Helping families face dementia

A stay in hospital

Going into hospital can be difficult for people with dementia due to the unfamiliar surroundings, people and routines. However, there are many ways to help them prepare for their hospital admission, make their stay more comfortable and help to plan their discharge when they are ready to leave.

Preparing for a planned hospital stay

If a person with dementia is going into hospital for a planned treatment or operation, they should be sent written information in advance, including details about whether they can eat or drink beforehand and how long their stay is expected to be.

The person may also have a pre-operative assessment (‘pre-op’) shortly before their procedure, which may involve blood tests, a blood pressure check and being weighed. This is an opportunity to ask any questions about their admission.

Before the person is admitted, let the relevant department know that they have dementia and if they have any care and support needs related to their condition. The hospital’s website may have information about support they can offer – there may be a dementia specialist Admiral Nurse or a hospital dementia team who can support the person and their family during their admission.

It is useful to complete a care passport/hospital passport for the person before they go into hospital. This provides information to help guide their care and support, for example:

- what they like to be called
- food likes and dislikes
- what comforts them when distressed
- interests or hobbies
- cultural or religious beliefs

You can ask if the hospital has a care passport template, or you could use our life story template – please see Sources of support on p18.

To help the person with dementia prepare for being in hospital:

- Tell them what to expect – for example, how long they are expected to stay, when you can visit etc – but be guided by your knowledge of them, as too much information may be overwhelming and alarming
- Involve them in packing their hospital bag if they are able. Discuss what clothes and belongings they would like to take, such as books, magazines, phone, music player (with headphones) or photo albums. Familiar objects may help them feel more settled
- Make a list of their property and label clothes and belongings with their name
- Be aware that valuable items may be accidentally misplaced or

damaged. Ask hospital staff if there are facilities for safekeeping; if not, it may be safer to leave them at home

- Remember to pack glasses, hearing aids and dentures
- Include an up-to-date record of the person's medication and allergies along with their care passport

An unplanned hospital stay

Sometimes a person with dementia may be admitted to hospital in an emergency. This could be particularly unsettling as they may not fully understand what is happening.

Try to explain clearly why they need to go to hospital and what to expect when they get there, using simple language. Think about what you could take that might bring them comfort – it may be useful to make a list of things to pack in their hospital bag in case of this situation, or even keep a bag prepared at home.

Make sure everyone involved in treating the person – including paramedics, if they require an ambulance – knows that they have dementia, and pass on any useful information such as advice on communicating with them.

If sitting in a waiting room is likely to cause the person distress, you could ask reception staff if there is another, quieter place they could wait. Try to provide distractions – for example, you could use your phone to look at photos together, or play music or a television programme (with headphones).

It may be helpful for another family member or friend to go to the hospital with you so they can stay with the person if you need to have discussions with the medical staff.

On arrival (admission)

On arrival, make sure the hospital staff know that the person has dementia and give them a copy of their care passport. If the person has made any formal plans to inform their medical care, such as an advance care plan, ReSPECT form or advance decision to refuse treatment, you should also give these to the hospital staff – please see p17-19 for more information.

Find out if the hospital has an Admiral Nurse or dementia team that can support the person during their admission and help you liaise with the medical team, and ask if you can stay with the person while they get settled on the ward.

During the stay

It is important that the person with dementia receives emotional support while in hospital, but staff may not have time to spend long periods with them. Family and friends can be a great source of support during visits. Between visits, or if you cannot visit, you might be able to keep in touch by phone or video call – the ward may have devices for patients to use.

Ask staff if there is any dementia support available within the hospital, such as a companionship or befriending service, to provide the person with stimulation and company when they have no visitors.

Try to build a good relationship with the ward staff so you can communicate regularly with those providing day-to-day care. If they seem very busy, ask to arrange a time to meet, rather than dropping in when they are not expecting you. If you cannot visit regularly, find out if there is a good time to phone the ward for updates.

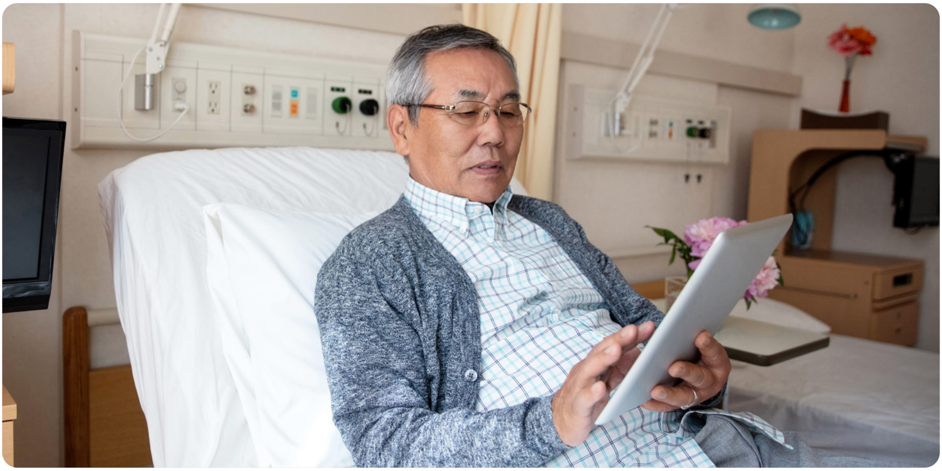
Check the visiting arrangements, and if you have any concerns discuss these with the ward manager. Many hospitals are signed up to John's Campaign (see p19), which welcomes unrestricted visiting for family carers of people with dementia. However, when there are concerns related to infectious diseases like norovirus or Covid, visiting may be more restricted.

Many hospitals are members of the Dementia Friendly Hospital Charter: a national initiative to improve the care of people with dementia and ensure families are involved. You can ask the hospital staff about this.

Activities

The person with dementia may benefit from having activities to occupy them during their hospital stay. These can be listed in their care passport – for example:

- favourite radio station or TV programmes
- smartphone or tablet
- daily newspaper
- magazines or books
- colouring books, jigsaws, puzzle books



- family photo albums
- comfort objects like a blanket or cushion
- games or films

The Admiral Nurse or dementia team may be able to support the person with these activities on the ward or in the day room.

Walking

Many people with dementia like to walk around and may become agitated if they are prevented from doing so. Ask the staff if it is safe and possible for the person to walk around the ward or visit the day room. They may be able to leave the ward with a visitor to go the hospital café or grounds. Some hospitals have dementia-friendly gardens for this purpose.

People with dementia may be prone to falls, especially if they are unwell and in an unfamiliar environment. Ensure the person has well-fitting footwear with a sturdy sole and good grip, and keep the area around the bed uncluttered. Make sure staff know if the person needs a mobility aid and encourages them to use it, and keep essential items such as glasses and hearing aids within easy reach.

Hospital staff may use monitoring equipment like a fall alert mat or chair sensor to alert them if the person gets up or falls so they can provide support.

Eating and drinking

When people are ill and in hospital, their appetite may be reduced. To ensure the person eats as well as possible, tell hospital staff their food and drink preferences, and record these in their care passport.

Picture menus may be available to show what the food looks like. Lighter, snack or finger food menus are often available for people who struggle with eating main meals. If the person has difficulty using cutlery, ask the staff if adapted or ‘easy grip’ cutlery is available, or bring some in from home, ensuring it is labelled with the person’s name.

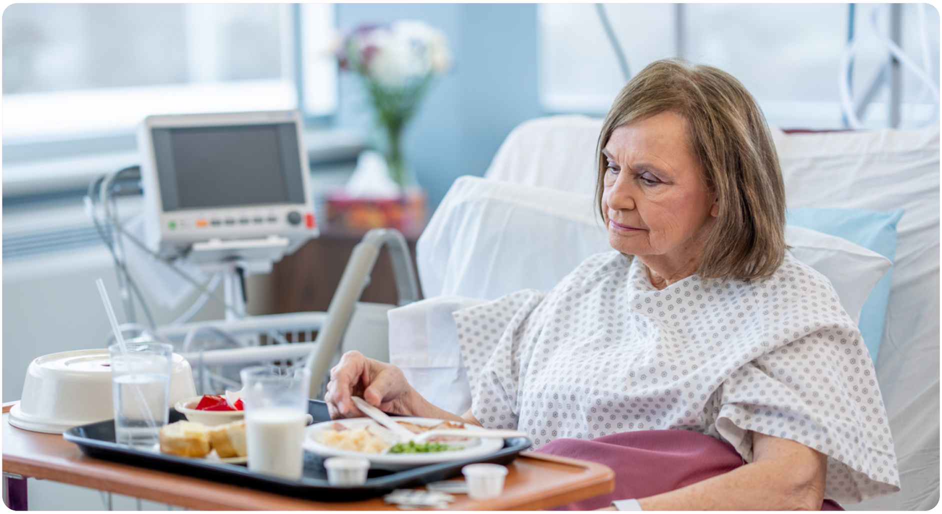
Some hospitals allow carers to visit at mealtimes to support the person with eating. They may also use a ‘red tray’ scheme or a sign above their bed to highlight which patients need extra assistance.

If the person has difficulty swallowing, they can be assessed by a speech and language therapist, who may suggest pureed food and thickened drinks to aid swallowing. If there are general concerns around their eating and drinking, a dietitian can offer support.

Please see Sources of support on p17 for our leaflet on eating and drinking.

Delirium

Delirium is a state of increased confusion that develops suddenly over a few hours or days and may occur when someone is unwell. It is a common condition in hospital, especially in people with dementia.



People who have delirium may become more restless or withdrawn, struggle to concentrate, or feel drowsy. It may be more difficult to communicate with them: they may ramble and jump from one topic to another. They may not know where they are and experience hallucinations or false beliefs.

Delirium is treated by addressing the underlying cause, such as an infection or dehydration. It can take days, weeks or even months to resolve, even after the cause is treated. In the meantime, the person may need extra support and reassurance. They will need staff and visitors to be calm and patient, and may need reminding where they are.

Please see Sources of support on p17 for our leaflet on delirium.

Pain

To avoid the person with dementia becoming unduly distressed, it is important to manage pain effectively. It may be difficult for ward staff to tell if the person is in pain if they cannot communicate clearly so always make them aware if you feel they are in pain. You can use their care passport to record possible signs of pain, for example:

- restlessness
- vocal sounds eg groaning, whimpering
- grimacing
- holding the affected area

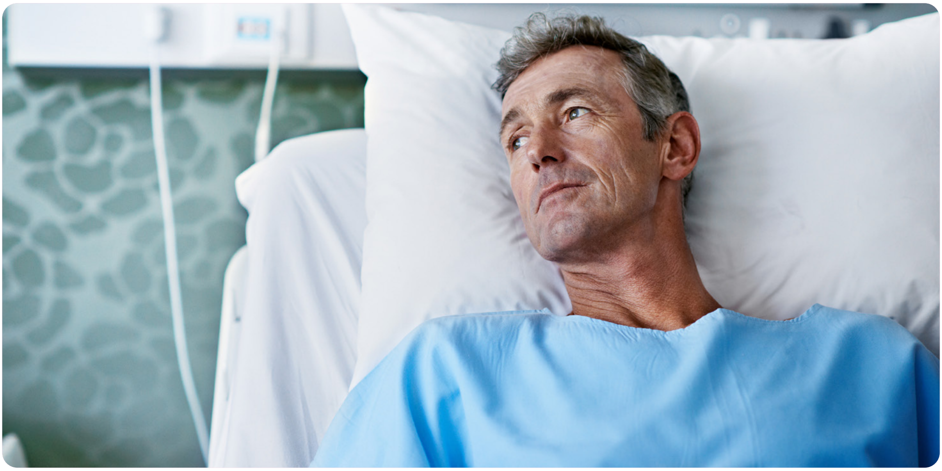
Please see Sources of support on p18 for our leaflet on pain in dementia.

Continence

Some family carers have reported concerns about people with dementia not being adequately supported with going to the toilet and instead being expected to use incontinence pads. This can lead to a lack of dignity and loss of long-term continence. These tips may help:

- If the person with dementia is likely to need support with going to the toilet, make sure staff are aware
- If they have mobility problems that may affect them getting to the toilet, ask about other options eg a commode or bedpan
- Let staff know if there are behavioural signs that the person might need the toilet (eg fidgeting, holding their crotch) especially if they struggle to express this verbally
- Encourage the staff to ask the person regularly if they need the toilet, and prompt them if they do not ask to go
- Ask if you or other visitors can take the person to the toilet when you visit

If the person has problems with incontinence, make sure staff know



about this, including how their difficulties are usually managed (eg do they use pads or a full brief? How often do they need to change?).

If you notice any problems with how the person's continence is being managed, for example soiled bed/clothes/pads, relying on pads rather than being supported to use the toilet, or personal care not being carried out discreetly, please see p12 for guidance on making a complaint.

Hospital admissions for people with young onset dementia

If a person with young onset dementia (where symptoms develop before the age of 65) is admitted to hospital, there may be additional issues to consider.

When the person is admitted, talk to staff about which ward they will be on. Staff on an older persons'/geriatric ward may have more experience in caring for people with dementia, but it may be harder for them to meet the specific needs of a younger person, who may, for example, be more mobile and active than older people.

On the other hand, if the person is admitted to a general ward where the patients are younger, staff may have little experience of caring for people with dementia and lack understanding of their needs.

If you have any concerns about which ward the person is admitted to, you can speak to the ward manager, but bear in mind that a lack of bed availability may mean there is little choice.

Whichever ward the person is on, make sure the staff are aware that they have dementia, as they may not expect a younger person to be living with the condition.

Younger people are also more likely to have rarer forms of dementia where symptoms like changes in behaviour, personality and vision are more prevalent than memory problems. This may mean hospital staff are less familiar with their condition, so explaining the type of dementia and how it affects the person will help them better understand their symptoms and care needs.

Many younger people with dementia will benefit from having their mobile phone, tablet or other form of technology with them, but be aware that valuables sometimes go missing in hospital. Inform the ward staff that the person has them, and if possible, set up face or fingerprint recognition and device tracking. Make sure the person has chargers and headphones.

If the person has children who would like to visit, find out if this can be accommodated – some wards have minimum age limits for visitors, or only allow children at specific times. If they cannot visit the ward, ask if there is an alternative space where they could meet, like a café or outdoor area. This may also be less stressful for the child, who may be bored or overwhelmed when visiting a ward.

Concerns and complaints

Most people in hospital feel well looked after. However, if you have concerns about the person’s care, talk to their named nurse in the

first instance, who may discuss your worries with the nurse in charge. If you are not satisfied with their response, you could ask to speak to the ward manager. If the concerns are dementia-related, the Admiral Nurse or dementia team may be able to help.

Try to stay calm and be specific about your concern, for example: “On two occasions the person’s meal was taken away before they had finished.” Be clear about how they can improve the situation and resolve your complaint. It is helpful to write a record of what was said and done, including dates, times and who you spoke to.

If you remain concerned, you could contact the hospital’s Patient Advice and Liaison Service (PALS). They can support patients and families in resolving problems. Please see Sources of support on p19 for information.

Making decisions

When a person is in hospital, important decisions may arise relating to their health and care. If the person with dementia has capacity to make decisions, they can do so themselves, with support if needed.

If the person lacks capacity but has a lasting power of attorney (LPA) for health and welfare (power of attorney in Scotland or enduring power of attorney in Northern Ireland), their nominated attorney can make certain decisions on their behalf. You should ensure the hospital knows if an LPA or equivalent is in place.

If the person has not made an LPA, you can apply to the Court of Protection to become their deputy. However, this process is expensive and can take a long time.

The person with dementia may also have:

- an advance care plan: a document recording their wishes for their care – this can be a useful guide, but is not legally binding
- a ReSPECT form: this states their wishes regarding emergency treatment – again, this is not legally binding
- an advance decision to refuse treatment (ADRT), also known as an advance decision or living Will: this states any medical procedures or treatments that they do not want and is legally binding

If the person has these, you should give copies to the hospital. Please see Sources of support on p17-19 for more information.

If there are no legal arrangements in place and a decision needs to be made about the person's treatment, a 'best interests decision' may be made in consultation with the medical staff, the person with dementia (if possible) and their family and/or other people close to them.

DNACPR decisions

DNACPR stands for 'do not attempt cardiopulmonary resuscitation'. It can also be referred to as DNR ('do not resuscitate'). If a person has a DNACPR in place, their medical team will not try to restart their heart if it stops.

It is possible that a doctor may recommend the person with dementia has a DNACPR, especially if they are frail and in poor physical health. This can come as a shock but may be in the person's best interests. CPR can cause distress and injuries like broken ribs and is often unsuccessful. Very few people make a full recovery after needing resuscitation.

Medical staff should explain why they feel a DNACPR is in the person's best interests and ask them about their wishes. You should also be given the opportunity to share your views. If the person with dementia lacks capacity to make a decision, the doctor should consult anyone who has LPA for health and welfare or deputyship.

If you disagree with the doctor you can request a second opinion, but ultimately, the decision can be made even if you do not agree.

Having a DNACPR does not mean that the person with dementia will not receive medical care and treatment if required – it will only apply if their heart stops. Please see Sources of support on p18 for further information.

Leaving hospital (discharge)

When the person is ready to leave hospital there will be a discharge planning process to develop a discharge plan that considers their needs, where they will be living and who will provide care or support. The process may differ depending on where you live, but may involve:

- ward doctors and nurses
- your Admiral Nurse
- dementia team
- physiotherapist

- occupational therapist
- speech and language therapist
- mental health team
- social worker
- discharge co-ordinator

It is important to talk to the people involved in creating the discharge plan and raise any concerns. It may help to make a list of who you have spoken to and their contact details.

A carer's assessment (for you) and needs assessment (for the person with dementia) should be carried out to establish what support the person and their carers will need when they are discharged. The person may also need a financial assessment to see if they qualify for funding towards their care. Please see Sources of support on p17-19.

If possible, any equipment and adaptations to help the person live safely at home should be in place prior to discharge, for example grab rails, toilet frames or hoists.

The person's discharge plan should be reviewed in the community to ensure that it continues to meet their needs.

At the end of life

If the person is too unwell to be discharged from hospital and is nearing the end of their life, they and their family and friends will usually be supported by a palliative care team. This is a team of specialist staff who aim to make sure they are as comfortable as possible and receive supportive end of life care tailored to their needs and preferences. The palliative care team can also help with the person's discharge plan or help to arrange transfer to a hospice, community hospital or care home.

Sources of support

To speak to a dementia specialist Admiral Nurse about a stay in hospital or any other aspect of dementia, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email › **helpline@dementiauk.org** If you prefer, you can pre-book a phone or video call appointment with an Admiral Nurse: visit › **dementiauk.org/book**

Dementia UK information

Advance care planning

› dementiauk.org/advance-care-planning

Advance care plan template

› dementiauk.org/advance-care-plan-template

The carer's assessment

› dementiauk.org/the-carers-assessment

Continence

› dementiauk.org/continence

Delirium

› dementiauk.org/delirium

Eating and drinking

› dementiauk.org/eating-and-drinking

Lasting power of attorney

› dementiauk.org/lasting-power-of-attorney

Life story work

› dementiauk.org/creating-a-life-story

Life story template

› dementiauk.org/life-story-template

Frailty

› dementiauk.org/frailty-and-dementia

Falls

› dementiauk.org/dementia-and-falls

Hydration for people with dementia

› dementiauk.org/hydration

Mental capacity and decision-making

› dementiauk.org/mental-capacity-and-decision-making

Pain

› dementiauk.org/pain-and-dementia

Recognising the later stages of dementia and moving towards end of life care

› dementiauk.org/end-of-life-care

Other resources

Advance decision to refuse treatment

› nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment

Do not attempt cardiopulmonary resuscitation (DNACPR)

› nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions

John’s Campaign

› johnscampaign.org.uk

Needs assessment

› nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment

ReSPECT for patients and carers

› resus.org.uk/respect/respect-patients-and-carers

What is PALS (Patient Advice and Liaison Service)?

› nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service

To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline:
0800 888 6678 or **helpline@dementiauk.org**

Book a virtual appointment:
dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan **the QR code**

Thank you.

Dementia UK
Helping families face dementia

dementiauk.org • **info@dementiauk.org**

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