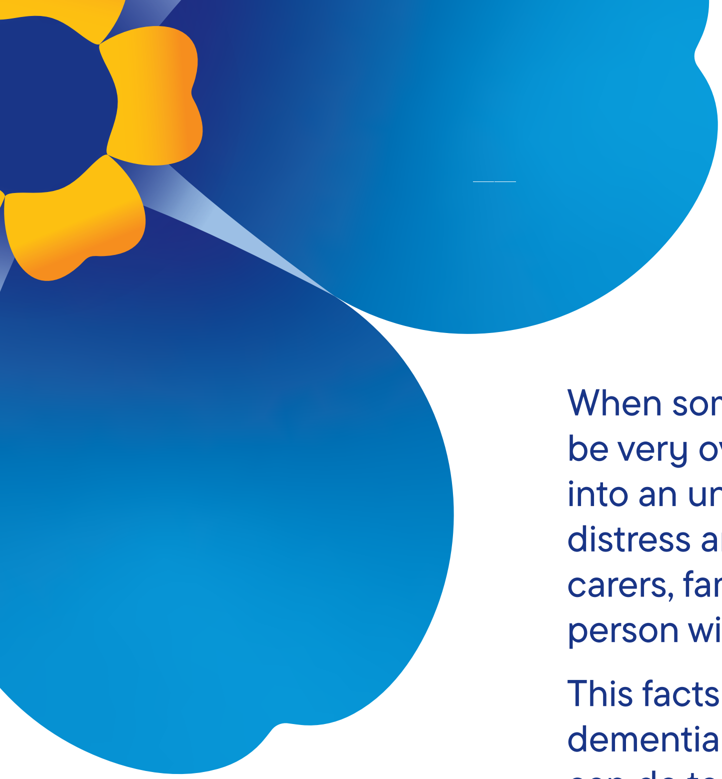
Hospital care

Alzheimer's Society

Together we are help & hope
for everyone living with dementia



When someone with dementia goes into hospital, it can be very overwhelming for them. The sudden change into an unfamiliar and noisy environment can cause distress and confusion. It can also be stressful for carers, family or friends who often worry how the person will cope.

This factsheet is to help those supporting a person with dementia during a hospital stay. It explains what you can do to help, how you can reassure the person, and what to expect when they are discharged.

Contents

1 Preparing for a hospital stay

There may come a time when a person with dementia may need to go into hospital. This could be planned, such as tests, treatment, or an operation. But it could also be unplanned following an emergency, such as a fall or illness. The following guidance can help you prepare for both.

Planned hospital stays

If the hospital stay is planned, the person will normally be sent a letter in advance with instructions. These can include whether they can eat or drink beforehand and details on how long their stay is likely to be.

You can contact the hospital department if you have any questions or concerns about a planned visit. You should also let them know if the person with dementia has communication needs. This could be needing an interpreter, someone to help them during conversations, or a communication tool. The hospital's website may have information about support they can offer.

How you can help

- **Read through the instructions together**. Note down anything they need to take with them, such as medication, glasses or hearing aids.
- **If the person is worried**, ask them what information you can find out to reassure them.
- **Involve them when deciding** which nightwear and clothing to pack in their hospital bag.
- **Discuss any belongings they may wish to take** with them to keep busy, such as a music device, books or magazines. You could also take any personal items that will help the person to feel more settled, like a smartphone or photo album. Keep important items in a safe place and avoid taking anything that is irreplaceable. Check insurance on anything valuable.
- **Label any clothing or belongings** with the person's name in case these get lost.
- **Ask if you can help with anything at home** while they're away, such as putting the bins out or watering the plants.
- **Arrange any transport** that may need to be booked ahead.
- **Consider filling in a This is me®** form to help hospital staff to know the person's likes and dislikes. See 'This is me' on page 6 for more details.

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Unplanned hospital stays

Not all hospital admissions can be planned in advance. Sometimes a person will suddenly have to be admitted to hospital. This can be due to an illness, a concern by healthcare professionals, or an accident or fall.

Sudden hospital admission can be very frightening for a person with dementia, as they may not fully understand what is happening. The following may help to prepare and support them.

How you can help

Have a hospital bag 'list'

It can help to have a list ready of things to pack in case of a hospital admission. The list could include everyday items that the person needs, like glasses and medication. You could also add their favourite snacks. Things that the person usually finds comforting, such as knitting or a blanket, can help them feel more 'at home' in an unfamiliar place.

Prepare a medical communication form

You may have a local scheme that can help the person with dementia to communicate their wishes in an emergency. These forms are usually completed by you and the person, such as MedicAlert®. Some forms, such as ReSPECT, need to be completed jointly with a clinician.

These forms can be a huge help to hospital staff or paramedics who may not be aware of the person's dementia. Filling in these forms sooner rather than later can help you prepare in advance of a hospital admission. You can ask your GP if they have the forms or go to **resus.org.uk** and **medicalert.org.uk**

Communicate with the person

One of the most important things you can do to help a person with dementia in hospital is to communicate with them as much as possible. Let them know what is happening and provide relaxed conversation as much as you can. This may be difficult if you are feeling worried or stressed yourself, but the person with dementia will really benefit from this.

Communication is not just what you say. It can also be your tone of voice and body language. Depending on the person, a reassuring smile or a squeeze of the hand can make a big difference to how they feel.

> “**Being ready would have greatly made my mum's times in hospital potentially easier to deal with for us as a family and hopefully less stressful for my mum.**
>
> Family member of a person with dementia”

If the person doesn’t want to go to hospital

Sometimes a person with dementia may refuse to go to hospital. It could be that they don’t understand what is happening or why they need treatment.

Dementia can affect decision-making. Legally, the ability to make a particular decision is known as having the ‘mental capacity’ to make it.

In some cases, a person with dementia will not be able to consent to being in hospital, as they lack the mental capacity needed to make this decision. In this case, someone (or a combination of people) will need to make a best-interests decision on their behalf. For more information, see factsheet 460 **Mental Capacity Act 2005**.

If the person has made a Lasting power of attorney (LPA) for health and welfare, their attorney (who might be you) has the power to decide if they go to hospital or not. If the hospital visit is for treatment that is life-sustaining, that power will only apply if the person with dementia has chosen that option on the LPA form.

In some cases, where the person lacks mental capacity to agree to being in hospital, their stay may also need to be authorised under the Deprivation of Liberty Safeguards (DoLS). The purpose of DoLS is to ensure that the person receives the treatment and care they need, even if it reduces their freedom and independence. For more information, see factsheet 483 **Deprivation of Liberty Safeguards (DoLS)**.

If the person needs to be assessed or treated in hospital for a mental health condition (not a physical one), they can be detained (or ‘sectioned’) against their will under the Mental Health Act 1983. This is regardless of their mental capacity. In Northern Ireland, this is known as the Mental Health (Northern Ireland) Order 1986. This can only happen if they are a risk to themselves or others and should be a last resort. For more information, see factsheet 459 **The Mental Health Act 1983**.

Hospital dementia support

> Hospitals differ in what they offer people with dementia and their families. Some will have specialist services or staff, such as liaison psychiatry services or a dementia lead. Some hospitals may use tools like carer passports to allow for longer visiting times. Others may use identification schemes, like a butterfly symbol to raise staff awareness and help provide appropriate care. Ask what is available for you.

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2 During a hospital stay

Being in hospital can be a frightening experience for a person with dementia. Hospital staff are often very busy and will not always have time to sit with their patients.

If a person with dementia doesn't receive enough stimulation and emotional support, or they are left alone for too long, this can cause their symptoms to become worse. There are ways you can help with this, if you are able to.

Supporting the person in hospital

Being in hospital can increase confusion and distress for a person with dementia. This can be for many reasons, such as being in an unfamiliar place, or due to their medical symptoms, such as pain or delirium. See 'Recognising delirium during a hospital stay' on page 8.

Increased confusion and distress can cause:

- agitation
- restlessness and increased 'walking about'
- anxiety
- poor eating and drinking
- resistance to help
- changes in behaviour.

Being aware of these possible issues may help you to understand any emotions or behaviours the person may be experiencing in hospital. You may decide to support them where you can. However, there is no pressure from the hospital for you to do this, especially if you have other commitments or can't get there. If you feel you can and wish to, then it may give you some comfort to help.

> **“It can be a heartbreaking experience having a relative or close friend in hospital and this is made even more difficult when they have dementia.**
>
> Family member of a person with dementia”

How you can help

Build good relationships with staff

Having good relationships with ward staff can be useful. Staff should be able to answer any questions and discuss any issues you may have. If they seem too busy to talk, ask for the name of the nurse who is responsible for setting up the person's care. You can then ask for a call or appointment with this named nurse. If you are worried about disturbing busy staff members, note down any questions you have and approach them during quieter times.

If you want to discuss the person's condition or treatment in more depth, you could ask the nurse when the doctor or consultant is next due on the ward. This is a common question, so don't worry about asking.

Share information about the person

Hospital staff might not be aware that someone has dementia, or they may not all have experience of working with people with dementia.

It can be helpful for family and friends to share information with ward staff on how the person's dementia affects them. Any information you can give about the person is useful as it will help staff to understand and respond to them as an individual.

As information can be lost or forgotten, it can help to write down some important facts about the person with dementia. This can then be given to the named nurse and held in the person's medical notes.

Useful information you could give about the person includes:

- **the name they like to be called** and the way they prefer to be spoken to. For example, in a casual way, such as 'Charlie', or formally, such as 'Mr Cohen'
- **details of their normal routines**, including whether they need reminders or support with things like washing, dressing, eating and drinking, going to the toilet or taking medication
- **any communication difficulties** and tips on how best to communicate with the person. For example, 'Mrs Sellers finds it helpful if people talk slowly and give one piece of information at a time'
- **foods they like or dislike**, or any difficulties they have when eating. For example, 'Ravi can feed himself with a spoon if someone cuts his food up for him'
- **details of any cultural or religious needs**
- **their usual sleeping patterns**
- **how active the person likes to be** – for example, if they usually walk about
- **what can calm the person** when they are agitated
- **if they have an advance decision** or a personal welfare Lasting power of attorney (LPA)
- **any other information** that can help staff build a friendly relationship with the person, such as knowing hobbies, pets or past occupation.

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> **Mum and I filled [the forms] in together after her medical details had been added. I also added this form to her This is me booklet.**
>
> Family member of a person with dementia

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This is me®

> Hospital staff might know that someone has dementia, but they may not know what their likes and dislikes are. To help with this, you may find our handy tool This is me® useful. This helps staff to know the person, their preference for care and things that reassure them.
>
> To download this for free, go to **alzheimers.org.uk/thisisme** or to order a hard copy, call **020 7423 7455**.

Making decisions in hospital

During a hospital stay, a number of important questions and decisions may need to be discussed. This may be difficult for the person with dementia if they don't understand the question or can't process the information. You and hospital staff should do what you can to help the person to make their own decisions.

If they don't have mental capacity to decide for themselves, having the following arrangements in place can be hugely helpful:

- **Lasting power of attorney (LPA) for England and Wales or Enduring power of attorney (EPA) for Northern Ireland**

  LPAs and EPAs allow someone to appoint another person to make certain medical or financial decisions for them. This is if they are no longer able to make those decisions themselves.

  An LPA for health and welfare will allow the attorney to make decisions about care and treatment. It's a good idea to let the hospital have a copy. It's important to note that an EPA only covers financial decisions and not health ones. This may be of limited help in a hospital situation but still worth letting the hospital know about.

  For more information, see our factsheets 472 **Lasting power of attorney** and NI472 **Enduring power of attorney and controllership**.
- **Advance decisions or directives**

  These legal documents allow someone to refuse, in advance, specific medical procedures or treatments. Like LPAs, advance decisions are legally binding. This means that health professionals have to follow these decisions if they can be applied in that specific situation.
- **Advance statements**

  These allow a person to explain what they like and don't like, and to set out their preferences for the future. Unlike LPAs and advance directives, advance statements aren't legally binding, but they must still be considered when people, such as doctors, make decisions on their behalf.

If the person you support would like to look into these options, they can find out more in our booklet 1510 **Planning ahead**.

Even if the person hasn't made any of these, you should still be consulted by doctors and other hospital staff about the person's best interests. This is if they cannot make decisions about care or treatment themselves.

Providing comfort and reassurance

Hospitals can be loud and unfamiliar places, and the person with dementia may not understand where they are or why they are there. If the ward is busy, such as during mealtimes and visiting hours, this can add to their confusion and increase their anxiety or agitation.

How you can help

- **Talk to the person**, read to them if you can, and provide emotional support. This can make a big difference because familiar faces can bring comfort and reassurance.
- **Place a whiteboard next to their bed** with answers to the questions they keep asking. This could be why they are in hospital, when they are leaving and where their personal items are kept.
- **Check their hearing aids** are on and at the right level for the person's new surroundings.
- **Make sure glasses are clean and labelled** with the person's name and type of glasses (such as 'reading glasses') if they have more than one pair. This is so they can see clearly, and the glasses can be returned if they misplace them.
- **Ask if there is a day room** where the person can visit to get a break from the ward, if this appeals to them.
- **Bring in familiar objects**, such as photographs of pets and family members. These can also provide staff with a good talking point.
- **Leave a notebook** so visitors can write messages, reminders and details of when they are next visiting.
- **Consider packing casual clothes** that are easy to wear. It may help the person feel more comfortable to wear their own clothes. It can also help them to settle into different routines for daytime and night-time.

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Recognising delirium during a hospital stay

Delirium is a condition that starts suddenly in someone who is unwell and is a different condition to dementia. However, it is common for people with dementia to become delirious when they are in hospital. This is because delirium has a range of causes and is usually the brain's reaction to a separate medical problem. These can include constipation, pain, an infection, or dehydration.

Delirium is usually treated by treating the medical problem that is causing it. Symptoms of delirium can start over hours or a few days. They can also come and go from one moment to the next. The person's symptoms can be frightening and may include:

- being unusually sleepy or agitated
- becoming disorientated – not knowing where they are or what day it is
- being unable to concentrate
- having disturbed patterns of sleeping and waking
- showing changes in behaviour and having mood swings
- experiencing hallucinations
- having abnormal or paranoid beliefs.

There are different types of delirium, and these are treated in different ways depending on the person's needs.

How you can help

- **Look for changes in the person's behaviour** and speak to a nurse or doctor immediately if you notice any. Family, friends and carers often recognise changes first as they know the person best.
- **Try to make the person's surroundings familiar** to them by bringing in objects from their home. Visits from people they recognise can also help, if possible.
- **Set up a dementia-friendly clock** or a wipe board to remind the person of the date, time and where they are, if this helps them. Keeping the room light and airy during the daytime can also help, where possible.
- **Try to stay calm** when communicating with the person. Talk slowly and provide plenty of reassurance.
- **Listen to their concerns**, even if they don't seem to make sense to you. Gently remind them where they are and what's happening. Being understanding can help them stay calm.
- **Help them to drink regularly** as dehydration can make delirium worse.

Eating and drinking

Mealtimes in a busy hospital can be difficult for a person with dementia. Staff may be able to let you stay beyond usual visiting hours if you want to help. Staff are often especially busy at mealtimes and may be grateful for any help you can offer.

If the person is struggling to eat and drink, let staff know of any particular difficulties they may have at mealtimes. This can help them provide better care while you're not there. For example, some hospitals use reminders, such as a different coloured plate or a sign by the bed, to alert staff if a person needs extra help to eat.

How you can help

- **Don't assume that the person isn't hungry** if they don't seem keen to eat. Try to make the food seem more appealing by talking positively about how it looks or smells.
- **Be aware that the person's food preferences may change**. They may no longer like the same foods that they used to.
- **Consider keeping snacks by their bed** if they do not want to eat an entire meal and prefer to eat little and often. Speak to the named nurse first to make sure the snacks are suitable.
- **Make mealtimes more sociable** by having a snack or a drink at the same time as them. Talking to them about their favourite foods could help increase their appetite.
- **Create a routine around meals**. If the person can sit in a chair rather than lying in bed, this might prompt them that it's time to eat.
- **Consider foods they can eat with their fingers** if they are struggling to use cutlery. Examples include bread rolls, potato wedges, spring rolls or samosas.
- **Help the person stay hydrated**. Hospital wards are often warm and staff may not have time to ensure that a person drinks enough. Offer drinks and hydrating snacks as often as possible. Water, tea, juices, jellies and soft fruits can all help.
- **Ask if food can be provided soft or mashed** if the person has difficulty chewing or swallowing. If you're not sure whether their difficulty is with swallowing or something else, ask if they have been referred for an assessment from a speech and language therapist.
- **Ask if the hospital has a separate dining room**. This can offer a change of scene for the person with dementia.

If the person isn't eating well, or is starting to lose weight, they should never be forced to eat. The named nurse should speak to the hospital dietitian who will set up a nutritional care plan with nursing and catering staff. This may involve high-energy drinks or specific foods.

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If they are very unwell, they may not want to eat or drink at all. If this continues for a long time, the clinical team may suggest other ways of keeping the person well-nourished, such as feeding through a tube. When deciding if the person needs to be tube-fed, staff should speak with carers or relatives to discuss what's in the person's best interests.

Medication and managing pain

Managing pain can be difficult when hospital staff don't know the person well. Dementia and being in pain can affect a person's ability to communicate. This can mean that they aren't able to tell others how they feel.

If a person is in pain and can't tell others, they may start to behave differently. For example, they may scrunch up their face or rock backwards and forwards.

How you can help

- **Check for things that might be hurting the person** if you cannot see an obvious cause for their pain. Examples include sores in their mouth or bruises on their body.
- **Ask staff for an assessment** if you think they are in pain. The doctor may prescribe medication that can help. Doctors should speak with you and the person before they make any changes to the medication.
- **Consider alternative pain remedies** that do not involve medication, such as heat pads or massage therapy. Hospitals will differ in what they can offer, so ask what is available.
- **Be aware of the risks of sedation**. Hospital staff might prescribe a sedative if the person's pain is making them agitated. Sedatives do not treat pain and can make the person more confused. They should only be used if the person is putting others at risk, and after the doctor has looked into what could be causing their behaviour. Talk to the doctor if you have any concerns. It may be possible to reduce the dose or stop the medication. If the person gets agitated, other solutions could include stimulating activities or extra support from a healthcare assistant.

Helping at the hospital

> If you feel you want to help, there are things you can do for a person with dementia while they are in hospital. This can include practical help with things like eating and washing, as well as providing them with company, stimulation and emotional support. However, not everyone will be able to do this, and the hospital staff will not expect you to.

Walking around

Someone with dementia might try to get up and walk around the ward. It can be good for them to be active during a hospital stay, but it's important that they are safe and don't become lost. Never leave the ward with the person with dementia without informing ward staff.

How you can help

- **Ask staff for adjustments to help them walk safely**. They might let the person walk on the ward at quieter times or when visitors are with them. Some wards have rooms with space for people to walk around or watch a film while exercising. They may need to be supervised, so discuss this with staff beforehand.
- **Explain to staff why walking might help**. Some people can become stiff if they don't move around, making them more likely to have falls when they do get up again. Other people may feel threatened, agitated or angry if they're stopped from walking.
- **Ensure all risks are considered**. Agree on ways to reduce risk such as certain footwear, familiar routes or accompanied walks.
- **Encourage movement**. If the person likes to be active, it might help to involve them in suitable activities like chair-based exercises.
- **Help them walk comfortably** by bringing slippers or comfortable footwear.

Incontinence

> Ward staff should always try to support a patient to get to the toilet if they are able to. You can help by explaining what kind of support they need. Although continence aids can be reassuring for some patients, most would prefer to go to the toilet if they can. Using pads when there is no assessed need can de-skill the person and impact their dignity and wellbeing. Request that a continence assessment is done before pads are used.

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> **I included [behaviour] in mum's book, and always drew attention to it when I was visiting, both to her and any staff. Mum was a wanderer.**
>
> Family member of a person with dementia

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Complaints

Most people receiving treatment in hospital feel supported and well looked after. However, sometimes things can go wrong, and you might want to complain.

If you have any problems with the person's treatment or care, discuss these first with the named nurse. They should explain why things went wrong and how they will be put right.

If you still want to make a complaint, consider the following tips:

- **Try to stay calm and polite** – this will help you and the person.
- **Be specific about your concerns** – for example, on three occasions you came in and saw that the medicines on the table had not been taken. It may help you to have the details written down with dates and times.
- **Be clear about what you would like them to do** to improve the situation and resolve your complaint.

If it is not possible to sort the problem out straightaway, try to keep notes, as it is easy to forget details. The notes should include:

- what happened and when
- who you contacted or spoke with
- what their response was.

If the problem still cannot be resolved, ask to see the ward manager or make an appointment with the consultant.

If you are in England or Wales, you may prefer to contact the Patient Advice and Liaison Service (PALS), which is based at the hospital. If you are in Northern Ireland, you can contact the Patient and Client Council (PCC). This is a national body which has a similar role. See 'Other useful organisations' on page 23 for details. PALS and PCC can represent patients and families in discussions with hospital staff to help resolve problems and concerns quickly.

Think about welfare benefits

> Keep the DWP (or Department of Communities in Northern Ireland) informed about planned and unplanned hospital stays. This will avoid overpayment of benefits. See page 26 of factsheet 413 **Benefits for people affected by dementia**.

3 Hospital discharge

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During a hospital stay, you will hear the word ‘discharge’. This is the term used for when a person is considered ready to leave the hospital by medical professionals. It involves putting a plan in place to ensure the person is supported and safe when they leave. See ‘Hospital discharge process’ on page 14.

Discharge conversations with hospital staff can often cause a great deal of worry for carers, family and friends. This is because it can be hard to decide what is the best option. You may want to provide care for the person but feel unable to due to your own commitments or health. You may also have feelings of guilt over the person needing outside help or a care home. These thoughts and feelings are very common, and normal.

Hospital staff may ask you if you are able to provide care for the person. It is important to consider this request very carefully. This may be a big change for you and the person with dementia, and it’s difficult to know what to expect.

If you do wish to help, and feel able to, be very clear which tasks you can help with and for how long. If you are worried that you won’t be able to provide the care they need, you must say. Although it can be emotionally difficult to refuse, it is important to be realistic about what you can manage. Sometimes providing the best care is knowing the limits of what you are able to provide without additional help. See various options in ‘Following a stay in hospital’ on page 16.

You cannot be made to provide care for the person, no matter what your relationship is. The decision is yours and how it affects your life and health.

If you decide you aren’t able to provide care for the person, the local authority may be under a duty to meet their needs. But if you agree to provide care on an ongoing basis, this means the local authority are no longer under a duty to meet that need. Talk this through with the person and anyone involved in their care.

If you agree to provide care after discharge, but later change your mind, you will need to contact the local authority directly and request an assessment. Ask how long assessments are taking locally as there may be some delay.

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Assessment for hospital discharge

A doctor at the hospital will decide if a person is able to be discharged. To prevent delays, some hospitals operate a 'criteria-led' or 'nurse-led' discharge process. This is where a doctor will identify the criteria (goals) that are tailored to a person's circumstances. When these criteria are met, the person will be able to be discharged without having to wait for another review from a doctor.

A discharge should only happen once they assess that the person is 'medically optimised'. This means that they no longer need the same level of medical attention that they have been receiving in hospital.

Many people with dementia are likely to require some level of short-term care once discharged from hospital. A case manager (sometimes known as a discharge coordinator) should be allocated to ensure a safe and timely discharge. They should liaise between any professionals that need to be involved both within and outside the hospital. This can include a social worker, a care home manager or home care provider.

Hospital discharge process

Hospital discharge should be discussed as soon as possible following admission. There is now a legal duty in England to involve carers in discharge planning where a patient is likely to need care following their stay.

Hospital staff and social care departments will consider the person's short-term needs, and how to keep them safe after discharge. Their long-term needs must no longer be assessed in hospital. Wherever possible, patients will be supported to return to their home for assessment of their long-term needs, after a period of recovery.

In England, patients may be allocated a 'pathway' dependent on what care and support they may need after discharge. These include:

Pathway 0 – for people who are well enough to return to their home setting with no extra support. If the person previously had professional care in place which has lapsed, it may need to be restarted. In Pathway 0, discharge is usually managed by ward staff. There may be a local voluntary organisation which offers a 'Home from Hospital' scheme. This can help with tasks such as shopping or cleaning. The person should be transferred to a discharge area as soon as possible and should be able to leave hospital the same day.

Pathway 1 – for people who need additional time-limited support. This will usually involve recovery and relearning skills at home, or within the care home they lived in before admission. This may be referred to as intermediate care or reablement. They will be allocated a case manager, and their discharge will be managed by the care transfer hub, rather than the ward staff.

Pathway 2 – for people who need a very high level of care. If the person cannot stay in hospital, they may be discharged to a care home, community hospital or to a bed-based rehabilitation facility.

Pathway 3 – for more complex discharges including those with significant health and social care needs. This is usually for people who cannot return to where they lived before and are likely to need a longer-term placement.

Other than in exceptional circumstances (for example if the person is not expected to recover or gain any independence again), no one should be discharged directly into a permanent care home placement. They should be given the opportunity to recover in a temporary placement before their long-term needs are assessed.

Hospital beds

> As soon as a doctor decides that a patient is ready for hospital discharge, their bed will need to be used to treat the next patient. People do not have the right to remain in a hospital bed until their preferred care option becomes available. If they can be discharged to a safe place, then they must leave the hospital.
>
> If you don't think the alternative offered is safe or suitable, you can share your concerns with the ward manager or nurse-in-charge. Safe means meeting the person's assessed short-term needs. Suitable means meeting preferences and a good fit for that person, for example a reasonable distance from the family. However, safety needs will likely be the priority.

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4 Following a stay in hospital

After leaving hospital, the person may need more support than they did before. If this is the case, where they move to may have to change.

Sometimes this will be temporary, such as being discharged to a smaller community hospital or care home until they fully recover. Sometimes, this change will need to be permanent to keep the person safe. It usually won't be clear whether the arrangement will be short or long term until their needs are assessed following a period of recovery.

If a care home or nursing home is required, patients and their families should be given as much choice as possible. People with dementia should be supported to make fully informed decisions. If they lack mental capacity to decide, a best-interests decision will need to be made. This may be made by their attorney under an LPA for health and welfare (if they have one) or by family members alongside professionals such as medical staff or social workers.

However, as the immediate placement must be available quickly and is only required to meet the person's short-term needs, the choice may be limited. This may mean they are initially discharged somewhere which isn't ideal if more care is required in the long term.

If a person disagrees with the placement, they should clearly explain the reasons why. As the placement is not designed to meet long-term needs, it is important to focus on why the placement isn't suitable in the short term. Moving more than once in a short period of time can make some people with dementia feel disorientated or unsettled. So this may be worth raising.

How you can help

- **Make it clear if you want to be involved** in discussions about discharge.
- **Discuss options with the person** with dementia and involve them where possible.
- **Ask to see a copy of the hospital discharge policy** and if a pathway has been allocated.
- **Make a list of the names of people you have spoken** to and their contact details. A lot of people may be involved in the assessment, so this can help you keep track.
- **Research local care homes or homecare agencies** if the person is in hospital for a while. Ask who currently has availability for temporary and long-term placements. This can help you feel prepared if one is suggested as a discharge placement. You may also be able to suggest one as an alternative option to be considered if you don't like the suggestions that have been made.
- **Ask who will be funding care** and for how long in any discharge meeting. See 'Paying for short-term care after discharge' on page 19.
- **Ask about the fees of any care home suggested** if they are likely to require a care home long term. Social care is means-tested, which means dependent on their finances they may need to pay some or all the costs. If they are eligible for a contribution from the local authority, it's important to know if the home suggested requires an additional payment from a friend or family member. This is known as a 'top up' and should always be a choice. Local authorities must identify at least one home which does not require a top up and can meet your needs. Self-funders, who are expected to cover all their own fees, should consider how long their savings will last in any placement to avoid moving again in the future.

For more information on the financial assessment for social care, see our **Paying for care and support** factsheets 532 (England), W532 (Wales) and NI532 (Northern Ireland).

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At the end of life

If someone with dementia is nearing the end of their life, they will not usually be kept in hospital. Instead, the community palliative care team will organise for them to be discharged to a care home or hospice.

Even after discharge from hospital, end of life care plans should still focus on supporting the person's physical and spiritual needs. This can include relearning skills and abilities to maximise their independence. These plans should always involve the person and their family, as well as a number of different professionals.

Patients with a 'rapidly deteriorating condition who may be entering a terminal phase' may require 'fast-tracking'. This is for the immediate provision of NHS continuing healthcare. Ask staff if they have considered this. This funding may support the person to return home with the appropriate care package.

If the person's doctor or medical professional has told them that they might have less than 12 months to live, ask if they can complete an SR1 form. This will ensure the person with dementia can receive any benefits they are entitled to quickly. This process is known by the DWP as 'Special rules'.

For those who are in their last few days or hours of life, they may stay in hospital rather than being discharged. Most hospitals have specific guidelines for care at the end of life. These ensure that:

- staff check in with the person and their relatives frequently and in a sensitive manner
- the person at the end of life and their family are involved in treatment and care decisions
- decisions about care are made according to the person's needs and wishes
- care will focus on prioritising the person's comfort and quality of life.

This can be a very difficult time for everyone involved. Hospitals can help make things as comfortable as possible for the person with dementia and their family, friends and carers. For example, it might be possible to stay beyond visiting hours, or overnight. You could ask if it is possible to be moved from a main ward to a quiet side room, if one is available.

You might also want to speak to a member of the palliative care team. They specialise in providing comfort and pain relief at the end of someone's life. If the person has any spiritual and cultural needs, such as the involvement of a faith leader, it is a good idea to make staff aware. For more advice on supporting someone at the end of life, see factsheet 531 **End of life care**.

> **“I didn't want [dad] being admitted to intensive care as I knew this would be very distressing for him and he wouldn't understand what was going on. They understood my concerns and he was put into a standard ward for the last few days of his life and made comfortable.**
>
> Family member of a person with dementia”

Resuscitation

Depending on the nature of the person's illness, you may need to think about the person's views on resuscitation. For example, this could be if the doctor feels the person is likely to have a heart attack.

Resuscitation is a medical process that can be attempted when a person's heart stops beating or if they stop breathing. The medical team should always discuss this with the main carer or family members. If anything is unclear, ask them to explain it to you in a different way. It may help to talk it through with family or friends.

The person may have specified treatments they don't want and when, including resuscitation, in an advance decision. An advance decision must be followed if it applies to the situation. For more information, see factsheet 463 **Advance decisions and advance statements.**

Paying for short-term care after discharge

In some areas, funding is provided to all hospital patients who need additional care following discharge. This is usually for a set number of weeks, or until their long-term needs have been assessed. In England, this may be known as 'Discharge to Assess funding' or 'Section 75 funding'. Availability varies by area, so you will need to ask if this is available at your hospital.

The hospital discharge assessment might also consider if the person with dementia would benefit from 'intermediate care'. This refers to a range of support which can help people regain independence after a stay in hospital.

Intermediate care is sometimes referred to as 'step-down' care. This might mean that the person receives extra nursing and care services for a short period of time after discharge. It could involve the person staying in a residential rehabilitation unit to regain confidence.

Intermediate care generally lasts for up to six weeks and is free of charge. Anyone discharged home under pathway 1 or to a care home under pathway 2 should ask if they will receive this funding.

Not everyone will be eligible for intermediate care – for example, if time limited support is unlikely to help them regain independence. Staff will require the person to be able to agree what their goals are, such as making a meal or mobilising.

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Someone with dementia should not be excluded based solely on their diagnosis. It should depend on each person's ability to follow the process. Sometimes people with dementia may not be eligible if staff don't think they can understand or remember instructions.

Longer-term care funding

Aside from short-term funding, there are different types of financial support available to help pay for care. The assessment for these other types of financial support now take place after the person has left hospital.

Care provided by the local authority or trust

Some care services are provided by the local authority (or local council) in England and Wales, or the local trust in Northern Ireland.

Local authorities have a duty to assess what care a person with dementia needs. This is part of the assessment arranged following hospital discharge. Any person has a right to this part of the assessment, even if they then end up paying for their own care.

The assessment will consider the person's needs. This will help decide whether or not they meet the requirements for receiving that type of support. Most social care is means tested. This means that qualifying for that care will also depend on the person's income and capital – for example, their savings.

The person's carer can also have their needs assessed by the local authority's social services department. For more information, see our **Assessment for care and support** factsheets 418 (England), NI418 (Northern Ireland) and W418 (Wales).

If the care assessment shows that the person has care needs, the local authority will then look at how this care will be paid for. To do this, they will complete a financial assessment, also known as a 'means test'. This will decide whether the person can fund their care themselves or whether the local authority will contribute to some or all of the cost.

For more information on the rules around paying for care, see our **Paying for care and support** factsheets 532 (England), NI532 (Northern Ireland) and W532 (Wales).

NHS continuing healthcare (CHC)

Some people who leave hospital qualify for free NHS care. This is known as NHS continuing healthcare (CHC) and is put in place if the person requires further help with health needs. It is not available to people who primarily require social care, which is help with daily living, like washing or dressing.

The hospital discharge process should consider whether the person may qualify for CHC. This process starts with a short checklist. If this checklist shows that the person may qualify for CHC, the person will then go through a more detailed assessment. This assessment is often completed after someone has been discharged from hospital as this gives a better idea as to how well the person can manage.

In most cases, people with dementia are not classed as having a 'primary health need'. Therefore, they may need to rely on means-tested social care instead of CHC.

It is always worth asking for an assessment if you feel the person with dementia may qualify for CHC though. For more information, see booklet 813 **When does the NHS pay for care?**

Funded nursing Care (FNC)

Some people with dementia will need the support of trained nursing staff. They will be assessed as needing to enter a nursing home, rather than a residential care home.

If they don't qualify for NHS continuing healthcare (CHC) but do need a nursing home, they should receive NHS-funded nursing care. This is a set amount of money paid directly to the home to cover some of the nursing home fees.

The rest of the fees will be covered by the person themselves or by the local authority. This will depend on the results of the financial assessment carried out by the local authority (see 'Care provided by the local authority or trust' on page 20). The amount of money FNC pays is different for people living in England, Northern Ireland and Wales.

Care fees and the Mental Health Act 1983 (section 117 aftercare)

If the person was treated in hospital under section 3 of the Mental Health Act 1983, the local authority and NHS are responsible for providing and funding any related care needed after discharge. This can include any care that the person needs in their own home or in a care home. For more information, see factsheet 459 **The Mental Health Act 1983**.

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Deciding where the person will live longer term

Generally, the person will choose where they wish to live once they are discharged from hospital. However, some people with dementia will be unable to make this decision for themselves. This is known as lacking 'mental capacity' to make the specific decision. In that case a best-interest decision will need to be made about where they live. For more information, see factsheet 460 **Mental Capacity Act 2005**.

Depending on the person's individual circumstances, all options for where they live should be considered and discussed with them. Options may include:

- living in their own home (with some support from family or paid carers)
- assisted living (living independently but with assistance available if needed)
- a residential care home or nursing home.

For more information about who makes the decision and how, see booklet 689 **Care homes and other options: Making the decision.**

Other useful organisations

Court of Protection
0300 456 4600
courtofprotectionenquiries@justice.gov.uk
www.gov.uk/courts-tribunals/court-of-protection

The Court of Protection helps people who have difficulty making their own decisions by making the decisions for them or appointing someone else to do so.

Cruse Bereavement Care
0808 808 1677 (9.30am–5pm Monday and Friday, 9.30am–8pm Tuesday–Thursday, 10am–2pm Saturday and Sunday)
www.cruse.org.uk

Cruse Bereavement Care offers support, advice and information to children, young people and adults when someone dies.

Northern Ireland Ombudsman
0800 34 34 24
nipso@nipso.org.uk
www.nipso.org.uk

The Northern Ireland Ombudsman is responsible for considering complaints against government bodies and public administration in Northern Ireland.

Parliamentary and Health Service Ombudsman
0345 015 4033 (8.30am–5pm Monday–Thursday, 8.30am–12pm Friday)
www.ombudsman.org.uk

The Parliamentary and Health Service Ombudsman is responsible for considering complaints by the public about government departments, public authorities and the NHS.

Patient Advice and Liaison Service (PALS)
www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service

For residents of England and Wales, each hospital has a PALS (Patient Advice and Liaison Service) who can help with complaints and provide advice and information on health-related matters. The NHS website offers a search by location to find your local PALS office.

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Patient and Client Council Northern Ireland
0800 917 0222
info@pcc-ni.net
pcc-ni.net

The Patient and Client Council is an independent voice on health and social care issues. It can help people in Northern Ireland with complaints, and provide advice and information on health-related matters.

Professional Standards Authority
020 7389 8030
info@professionalstandards.org.uk
www.professionalstandards.org.uk

The Professional Standards Authority for Health and Social Care is a group that oversees the statutory bodies that regulate health and social care professionals in England and Wales.

Factsheet 477
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This factsheet has 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**

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

We have more information on **Hospitalisation**.

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

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

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