HEALTH CONDITIONS AND CARE AT HOME

When someone with dementia refuses care: a guide for families

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IN BRIEF

When someone with dementia refuses help, it is usually fear of losing control, or not recognising their own difficulties, rather than stubbornness. If they can make the decision themselves, it is theirs, even if it seems unwise; if they cannot, help can be arranged in their best interests, choosing the option that restricts them least. Starting small, framing help around what matters to them and giving it time works far more often than pressure.



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Why people with dementia refuse help

"No" is rarely about the help itself. Common reasons include:

- **Fear of losing independence,** or of being "put in a home".
- **Not recognising the problem.** Dementia can affect a person's awareness of their own difficulties, so help feels unnecessary or insulting.
- **Embarrassment** about needing help with washing, dressing or the toilet.
- **Not understanding** what is being offered, who the stranger is or why they are there.
- **Wrong time, wrong approach:** too tired, in pain, rushed, cold, or asked in front of others.
- **A bad past experience** with carers, hospitals or being told what to do.
- **Low mood,** which can sap the will to wash, eat or see people.

Working out which reason applies is the key to what will help.

First, ask: can they make this decision?

The Mental Capacity Act 2005 starts from the assumption that every adult can make their own decisions. A dementia diagnosis does not change that. Capacity is about **one decision at one time**: someone may be able to decide what to wear, but not understand the risks of living without help at home.

- **If they can make the decision,** their refusal must be respected, even if it seems unwise. You can still keep offering, keep the door open and try again later.
- **If they cannot,** the decision is made in their best interests by whoever is responsible for it, taking into account their past and present wishes, values and beliefs, consulting family, and choosing the least restrictive option.
- **If there is a registered health and welfare Lasting Power of Attorney,** the attorney makes the decision when the person cannot.

Even when someone lacks capacity, care is never forced as a first step. Our guide to mental capacity and best interests explains assessments and how to be involved.

Approaches that often work

- **Start small and familiar.** Help with the garden, shopping or lunch is easier to accept than "a carer for personal care".

- **Lead with what matters to them.** Staying at home, keeping the dog, getting to church, seeing grandchildren.
- **Talk about practical benefits,** not about what they can no longer do.
- **Frame help as shared.** "It would help me" is often true, and easier to hear.
- **Use someone they trust.** A GP, nurse, faith leader or old friend may be listened to where family are not.
- **Choose the moment.** A good time of day, after a meal, when nobody is rushed.
- **Offer choices, not questions.** "Shall Sarah come on Tuesday or Thursday?" rather than "Do you want a carer?"
- **Give it time.** Let the idea settle and come back to it in a few days.
- **Use a trial.** The Alzheimer's Society suggests asking an agency about a trial period, or building visits up gradually.

Gentle words to try

Introducing the idea:

> "I worry about you when I'm at work. Would you let someone pop in at lunchtime, just so I know you're all right? It would really help me."

Introducing a carer as a helper:

> "This is Anna. She's going to help with a few jobs around the house and keep you company for a bit."

Offering help with washing:

> "The water's nice and warm. Would you like to start with your hands or your face?"

When they say they don't need help:

> "I know you manage really well. This is just so things are a bit easier for both

> of us."

Bringing in the GP's voice:

> "Dr Patel said it would be good to have someone help with your tablets. Shall we give it a try for a month?"

Avoid words that sound clinical or permanent, such as "care package", "personal care" or "from now on".

Introducing a carer step by step



1. Tell the care provider what the person enjoys, what upsets them, and what to call them.
2. Arrange the first visit when you can be there, framed as a visitor or helper.
3. Keep early visits short and social: a cup of tea, a walk, a shared job.
4. Let personal care come later, once trust has grown.
5. Keep the same carer wherever possible.
6. Step back gradually, so the person gets used to the carer without you.

When they refuse washing or personal care

The Alzheimer's Society suggests trying to find out why: they may have forgotten the steps, think they have already washed, feel cold or exposed, or be frightened of the bath. Practical ideas:

- Change the time of day, or try a wash at the basin or a bed bath instead of a bath or shower.
- Warm the room and towels, and cover the parts of the body not being washed.
- Offer simple choices, such as which towel or which clothes.
- Ask whether they would prefer a male or female carer.
- If they resist, stop and try again a little later.

Respect their choices about how often they wash, while making sure hygiene is enough to keep them well: the Alzheimer's Society says the face, bottom and genitals should be washed daily to prevent infection.

When they refuse medicines

- Never force tablets. Note what was refused and when.
- Ask why: difficulty swallowing, a bad taste, side effects or not understanding what the tablet is for.
- Ask the GP or pharmacist about liquid versions, patches, different timings or stopping medicines that are no longer needed.
- Tell the GP promptly if an important medicine is being missed.

Never hide medicines in food or drink on your own: the questions below explain the formal process. See also medication management at home.

When refusal puts them at risk

Sometimes refusal leads to real danger: not eating, unsafe heating, falls, scams or serious self-neglect. The Care and Support Statutory Guidance recognises self-neglect, which covers neglecting personal hygiene, health or surroundings, as a possible safeguarding issue, and the council will consider whether the person can protect themselves.

If you believe the person is at risk, contact the council's adult social care team or their safeguarding team, and speak to the GP. You can say:

> "I am concerned about [name, address, date of birth], who has dementia and lives alone. They are refusing all help, and [describe the risks: weight loss, no heating, falls, unpaid bills]. I don't think they understand the risks. Please could

> you arrange an assessment, considering whether they have capacity to refuse and whether there is a risk of self-neglect?"

In an emergency, call 999.

Mistakes to avoid

- Arguing about whether they need help, or listing their failures.
- Springing a carer on them without warning.
- Calling help "temporary" if it is not, or making promises you cannot keep.
- Asking yes-or-no questions that invite a no.
- Giving up after the first refusal.
- Carrying on alone until you are exhausted.

Where to get support

- **Alzheimer's Society Dementia Support Line:** 0333 150 3456. Monday to Wednesday 9am to 8pm, Thursday and Friday 9am to 5pm, weekends 10am to 4pm.
- **Dementia UK Admiral Nurse Dementia Helpline:** 0800 888 6678 (free). Monday to Friday 9am to 9pm, weekends 9am to 5pm.
- **Age UK Advice Line:** 0800 678 1602 (free). 8am to 7pm, every day of the year.
- **Carers UK Helpline:** 0808 808 7777. Monday to Friday, 9am to 6pm.

What to do next

1. Write down what the person is refusing, when, and what you think the reason is.
2. Ask the GP to check for pain, infection, low mood and medicine side effects.
3. Check whether there is a Lasting Power of Attorney, and make one if the person still can.
4. Ask the council for a care needs assessment, and a carer's assessment for yourself.
5. Start with one small, appealing piece of help and build from there.

How we can help

Day and Nightcare has supported people at home since 2008. We provide home care visits from one hour, waking nights and sleep-ins across Oxfordshire, and 24-hour care with carers working in shifts anywhere in England, and fully managed live-in dementia care anywhere in England from £1,550 a week. Our free assessment is a chance to talk about the person, what matters to them and how help could be introduced gently. Call us on 01865 715780.

Common questions

Can we make a parent with dementia accept care?

Not simply because the family thinks it is best. If the person has the mental capacity to decide about their care, they can refuse, even if others think it unwise. If they lack capacity for that decision, care can be arranged in their best interests, involving them as much as possible and choosing the least restrictive option. Restraint is only lawful when it is needed to prevent harm and is proportionate. Significant restrictions the person objects to may need legal authorisation.

What if they refuse a council care needs assessment?

Under section 11 of the Care Act 2014, the council does not have to assess someone who refuses. But it must still assess if the person lacks capacity to refuse and an assessment would be in their best interests, or if they are experiencing, or at risk of, abuse or neglect, which can include self-neglect. If they refuse now, the duty to assess comes back if they later ask, or if their needs or circumstances change.

Can medicines be hidden in food or drink?

Only after a formal process, never on your own. CQC guidance says hiding medicines (covert administration) is only likely to be appropriate when the person actively refuses, lacks the capacity to understand the consequences, and the medicine is essential. It must be a best interests decision involving the prescriber, a pharmacist's advice, the care team and family, recorded in writing, agreed for each medicine and reviewed regularly. Crushing some tablets can make them dangerous.

Who decides whether someone with dementia lacks capacity?

The person who needs the decision to be made. For a care package that is often a social worker; for medicines, the prescriber; for everyday care, the carer helping at the time. Capacity is assessed for one decision at one time, so someone may be able to choose their meals but not to understand the risks of living without help. If a registered health and welfare Lasting Power of Attorney covers the decision, the attorney decides when the person cannot.

Why will Mum accept help from a carer but not from me?

This is very common and nothing to feel hurt by. Many people find it easier to accept intimate help, such as washing, from a professional than from their own child or partner, because it protects their dignity and the family relationship. A trained carer also arrives fresh, without the history of earlier disagreements. It often frees the family to go back to being a daughter, son or partner rather than a carer.

Sources and further information

- legislation.gov.uk: Mental Capacity Act 2005
- legislation.gov.uk: Care Act 2014, section 11 (refusal of assessment)
- Alzheimer's Society: Support and care when a person won't accept their diagnosis
- Alzheimer's Society: When a person with dementia doesn't want to change their clothes or wash
- CQC: Covert administration of medicines
- GOV.UK: Care and support statutory guidance

Read next

LEGAL MATTERS AND PLANNING AHEAD

Mental capacity and best interests: a guide for families

How the Mental Capacity Act 2005 works in England and Wales: the five principles, how capacity is assessed, best interests decisions, deprivation of liberty after the 2026 Supreme Court ruling, the position on LPS, and how to support someone to decide.

Read the guide →

HEALTH CONDITIONS AND CARE AT HOME

Dementia care at home: a practical guide for families

How to support someone with dementia at home: the stages, communication, routines, eating and drinking, sundowning and nights, wandering and safety, Lasting Power of Attorney, support for carers and how care is funded, including NHS Continuing Healthcare and council tax.

Read the guide →

LEGAL MATTERS AND PLANNING AHEAD

Lasting Power of Attorney: a guide for families

How Lasting Power of Attorney works in England and Wales: the two types, why to make one early, how to make and register it online or on paper, the £92 registration fee, the certificate provider, and what happens without one (deputyship and the Court of Protection).

Read the guide →

All guides in the information centre Check what help you could get

Talk to our care team: 01865 715780

enquiries@dayandnightcare.co.uk · Out of hours: 07775 686272

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CQC overall rating: Good (report published 20 April 2018)

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Information, not advice: please check anything important with the organisation named.