



COMING HOME GUIDE

Caring for someone with dementia: a family guide

For England, Wales, Scotland and Northern Ireland

Version 1.0.1 • October 2026. Next review: October 2027

About this guide

This guide is correct at October 2026, version 1.0. We've written it in good faith as general guidance to help carers and families. It isn't legal, financial or medical advice. Rules and rates change, so before you act, please make sure you have the latest version of this guide and look at the official sources: GOV.UK, Social Security Scotland, nidirect and your local council. To the extent the law allows, we can't accept liability for any errors or omissions, or for decisions made on the strength of this guide. In a medical emergency call 999. For urgent advice, contact NHS 111.

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How to use this guide

Version 1.0.1. October 2026. Next review: October 2027. Information read on 3 October 2026. We review this guide every year, and straight away if a service or rule it describes changes.

Who this guide is for: you, if you look after someone with dementia. That might be your mum or dad, your partner, a grandparent or a close friend. You might live with them, live nearby, or help from far away. It covers England, Wales, Scotland and Northern Ireland.

How to use it: you don't need to read it all at once. Section 1 is about you. Sections 2 to 6 cover everyday life: what families often notice, talking together, care at home, and what to do if things change suddenly. Section 7 is about planning ahead, and sections 8 and 9 cover money, rights and services. Section 10 is about looking after yourself. Every fact has a source and a date, and the full list is in "Sources" at the back.

Guidance, not advice. This guide describes what many families experience, and where to get help. It can't tell you what's happening for the person you care for, what will happen next, or what care or medicines they need. Only their GP and the health professionals who know them can do that.

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

For dementia support, call the Alzheimer's Society Dementia Support Line on 0333 150 3456 (see "Who to call").

01

You're not on your own



If you're reading this, you're probably carrying a lot. You might be worried, tired or sad. You might feel close to the person one day and frustrated the next. You might feel guilty for wanting time to yourself.

All of that is common. Alzheimer's Society says that having negative feelings about the person or the situation doesn't make you a bad person, and that guilt, anger and frustration are common emotions for carers ([Alzheimer's Society, Your emotional wellbeing as a carer, 17 Mar 2025](#)).

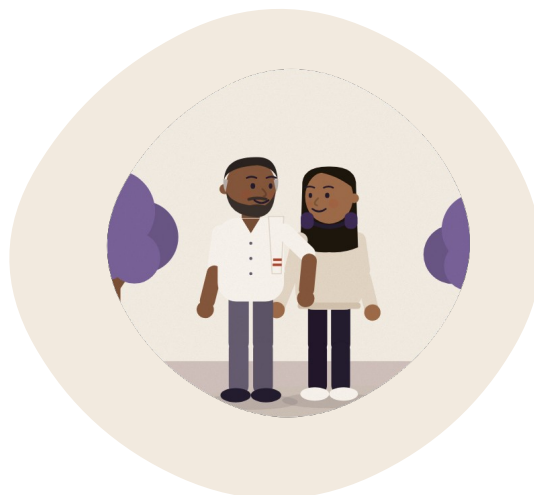
You may not think of yourself as a carer, especially if the person is your partner, parent or close friend. But you both need support, and your needs matter as much as theirs ([NHS, Looking after someone with dementia, reviewed 8 Jan 2025](#)).

What this guide does: it brings together practical ideas from the NHS and dementia charities, the help you can ask for, and the money and rights that might apply.

What it doesn't do: it doesn't say what type of dementia someone has, how it will change, or what care or medicines are right for them. Everyone experiences dementia differently ([NHS, Staying independent with dementia, reviewed 9 Jan 2025](#)).

02

What dementia is, in plain words



The NHS describes dementia as a group of related symptoms linked to an ongoing decline in how the brain works. It isn't only about memory. It can also affect the way someone speaks, thinks, feels and behaves. It isn't a natural part of ageing. There are many different causes and types ([NHS, What is dementia, reviewed 20 Jul 2023](#)).

More than 944,000 people in the UK have dementia, so many families are going through something like this ([NHS, What is dementia](#)).

If you're worried about someone's memory: the NHS says to talk to a GP if memory problems are affecting daily life or worrying them, or you ([NHS, What is dementia](#)). The GP can refer them to a memory assessment service.

Once it's confirmed, the person should have a care plan. It sets out how they can keep doing the things that matter to them, which services can help, and who will coordinate their support. It should be looked at again at least once a year ([NHS, Help and support for people with dementia, reviewed 19 Sep 2024](#)). Ask the GP or memory service about it, and ask to be involved, with the person's agreement.

In Scotland, people are offered post-diagnostic support (section 11). In Northern Ireland, dementia navigators can help (section 11).

03

Day to day: what families often notice



This section describes changes that many families talk about. Not everyone has them, and they're not a checklist. If something worries you, talk to the GP.

Repeating questions

The person may ask the same question again and again, because they can't remember asking. The NHS reminds carers that they're not being deliberately difficult. It suggests staying calm and kind, helping them find the answer themselves (for example, a clock that's easy to read if they keep asking the time), and offering reassurance if there's a worry behind the question ([NHS, Coping with dementia behaviour changes, reviewed 2 Jan 2024](#)).

Restlessness and walking about

Some people pace, fidget or want to go out. The NHS suggests making sure they have plenty to eat and drink, a daily routine with a daily walk, going with them to the shops, and giving them something to keep their hands busy, like a box of items that mean something to them (NHS, Coping with dementia behaviour changes). Section 5 covers what to do if someone gets lost.

Following you around

Some people follow their partner or carer everywhere, because they feel insecure and need to know they're not alone. Having them with you while you do chores, and telling them they're safe, can help (NHS, Coping with dementia behaviour changes).

Changes in behaviour

The NHS says changes in behaviour may be how someone is telling you how they feel, and they can come from frustration or from a home that now feels unfamiliar. It can help to work out what sets things off. Does it happen at a certain time of day? Is the home too noisy or cluttered? Keeping a diary for 1 to 2 weeks can help you see a pattern (NHS, Coping with dementia behaviour changes). A quiet, calm space, music and activities they enjoy can all help.

Sleep

Dementia can upset someone's body clock. They may get up in the night, not knowing it's night-time. The NHS suggests plenty of daylight and activity during the day, a clock by the bed that shows whether it's night or day, less caffeine and alcohol in the evening, and a night light or blackout blinds. If sleep problems carry on, talk to the GP or community nurse (NHS, Looking after someone with dementia).

Eating and drinking

People with dementia may not drink enough because they don't realise they're thirsty. They may not recognise foods, or may forget what they like. The NHS suggests involving them in preparing meals if they can, allowing enough time, smaller portions of food they like, finger foods if cutlery is hard, and drinks in a clear glass or a coloured cup that's easy to hold. Regular dental appointments help, because a sore mouth or loose dentures can put people off eating (NHS, Looking after someone with dementia).

Using the toilet

Problems with the toilet can be upsetting for both of you. The NHS says it's important to be understanding, and to remember it isn't the person's fault. A sign on the toilet door with a picture and a word, leaving the door open with a light on at night, and making the toilet part of a daily routine can help. If problems carry on, ask the GP about a continence adviser (NHS, Looking after someone with dementia).

Washing and bathing

Some people become anxious about washing. They may worry about deep bath water, the noise of a shower, or getting undressed in front of someone, even their partner. Washing is private, so ask how they'd like to be helped, reassure them, and use a bath seat or a handheld shower and the soap or shampoo they like (NHS, Looking after someone with dementia). Our Adapting a home guide covers equipment for the bathroom:

www.cominghomecare.app/guides/adapting-a-home?ref=guide-dementia

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.



04

Talking and staying connected



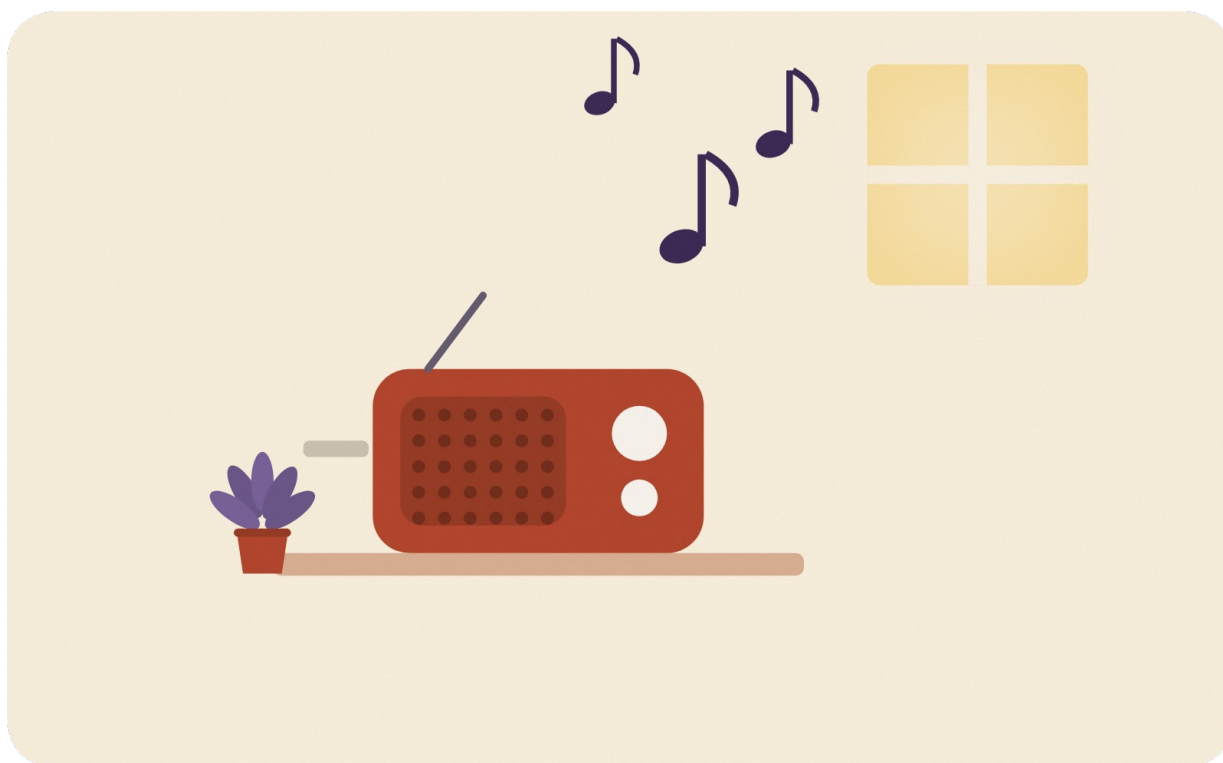
Dementia can change how someone talks and understands. You'll probably find yourself changing how you talk and listen too. That's part of caring, not a sign you're doing it wrong.

Ideas from the NHS (NHS, [Communicating with someone with dementia](#), reviewed 13 Feb 2023):

- Speak clearly and slowly, in short sentences, and make eye contact.
- Give them time to answer. Hurrying can make them feel under pressure.
- Offer simple choices, not complicated ones.
- Let them speak for themselves in conversations about their health and care.
- Show you've heard them, even if their answer doesn't fit the question.
- Try not to patronise them or make fun of what they say.
- Turn off the television or radio while you talk, if they're happy for you to.

Without words: gestures, facial expressions and touch matter more when talking gets harder. Keep your voice calm and friendly. Sit at the same level as them, or lower. Holding their hand can be reassuring, if they're comfortable with it (NHS, [Communicating with someone with dementia](#)).

Doing things together: the NHS says it's important to help the person keep their skills and an active social life, which can also help how they feel about themselves. Let them help with everyday tasks, such as shopping, laying the table, gardening or walking the dog (NHS, Looking after someone with dementia). Music, dancing and activities that give them pleasure and confidence can help too (NHS, Coping with dementia behaviour changes).



05

Practical care at home



A calmer home

Small changes can help someone find their way around and feel more settled. You don't need to change everything at once. The NHS suggests ([NHS, How to make your home dementia friendly, reviewed 23 Jan 2025](#)):

- **Light:** bright, even light, especially on the stairs and in the toilet. Open curtains in the day, and make the bedroom dark at night.
- **Less noise:** turn the television or radio off when nobody's watching or listening.
- **Floors:** take away rugs and mats, and avoid shiny floors, which can look wet.
- **Contrast:** a toilet seat, doors and banisters in colours that stand out from the walls and floors, and plates that contrast with the table.
- **Signs and labels:** a picture and a word on cupboards and doors, or a photo of what's inside.
- **Mirrors:** cover or move them if the person is upset by their reflection.
- **Eyes and ears:** keep up regular eye tests and hearing appointments.

Everyday aids and technology

Clocks that show the day and date, reminder devices for medicines, and phones with big buttons can help. Telecare means sensors and devices that send a message to a family member or carer by phone if help is needed. After a needs assessment, the council may provide telecare, and you may have to pay towards it ([NHS, Staying independent with dementia, reviewed 9 Jan 2025](#)).

Medicines

If remembering medicines is hard, ask the pharmacist or GP what could help, such as a reminder device or a different way of packing the medicines. Don't change how someone takes a medicine without asking them first.

If they get lost: the Herbert Protocol

The Herbert Protocol is a form you fill in now, with details the police would need if the person went missing: a recent photo, a description, their medicines, their daily routine and places that matter to them. Keep it somewhere safe and up to date, and give copies to family or neighbours if you like. You only give it to the police if the person goes missing ([police.uk, Herbert Protocol form, read 3 Oct 2026](#); [Police Service of Northern Ireland, Herbert Protocol, read 3 Oct 2026](#)). In Scotland, ask your local police office about it.

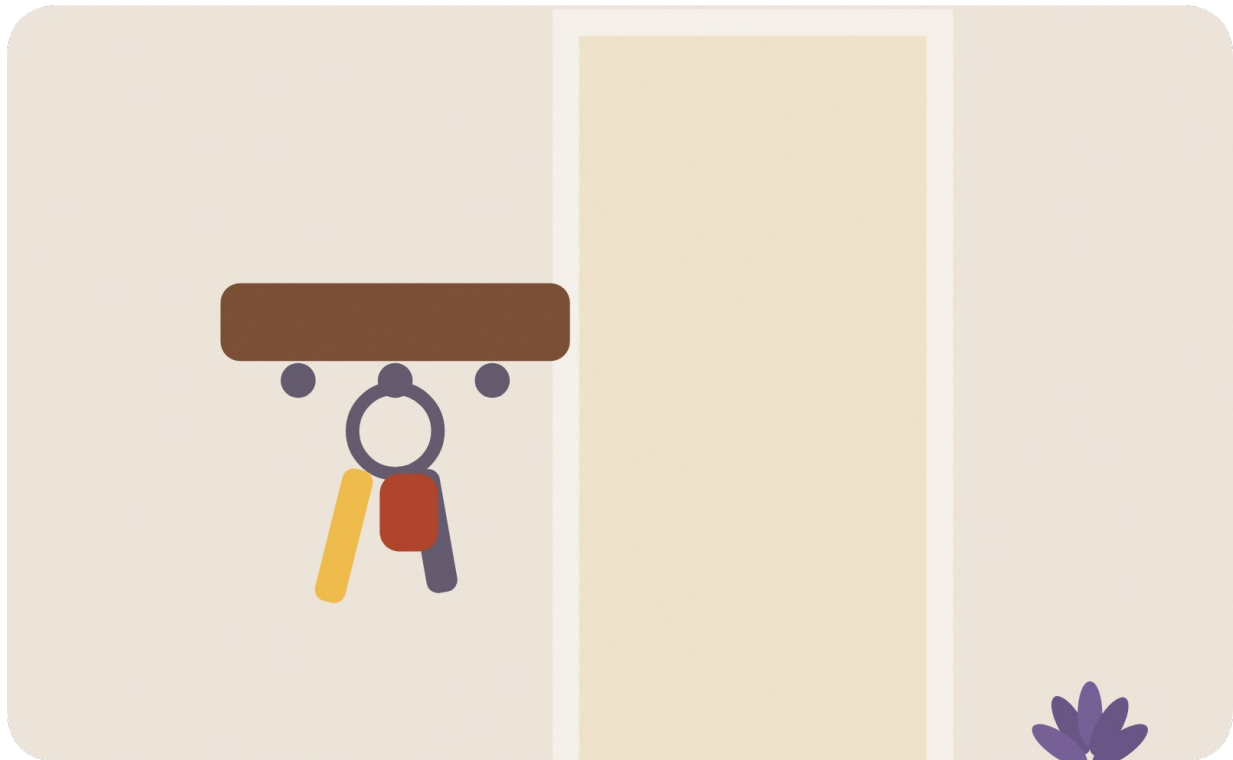
If someone is missing, call 999.

Driving

In Great Britain, someone with dementia must tell DVLA. They can report it online or on form CG1. If they drive a bus, coach or lorry, they must stop driving straight away ([GOV.UK, Dementia and driving, read 3 Oct 2026](#)). Not telling DVLA can lead to a fine of up to £1,000. In Northern Ireland, they must tell the Driver and Vehicle Agency (DVA) right away, by post, phone or online. Not telling DVA is also an offence, with a fine of up to £1,000 ([nidirect, How to tell DVA about your medical condition, read 3 Oct 2026](#)).

Adapting the home

For grab rails, stair rails, bathroom changes and help from an occupational therapist, see our Adapting a home guide (link in section 3) and our Disabled Facilities Grants guide: www.cominghomecare.app/guides/disabled-facilities-grants?ref=guide-dementia



06

If things change suddenly



Some changes happen slowly. But if the person becomes much more confused, drowsy, agitated or unwell over hours or a few days, don't wait. The NHS says a sudden change in behaviour may be caused by a health problem, such as pain or discomfort, and to ask a GP to find out (NHS, Coping with dementia behaviour changes).

- **The same day:** contact their GP, or NHS 111 if the surgery is closed.
- **In an emergency:** call 999.

It helps to tell them what's different from usual, and when it started. Your notes from section 3 can help.

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

07

Planning ahead together



It can be hard to think about the future when you're coping with today. But planning ahead while the person can still take part means their wishes are known, and it can make later decisions easier for you. The NHS calls this advance care planning ([NHS, Dementia and end of life planning, reviewed 8 Jan 2025](#)).

Power of attorney. Many people assume a husband, wife or civil partner can automatically deal with their bank account or make decisions about their care. That isn't true. Without a lasting power of attorney, they can't act for them. The person needs to have mental capacity to make one ([NHS, Managing legal affairs for someone with dementia, reviewed 30 Apr 2025](#)). Scotland and Northern Ireland have their own systems. Our Power of attorney guide explains all four nations:

www.cominghomecare.app/guides/power-of-attorney?ref=guide-dementia

Their wishes. An advance statement is a written note of their preferences, wishes, beliefs and values about future care. For example, where they'd like to be cared for, how they like to do things (a shower instead of a bath), and the music or programmes they enjoy. It isn't legally binding, but their attorney and their healthcare team take it into account ([NHS, Dementia and end of life planning](#)).

Refusing specific care in future. An advance decision lets someone refuse specific kinds of medical care in future, in case they can't decide for themselves then. It's legally binding if it meets certain rules. The NHS suggests talking it through with their doctor first ([NHS, Dementia and end of life planning](#)).

A will. If they haven't made one, the NHS suggests doing it while they still can (NHS, Dementia and end of life planning).

Their care plan can include their wishes too. It should be looked at again at least once a year (NHS, Dementia and end of life planning).

Take it gently. You don't have to do it all in one conversation.

08

Money and rights



You may be able to get help with money. The figures and rules are in our other guides, so they stay up to date in one place.

For the person you care for:

- **Attendance Allowance**, if they're over State Pension age:
www.cominghomecare.app/guides/attendance-allowance?ref=guide-dementia
- **Personal Independence Payment**, if they're under State Pension age:
www.cominghomecare.app/guides/pip?ref=guide-dementia
- In Scotland, these are Pension Age Disability Payment and Adult Disability Payment. Both guides cover Scotland.

For you:

- **Carer's Allowance**, or Carer Support Payment in Scotland, if you care for 35 hours a week or more. Talk it through first, as it can affect the other person's benefits:
www.cominghomecare.app/guides/carers-allowance?ref=guide-dementia
- **Other help**, such as Council Tax, energy and travel:
www.cominghomecare.app/guides/money-and-help?ref=guide-dementia

Council Tax. There's a Council Tax discount for people with dementia or another mental impairment. GOV.UK calls this being "severely mentally impaired" ([GOV.UK, Council Tax: discounts for disabled people, read 3 Oct 2026](#)). The person needs a certificate from a medical professional, such as their GP, and to get certain benefits (ask the council which). If they live alone, the discount can

be 100%. If you live with them and there are no other adults, or the other adults are disregarded, you can get 25% off. Apply to the council that sends the bill. In Northern Ireland, homes pay rates instead, so ask Land and Property Services.

Blue Badge. As well as people who find walking very hard, people may be able to get a Blue Badge if they find it very hard to plan or follow a journey, find it difficult or impossible to control their actions and aren't aware of the effect on others, or become extremely anxious or fearful in public or open spaces. The council decides, and it may take 12 weeks or longer ([GOV.UK, Can I get a Blue Badge?, read 3 Oct 2026](#)). Northern Ireland has a different way to apply.

NHS continuing healthcare. If someone has complex health and care needs, the NHS may pay for all their care, at home or in a care home. Having dementia doesn't automatically mean someone qualifies. A team of health professionals assesses them ([NHS, Dementia, social services and the NHS, reviewed 13 Aug 2025](#)). Ask the GP or social worker about it.

Hospital stays. If they go into hospital, our Hospital discharge guide explains what should happen before they come home:

www.cominghomecare.app/guides/hospital-discharge?ref=guide-dementia

See what else you might be able to get. Our Benefits finder asks 8 quick questions: www.cominghomecare.app/benefits-check?ref=guide-dementia

09

Help from services



You don't have to do this alone, and asking for help isn't giving up. Alzheimer's Society suggests getting support before you think you need it, as some services have waiting lists (Alzheimer's Society, Your emotional wellbeing as a carer).

A needs assessment for them. The council's adult social services can help with personal care and everyday tasks. They might offer carers to help with washing and dressing, meals delivered to the home, laundry, equipment and adaptations, or a day centre. A needs assessment costs nothing and anyone can ask for one. Afterwards, the council does a financial assessment to see whether it pays towards the care ([NHS, Dementia, social services and the NHS, reviewed 13 Aug 2025](#)).

A carer's assessment for you. This looks at what would make your life easier. It might suggest someone to take over so you can have a break, help with housework, training, or local support groups. It costs nothing, anyone over 18 can ask, and you can ask for it at the same time as their needs assessment ([NHS, Carer's assessments, reviewed 1 Jul 2022](#)). Contact adult social services at the council.

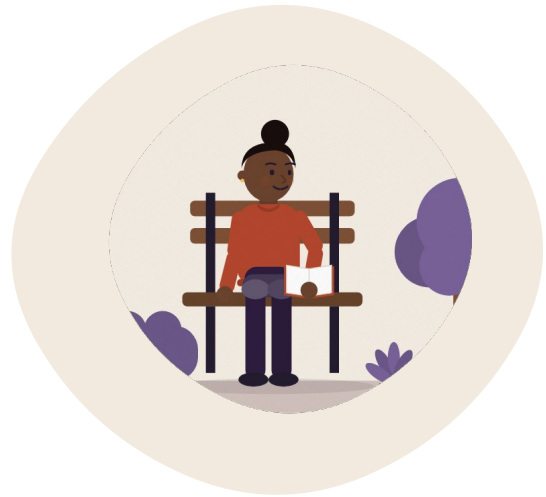
Breaks. Family and friends might give you an hour or two, or take the person to an activity or a memory café. Day centres and respite care, at home or for a short stay in a care home, are other options (NHS, Looking after someone with dementia). Councils may have a sitting service or a befriending service (Alzheimer's Society, Your emotional wellbeing as a carer).

Admiral Nurses. These are specialist dementia nurses who give practical guidance and emotional support. In some areas the NHS provides them with the charity Dementia UK (NHS, Dementia, social services and the NHS). Ask the GP or social worker whether there's one near you, or call the Admiral Nurse Dementia Helpline (see "Who to call").

Support groups. Talking to other carers can help, because they understand. If you can't get to a group, there are online forums run by Carers UK and Alzheimer's Society (NHS, Looking after someone with dementia).

10

Looking after yourself



Carers often put the other person first, every time. Over months and years, that can wear you down. Looking after yourself isn't selfish. It helps you keep going, and it helps the person you care for too.

Your feelings. Alzheimer's Society lists reasons carers often feel guilty: feeling angry or frustrated, thinking they're not doing well enough, comparing themselves with other carers, wanting time alone, and hard decisions such as a move into a care home. It says to be kind to yourself, that nobody is perfect, and not to compare yourself with others, because dementia affects everyone differently (Alzheimer's Society, [Your emotional wellbeing as a carer](#)).

Grief before goodbye. Many families feel grief and loss long before the end of someone's life: around the time it's confirmed, and as things change. You might feel you're losing the relationship, the conversations, the things you did together, or the future you'd planned. Some people also feel relief at times, and that's common too ([Alzheimer's Society, Grief, loss and bereavement when a person has dementia, read 3 Oct 2026](#)).

Signs you might be struggling. Alzheimer's Society suggests talking to your GP if you're feeling hopeless, constantly on edge, often angry or irritable, can't sleep, or are missing appointments (Alzheimer's Society, [Your emotional wellbeing as a carer](#)).

Small things that help:

- Tell your GP you're a carer, so they can take it into account (NHS, Looking after someone with dementia).
- Do something you enjoy every day, even if it's only listening to a song you like (Alzheimer's Society, Your emotional wellbeing as a carer).
- Write a to-do list, and focus on what really needs doing this week.
- Let people know what they could do to help. Even small things, like picking up a prescription, make a difference.
- Talking therapies can help. You can ask your GP, or in England refer yourself to an NHS talking therapies service (NHS, Looking after someone with dementia).

If you're worried about your own health, contact your GP or NHS 111. In an emergency call 999.



11

Across the four nations



England: the NHS dementia pages, your council's adult social services, and Alzheimer's Society.

Wales: NHS 111 Wales has a dementia page with advice for carers ([NHS 111 Wales, Dementia, read 3 Oct 2026](#)). Alzheimer's Society has a Welsh language support line on 03300 947 400 ([Alzheimer's Society, Dementia Support Line, read 3 Oct 2026](#)).

Scotland: once dementia is confirmed, people are offered at least a year of post-diagnostic support from a named link worker. In many areas, Alzheimer Scotland's link workers provide it for the NHS. Ask the GP to refer them ([Alzheimer Scotland, post-diagnostic support page, read 3 Oct 2026](#); [Scottish Government, NHS Scotland performance against LDP standards: dementia, updated 8 Sep 2022](#)). As a carer, you can ask the council for an Adult Carer Support Plan ([mygov.scot, Help if you're a carer, read 3 Oct 2026](#)). NHS inform has dementia information ([NHS inform, Dementia, read 3 Oct 2026](#)).

Northern Ireland: the Health and Social Care Trust does the needs assessment and the carer's assessment ([nidirect, Assessments for carers, read 3 Oct 2026](#)). Dementia navigators are a point of contact for people with dementia, their families and carers. They can talk things through, explain what's available, and help make a plan ([nidirect, Help and support for people with dementia, read 3 Oct 2026](#)). Ask the GP or Trust about them.

12

How Coming Home can help



Coming Home: Family Care is an iPhone app for families looking after someone. It's coming soon. It helps you organise. It isn't medical advice, and it can't tell you what's happening for the person you care for.

The family care diary helps you note changes in sleep, eating or mood, so you have dates and examples ready when you talk to the GP, or fill in a benefit form.

The care circle brings the family, friends and neighbours who help into one place, with shared notes, tasks and a calendar. Use it to share who's doing the next visit, who's chasing the council, and what the GP said.

Everyone in the circle can join at no cost.

Every plan includes the 8 quick questions on what you might be entitled to, and a lasting power of attorney to-do list.

Care Plus (£14.99 a month or £99.99 a year) includes a 20 GB document vault, stored in the UK, for the care plan, the power of attorney and the letters that go with them.

To hear when Coming Home is ready, join the waitlist:

www.cominghomecare.app/?ref=guide-dementia

Built by people who know home care.

13

Who to call



This guide is guidance, not advice. For support and advice:

- **Alzheimer's Society Dementia Support Line:** 0333 150 3456 (Relay UK: 18001 0333 150 3456). Monday to Wednesday 9am to 8pm, Thursday and Friday 9am to 5pm, Saturday and Sunday 10am to 4pm. Welsh language: 03300 947 400 ([Alzheimer's Society, Dementia Support Line, read 3 Oct 2026](#))
- **Dementia UK Admiral Nurse Dementia Helpline:** 0800 888 6678. Monday to Friday 9am to 9pm, Saturday and Sunday 9am to 5pm ([Dementia UK, Admiral Nurse Dementia Helpline, read 3 Oct 2026](#))
- **Alzheimer Scotland 24 hour Freephone Dementia Helpline:** 0808 808 3000 ([Alzheimer Scotland, read 3 Oct 2026](#))
- **Carers UK Helpline:** 0808 808 7777, Monday to Friday 9am to 6pm ([Carers UK, Helpline and other support, read 3 Oct 2026](#))
- **Age UK Advice Line:** 0800 678 1602, 8am to 7pm, every day of the year ([Age UK Advice Line, read 3 Oct 2026](#))
- **Advice NI:** 0800 915 4604 ([Advice NI, Contact, read 3 Oct 2026](#))
- **Your council's adult social services** (the Health and Social Care Trust in Northern Ireland) for a needs assessment and a carer's assessment
- **If someone is missing:** call 999

If you're worried about their health, contact their GP or NHS 111. In an emergency call 999.

14

Sources

All read on 3 October 2026 unless another date is given. Dates in brackets are the page's own published, updated or reviewed date.

NHS

- NHS, What is dementia (reviewed 20 Jul 2023): www.nhs.uk/conditions/dementia/about-dementia/what-is-dementia/
- NHS, Looking after someone with dementia (reviewed 8 Jan 2025): www.nhs.uk/conditions/dementia/living-with-dementia/looking-after-someone/
- NHS, Coping with dementia behaviour changes (reviewed 2 Jan 2024): www.nhs.uk/conditions/dementia/living-with-dementia/behaviour/
- NHS, Communicating with someone with dementia (reviewed 13 Feb 2023): www.nhs.uk/conditions/dementia/living-with-dementia/communication/
- NHS, How to make your home dementia friendly (reviewed 23 Jan 2025): www.nhs.uk/conditions/dementia/living-with-dementia/home-environment/
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Official

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Charities

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- Alzheimer's Society, Your emotional wellbeing as a carer for a person with dementia (17 Mar 2025): www.alzheimers.org.uk/get-support/help-dementia-care/caring-for-person-dementia
- Alzheimer's Society, Grief, loss and bereavement when a person has dementia: www.alzheimers.org.uk/get-support/help-dementia-care/grief-loss-and-bereavement
- Dementia UK, Admiral Nurse Dementia Helpline: www.dementiauk.org/information-and-support/how-we-can-support-you/admiral-nurse-dementia-helpline/
- Alzheimer Scotland, 24 hour Freephone Dementia Helpline: www.alzscot.org/about-us/care/helpline/
- Alzheimer Scotland, post-diagnostic support page: www.alzscot.org/about-us/care/post-diagnostic-support/

- Carers UK, Helpline and other support: www.carersuk.org/help-and-advice/helpline-and-other-support/
- Age UK Advice Line: www.ageuk.org.uk/services/age-uk-advice-line/
- Advice NI, Contact: www.adviceni.net/contact

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Changelog

Version	Date	What changed	Why
1.0	October 2026	First published	Information read on 3 October 2026

1.0.1. October 2026. Corrected the line about who builds Coming Home (section 12). Accuracy. No change to the advice.

The next review is due in October 2027, or straight away if a service or rule changes. The latest version is always at www.cominghomecare.app/guides/dementia



Coming Home

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This edition

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