DEMENTIA
CARERS COUNT

16 July 2025

What if...dementia carers had a single point of contact for support?

Briefing for the Casey Commission

Improving support for all dementia carers

Dementia Carers Count supports, advocates and campaigns for dementia carers so that no one feels isolated, invisible or alone.

There are nearly one million people in the UK living with a dementia diagnosis and dementia prevalence is on the increase. Half of us will either become dementia carers or need care ourselves.

We believe that all dementia carers must be given the help, support and care they need to cope today and to plan for tomorrow.

Our recent survey heard from over 1200 dementia carers. They overwhelmingly told us that they do not receive the support they need (71%) with over half (52%) receiving no support at all. 9 in 10 carers told us they have reached crisis point.

Dementia carers also told us about their fears for the future and the uncertainty around what will happen if they can no longer care. One in three dementia carers can see a time ahead when they won't be able to care.

What we have outlined here is what dementia carers have told us would make the most difference to them and the person they care for.

We have also provided information about our Carer Support Service. This service has evolved in response to feedback from dementia carers and we continue to gather evidence and carer input to make sure we are directing our resources to where they will have the most positive impact for carers.

Dementia care must be recognised as having unique challenges which cross age, working situation, economic background and demographics. These challenges must be addressed as health and care systems are reformed.

No dementia carer should feel overwhelmed or alone.

The experience for dementia carers

There are currently huge differences in the support offered to carers and how this is delivered across the UK.

While some parts of the UK offer a period of support following diagnosis, many carers will not receive support until a point of crisis or significant change in the person they are caring for.

The support they then receive depends on what is available locally, their ability to pay and their ability to access the support.

> **“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.”**

A friend or family member approaches their GP because they have concerns about changes in the behaviour of someone close to them that might indicate dementia...

This is a very familiar scenario for many people across the country every day.

These individuals are already providing care and support to someone who may increasingly rely on them. They are at the start of a journey that may last for years.

Many are already feeling worried and anxious about what a dementia diagnosis might mean and what the future holds.

We know from our contact with dementia carers that far too many are not getting the support that they need to enable them to cope.

We know what would make a difference.

What dementia carers have told us should happen next

Our blueprint for dementia carers recognises that the time it takes to receive a diagnosis of dementia has now risen to almost five months.

This wait can be stressful, and families should be referred on for support whilst waiting for a diagnosis.

It is essential that:

- Dementia carers' concerns are heard
- An appointment is booked for the person with the potential diagnosis and their carer, and an assessment / decision is made as soon as possible
- Next steps are considered and clearly explained. These are likely to be either
  - Referral to a memory clinic
  - Referral to a specialist

If a dementia diagnosis is made

- A referral is made back to the GP (or relevant healthcare professional) where a clear and individual diagnosis is given

- The likely impact is explained in terms of care needs and changes that might be experienced in relation to the specific diagnosis

- The dementia carer is noted as such in their records and across systems

- The dementia carer is introduced to a dementia care coordinator. They will provide a link between the GP surgery and Local Authority support provision as well as any other health and care professionals supporting the person with dementia. They will be a single point of contact for the dementia carer.

The role of a dementia care coordinator

- Provides triaging and initial advice, and support

- Supports the carer to understand their caring role and outlines their rights

- Links the carer to more specialist or sustainable support as required.

- This might include:
  - Emotional support
  - Advocacy to help with complex issues
  - Welfare and legal advice
  - Information
  - Peer support
  - Respite support

- Coordinates, as necessary, with the carer and with other health and care professionals involved in the person with dementia's care

- This is a non-clinical, carer focused role.

After the diagnosis

- The dementia carer is proactively offered an assessment of their support needs.
- The dementia care coordinator helps the carer prepare for the assessment and talks the carer through their rights and choices as a carer.
- The preparation is based on the specific dementia diagnosis, the needs of the person with dementia and the needs and preferences of the carer.
- These assessments should be proactively offered and take place at least annually but be available as and when needed and when circumstances change, or if requested by the dementia carer.

- The dementia carer is encouraged to think about the support and information they need to help them. This support should be tailored to suit their location, situation, respite needs and to help them continue to work and / or with their own interests.

- This should include planning for times in which they might not be able to care.

- Following the assessment, the dementia carer is given their personalised care plan and linked to appropriate and useful local services and support.

- The dementia coordinator talks the carer through anything they might not understand or want to query.

Coping with the day to day

As well as the carer's assessment, the dementia care coordinator goes through some of the basic legal and financial considerations the dementia carer might have to think about over the years they might be caring.

This could include:

- A referral for the dementia carer to receive a full benefits check
- Discussing the carer making decisions on someone else's behalf
- Talking through the person with dementia's treatment preferences and perhaps, as appropriate, their end-of-life choices
- Looking at who else the carer might have to draw on for caring and non-caring support

Depending on how the dementia carer is managing and the stage of the dementia of the person they are caring for, the coordinator might suggest some things the dementia carer could start thinking about for the future for e.g. greater practical help or adaptions to the home.

Each one of these sessions might last a few hours or even longer. Once the initial assessments and reviews have taken place, the dementia care coordinator, will discuss their longer-term support options with the dementia carer.

Ongoing, longer-term support

Once the more intensive initial sessions have taken place, the dementia care coordinator will agree with the dementia carer about the frequency of future meetings.

This agreement should be revisited regularly and at least annually.

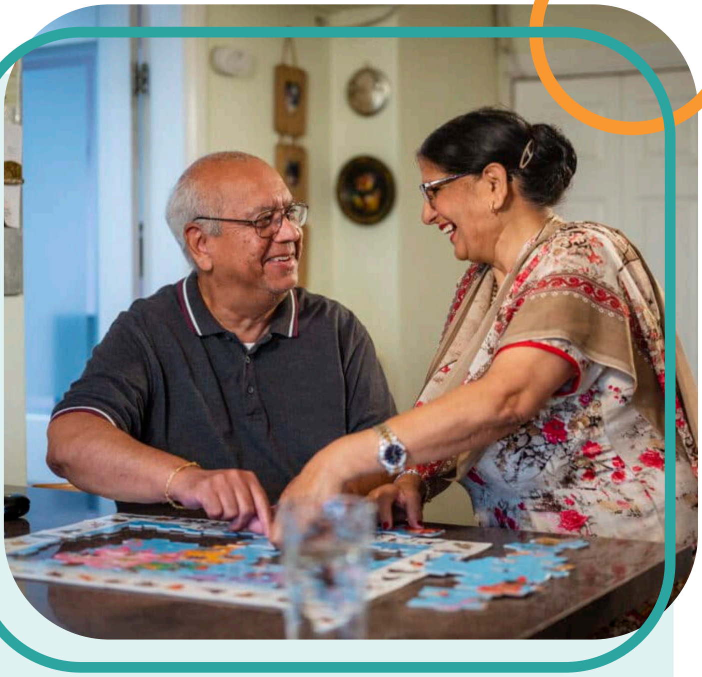
A recommended pattern might be a monthly check in, but this will vary to respond to different needs at different stages. This support should continue for an agreed period after caring responsibilities have ended.

The dementia care coordinator will not directly provide practical help but will be there to support the dementia carer, talk through practical issues or provide basic advocacy – for example they might approach social services, arrange care support with professional agencies on the dementia carer's behalf, or advise the dementia carer on what might be needed as and when the dementia progresses.

Anything more complex or which proves beyond the responsibilities of the dementia care coordinator should be referred to a specialist support service (or relevant body) for resolution.

The financial benefits of acting

While there are no official estimates of the cost to the Treasury of not properly supporting unpaid carers, a recent parliamentary committee report cited research estimating the amount at £1bn.



More generally, the report suggests, it has been estimated that every £1 invested in the sector would generate a £1.75 return to the wider economy.

In addition, when asking dementia carers about their experience in the workforce, our 2022 survey found that:

- **55% have given up their job or reduced their hours to care**
- **6% had to change jobs**
- **48% would have stayed in employment with support from their employer**

Source: Adult Social Care Reform: the cost of inaction

The time for change is now

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. This must include a commitment to provision of sustainable resourcing for local authorities to be able to review, provide and/or commission local services which provide support to carers at no cost to the carer for as long as this support is needed.

There is legislation and guidance in place, but to realise its ambition, there is a need for much better understanding and resourcing. Such ambition must be supported by steps to empower a skilled and motivated workforce.

Our recommendations

Carers are identified and their caring role is recorded and shareable amongst health and social care systems.

- There should be a distinct code recognising someone as a dementia carer.
- GPs should routinely ask all patients if they care for someone to support fuller identification.
- The records of the person with dementia should be linked with the person or people involved in their care.

At the point of identification, carers should be provided with a dementia care coordinator who they can turn to throughout their caring experience to provide or connect them with relevant advice, information and support. This must include emergency situations and out of hours support.

- This role should be in addition to, but link with, for example, Admiral nurses or generalist carer support.
- This role would provide the link to local support, for example, peer or respite support as well as national support , for example specialist counselling or welfare support and advocacy.
- This role would also build a local directory of dementia support to ensure up to date information and services and support

Carers are invited to have an assessment of their needs and choices as a carer and priorities as an individual. This must include conversations about alternative care arrangements for when they are unable to care and link them to tailored support and advice shaped around and co-designed with the carer.

- The dementia care coordinator should work with the carer to prepare for the assessment, helping the carer to understand and get the most out of the opportunity.
- Health and care professionals offering these assessments should work with the carer and the dementia care coordinator to find the most suitable support.
- Support available to all dementia carers should include advice and information, practical support, peer support, financial and legal support, emotional support and support to maintain physical wellbeing as well as tailored respite care including overnight support.

This support should be adaptive and assessments and alternative care arrangements should be updated whenever caring responsibilities change, or if required by the carer, and proactively offered at least annually.

- This should be managed between the GP and the dementia care coordinator to ensure a holistic assessment update.

There must be nationwide standard quality and wide range of accessible and inclusive support offered regardless of where someone lives. This must ensure support which is shown to be effective for carers and easy to access and navigate.

Carers in the workforce must be supported through flexibility in their work responsibilities and through paid carers’ leave. Employers must be supported to help carers in their employ to juggle their work and caring responsibilities.

The care workforce must be valued. They should have pay and conditions that reflect the vital work they are doing and the recognition and professional rewards that are due to them.

All staff in health and social care and frontline staff in the public sector should be trained in relevant dementia awareness.

Our Carer Support Service

Our Carer Support Service delivers

- one-to-one confidential advice
- guidance on practical, emotional and financial issues
- advocacy and casework on behalf of carers
- counselling
- support groups

> **“Dementia Carers Count was a real lifeline. The charity’s support has been amazing. I’ve learnt so much from the information and resources it has. After a diagnosis, you’re on your own, in a vacuum, and there’s no one place to find help. I don’t know what I would have done without Dementia Carers Count.”**

How we'd like to support the Casey Commission:

We would like to see the Commission recognise the unique challenges that caring for someone living with dementia presents in their recommended reforms of Adult Social Care.

We believe that the Commission should make specific recommendations for improved care and support for dementia care to ensure better outcomes for people living with dementia and their carers.

We would like to encourage the Commission to meet dementia carers to understand their experiences. We would be delighted to help facilitate dementia carer engagement.

We continually develop our understanding of carers needs and would be happy to share our findings with the Commission. Over the next few months, we will be:

- Commissioning an independent evaluation of our Carer Support Service.
- Polling dementia carers about the dementia care co-ordinator role.
- Drafting and sending out our Annual Survey which in previous years has reached over 1200 dementia carers.

> **“There is no automatic entitlement to social care and no single point of contact for support, information or advice. This is causing huge emotional and financial distress to many thousands of dementia carers, and it must change.”**
>
> *Helen Pyper, Head of Policy and Campaigns*

For more information about this or other policy positions and what would make the most difference to dementia carers, please contact helen.pyper@dementiacarers.org.uk

About Dementia Carers Count

Dementia Carers Count is a small but mighty charity, powered and inspired by dementia carers’ experiences and insights and driven by the urgent need for change. We are here to listen, to support and to help unpaid dementia carers look after themselves as well as the person they care for. We provide free, personal and confidential practical advice and emotional support. Every day our team of specialist advisors supports carers across the UK.

dementiacarers.org.uk

Carer Support Line: 0800 652 1102 Mon-Fri 9am-5pm

Dementia Carers Count is the working name for The Royal Surgical Aid Society. Charity registered in England & Wales (216613) and Scotland (SC051929). Company registered in England and Wales (515174).