DEMENTIA
CARERS COUNT

What if...I’m not there to care?

Findings from our 2024 survey of UK dementia carers

When there is no-one else to care

We all know someone who is caring for someone else.

It's very likely that we know someone who is caring for a family member who's living with dementia.

What we perhaps don't realise, is that most dementia carers, who are looking after a spouse or partner or parent, have no arrangements in place for when they can't care.

This creates huge anxiety, worry and stress for family carers. It also prompts questions around what support carers should have a right to expect when they're unable to care.

Many dementia carers are also contending with their own physical and mental health challenges. They can see a time when their own needs will impact their ability to care. Carers may need hospital treatment. Carers may no longer be able to physically move the person they are caring for or to cope mentally or emotionally with the challenges of dementia care. Carers may be concerned about what will happen to the person they care for when they die.

Our 2024 survey of dementia carers has prompted us to ask

'What if all dementia carers knew what would happen to their loved one when they can't care for them?'

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

No dementia carer should feel overwhelmed and alone.

Frances Lawrence, CEO

Dementia Carers Count

Acknowledgements

This report has been produced with thanks to the 1,238 dementia carers who took part in our 2024 survey. Your experiences and insights have informed our recommendations as to how dementia carers can be better supported.

Thank you also to all the organisations and people who shared our survey with dementia carers.

Methodology

This is our third annual survey of dementia carers. We used Survey Monkey to collect responses. We invited responses from anyone across the UK who provides, or who has provided, support for a friend or family member living with dementia.

The survey ran from 12th September to 1st December 2024. It was promoted widely via supporters, social media channels and other organisations, community groups and dementia support groups.

The situation for dementia carers

> **“Often carers worry about what will happen if they can't continue to care, but they don’t know who to talk to and what alternative arrangements might be possible.”**
>
> *Steve Dubbins, Director of Services*
> *Dementia Carers Count*

Contingency or alternative care planning support for carers is not consistently commissioned or provided. The support to create or to action a plan, and provide replacement care, varies across the UK.

Contingency care

Contingency or alternative care arrangements are plans for when unpaid carers are unable to provide care. For example, in the short term because they are in hospital overnight, or in the long term because they have become too frail to cope with the physical demands of caring.

Inconsistent identification of carers, and challenges around sharing relevant information within local health and social care systems, means that the needs of dementia carers are not being met.

Carers assessments, which all carers are entitled to, are not routinely taking place. This removes an important opportunity to discuss potential alternative care arrangements with carers.

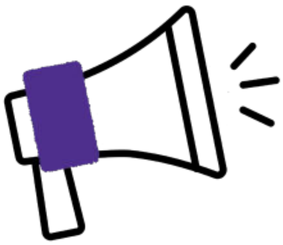
If contingency or alternative care is discussed and a plan is made, it is not clear how this is recorded and who is responsible for setting arrangements in motion if needed.

If there is no contingency plan, then this is not only stressful for carers, but it also means that replacement care is put in place in a crisis. This can mean that the person with dementia can be placed in a setting that is not the best one for them.

Our 2024 survey of dementia carers highlights that most carers do not have any arrangements in place which outline what will happen if they are unable to care. Our findings also show that many carers have no one else to turn to for help with their caring responsibilities. They are caring without any support and are often managing with their own health issues.

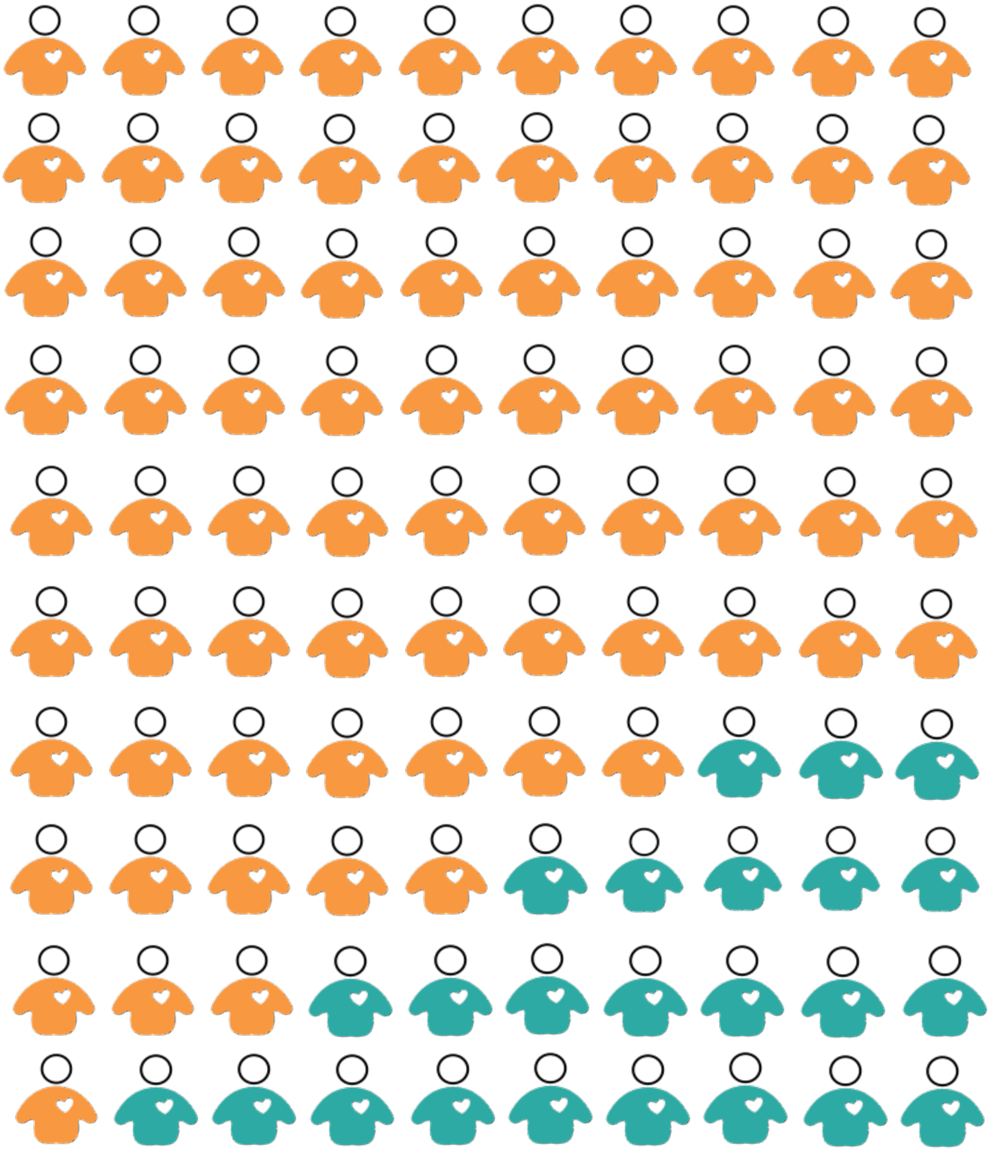
Many people caring for someone living with dementia, can see a time in the future when they won't be able to keep caring.

This should prompt urgent concern about the lack of alternative care arrangements that are in place across the UK, especially at a time when health and social care services are already stretched.



> **"I worry about what will happen to my wife if I become ill - there is no fallback plan."**
>
> *Anonymous 2024 survey respondent*

Dementia carers are on their own



76% **of dementia carers have no arrangements in place which outline what will happen if they cannot continue to care**

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Who cares?

47%

of dementia carers are caring for a spouse or partner

45%

of dementia carers are caring for a parent

49%

of dementia carers share a home with the person they care for

73%

of dementia carers did not choose to become carers

51%

of dementia carers said there was no-one else able to care

13%

of dementia carers said they preferred not to think of themselves as a carer

43%

of dementia carers said they were the most obvious person to take on caring responsibilities

> **"I'm sick of the responsibility being dumped on me just because I live at the same address."**
>
> *Anonymous 2024 survey respondent*

There's no let up

31%

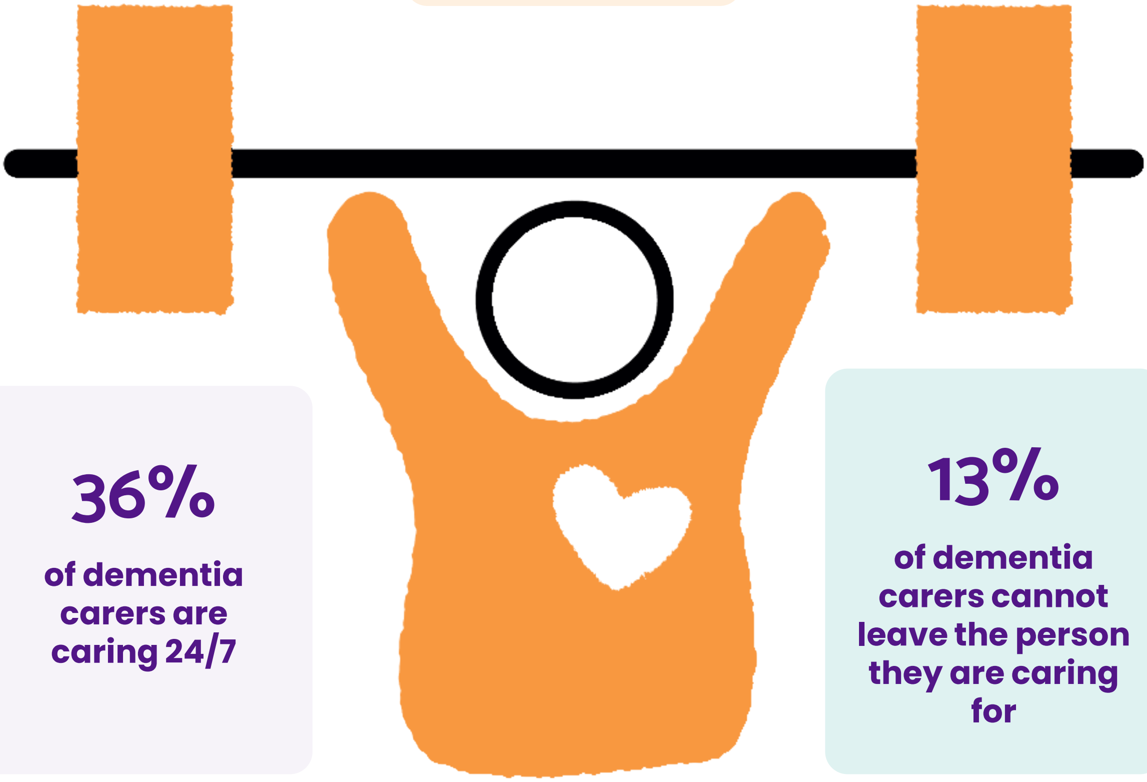
of dementia carers have been caring for 3–5 years

25%

of dementia carers have been caring for 5–10 years

8%

of dementia carers have been caring for over 10 years



36%

of dementia carers are caring 24/7

13%

of dementia carers cannot leave the person they are caring for

> **"I feel now that I have no identity. I am only Jimmy's carer. My whole life revolves around looking after him and trying to make him settled if I can."**
>
> *Anonymous 2024 survey respondent*

Dementia carers have health challenges too

28% **of dementia carers consider themselves to be disabled**

Of these

39%

consider themselves to have a mental health condition such as depression or anxiety

49%

of dementia carers consider themselves to have a physical or mobility limiting condition

34%

of dementia carers have a long standing chronic or fluctuating condition such as cancer, Parkinson's or Multiple Sclerosis (MS)

4%

of dementia carers are visually impaired

19%

of dementia carers are D/deaf or have hearing loss

> **"Caring is making my chronic health problems worse and destroying my mental health."**
>
> *Anonymous 2024 survey respondent*

Dementia carers worry they won't be able to carry on caring

33%

think their physical health is getting worse and will impact their ability to care

34%

think their mental health is getting worse and will impact their ability to care

26%

aren't sure if their physical health will stop them from caring

28%

aren't sure if their mental health will stop them from caring

> "Due to strain on my own health, I worry I will have a heart attack before my husband passes. Then he will have no one to care for him."
>
> *Anonymous 2024 survey respondent*

There's minimal support for dementia carers

71%

feel they don't receive the support they need

52%

don't receive any support at all

38%

have had a Carer's Assessment

40%

feel negative about being a carer

85%

have reached crisis point

> **"We are family members who become carers out of love and need. We are people as well who need to be cared for out of physical and mental exhaustion. Us carers are amazing, but sadly we're not superhuman."**
>
> *Anonymous 2024 survey respondent*

It's hard for dementia carers to connect with health and social care professionals

24%

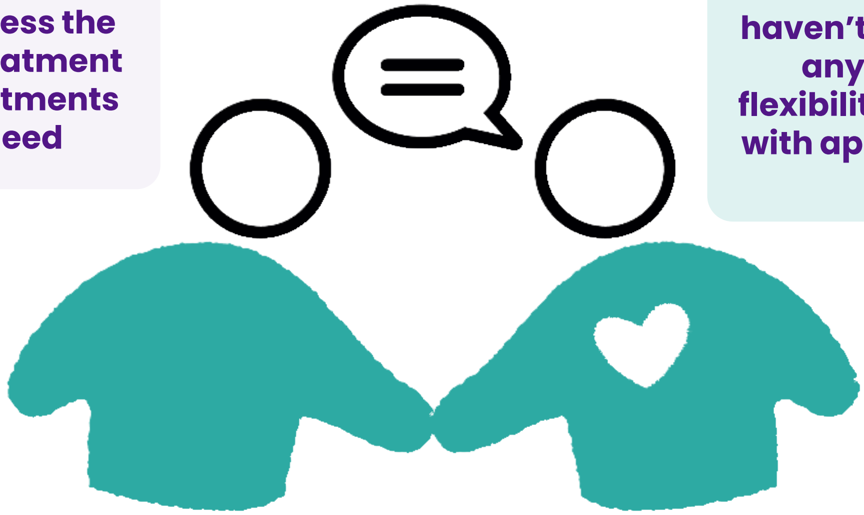
aren't able to talk to a health or social care professional about caring options as their responsibilities change

20%

can't access the health treatment or appointments they need

62%

haven't been given any greater flexibility or priority with appointments



> "Our social worker changes every month. It is time-consuming and frustrating having to tell someone new what is going on."
>
> *Anonymous 2024 survey respondent*

Lisa had to cancel surgery

Lisa cares for her husband who has mixed dementia - Alzheimer's Disease and vascular dementia - as well as other significant health conditions.

The only time Lisa has left him alone, is to walk the dog. An overnight stay away is out of the question.

When Lisa experienced post-menopausal bleeding, she didn't immediately contact her GP. She started to worry about what would happen to her husband if she needed treatment.

After seeing her GP and a specialist, Lisa was urgently referred for surgery. With no family members able to care for her husband, Lisa tried to organise some respite care.

Despite multiple attempts, it proved impossible to coordinate surgery dates and a respite bed in a care home.

In the end, Lisa asked to be removed from the treatment list. She has not had surgery.

> "Getting everything synchronised is impossible. It's like pinning clouds to a wall. It's very stressful for an already stressed person who can no longer think straight and is frightened.
>
> You ask yourself *is it worth the hassle?* If the answer is '*no*', then there is something very wrong with the system."
>
> *Lisa*

How dementia carers should be supported with contingency planning

For effective contingency or alternative care planning, carers need to understand the benefits of making the plan and what support is available locally.

> **"Dementia carers must be supported to discuss and outline what they would like to happen should they be unable to care. They should also have confidence that their wishes will be acted on.**
>
> **"Any contingency or alternative care arrangements which are agreed must be flexible and reviewed regularly to ensure they continue to meet carers' changing situations and needs. "**
>
> *Helen Pyper, Head of Policy and Campaigns,*
> *Dementia Carers Count*

Dementia carers should be supported by

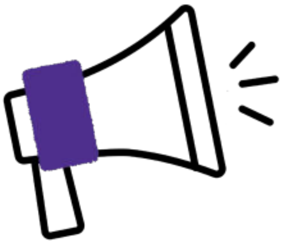
- **National governments**
- **Local authorities**
- **Health and care commissioners**
- **Health and social care professionals**

How national governments should support dementia carers

National governments must implement carers' strategies, which outline carers' rights and what support they should receive.

National carers' strategies should include provision for regular, proactively offered and frequently reviewed assessments of carers' needs and plans for contingency or alternative care.

Adult social care must be adequately resourced to enable delivery of national carers' strategies so that what exists on paper is delivered.



> **"As one of three siblings, I was the only one healthy enough to care for our parents, the other two suffering from different forms of cancer. It was physically and emotionally exhausting.**
>
> **"The government must listen to carers and develop a nationwide strategy that is fair."**

Anonymous 2024 survey respondent

How local authorities should support dementia carers

The Care Act 2014 outlines the duty on local authorities to provide family carers with a care and support plan. However, too many carers are not having their needs assessed or met.

The National Institute for Health and Care Excellence guideline is clear about the need to ensure that contingency or replacement care is discussed with carers.

Local authorities must gather reliable local data about the number of carers in their area and their individual needs. They should be aware of carers wishes for contingency arrangements. They must be able to quantify the funding needed to meet the needs of dementia carers today and in the future.

> **“Caring has resulted in burnout. I am now on anti-depressants. It is heartbreaking to watch both my parents deteriorate and exhausting trying to juggle their care needs. I strongly feel that no one is interested.”**
>
> *Anonymous 2024 survey respondent*

How health and care commissioners should support dementia carers

Health and care commissioners have responsibility for planning and paying for health and care services in a particular geographic area. Commissioners should:

- Know how many dementia carers are in their locality
- Know how many carers have contingency or alternative care plans in place
- Prioritise improving information sharing so that alternative care plans are recorded in a carer's health and care record and are available to all involved in providing care when it is needed
- Ensure flexible replacement care options are available and co-designed with carers. This includes short-term options for a few days and longer-term arrangements

- Make sure health and social care professionals have appropriate training to have conversations sensitively with dementia carers. It must be clear that it might take several conversations for contingency or alternative care plans to be developed and agreed
- Regularly assess whether local contingency arrangements are working for carers, the person they are caring for and the professionals involved in the delivery of care

> **“My physical and mental health have deteriorated. I feel very isolated and trapped if my sister is unwell and can't pop in to help me. I have had very low moments where I thought of self-harming myself as a release.”**
>
> *Anonymous 2024 survey respondent*

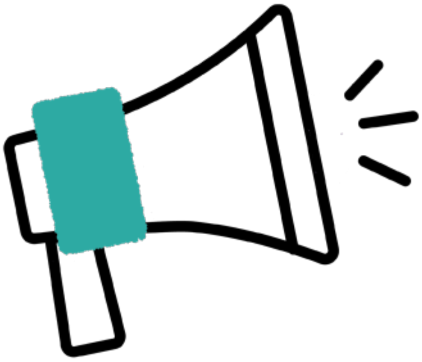
How health and social care professionals can support dementia carers

Health and social care professionals should:

- Record dementia carers on health and social care systems as soon as they are identified as a carer
- Make sure that identification of a carer triggers a proactive offer of a carer's assessment, which should include the opportunity to discuss and agree contingency care arrangements (covering short term needs and what might happen longer term, if a carer is no longer there or able to care)
- Take part in training to ensure sensitive communication with carers and a good understanding of when alternative care may be needed
- Keep up to date with what local options exist for contingency care and signpost carers to where they can get support

- Know when and how to put a carer contingency plan into action
- Regularly review contingency or alternative care plans with dementia carers to respond to the changing needs of the carer and the person with dementia

> **"Both my physical and mental health are worsening. I can't rely on the only other people in my life as they have health issues too."**
>
> *Anonymous 2024 survey respondent*



> **"I am human, so I become ill. I would like it if there was care support to take over while I'm recovering. I'd like some sleep."**
>
> *Anonymous 2024 survey respondent*

We're here to support dementia carers. If you don't have any continency arrangements in place and would like some support to start thinking about what might be best for you and the person you are caring for, **call our Carer Support Line free on 0800 652 1102**.

Links to useful resources

Carers UK online tool: MyBackUp

In Scotland: Emergency and future planning | CareInformation Scotland

In Wales: Your rights as a carer

For more information about our campaigns, and to share your experience of setting up and accessing contingency or alternative care, 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

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