

Care homes and other options: Making the decision



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia

About this booklet

As dementia progresses, a person's needs will change and they will need more care. If you are a carer, friend or family member of someone with dementia, you may have concerns about them or their current care where they live. You might be considering the option of a care home.

It can be very difficult to think about these things. You may be feeling a range of emotions, such as guilt, relief or loss. This is completely normal. Caring for someone with dementia can be difficult – it can take a lot of time, energy and mental strength.

Before making any decision it's important to think about the person and their needs. There are many factors to think about as the person needs more support, and there can be many options. This booklet sets out alternatives for where the person lives and care that's available. You'll find information and suggestions that will help you and the person you care for decide on the best options. This booklet also contains support for your emotional wellbeing.

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1 Can a person with dementia stay at home?

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Staying at home is the preference for some carers and people with dementia. Remaining at home but with extra support can be a good option for some people with dementia. It allows them to stay in a place that feels familiar and safe to them.

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It is important to make sure that the person can remain safe and well and get the support they need at home. If they've not already had a care needs assessment, this is a good place to start. This will show what care they need and what support is available to them. If you are the person's carer, you can also get a carer's assessment. These are provided by the local authority in England and Wales. In Northern Ireland, they are provided by the health and social care trust. They must be provided free of charge, no matter what the person's financial situation.

These assessments can help you decide what sort of care will be most appropriate for the person with dementia.



For more information see factsheet 418, **Assessment for care and support** (for England), W418 (for Wales), or NI418 (for Northern Ireland).



Supporting the person at home

In some cases, the person's needs can be managed at home with additional help. If you are considering this, it can be useful to follow these steps:

- 1.** Talk to the person and make a list together of what more support they need. You should also include anything that you are finding difficult to manage as their carer.
- 2.** Think about possible solutions you can try to help them with. If you're not sure where to start, consider the following options:
 - Check if the local authority or trust offers any services that you can use.
 - There may also be other organisations that can offer support. For example, some private providers offer respite sitting services and day care options.
 - Some charities may offer support groups for carers or people with dementia.
 - Speak to local carers to find out what's available near you, or use our online directory at **alzheimers.org.uk/dementiadirectory**



- 3.** You may have to try a few different solutions before you find an option that works for you and for the person with dementia.
- 4.** If you've still got concerns, you will have to consider carefully whether the benefit the person gets from staying at home outweighs the risk.

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Some common reasons why people with dementia need extra support at home are listed below.

Incontinence – If the person has issues with going to the toilet, check if there is a local continence advisory service. They should be able to give advice on supporting someone to use the toilet, and may suggest helpful products. You could also look into laundry and cleaning services. Check if your local authority can provide this or arrange it through a private service. **For more ideas see factsheet 502, [Contenance and using the toilet](#).**

Falls – If the person with dementia has frequent falls, ask your GP for a referral to an occupational therapist, falls clinic or physiotherapist. They can provide guidance to help the person move around safely. They can also advise on equipment and adaptations, such as handrails or toilet frames. There may also be devices that can support the person and provide reassurance. For example, a community alarm could allow the person to get help quickly if they have a fall. **For more information see factsheet 429, [Using equipment and making adaptations to the home](#) and factsheet 437, [Using technology to help with everyday life](#).**



Aggression – A person with dementia may sometimes behave in an aggressive way. This can be due to pain, discomfort or infection. Arrange a health check with the person's GP to see if any of these may be causing the person's behaviour. Aggression may also be the result of frustration or boredom. You could look into local groups or activities that the person may be able to join to keep them stimulated and engaged. **For more advice see factsheet 509, Aggressive behaviour.**

Walking – Some people with dementia may start repeatedly walking around the home or leave the house. There are many reasons why they might do this. For example, if they are not doing enough exercise during the day, they may have too much energy to stay sitting in one place. You could arrange for the person to take part in an exercise class or join a walking group. **For more information see factsheet 501, Walking and dementia.**

Forgetting to take medicines – If the person with dementia has memory loss, they may forget to take their medicines. Ask the pharmacist if they can arrange the person's medication into a blister pack so they know what they need to take each day. You could also try reminder charts or an electronic pill box that reminds the person to take their medicines. **For more ideas see factsheet 526, Supporting a person with memory loss.**



Issues with eating or drinking – If the person with dementia is having difficulties with eating or drinking, there may be local food delivery services that can help. For example, the local authority may offer a ‘meals on wheels’ service that can deliver healthy meals to the person. It is often easier to encourage a person to eat and drink when they can do this with other people. You could arrange for them to attend a local lunch club, or ask family, friends or a befriending service to sit with the person at mealtimes. [For more ideas see factsheet 511, Eating and drinking.](#)

Safety concerns – You may be concerned that the person with dementia is no longer safe at home. For example, they may leave the gas on without realising. If this is the case, you could contact their gas supplier about fitting a gas safety valve. This can stop the gas from being left on by accident. [For more advice on how a person with dementia can stay safe at home see booklet 1502, Keeping safe at home.](#)



2 Getting homecare

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One way of getting extra support at home is by arranging for other people to help the person with specific tasks. This could be a cleaner, gardener or a professional carer. This can work well if the person needs help around the home with particular aspects, or if they can get support from family members and friends at other times.



Another option for homecare is hiring a personal assistant (PA). This may be especially suitable if the person has young-onset dementia. A PA can give more flexible support than traditional care arranged through social services. For example, they can help people keep up with hobbies and access community services, such as social groups and courses. Skills for Care has a range of guides to help you recruit and manage a PA. See 'Other useful organisations' on page 60. You may be able to get funding for a PA through direct payments from the local authority. Speak to the person's social worker about this.

The person with dementia could also get 'live-in' care. This is where a paid carer moves into the person's home to provide care during the day and at night. Employing professional carers can be expensive. The local authority or trust may contribute to the cost, but it won't usually cover care at all times of day and night. You may be able to arrange carers through a private agency, but this won't be affordable for many people.

Having full-time professional carers at home (such as a live-in carer) can be confusing for some people with dementia. It can also affect what 'home' feels like for the person and anyone who lives with them. It may not be the right option for some people.



3 Other types of care to consider

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If the person with dementia can't be supported at home but doesn't yet need the level of support that care homes provide, there are other housing options to consider.

Respite care and Shared Lives

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Respite care is a form of temporary care for the person with dementia. It aims to give the carer a break from their caring role, and to give both the carer and the person with dementia some time away from each other. It is also known as restorative care, short-break care or replacement care.

Some respite care will be in the person's home – this is sometimes known as a 'sitting service'. It could also involve the person being cared for elsewhere, like in a day centre or on a short holiday. Some care homes also offer short stays for people who want to try respite care. This can give the person with dementia a chance to experience a care home for a temporary period. Some people move into the care home permanently after this.



Another option for respite care is the Shared Lives scheme. This is where a person who has care needs stays in the home of someone who is an approved Shared Lives carer. The carer can then provide support to the person with dementia during their stay. You can search for Shared Lives services near you on the NHS website – see ‘Other useful organisations’ on page 60.

You can arrange respite care yourself, or get support to do this. Support comes from the local authority (in England and Wales) or your health and social care trust (in Northern Ireland).



For more information see factsheets 462, **Replacement care (respite care) in England**, W462, **Respite care in Wales** or NI462, **Respite care in Northern Ireland**.



Sheltered housing and assisted living

You may also want to consider whether a form of sheltered housing or assisted living would be a good option for the person. These are types of housing where a person can live independently but have support on hand should they need it.

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Sheltered housing is housing that can be bought or rented as part of a sheltered housing scheme. It is sometimes known as retirement housing.

These schemes offer different services, but most will include:

- support from a manager or warden – ask how much time they spend on site, as this can vary
- links to local services such as a bus to the shopping centre or hospital
- an alarm system providing emergency assistance at any time of day or night
- communal areas, such as gardens or lounges, where social events may take place.

Sheltered housing schemes do not offer personal care services, such as help with dressing or getting ready for bed. If the person requires this type of additional support, assisted living may be more suitable for their needs.



Assisted living is housing that's been built or adapted to suit people with long-term conditions or disabilities. It is also known as supported living or extra care housing. This housing can be bought or rented privately, or may be arranged by the local authority.

Assisted living arrangements offer more support than sheltered housing. They can include domestic support, like shopping or laundry services. They can also include help with personal care, like washing and dressing. The services offered will be different for each scheme.

These arrangements can be a good first step for someone who needs a little more support with daily tasks. However, as the person's dementia progresses, their needs will increase. In the future, they may need to move somewhere where they can receive more support. It can be disorientating and unsettling for some people with dementia to move homes more than once. Bear this in mind if you're looking at this type of living arrangement.

The Elderly Accommodation Counsel (EAC) has a service called Housing Care. It can provide more advice and information on these types of housing. See 'Other useful organisations' on page 60 for contact details.

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Considering care options for a person with young-onset dementia

Finding appropriate care options for a person with young-onset dementia can be challenging. Many care services that support people with dementia are tailored to the needs of older people, and will not accept people under the age of 65. Care providers that do accept younger people are usually specialised for younger people with mental health or learning difficulties, not for people living with dementia.

Dementia UK's admiral nurses can often give advice on care options near you that may be adapted for someone with young-onset dementia. See 'Other useful organisations' on page 60 for contact details.



For advice on finding a care home for a person with young-onset dementia see booklet 690, **Choosing a care home for a person with dementia**.





People with young-onset dementia and their carers may need to stop working earlier than they planned to. They are also more likely to have children or relatives who depend on them financially. This can impact your choice of care for the person with dementia.

It's worth checking if there are any benefits available for the person or you. Talk to the local authority's welfare rights team or to Citizens Advice to arrange a benefits check for the person.



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4 Is a care home the right option?

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Dementia symptoms get worse over time, so every person with the condition will begin to need more support. Solutions that have been working well at one stage may no longer be enough to keep the person safe. For example, you may be able to put support in place if the person with dementia is leaving the house and getting lost in the daytime. However, if this starts to happen at night, that will be more of a challenge.

Care homes are sometimes seen as a last resort, but they are often the best way for the person to stay safe and well. Many carers reach a point where they feel unable to continue at home, even with additional support. Some wish they had discussed care homes sooner.

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Sometimes, accepting that the person needs more help than you can provide is the best way to support them – even if it means moving to a care home. For more advice on coping with this decision see ‘Dealing with your emotions’ on page 55.

You may find that over time, the risks of the person staying at home, or even in supported or assisted living, outweigh the benefits. This might be the right time to consider a move to a care home.



There are different types of care home. These include:

- **residential care homes** – these can be helpful for people who need support or supervision to complete daily tasks, such as eating, washing, dressing and going to the toilet.
- **nursing care homes** – like residential care homes, nursing homes support residents with their daily care needs. They also provide help with nursing care – for example, if the person has medical needs or issues with continence.

To find out whether someone needs nursing care, an NHS continuing healthcare (CHC) checklist should be used. Ask your local authority, trust, or a medical professional to arrange this. This should show whether the person is eligible for CHC or funded nursing care. If they are, they should live in a nursing care home, rather than a residential care home.

Funded Nursing Care and CHC are different types of funding, but the same checklist is used to see if someone is eligible.



For more information see booklet 813, **When does the NHS pay for care?**



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I had to make the same decision myself [...] it is heartbreaking but keep thinking it through, talk it over with family – you will come to the right decision because you have been and are continuing to do your best.

Family member of a person with dementia

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The benefits of a care home

There are many benefits to care homes for people living with dementia. Some of these are listed here.

- **Care at all times of the day**

A care home will have trained carers who can provide continuous support day and night. This is important as the person's dementia progresses and their needs become more complex.

- **Support with a variety of tasks**

A care home will also have a team of people who provide support in other ways. This could include cooks, cleaners and activity coordinators. It can be very difficult for family and friends to perform all of these roles themselves if they are caring for the person at home.

- **Social benefits**

Residents can meet one another and join in group activities. This can help a person with dementia to maintain social skills and self-confidence.

- **Meals**

Care homes will provide regular, nutritious meals according to the residents' dietary needs. Carers can be assured that the person is getting the nutrients they need and that they won't forget mealtimes.



● Staying hydrated

The staff will ensure the person stays hydrated. This can prevent urinary tract infections (UTIs), which can make confusion worse.

● Medicines management

Care home staff will ensure the person takes their medication at the right time and at the correct dose.

● Care tailored to their needs

Although there will be a number of residents, everyone who lives in a care home should receive person-centred care and have their own care plan. This means that each person should be given support that is tailored to their needs, interests and personality. For example, if they prefer to go to bed at a later time, they should be supported to do this where possible.

● Activities

The person can continue to do things that are enjoyable and meaningful to them. Care home staff can adapt activities for the person's skill level. They can also introduce them to new types of activities. This can help with self-esteem and ensure the person with dementia stays engaged and stimulated.

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- **Affordability**

If the person needs constant support or supervision, homecare costs can be very high. In some instances, care homes are a more affordable way for people with dementia to access the level of care they need as the condition progresses.

- **No maintenance or adaptability responsibilities**

The person can use and enjoy the living environment, communal areas and any outside areas of the home without having to maintain them. These spaces are likely to have been designed with people with dementia in mind. For instance, there may be signs, helpful lighting and grab rails that help the person move around safely.

- **Visits**

The person with dementia can still see family and friends during visits to the care home. They may also be able to leave the home for trips or weekends away. This allows family and friends to spend quality time with the person, without focusing on their day-to-day care.



Considering costs when looking at care homes

The cost of a care home varies. It depends on:

- the type of home and support provided
- who is paying the fees
- where the care home is.

It's worth looking into care home fees as early as you can. It may help to ask the following questions:

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- **What level of support does the person with dementia need?** Asking the local authority or trust for an assessment will help identify what help is needed and where their needs can be met.
- **Who will fund the person's care?** The person may pay for their own care – this is known as being a 'self-funder'. Or they may get financial assistance from the local authority, trust or the NHS. If you're not sure if the person is eligible for this support, ask the local authority or trust to arrange for the person to have a financial assessment. This will look at the person's savings and their income. It will show whether:
 - the person has to pay for all their care fees, or
 - whether the local authority or trust will contribute to the cost.



The local authority should also arrange for an NHS continuing healthcare checklist to be completed if they feel the person may qualify for funding through the NHS.

● **How much do different care homes cost?**

The website payingforcare.org has an online calculator to help work out the average cost of a care home in your area. See 'Other useful organisations' on page 60 for details. If you think the person may be eligible to receive financial help to fund their care, talk to your local authority or trust. This should give you some idea of the budget that may be available. You can also ask them for information on local market rates.

Your choice of care home may be limited by the cost, especially if the person's care is being funded by the local authority or trust. This is because there is usually a limit to how much they can fund. This may affect your decision about whether a care home is the right option for the person with dementia.

It is a good idea to start looking at care homes earlier than needed to get a sense of what is available, and the costs involved.



For more information on paying for care see factsheet **532 Paying for care and support** (for England), **W532** (for Wales) or **NI532** (for Northern Ireland). To find out more about NHS-funded care in England see booklet **813, When does the NHS pay for care?**



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5 When should a person with dementia move into a care home?

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Each person is different and there isn't a time that is right for everyone. Often, a person will move into a care home because it is no longer possible for them to receive the right level of care where they currently live.

Their situation may have changed for many reasons such as:

- **Not managing at home as well as they used to** – for example, they are no longer able to do daily tasks, like eating, without the support of another person. Living alone can also lead to feeling isolated, which can affect someone's mental health.
- **Not being safe at home** – for example, they keep having falls. This is likely to affect how well they can continue living at home, for instance if they have to use stairs to get to parts of the house. If the person doesn't feel safe at home, this can also affect their confidence and cause anxiety.
- **Something unexpected happening that means the person with dementia can no longer be cared for at home** – for example, the person's carer becomes ill and is no longer able to care for them as they did before.
- **Needing continuous care day and night after a stay in hospital** – the person may also have nursing care needs that are difficult to cope with at home, such as needing medicines to be given by injection.

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- **Their needs become too challenging for others to manage at home** – for example, they are awake all night or begin to experience distressing hallucinations. Family or friends may not be able to provide the level of care that the person needs at home, or they may feel unable to cope. In situations like these, the person will need more support. They will likely have to move into a care home to access the level of care they need.

Being prepared

Quite often, a person with dementia will move out of their home because their needs suddenly change. This might be after an unexpected event, like a hospital admission. This means you may not always be expecting it and a decision has to be made very quickly about what to do. If you can, try to talk to the person with dementia about different care options as early as possible. This can help you both to feel prepared if the person has to move out of their home.



For more information on planning for the future see booklet 1510, **Planning ahead**.



6 Who makes the decision?

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Deciding whether a care home is the right option for a person with dementia can be difficult. Some people with dementia will be able to make the decision themselves. Most often, the decision will need to be made for them.

The person with dementia

If the person is capable of making the decision, they must choose themselves whether or not they move into a care home. In this case, nobody can decide for them. If they need support to do this, they should be offered it. For instance, you could present the options in pictures if the person would understand that better than words.

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You may worry about what the person's decision will mean for you, if you do not feel able to care for them yourself. It's important to be aware that you can't be forced to provide care for the person, at home or anywhere else. It can be hard to say no, but this is always a choice you are free to make.

If the person chooses not to go into a care home and you cannot provide the care they need, you may be able to arrange care for them at home (if they agree). This might be arranged privately or through the local authority or trust, depending on the person's finances. A small number of people may qualify to receive NHS continuing healthcare at home, but that is rare. That would not depend on the person's finances.



If the local authority or trust is arranging care, they may take into account the amount of help the person has from those close to them. They can only do this if the carer is able and willing to provide that care. Tell the local authority or trust if you do not feel that you can.

These situations can be very hard, especially if you feel that the person's needs would be best met in a care home or if they refuse to accept care at all. It can be particularly difficult if you and the person live together. In these cases it can be a good idea to involve the local authority or trust. If the person is neglecting themselves, the safeguarding team at the local authority or trust also have to be involved.

If the person is unable to make decisions

Often, by the time the person with dementia needs the level of care provided by a care home, they do not have the ability to make this decision for themselves. The ability to make these decisions is also known as 'mental capacity'. If they lack mental capacity to decide, another person or group of people will need to make this decision for the person. This might be an attorney, deputy, family members, professionals or a combination of these.



When this happens, the person or people making the decision must always act in the best interests of the person with dementia. They should:

- try to identify any issues that the person would take into account if they were making the decision themselves
- involve the person as far as possible
- not prioritise their own personal preferences or circumstances above what is best for the person with dementia.

The ability or willingness of carers to provide care themselves will be relevant in deciding how best the person can be cared for.

Making the decision may also involve consulting others about the most appropriate care for the person. This might mean talking to carers, loved ones, or healthcare or legal professionals.

Acting in the person's best interests also involves making sure that their freedom is restricted as little as possible. See also 'Deprivation of Liberty Safeguards' on page 50.

The person's attorney, deputy or controller

If the person is not able to make the decision about their care, there may already be a legal arrangement in place that allows someone else to decide this for them. The person may have:

- an attorney, under a health and welfare Lasting power of attorney, or
- a personal welfare deputy.

If this is the case, the attorney or deputy would usually make this decision for the person.

The person may have an attorney or deputy for property and financial affairs, instead of for health and welfare. If this is the case, the attorney or deputy may still be able to make this decision for the person with dementia. This is because they have the legal power to use the person's finances to pay for care.



For more information on attorneys and deputies see factsheet 472, **Lasting power of attorney** and factsheet 530, **Deputyship**.



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Lasting powers of attorney and deputyships only apply in England and Wales. In Northern Ireland, there are Enduring powers of attorney and controllerships. These are only possible for property and financial affairs, not health and welfare. However, as the attorney or controller may be involved in paying for the person's care, they may still be involved in the decision-making.



For more information see factsheet NI472,
Enduring power of attorney and controllership.



Health and social care professionals and people close to the person

The person with dementia may not have an attorney, deputy or controller who could decide for them. If they also do not have mental capacity, the decision has to be taken by others. Ideally, this should be a shared decision with health and social care professionals and those close to the person. For example, this could be social workers or a community nurse and the person's friends or family. The decision will probably be led by whoever is paying for the person's care, for example:

- The person may be paying for their own care. This means there may not be any health or social care professionals involved in the decision. If this is the case, the person's carer, friends or family should decide. You can always ask for advice from professionals if you need it.
- The local authority, trust or NHS may be paying for the person's care. In this case, the health or social care professionals involved in the care will have more of a say in the decision. You should still be involved where possible as you are likely to know the person best and you may have an idea of what the person would want.

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The person may not have someone who knows them well enough to be involved in these discussions. In this case, the local authority (in England and Wales) should appoint an independent mental capacity advocate. The advocate will speak on the person's behalf.



For more information see factsheet 460, **Mental Capacity Act 2005**. In Northern Ireland, the Mental Capacity Act 2005 does not apply, but an advocate should still be appointed for the person.

Involving the person in the decision

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The person with dementia is likely to have feelings about what type of care they would like, even if they don't have capacity to decide themselves. They may also have expressed wishes in the past. It's important to involve them in the discussion as much as possible. The person's preferences – past and present – should be taken into account by anyone making a best interests decision on their behalf.

It can be difficult to talk about future care needs. Gently raise the subject of moving to a care home to find out how the person with dementia feels about it. Try to find out what concerns they might have and consider ways to help. For example, if the person is worried about losing privacy in a care home, let them know that they would have their own room.



If people will be able to visit, you could reassure them that they will see friends and family regularly.

Sometimes the person with dementia may not recognise that they need extra support, due to denial or lack of insight into their condition. It can be helpful to talk about the benefits of moving into a care home, rather than convincing them that they are having difficulties. For example, you could say they will not have to worry about housework or cooking.



What if there is a disagreement?

You may disagree with the decision made by the person's attorney, deputy or controller, or by a health and social care professional. This could be the case if you feel that their decision is not in the best interests of the person with dementia. Equally, someone like a social worker may disagree with a decision that you yourself have made.

It is best to try and resolve any disagreements through a discussion, but if that fails, it is possible to challenge the decision:

- **If someone has concerns about an attorney, deputy or controller**, they can speak to the Office of the Public Guardian in England and Wales, or the Office of Care and Protection in Northern Ireland. See 'Other useful organisations' on page 60 for contact details.
- **If they have concerns about health and social care professionals**, they should speak to the organisation they work for. The organisation will have its own complaints process to follow. If it is not possible to resolve the issue that way, a complaint can be made to an ombudsman. This is a public official who looks into complaints. Which ombudsman to use will depend on the organisation being complained about. This should be explained in the organisation's complaints process. See 'Other useful organisations' on page 60 for contact details.



Another option is to get legal advice to see if there is any legal action that can be taken. This would normally have to be arranged and paid for privately. In England and Wales, the Court of Protection decides what is in the person's best interests if they lack mental capacity to decide themselves. In Northern Ireland, the Office of Care and Protection does this.



Things to consider

If you are finding this decision difficult, it may help to weigh up the options using the following list:

- Is the person able to make a decision themselves about the type of care they would like?
- Has the person been given all possible support to make a decision themselves?
- Have you considered other options, such as homecare, that may help the person to get the care they need? Remember: if a less intrusive or restrictive form of support could address the person's care needs, then that approach should be taken over more intrusive or restrictive options.
- Would some respite care or a short break help you to feel more able to cope, or to see how the person with dementia gets on in a new environment?
- Would sheltered or extra care housing be a better option for the person than a care home?
- Is a Shared Lives scheme available locally, with a carer able to help them?
- What would be the benefits for the person with dementia and for you if the person moved to a care home?

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- In what ways might care staff be able to provide better care than you? For example, does the person need nursing care or care both during the day and at night?
- If the person with dementia goes into a care home, how could you still be involved in their care (if that is what you want)?
- What things make the person feel comfortable, safe and content? Does the care home you are considering offer these?
- If the person goes into a care home, what would the impact be on them, you, and other people?



If you decide to look for a care home, see booklet 690, **Choosing a care home for a person with dementia.**

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For me it's been really hard to accept that this is how the final years of their life will be. But I know I have done the right thing for both of them.

Family member of a person with dementia

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Deprivation of Liberty Safeguards

When making decisions on behalf of the person with dementia, their freedom should be restricted as little as possible. This should be the case in whichever care setting is chosen.

Sometimes, however, care arrangements will involve restrictions on the person's freedom. For example, there may be limits on where the person can go or the activities they can take part in. They may also be under supervision to protect them from harm. For someone with dementia, this is likely to apply if they move into a care home.

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These limits may amount to what is called a 'deprivation of liberty'.

Where a deprivation of liberty is to occur, it is the care home's responsibility to seek authorisation from:

- the local authority in England and Wales
- the local trust in Northern Ireland.

This procedure is called the Deprivation of Liberty Safeguards (DoLS).



The deprivation of liberty will only be allowed if the restriction is proportionate to the risk of harm the person faces. For example, it may be unsafe for the person to leave the care home on their own, but it may be possible for them to go out with someone else. This would be a more proportionate way of dealing with the risk than simply not allowing them to go out.

DoLS helps to ensure that the person with dementia is not restricted more than is needed and that their human rights are respected. It is important to bear this in mind when planning for the person's care.

A deprivation of liberty can also apply in other settings, such as the person's own home. There are different procedures in these situations.



For more information see factsheet 483, **Deprivation of Liberty Safeguards (DoLS)**.



7 If you are struggling with the decision

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The idea of moving to a care home can be upsetting for both you and the person with dementia. However, it may be necessary for both the person's wellbeing and for yours.

It's important to ask yourself what is in the best interests of the person with dementia. You may feel that you can no longer provide the care that the person needs to help them to live well. In this case, it will be better for them to move somewhere where professional care staff can do this. Similarly, the person may not be able to live independently anymore, if they cannot care for themselves or stay safe and well. This may be the right time to think about alternative care.



Dealing with your emotions

For many people, thinking about whether someone should move into a care home is one of the most difficult things they have to do as a carer. Some people have to make the decision in a rush, for example if the person has been admitted to hospital and can't be discharged back home. This can make it even harder to deal with any emotions that may come up.

Whatever the circumstances, you're likely to feel a wide range of emotions that can be hard to deal with and can make it difficult for you to know what to do.

Some people feel a sense of loss and sadness that the person's condition has progressed to this stage. It is also common to feel guilt at the idea of the person moving into a care home. Perhaps you feel that you should be able to do more to support them, or that you are letting them down. You may have promised the person that they would always be able to live in their own home and never have to move to a care home. There may also be disagreement from family members or cultural pressure around the person moving into a care home. This can make the decision even harder and can feel like a betrayal.

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It is important to accept the limits of how much care you, or any one person, are able to give, and for how long. Dementia is a complex condition that gets worse over time. It is common for people to get to a stage where they need a higher level of care than what they can get at home. This may mean that the only way to continue to keep them safe and healthy will be by moving to a care home. It may be the option that puts the person at the least amount of risk.

Try to keep in mind that you are making this decision because it is in the best interests of the person, given the circumstances. You may find that you feel a sense of relief at accepting this, and knowing that the person will be getting a level of care that you are not able to provide.

If the person is upset or angry with you for considering a care home, try to talk to them about it and understand their point of view. There may be ways that you can reassure them – see ‘Involving the person in the decision’ on page 44.

Though it may not be what you or the person would prefer to do, there can be many positives to moving into a care home. See ‘The benefits of a care home’ on page 27. Focusing on these points should help if you or the person are finding it hard to come to terms with the decision.



The following reminders may help if you are struggling with the idea of the person with dementia moving into a care home:

- Remember that there is no right or wrong way to feel. You will experience your own feelings in your own way.
- Whatever you decide, you are doing what you think is the best option for the person in a very difficult situation.
- If you decide the person does need to move into a care home, remind yourself that they will be getting the care and support they need.
- You don't stop being a carer just because you no longer do the practical day-to-day tasks. You can still be involved in the person's care if you want to be.
- Try talking to other people who have experienced the same thing. It may help you to know that what you're feeling is normal, and to hear from others about how they dealt with similar situations.
- Remember to also get the care and support that you need while making this difficult decision.



Where to get support

It can be upsetting to think about the person you care for moving into a care home. This can be especially hard if the person with dementia is young.

You don't have to go through this alone. It can often help to talk the decision through with others who have experience of it. To find support and advice, you could try the following:

- Friends and family are likely to know you and the person well, and may be best placed to support you through this process.
- Consult the person's GP or other professionals involved in their care. They can give you a professional opinion on the person's needs.
- Consider speaking to a counsellor or therapist. They provide impartial advice and support that may help you cope with the emotional impact of the decision.
- A community or faith leader may be able to provide guidance and reassurance to both you and the person with dementia.
- Visit The Dementia Support Forum. It is a good place to share your experiences and talk to people in a similar situation – go to **forum.alzheimers.org.uk**



- Use our online directory to search for peer support groups near you – go to **alzheimers.org.uk/dementiadirectory**
- Speak to one of the trained dementia advisers on our support line – they can give you advice or simply provide a listening ear. Call **0333 150 3456**. If you speak Welsh, the number is **03300 947 400**.

7

“

All I can say is - hold on, and try to look after yourself. Not easy, but if it is a good care home the staff will be supportive and reassuring to you.

Family member of a person with dementia

”



Call our Dementia Support Line on **0333 150 3456**

Other useful organisations

Care and Social Services Inspectorate Wales

0300 790 0126

www.careinspectorate.wales

The CSSIW inspects and reviews local authority social services in Wales. This includes care settings and agencies.

Care Quality Commission (CQC)

03000 616161

www.cqc.org.uk

The CQC regulates, inspects and reviews all adult social care services in the public, private and voluntary sectors in England.

Care Rights UK

020 7359 8148

020 7359 8136 (helpline, Monday–Friday 9.30am–1.30pm and Thursday evenings 6pm–8pm)

team@carerightsuk.org

www.carerightsuk.org

Care Rights UK advises relatives and close friends of people in care homes on a range of topics, from how to get an assessment to what to do when problems occur in a home.



Dementia UK

0800 888 6678

(helpline, 9am–9pm Monday– Friday,
9am–5pm Saturday and Sunday)

helpline@dementiauk.org

www.dementiauk.org

Dementia UK is committed to improving quality of life for all people affected by dementia, including people affected by young-onset dementia. It provides Admiral nurses who are mental health nurses specialising in dementia care. YoungDementia UK is now part of Dementia UK.

Elderly Accommodation Counsel (EAC)

www.eac.org.uk

www.housingcare.org

The EAC is a national charity that aims to help older people make informed choices about meeting their housing and care needs.

Local Government and Social Care Ombudsman

www.lgo.org.uk/adult-social-care/complaints-about-health-and-social-care

The Local Government and Social Care Ombudsman investigates complaints about social care services in England, for example complaints about local authority social services.



Call our Dementia Support Line on **0333 150 3456**

Northern Ireland Public Services Ombudsman

www.nipso.org.uk

The Northern Ireland Public Services Ombudsman investigates all complaints about public services in Northern Ireland, including about health and social care trusts.

Office of Care and Protection (OCP)

www.justice-ni.gov.uk/topics/courts-and-tribunals/office-care-and-protection-patients-section

The OCP can deal with concerns about EPA attorneys and controllers in Northern Ireland.

Office of the Public Guardian (OPG)

www.gov.uk/government/organisations/office-of-the-public-guardian

The OPG supervises LPA and EPA attorneys and deputies in England and Wales. They will look into concerns raised about attorneys and deputies.

Parliamentary and Health Service Ombudsman

www.ombudsman.org.uk

The Parliamentary and Health Service Ombudsman investigates complaints about the NHS in England.



PayingForCare

www.payingforcare.org/calculators

PayingForCare is a website designed to help people make more informed decisions about the arrangements and funding for their long-term care. They provide online calculators to help work out the cost of care.

Public Services Ombudsman for Wales

www.ombudsman.wales

The Public Services Ombudsman deals with all complaints about public services in Wales. This includes complaints about local councils and the NHS.

The Regulation and Quality Improvement Authority (RQIA)

028 9536 1111 (9am–5pm Monday–Friday)

info@rqia.org.uk

www.rqia.org.uk

The RQIA is an independent body that is responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland.



Shared Lives directory

[www.nhs.uk/service-search/other-services/
Shared%20lives/LocationSearch/1834](http://www.nhs.uk/service-search/other-services/Shared%20lives/LocationSearch/1834)

You can find your local Shared Lives service by searching the directory on the NHS website.

Shared Lives Plus

0151 227 3499

info@sharedlivesplus.org.uk

sharedlivesplus.org.uk

Shared Lives Plus is a charity for Shared Lives carers and schemes in the UK.

Skills for Care

[www.skillsforcare.org.uk/Employing-your-own-care-
and-support/Information-for-individual-employers/
Recruiting-a-PA.aspx](http://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Information-for-individual-employers/Recruiting-a-PA.aspx)

Skills for Care is a charity that works to improve adult social care in England. It provides an online toolkit for recruiting a personal assistant (PA).



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Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Professor Tom Dening, Professor of Dementia Research, Institute of Mental Health, University of Nottingham and by Rebecca Minto, Associate, Mills & Reeve LLP and member of Solicitors for the Elderly

This booklet has also been reviewed by people living with dementia.

To give feedback on this booklet, or for a list of sources, email **publications@alzheimers.org.uk**

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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Care homes**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



Patient Information Forum



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia

Alzheimer's Society
43-44 Crutched Friars
London EC3N 2AE

0330 333 0804
enquiries@alzheimers.org.uk
alzheimers.org.uk

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