

Hospital care

Hospitals can be disorientating and frightening for someone with dementia, but there is a lot that can be done to make their stay easier to manage. This factsheet covers some of the issues that you should think about when someone with dementia goes into hospital. It gives tips on how to reassure and support them during their stay and what you need to consider when they are ready to leave.

Going into hospital

Someone with dementia may have to go into hospital for a planned procedure such as an operation, during a serious illness or if they have an accident or fall. This can be disorientating and frightening and may make them more confused than usual. Hospitals can be loud and unfamiliar, and the person may not understand where they are or why they are there.

Help from hospital staff

Hospital staff will not necessarily know whether someone has dementia, or they may lack experience of working with people with dementia. It is important that all staff are aware of the person's dementia as it may affect the type or nature of medical treatment they receive.

Some hospitals may have a 'dementia identification scheme' where people with dementia are identified by a small symbol on their hospital identification bracelet. One example is the Butterfly scheme, which uses a butterfly symbol to help staff to recognise people with

dementia or memory problems. You may want to ask the ward manager or nurse in charge about such schemes and ensure a note is made on patient notes to alert medical staff who may come into contact with the person with dementia.

Staff should be able to answer any questions and discuss any issues you may have. If they seem too busy to talk, ask to make an appointment – ideally with the named nurse. The named nurse will be responsible for co-ordinating the person’s care. This meeting will be an opportunity to discuss any concerns you or the person with dementia may have, and should provide a good basis for future communication. If any problems arise later, they can then usually be dealt with through the named nurse. If you want to discuss the person’s condition or treatment in more depth, ask to make an appointment to see the doctor or consultant.

Mental health staff

Some hospital trusts provide a mental health service (sometimes referred to as a ‘hospital liaison team’ or a ‘Rapid Assessment Interface and Discharge’ (RAID) team). This team might include psychologists, mental health nurses and mental health specialist doctors.

They can assess people with dementia and advise other nursing and medical staff about mental health issues related to dementia, such as depression. If you are concerned that the person’s dementia is deteriorating or not being considered fully, you should make an appointment with this team.

Information about the person with dementia

It is helpful for relatives and friends to share information with ward staff on how the person’s dementia affects them. You can also suggest tips on the best ways of assisting and communicating with the person. Any other information you can add is valuable as it will help staff to see and respond to the person with dementia as an individual. For example, tell staff how the person prefers to be addressed – informally, such as ‘Charlie’, or formally, such as ‘Mr Cohen’. The named nurse should share this with other members of staff on the ward.

As information can be lost or forgotten, it can help if a friend, carer or family member writes down some important facts about the person with dementia. This can then be given to the named nurse at the first meeting and should be held in the person's medical notes. Alzheimer's Society has produced a leaflet called **This is me** which can be used to record this information. When filled in it provides a snapshot of the person with dementia, giving details about them as an individual, such as their personal background, needs, preferences, likes, dislikes and interests. The leaflet can be downloaded from alzheimers.org.uk/thisisme or ordered from Alzheimer's Society Publications Orderline on 0300 303 5933.

If you prefer to do this on paper, one side of A4 is usually enough. Useful information to give about the person includes:

- the name they like to be called
- brief details of their normal routines, including whether they need reminders or support with washing, dressing, eating and drinking, going to the toilet or taking medication
- any difficulties the person may have with communication, and information on how best to communicate with them
- information about foods they particularly like or dislike, or any difficulties they have eating
- illness or pain that may bother them
- any cultural or religious needs
- information about sleeping patterns
- whether they like to be active or inactive – for example, if they walk about – and what can calm them when they are agitated
- whether they have an advance decision or a personal welfare Lasting power of attorney (LPA).

It may also be helpful to include some tips for staff. For example:

- ‘Mr Cohen finds it helpful if people talk slowly and give one piece of information at a time.’
- ‘Saul is more likely to understand if people maintain eye contact while they are talking to him.’
- ‘Miss Sellers can feed herself with a spoon if someone cuts her food up.’
- ‘Ravi often rocks and holds his tummy if he is in discomfort or pain.’

It may also help staff to communicate with the person with dementia if they have details of the person’s:

- close family members or friends
- pets
- living situation – for example, whether they live with others or alone
- past occupation
- interests.

If the person with dementia frequently walks around the ward, this may make staff anxious. If this is likely, explain that the person finds it comforting to walk around and that staff will need to accommodate this. It may help to point out that preventing the person from doing an activity they wish to do, such as walking, may make them feel threatened, agitated or angry. This must be balanced with making sure the person is safe and does not become lost.

You could also emphasise the benefit of involving the person in suitable activities on or away from the ward. Such activities may include chair-based exercises, and some wards have day rooms where people can watch a film while exercising. You may need to describe how much supervision would be required for this.

How you can help during a hospital stay

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.

Practical help

If you choose, you may be able to help with the individual's personal care – for example, taking them to the toilet or supporting them at mealtimes. If you would like to do this, discuss it with the named nurse. Other ways in which you can help might include:

- making sure clothes are labelled in case they are mislaid
- cleaning glasses and checking on hearing aids
- checking the person's mouth for signs of soreness
- thinking of enjoyable pastimes or entertaining personal possessions to occupy the person's time.

Providing comfort and reassurance

- Familiar objects, such as photographs of family members or a much-loved pet, can be very reassuring. They can also provide staff with a good talking point.
- If the person still reads, you could provide a notebook, so staff and visitors can write messages, reminders and details of when they are next visiting.
- Familiar faces may bring comfort and reassurance. Talking to the person, reading to them, and providing them with emotional support can make a big difference.

- Noise and bustle on the ward can add to the person's confusion and heighten their levels of anxiety or agitation – particularly at busy times, such as ward rounds or visiting hours. You could ask if there is a quiet room or day room that the person can visit to get away from the bustle.
- If you think a person is in pain, mention this to a member of hospital staff and ask for an assessment. People behave differently when they are in pain (eg grimacing, rocking) and you will know best how someone you know acts when in pain.

Eating and drinking

- Mealtimes in a busy hospital environment can be difficult and stressful for a person with dementia. Make staff aware of any difficulties that the person has at mealtimes and how they can help.
- Make sure the person is given the option of eating in the dining room, if there is one, or at their bedside, if they prefer.
- Make sure staff help the person with dementia to eat and choose food and support them with eating, if necessary. Don't assume that they are not hungry or don't want their food if they don't seem keen to eat it. Some people with dementia cannot eat their food without reminders and prompts at mealtimes.
- Staff are often particularly busy at mealtimes and may be grateful for any help you can offer. You may like to discuss this with the ward staff. Some hospitals use cues, such as a different coloured plate or a sign by the bed, to alert staff if a person needs extra help to eat.
- If a person is struggling to eat using cutlery, consider offering them foods such as bread rolls, potato wedges, celery sticks or seedless grapes that can be easily picked up and eaten with fingers.
- If the person has difficulty swallowing, ask if they can be assessed by a speech and language therapist, or if food can be provided in a soft or puréed texture. If the person is not eating well, or is losing weight, the named nurse should contact the hospital dietitian. The dietitian

will co-ordinate 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. Tube feeding may be suggested by the medical team as a means to help them receive food and fluids. The terms ‘nasogastric’ or ‘gastrostomy’ (PEG) tubes are often used. The decision to tube feed should only be made respecting the wishes of the person and in full discussion with carers or relatives.

Medication

Doctors should discuss the person’s medication and any changes with the person with dementia and their carer or relatives. 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.

Additional support

Being in hospital can be a disorientating and frightening experience for a person with dementia, and they may require a lot of support from carers, family and friends. Not receiving stimulation and emotional support, or being left isolated and alone, can cause a person’s condition to become worse.

Hospital staff are usually very busy and will not generally have the time to stay with the person for long periods, talk to them, read to them or do many of the things that a person with dementia needs to keep their condition from deteriorating.

Carers of people with dementia should be able to spend as much time as necessary with the person, whenever they need to. Some hospitals run a ‘carer’s passport’ or similar scheme. This might allow carers to have unrestricted visiting hours on the hospital by using a card that can be shared among other family members or close friends. It may allow a carer to stay overnight with the person or offer free or

reduced-fare parking. Ask the ward manager about this and extended or flexible access rights. Explain to them the effect that being in hospital can have on the person with dementia, and the benefit of this flexibility – working together with them. You are not being unreasonable to highlight this so present your case confidently as someone focused on the well-being of the person with dementia.

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’. A person with dementia may have complex needs that should be considered before they can be safely discharged. For example, they may need to move into a care home or need adaptations made to their existing home, such as a stair-lift. Others may need support in their own home or in the home of a relative or friend.

Every hospital has a hospital discharge policy. This is a public document that anyone can ask to see. It should include details of how the hospital staff will arrange the discharge.

Plans about the date and time of discharge should be discussed with the person and their carer, if they have one. Ideally these plans will start to be discussed a reasonable period of time before discharge, and will include details about where the person will be living and the care that they will need.

Hospital staff must ensure that transport to the person’s home or care home has been arranged. They should also take extra care when making plans to discharge someone on a Friday or during a weekend or a public holiday as it may be difficult to contact homecare workers and GPs on these days.

The hospital discharge process should include:

- an assessment of the person’s needs and living environment, with consideration given to the people involved in supporting them – often referred to as their ‘support network’

- a written care plan that records these needs
- a system for monitoring and, if necessary, adjusting the care plan to meet any changes in needs
- confirmation that any required services are in place in time for the discharge – for example, home visits needed to help with personal care, or grab rails in the home to help with support and stability
- an assessment to see if the person qualifies for NHS continuing healthcare (see ‘NHS continuing healthcare’ below).

Assessment for hospital discharge

Before a person is discharged, their physical, psychological and social needs must be assessed. Any support or care services that are required should be arranged before they leave hospital. Any organisations that will be providing these services must be informed of the date and time of the person’s discharge, and when they should start to provide the services.

If the person’s needs have changed considerably since they were admitted to hospital, they may require an assessment involving several health and social care professionals. This might involve a hospital consultant, nursing and ward staff, physiotherapists, occupational therapists, social workers, psychiatrists and registered mental health nurses. It may help to make a list of the names of people you have spoken to and their contact details.

The person with dementia and someone involved in their day-to-day care should be fully involved in this assessment. The assessment may include the person returning home briefly before they are discharged to see how they will cope and what help and adaptations they might need. This brief return home might highlight whether and where certain adaptations are needed, such as grab rails or a ramp. It will also allow these adaptations to be arranged before the person returns home. If the person’s needs have not changed considerably, they may need a more brief assessment.

At the time of the assessment, the person with dementia, their carer or relatives are entitled to have explained to them in writing:

- the health authority's national eligibility criteria for NHS continuing care (see 'NHS continuing healthcare' below)
- any services that the health services will provide (in England this will generally be by the local clinical commissioning group (CCG), in Wales by the local health board, and in Northern Ireland by the Department of Health, Social Services and Public Safety)
- the services that the local authority will provide or arrange, including the likely cost of these and any welfare benefits that the person or their carer may be able to claim to help pay for them
- the complaints procedures of the healthcare provider and local authority.

It's also important to note that the person's carer is entitled to have their needs assessed by the local authority's social services department as well. For more information see factsheets 418, **Assessment for care and support in England**; W418, **Community care assessment in Wales**; or NI418, **Community Care Assessment**, for those in Northern Ireland.

Deciding where the person will live

Generally, a 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, and so someone will have to make it for them.

The ability to be able to make a decision like this is called 'mental capacity'. Some people with dementia will not be able to do this and so are said to 'lack capacity'. There is a legal test for assessing someone's mental capacity. This is outlined in factsheet 460, **Mental Capacity Act 2005**. There is currently no capacity law in Northern Ireland, so this section is mostly about decisions made by people in England and Wales.

England and Wales

Who decides where a person will live will depend on their circumstances. If the person has set up a Lasting power of attorney (LPA) for health and welfare, their appointed attorney will make the decision. An LPA is a legal tool that allows someone to appoint another person to make certain decisions on their behalf in the event that they are no longer able to make them for themselves. For more information, including information about the previous Enduring power of attorney, see factsheet 472, **Lasting power of attorney**.

Alternatively, the Court of Protection (see ‘Other useful organisations’) can appoint a deputy to make these decisions for the person. If this has been done, the deputy will decide. For more information see factsheet 530, **Becoming a deputy for a person with dementia**.

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 consulting with colleagues. 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. In the event that the person doesn’t have any friends or family to speak on their behalf, an independent mental capacity advocate (IMCA) should be appointed to help ensure that their views and wishes are taken into account. A professional (usually a doctor or social worker) should organise this.

It may be that the person’s needs will be best met living at home. Alternatively, it might be that they are best met in supported housing or residential accommodation. This decision must be made in the person’s best interests.

For more information on selecting and moving into a care home see factsheet 476, **Moving into a care home**.

There may be concerns that moving a person with dementia who lacks mental capacity to a care home may deprive them of their liberty. This is because in a care home they would be under continuous supervision and would not be free to leave.

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, and is the least restrictive option. This is an additional safeguard to ensure that, when someone's freedom is being restricted, it is the right thing to do and in the person's best interests. For information see factsheet 483, **Deprivation of Liberty Safeguards (DoLS)**.

Northern Ireland

In Northern Ireland, if a person cannot decide for themselves where they will live following discharge from hospital, this decision will be made by professionals as part of the discharge process. This will usually be by the social worker, and they must consider the person's needs and wishes, as well as any doctor's or consultant's recommendations. Carers and relatives should also be involved in these discussions.

Equipment and adaptations

The planning that happens when a person is discharged from hospital should include arranging to provide any equipment and adaptations they will need to help them live safely at home – for example, wheelchairs, hoists or grab rails. Care homes providing nursing care (nursing care homes) will usually have this sort of equipment.

For advice on equipment, adaptations and the financial help that is available see factsheet 429, **Equipment, adaptations and improvements to the home**.

Intermediate care

The hospital discharge assessment might take into account whether the person with dementia will benefit from intermediate care. Intermediate care refers to a range of support services and equipment designed to help people regain some or all of their independence after a stay in hospital. This may mean they can go home with the reduced risk of an incident (eg a fall or urinary tract infection) that might cause

a return to hospital. Intermediate care could be a stay in a residential rehabilitation unit to regain confidence, or nursing and care services for a short period of time after the person is discharged.

Intermediate care generally lasts for a maximum of six weeks and is provided free of charge. Other rehabilitation services can be provided for a longer period and may be charged for.

Care provided by the local authority (council) or trust

Services provided by the local authority in England and Wales, or the local trust in Northern Ireland, are often means-tested. This means the person with dementia might have to contribute towards the cost, although they (or their carer) might be eligible for certain benefits to help them pay for this. The hospital discharge assessment should consider this.

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

The Care Act (2014) says that everyone who has eligible care needs in England must be allocated a personal budget. This is money that must be used to pay for the things agreed in the person's care plan in order to meet their needs. The local authority has a duty to offer direct payments (meaning the person receives the personal budget as a cash sum), but the person has the option to refuse and request that social services manage their personal budget for them. More information can also be found in factsheet 473, **Personal budgets**.

Many people in Wales will also be allocated a direct payment. For specific information on direct payments in Wales see the wales.gov.uk website.

NHS continuing healthcare

Some people with dementia are entitled to free NHS care once they have left hospital, known as 'NHS continuing healthcare'. This is available to people whose primary need is for healthcare, rather than social care. In most cases, only people with significant healthcare needs will be eligible.

Before leaving hospital, the hospital discharge assessment should consider whether someone is eligible for continuing healthcare. This process starts with a brief initial assessment, and if this shows that someone may be eligible, they will receive a more detailed assessment.

Some people with dementia who are eligible to receive it may not currently be receiving it. It is always worth asking if you feel you or the person you are caring for may be eligible.

For more see Alzheimer's Society's booklet 813, **When does the NHS pay for care?**

Delayed discharge from hospital

The Care Act in England and the Community Care (Delayed Discharge) Act 2003 in Wales aim to ensure that people do not stay in hospital longer than necessary (sometimes referred to as 'bed blocking').

When a person is becoming ready for discharge, the hospital must inform the local authority. They must assess the person's needs and arrange any necessary services within a certain period of time so that the person can be discharged safely and in a timely manner. If the local authority does not make these arrangements on time, it may have to pay a fine to the hospital (or relevant NHS body).

The processes that the local authorities and hospitals must follow to comply with this can result in people feeling pressured to leave hospital quickly and to accept a care home placement they do not want. If this happens it is sometimes appropriate to make a complaint. For more information see the 'Complaints' section below.

At the end of life

Some people with dementia will unfortunately not be well enough to be discharged home and will live their last days in a hospital ward. This can be a very distressing time for everyone involved. However, hospitals have certain procedures to make things more comfortable for the person with dementia and their family, friends and carers.

Some things you might want to consider in this situation:

- If the person is in the last stages of life, those who are close to them may want to stay with them outside visiting hours. Discuss possible arrangements with staff.
- People at the end of life may be able to be moved from a main ward to a quiet side room.
- 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 consider your views on resuscitation. The medical team and consultant should always discuss such issues and decisions with the main carer or family members. It may help to talk it through with family or friends. If anything is unclear, ask them to explain any terminology they use. The person may have set out their own wishes regarding resuscitation in an advance decision and these should be followed (see factsheet 463, **Advance decisions and advance statements**, or Northern Ireland factsheet NI467, **Financial and legal tips**).

Most UK hospitals have specific guidelines for care at the end of life. These ensure that:

- decisions about care are made in accordance with a person's needs and wishes
- staff communicate regularly and sensitively with the person and their relatives

- the person at the end of life and their relatives are involved in treatment and care decisions.

Complaints

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.

Alternatively, you may prefer to contact the Patient Advice and Liaison Service (PALS) based at the hospital, if you are in England and Wales. If you are in Northern Ireland, you can contact the Patient and Client Council (PCC), a national body which performs a similar role (see 'Other useful organisations' at the end of this factsheet for details). PALS and PCC both act on behalf of patients and families, and liaise with hospital staff to help resolve problems and concerns quickly.

Use the following tips to effectively make a complaint:

- Stay calm and polite
- Be specific about your concerns – for example, on three occasions you came in and saw that the drugs 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 to see happen to resolve your complaint.

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

- what occurred and when
- who you contacted or discussed it 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.

Other useful organisations

Care Quality Commission

CQC National Customer Service Centre
Citygate
Gallowgate
Newcastle upon Tyne NE1 4PA

T 03000 616161

W www.cqc.org.uk (includes contact form)

The independent regulator of health and social care in England and Wales that checks whether hospitals, GPs, care homes and dentists are meeting national standards.

Court of Protection

PO Box 70185
First Avenue House
42–49 High Holborn
London WC1A 9JA

T 0300 456 4600

E courtofprotectionenquiries@hmcts.gsi.gov.uk

W 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 the person or appointing someone else to do so.

Northern Ireland Ombudsman

Freepost BEL 1478
Belfast BT1 6BR

T 0800 34 34 24
E ombudsman@ni-ombudsman.org.uk
W www.ni-ombudsman.org.uk/

Responsible for considering complaints against government bodies and public administration in Northern Ireland.

Parliamentary and Health Service Ombudsman

T 0345 015 4033
W www.ombudsman.org.uk/

Responsible for considering complaints by the public about government departments, public authorities and the NHS.

Patient and Client Council Northern Ireland

T 0800 917 0222
E info.pcc@hscni.net
W www.patientclientcouncil.hscni.net/home

An independent voice on health and social care issues, can help people with complaints, and provide advice and information. Note, 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.

The Professional Standards Authority for Health and Social Care

157–197 Buckingham Palace Road
London SW1W 9SP

T 020 7389 8030
E info@professionalstandards.org.uk
W www.professionalstandards.org.uk

A group that oversees the statutory bodies that regulate health and social care professionals in England and Wales.

The Regulation and Quality Improvement Authority

9th Floor Riverside Tower
5 Lanyon Place
Belfast BT1 3BT

T 028 9051 7500
E info@rqia.org.uk
W www.rqia.org.uk

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

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Factsheet 477LP

Last updated: September 2015
Next review due: September 2018

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This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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