

# Care homes: when is the right time and who decides?

Factsheet 476LP  
December 2017



A person with dementia will need more care and support as their condition progresses, and there may come a time when they will need to move into full-time or residential care. This could be because a care home may be able to meet the needs of the person better. Or, it could be because something changes that then makes it difficult for the person with dementia to stay living at home.

It can be hard to know when the time is right for a person with dementia to move into a care home and who should make this decision, if the person cannot make it themselves. This factsheet is aimed at carers, friends and family of a person with dementia. It provides information and explains what might need to happen in these situations. It also talks about some of the feelings you might have when the person with dementia moves into a care home, such as relief, loss or guilt.

We also have a booklet that will help you to find the right care home – booklet 690, **Selecting and moving into a care home**. It explains the process of finding and visiting homes, and has checklists and tips of things to consider when deciding which home is the right one.

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## Care homes: when is the right time and who decides?

### Who makes the decision?

In some cases the person with dementia will be able to decide for themselves whether or not they need to move into a care home. If this is the case, then they should make their own decision – and be offered any help they need to do so. However, often by the time the person with dementia needs the level of care that a care home provides, they have lost the ability (known as ‘mental capacity’) to make this decision for themselves.

If the person is not able to make this decision, someone else will need to make this decision for them. This would usually be the person’s attorney under a health and welfare Lasting power of attorney, or their personal welfare deputy, if they have one. Any attorney or deputy must make decisions in the best interests of the person.

An attorney or deputy for property and financial affairs (not health and welfare) is often able to make this decision for the person with dementia. This is because they have the legal power to arrange the finances to pay for this care. However, professionals or members of the person’s family can challenge this decision.

For more about mental capacity in England and Wales, and how to know if someone is able to make decisions for themselves, see factsheet 460, **Mental Capacity Act 2005**. For more information on attorneys and deputies see factsheet 472, **Lasting power of attorney** and factsheet 530, **Deputyship**.

In Northern Ireland there are Enduring powers of attorney and controllerships rather than Lasting powers of attorney and deputyships. These are only possible for property and financial affairs, not health and welfare. For more information on these see factsheet NI472, **Enduring power of attorney and controllership**.

The person with dementia may not have an attorney, deputy or controller. In this case, the decision should ideally be made between health and social care professionals (such as social workers or health care professionals) and those close to the person. If there is a disagreement, it would normally be the health and social care professionals who make the decision, but again this could be challenged by the person's family or friends.

Whoever makes the decision to move someone to a care home must think about why it is in the best interests of the person with dementia. For more on making this decision see 'How do you know if someone needs to move into a care home?' on page 5. The person should be involved in the discussion too if possible, even if they don't have capacity to make the decision themselves. This is because they are likely to have preferences and feelings about the decision.

Many carers, family members or friends will also have an idea about what the person with dementia would want. You might be the people who know the person best, or have talked to them about what they want for the future. You should be consulted where possible and should say what you think the person would want.

If the person doesn't have someone who knows them well enough to be involved in these discussions, an Independent Mental Capacity Advocate (IMCA) may be appointed by the local authority in England and Wales. This is someone who can speak on the person's behalf in these discussions. For more information see factsheet 460, **Mental Capacity Act 2005**.

## How do you know if someone needs to move into a care home?

If you are a family member or carer, or the person's attorney or deputy, you may have to decide whether you think the person with dementia needs to move into a care home. You may find it difficult to make this decision, seeing both advantages and disadvantages to each option. If you're struggling, don't worry – it's normal to feel confused or unsure.

You should ask yourself, first and foremost, what is in the best interests of the person. If you feel you can no longer provide the care that the person needs to help them to live well, then it may be better for them to move somewhere where professional care staff can do this. Similarly, if the person cannot live independently any more – for example, cannot care for themselves or stay safe – then it might be the right time to think about alternative care.

However, moving someone into a care home doesn't have to be the only thing you should consider. You might want to think about other care options that would enable the person to stay living at home – for example, seeing what other care and support can be provided within the person's home, or whether different housing options might be better.

Many carers, family members or friends will also have an idea about what the person with dementia would want. You might be the people who know the person best, or have talked to them about what they want for the future. You should be consulted where possible and should say what you think the person would want.

### Other care options to consider

Respite care (sometimes referred to as short-break or replacement care) is one option, and could be the first step towards longer-term residential care. Respite care is temporary care for the person with dementia that aims to give the carer a break, as well as giving both the carer and the person with dementia some time away from each other.

Some respite care will be in the person's home, but some care homes also offer short stays. This offers the person with dementia a chance to experience a care home for a temporary period. Some people use a respite stay as a 'trial period' and many care homes are willing to offer a short-break as they find that people who like it there may eventually move in permanently when they are ready.

If you think extra support in the home or respite care may be a good option, you should contact your local authority for a needs assessment. This is where they make a full assessment of a person's needs and decide what support they are eligible for.

For more information see factsheets 418, **Assessment for care and support in England**, W418, **Assessment for care and support in Wales**, and NI418, **Assessment for care and support in Northern Ireland**.

You may also want to consider whether a form of sheltered housing or extra care housing would be a better option for the person. These are living arrangements where someone lives independently, but has support on hand if they should need it (though you should check what is available in each case).

This can be a good first step for someone who needs a little extra help. However, as the person's dementia progresses, their needs will increase and in the future a care home may be the best option. For some people moving more than once may not be a good idea as it can make them disorientated or unsettled. You will need to think about the person and what they would want in this case.

Moving someone into a care home doesn't have to be the only thing you should consider. You might want to think about other care options that would enable the person to stay living at home – for example, seeing what other care and support can be provided within the person's home, or whether different housing options might be better.

### The benefits of moving into a care home

Deciding that someone needs to move into a care home is often a very difficult decision. It is common to feel a sense of guilt at making this decision. You may feel that you should be able to do more to support the person, or that you are letting them down. However, it's important to remember that you are doing this because it is right for the person, and that there can be lots of positives to moving into a care home.

A care home will have staff who can provide continuous, 24-hour support, which may be more than you are reasonably able to do. A care home with nursing will also have a registered nurse on site 24 hours a day, for example. There are also important social benefits of living in a care home. Residents can meet one another, and join in group activities.

Just because the person moves into a care home, it doesn't mean they will have to stop doing the things they enjoy. They will still be able to see family and friends, or do things that are meaningful to them. When the person is living in a care home, some people find it allows them to visit and spend quality time with the person, without having to focus on providing day-to-day care.

For more on feelings of guilt or other emotions see 'Dealing with your emotions' on page 13. For more on the different types of care homes see booklet 690, **Selecting and moving into a care home**.



## Being prepared

Quite often, a person with dementia will move into a care home because of some unexpected event. For example:

- a hospital admission
- a carer becoming ill and being unable to care for the person
- safety concerns about the person
- the person with dementia experiencing behaviours that challenge, such as being awake all night, or becoming aggressive or agitated.

This means you may not always be expecting it, and may have to make a decision very quickly about what to do.

It can help to be prepared for this situation, and talk to the person with dementia about it as early as possible. It can help to know how they feel about a move – for example, it may be reassuring for you to know that you're doing what they would want you to do. This can make the decision slightly easier when the time comes.

You could try talking things over with other people, such as friends or family members. You could also speak to health and social care professionals. They will be able to give their professional view of the person's needs. You may also be able to get an assessment of a person's needs from your local authority, or in Northern Ireland your health and social care trust. This is where they carry out a full assessment of all a person's care and support needs, which may help you make a decision about what is in the person's best interests. Both carers and people with dementia can get an assessment, and the local authority or trust has a duty to carry one out if you request it.

For more on getting a needs assessment see factsheet 418, **Assessment for care and support in England**, W418, **Assessment for care and support in Wales**, and NI418, **Assessment for care and support in Northern Ireland**.



### What things should you consider?

If you are finding this decision difficult, it might help to think clearly about the following things. It might also be useful to write everything down as this can help you to weigh everything up and get other people's help.

- Is the person able to make a decision about their care, and where to receive it, for themselves?
- Has the person been given all possible support to make a decision themselves?
- Have you considered other options, such as care at home, that may help the person to get the care they need?
- 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?
- What would be the benefits for you and the person with dementia if they moved to a care home?
- In what ways might care staff be able to provide better care than you – for example nursing or 24-hour care?
- If the person with dementia goes into a care home, how could you still be involved in their care?
- 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?
- Do you think your feelings (good or bad) about placing the person with dementia in a care home could change over time?
- Is there someone you can discuss your feelings with?
- Has the person ever expressed any opinions about going into a care home?
- Have you spoken to the person about the move? Even if they don't seem to understand it or are unable to make the decision themselves it is important to involve them as much as possible.

## Who chooses the care home?

If the person is able to decide which care home they will move into, they can make the decision themselves. However, in a lot of cases the person with dementia may lack the capacity to choose. And so someone else, perhaps you, will need to make the decision for them.

It's also important to know that for some people there is no choice – the care home nearby may be the only one, or there may be limited spaces in others, meaning there is only one option.

If there is a choice of homes however, the process will be similar to deciding whether or not the person needs to move into a care home. This means the person's attorney or deputy for health and welfare (if they have one) should make the choice. If the person only has an attorney or deputy for property and financial affairs, they can often make this decision too. If the person has no attorney or deputy, health and social care professionals and those close to the person should decide together. The home also has a choice about whether or not to accept a potential resident.

The decision may also depend on who is funding the care. If the person is paying for their own care, there will be more choice about the care home than if the local authority or NHS (or health and social care trust in Northern Ireland) is paying. If the local authority or trust is paying, the person choosing the home should still have a choice of care home. However the list will be limited to the homes that the local authority or trust will fund. See 'Who pays for the care home?' on page 12.

Just because the person moves into a care home, it doesn't mean they will have to stop doing the things they enjoy. They will still be able to see family and friends, or do things that are meaningful to them. When the person is living in a care home, some people find it allows them to visit and spend quality time with the person, without having to focus on providing day-to-day care.

If the person with dementia has made an advance statement – a document that allows them to state their wishes for their future care – or has expressed their wishes in other ways, you should follow this as far as possible. For example, someone may have said they would like access to outdoor space, so you can look at care homes with gardens.

You should also use your knowledge of the person and what they would want in order to act in their best interests. Each person will have different needs and preferences about their care and what they like. These should be taken into account when choosing a care home.

Carers or relatives of a lesbian, gay, bisexual or transgender (LGBT) person may need to consider additional factors when selecting the right care home. This could be choosing a home that is aware and supportive of LGBT issues and the specific needs of LGBT people. Younger people with dementia may also have different needs to older people, and you may want to look for a care home that can provide age-appropriate support.

If the person has cultural, spiritual or faith needs, they will want a care home that can meet these. There are homes that cater for people of specific faith or cultural backgrounds, or where residents and staff speak a language other than English.

For anyone with specific needs like these, it can be a good idea to start thinking about care homes earlier than needed, as it can be harder to find one that will be right for them. You may have to make difficult decisions about the benefits of a local home or a specialist home that is further away.

For more detailed information on things to consider when selecting a care home, see booklet 690, **Selecting and moving into a care home**. For advice on some of the issues that affect younger or LGBT people with dementia see factsheet 440, **What is young-onset dementia?** and factsheet 480, **Supporting an LGBTQ+ person with dementia**.

## Who pays for the care home?

Who pays for the person's care will depend on the person's individual situation. It will be based on an assessment of their needs and (in most cases) their financial situation. For some people, the local authority or the NHS (or health and social care trust in Northern Ireland) will pay the care home fees, and others will need to pay themselves. Sometimes it may be a combination of these.

If a public body (local authority, NHS or health and social care trust) is paying for the care home, there may be less choice than if the person is paying themselves. If the local authority or trust is paying it will sometimes provide a list of suitable care homes to choose from. They consider a care home suitable if it meets the person's needs, meets the local authority's budget and has a place available.

For more information on having the person's needs assessed see factsheets 418, **Assessment for care and support in England**, W418, **Assessment for care and support in Wales**, and NI418, **Assessment for care and support in Northern Ireland**.

For more about paying for care see factsheets 532, **Paying for care and support in England**, W532, **Paying for care and support in Wales**, and NI532, **Paying for care and support in Northern Ireland**. For more information about NHS-funded care in England see booklet 813, **When does the NHS pay for care?**

Some people will be self-funding – this means they can arrange their place and pay for care home fees independently. This will probably also mean they have more choice over which home to move into, but it still might be limited. For more practical advice on choosing how to decide which is the right care home, see booklet 690, **Selecting and moving into a care home**.

## 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've had to do as a carer. You're likely to feel a wide range of emotions that can be hard to deal with and can affect your decision.

Some people will feel that moving into a care home is the right thing to do, but for others, feelings of guilt or loss might make it hard to think clearly and be objective. It can be harder if the decision to move into care has to be made in a rush (for example, if the person has been admitted to hospital and can't be discharged home).

It's important to learn to deal with these emotions, and not let them get in the way of doing the right thing for the person with dementia. The suggestions on page 14 may help.

**For anyone with specific needs like these, it can be a good idea to start thinking about care homes earlier than needed, as it can be harder to find one that will be right for them. You may have to make difficult decisions about the benefits of a local home or a specialist home that is further away.**

### Tips for carers: Dealing with your emotions

- Remember, 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 best for the person.
- If you decide the person does need to move into a care home, remind yourself that they will be getting the care they need to help them to live well.
- Accept that you are human and there is only so much you can do. The person would want you to take care of yourself as well.
- You don't stop being a carer just because you no longer do the practical day-to-day tasks. You will still be able to be involved in the person's care if you want to be.
- Talking to other people who are going through, or have been through the same thing can help. It may help you to know that what you're feeling is normal, and to hear from others about how they dealt with this difficult situation.

**Talking Point, our online community, is a good place to share your experiences and talk to people in a similar situation – go to [alzheimers.org.uk/talkingpoint](https://alzheimers.org.uk/talkingpoint)**

### After the person has moved into a care home

Once the person has moved, you may feel a strong sense of loss – not just of the person, but also your relationship with them, your role as a carer and your plans for the future. These feelings can be very strong if the person with dementia is your partner or has been living with you. You may feel that you have lost your sense of purpose. You might be unsure what role you will play in the person's care. It can take time to adjust.

You may miss the person and find yourself struggling to know what to do now that you are no longer responsible for their day-to-day care. Building a good relationship with the care home can help with this. You may feel lonely and isolated at home without them, and find it difficult to find a new role for yourself, or to pick up past interests or relationships. It is okay to feel like this, and in time it may start to get easier.

You may feel guilty about the situation or that you have let the person down. You may feel that you should be able to do more or cope better. You may worry about how the person will settle in, and whether the care they receive will be good enough. These feelings can be complicated if your family or culture has strong views on how people should be cared for, or if other people disagree with the decision. All of this may contribute to increased feelings of guilt and sadness, even if you know the decision was in the person's best interests.

You may also experience more positive feelings as well. You might be relieved that the person is getting the care they need and that they are safe. You may feel relieved that you are able to take care of yourself and focus on your needs or on those of other people in your life.

It is important to know that these feelings are all normal, and lots of other carers and family members feel the same. The following tips may help.



### Tips for carers: After the person has moved into a care home

- Talking is often the first step to dealing with your emotions. It may seem like a small thing, but it can make you feel less isolated and stressed, and it can help to put things in perspective. If you don't have someone you can talk to, try Talking Point – go to **[alzheimers.org.uk/talkingpoint](https://alzheimers.org.uk/talkingpoint)**
- Support groups are a great source of information and are likely to offer you the chance to discuss how you are feeling with people in a similar situation. To find a support group near you go to **[alzheimers.org.uk/find-support-near-you](https://alzheimers.org.uk/find-support-near-you)**
- If you still want to be involved in caring for the person, speak to the care home staff. Let them know how involved you would like to be and discuss how you can work together. It can help to think of ways you can support the person, such as telling the care home about their life history and interests and making sure staff know what the person likes and dislikes.
- You may want to focus on having an enjoyable time with the person and spend your time together doing things you enjoy such as listening to music, going through photo albums or playing games.
- Ask the care home if they have a group for family and friends of residents. Get involved with this or other activities in the home, such as special celebrations or events (for example, if they have a barbeque in summer). If not you could try talking to a support organisation such as Relatives and Residents Association (see 'Other useful organisations').
- If you find yourself becoming depressed, it's important that you seek support. Start by contacting your GP. There are a range of therapies that may be beneficial. For more information see factsheet 444, **Supporting a person with dementia who has depression, anxiety or apathy**.

You could also try talking things over with other people, such as friends. It can help to be prepared for this situation, and talk to the person with dementia about it as early as possible. It can help to know how they feel about a move – for example, it may be reassuring for you to know that you're doing what they would want you to do. This can make the decision slightly easier when the time comes.

## Other useful organisations

### Age UK

0800 678 1602 (advice line, 8am–7pm)  
[www.ageuk.org.uk](http://www.ageuk.org.uk)

### Wales – Age Cymru

0300 303 44 98 (advice line, 9am–4pm Monday–Friday)  
[advice@agecymru.org.uk](mailto:advice@agecymru.org.uk)  
[www.ageuk.org.uk/cymru](http://www.ageuk.org.uk/cymru)

### Northern Ireland – Age NI

0808 808 7575 (advice line, 9am–5pm Monday–Friday)  
[advice@ageni.org](mailto:advice@ageni.org)  
[www.ageuk.org.uk/northern-ireland](http://www.ageuk.org.uk/northern-ireland)

Age UK, Age Cymru and Age NI provide information and advice for older people in the UK.

### Care Inspectorate Wales

0300 790 0126  
[ciw@gov.wales](mailto:ciw@gov.wales)  
[www.careinspectorate.wales](http://www.careinspectorate.wales)

The Care Inspectorate reviews local authority social services and regulates and inspects care settings and agencies across Wales.

### Care Quality Commission (CQC)

03000 616 161 (8.30am–5.30pm Monday–Friday)  
[enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk)  
[www.cqc.org.uk](http://www.cqc.org.uk)

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

### **Dementia UK**

0800 888 6678 (helpline, 9am–9pm Monday–Friday,  
9am–5pm Saturday–Sunday)  
helpline@dementiauk.org  
www.dementiauk.org

Dementia UK is a charity providing specialist dementia support for families through its Admiral Nurse service. They also provide support for people with young-onset dementia.

### **Elderly Accommodation Counsel (EAC)**

0800 377 7070 (advice line)  
info@firststopaadvice.org.uk  
www.eac.org.uk  
www.housingcare.org  
hoop.eac.org.uk/hooptool

Elderly Accommodation Counsel (EAC) is a national charity that aims to help older people make informed choices about housing and care. They offer two services. The EAC FirstStop Advice service uses an online questionnaire to help people with housing. This questionnaire is known as the Housing Options for Older People (‘HOOP’) tool. The EAC also provide advice and guidance via their website HousingCare.org – the site includes a search tool for people to find care homes in their area.

### **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 responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland.

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### **Relatives & Residents Association**

020 7359 8136 (helpline, 9.30am–1pm Monday–Friday)

[helpline@relres.org](mailto:helpline@relres.org)

[www.relres.org](http://www.relres.org)

The Relatives & Residents Association 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.

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

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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 Jill Manthorpe, Professor of Social Work, Director of the Social Care Workforce Research Unit, King's College London and David Sinclair, Partner, Acorn Solicitors and Claire Davis, Partner, Howells Solicitors, both Directors, Solicitors for the Elderly

This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email [publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk)

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

To make a single or monthly donation, please call us on **0330 333 0804** or go to [alzheimers.org.uk/donate](https://alzheimers.org.uk/donate)

We are Alzheimer's Society. We are a vital source of support and a powerful force for change for everyone affected by dementia. We provide help and hope.

For support and advice, call us on **0333 150 3456** or visit [alzheimers.org.uk](https://alzheimers.org.uk)



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