



**DEMENTIA
CARERS COUNT**
Supporting Family Carers

Our strategy
for 2024-2026

Support.

Campaign.

Sustain.

Supporting people through the caring crisis

“ We believe dementia carers count. This strategy is dedicated to all carers who feel invisible. We see you. We hear you. You are not alone. ”

*Trevor Salomon
Chair, Carers' Advisory Panel*



*Introduction by
Trevor Salomon, Chair
of Carers' Advisory Panel*

In the UK, there are nearly one million families caring for someone with dementia. Over the coming decade, that number is set to grow exponentially. And yet support for carers has failed to keep pace with the increasing rates of dementia diagnosis.

We know that caring for someone with dementia is not easy. Moments of profound connection are matched with uncharted challenges, and the emotional and physical toll cannot be underestimated.

Time and again, dementia carers tell us they feel isolated and alone. In our 2023 survey of dementia carers, nine in ten told us that they have reached or were reaching crisis point. Without action, this growing crisis threatens to overwhelm our already stretched adult social care system.

We believe dementia carers count. We're here to support them every step of the way and campaign for change with them.

With carers' help, we have drafted this ambitious strategy for the next three years. Our goal is to ensure that we can continue to work with dementia carers well into the future, and campaign for the changes that we all so desperately need.

We stand with dementia carers, and this strategy is for them.

Front cover:

“A lot of services focus on the person with dementia, but DCC focuses on the carer”

- We supported Keiko as she was caring for her husband Javed. *Photo: Alexander Caminada*

What we stand for



“ **It’s a huge responsibility to care for another adult.** ”

Dementia carer

Our purpose

We support, advocate and campaign for dementia carers so that no one feels isolated, invisible or alone.

Our vision

Dementia carers will no longer feel isolated or invisible. They receive timely support that meets their needs within a reformed and adequately resourced social care landscape.

Our values

- C**hangemakers for dementia carers
- A**lways there for carers
- R**eflective and responsive
- E**asy to work with

Our theory of change

Because we want to

Solve the systemic isolation and overwhelming lack of support for the million+ carers¹ in the UK.



We work with

- ♥ Dementia carers and their families
- ♥ Professionals in the care, health and allied sectors who work with dementia carers
- ♥ Policy makers and service commissioners



In order to

- ♥ Provide practical and emotional support to carers
- ♥ Advocate for policy change
- ♥ Offer consultancy services to organisations

Which means

- ♥ A reduced burden on NHS and local authorities
- ♥ Healthcare & allied professionals feel more dementia care confident
- ♥ Future needs are understood and planned for
- ♥ Better support means carers stay in work longer, with wider economic benefits

AND ULTIMATELY

DEMENTIA CARERS WILL NO LONGER FEEL ISOLATED OR INVISIBLE.



1. Alzheimers Research UK, 'Prevalence and incidence of dementia', accessed 7 May 2024; R Luengo-Fernandez and F Landeiro (in preparation), 'The economic burden of dementia in the UK'.



Our strategic priorities

2024 - 2026

38%
of family carers
are *caring 24/7*



Including and
supporting
more carers



A stronger
voice for carers



Delivering
long-term
sustainability

Including and supporting more carers



We will establish our Carer Support Service as a model of excellence, providing in-depth practical and emotional support to more carers for as long as they need it.

We will:

- ♥ Link carers to specialists who can provide advice and support
- ♥ Support carers from the moment of diagnosis onwards
- ♥ Partner with other organisations to reach and support more carers



How will we know if we are making a difference?

- ♥ We'll support 4,500 dementia carers over three years
- ♥ Carers will receive quality support
- ♥ Carers will feel better able to cope

A stronger voice for carers

Unpaid carers provide care to a value of

£ **16.2**
billion per year²

“Being a carer is a hidden role. Even though my family knows about it, they don’t know what it’s like. A lot of carers might feel like no one cares what they are doing, but DCC does care.”

We supported Kelly as she cared for her grandmother with dementia.

2. May 2021, Carers UK and Centre for Care, Valuing Carers 2021 valuing-carers-report.pdf (carersuk.org)



Working alongside carers, we will raise the challenges they face to make sure they are heard and to bring about lasting change.

We will:

- ♥ Grow understanding of the challenges facing dementia carers
- ♥ Ensure carers’ experiences inform our work and priorities
- ♥ Influence health and social care policy and inspire people to campaign for change with us

How will we know if we’re making a difference?

- ♥ Our research findings are shared publicly
- ♥ Dementia carers campaign for change with us
- ♥ Our partners and campaigners engage decision makers and influencers using our calls

Delivering long-term sustainability



We will make sure that everything we do from directly supporting carers, to generating income and campaigning, has an impact and helps us achieve our goals.

We will:

- ♥ Invest in our infrastructure ensuring strong foundations for growth
- ♥ Grow our fundraising income and develop new partnerships
- ♥ Establish new ways of working to fulfil our potential

How will we know if we are making a difference?

- ♥ We'll be less reliant on reserves
- ♥ Our workforce will feel motivated



Kath's Story

We've always been a close family.

About 20 years ago, when my father died, my husband and I built a granny annex so that my mum could come and live next to us. It was around eight years ago that mum was diagnosed with vascular dementia and Alzheimer's.

Gradually, things started to go a bit pear shaped and we've needed to support her more and more. Mum would go out in her car for example and forget how to start it. We have power of attorney and look after her finances. I've been lucky that I have my own business; I work from home and I can take time out if I need to. This has been a godsend.

However, over the last year or so the challenges in looking after mum have increased. Mum hasn't had any aggressive behaviour or personality changes - but

she's a determined 92 year old, able to use an iPad and is good at masking what's really going on. I've found this hard to manage.



“ Mum started to get very distraught and was ringing me about 100 times a day...that's when I called the DCC telephone support line. ”

“ The support on offer is outstanding. ”

Mum's mobility has been declining. In early 2022, she stopped being able to get out of her chair without help, meaning that she wouldn't be able to remain living independently. However, mum found a trial period in respite care very distressing. She started calling me constantly and it all got too much. That's when I called the Carer Support Line.

I found it incredibly helpful to have someone listen to me and to provide support and advice over the phone - no need to leave the house and no need for Zoom. As carers, we have little experience or knowledge when dealing with situations for the first time. We're also feeling exhausted and emotional. The telephone support has been so important. To know you have someone on your side who is checking in on you to make sure you are supported and valued is really important. I am so appreciative of the support I have been given via these calls, it has made all the difference to the way I have been able to handle things when dealing with social services to arrange my mum's care.

Mum was able to return home and is now supported by visits from professional carers three times a day. This has really changed things. Mum is happier and this means that I am happier.

Dementia Carers Count was absolutely invaluable when I was struggling. The support on offer is outstanding. It was great to realise that I am not alone.



Join us

 Fundraise

 Campaign

 Partner

 Donate



We support, advocate and campaign for dementia carers, so that no one feels isolated, invisible or alone.

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