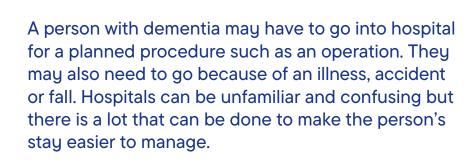
# Hospital care



Together we are help & hope for everyone living with dementia



This factsheet for carers covers some of the issues to think about when someone with dementia goes into hospital. It gives tips on how to reassure and support them during their stay and what to consider when they are ready to leave.

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# 1 Preparing for a hospital stay

Many people with dementia will need to stay in hospital because of tests, treatment or an operation. They should be given or sent written instructions to follow before their stay. These should include instructions about whether they can eat or drink before treatment and details on how long their stay is likely to be.

Contact the relevant hospital department if you have any questions or concerns about the visit. You should also contact them if the person with dementia has any communication needs, such as needing an interpreter. If you can, look online at the hospital's website – they may have information about any support they can offer to people with dementia and their families.

The following suggestions may help someone with dementia prepare for a planned stay in hospital:

- If they are worried, ask them what information you can find that may help 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. It can also help to bring any personal items that will help the person feel more settled, such as their smartphone or photo albums.
- 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<sup>®</sup> document see page 5 for more details.

#### Unplanned hospital stays

Not all hospital admissions can be planned in advance. Sometimes a person with dementia will have to be admitted to hospital suddenly. This can be frightening for the person as they may not fully understand why they need to go to hospital.

It can be useful to have a list ready of things to pack in a hospital bag, in case this ever happens. The list could include items that the person needs in everyday life, like glasses, and any medication that they are taking. You could also add snacks. If there is anything that the person usually finds relaxing – such as knitting or a blanket – this can help to make them feel more comfortable.

You may wish to check if there are any schemes that are used in your area such as ReSPECT or MedicAlert®. These can help the person with dementia to communicate their wishes in an emergency. If the person is admitted suddenly, hospital staff or paramedics may not be aware of their dementia. If these professionals know, it can be a huge help.

The most important thing you can do is to communicate with the person with dementia throughout their stay in hospital. This is often difficult when you feel worried or stressed yourself. The person with dementia will benefit from reassurance and feeling included in conversations where possible. 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.

## When the person doesn't consent to going to hospital

Most people in hospital have agreed to be there and agree to the treatment that is given to them. Sometimes, a person will refuse to go to hospital even though they need the treatment. In this case, the Mental Health Act enables someone to be admitted and kept in hospital to receive treatment if it is absolutely necessary to protect that person or those around them. For more information on this see factsheet 459, **The Mental Health Act 1983**.

As their condition progresses, some people with dementia may lose the ability to make some decisions for themselves. This is known as losing 'mental capacity' to make that particular decision. In some cases, a person will not be able to consent to being in hospital as they lack the mental capacity needed to make this decision. In these cases, the care may need to be authorised under the deprivation of liberty safeguards (DoLS). The purpose of DoLS is to ensure that the person's hospitalisation is needed, even if it reduces their freedom and independence. For more information on DoLS see factsheet 483, **Deprivation of Liberty Safeguards (DoLS)**.

#### Making decisions

While the person is in hospital a number of important questions and decisions can come up. If the person has lost the ability to answer or make those particular decisions, having the arrangements below 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, if they are no longer able to make those decisions themselves.
   For more information see 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 taken into account.

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

If someone no longer has the capacity to appoint an attorney or make an advance decision, you can apply to the Court of Protection to become their deputy. If your application is approved, this will allow you to make decisions in their best interests. However, the process of becoming a deputy is expensive and can take a long time. For more information on deputyship see factsheet 530, **Deputyship**.

### 2 During a hospital stay

Being in hospital can sometimes be a confusing and frightening experience for a person with dementia. Hospital staff are often very busy and will not always have time to stay with their patients for long periods. If a person with dementia doesn't receive stimulation and emotional support, or they are left alone, this can cause their condition to become worse.

However, carers, family and friends can often help the person by lending them extra support during their hospital stay. Being able to support the person can also be comforting for the people around them.

#### Supporting the person in hospital

Being aware of the issues that can affect a person with dementia can help you to provide support. You may not feel able to provide all or any of this support for the person yourself. For instance, the hospital may have visiting restrictions or it may not be possible for you to visit the hospital easily.

It can help to build up a good relationship with ward staff. 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. Then ask for a call or appointment with this named nurse. If you want to discuss the person's condition or treatment in more depth, ask for an appointment to see or speak with the doctor or consultant.

Try to remain friendly and open with everyone involved in the person's care, including non-medical staff such as catering assistants and cleaners. You may be able to pass on some of your knowledge about the person to them. This can encourage better communication and help the person feel more at ease on the ward.

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 such as a butterfly symbol to raise staff awareness and help provide appropriate care. Ask what is available for you.

#### Sharing information about the person

Hospital staff might not know that someone has dementia, or they may not have experience of working with people with dementia. So it's 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.

#### How you can help

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
- details about any difficulties the person may have with communication, and tips on how best to communicate with them – for example 'Mrs Sellers finds it helpful if people talk slowly and give one piece of information at a time'
- information about 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
- information about their usual sleeping patterns
- details of how active the person likes to be for example, if they usually walk about
- advice on what can calm the person when they are agitated
- whether 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 details of hobbies, pets or their past occupation.

Hospital staff might not know that someone has dementia. They may not know how best to care for them. To help with this, Alzheimer's Society produces a leaflet called This is me<sup>®</sup>, which can be used to record information about the person, including details like those listed above. To download go to alzheimers.org.uk/thisisme or to order call 020 7423 7455.

#### Providing comfort and reassurance

Hospitals can be loud and unfamiliar, and the person may not understand where they are or why they are there. If the ward is busy and noisy, this can add to the person's confusion and increase their levels of anxiety or agitation – particularly at peak times, such as ward rounds or visiting hours. You can help to reassure them by:

- checking hearing aids are on and at the right level for the person's new surroundings
- making sure glasses are clean and labelled with the person's name so they can see clearly and the glasses can be returned if the person loses them
- asking if there is a day room that the person can visit to get a break from the ward
- bringing in familiar objects, such as photographs of family members or a pet. These can also provide staff with a good talking point
- giving them a notebook, so staff and visitors can write messages, reminders and details of when they are next visiting
- talking to the person, reading to them, and giving emotional support. This can make a big difference because familiar faces can bring comfort and reassurance
- considering packing some casual clothes that are easy to wear if the person would feel more comfortable wearing their own clothes during the day. This can also help the person to settle into different routines for daytime and night-time.

#### Recognising delirium

Delirium is a condition that starts suddenly in someone who is unwell. 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, such as constipation, pain, an infection, or dehydration. Delirium is usually treated by treating the separate medical problem that is causing it.

Symptoms of delirium can come on over a matter of hours or over a few days. They can also appear and disappear from one moment to the next. The person's symptoms 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

- If you notice a change in the person's behaviour, speak to a nurse or doctor immediately. Family, friends and carers are often well placed to recognise changes 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 this is possible.
- Set up a dementia-friendly clock or a wipe board to remind the person of the date, time and where they are. Keeping the room light and airy during the daytime can also help with this.
- For some types of delirium, it can help to dim the lights and reduce any noise for a short period of time.
- Although delirium can be frightening, try to stay calm when communicating with the person – talk slowly and provide plenty of reassurance.
- Even if they don't seem to make sense to you, listen to any concerns that the person has and ask how you can help.

#### **Eating and drinking**

Mealtimes in a busy hospital can be difficult and stressful for a person with dementia. If ward mealtimes fall outside of visiting hours, it's worth asking the hospital staff if you can stay beyond these. Staff are often especially busy at mealtimes and may be grateful for any help you can offer.

As you may not always be around to help, it's also a good idea to make staff aware of any difficulties that the person has at mealtimes. This can help them provide better care for the person. 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

- Some hospitals have a separate dining room. This can offer a change of scene for the person with dementia, so give them the option of eating there, if possible.
- Don't assume that the person isn't hungry or doesn't want their food if they don't seem keen to eat it. Instead, try to engage them in different ways. Try to make the food seem more appealing by talking positively about how it looks or smells.
- Make mealtimes more sociable by having a snack or a drink at the same time as the person does. Try speaking to the person about their favourite foods – this could help increase their appetite.

- Some people with dementia cannot eat their food without reminders at mealtimes. If the person can sit in a chair rather than lying in bed, this might prompt them that it's time to eat.
- If a person is struggling to eat using a knife and fork, consider selecting foods that they can eat with their fingers, such as bread rolls, potato wedges, celery sticks or seedless grapes.
- If the person has difficulty swallowing, ask if their food can be provided soft or mashed. If you're not sure whether their difficulty is with swallowing or something else, ask for an assessment from a speech and language therapist.

If the person is not eating well, or is starting to lose weight, the named nurse should speak to the hospital dietitian. The dietitian will set up a nutritional care plan with nursing and catering staff, which may involve prescribing high-energy drinks or specific foods.

If the person with dementia is very unwell, they may not want to eat or drink. If this continues over a long period of time, the medical team may suggest tube feeding – when a person is fed through a tube in their nose. These are sometimes called 'nasogastric' or 'gastrostomy' (PEG) tubes. This will make sure the person receives the food and fluids that they need. When deciding if the person needs to be tube-fed, staff should speak with carers or relatives and make sure to respect the person's wishes.

#### Medication and managing pain

Managing pain can be difficult when someone is in hospital and ward staff don't know them very well. Being in pain can affect a person's ability to communicate and mean that the person is not able to tell others how they feel. If a person is in pain and can't communicate it properly, they may start to behave differently. For example, the person may scrunch up their face or rock backwards and forwards.

#### How you can help

- If the person looks as if they might be in pain, but you cannot see an obvious cause for this, check for things that might be hurting them, such as sores in their mouth or bruises on their body.
- If you think the person may be in pain, mention this to a member of staff and ask for an assessment. The doctor may prescribe medication that can help. Doctors should speak with you and the person before they make any changes to the person's medication.
- Consider trying pain remedies that do not involve the person taking medication, such as heat pads or massage therapy.
   Hospitals will differ in what they can offer, so ask what alternatives are available.

- If the person with dementia is in pain, they may become agitated. If their behaviour is challenging for hospital staff, the person may be prescribed a sedative. Sedatives are not prescribed to treat pain and should only be used if the person is putting other people at risk. The doctor should always look into what might be causing the person's behaviour before prescribing sedatives.
- If the person is prescribed sedative medication, this may make them more confused. If you have any concerns, discuss these with the doctor – it may be possible to reduce the dose or stop the medication altogether. If the person gets agitated again, the medical team may be able to offer alternative solutions, such as engaging the person in stimulating activities or getting extra support from a healthcare assistant, if available.

There is a lot that 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.

#### Walking around

Someone with dementia might try to get up and walk around the ward, and this might make staff anxious. It's important that the person is safe and does not become lost. However, it can be good for the person to be active during a stay in hospital.

#### How you can help

- If the person wants to walk around the ward, and it is safe and possible for them to do so, ask if the staff could help with this. Explain to staff why walking might help the person. For example, some people can become stiff if they don't move around, and this can make them more likely to have falls when they do get up again.
- If the person is being prevented from walking around, it may make them feel threatened, agitated or angry. Ask the staff if they can make any adjustments to support the person.
   For example, they might let the person walk on the ward at quieter times or when the person has visitors.
- If the person likes to be active, it might help to involve them in suitable activities on or away from the ward, like chair-based exercises.
- Some wards have day rooms where people can watch a film while exercising. Ask if the hospital has any room where the person can go to walk around. The person may need to be supervised if they do this, so discuss this with staff beforehand.

 If it's possible for the person to walk around the ward, bring in some slippers or comfortable footwear to support them with this.

#### **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:

- Stay calm and polite.
- 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 occurred 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 19 for details). PALS and PCC can represent patients and families in discussions with hospital staff to help resolve problems and concerns quickly.

## 3 Hospital discharge

'Discharge' is the term used when a person leaves hospital. This should only happen once a doctor at the hospital decides that the person is 'medically fit'. This means that the person no longer needs the same level of medical attention that they've been receiving in hospital.

The discharge process has changed significantly since the coronavirus pandemic began in 2020. It is likely to change even more with time. The discharge process may also be different depending on where people live. The following information is correct at time of print.

#### Assessment for hospital discharge

Currently, hospitals in England and Wales use a 'discharge to assess' model. This means that only a short assessment will be completed in hospital. This is because the requirements for people staying in hospital are now stricter. This means that discharge can happen very quickly. People who need support after leaving hospital will be given a longer assessment.

The professionals involved in an assessment (both before and after leaving hospital) could include:

- doctors, such as consultants
- nursing and ward staff
- physiotherapists
- occupational therapists
- social workers
- psychiatrists
- registered mental health nurses.

If a lot of people are involved in the assessment, it may help to make a list of the names of people you have spoken to and their contact details.

The assessment for hospital discharge should involve:

- considering the person's needs and where they are currently living and looking at their 'support network' (people involved in supporting the person)
- writing out a care plan recording these needs
- setting up a system for checking that the care plan continues to meet the person's needs, and for adjusting the plan if those needs change
- looking into the person's finances and checking their eligibility for different types of funding. See 'Care and support following discharge' on page 17 for more information on funding

 arranging any equipment and adaptations to help the person live safely at home – for example, grab rails, toilet frames or hoists. For more information on this see factsheet 429, Using equipment and making adaptations at home.

#### Hospital discharge process

Once it has been decided that a person should be discharged from hospital, the person and their family or carer should be informed. For people who are well enough to return to their home setting with no extra support, the ward staff should arrange the discharge. The person should be transferred from their ward to a discharge area as soon as possible. They should be able to leave hospital the same day.

If the person will need continued support or care after leaving the hospital, they should be assigned a case manager. The case manager will arrange their discharge and follow-up care. Case managers should work with ward staff to make sure that the person and their family are fully informed of the next steps. They should also arrange transport and 'settle in' support, which could include services like help with shopping. The case manager will also arrange for other teams of professionals, such as local 'single point of access' schemes, to arrange an assessment of the person's longer term needs once they have left the hospital.

After a stay in hospital, some people will need a very high level of care. In this situation, if the person cannot stay in hospital, they may be discharged to a care home or to a rehabilitation bed.

If the person is being discharged to a care home setting, they should be tested for coronavirus. If they test positive, they can still be discharged if the home is satisfied they can be cared for safely.

#### 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 home or hospice. This is a new policy that was brought in because of the coronavirus pandemic.

Even after discharge from hospital, end of life care plans should still focus on supporting the person's physical and spiritual needs. These plans should always involve the person and their family, as well as a number of different professionals. The discharge policy does not apply to people who are in their last few hours of life. If this is the case, the person will be kept in hospital. 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 provide help and support to 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. If a room is available, you could ask if it is possible to be moved from a main ward to a quiet side room.

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 of these. For more advice on supporting someone at the end of life see factsheet 531, **End of life care**.

Depending on the nature of the person's illness – for example, if the doctor feels the person is likely to have a heart attack – you may need to think about your and the person's views on resuscitation. This is a medical process that can be attempted when a person's heart stops beating. 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 set out their own wishes about their care at the end of life, including resuscitation, in an advance decision. These must be followed. For more information on this see factsheet 463, **Advance decisions and advance statements** for England and Wales or factsheet NI467, Financial and legal tips for Northern Ireland.

# 4 Following a stay in hospital

After leaving hospital, the needs of a person with dementia may have changed. They may need more support than they did before going into hospital. 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 in order to keep the person safe.

#### Deciding where the person will live

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. For more information on this see factsheet 460, **Mental Capacity Act 2005**.

Depending on the person's individual circumstances, all options for where they live should be discussed with them, any attorneys or deputies they have, and the professionals involved in their care.

#### In their own home

Some people will recover in hospital and will be able to continue with their life as before. If the person lives at home, they may still benefit from extra support, such as equipment to help with daily living or visits from a paid carer. These small changes could help someone with dementia keep their independence and help reduce the risk of returning to hospital.

#### In assisted living

Some people with dementia may be able to move in with friends or family who can help care for them. Sheltered housing or extra care housing may also be options for the person. These are set up so that the person with dementia can live independently but has support on hand should they need it. You should check what is available locally and whether it can provide all the help that is needed.

As the person's dementia progresses, their needs will change and increase. This means that a care home may be the most appropriate option for them. Moving more than once in a short period of time could make the person feel very disorientated or unsettled. Take this into account when looking into options for assisted living and the level of care they are able to provide.

#### In a residential care home

Maintaining independence can be helpful for people with dementia, so options for living at home or living with extra support should be considered first. However, some people with dementia will not be able to live independently – for example, if they cannot care for themselves or stay safe.

If this is the case, they may need to move into a care home, where staff can support the person with daily care. This can include help with eating, washing, dressing and going to the toilet. Some people have trial periods in residential care when they are discharged from hospital. This can help when deciding whether residential care is the best option for the person, without committing to it.

Before the coronavirus pandemic, people were sometimes able to stay in hospital until a room became available in their first choice of care home. Due to changes in the hospital discharge process, this is no longer possible. This may mean that the person with dementia has to move into a care home that is not their first choice. For example, it may be further away from family, or cost more than the person is able or willing to pay. If this happens, it can be useful to check the standard rate for care home fees in that area. For more information on funding for care, see 'Care and support following discharge' on page 17.

#### In a nursing home

Staff in care homes support with daily living, but do not provide nursing or medical care. If someone has difficulty moving, issues with continence or medical needs, a nursing home may be better suited for them. Like residential care homes, nursing homes support residents with their daily care needs, but they can also provide help with nursing care. They must always have a registered nurse present to provide the medical support that the residents need.

#### Who can decide where the person lives?

If the person with dementia is not able to decide where they will live, someone else will have to make this decision for them. Who makes this decision will depend on which country the person lives in, and whether they had already put plans in place.

#### In England and Wales

Deciding where the person will live will depend on their situation. For example:

- If the person has set up a Lasting power of attorney (LPA) for health and welfare, their appointed attorney may be able to make the decision.
- If the Court of Protection has appointed a deputy for the person, the deputy may be able to decide.
- If there is no deputy or attorney, the decision will be made by a health or social care professional, such as the hospital social worker. They may also ask colleagues for advice.

Whoever the decision-maker is, they must consider what is in the person's best interests, and they should ask family and carers for their opinion. Some people may not have friends or family who can help represent them. If this is the case, an independent mental capacity advocate (IMCA) should be appointed to help ensure that the person's views and wishes are taken into account. A professional (usually a doctor or social worker) should organise this.

There may be concerns that moving a person who lacks mental capacity to a care home or nursing home may limit their freedom. This is because they would be supervised and would not be free to leave. If someone's freedom is limited, this is known as a 'deprivation of liberty'.

If someone's proposed care may result in them being deprived of their liberty, the care will need to be 'authorised'. This means that an assessment will take place to ensure that the care is in the person's best interests. The assessment will also make sure that there isn't another workable option that would be less restrictive. For more information see factsheet 483, **Deprivation of Liberty Safeguards (DoLS)**.

#### In Northern Ireland

If a person cannot decide where to live following discharge from hospital, this decision will be made by professionals as part of the discharge process. The decision will usually be made by the social worker. They must consider the person's needs and wishes, as well as any advice from the doctor or consultant. Carers and relatives should also be involved in these discussions.

#### Care and support following discharge

There are different types of financial support available to help pay for care. The assessment for these other types of financial support will now take place after the person has left hospital. 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. Some types of care are also 'means tested'. This means that qualifying for that care will also depend on the person's income and capital – for example their savings.

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

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 factsheets 532 **Paying for care and support** (for England), W532 (for Wales), NI532 (for Northern Ireland).

#### NHS continuing healthcare

Some people with dementia qualify for free NHS care once they have left hospital. This is known as 'NHS continuing healthcare'. This is available to people who need healthcare, which is care that involves medical support. It is not available to people who only need social care, which is care that involves help with daily living, like washing or dressing.

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

It is always worth asking for an assessment if you feel the person with dementia may qualify for continuing healthcare. In most cases, only people with serious healthcare needs will qualify for it. For more information see booklet 813, **When does the NHS pay for care?** 

#### **Funded nursing**

Some people with dementia 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 but do need a nursing home, they should receive NHS-funded nursing care. This is a set amount of money given to the person to help 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'). The amount of money is different for people living in England, Wales and Northern Ireland.

## 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 that is 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**.

#### Intermediate care

The hospital discharge assessment might also take into account whether the person with dementia would benefit from intermediate care. Intermediate care refers to a range of support services and equipment designed to help people regain independence after a stay in hospital. It is sometimes referred to as 'step-down' care.

This might involve the person staying in a residential rehabilitation unit to regain confidence, or it might mean that the person receives extra nursing and care services for a short period of time after discharge.

Intermediate care generally lasts for a maximum of six weeks and is provided free of charge.

### Other useful organisations

Care Quality Commission 03000 616161 enquiries@cqc.org.uk www.cqc.org.uk (includes contact form)

The Care Quality Commission is the independent regulator of health and social care in England and Wales. It checks whether hospitals, GPs, care homes and dentists are meeting national standards.

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.

# Patient and Client Council Northern Ireland 0800 917 0222 info@pcc-ni.net www.patientclientcouncil.hscni.net/home

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.

# Regulation and Quality Improvement Authority 028 9536 1111 info@rqia.org.uk www.rqia.org.uk

The Regulation and Quality Improvement Authority is an independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland.



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

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We are reviewing this publication. If you would like to give us any feedback, you can email us at publications@alzheimers.org.uk or call us at 020 7423 7455

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** 





Patient Information Forum



Together we are help & hope for everyone living with dementia

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