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RESEARCH REPORT

# Alzheimer's Society **Personal Experiences of the Dementia Journey – The True Picture**

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Prepared for Alzheimer's Society by Walnut Unlimited



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The human understanding agency.

# What this report covers...

## INTRODUCTION



Research objectives



Methodological summary



Who we spoke to

## MAIN REPORT



Executive summary



Priorities that need to be addressed



What needs to change

THE TRUE PICTURE

# Research background & objectives

Walnut Unlimited carried out research on behalf of Alzheimer's Society to help them **profoundly improve the lives of those living with dementia**, and their carers, by amplifying their voices, reliably informing evidence-based policy making and influencing decision-makers to make positive changes.

As such, the objectives of the research were to:

1. Gain a rich and strong understanding of the **experiences of people living with dementia** at each stage of the journey and at key points of transition, including accessing health and social care services
2. To reliably represent the **views of people living with dementia and those close to them**, in terms of their perceptions of dementia services, what needs to improve and what is working well

All aspects of the research were conducted in accordance with the MRS Code of Conduct as well as ISO 20252 and ISO 27001, the international standards for market research and information data security.



# Methodology

## How

15-minute online survey (10-12 key questions for those living with dementia excluding classification questions) between 6th February 2024 – 1st March 2024

The sample consisted of adults aged 16+

3,476 participants completed the survey across England, Wales and Northern Ireland

- 2,800 in England
- 400 in Wales
- 276 in Northern Ireland

The survey was offered in English or Welsh and there was an option to complete the survey via telephone.

## Understanding the data

Broad regional quotas were set, and other demographic quotas, such as age and gender were monitored closely.

A working group of 4 people with lived experience of dementia were involved in the development of the questionnaire and research report.

## The report

All data shown is for England, Wales and Northern Ireland combined, unless otherwise specified.

Overall, there are very few significant differences between the datasets for England, Wales and Northern Ireland.

Key sub-group analysis is shown throughout the report including by stage of dementia, disability and ethnicity.

Any significance testing between sub-groups is significant at 95% confidence level.



THE TRUE PICTURE

# Who we spoke to

# Who we spoke to

Overall, we spoke to **3,476** people  
who are close to someone with dementia or living with symptoms

## Living with dementia

N=76

*This includes those diagnosed with dementia or living with symptoms of dementia*

## Know someone living with dementia\*

N=2,709

*In the report the data for this group will be combined with those caring with someone with dementia.*

*This group could know someone currently or have known someone in the past.*

## Those caring for someone with dementia\*

N=691

*By caring for someone, we mean attending medical or health & social appointments with them, helping sourcing support or treatment, or being a live-in 24/7 support.*

*This could be currently or in the past.*



THE TRUE PICTURE

# What the research is telling us

And the importance of it amongst the dementia community and for wider society



# There is a call for change to happen, and for the experiences of those associated with dementia to be taken more seriously

**Giving people associated with dementia the sense their opinions will lead to change**



It's good to know that there are questions being asked on **how to improve the life of people affected by dementia.**

*Knew someone with middle-stage dementia*



Excellent survey and relevant questions **hopefully leading to an improvement for people with dementia.**

*Living with dementia*

**Having a vehicle to voice their opinions that otherwise seems lacking or having to manage their challenges alone**



The survey helped me **reflect on experiences** I have not been able to think through on my own.

*Knows someone with late-stage dementia*

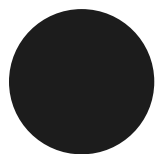


Thank you, this survey was very relevant, and it **helped me to realise my family are not alone in this difficult journey.**

*Knew someone living with symptoms of dementia*



# The research tells us these are the priority areas to focus on



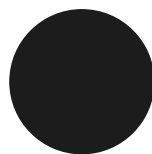
The status quo is causing suffering

## **Those living with dementia or caring for them do not feel heard**

Those living with dementia often feel anxious or worried, and helpless. The mental or physical health of those caring for someone with dementia is negatively affected as a direct result of their experience supporting that person.

This makes those living with dementia and those caring for them feel isolated, which is coupled with not always feeling comfortable talking about the diagnosis with others.

Only a minority agree that the government is prioritising dementia. This is likely contributing to a feeling of being 'sidelined' for the community and a lack of confidence that significant change will ease the challenges they are experiencing.



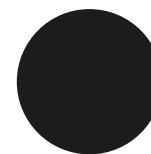
The experience with the system can be negative

## **Diagnosis is stressful and slow, resulting in difficulties accessing the right care**

The diagnosis process is taking too long; for three in ten it takes longer than 6 months. This is far behind the guidelines for other health concerns such as cancer.

Over six in ten carers agree that the diagnosis process is stressful, often involving having to speak to many different people. Compassion and clear communication is not always received from health care professionals and less than half felt respected by health care and social care professionals.

There is a call for a quicker diagnosis process to improve the lives of those living with dementia and to allow them to access the right care.



There are barriers to accessing support

## **A significant minority are not aware of any support, and more skilled support is required**

One in five carers have not heard of any sources of support, and half have not received support from dementia support services such as carer's allowance.

Only three in ten agree that dementia healthcare and social care support is easy to access.

There is a need for improved access to skilled carers or support e.g. dementia skilled care workers, as well as a single point of contact for support and advice.



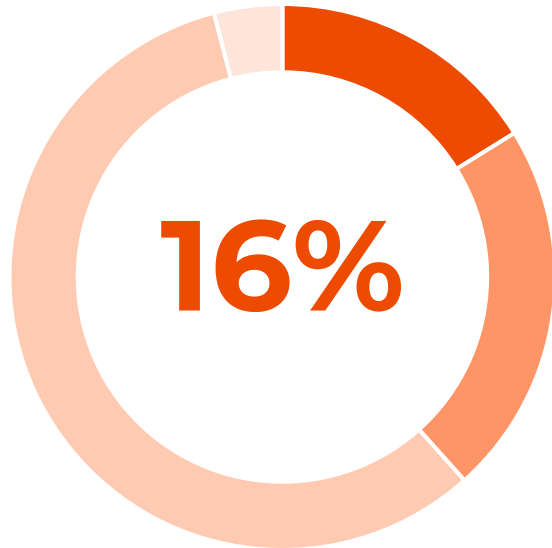
P R I O R I T I E S   T O   B E   A D D R E S S E D

The status quo is causing suffering

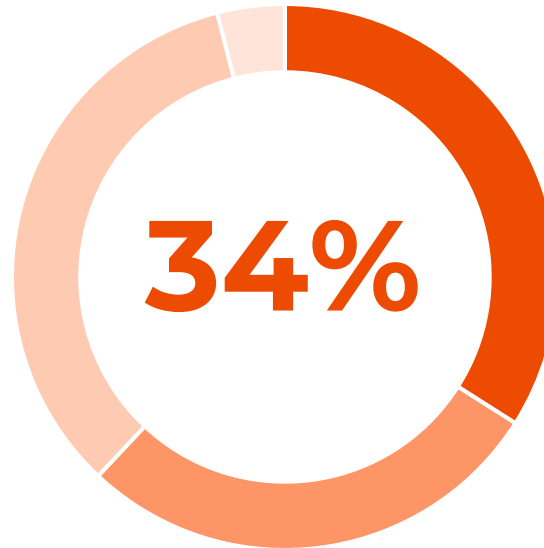
# Only a small minority agree that the government considers dementia to be a priority

A minority also agree the NHS and social care are prioritising dementia

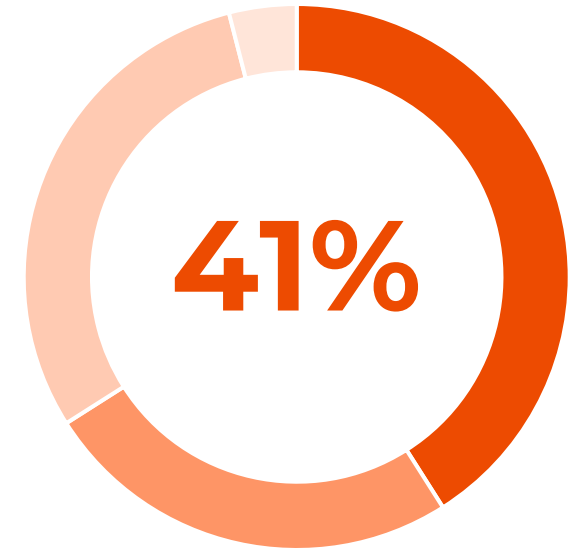
**The government** considers dementia a priority  
% Net Agree



**The NHS** considers dementia a priority  
% Net Agree

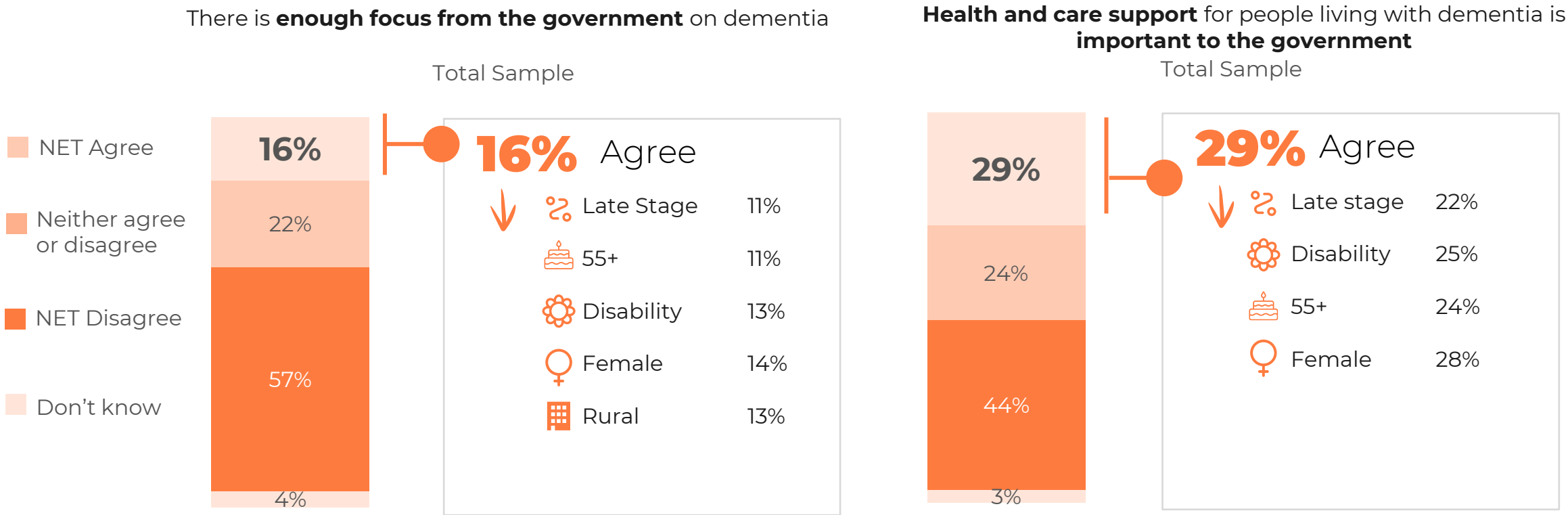


**Social Care** considers dementia a priority  
% Net Agree



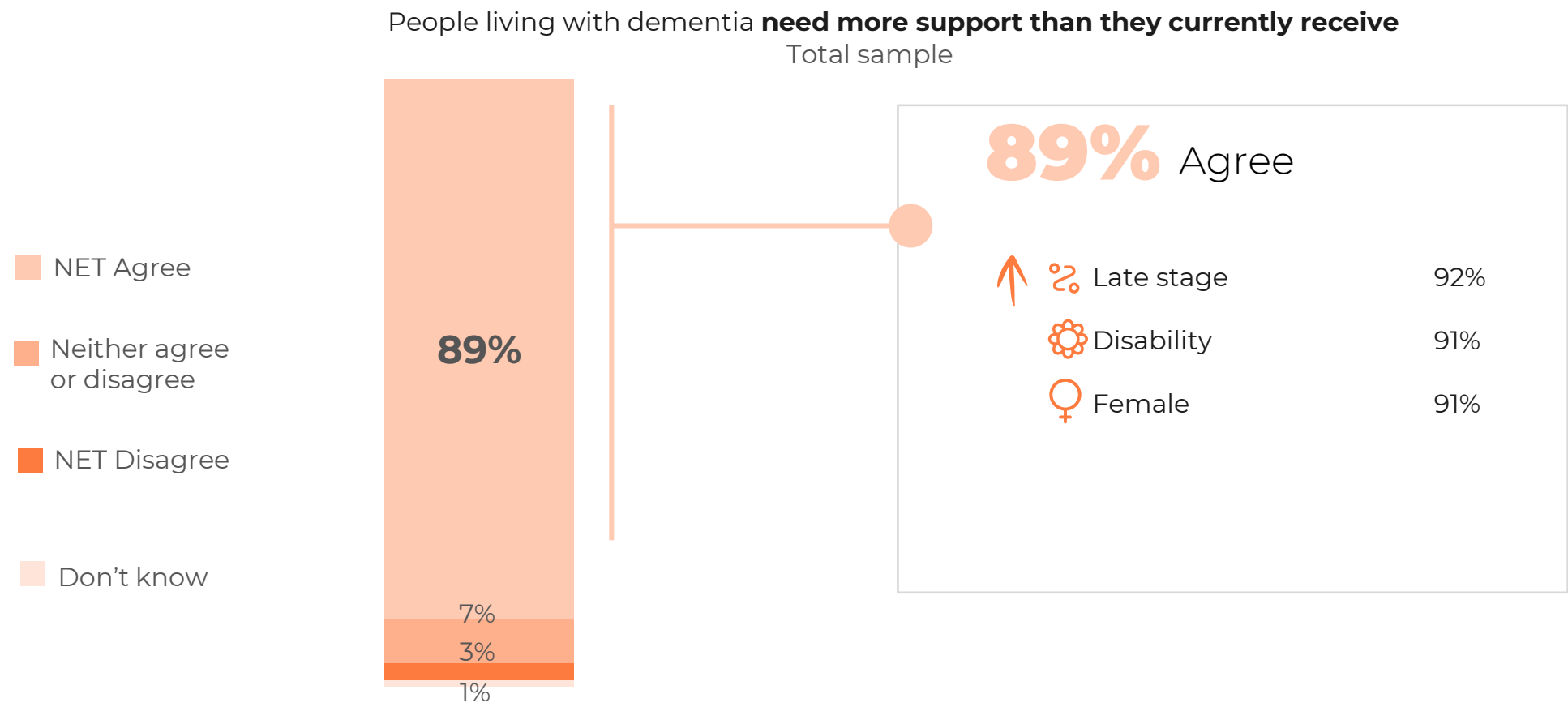
NET Disagree   Neither agree or disagree   NET Agree   Don't know

# Those with experience of late stages, who are disabled or in rural areas are less likely to think there is enough government focus



# 9 in 10 agree that people living with dementia need more support than they currently receive

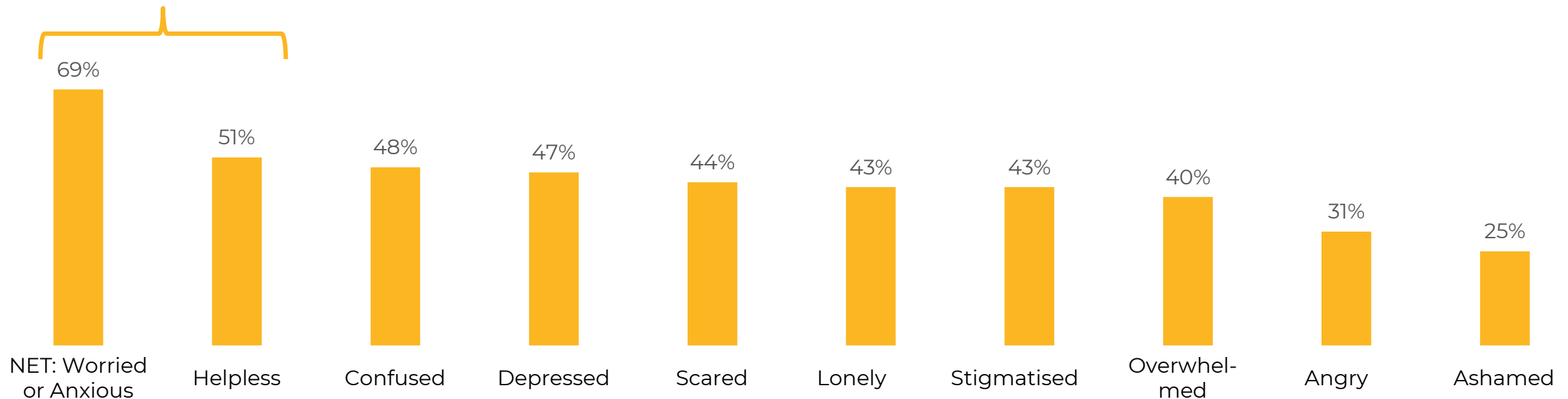
This is felt most by those with experience of the late stages of dementia



# 7 in 10 feel worried or anxious to live with symptoms of dementia, and two in five *also* feel helpless

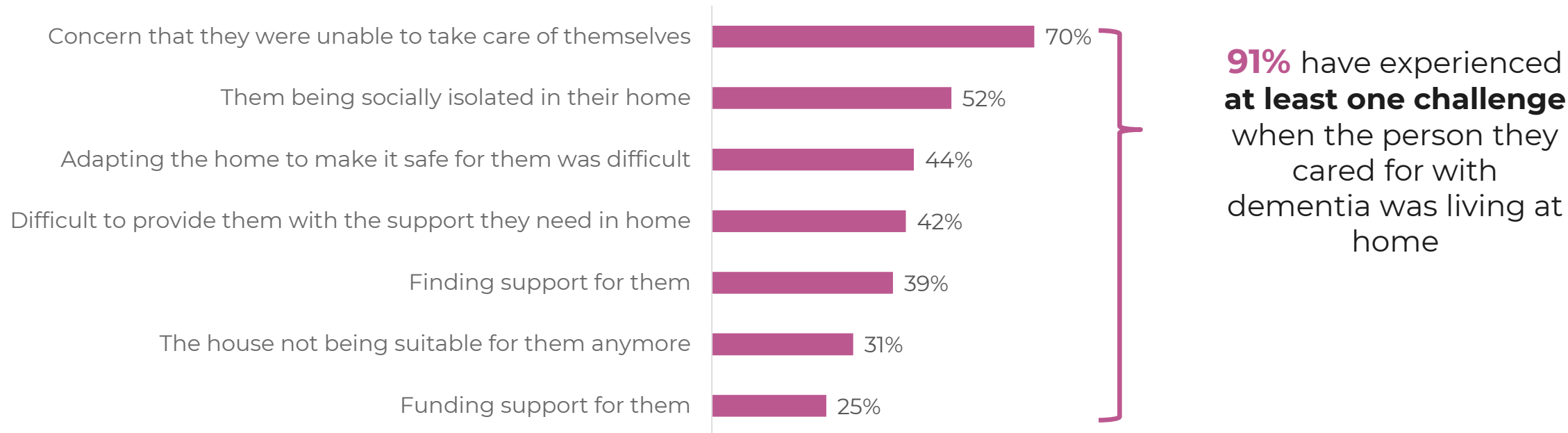
How does it **make you feel to live with symptoms of dementia?**

**2 in 5 (39%)** feel anxious or worried, **and** helpless



In terms of living at home, almost all carers faced challenges, primarily concern that the person living with dementia would be unable to take care of themselves and be socially isolated

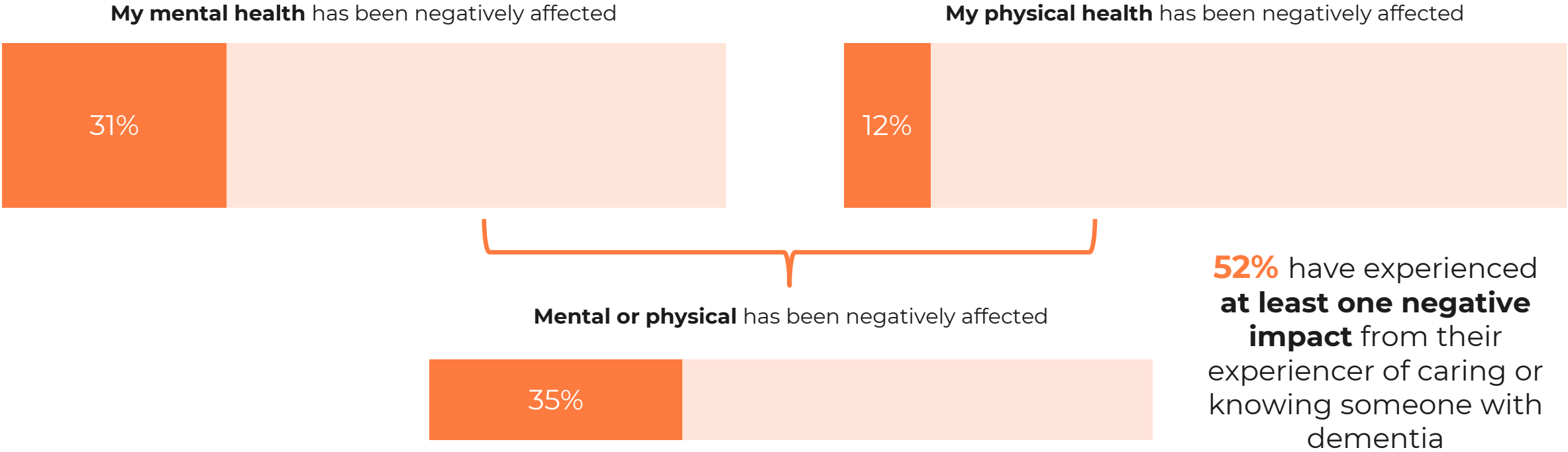
**Challenges faced** when the person with dementia was **living at home**





# Over a third who know someone living with dementia have experienced a negative impact to their mental or physical health

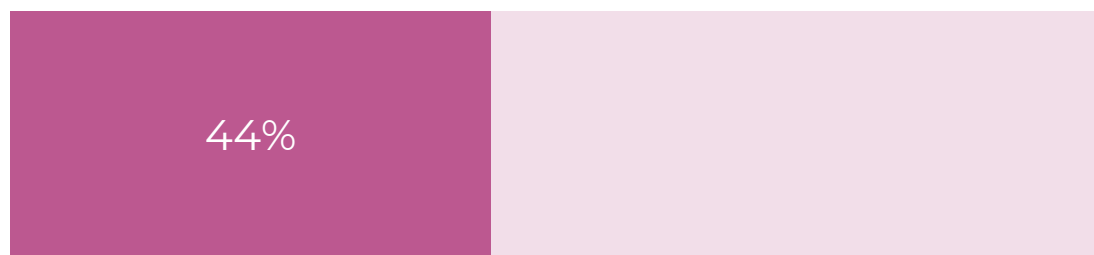
**Describe your experience** of caring or knowing someone with dementia



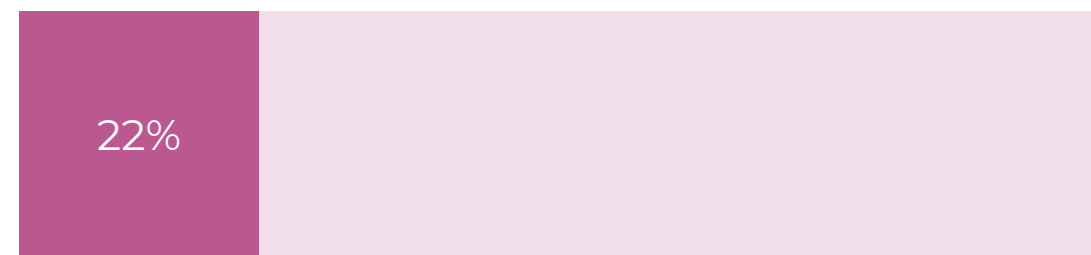
# Among those who care for someone with dementia, half have experienced a negative impact to their mental or physical health

**Describe your experience** of caring or knowing someone with dementia

**My mental health** has been negatively affected



**My physical health** has been negatively affected



**Mental or physical** has been negatively affected

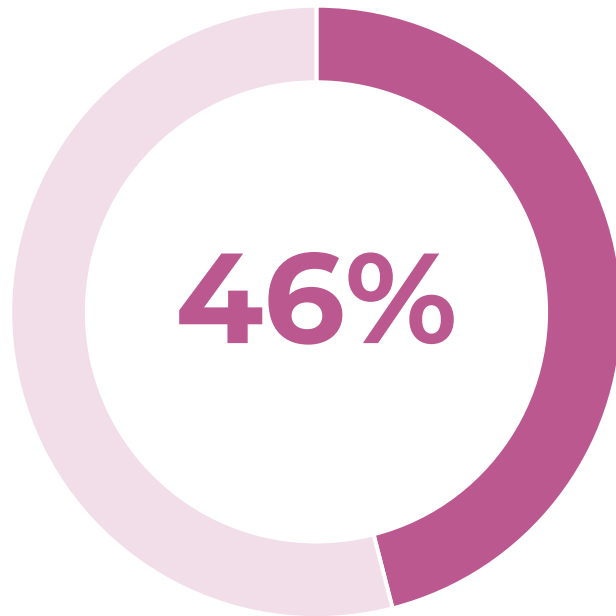


**75%** have experienced **at least one negative impact** from their experience of caring or knowing someone with dementia

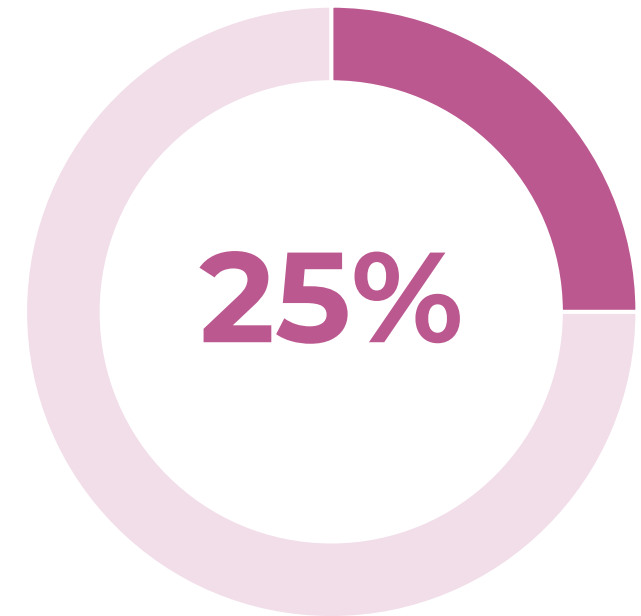
# Two in five of those who care for someone with dementia spend less time on activities they enjoy, and a quarter feel more isolated

## Describe your experience of caring someone with dementia

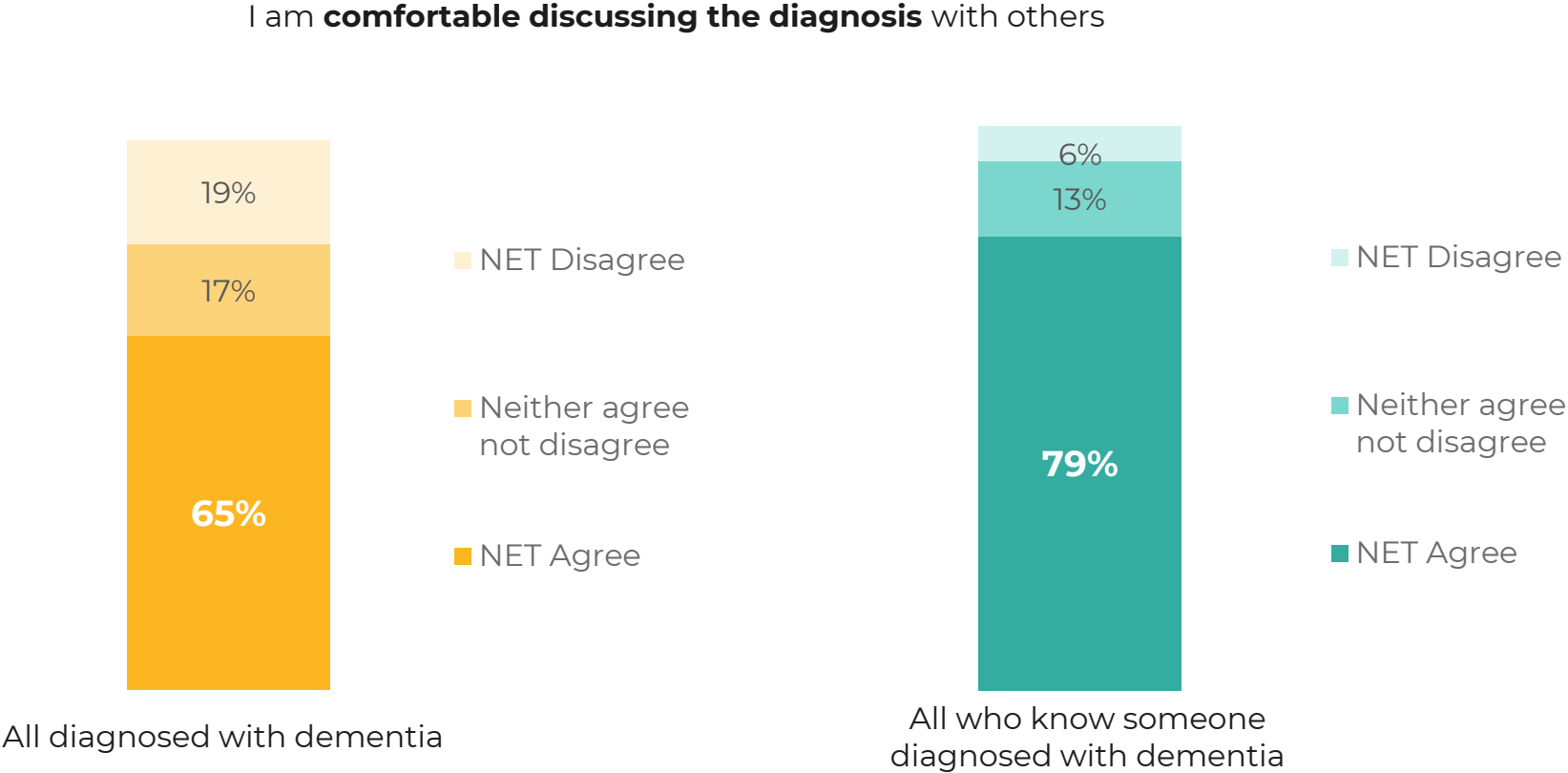
I **spend less time** in activities that I enjoy



I am more **isolated socially**

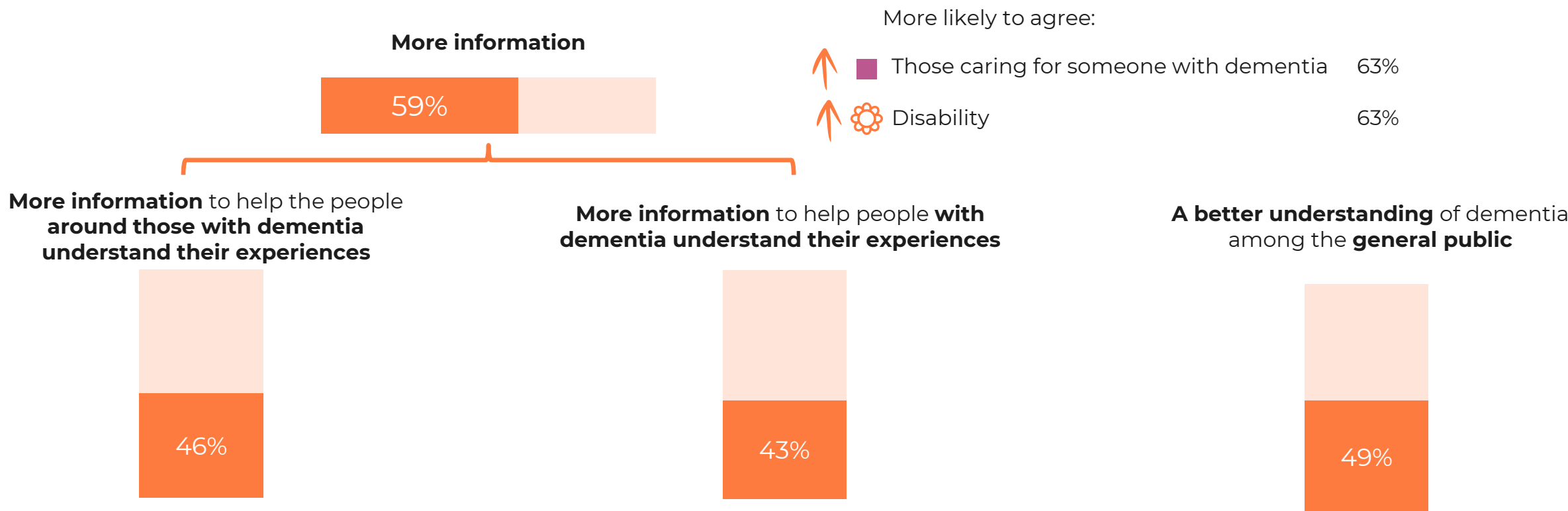


Though two thirds of those living with dementia are comfortable discussing their diagnosis, almost one in five are not



# 6 in 10 think **more information** would improve the lives of those living with dementia, whilst half think a **better understanding** among the general public would do so

Overall, what would best help to improve the lives of people living with dementia?





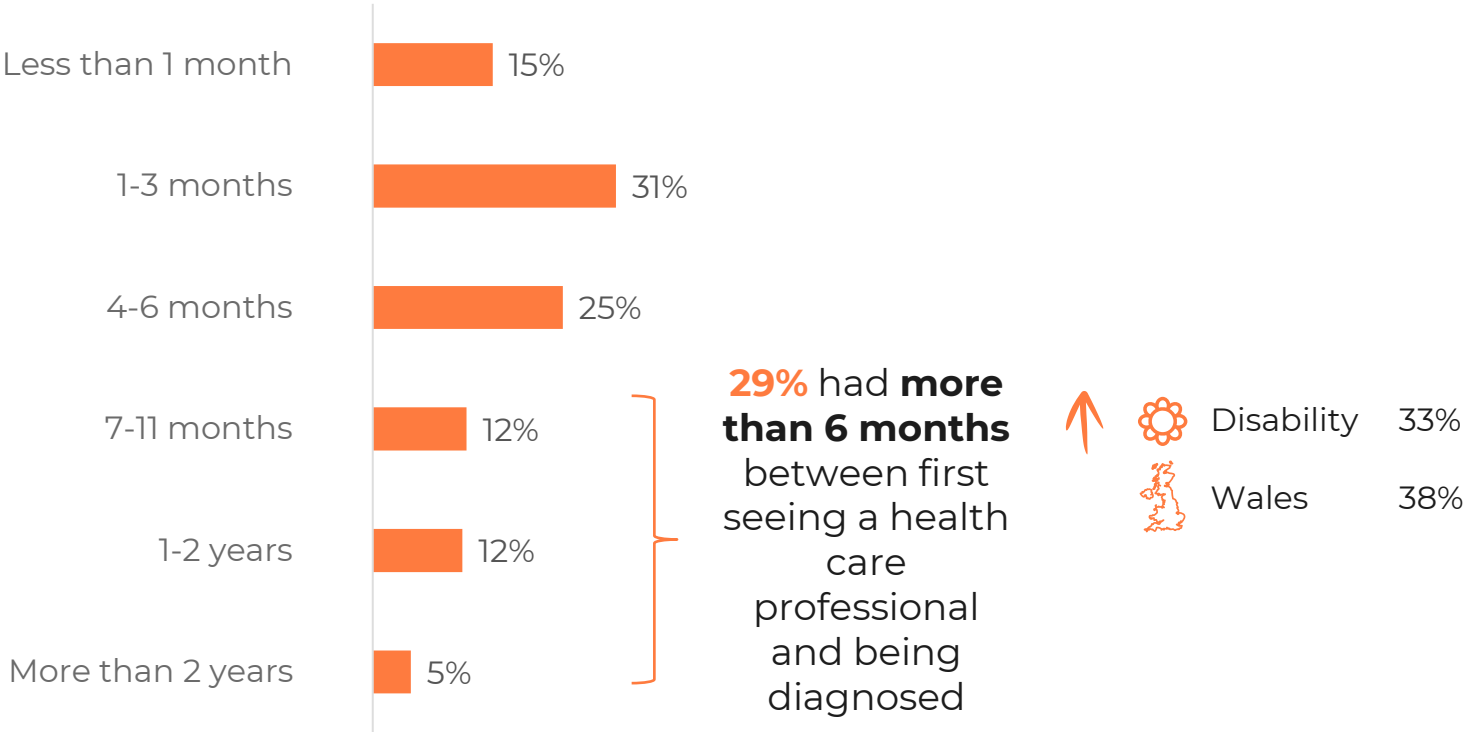
P R I O R I T I E S   T O   B E   A D D R E S S E D

The diagnosis process is taking too long

# For three in ten, the diagnosis process took longer than 6 months

In contrast, the NHS aims to give patients the outcome of a cancer diagnosis within 28 days of being referred

How long did it take **between that first appointment** with a healthcare professional and **being officially diagnosed**?

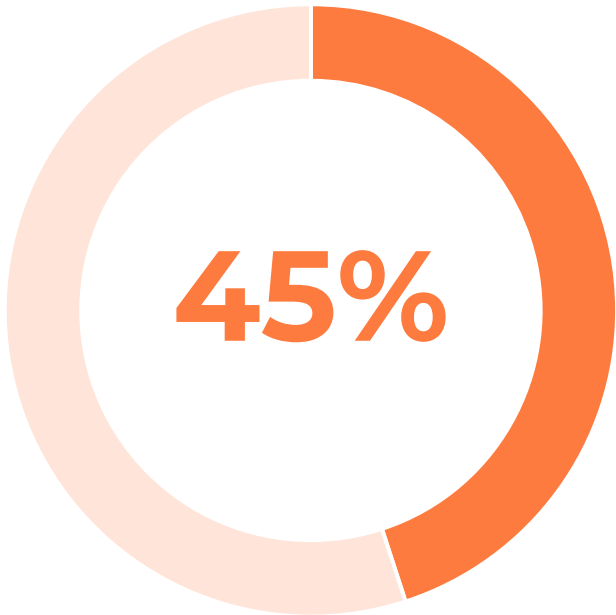




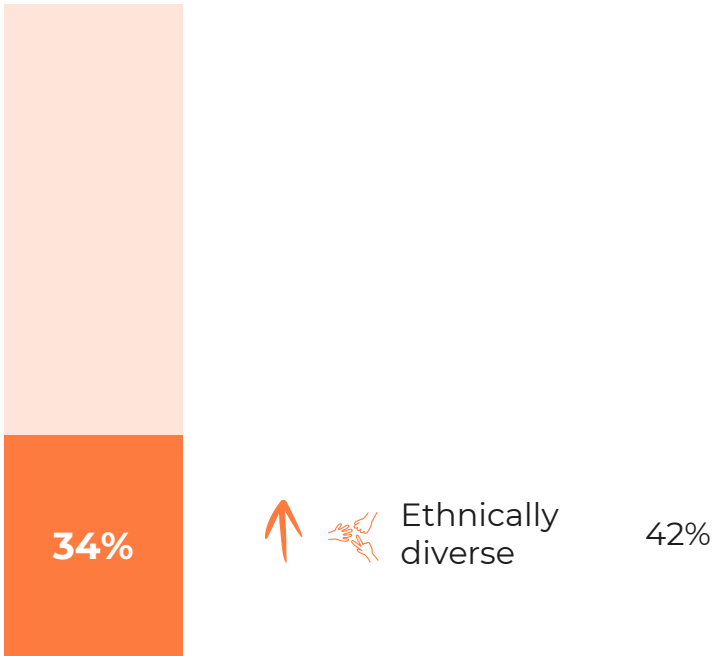
# Long waiting times has made it difficult for people to get a diagnosis

Those who are ethnically diverse are most likely to report these difficulties

The diagnosis process took **longer than expected**  
%NET agree



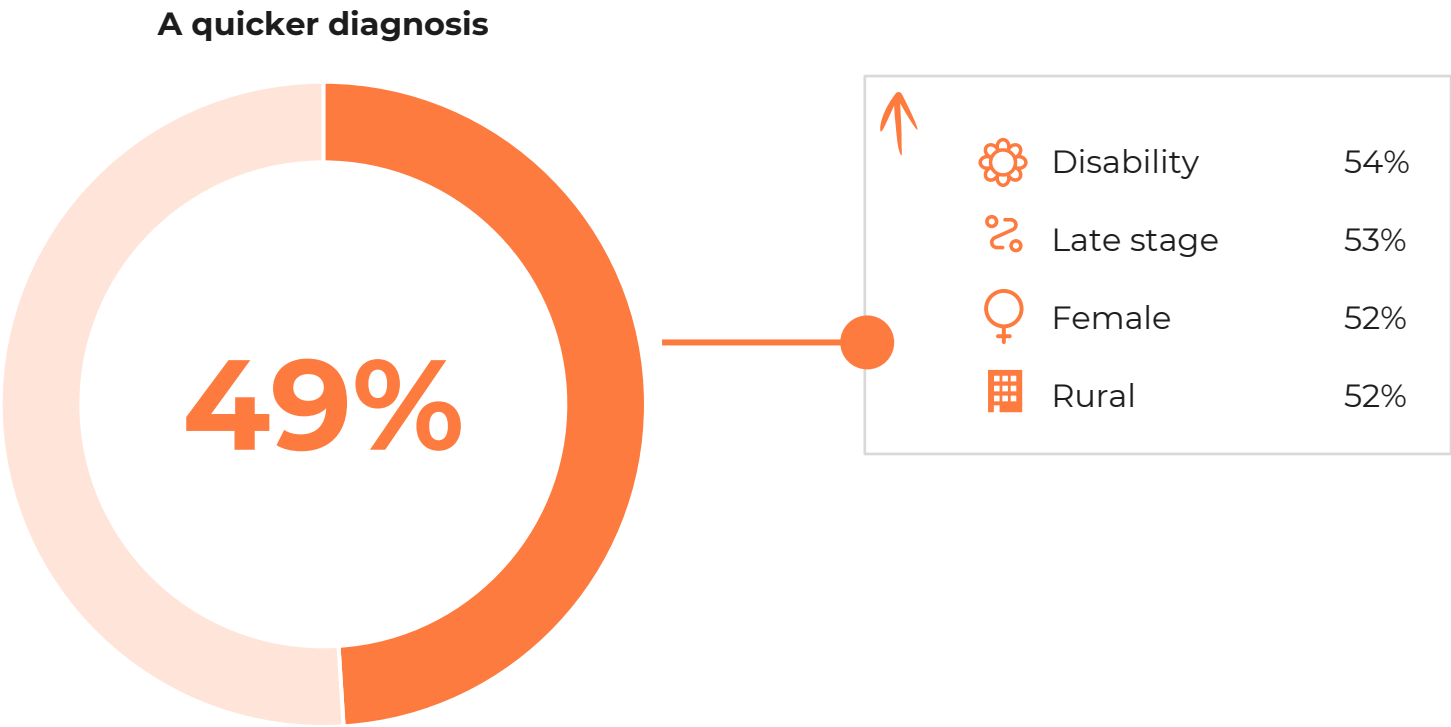
Was there anything that made it **difficult getting a diagnosis?**  
Long waiting times to see a healthcare professional



# Nearly half agree that a quicker diagnosis would improve the lives of those with dementia

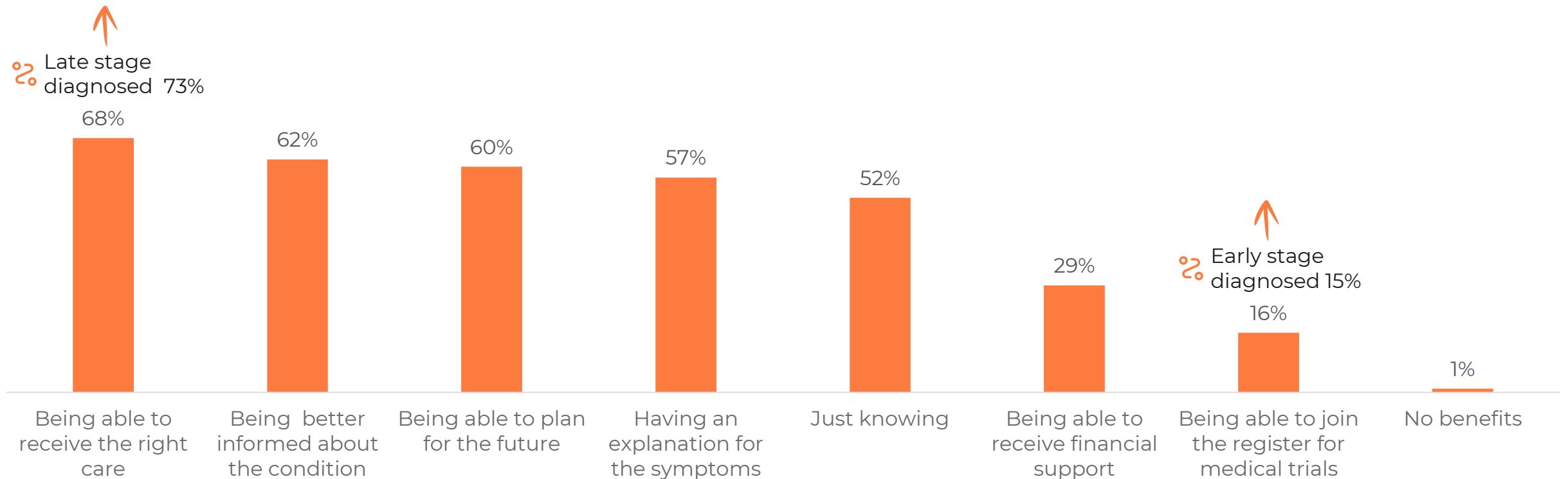
Those who are disabled and living in rural areas are more likely to agree

Overall, what would best help to improve the lives of people living with dementia?



# Almost everyone sees a benefit to receiving a diagnosis; for 7 in 10 it is being able to receive the right care

What do you think the **benefits** are of receiving a diagnosis?



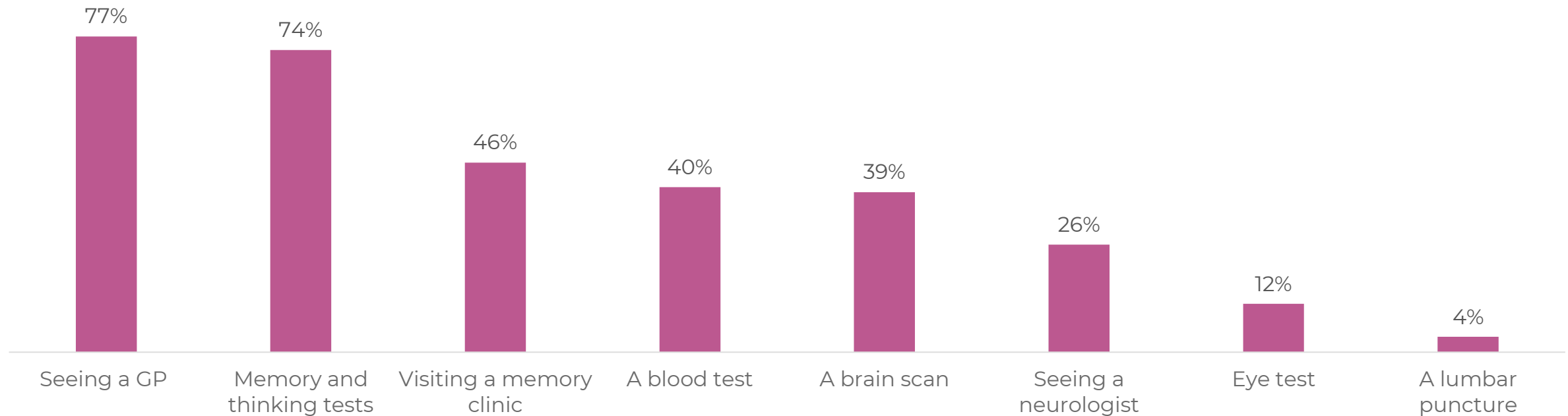


PRIORITIES THAT NEED TO BE ADDRESSED

The experience with the system can be negative

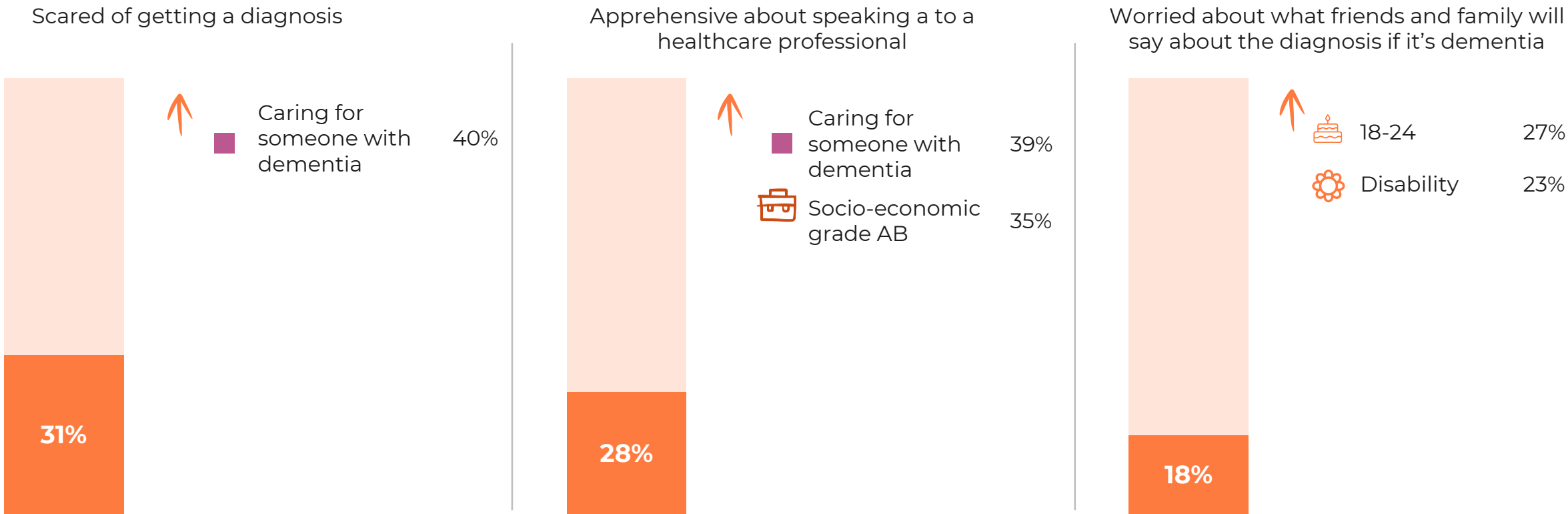
# When getting a diagnosis, only a quarter have seen a neurologist and less than four in ten had a brain scan

Which of these were **experienced** when getting a diagnosis?



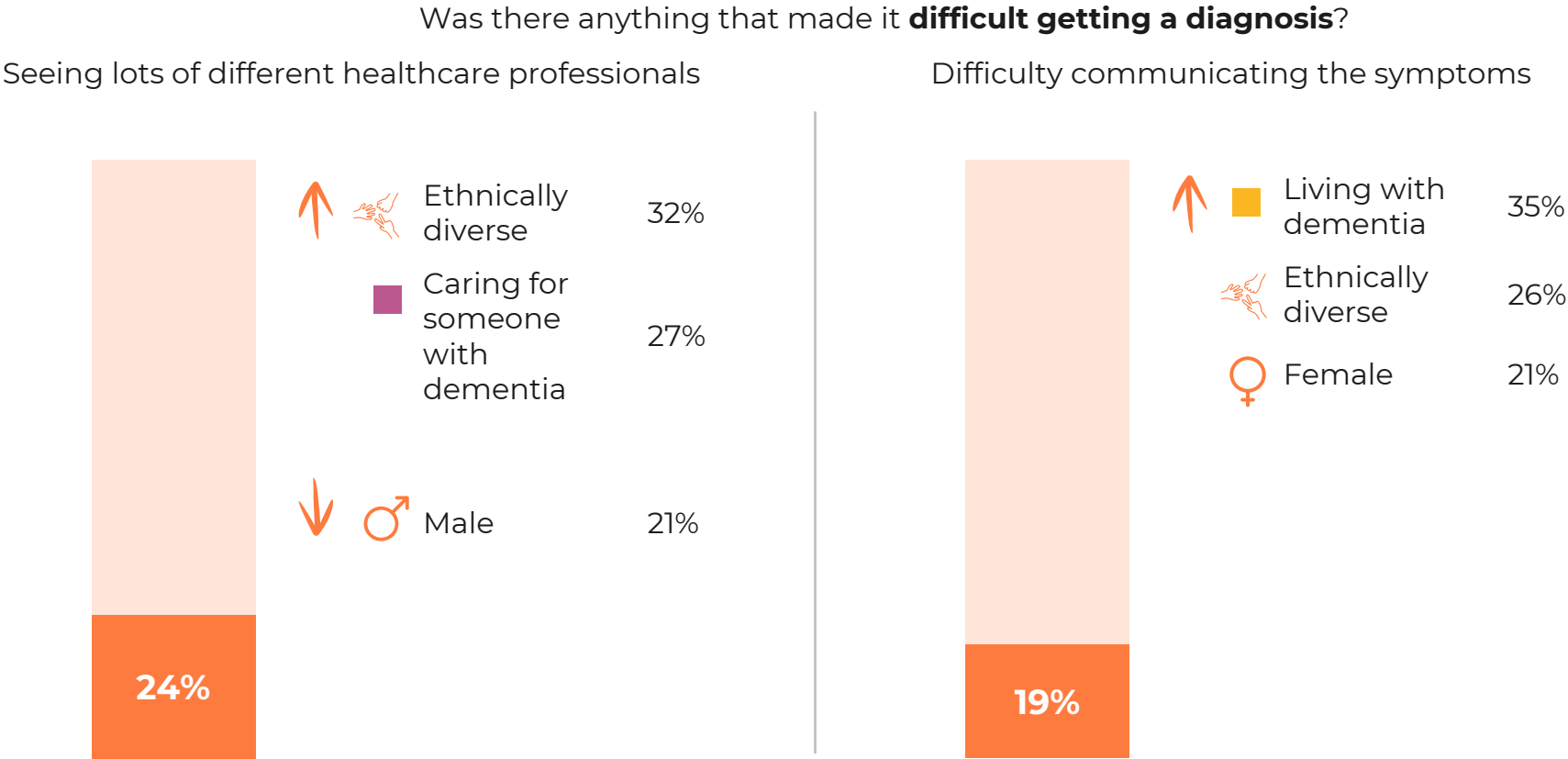
# Fear of getting a diagnosis and apprehension about speaking to a healthcare professional are preventing many seeking help

Reasons for **not seeing** a healthcare professional to **get a diagnosis**



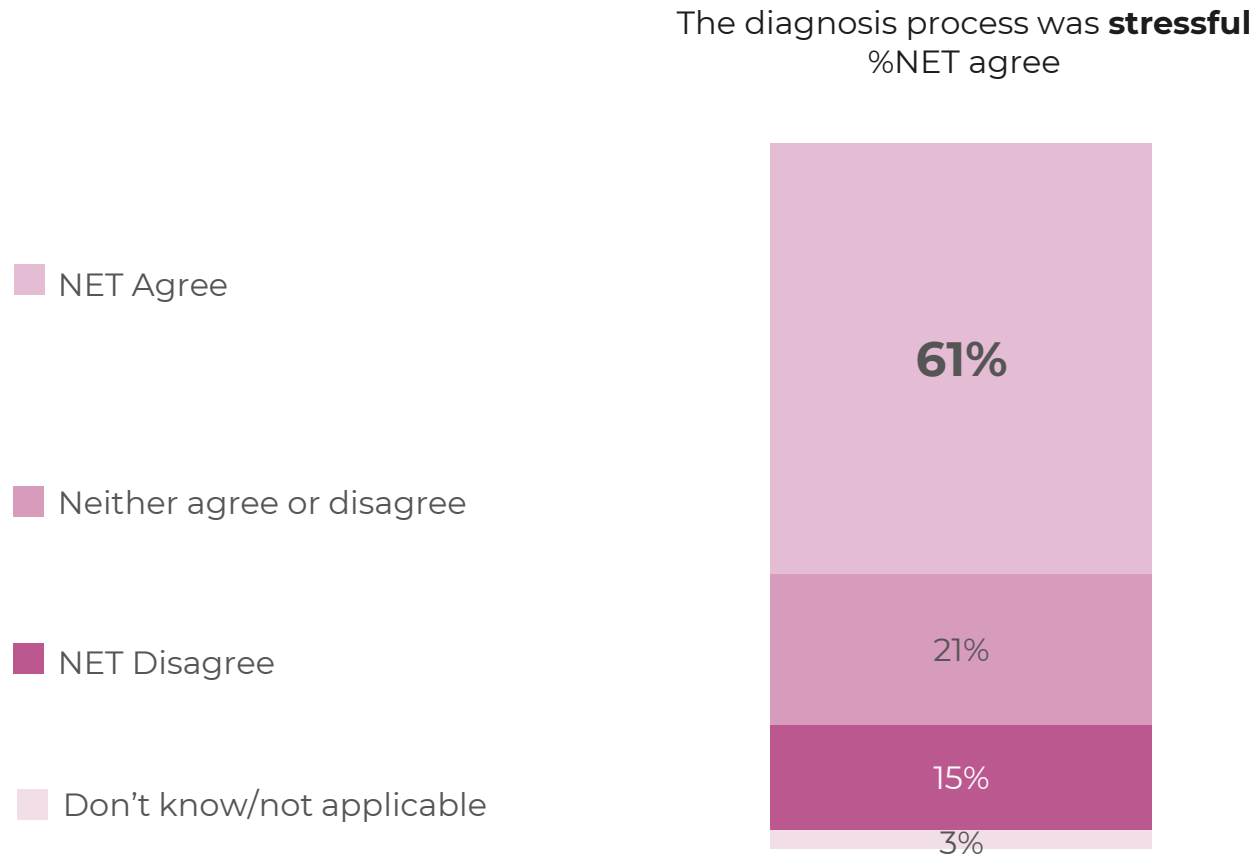
# Seeing different health care professionals and communicating symptoms has made it hard for some to get a diagnosis

Those who are ethnically diverse are most likely to experience these difficulties



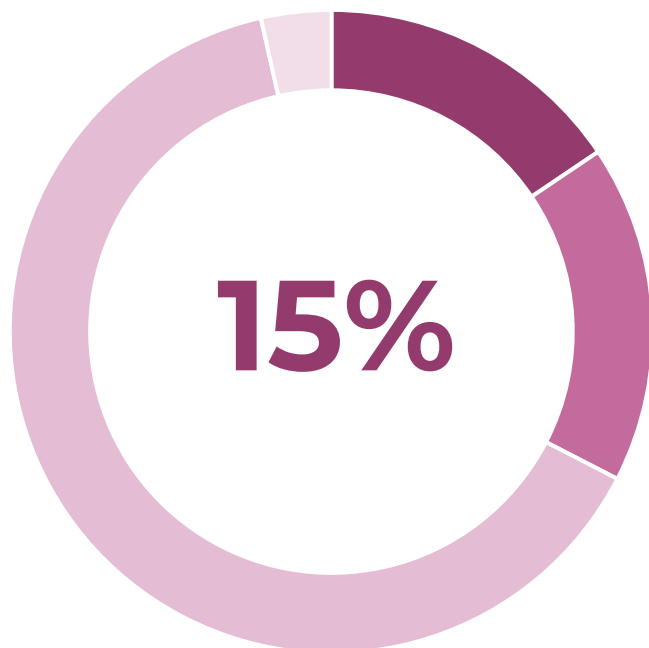


# Over six in ten found the diagnosis process stressful

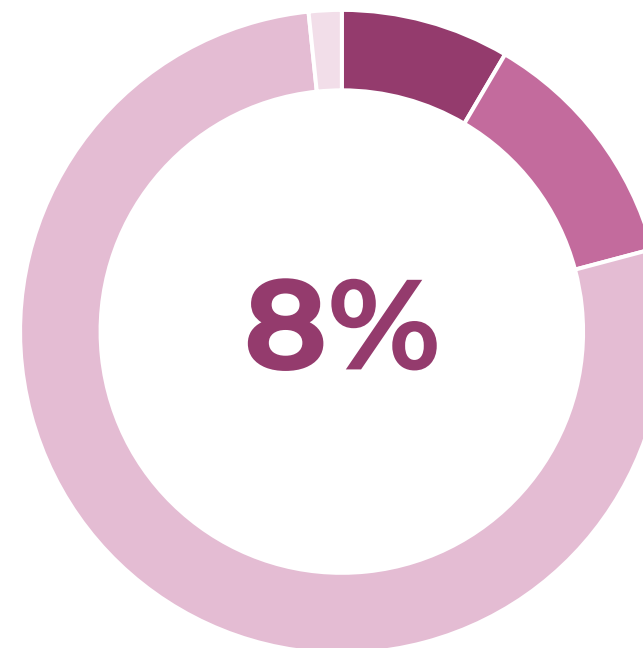


# A notable minority disagree that healthcare professionals clearly communicated and that they were compassionate

The healthcare professionals **clearly communicated**  
% Net Disagree



The healthcare professionals **were compassionate**  
% Net Disagree



■ NET Disagree ■ Neither agree or disagree ■ NET Agree ■ Don't know

# Less than half felt respected as carers by healthcare or social care professionals

I feel **respected** as a carer by **healthcare professionals**



■ NET Disagree ■ Neither agree or disagree ■ NET Agree ■ Don't know/not applicable

I feel **respected** as a carer by **social care professionals**



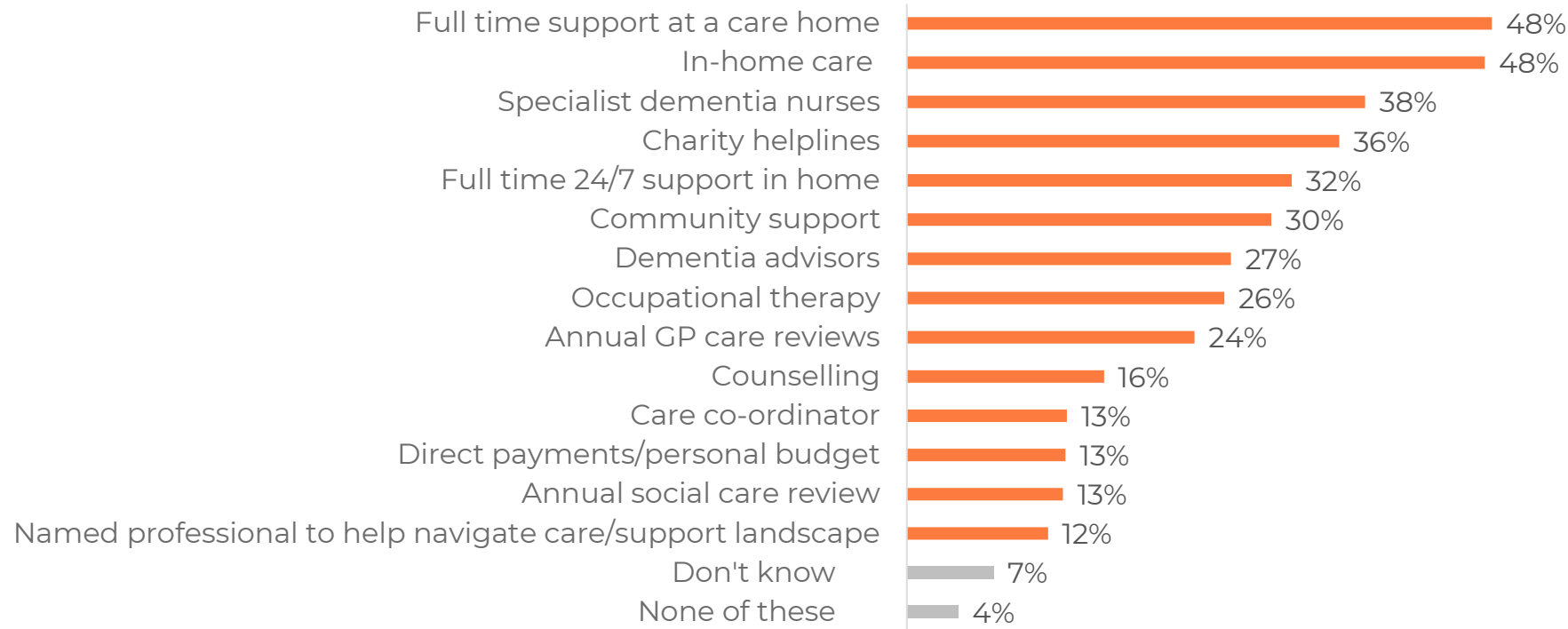


PRIORITIES THAT NEED TO BE ADDRESSED

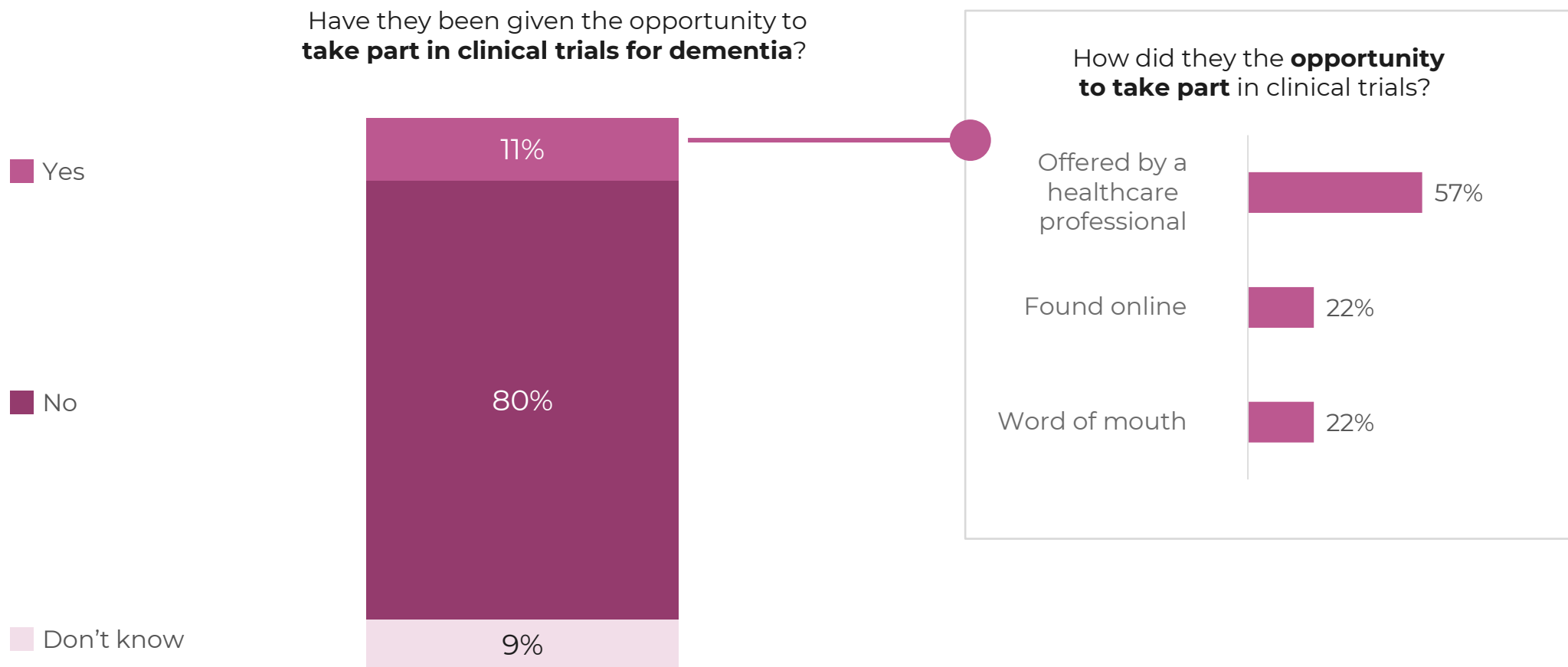
There are barriers to accessing support

# Full-time and in-home care are well-known sources of support, but only a minority know about other types e.g. care co-ordinator

Are you aware of any of the following sources of **support for people with dementia?**



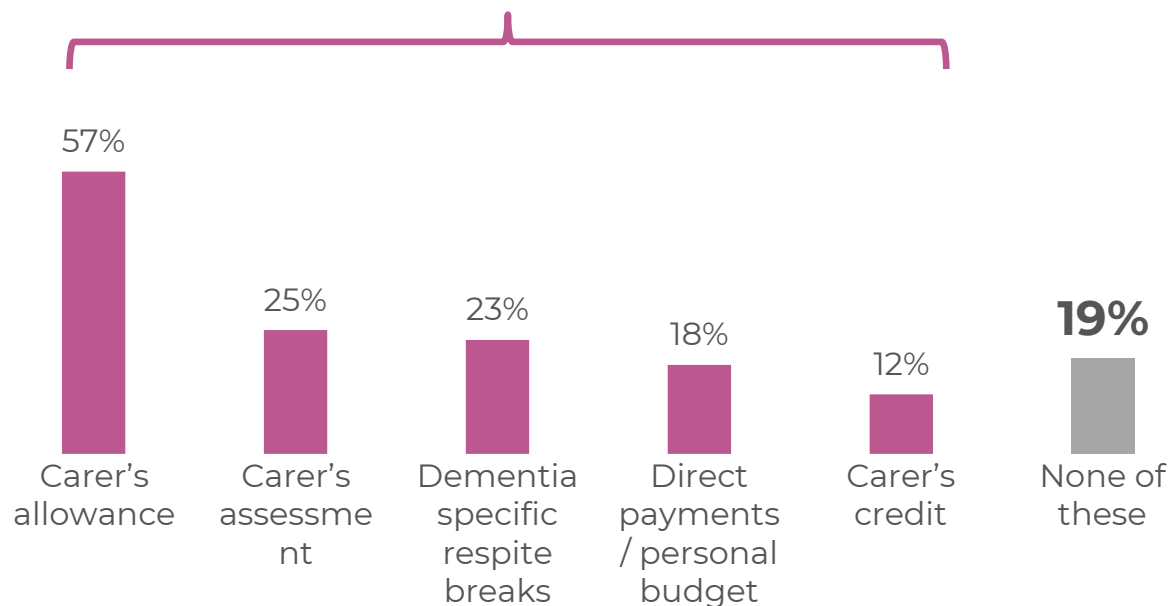
Only one in ten were given the opportunity to take part in clinical trials; one in five heard about it online or through word of mouth



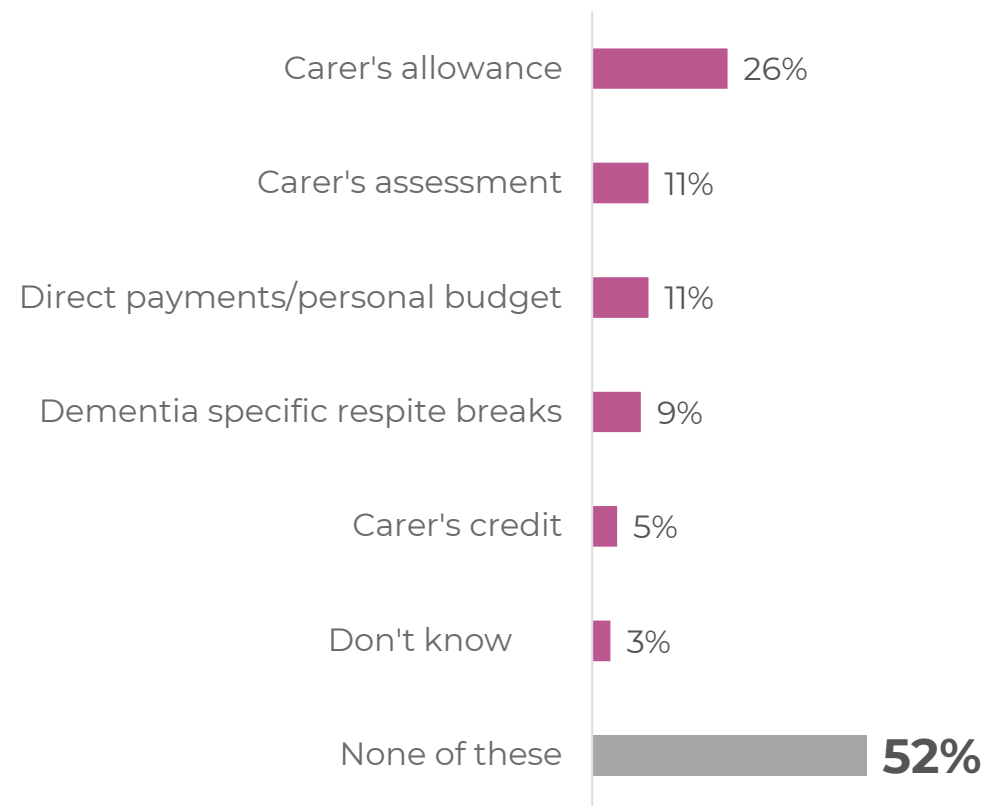
# A fifth are not aware of any areas of support that are available for carers, and over half have not received any help

Are you **aware of the following areas of support** available for carers of those with dementia?

**71%** are aware of **at least one area of support** for carers



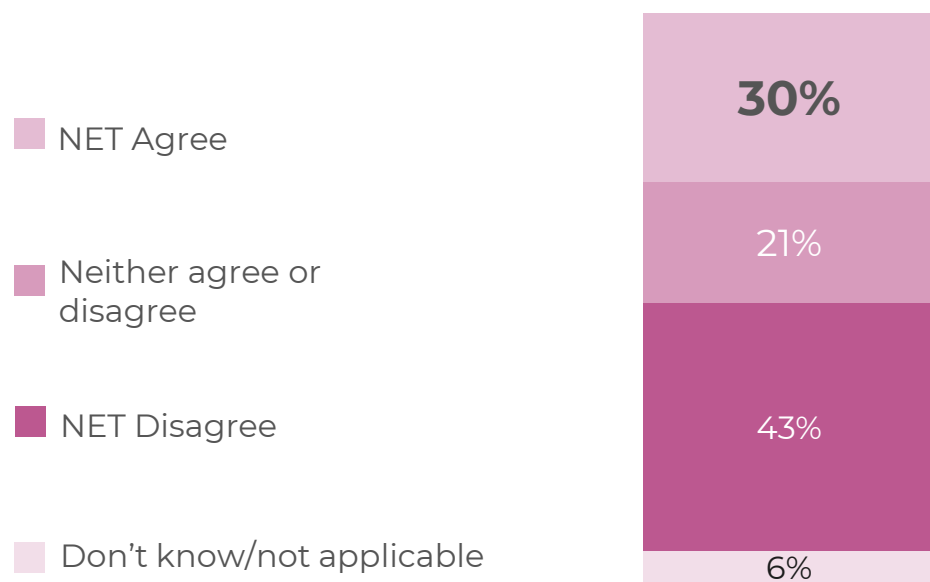
Have you **received any support available for carers** of those with dementia from the following sources?



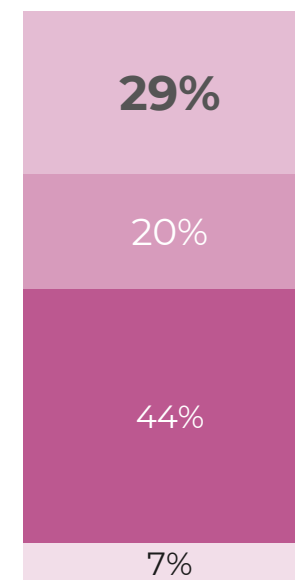


# Just three in ten agree that healthcare support or social support for dementia is easy to access

Dementia **healthcare support** is **easy to access**



Dementia **social support** is **easy to access**

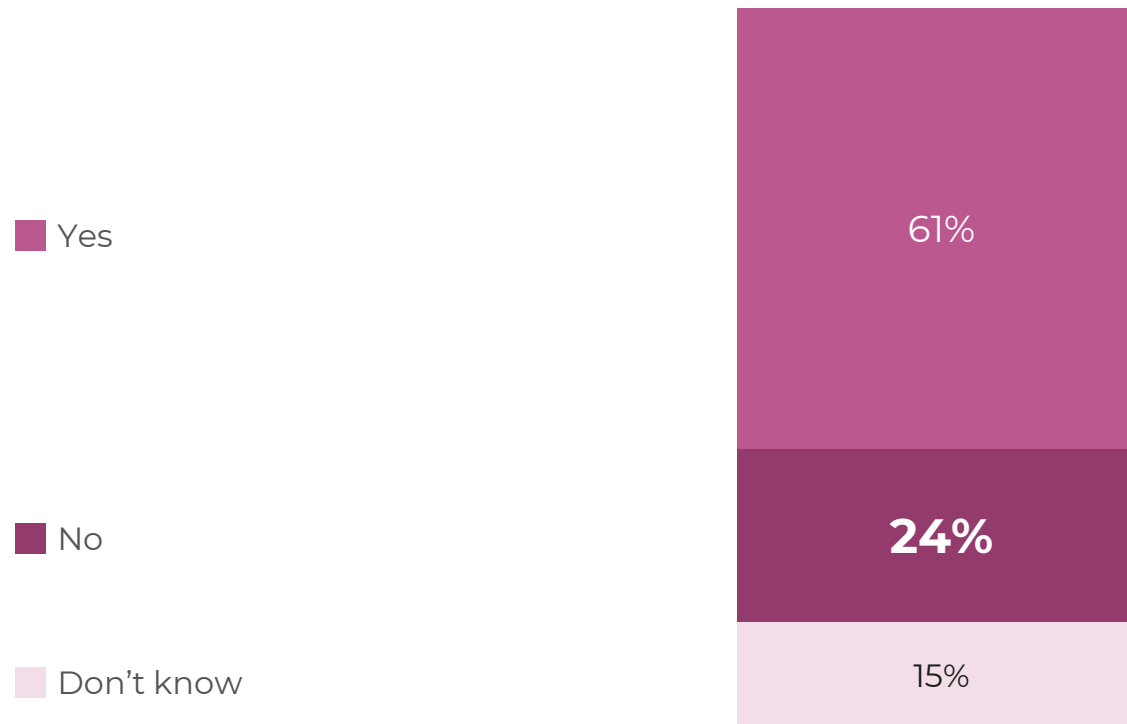


There officially appears to be quite a lot of social care assistance, but **when one asks for help it just doesn't really exist**

*Caring for someone with middle-stage dementia*

# A quarter were not told how to seek support following their diagnosis

Was the person you know with dementia **given advice about how to seek support**, following the diagnosis

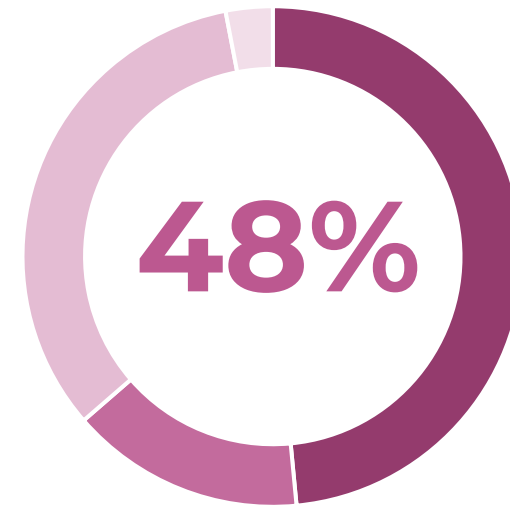


# Only half know who to contact if they need healthcare or social care support

I know who to **contact** if I need **health care support**  
%NET agree



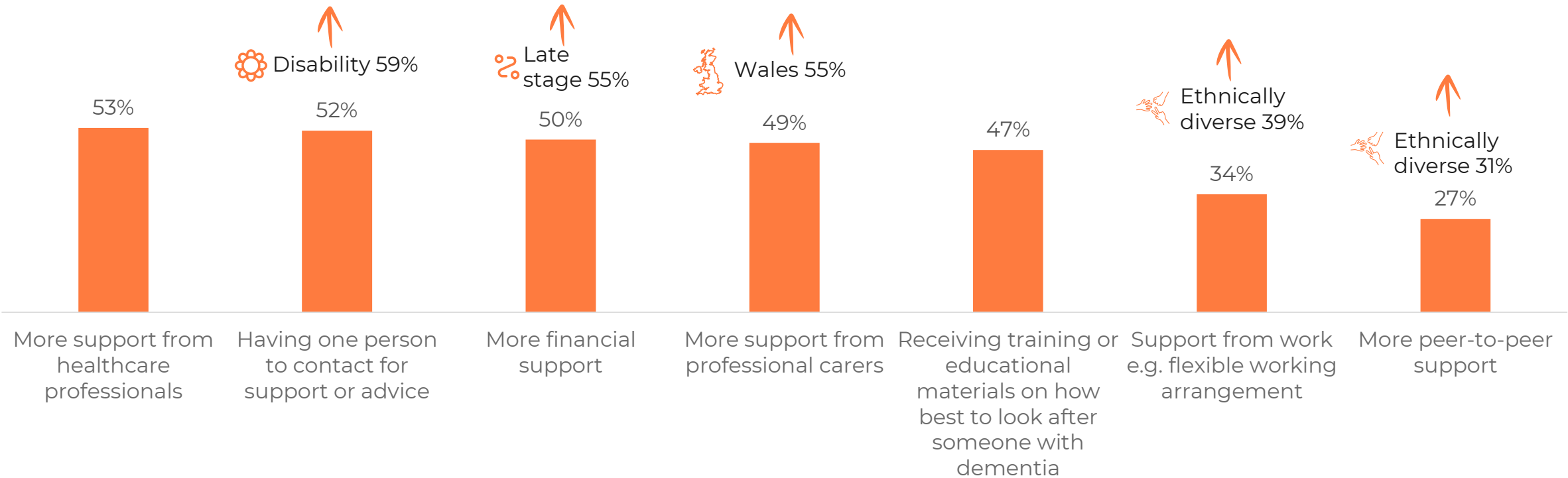
I know who to **contact** if I need **social care support**  
%NET agree



■ NET Agree ■ Neither agree or disagree ■ NET Disagree ■ Don't know

# More support from professional carers and having one person to contact for advice would help carers, as well as financial support

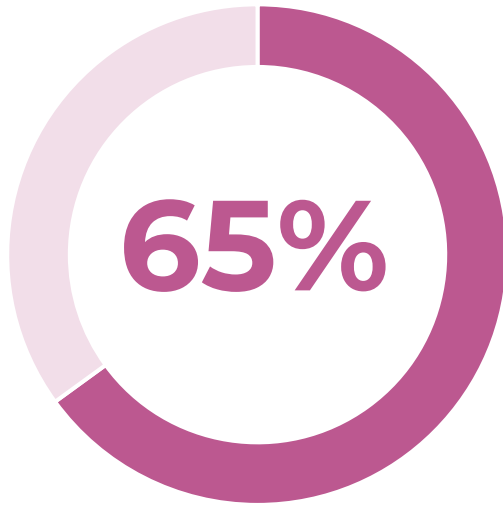
How could **support for carers** of people with dementia be **improved**?



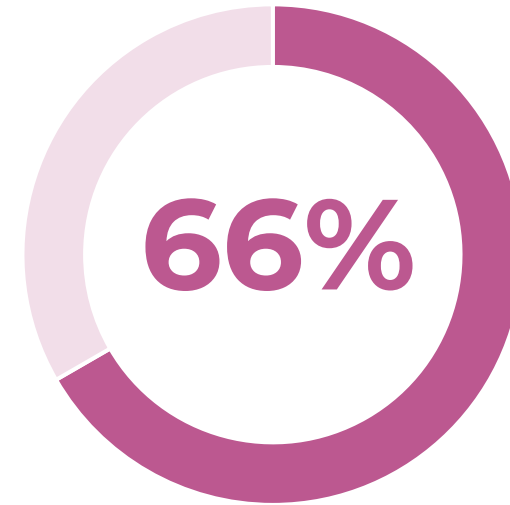
# There is demand for more support from dementia-skilled care workers to help those affected

Overall, what would best help to improve the lives of people living with dementia?

More **care workers who are skilled** in caring for those with dementia

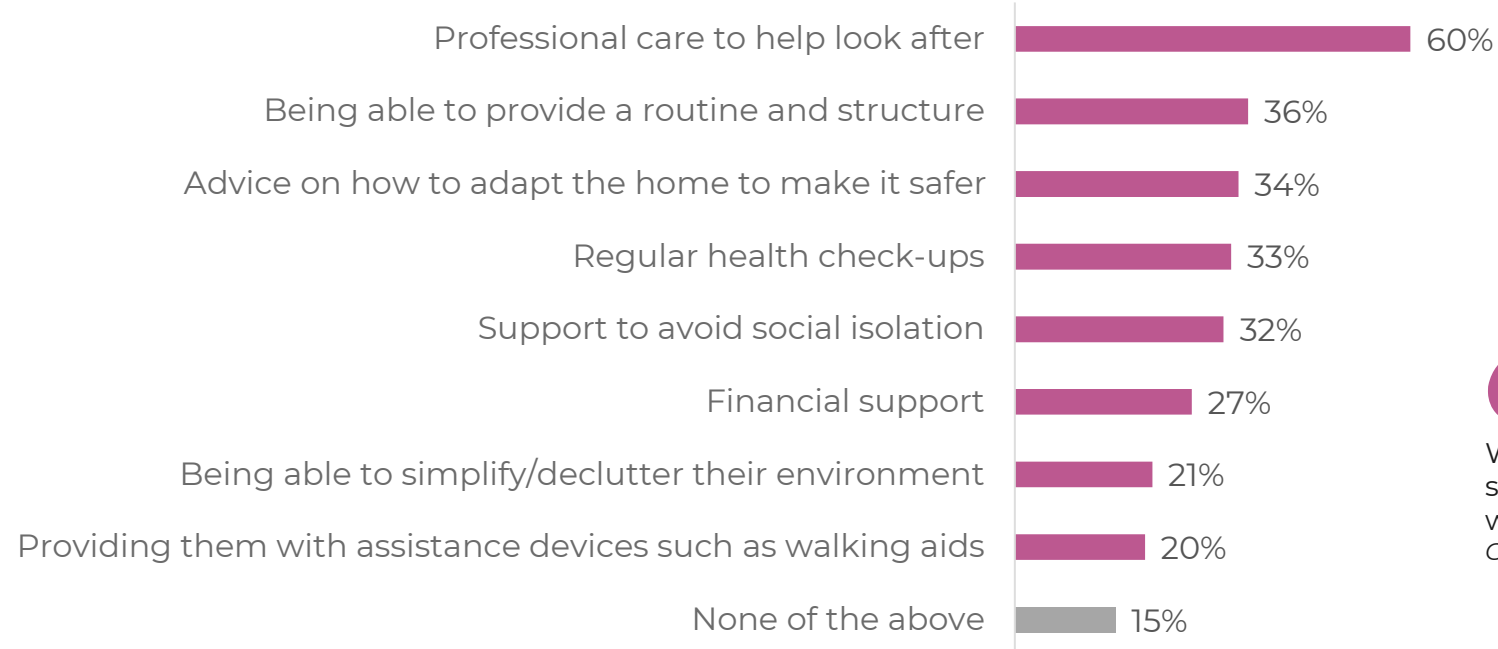


More **support for those caring for people** with dementia



# Six in ten carers think having professional care would have helped the person living with dementia to live at home for longer

What would have **helped them live at home** for longer?

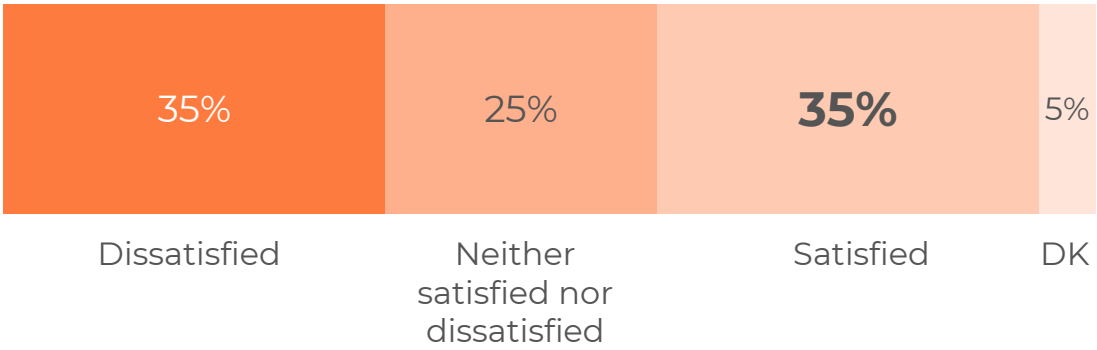


We **couldn't access enough care at home** so she had to go into a care home which wasn't what she wanted

*Caring for someone with late-stage dementia*

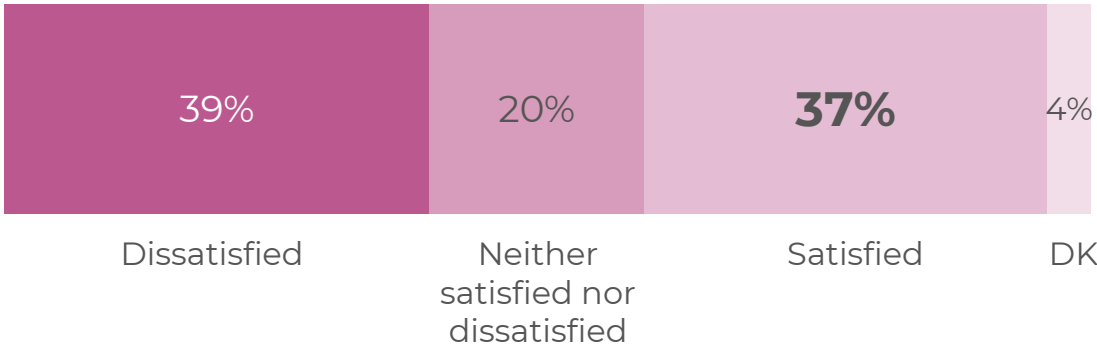
# Less than four in ten are satisfied with the support available for people living with dementia and for those caring for them

How satisfied are you with the **support available for people with dementia?**



All

How satisfied are you with the **support available for those who care** for people with dementia?



All caring for someone with dementia



FINAL THOUGHTS

# What needs to change



# What needs to change

## Increase the speed of diagnosis, and reduce stigma around it

Three in ten are scared of getting a diagnosis and are apprehensive to speak to a healthcare professional about it.

Thus, the **stigma around getting a diagnosis needs to be reduced** and **education about it must increase**.

The diagnosis process needs to be **quicker and clearer**, which should enable more people to access the right care.

## Clearer and more compassionate healthcare and diagnosis services

A significant minority do not feel that healthcare professionals are clear or compassionate, which can leave carers feeling disrespected.

A **consistent, clear and compassionate experience** is needed across the board.

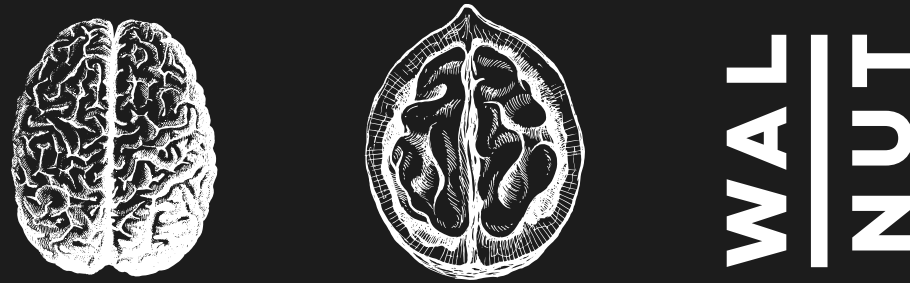
One **consistent point of contact**, wherever possible, to be available to support those caring for others and living with dementia.

## Easier access to support

Clearer direction and information about how to access support needs to be more consistently available to everyone.

**Better access to dementia-trained carers** – a call to the Government to prioritise dementia through:

- Appropriate access to dementia trained carers for those affected by dementia
- Appropriate funding of care for those who need it



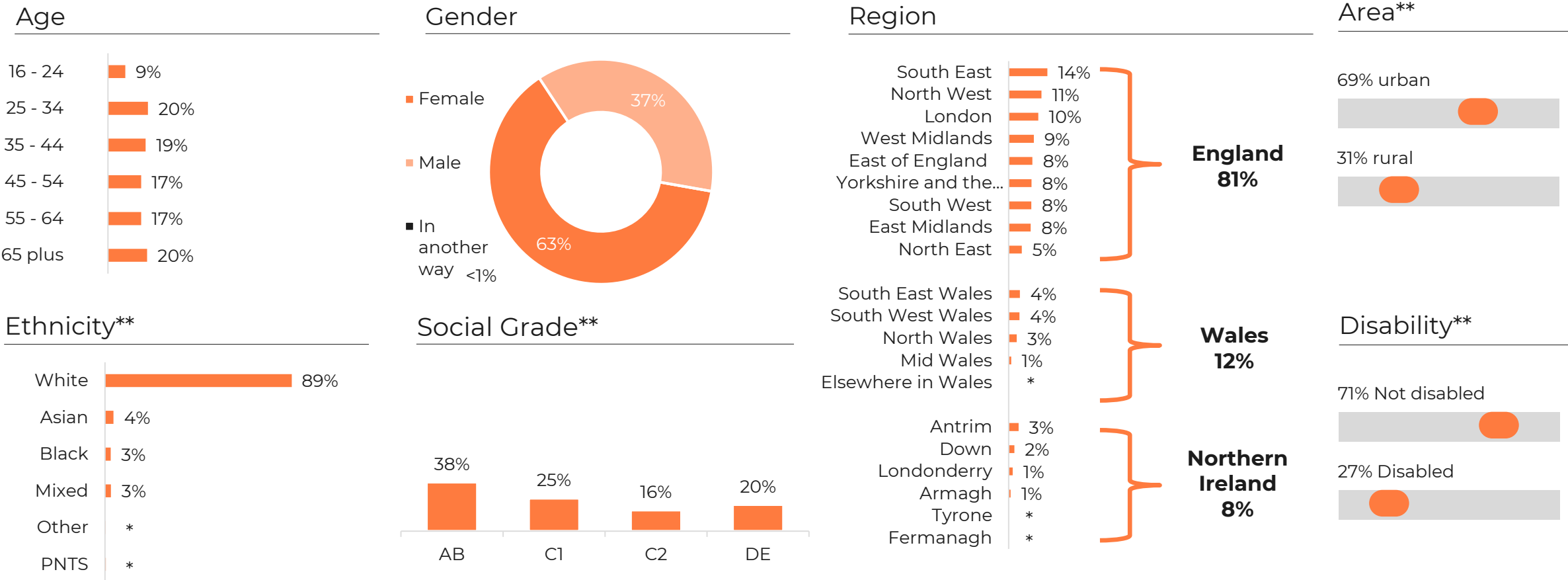
The human understanding agency.



# How we defined stage of dementia in the survey

<b>Early-stage dementia</b> – symptoms were often relatively mild. Typically living independently and only needed a bit of assistance with daily living.	1
<b>Middle-stage dementia</b> – symptoms were more noticeable, and more support was required to manage their daily life.	2
<b>Late-stage dementia</b> – dementia had a severe impact on everyday life. Full-time care and support was needed for daily living.	3

# Who we spoke to: **total sample**

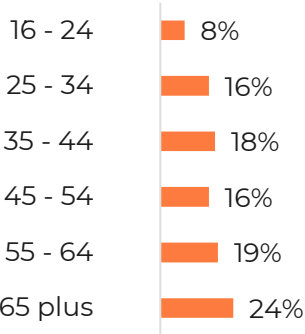


Base: All respondents (3476)  
\*\* questions asked just among those who know someone with dementia (3400)  
Disability based on question F4b. Does your condition or illness reduce your ability to carry out day to day activities?  
Re-based on total sample. Chart excludes PNS at 2%

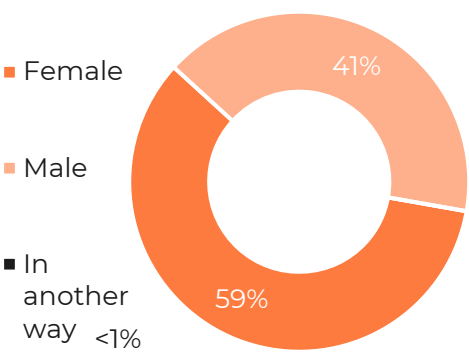
An asterisk (\*) represents a value of less than one half of one per cent, but not zero.  
Urban area is those living in the centre or a town/city or just outside of it  
Rural area is those living between a town or city and the countryside and those living in the countryside

# Who we spoke to: **Wales**

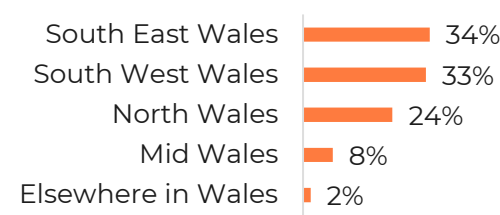
## Age



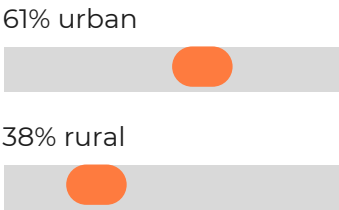
## Gender



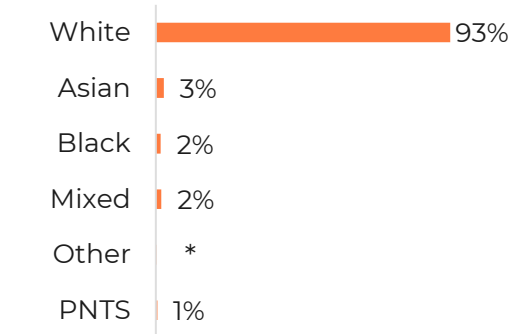
## Region



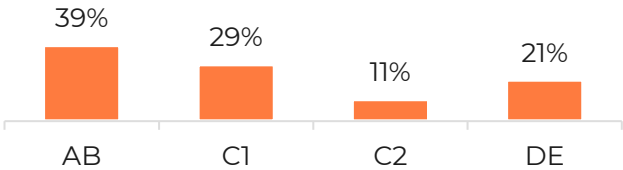
## Area\*\*



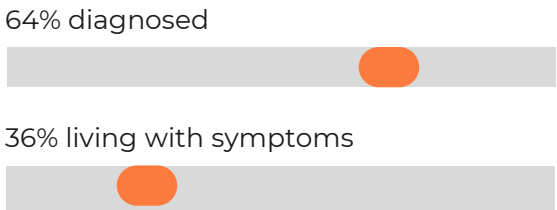
## Ethnicity\*\*



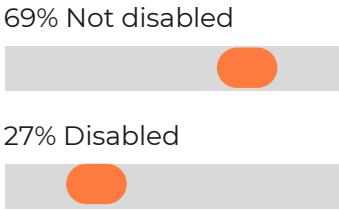
## Social Grade\*\*



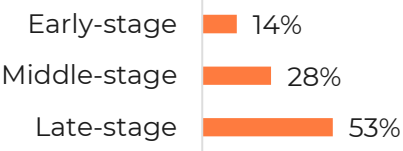
## Living with dementia



## Disability\*\*



## Stage of dementia

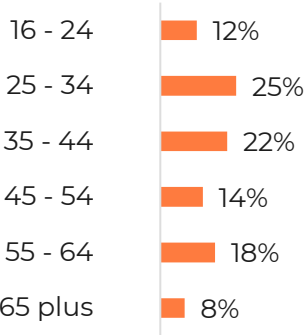


Base: All respondents (400)  
\*\* questions asked just among those who know someone with dementia (395)  
Disability based on question F4b. Does your condition or illness reduce your ability to carry out day to day activities?  
Re-based on total sample. Chart excludes PNS at 4%

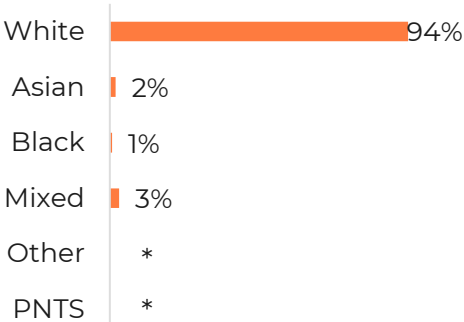
An asterisk (\*) represents a value of less than one half of one per cent, but not zero.  
Urban area is those living in the centre or a town/city or just outside of it  
Rural area is those living between a town or city and the countryside and those living in the countryside

# Who we spoke to: Northern Ireland

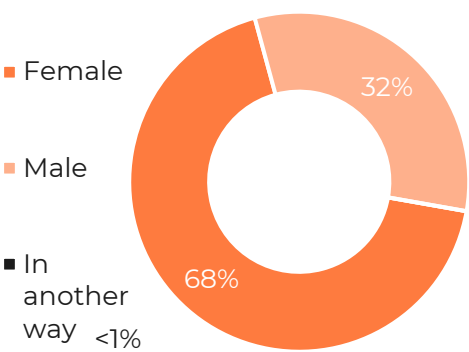
## Age



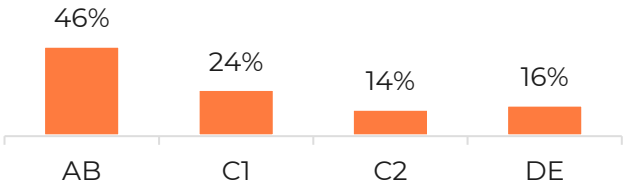
## Ethnicity\*\*



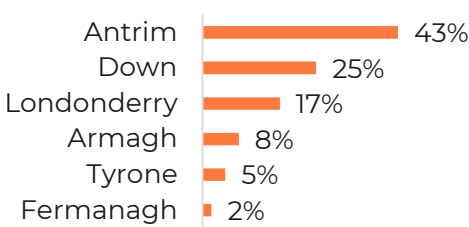
## Gender



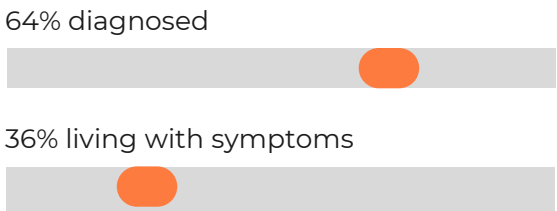
## Social Grade\*\*



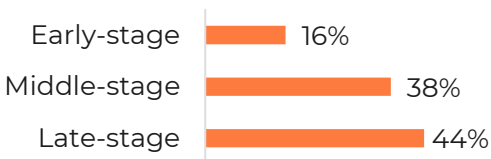
## Region



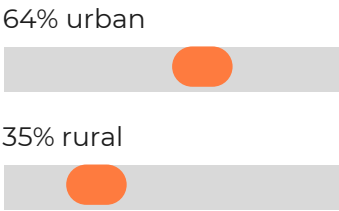
## Living with dementia



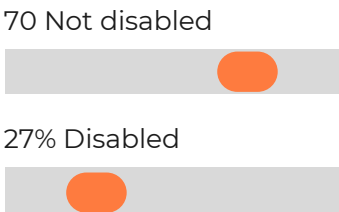
## Stage of dementia



## Area\*\*



## Disability\*\*

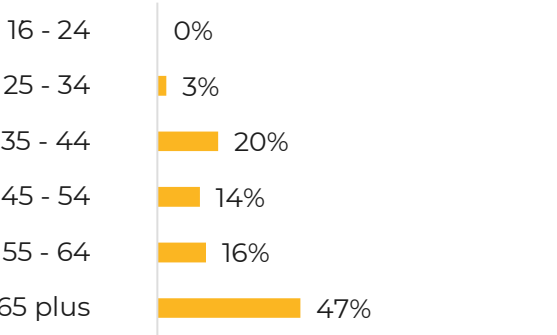


Base: All respondents (276)  
\*\* questions asked just among those who know someone with dementia (268)  
Disability based on question F4b. Does your condition or illness reduce your ability to carry out day to day activities?  
Re-based on total sample. Chart excludes PNS at 3%

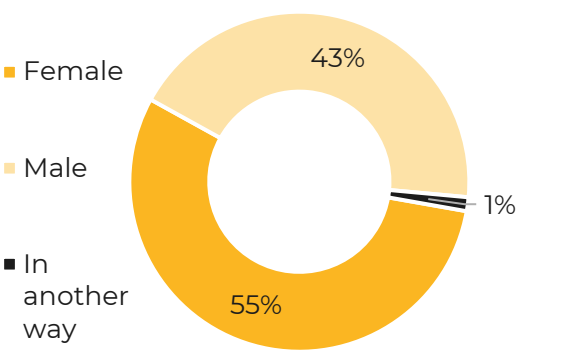
An asterisk (\*) represents a value of less than one half of one per cent, but not zero.  
Urban area is those living in the centre or a town/city or just outside of it  
Rural area is those living between a town or city and the countryside and those living in the countryside

# Who we spoke to: **those living with dementia**

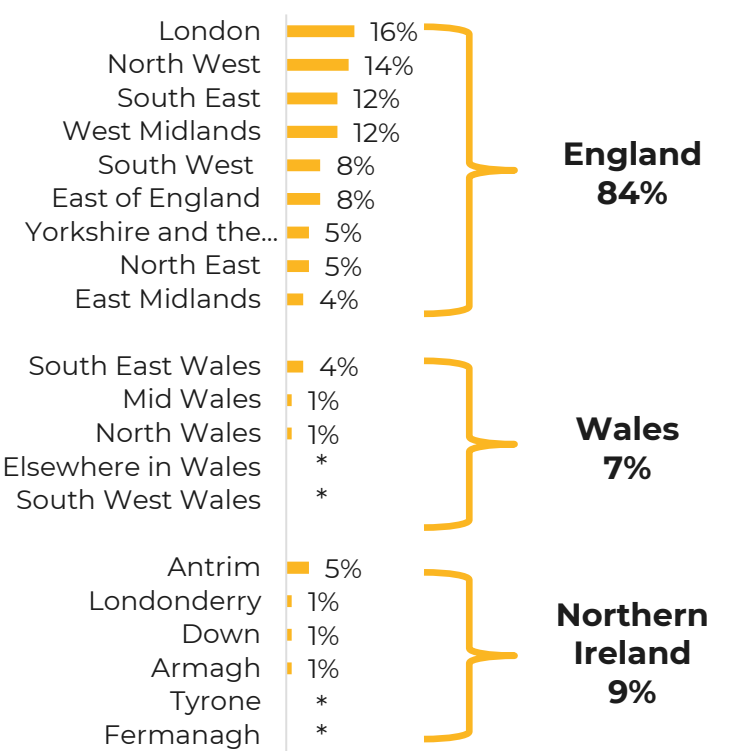
## Age



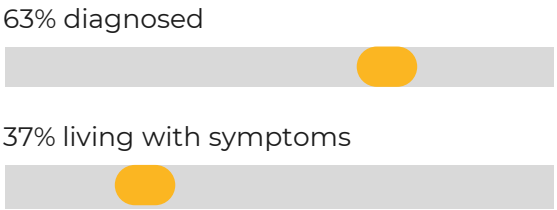
## Gender



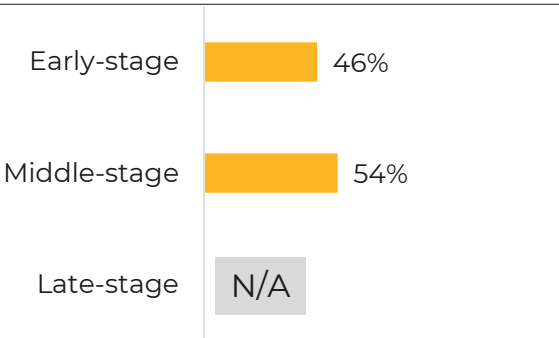
## Region



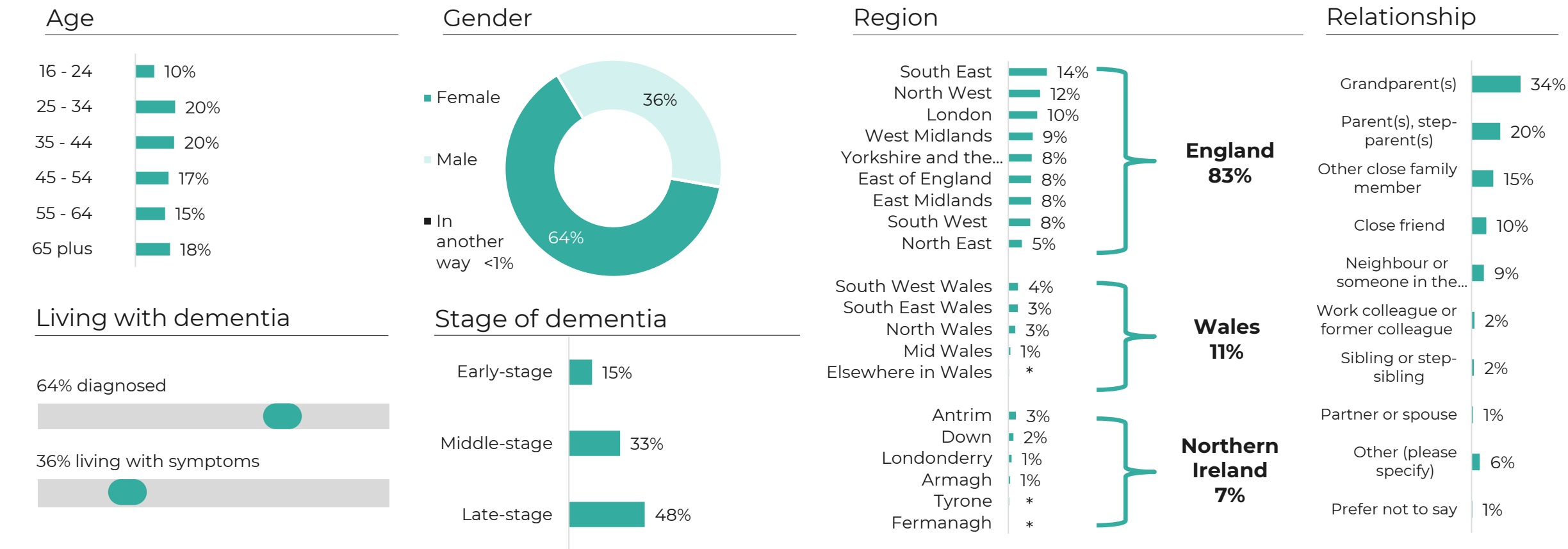
## Living with dementia



## Stage of dementia



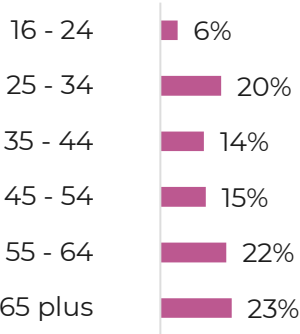
# Who we spoke to: those who know someone living with dementia



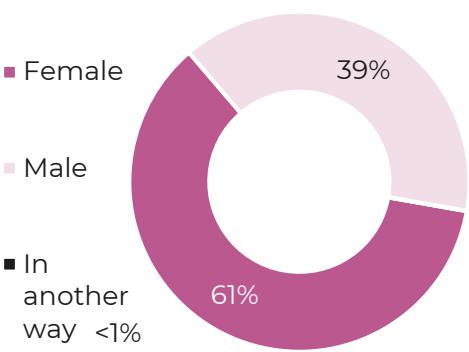


# Who we spoke to: **carers supporting someone with dementia**

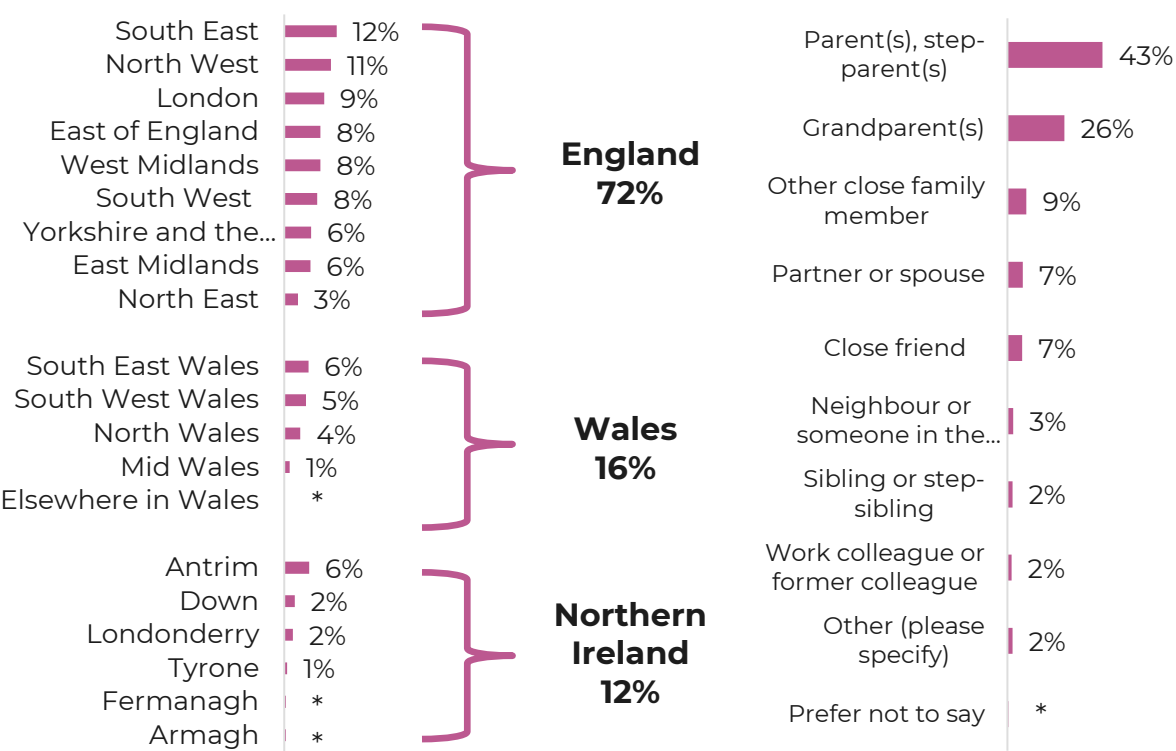
## Age



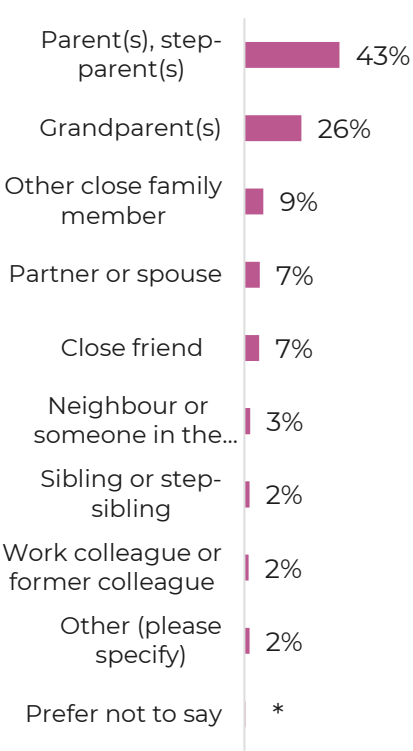
## Gender



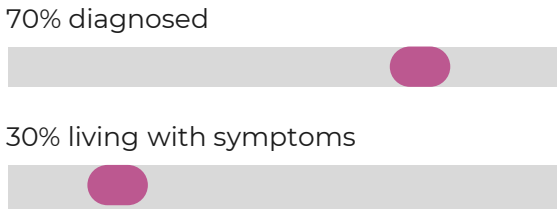
## Region



## Relationship



## Living with dementia



## Stage of dementia

