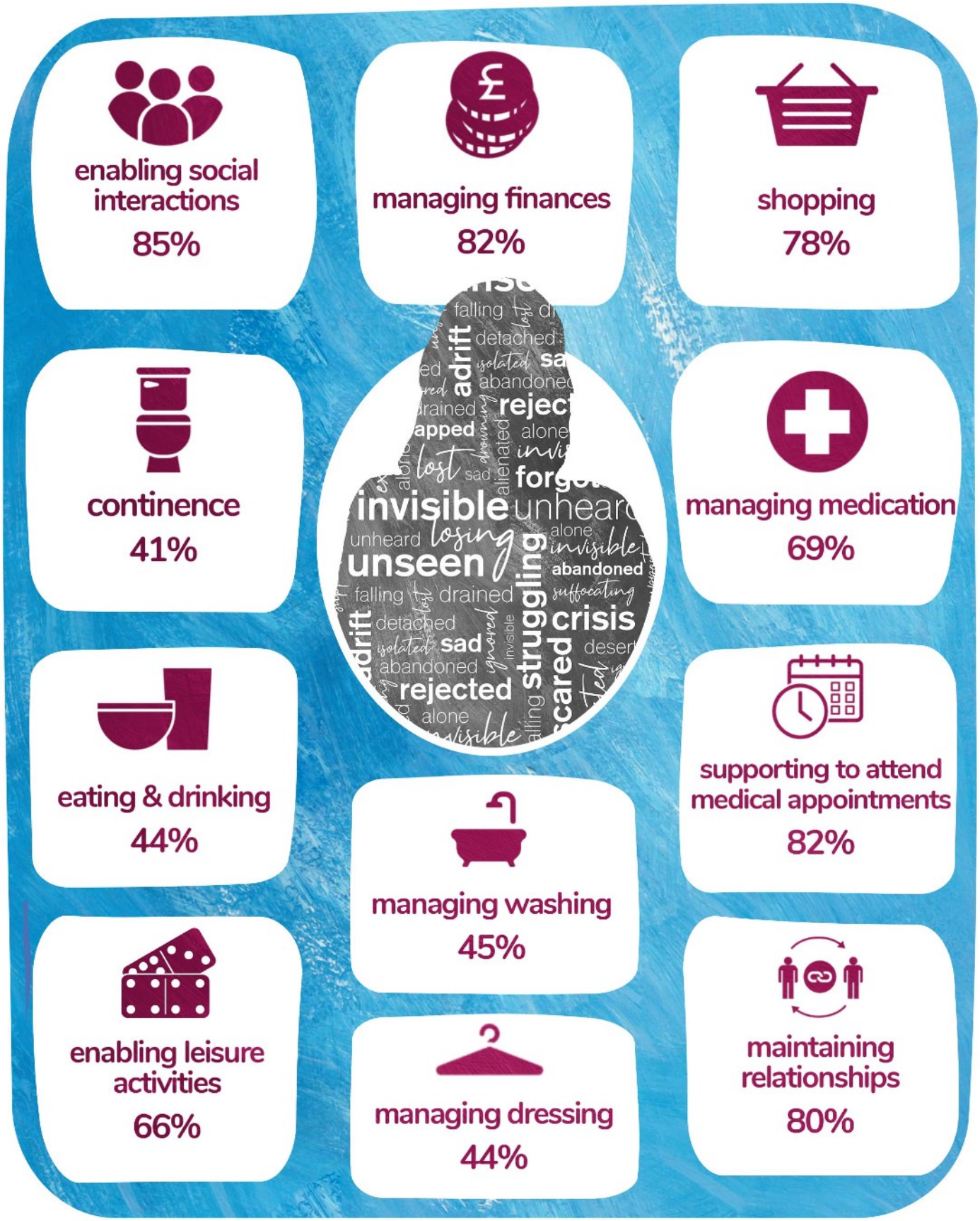
88%

are caring for close family members, either a spouse, partner or parent

33%

have poor or very poor mental health

What care are they providing?



In Crisis

Carers are increasingly struggling to cope.

Our findings indicate that **9 in 10 dementia carers are reaching crisis points** – with just over half of carers experiencing crises from time to time and **over a quarter often reaching crisis points**.

> *"Laugh and the world laughs with you, cry and you cry alone."*

Legislation and guidelines exist which set out the support carers are entitled to. This support should help prevent carers from feeling overwhelmed and in crisis. However, carers have told us that they are not getting the support they need when they need it. Instead, they feel invisible to those they care for, invisible to health and social care professionals, invisible to policy makers, and invisible to society at large.

This feeling of being invisible makes carers increasingly fearful of what lies ahead. They are worried about how they will manage the next challenge and whether they will be able to cope.

We are giving voice and visibility to dementia carers and their experiences. This report sets out what could make a difference to them in terms of meaningful support in the present and what could reduce their anxiety about the future.

The invisible carer:

Unrecognised

1 in 3 carers who responded to our survey described their emotional health as either bad (27%) or very bad (7%)

> *"I feel sad a lot of the time. It's hard no longer being able to share life and memories in the same way with my husband. I feel I am gradually losing my best friend and have shed many tears, after 49 years of marriage - it's so hard."*

The challenge

Most dementia carers are caring for a close family member, but these relationships are likely to irrevocably change. Time and again, carers describe role reversals and shifting relationship dynamics. Some share the devastation of feeling **"unloved"** by and **"invisible"** to the person they are caring for.

As dementia progresses, the behaviour, personality and awareness of the person with dementia can change in unpredictable ways. This can make life very challenging for carers and they worry about what will happen next. The relationship between the person caring and the person they are caring for changes. Carers often need to adapt to new dynamics that they had never imagined. This can be emotionally draining and distressing.

In some cases, the person living with dementia may no longer recognise the person looking after them. They may confuse them with being someone else or refuse to believe that they are who they say they are. This can have a devastating emotional impact on carers. If a carer's identity as a spouse or partner or child or sibling is not accepted by the person they are caring for, this can be profoundly unsettling. Some carers describe grieving for the relationship they are losing.

At the same time, some carers find that it can start to become difficult to remember the person somebody was before their diagnosis. The emotions carers experience are complex, and many feel depressed.

What makes a difference

Personalised support

Being able to access personalised support whenever this is needed, including access to advocacy services and counselling and, to help manage complex emotions.

Tailored advice & information

Advice and information to help carers understand the stage and type of dementia that the person they are caring for has been diagnosed with. This can help carers understand why someone's behaviour and personality may be changing.

Connecting with others

It's easy to feel isolated when caring for someone with dementia. Connecting with other carers who are having similar experiences can provide opportunities to exchange tips and advice and to receive invaluable support.

The invisible carer:

Unsupported

Only 29% of carers feel that they have been able to access support when they have needed it. Instead, many carers have simply felt **"ignored"** or that they **"don't matter"**.

> *"Carers are invisible to most of the authorities. It would be nice, if you are known as a caregiver, if sometimes you were asked – 'How are you? Can we do anything to make life easier for you?' It would be great to be valued enough to be cared for too."*

The challenge

The support that carers might need can be extremely varied from information about dementia to advice on financial matters and benefit entitlements, to an understanding of their legal rights, to personal care, guidance from continence care services, speech and language therapists and occupational therapists to psychological support and counselling. Often, carers can feel so overwhelmed many don't even know what help and support to be asking for and half (49%) are confused by the information available.

The 2014 Care Act (Social Services and Wellbeing (Wales) Act 2014 and Carers (Scotland) Act 2016) make provisions about the support carers are entitled to but there can be significant discrepancies between the spirit of the legislation and the implementation. While legislation outlines how local authorities and primary care services should be supporting carers and meeting their needs, there is no statutory requirement for them to identify carers and maintain regular contact or proactively reach out to carers. Too many carers say that they are ignored when they say they need help. All too often, it is only when a carer reaches a crisis point that they are offered support, and this is often inadequate.

All carers are entitled to an assessment of their needs. They should also be provided with information about services and support that might help them, even if they do not qualify for any financial assistance or local authority funded support.

Our survey indicates that 51% of carers have had a carer's assessment, and this has not always led to meaningful help and support.

Indeed, over a third of carers who have had an assessment (36%) told us they never received their support plan. Those who did, shared that the support offered was **"limited"**, **"inflexible"** and **"inappropriate"**. Many said their caring responsibilities meant that it wouldn't be possible for them to benefit from a suggested service. For example, carers were told to "get out more", but were not given any options for respite care to enable them to do so - whether self-funded or paid for by the local authority.

When carers had funds to pay for support, 46% struggled to get advice from their local authority about how to pay for and organise any support.

Only 35% of the carers who did receive support found that the support they received could respond to changes in their caring responsibilities.

Carers also raised concerns about who will look after them or what will happen to the person they care for if their health deteriorates or they are unable to care. Many have no contingency plan in place and no health or social care professionals have discussed what the options might be with them.

What makes a difference

Carer's assessment

A prompt offer of a holistic carers assessment and regular reviews.

Proactive outreach

Proactive outreach - with regular contact with carers.

Early identification

Early identification and recognition as a carer.

Respite care

Appropriate and flexible respite care.

Involvement

Recognition that carers are an equal partner in the care of the person with dementia. Better involvement of carers in service design and delivery.

Contingency plan

An agreed contingency plan to help remove some of the fear about the future.

The invisible carer:
Unheard

31% of carers feel negative or very negative about their caring experience

> *"Our situation changed so quickly that the Carer's Assessment was irrelevant within weeks. We asked constantly for help but got none."*

The challenge

Time and again, subsequent governments have overlooked the many thousands of unpaid family carers. But with approximately 165,000 vacancies in the adult social care workforce in England[1], unpaid carers are ultimately filling gaps and holding together our under-funded social care system.

The role and contribution of carers to health and social care is critical. Findings from Carers UK and the University of Sheffield show that unpaid carers in England and Wales contribute £445 million to the economy in England and Wales every day - £162 billion per year.[2] Essentially equivalent to a second NHS in England and Wales.

Estimates have predicted the number of cases would grow from 770,000 in 2016 to 1.2 million by 2040. New research suggests this might be a significant underestimation with potentially one in 16 people over 50 being predicted to be living with dementia in 17 years.[3] This has huge implications for the demands on social care in the coming years.

Yet while carers are now recognised in law, the intent of the legislation has never been backed up with adequate ring-fenced resources and given the priority needed to encourage local authorities to proactively reach out to carers. As a result, family dementia carers are being left with no support, effectively abandoned as soon as they take on caring responsibilities. This is not sustainable, and it is not fair.

[1] November 2023, Adult social care workforce in England - House of Commons Library (parliament.uk)
[2] May 2021, Carers UK and Centre for Care, Valuing Carers 2021 valuing-carers-report.pdf (carersuk.org))
[3] November 2023, Chen, Brunner et al, Lancet Public Health 2023; 8: e859–67

What makes a difference

National prioritisation

National prioritisation of adult social care.

Ring fenced funding

Ring fenced funding for local authorities to support the needs of unpaid carers.

Carer recognition

Recognition of carers in national and local decision making.

Workforce training

Workforce training in dementia and dementia care.

The invisible carer:

Unseen

Nearly half of all dementia carers say they care '24/7' (39%) or that they cannot leave the person they care for on their own (8%)

> *"My world is becoming smaller, socialising is difficult, seeing my grandchildren is now a struggle."*

The challenge

Despite its prevalence, many people do not have a good understanding of the different symptoms of dementia. It is a term which is used interchangeably to cover over 200 different sub-types of brain disease, which impact on how people think, remember, reason and speak. There is little awareness of how different dementias may progress and how carers' lives can become very limited very quickly. Nobody really understands what is happening in a carers' world.

Carers can feel incredibly lonely. Often their caring role impacts on other aspects of their life and identity, including their ability to continue working or to have time for other relationships. Carers talk about how their world shrinks, how friends disappear and how a lack of social interaction makes them feel isolated and alone. The longer someone is a carer, the more isolated they may start to feel.

Dementia carers tell us they have no support and describe feeling **"trapped"** - often physically in their own home. A lack of appropriate respite options means that carers are not supported to benefit from social contact with other people. Not being able to socialise or connect with others can compound a carers' sense of being invisible.

The stigma experienced by carers of people with dementia can be a significant cause of the isolation they feel. A carer's own understanding of their role and responsibilities, the assumptions made in their families and communities about dementia, or the unpredictable and often challenging behaviour of the person with dementia, can stop many carers reaching out for the understanding and support they need from their wider family, friends and communities.

What makes a difference

Respite support

Easy access to respite support tailored around the needs of the carer and the person living with dementia.

Broader awareness

Broader awareness and understanding of dementia symptoms and the progress of the disease.

Prompt identification

Prompt identification of unpaid dementia carers.

Small gestures

Small gestures from friends, family members, colleagues and community members that show a carer has not been forgotten.

Local carer support groups

Dementia Carers Count Recommendations

> *"Dementia carers are in desperate need of emotional and practical support to help them cope with the complexities of caring for someone living with dementia."*

Prioritisation of social care across the UK

Significant investment in social care and the social care workforce is long overdue. The importance and contribution of social care must be valued equally and in partnership with health care. Funding should be sufficient to ensure that statutory duties to support carers can be met by local authorities on a timely basis and provide for an informed workforce with understanding of dementia and dementia care.

A carer's strategy in England and the prompt implementation of carers' strategies in Scotland and Wales

These must be long-term and fully funded. They should prioritise carers' well-being through:

- Better identification of people who take on unpaid care responsibilities.
- Recognition of the different needs of people who care for others.
- Awareness of carers' rights.
- Ensure carers have access to free, condition-specific, personalised support and learning opportunities at every stage of their caring journey (including before diagnosis, at diagnosis, while caring for the person living with dementia, at end of life and coping with anticipatory grief and bereavement).

Collaborative working to ensure early identification

Recognition, identification and support of unpaid carers requires strong collaborative working between health, social care and voluntary, community and social enterprise organisations, especially as not all unpaid carers will identify themselves or recognise themselves as a carer.

- Unpaid carers should be registered in primary care as soon as they are identified, and a record of their carer assessment and contact with health and social care professionals should be shared.
- Their carer contingency plan should be included in these records.

Health and care systems must allow for this collaboration to ensure carers are identified and supported appropriately by health and social care professionals.

Earlier recognition and involvement of family carers

As laid out in legislation, as soon as someone identifies themselves, or is recognised as a carer, they should be offered the choice of becoming a carer and then of the levels of care they are comfortable to provide.

- The carer should be supported to feel empowered and understand their options to make the best choice for them and the person they might be caring for.
- Carers should be recognised and treated as an equal partner in care.

Effective ways of enabling all friends and family members to be part of a care network must be found.

Carer's assessments which provide access to a personalised support plan

All family carers are entitled to a carer's assessment which should identify the individual support needs of the carer.

- Every carer's health and well-being needs should be assessed and addressed when they are first identified as a carer.
- Professionals conducting the carer's assessment should prompt consideration of options for contingency care in case of an emergency or other reasons why a carer may no longer be able to provide support.
- Carers should receive a tailored support plan after their assessment. This, along with their contingency plan, should be reviewed at least once a year or when a carer's needs or situation changes.

Contact with carers by health or social care professionals should be proactive with regular outreach made by a named contact to check on carers' well-being and so that local health and social care services are up to date with a carer's changing needs.

The support plan offered should include emotional, practical and financial support and should be mindful of a carer's health, location, transport options, culture, faith, community, family relationships and financial circumstances as well as any other identified support needs. It should include access to free, flexible and locally available respite care which is shaped around a carer's needs and preferences and those of the person living with dementia.

Support should be offered after caring responsibilities have ended. It should also include coping strategies that go beyond their caring responsibilities and recognises a carer's personal needs and ambitions.

Personalised support, addressing practical, emotional and financial needs

Dementia carers must be able to access quality and varied support and information which should be informed by and co-produced with carers.

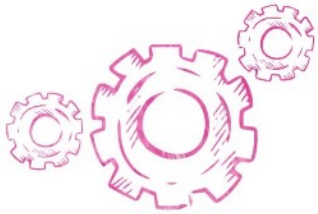
- The information and support carers are offered must be adaptive to the stage and type of dementia of the person they are caring for and all carers should be helped to understand a specific dementia diagnosis. Furthermore, guidance should be tailored to be relevant to different caring situations, such as working carers, carers who self-fund, carers who have additional support needs, multiple carers within the same caring network.
- Information and support should be available in person, online and over the phone, and it should be a priority to connect a carer to local peer support.

A better informed, supportive public

It is essential for carers' well-being and their longer-term ability to provide care that carers feel supported and understood by wider society.

Carers' isolation could be greatly reduced by national and local education campaigns which inform the public about dementia as a health condition to help remove stigma and which share ways in which people might be able to support dementia carers.

Methodology



We describe dementia carers, as anyone who offers or has offered help and support to a friend or family member to live well with dementia. **We had 1,314 responses to our survey. Respondents came from across the UK. The survey ran from 7th June - 15th September 2023.**

This is Dementia Carers Count's second annual survey of dementia carers. The findings build our understanding of the issues facing dementia carers right now and help us to develop services and shape our campaign priorities. Our recommendations are directed by what carers have told us in this survey.

The survey was developed using Survey Monkey and open to responses from anyone who provides or had provided unpaid care to someone living with dementia. It was promoted widely via our supporters, social media channels, and other charities and organisations, community groups and dementia support groups.

These survey results are intended to provide a valuable snapshot of unpaid dementia carers' experiences and views across the UK.

About Dementia Carers Count

We are here to listen, to support you, and to help you look after yourself as well as the person you care for. Every day our team of health and care professionals works with carers, like you, across the UK. To find out more, visit: **www.dementiacarers.org.uk**

If you are a carer for someone living with dementia you can call our **Carer Support Line** on:

0800 652 1102

For more information about this report, please contact Helen Pyper, Head of Policy and Campaigns: **helen.pyper@dementiacarers.org.uk**