

Supporting Dementia Carers

This booklet is designed for professionals and for family and friends supporting someone who cares for a person with dementia.





Caring for someone living with dementia can be one of the most meaningful things a person does, but it can also be incredibly demanding.

It takes patience, adaptability, and compassion every single day. Not just for the person with a diagnosis, but for the carer too.

Do you know someone who cares for a person living with dementia?

At ADSS, we worked closely with carers through a series of co-creation sessions to better understand their experiences, the challenges they face, how their lives are impacted, and what truly helps.

This booklet brings those voices together.

Whether you are a carer, friend, family member, or professional, it aims to help you better understand what caring for someone with dementia really feels like, and how you can offer meaningful support.



Health & Wellbeing of Carers

When you're caring for someone else, it's easy to forget about yourself.

Many carers put their own health and wellbeing last, often without even realising it.

I feel constantly worried and stressed

How this affects carers:

Ongoing stress can take a serious toll. It may worsen existing health conditions or lead to new ones.

It can affect mood, lower resilience, and leave carers feeling anxious, low, or overwhelmed.

Sleep is often impacted too and when sleep suffers, everything feels harder.

What can help:

- Recognise that carers may have their own health needs
- Give them time and space to talk openly
- Offer reassurance and emotional support
- Help them explore services or support available to them.



I don't think about my own needs

How this affects carers:

Even when carers know they need support, they may feel too afraid or unsure to ask.

This can lead to isolation, increased stress, and avoiding professional help altogether.

What can help:

- Ask open, gentle questions
- Create opportunities for honest conversation
- Reassure them that their needs matter too.

As a male carer, I find it hard to talk

How this affects carers:

Some male carers may feel less able to open up, which can lead to loneliness, stress, and burnout.

They may also feel uncomfortable attending support groups that are often female-dominated.

What can help:

- Don't assume they are "coping fine"
- Encourage open conversations without pressure
- Reassure them that asking for help is a strength, not a weakness
- Support early access to help to prevent crisis.





I feel like I'm suffering in silence

How this affects carers:

Carers may feel they've lost the person they used to confide in.

They may avoid sharing their feelings to protect their loved one, leaving them with no outlet. This can lead to deep isolation.

What can help:

- Notice changes in their behaviour or mood
- Check in regularly - even a simple message can help
- Be someone who listens without judgement
- Encourage peer support or befriending services.

What if I become unwell?

How this affects carers:

For carers who are the main or only support. The thought of becoming ill or injured can be frightening. It can create anxiety about what would happen to their loved one if they were suddenly unable to care.

What can help:

- Encourage having an emergency or advance care plan in place
- Make sure trusted people know what support would be needed
- Have open conversations with family and professionals early
- Reassure carers that forward planning is a positive, protective step.

My mental health is suffering

How this affects carers:

Caring can feel overwhelming. Adjusting to new responsibilities, changes in a loved one's personality, and navigating health and social care systems can take a toll.

Carers may feel exhausted, low, or unable to cope, which can affect relationships, daily functioning, and the care they provide.

What can help:

- Encourage connection with local support groups
- Promote peer support - speaking to others who understand can be powerful
- Give carers time to talk and be heard
- Offer guidance and signpost to appropriate services.



I find it hard to accept help

How this affects carers:

For those used to being independent, accepting help can bring mixed emotions.

Some feel relief, others may feel guilt, disappointment, or a sense of failure.

This can impact confidence, self-worth, and willingness to seek further support.

What can help:

- Normalise asking for help - it's not a failure
- Share experiences if you've been in a similar position
- Offer practical support (e.g., attending appointments, helping with calls or forms)
- Reassure them they are doing the right thing.



Our relationship has changed

How this affects carers:

Carers may feel like they are losing the relationship they once had.

They may also drift away from friends or social networks. This can lead to feelings of loneliness, loss of identity, and disconnection.

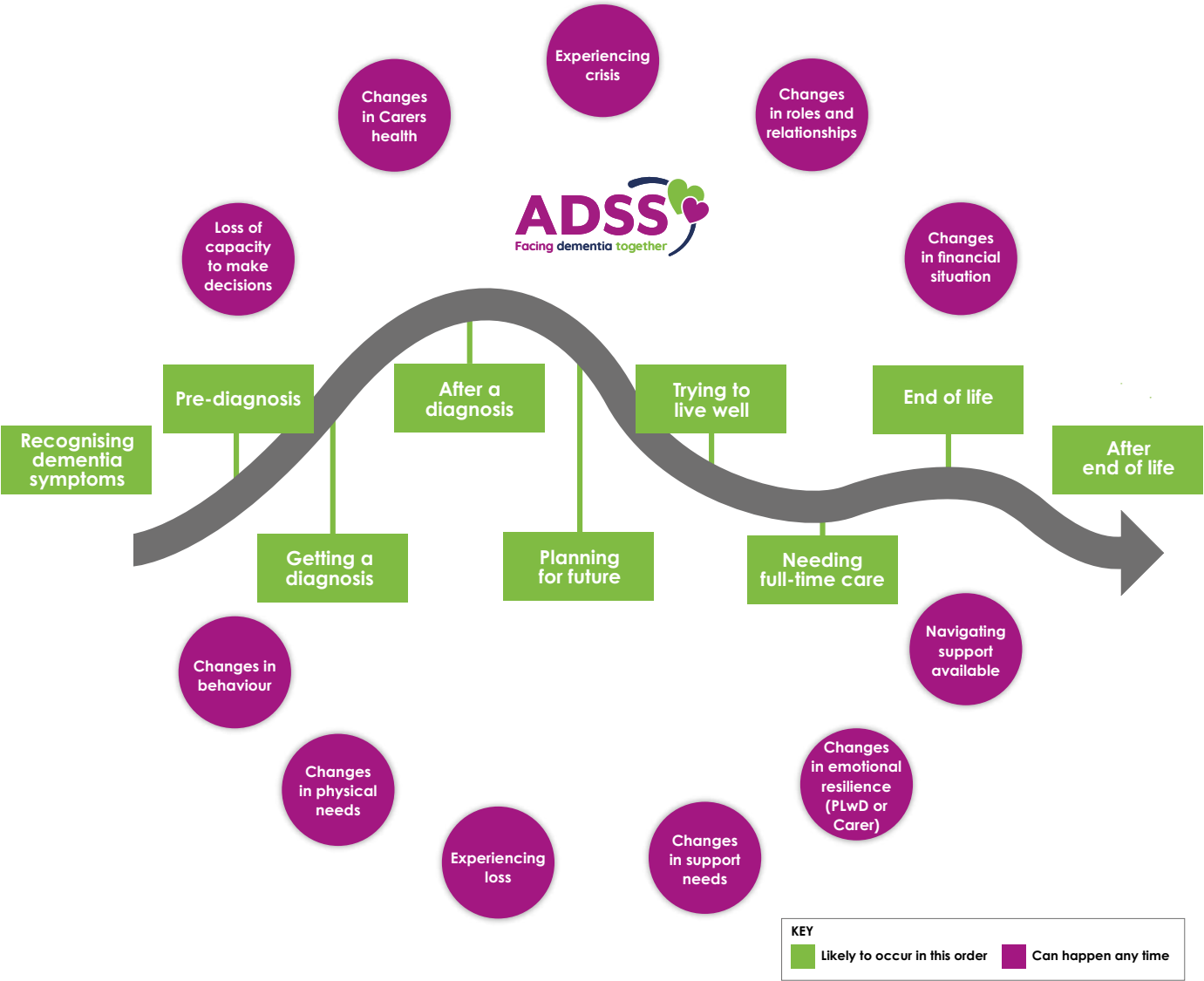
What can help:

- Maintain your relationship with them, not just focusing on their role as a carer
- Be patient if they need to talk or repeat their experiences
- Continue to include them socially where possible
- Help them feel seen as a person, not just a carer.



Carers Journey

This map illustrates the journey carers may go through when supporting a person living with dementia and was co-created with carers who have lived experience.





I feel a sense of loss, even though they're still here

How this affects carers (Anticipatory grief):

Carers may grieve the future they had planned.

Changes in their loved one, finances, and daily life can bring feelings of sadness, frustration, and even resentment.

These feelings are natural but can also be confusing and difficult to process.

What can help:

- Help carers understand that these feelings are valid
- Encourage open conversations about grief and change
- Support them in adapting plans rather than giving them up completely
- Remind them that meaningful moments are still possible.



Impact on Finances

Caring can also bring unexpected financial pressures, which can feel overwhelming alongside everything else.

I don't know what support we're entitled to

How this affects carers:

Understanding benefits can feel confusing and daunting.

Many carers are unaware of what they or the person they care for may be entitled to.

What can help:

- Provide clear information about available benefits (e.g., Carer's Allowance)
- Signpost to organisations that can offer guidance
- Reassure carers that financial support is there to help them.





The forms are overwhelming

How this affects carers:

Long, complex forms can feel exhausting and emotionally difficult to complete.

They often require carers to describe challenging situations in detail, making everything feel more real.

What can help:

- Offer to go through forms together
- Help them understand how to answer questions
- Refer to local organisations that support with form filling
- Break tasks into smaller, manageable steps.

I've had to take over the finances

How this affects carers:

If their loved one previously managed finances, this can feel like a huge responsibility. Carers may feel unsure, anxious, or worried about making mistakes.

What can help:

- Encourage early conversations about finances
- Promote awareness of bills, contracts, and important dates
- Highlight the importance of setting up a Lasting Power of Attorney
- Support carers in keeping simple records and reminders.

I'm worried about doing the wrong thing

How this affects carers:

Managing someone else's finances especially under a Lasting Power of Attorney can feel like a heavy responsibility.

Carers may fear making mistakes or not acting correctly.

What can help:

- Explain clearly when and how a Lasting Power of Attorney can be used
- Reassure carers that acting in the person's best interests is key
- Encourage seeking advice if they are unsure

It's hard to ask professionals for help

How this affects carers:

Carers may feel uncomfortable asking for support, even when it's required such as requesting medical evidence for benefit claims.

Delays and costs can add further stress.

What can help:

- Encourage professionals to be understanding and responsive
- Acknowledge the pressures carers face
- Offer clear guidance on processes and expectations
- Reduce delays where possible

This is even harder with young onset dementia

How this affects carers:

When dementia affects someone younger, the financial impact can be significant.

Loss of income, reduced working hours, and increased care responsibilities can place strain on the whole family.

Carers may also lose the social connection and identity that work provided.

What can help:

- Provide tailored advice on benefits and financial support
- Support carers in balancing work and caring responsibilities where possible
- Signpost to specialist young onset dementia services
- Acknowledge the unique challenges and emotional impact



The cost of care worries me

How this affects carers:

Paying for additional care, whether at home or through respite services, can create financial strain.

Carers may feel guilty about the cost but also recognise the need for support.

What can help:

- Explore all available financial support options
- Ensure benefits are being fully claimed
- Consider support from social services where appropriate
- Emphasise the importance of respite for long-term wellbeing
- Reassure carers that taking a break helps sustain their caring role

The hidden impact on carers

Carers often come second to everything else

They focus so much on the person they care for that their own health, physical and mental, gets pushed aside. Over time, stress, poor sleep, and anxiety can build up and affect their ability to cope.

Isolation is a major issue

Many carers feel like they're "doing it alone," especially if their relationship with their loved one has changed. That sense of losing someone while still caring for them (anticipatory grief) can be very hard to talk about.

Asking for help isn't easy

Even when support exists, carers may feel guilty, embarrassed, or like they're failing if they reach out. This is especially true for some male carers, who may feel less comfortable opening up.

Practical pressures add up

Finances, paperwork, benefits, and legal responsibilities like Lasting Power of Attorney can become overwhelming especially if these were never their responsibility before.



How you can help

From what carers consistently say, small and consistent actions from others can have a big impact:

- **Check in regularly – not just “How is the person you are caring for? but “How are you?”**
- **Listening without trying to fix everything**
- **Offer specific help (e.g., “I can sit with the person you are caring for, for an hour” rather than “Let me know how I can help”)**
- **Encourage them to take breaks and respite without guilt**
- **Help navigate systems, go one step further than signposting by making the call on their behalf.**

Final thought

Caring for someone living with dementia is not something anyone should have to do alone.

Small acts of understanding, patience, and support can make a meaningful difference.

Sometimes, simply being there to listen is enough.

Where to get advice



Alzheimer's and Dementia Support Services

www.adss.org.uk

info@adss.org.uk

0800 035 2221



Kent County Council Kent and Medway Carers

www.kent.gov.uk



Dementia Carers Count

www.dementiacarers.org.uk

info@dementiacarers.org.uk

0800 652 1102



Thank you to the members of Harbour of Hope

- a working group of people living with dementia plus their carers - for sharing their experiences, knowledge, and insights that helped shape the co-creation of this booklet.

Plus check out our website
www.adss.org.uk for regular blogs
relating to dementia and our work



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