

# Supporting a person with dementia in a care home



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia



## About this booklet

This booklet gives advice on how to support a person with dementia in a care home. It includes practical tips on how to help the person to settle in and ways to stay connected. It describes common emotions you and the person may have. It also gives information on managing the financial side.

For information on deciding and choosing a care home, see booklet 689, **Care homes and other options: Making the decision** and booklet 690, **Choosing a care home for a person with dementia**.

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# 1 Making the move to a care home

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# A big step

1 Moving home is a big step for anyone. It can be very difficult to leave a familiar place for a new one. For a person with dementia, moving into a care home can be even more unsettling. For carers, friends and family, this change can be emotional with feelings of loss, worry and guilt.

It may be helpful to remember that the move is to meet the person's increased needs in a safe environment. It can take time to settle in, and there may be good and bad days to start with.

A person with dementia is likely to move into a care home when their needs can no longer be met at home. This is often a necessary decision after a period of struggling to cope. It may follow a stay in hospital due to illness or a fall. A care home can provide the care they need throughout the day and night.

As a family member, carer or friend, there are things you can do to help the person with dementia to have a positive start in their new home.



# Before the move

Whether the person is moving from their own home or a hospital setting into a care home, the following tips may be helpful to do beforehand:

- 1 **Let staff know about the person's feelings and preferences before they move in.** They may be able to suggest ways that will make the move easier. See 'Helping staff to know the person' on page 23.
- Set up their new room in advance.** Ask the care home manager if you can set up the room with the person's familiar items to help them feel at home when they arrive. This can also reduce stress on the day and allow you to focus on the person.
- Reassure the person about any concerns before the move.** Think about what may be causing the person's stress or anxiety. For example, if they are worried about having to enter the care home by themselves, reassure them that you will be there too.
- If possible, arrange to move in on a weekday.** There will be more staff around to welcome and support them.
- If the person has previously had respite care in the home,** they will be more familiar with it. This could make the move easier for them. Speak to staff about this.



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  - **If moving from another care home**, ask staff at the new care home how best to manage the move. It may help to tell them what worked in the previous place.
  - **Ask if the person can visit the care home before moving day.** Some care homes invite future residents to meet staff and other residents before they move in. This can help to reassure the person. When visiting, consider taking photos of their room or dining area. Looking at these might help them become familiar with the home. This may also help if they are unable to visit. Some homes may offer a video tour.
  - **If the person has to move in with very short notice due to emergency care**, don't worry if you haven't thought of everything. Focus on their safety. Just organise the essential things they need, such as their glasses, medicines, dentures or hearing aid. Once they are safe in the home, you can look at organising the rest. Try to stay calm and ask people to help you if possible.

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**Whilst we had started thinking about a permanent placement, the transition actually happened as emergency respite/palliative care.**

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Family member of a person with dementia



# The day of the move

The day of the move can be the most emotional. Not only is there a lot happening, but you may have many different feelings yourself. You might find you are anxious but also feel relief that the person will finally be getting the support they need.

These practical and wellbeing tips can help on the day:

- **Try not to hurry the journey and arrival.** Leave plenty of time to reduce the shared pressure and stress you may be feeling.
- **Try to arrive during the daytime** when it's still light. This can give the person time to adjust to their new surroundings. Some people with dementia regularly become agitated or distressed later in the day. This is known as 'sundowning'. Arriving earlier in the day can avoid making these symptoms worse. **See factsheet 534, Understanding sleep patterns, night-time disturbance and dementia.**
- **Involve the person as much as possible with the move.** When unpacking, ask them where they would like their personal items in the room. This can help them to feel more in control.
- **Place familiar objects**, such as photos and ornaments, where the person can see them easily. This can help them to feel more comfortable and settled.



- **Try to view the whole place as their new home, not just their room.** Explore the living rooms and any gardens or courtyards together.
- **Check how the person is feeling throughout the day.** Ask them about their thoughts and emotions. If they are tired or becoming upset, leave the unpacking for another time.
- **Avoid doing too much at once.** Take breaks and have a drink or snack. This kind of familiar activity can often be reassuring.

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If you are accompanying the person to the care home, try to think about what you will do when it's time to leave. Saying goodbye can be distressing and unsettling for both you and the person with dementia. Being prepared for this may help you.

For some people, it may be better to leave when the person is engaged in an activity or about to have a meal. For others, this may not be appropriate. Speak with the care home staff and try to decide what you'll do in advance. You are likely to have a good idea about how best to approach the situation.

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**As one of four sisters, we were all involved in moving Mum but in different ways. One of my sisters took charge of the financial, legal side and I was more involved in the visiting and settling in.**

Family member of a person with dementia

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## If the person refuses to move

Understandably, some people with dementia may be reluctant to move into a care home and refuse to go on the day. This can be very stressful for both of you.

1 Ask what is upsetting them about the move. For example, if they say they will miss having familiar faces around, reassure them that they are likely to make new friends. If the idea of moving is overwhelming for them, break the day down into separate tasks. Focus on the journey to the home first, then on unpacking clothes, and so on. This might feel more manageable.

If the person has already had a chance to visit the care home, talk about things they enjoyed or liked about it. You could show them any photos you have taken. It can help to focus on fun activities and opportunities to be around others.

You should never use force to move the person. If they refuse to come with you, ask your local social services team for support.



For more on the benefits a care home can offer, see booklet 689, **Care homes and other options: Making the decision.**



# Adjusting to your changing relationship

When someone moves into a care home, the relationship between you may change. As their condition progresses and their needs develop over time, you may begin to feel like an intruder or outsider. It might feel strange to you that the care home staff now know more about the person's daily life than you do.

This can be very difficult to come to terms with. It can help to remember that even though your relationship with the person is changing, you are no less important in their life.

Without the pressure and stress of being the person's main carer, you may even find that your relationship improves in many ways. This is because you can focus on spending quality time with them rather than supporting them with their daily care.

When visiting, try to live in the moment rather than focusing on the past or the future. Enjoy your time together and try to do things you both take pleasure in.

You may also find new ways to look after them, such as contributing ideas to their care plan. See 'Care plan' on page 23.

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If you have previously provided care to the person, it is natural to feel a wide range of emotions when they move into a care home. These could include:

- 1** ● **Guilt** – you may feel that you have somehow betrayed the person or feel guilty that you weren't able to keep caring for them yourself. It's important to bear in mind that dementia is a complex condition and requires a high level of care. It is often not possible to provide this support at home. Try to focus on the benefits that the care home can bring, both for the person's wellbeing and for yours.
- **Loss** – you might miss them and the things that you used to do together. Try to remind yourself that your relationship has not ended. You may find that you have more quality time to spend with them now that you no longer have to focus on their daily care needs.
- **Sadness** – it can be upsetting to see that the person's condition has worsened to the point where they need much more care. Try to focus on the things that they can still do, and the ways you can still engage with them.
- **Feeling lost** – if you are used to having caring responsibilities, it can be difficult to adjust to your new role. You might feel lost or as though you have too much free time. Think about activities that you enjoy but have not been able to do while caring for the person. There may be ways that you can stay involved in their care. See section 4 'Helping with the person's care' on page 40.



- **Relief** – you may feel a sense of relief once the person has moved into a care home. This could be because you know that they are getting the care they need. Or it may be because you're now able to do more things for yourself. Feeling relief is very common and completely natural. Though caring can be rewarding, it can also be exhausting and stressful. It may help to talk to other people who have been through the same thing. See 'Where to get support' on page 14.

These emotions are likely to come and go. You might find yourself feeling fine one moment and then tearful the next. It is important to know that your feelings are valid – this is a big change for you too. Give yourself time to adjust to this new period of your life.

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**My overriding emotion since my mum moved into residential care has been one of guilt...that I can't make her better and can't care for her myself.**

Family member of a person with dementia

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# Where to get support

It is important to look after yourself and get the support you need through this difficult process. Ask friends and family if you feel able to.

**1**

Your relationship with staff in the care home will be very important to helping you feel connected and involved. See 'Helping staff to know the person' on page 23.

Speaking to friends and family members can also be helpful. If you attend faith services, this could be a continuing source of support and reassurance. If you would like to chat to someone over the phone, call our Dementia Support Line on **0333 150 3456**. Our trained advisers would be happy to talk.

You might also find it useful to join carer support groups or talk with people going through similar experiences. This could be in person or through the internet. Search our online directory for local groups **[alzheimers.org.uk/dementiadirectory](https://alzheimers.org.uk/dementiadirectory)** or join our online community Dementia Support Forum by visiting **[forum.alzheimers.org.uk](https://forum.alzheimers.org.uk)**

Some people find it helpful to try talking therapies, such as counselling. This can give you a safe and supportive environment where you can talk about how you're feeling with someone who is trained in providing support.





For more information see ‘How can talking therapies help carers?’ on page 18 in factsheet 444, **Supporting a person with dementia who has depression, anxiety or apathy.**



# 2 Helping the person to settle in

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## Settling-in period

It is natural for anyone to feel unsettled when moving to a new place. With the added confusion that often comes with dementia, this can cause upset and restlessness.

There are several ways in which you can help a person settle into a care home:

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- **Consider giving the person time to connect and build relationships** with staff and other residents. Think about allowing time for them to get used to a new routine with others. Some people find this useful when they are planning their visits. Once the person is more settled, you can visit more frequently. Find out what works best for you both.
- **Ask care home staff to keep you updated** on how the person is settling in once you have left. They will have experienced this many times and may have suggestions to make things smoother. For example, some carers leave photographs or notes to reassure the person in between visits.
- **Find out how the person can contact you** – for instance, by using a mobile phone or tablet, or having access to a landline phone. Ask the manager as this could be reassuring for you both.



- **Plan activities you can do together on your visits.**

This can be a nice way to remain connected. Consider having an ‘activity box’ with items such as photos, games or books in the person’s room. You can then choose what to do together. See ‘Visiting the care home’ on page 30 for ideas of activities.

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**The day we took Mum to the care home and left her to have lunch was probably the hardest day of my life. She was angry and confused. I left feeling completely broken. The staff sent me a recording of Mum singing, laughing and clapping three hours later. I was very grateful for that.**

Family member of a person with dementia

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# Keeping belongings safe

Care homes can be busy places, especially in the mornings. This can sometimes lead to personal items being misplaced and lost. Try the following to help reduce this risk:

- **Label clothes with the person's name.** You can use a fabric pen, or try iron-on or adhesive labels.
- **Mark or engrave the item.** Add dots of permanent marker or nail varnish to items. You could also use an engraving pen to etch the person's name onto an item – for example, onto a pair of glasses. Some dentures can be engraved too, though check with the person's dentist before doing this.
- **Keep valuable items in a separate location.** For example, lock them in a cabinet or look after them at your home.
- **Make copies of important documents or photographs.** You could keep the originals at your home and use the copies in the care home.
- **Tag items that the person uses frequently.** You may be able to tag some items with a Bluetooth tag or tile. You can then use a smartphone to locate the item if it gets lost.
- **Do an inventory of the person's belongings.** Care homes usually do their own inventory, but it can be helpful for you to do one too. This can be a list of items and can include photographs of any valuables. You can give a copy to the manager to keep on file.



# Supporting the person with their emotions

The person with dementia may become tearful or unhappy when you visit. Or they may be angry that they're in a care home and blame you for it. Try to keep calm and understand their point of view. They might be having a difficult day. Keep in regular contact with the care home manager to get a sense of how the person is settling in when you're not visiting.

It is not uncommon for someone with dementia to say they want to go home. This can be upsetting to hear, especially if they have recently moved into a care home.

If the person asks to go 'home', they could be referring to where they grew up or to somewhere they lived as a younger adult. This could be due to 'time-shifting', where they believe they are living at an earlier time in their life. In this situation, try not to disagree with them as this can cause further distress.



For more advice on how to support someone who is experiencing time-shifting, see factsheet 527, **Changes in perception.**



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

For some people, 'home' is more of a feeling than a location – somewhere where they felt comfortable and secure. Gently ask the person what it is they liked about their 'home' to find out what they mean by that word. This could give you a sense of what they need to feel more relaxed. A photograph album of family and home could help them feel happier and more comfortable in their new environment.



# Helping staff to know the person

Before a care home can welcome in a new resident, the manager will review the person's needs. This is to make sure the home and staff are able to provide care for them safely.

## Care plan

The manager (or sometimes a nurse) will assess the physical and wellbeing needs of the person with their carer, family or close friend. A social worker may also be involved. This assessment will help to create a 'care plan' to guide staff on how to meet the person's needs and preferences for care. The care plan should be reviewed regularly.

Proper care planning is a legal requirement for care providers. You and the person with dementia should be involved in the care plan and stay involved with it as things change.

You can contribute to the care plan by sharing key information with staff. This can include:

- cultural or religious beliefs and practices that the person takes part in, like prayer or attending services
- any place of worship or community group they might want to keep contact with



- friends and family members who are important to them and who they might want to see or talk to
- dietary needs or requirements, such as allergies, specific diet and likes/dislikes of certain foods
- if they prefer tea or coffee, hot or cold drinks
- the person's sexuality and gender identity, and how or whether they wish to express this
- medicines, including name, dosage and information on how the person prefers to take it – for example, with a warm drink or after a meal
- preferences for personal care, for example, method of shaving
- interests and hobbies, such as football, music, arts and crafts
- any advance statements and wishes for end of life care or advance decisions to refuse treatment (**see factsheet 531, End of life care**). Being aware of these will allow the care home to make arrangements that respect the person's choices, as much as possible.

You could also let staff know what the person likes and dislikes and what cheers them up or calms them down. Consider other details that you feel are relevant to their daily care.



There may be aspects of the person's life history that are important to mention but that are too sensitive or private to share openly. For example, the person may have experienced abuse earlier in their life. If so, they may not feel comfortable receiving personal care from someone of a specific gender. It is important to let the care home manager know this type of information so that they can arrange suitable care.

## A useful tool

Alzheimer's Society produces a free tool called **This is me**<sup>®</sup>. On this form, you can include information about the person's cultural and family background, as well as their preferences and routines. Order **This is me** for free on our website ([alzheimers.org.uk/thisisme](http://alzheimers.org.uk/thisisme)) or over the phone **0300 303 5933**.



**This is me**<sup>®</sup>

This leaflet will tell you all about who I am, to help you support me.

Name I like to be called \_\_\_\_\_

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**This space is for you.**

You can attach a favourite photo here – of yourself, your family, a pet or a place you've visited.

   

OR list four things that interest you:

1 \_\_\_\_\_

2 \_\_\_\_\_

3 \_\_\_\_\_

4 \_\_\_\_\_

Keep this in a suitable and safe place where anyone caring for you, at home or elsewhere, can refer to it easily. You can also take it with you if you need to go into hospital.

 



## Powers of attorney and future care planning

You or someone else may hold a Lasting power of attorney or Deputyship for the person. In Northern Ireland, this is called an Enduring power of attorney or Controllership. If you do, you should let the care home know and provide a copy.

**2** Lasting power of attorney for health and welfare is only possible in England and Wales. This may give the attorney the power to decide whether the person goes to hospital or not in certain circumstances. It is very important for the care home to know about this in advance of any emergency. Similarly, the care home must be aware if the person has made an advance decision to refuse treatment.



For more information see factsheets 472, **Lasting power of attorney**, 530, **Deputyship** and **NI472 Enduring power of attorney and controllership** (Northern Ireland).



# Building relationships with staff

Building a relationship with staff is a good way to make a care setting feel more like a home. Start by getting to know the care home manager and the person's key worker – who will likely be your regular point of contact.

Visiting at different times of day will allow you to get to know other staff members. Some care homes have meetings with residents and family members to share updates. Do ask about these as they could be a good way to meet the rest of the care team.

Try to communicate openly and regularly with care home staff. This can help to reassure you about the care the person is receiving. Having an open dialogue can also make it easier to give feedback. If you are comfortable communicating with care home staff, raising a concern is less likely to feel like a confrontation.

You can also help staff to support the person with dementia. This is another way to get to know them. Ask if you can be involved with any activities or help at mealtimes. See section 4 'Helping with the person's care' on page 40.

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# 3 Keeping connected

## 3

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# Visiting the care home

Regular visits to the care home can help you to stay connected. If you're not able to visit the home, you can also stay in touch using the phone or other technology. Each care home will have its own visiting policy, so ask staff about this ahead of your first visit. When you visit, think about ways to stimulate conversation or connection with the person. It can be reassuring to have some plans in place, even if you don't end up doing them. Some suggestions are listed below.

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- **Listen to music.** The charity Playlist for Life and the BBC Music Memories website help to create playlists for people living with dementia. See 'Other useful organisations' on page 80.
- **Look at newspapers and magazines.** These can provide a good basis for conversation. You could read articles out loud to them. For some people, a magazine with pictures will be more stimulating.
- **Do activities together.** These could include games, puzzles or arts and crafts. Choose an activity that suits the person's interests and current abilities. Activities that stimulate the person's senses, such as sound or smell, can be comforting for some people in the later stage of dementia. Try tactile games, fidget toys or sensory kits. You can buy these from our online shop – go to [alzheimers.org.uk/shop](https://www.alzheimers.org.uk/shop)



- **Join in organised activities.** Care homes often have a timetable of activities to choose from.
- **Create a memory box.** The person can choose photographs and objects that have happy or interesting memories for them. You could then use the objects to prompt conversation on future visits. If you're not able to put a box together, some libraries offer general reminiscence boxes that you can hire.
- **Do small jobs or chores.** Some people with dementia get a sense of achievement from doing tasks in the home. You could ask the person to help you dust their room or fold their clothes, if they are able. Ask the staff in the care home if the person could support with simple household tasks.

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Activities can be a good source of fun and connection, as well as cognitive stimulation for the person with dementia. Make sure that you adapt your plans to their mood and energy levels. They may be more willing to engage in conversation and activities on some days than on others.

If you're doing activities that involve reminiscence, some items (such as music or photographs) may bring back upsetting memories for the person. If you see them becoming agitated or distressed, stop the activity. Make a note to avoid things that remind them of this time. Let the care staff know too. Things that trigger memories of bad experiences are useful to include in the person's care plan.





# Taking day trips

Depending on the person's care needs, you may be able to take them out of the home. For example, you can go out for lunch or a community group session.

You may also be able to go out for a full day. This can be a nice way for them to engage with bigger groups of people or spend time with children. Simple activities like a short walk can be a good way to build up to a full day. Ask the care home staff how they may be able to support you.



For activity ideas see booklet 77AC, **The activities handbook**. Our magazine, **Dementia together**, can also provide inspiration for things you can do with the person. Visit [alzheimers.org.uk/magazine](https://www.alzheimers.org.uk/magazine).



## Celebrating special occasions

Speak to staff about how they celebrate occasions, such as birthdays, cultural holidays and religious events, in the care home. Let them know about how the person likes to celebrate – for example by eating specific foods or with important symbolic items. If you know what they do and don't enjoy, let staff know. Some care homes have private dining or 'celebration' rooms that relatives can book, so you could ask about this.

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Showing the person photos of previous celebrations can be a good way to reminisce and connect with them. You may have your own plans for a celebration or would like a faith leader to visit the home. Discuss these with staff well in advance. Make sure that plans are suitable for the person and adapted to their needs. For instance, if they would be overwhelmed by lots of people visiting at once, spread the visits out.



# Relationships with family, friends and other residents

When someone with dementia moves into a care home, it's likely that some of their relationships will change. Family members and friends who visit may not be sure about what to say or how to react. They may find visits too upsetting. If you feel able to, talk to them about how to make this easier. For example, they can take part in an activity with the person.

The person is likely to be interacting with more people than usual once they move to the care home. They may develop new friendships or relationships. This can be a source of comfort and enjoyment for them.

They may begin a romantic or sexual relationship with another resident. If this happens, the care home has a duty to make sure both partners have mental capacity and can consent to any intimacy. **For more information see factsheet 514, [Sex, intimacy and dementia](#).**

If the person is having difficulty with a particular resident, speak with the care home staff to find out more about the issue. Try to work together to find ways to resolve it.

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## If the person doesn't recognise you

There may come a time when the person with dementia doesn't recognise you. This can be very upsetting and difficult to understand. Consider sharing your feelings about this with friends, family or a professional such as a counsellor.

There are things you can do to help in these situations, such as planning visits at times when the person seems less confused. **For more information see factsheet 527, Changes in perception.**

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The person's confusion may come and go. This means there may be times when they do recognise you and times when they don't. It can be extremely distressing when someone you love doesn't seem to know who you are. It may be helpful to take a short break from visiting, or take someone with you for support.

See 'Benefits of visiting' on page 37, including when the person no longer seems to recognise you at all.

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**I plan my visits, have things to show Mum and I like to join in the activities at the home. I have to remember that she is safe, but I do cry after each visit.**

Family member of a person with dementia

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# Benefits of visiting

There can be benefits to visiting for both the person and you, even when this feels more difficult. This includes when they don't seem to know who you are:

- If the person enjoys your company, they may feel happy or safe around you, even if they don't recognise you.
- You could still have meaningful experiences with the person. For example, you can look through old photos, play songs or bring in items to prompt shared memories.
- You can still talk with them about events or people in their life. This can help them to feel included and maintain a sense of identity. This is very important for the person's mental wellbeing. It can help prevent them from becoming withdrawn or depressed. Conversations and activities can also provide good stimulation.
- If the person receives regular visits, they are less likely to become disorientated. For example, if you always visit on a Sunday, this will help them to keep track of the week. Sitting outside when it's warm, or talking about the weather, can help keep them in touch with the seasons.

3





You may get to a point where you feel unable to continue visiting. This can be very difficult. This is your personal decision and there is no right or wrong way to feel about it.

It may help to speak to others about how you feel, especially if they have experienced something similar. Our online community Dementia Support Forum provides support and understanding for people in difficult situations. To join, go to **[forum.alzheimers.org.uk](https://forum.alzheimers.org.uk)**



For more information visit **[alzheimers.org.uk](https://alzheimers.org.uk)**

# If you're not able to visit

If you are feeling unwell, exhausted or cannot visit for another reason, take a break from visiting and stay in touch in other ways. It's very important that you look after your own wellbeing. Care home staff should still be able to update you on how the person with dementia is, if you would like that.

It may help to arrange a regular day or time to speak with the person. If they are able to use a device with a messaging app, such as WhatsApp, family and friend groups can be a good way to keep in touch. Sharing photos and news about each other's lives can help you all stay connected.

You can ask staff if they can support you with certain methods of contact. For example, they can help the person to answer a video call or charge their phone. This is likely to depend on how busy staff members are. Discuss this with them and try to find a time of day that is suitable for everyone.

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# 4 Helping with the person's care

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## Personal care

Personal care is helping someone with their daily needs such as washing, dressing and grooming. The person is likely to need more help with this as their dementia gets worse. Details will be in their care plan for staff to follow. You can contribute to the person's care plan by telling the manager what they like and don't like, including how they prefer to wash. For example, some people with dementia don't like showers due to the noise, and the feeling of water hitting their head.

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If the person usually has their hair done once a week, ask if this can be arranged. The home may have a visiting hairdresser. If so, ask if the hairdresser works with the person's specific hair type.

Let staff know about the person's usual routine and any assistance they may need. Highlight any aspects that are important to their culture or background. For example, if they usually wear a turban, make sure that staff are aware of this.



For more advice see factsheet 504, **Supporting a person with washing and dressing.**





The person with dementia may refuse help with personal care. There can be many reasons for this. For example, the person may be unfamiliar with their carers, or they may be fearful of care from someone of a particular gender. This can be due to upsetting past experiences. They may also be uncomfortable receiving care from certain staff members. Where possible the care home should try to make alternative arrangements.

If you've helped with the person's personal grooming before, you may want to continue to help where you can. It can also be a nice way to spend time together – for example, going for a pedicure or visiting the hairdresser. Speak to the care home manager about arranging this.



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

The person may also need support with:

- Mouth care – Care homes need to ensure that their residents have healthy dental hygiene. Speak with the care home manager to find out what the home's policy is on this. **See factsheet 448, Dental and mouth care.**
- Using the toilet – Let the person know where the toilets are in the home. There should be signs or pictures pointing to their location. If not, talk to the care home manager about this. If the person uses continence products, such as incontinence pads, let the care home know. **See factsheet 502, Continence and using the toilet.**
- Eyesight and hearing tests – Ask the care home staff how they encourage residents to wear their glasses and hearing aids, and how they arrange regular sight and hearing tests.
- Foot care – This area can be missed but can cause discomfort if issues are untreated. Speak to the home manager regarding their policy on foot care and visits from chiropodists.

Be aware that some services can cost extra. Ask the home manager in advance about any additional costs.





# Eating and drinking

Care homes have a duty to make sure that residents are eating and drinking well, and to report any concerns. If anything worries you, for example if you notice that the person is losing weight, speak to care home staff and their GP.

Ask to see the meal plan. If you see anything on there that you know the person doesn't or can't eat, let the care home staff know. If you are considering bringing any meals into the home, always ask the manager first. Some homes don't allow this for food safety reasons.

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The person may need prompts to eat or may feel uncomfortable eating in a busy dining area. You might want to offer to visit at regular or some mealtimes to encourage or help them to eat. This can be comforting for them and another way to connect.



For more information on helping a person who is not eating or drinking enough, see factsheet 511, **Eating and drinking**.



# Behaviour that challenges

There may be times when the person behaves in ways that are out of character. This is difficult for the care home to manage. These behaviours can happen for a wide range of reasons. The care home should try to identify what might be causing them.

Let staff know of anything that could be contributing to the change in the person's behaviour, or what can help to settle them.



For more information see factsheets 525, **Changes in behaviour** and 509, **Aggressive behaviour**.

4



# 5 Speaking up for the person

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## When problems arise

Problems come up from time to time during a stay in a care home. These can range from items of clothing going missing, to the person being physically ill or becoming withdrawn or depressed. Sometimes, there might even be serious concerns about the care that they are receiving.

As someone who knows the person best, you are likely to notice any issues earlier than others. Try to be alert to signs that the person is struggling. For example, how do they usually show they are in pain or unhappy? Some people become withdrawn or stop taking care of themselves.

**5**

If you're in contact with other people who visit or talk to the person, you could discuss your concerns with them. Ask them for their opinion, or to look out for any issues when they can. If you think that something is wrong, gently ask the person how they're feeling. Give them time to express what is bothering them.

Try to reassure them that it is OK to say if something is not right. Some people will worry about making a fuss or getting into trouble. But care homes have to listen to the concerns of residents. They can't penalise someone for raising a concern. If you think there is an issue with the person's care, you should discuss this with the care home.

If you don't feel able to speak up for the person yourself, ask your local council or trust about getting an advocate for them. An advocate is someone who is trained to find out the views of the person and help them to be listened to.



You can also find out about local advocacy services by using our online directory **alzheimers.org.uk/dementiadirectory** or call our Dementia Support Line on **0333 150 3456**.

## If the person doesn't want you to raise a concern

The person may not want you to raise a concern. In this case, you should consider whether they have the ability to make this decision themselves. This is known as having 'mental capacity'.

- If the person **does not have the mental capacity** to make this decision, you should consider whether it is in their best interests to make it on their behalf.
- If the person **does have the mental capacity** to make this decision, you should respect their choice. The only exception to this is if you are worried about the person being unsafe, or if you think they are at risk of abuse or neglect (including self-neglect). This is known as a safeguarding concern. See 'Reporting safeguarding concerns' on page 56.



For more information about assessing mental capacity and making best interests decisions, see factsheet 460, **Mental Capacity Act 2005** (for England and Wales) or factsheet NI472, **Enduring power of attorney and controllership** (for Northern Ireland).



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



## Discussions with staff

Ideally, staff at the care home should discuss the person's care with you regularly, especially if there are any concerns about their wellbeing. However, if you notice an issue that hasn't been raised, it is best to bring this up with staff yourself.

It's not always easy to approach someone with a concern. Many people feel nervous doing so. Perhaps have an informal chat with a staff member first, either in person or over the phone.

If this makes you worried, try to remember that you are doing this on behalf of the person with dementia. It may help to have support from someone else, such as another family member. Try to stay calm, even if you feel angry or upset. A calmer approach will focus on the person's needs and result in a more productive discussion.

As care home staff are often very busy, ask if you can talk to them when they next have a quiet period. They are more likely to focus on your concerns if they're not in the middle of a task. If you have suggestions, mention possible solutions for staff to try. They may have already tried those methods, or perhaps the person's needs have changed. You may be able to come up with some ideas together.

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# Making a complaint

If you have raised your concerns with staff members and the issues haven't been resolved, you should consider making a formal complaint. All care homes must have a complaints process. Ask the care home manager about it.

You will usually need to put a formal complaint in writing. Include as much evidence as possible, explaining how the issue impacts the person with dementia. You may wish to include medical reports or statements from professionals involved in their care.



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If you're not sure how to access the person's records, see booklet 882, **Accessing and sharing information on behalf of a person with dementia**.



If you have submitted a formal complaint but the issue remains, you may need to take the complaint to another organisation. Who this is will depend on who pays for the person's care and where the care home is:

- If the person is **paying for their own care**, you should complain to an ombudsman. They are a public official who has been appointed to look into complaints. See 'Other useful organisations' on page 80.
- If **the local trust or council funds** the person's care, you should take your complaint to them. If that doesn't work, you should complain to the relevant ombudsman.
- If **the NHS funds** the person's care, you should take your complaint to the NHS body funding the care. If that doesn't work, you should complain to the relevant ombudsman.

There is no charge for making a complaint.

If you think that the care home is failing in its duty of care or isn't meeting its side of the contract, you could also get legal advice from a solicitor. You would have to cover the cost of this yourself.



# Reporting safeguarding concerns

Sadly, there are times when neglect or abuse can occur in care homes. Because this can put the person with dementia at risk, these are known as ‘safeguarding’ issues. They should be reported to the local council or trust immediately. Councils and trusts have a duty to look into any reports and take action if necessary.

There are many types of abuse, including physical, sexual, psychological, emotional and financial. As someone close to the person with dementia, you may notice signs of abuse. These could be:

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- unexplained bruises
- fear of personal care
- withdrawal
- changes in behaviour.

You may also notice signs of neglect, including self-neglect. These could be:

- poor personal hygiene
- a dirty room
- pressure sores
- unexplained weight loss
- dehydration
- inadequate clothing.



These are not the only signs of abuse or neglect, which will differ for everyone. Use your knowledge of the person to assess the situation.

If you believe the person with dementia is experiencing – or at risk of – neglect or abuse, you should report a safeguarding concern. The care home should make its own separate report.

To report a safeguarding concern, phone or email the safeguarding team at your local council or trust. You can find out who your local council is using your postcode – go to **[www.gov.uk/find-local-council](http://www.gov.uk/find-local-council)**

If you can, involve the person with dementia when you make the report. If the person has mental capacity to decide whether a report should be made, they may not want you to make one. However, if you feel that the situation is serious enough, you may decide to make a report anyway.

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# Restrictions on the person's freedom

A care home must keep residents safe. This may involve certain restrictions, such as preventing the person from leaving the home on their own.

Any restrictions will be highlighted in the person's care plan. If there are a lot of restrictions, this may legally amount to a 'deprivation of liberty'. If the person lacks mental capacity to agree to that, a process called the Deprivation of Liberty Safeguards (DoLS) will apply. This is a legal check.

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

The law is different in Northern Ireland. For more information from the Department of Health for Northern Ireland, go to **[www.health-ni.gov.uk/mca](http://www.health-ni.gov.uk/mca)**



As part of this process in England and Wales, the council or trust should appoint someone as the ‘relevant person’s representative’ (RPR). This is called the ‘nominated person’ in Northern Ireland. Their role is to represent the person if any deprivation of liberty issues arise. They can also, in some cases, challenge a restriction put in place.

If you have concerns about how the person’s freedom is being restricted, you should discuss this with the RPR or nominated person. If you are the RPR or nominated person, you should raise your concerns with the council or trust.

When a person has dementia, they may be less able to speak up for themselves. Standing up for the person’s rights can be a powerful way to continue your caring role. However, it can be exhausting and difficult. If you need support, we are here to help. Call our Dementia Support Line on **0333 150 3456** or join our online community Dementia Support Forum at **[forum.alzheimers.org.uk](http://forum.alzheimers.org.uk)**

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# 6 Managing finances

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## Change in benefits

If the person with dementia is receiving benefits when they move into a care home, this counts as a change of circumstance. This has to be reported to the benefit provider.

If you are the person's attorney or appointee, you should be able to do this yourself. Who you tell depends on which benefits the person gets. For contact details of different departments, visit **[www.gov.uk/report-benefits-change-circumstances](http://www.gov.uk/report-benefits-change-circumstances)**

When you report the move to the benefit provider, they will be able to tell you how this affects the person's benefits. Some benefits may continue, whereas others will stop.

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If you can, arrange for the person to have a full benefits check once they have moved to the care home. This can ensure that they are claiming all the benefits they are entitled to. If the person leaves the care home for weekend breaks, they may be able to claim some benefits at a daily rate. This is even if they don't receive them while in the care home.

You can find a local benefits adviser through the charities Age UK and Citizen's Advice. See 'Other useful organisations' on page 80.



The person's move to the care home can also affect benefits you receive, for example, if you receive Carer's allowance. Discuss this with the benefit provider. You may also want to consider getting a full benefits check.



For general information on benefits, see factsheet 413, **Benefits for people affected by dementia.**



# Care home fees and changes to them

Be clear from the start about how much the person's care home fees are, who is paying them and for how long. This is especially the case in either of the following circumstances:

- the person has moved straight from hospital, or
- the person has become a resident in the care home after a period of respite care.

Sometimes, public funding (from the NHS or local authority) may have paid for the person's care for a limited period. After this, the person may need to fund their own care. This could be if they do not qualify for longer term public funding, which can come as a surprise. It is important to ask the care home and local authority or trust for clarity at the outset.

If the person is moving straight from hospital, this should be discussed as part of the discharge process. Care homes should provide clear information about their fees at the start. This should outline what is included in the fees and what would be an additional cost.

Care homes can increase their fees in certain circumstances. These should be stated in the person's contract, alongside an explanation of how the increase is calculated. If a care home advertises a 'fixed rate' for new residents, always check the terms of this. Most homes will have an annual fee increase. If you would like an idea of what to expect, ask the home how much this increase was over the previous five years.

There are other circumstances in which care homes can increase their fees. For example:

- **There may be a change in the law** that makes it more expensive for the home to provide care services.
- **The person may choose to receive a more expensive service**, such as moving to a bigger bedroom.
- **The person's care needs may increase significantly**. For example, if they have a fall, they may need individual supervision or support. If you dispute this, the home will need an independent professional to support their assessment.

The care home should provide 28 days' notice before increasing their fees. They may reduce this to seven days if the increase is unexpected. This could be if the person needs immediate support.

If you think any fee increases do not follow the contract or are unfair, contact Citizen's Advice. See 'Other useful organisations' on page 80. You may also want to complain. See 'Making a complaint' on page 54.





# Paying for nursing care

If the person starts to need nursing care because their care needs increase, they may need to move to a different section of the care home. If the care home can't provide nursing care, the person may have to move to a nursing home. This can affect who pays for their care.

To decide this, an NHS continuing healthcare checklist should be completed for the person. This can be arranged by the care home, the local authority or trust, or by a medical professional. The checklist will show whether the person qualifies for any funding from the NHS.

If this checklist hasn't been completed and you think it should be, you can request it. You can also request an assessment if you think the person's needs have changed since they were last assessed.



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

The home should provide a written breakdown of the fees in the contract. If the person has funded nursing care, it should be clear what difference this payment makes to the total cost. Speak to the care home's finance department if you are unsure that the contract outlines the nursing costs and funding.



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

## When personal funding runs out

The person with dementia might be funding their own care. If their financial situation changes, they may be eligible for financial support from the local authority or trust.

To assess this, the local authority will ask them to complete a financial assessment. Depending on the outcome, the local authority or trust may start to pay for all or part of the person's care home fees.

When the local authority or trust is paying for care home fees, they will usually only pay for a care home that is within their standard rate. This is a set limit that the local authority will pay for someone's care. The person with dementia might be currently living in a care home that costs more than the standard rate. In this case, the local authority may ask them to move to a less expensive care home.

The local authority should always consider the person's health and wellbeing before requesting a move. If you think the move will have a negative impact on the person, you may wish to complain. See 'Making a complaint' on page 54.

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The local authority has to find a home that meets the person's eligible needs, as laid out in their support plan. You, or the person themselves, may prefer them to remain in a home that charges more than the standard rate. In this case you can choose to cover the extra cost. This is often called a 'top-up' agreement because you are 'topping up' what the local authority or trust is willing to pay. Top-ups must come from a third party, such as a friend or family member. First party top-ups, paid by the person in care, are not usually allowed.

Top-up payments should only be made voluntarily. If the person's eligible needs can only be met in a more expensive home, the local authority should increase their budget. They should never ask someone to pay a top-up fee for a more expensive care home if that care home meets the needs outlined in the person's support plan.



For more information on the financial assessment, see factsheet 532, **Paying for care and support in England**, NI532, **Paying for care and support in Northern Ireland** or W532, **Paying for care and support in Wales**.



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



# Managing the financial impact on the person's partner or family

A move to a care home is likely to have a financial impact on the person's partner and family. This can be worrying, especially if you have financial commitments such as mortgages and dependent children.

If you are the person's partner or child, let the local authority know about your financial situation. Ask them what they allow in their charging policy. There are some situations where the person may be able to keep more of their money.

You should also get a full benefits check as the person's move may affect which benefits you qualify for. For more information see 'Change in benefits' on page 62.

If you are worried about money, MoneyHelper can offer information and support. See 'Other useful organisations' on page 80. Your local authority may also be able to signpost you to sources of support and information.

6



# 7 Leaving the care home

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# Moving to a different care home

If you feel that the person isn't receiving good care in the home, you may be considering a move to a different care home. The person may also have to move if they are no longer able to fund a place in the care home they are currently in. See 'When personal funding runs out' on page 68.

Whatever the situation, it's important to think about how this move may affect the person with dementia. A change in routine can be confusing and may cause them distress. But the move may also allow them to live in a more supportive environment, where they receive better care or are closer to family and friends.

**7** Involve the person as much as possible, both in the decision-making and during the moving process. If they are able to make the decision for themselves then they should be allowed to do so.



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



A person whose care is fully funded may also be asked to move to a different care home by the local authority, trust or NHS body that is paying their care fees.

Sometimes, care is funded by the local authority, and the person needs to move to a care home in a different area. This then leads to confusion about which authority should pay for the person's care home fees. This should not affect their care. They should continue to receive the support they need.



# When a care home asks a resident to leave

It is worth knowing that in some cases, the care home may ask the person to leave. This decision should be taken very carefully and is usually because the home can no longer meet the person's needs – for instance, if they require nursing care.

Sometimes, the care home manager may feel that the person is causing distress or harm to staff or other residents. This situation can be very upsetting and may cause you a lot of stress, especially if you disagree with the care home's reasons. The following advice is about practical steps you can take. But also try to do things that help you to feel better at difficult times (see 'Where to get support' on page 14).

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Start by checking the contract that the person has with the home. This will set out the situations where the care home is entitled to ask the person to leave. The Competition and Markets Authority (CMA) has guidance about consumer rights for care home residents and their families. These rights apply regardless of who is paying for the person's care. See 'Other useful organisations' on page 80.



The CMA's guidance states that the care home must have valid reasons for asking a resident to leave. An example of this would be if they can no longer meet the person's care needs, even after making reasonable adjustments. Ask the care home manager what adjustments they have made to meet the person's needs. If the person's behaviour is causing harm to other residents, the care home could ask for support from the local community mental health team, district nurse or social services.

It might also help to think about the causes of the person's behaviour. This could highlight changes that the home could make before asking them to move. For example, it could be that their behaviour is due to poor care.

The care home should consult the person or their carer before asking them to leave. They should also give the person at least 28 days' written notice to leave. If you feel that the care home hasn't discussed this with you properly, you should consider complaining. You can also complain if you think they've asked the person to leave without trying to meet their needs first. See 'Making a complaint' on page 54.

In some cases, you may be able to challenge the care home's decision in court, though this could be expensive. Contact Citizen's Advice for support. See 'Other useful organisations' on page 80.



# Final arrangements

Whatever the reasons for the person leaving a care home, or if they stay there until the end of their life, there will be some final arrangements to see to:

- **Clear the person's room of all personal items.** Firstly, ask how long you have to clear the room, as leaving belongings can lead to extra charges. If the person is moving to a new home, check which mobility equipment is theirs to take. If they have stayed at the home until the end of their life, clearing their room can be very emotional. See 'End of life' below.
- **Pay outstanding invoices.** The care home will issue a final invoice if the person was paying for their own care. Read the invoice carefully and speak to the care home manager if you are unsure of anything. Make sure the care home has taken account of any deposit paid at the start. If the person has died, paying the invoice will be the responsibility of whoever is looking after their estate.

## End of life

It may be that the person with dementia stays in the care home until the end of their life. This can be upsetting to think about and difficult to deal with. You may want someone you know well to support you, or if you want to talk to someone, the charity Cruse Bereavement Support may be able to offer support. See 'Other useful organisations' on page 80.





If you would like further information on this sensitive area, see our factsheet 531, **End of life care** and factsheet 507, **Grief, loss and bereavement**.

## Saying goodbye to staff

It is likely that you will have built up a relationship with staff during the person's time in the care home. If you become close to any staff members, it may be hard to see those relationships come to an end. Staff at the care home may also be upset to no longer be caring for the person. Goodbyes can be emotional but don't worry if you are unable to say goodbye to everyone, especially at such a difficult and busy time for you.

You may feel that you didn't have a particularly good experience with the care home and that it could be improved in areas. If this is the case, it could be helpful to give your feedback to the care home manager in a letter or email. This may help your own wellbeing, as well as the care of future residents. Equally, you can let the care home know if you feel the person was cared for well.

7



# Other useful organisations

## **Age UK**

0800 678 1602 (advice line, 8am–7pm Monday–Sunday)  
contact@ageuk.org.uk  
www.ageuk.org.uk

## **Wales – Age Cymru**

0300 303 4498 (advice line, 9am–4pm Monday–Friday)  
advice@agecymru.org.uk  
www.agecymru.org.uk

## **Northern Ireland – Age NI**

0808 808 7575 (advice service, 9am–5pm Monday–Friday)  
advice@ageni.org  
www.ageuk.org.uk/northern-ireland

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

## **BBC Music Memories**

musicmemories.bbcrewind.co.uk

The BBC Music Memories website offers themed music playlists for people living with dementia.

### **British Psychological Society (BPS)**

0116 254 9568

info@bps.org.uk

www.bps.org.uk

The BPS has information about clinical and counselling services, including a list of psychologists and therapists in different areas.

### **Carers UK**

0808 808 7777 (helpline, 9am–6pm Monday–Friday)

advice@carersuk.org

www.carersuk.org

Carers UK provides information and advice for carers about their rights and how to access support. For example, to find out about carers' assessments, see the Carers UK factsheet.

### **Citizens Advice**

0800 144 8848 (advice line, 9am–5pm Monday–Friday)

0808 223 1133 (consumer helpline, 9am–5pm Monday–Friday)

www.citizensadvice.org.uk

Your local Citizens Advice can give you information and advice in confidence or point you in the right direction. To find your nearest branch, look in the phone book, ask at your local library or look on the website.

### **Competition and Markets Authority (CMA)**

[www.gov.uk/government/publications/care-homes-short-guide-to-consumer-rights-for-residents](http://www.gov.uk/government/publications/care-homes-short-guide-to-consumer-rights-for-residents)

The CMA is set up to protect consumers from unfair trading practices. They have produced a guide to consumer rights for residents in care homes.

### **Cruse Bereavement Support**

0808 808 1677 (helpline, 9.30am–3pm Monday–Friday)  
[www.cruse.org.uk](http://www.cruse.org.uk)

Cruse Bereavement Support is a national charity for bereaved people in England, Wales and Northern Ireland. It offers face-to-face, telephone, email and website support.

### **Local Government and Social Care Ombudsman**

0300 061 0614 (10am–1pm Monday, Tuesday, Thursday, Friday; 1pm–4pm Wednesday)  
[www.lgo.org.uk/how-to-complain](http://www.lgo.org.uk/how-to-complain)

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

### **MoneyHelper**

<https://www.moneyhelper.org.uk/en> (England)  
<https://www.nidirect.gov.uk/contacts/money-helper>  
(Northern Ireland)  
<https://www.moneyhelper.org.uk/cy> (Wales)

MoneyHelper provides free, impartial advice about money.



## **Mind**

0300 123 3393 (infoline, 9am–6pm Monday–Friday)  
info@mind.org.uk  
www.mind.org.uk

Mind is a charity that offers information and advice on all aspects of mental health. It provides a range of support services through local Mind associations.

## **Northern Ireland Public Services Ombudsman**

0800 34 34 24 (9am–5pm Monday–Friday)  
nipso@nipso.org.uk  
nipso.org.uk/nipso/making-a-complaint

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

## **Playlist for Life**

0141 404 0683  
info@playlistforlife.org.uk  
www.playlistforlife.org.uk

Playlist for Life is a charity that supports people to create music playlists for people living with dementia.



**Public Services Ombudsman for Wales**

0300 790 0203 (10am–12.30pm and 1.30pm–4pm

Monday–Friday)

[ask@ombudsman.wales](mailto:ask@ombudsman.wales)

[www.ombudsman.wales/how-to-complain](http://www.ombudsman.wales/how-to-complain)

The Public Services Ombudsman for Wales deals with all complaints about public services in Wales, including about local councils and the NHS.

**Relate**

[www.relate.org.uk](http://www.relate.org.uk)

Relate offers relationship counselling for individuals, couples and families in England and Wales. It provides advice and support by phone, face-to-face and through its website. For Relate in Northern Ireland see [www.relateni.org](http://www.relateni.org) or call 028 9032 3454.

**The Association of Lifetime Lawyers**

0844 5676 173

[www.lifetimelawyers.org.uk](http://www.lifetimelawyers.org.uk)

The Association of Lifetime Lawyers is a national organisation of lawyers, such as solicitors, barristers and legal executives, who provide legal advice for older people, their families and carers.

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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: Lisa Betteridge, Senior Practice Lead and the Warrington Speak Up Team and Jessica Peterson, Specialist Practitioner, Dementia Team, East Kent Hospitals University Foundation NHS Trust

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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**

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for everyone living with dementia

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