

# Dementia Carers Count Survey 2022

## Introduction

Dementia Carers Count (DCC) is the only charity solely focused on supporting the 700,000 families living with dementia across the UK.

We want these family carers to be recognised and their voices heard. We want to raise awareness of the challenges they experience. We are campaigning for changes that they believe will make a difference to their ability to care and to look after their own well-being.

To this end, we conducted our first nationwide survey over the

summer of 2022, to ask people about their experiences of caring for someone with dementia and to find out what support they believe would make the biggest difference to their daily lives.

We had 435 survey respondents. Their responses give us invaluable insight into how they are coping and what support they need.

Our research found that the majority of carers have not chosen their caring roles, the caring experience is intense and most carers lack support. As a consequence, many are reaching crisis points, some on a regular basis. However, carers are clear about what could support them more.





# This is what carers are telling us

## 1. No choice

Most carers have not chosen their caring roles and can find the experience overwhelming.



**81%**  
had no choice in becoming a carer.

"As there is nobody else to do it, I just have to get on with it."

**44%**   
provide constant care for the person with dementia.

"I feel trapped in a life I did not choose. I feel I no longer exist as a person in my own right."



**Over two thirds**  
(69%) have been caring for over 3 years and a quarter (27%) for over 7 years.

"I have no life of my own anymore. It is totally restrictive."



## 2. Lack of support

Most family dementia carers are not receiving the support they need to be able to manage their caring responsibilities and look after their own well-being.



**Over half**  
of family dementia carers (52%) receive no 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."





### 3. Reaching crisis

Family dementia carers face a lot of day to day challenges. They are doing their best but most individuals reach crisis points.



**A fifth**  
reach crisis point  
on a regular basis.

"I feel as though I'm in the middle of a living nightmare."

**Over 80%**  
have reached crisis  
point at least once.

"Some days I am so stressed that I think I cannot go on."

**A third**  
(34%) are not  
coping well.

"I feel alone. Nothing to do with caring is easy."



### 4. Working & caring

Many family dementia carers find it impossible to remain in the workforce and balance their caring responsibilities.



**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%).

"I have feelings of resentment at times about the expectation that it is my role to care."

**48%**

of carers would have remained in employment longer with additional support from their employer.

"It is hard to stay ahead of the decline, look after my son and work a full-time job. I often feel broken."

**47%**

of carers are worried about their financial situation.







## 5. Carer's assessments



All carers are entitled to a Carer's Assessment. However, Carer's Assessments are all too often either not taking place or are failing to connect individuals with services and information which could make a huge difference to their daily lives.

Nearly  
**60%**  
of family dementia carers have not had a Carer's Assessment.

"When faced with being a carer, I was left to find support myself. There wasn't anyone to signpost me and I spent hours on the internet looking for help."

**70%**  
of family dementia carers who have received a Carer's Assessment do not subsequently receive the support they need.

"The Carer's Assessment pointed out what might be available to me but none of the recommendations were followed up. I just disappeared into the system without anyone advocating for us."



## The support carers are asking for

Most family dementia carers are not receiving the support they need to be able to manage their caring responsibilities and look after their own well-being.

### 1. Having a 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."

### 2. Support for the emotional toll of caring



"More support would be good - even if it was just a check in on the phone to reduce the isolation."

### 3. Clearer information about a dementia diagnosis, treatment and care



"Information and access to support is a constant battle. My main source has been family and others who are or have been a carer themselves."

### 4. More respite care



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

### 5. Feeling included and heard



"We shouldn't be forgotten members of society. We should be seen, heard, valued and appreciated more."



# We're listening

As well as conducting research to better understand and champion the needs of family dementia carers, Dementia Carers Count is there to provide free practical and emotional support to carers when they need it.

Dementia Carers Count offers a range of free services that give family carers the opportunity to understand more about dementia and to connect with others in a similar situation. We offer practical advice on the reality and challenges of being a carer.



Is someone in your life living with dementia? Call us for **FREE**  
**Mondays to Fridays from 9am to 5pm on**

**0800 652 1102**



If you are struggling to cope we also have a free text service which can be reached 24 hours a day, 7 days a week

**Text CARE to 85258**



Dementia Carers Count campaigns to demand that all family dementia carers receive the recognition, support and information they need. To add your voice to our campaign, join us as a volunteer or share your own story with us, get in touch at

**[campaigns@dementiacarers.org.uk](mailto:campaigns@dementiacarers.org.uk)**



Further details of the Dementia Carers Count 2022 Survey and the experiences of family dementia carers are available on request.

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



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Supporting Family Carers

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DemCarersCount



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