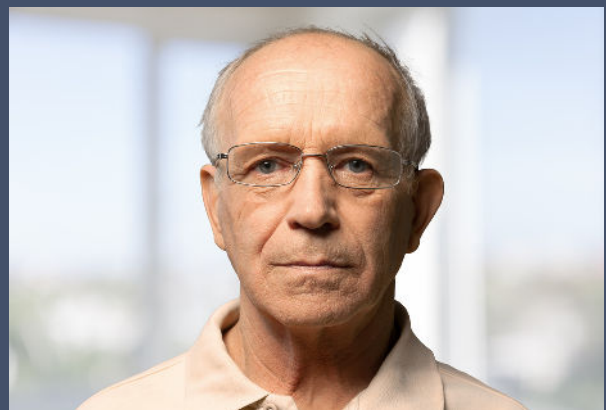
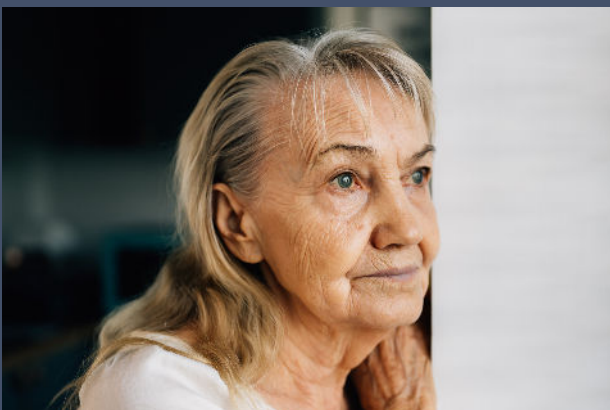




DEMENTIA  
CARERS COUNT

# Our Manifesto for Dementia Carers



## Carers in Crisis

There are nearly **one million** people living with dementia in the UK. Many are cared for by family members. It can be an overwhelming experience.

Research we conducted in 2023, involving over 1,300 dementia carers, found that most carers receive no support and struggle to cope with the intensity of care needed. Of the carers who responded, **39% provide care 24/7** and over a quarter (29%) have been caring for over five years. A quarter described their physical health as poor and a third described their mental health as poor or very poor. **Nine in ten carers shared that they had reached crisis points.**

The role and contribution of carers to health and social care is critical. Unpaid carers in England and Wales contribute £445 million to the economy every day – £162 billion per year. Essentially equivalent to a second NHS in England and Wales.\*

However, **family dementia carers are being left with no support**, effectively abandoned as soon as they take on caring responsibilities. Unpaid carers are ultimately filling gaps and propping up our under-funded social care system.

There is a moral imperative to design and fund a social care system that responds to carers' needs. Dementia carers deserve recognition and help not just to survive, but also to thrive.

We are calling on all political parties and individual parliamentary candidates to pledge their support for an ambitious and sustainable approach to dementia care. All family carers should receive tailored support, wherever they live, for as long as they need it.

*I didn't*  
sign up  
for this

Pledge your support  
to show carers they're  
not alone



[Pledge your support for dementia carers](#)

## Carers have told us they want

**S**ingle point of contact

**U**niversal and equitable availability of support regardless of location or income

**P**ractical, financial and emotional support (including support with bereavement)

**P**ersonalised information covering specific diagnosis and likely care needs

**O**pportunities to connect with other carers

**R**ecognition and understanding of their role

**T**ime for themselves



## Single point of contact

**“There is too much information on the internet. There are too many agencies that overlap. There is no single point of contact for help. It is overwhelming.”**

Carers tell us all the time about feeling unsure of where to turn for help or what to ask for. For many, the discharge at the point of diagnosis can be their last contact with a healthcare professional until they reach a crisis point.

Carers must have a clear route to ongoing personalised support. There must be better coordination between health and social care services as well as with charities, voluntary groups, and others, so that family dementia carers are promptly identified and directed to appropriate support following a dementia diagnosis.

Carers should be given a named point of contact who they can approach for support and information at any point during their caring journey.

## Our recommendations



- The prompt identification of carers
- A named point of contact within health and adult social care for example in GP surgeries



# Universal and equitable availability of support

“We asked constantly for help, but got none.”

All too often, carers tell us about the difficulties they have accessing support, even when it is outlined in their support plan. Carers who pay for care tell us they feel discouraged from approaching health and social care professionals even for guidance.

Evidence shows that specific groups of carers might experience a higher ‘carer burden’\*. This includes younger carers and carers with poor social and financial support.

Yet many carers have completely given up attempting to engage with health and social care systems. In doing so, they are losing out on practical help, financial assistance, and support.

Every carer must be able to access the advice and support they need to help them care and maintain their own health and well-being, regardless of where they live or their economic situation.

## Our recommendations



- The introduction of a national care service, free at point of need for everyone
- Sufficient funding for adult health and social care services to fill vacant posts and better value the workforce
- The impact of caring on health is considered in the same way as the impact of other inequalities
- Creation of a Commissioner for Care and Support to represent everyone in need of adult social care

# Practical, financial and emotional support

“Some days I am so stressed, I think I can’t go on.”

Most carers have not chosen their caring roles. Many find caring a struggle at times. Often dementia carers are providing constant care over a number of years. Every dementia carer has different needs, depending on their personal circumstances.

Carers must be able to access personalised support whenever this is needed, including access to advocacy services and counselling to help them manage their complex responsibilities.

Carers should also be able to access advice on benefits and grants, as well as free, tailored legal advice outlining their rights, responsibilities, and options as a carer.

Regular and proactively offered Carer’s Assessments should ensure that carers’ holistic needs are identified and kept under review. All support options must address the carer’s identified support needs and any access issues. Support should be flexible and available as the need arises, including urgent and out of hours support. It should be offered for as long as needed.

## Our recommendations



- Regular proactive assessments of carers’ support needs
- Sufficient government investment for long-term provision of tailored, flexible and fully funded support for all carers
- Reformed financial support which meets the needs of carers

## Carer's Assessments

Carers must have a clear route to personalised support. Carer's Assessments (in Scotland Adult Carer Support Plans) should enable carers to access a range of services which will help them cope with their caring responsibilities. All family carers are entitled to an assessment of their support needs from their local authority, but many do not know to ask for one, and it is not always offered.

These assessments should be proactively offered to family dementia carers and take place on an annual basis or at a change in circumstance. Carers should also be encouraged to request an assessment at any time, as their needs and caring responsibilities will change as the person's dementia progresses. All subsequent care plans should include a regularly reviewed contingency plan.

The recommendations made after an assessment must be followed up to make sure that families are receiving support that truly meets their needs.

## Support offered must be

- Fully funded and free of charge to family carers
- Evidence based
- Co-designed with the family carer / wider support network
- Proactively offered and considerate of differing life and journey stages
- Flexible and available, including urgent and out of hours support
- Personal, from a range of tailored options which are diverse and inclusive
- Standard across services, ending the postcode lottery
- Easy to access and navigate



## Personalised information

“There was nothing, no advice, no support, nothing. We were just given a diagnosis. There was no follow up and we were left to work things out as best we could.”

Carers describe feeling like they are walking down a dark tunnel, with no idea what is ahead of them. Some have described being given or accessing a vast amount of generic information which left them feeling more confused and isolated.

After being identified as a family dementia carer, individuals should receive, on an ongoing basis, clear, tailored information about the dementia diagnosis of the person they are caring for, appropriate to the stage of the dementia. This would help carers to develop their understanding of the diagnosis and support them to anticipate the potential care needs of the person with dementia.

## Our recommendation



- Provision of personalised information about dementia which is adaptive and updated to the specific dementia diagnosis, and the carer's situation and stage of caring



# Opportunities to connect with other carers

“Sharing with other carers always makes things a hundred times better, knowing that you are not alone.”

Family dementia carers often feel overwhelmed and isolated by their caring responsibilities. Connecting with other carers who are having similar experiences can provide opportunities to share knowledge and receive invaluable support.

NICE\* highlights the importance of individual befriending arrangements or support groups which help reduce social isolation and provide empathy and mutual emotional support.

These can be especially helpful to those carers who are caring alone or without a network of family and friends to support them.

All carers should be given opportunities to participate in face to face or remote opportunities to meet, listen and share experiences with other dementia carers in a safe and non-judgmental environment.

## Our recommendation



- Opportunities for all dementia carers to connect with other dementia carers



# Recognition and understanding of their role

“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.”

Dementia carers must be recognised as equal partners in the care of the person with dementia. Carers should also be involved in the design and delivery of services and support for dementia carers.

Many carers find it impossible to remain in the workplace and balance their caring responsibilities. Our research shows that nearly half of all family dementia carers, who were in paid employment when they became a carer, have had to either give up their job to care (28%) or reduce their hours (21%).\*

Carers’ rights, including their employment rights, must be adequately enshrined in legislation.

We would also like to see broader awareness of dementia and dementia care as well as the profile of social care raised within wider society.

## Our recommendations



- Ensure carers’ rights are protected by legislation, including recognition as a protected group in terms of equality in the Equality Act 2010
- Ensure a better understanding of demands on carers in the workforce and help employers to support carers in their organisations
- Better community engagement and awareness

## Time for themselves

“It is hard to get support. There is usually a long waiting list or delays in accessing services.”

Many carers struggle to maintain their own wellbeing and often overlook their own needs because of their caring responsibilities. Carers describe a desperate need for flexible respite support, including during the night, but find the current availability lacking, inflexible or of poor quality.

Family dementia carers must have flexible access to respite care, whether this is on a regular or ad hoc basis, in their own home, in the community, or in a care home setting.

## Our recommendation



- Access for all dementia carers to free respite care that meets their often changing needs



## A strategy for dementia carers

The current social care system is broken. We have a national framework but local funding and delivery which leads to fragmentation and inequality of service provision. This has been exacerbated by local authorities facing reduced budgets. Carers tell us of feeling like they are being **'kept out'** of the system.

We need a long-term approach to dementia care which must include a commitment to provision of sufficient long-term funding for local authorities to be able to review, provide and/or commission local services which provide support to carers and former carers for as long as this support is needed.

There is no need for new legislation to ensure holistic support for the wellbeing of dementia carers, but there is a need for better understanding and resourcing of how the respective legislation in place in England, Scotland and Wales can be successfully implemented. Such ambition must be supported by steps to empower a skilled and motivated workforce.

This is why **Dementia Carers Count** is calling for the **implementation of a dementia carer's strategy in each of the nations across the UK.**

## Contact us

For more information about the support dementia carers need, and the support that we can provide, please contact us: **0203 5400 700** or email [info@dementiacarers.org.uk](mailto:info@dementiacarers.org.uk)

[www.dementiacarers.org.uk](http://www.dementiacarers.org.uk)



**Including and supporting  
more carers**



**A stronger voice for  
carers**



**Delivering long term  
sustainability**



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