Helping families face dementia

Changes in care

A stay in hospital

A stay in hospital

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

Preparing for a stay in hospital

Planned hospital stay
People with dementia may need to go into hospital for treatment or an operation. They should be sent written information in advance, including details about whether they can eat or drink before they arrive and how long their stay is expected to be.

A common concern is whether the hospital staff will be able to communicate with the person with dementia. You should let the relevant department know in advance that the person has dementia and if they have any communication needs.

The hospital's website may have information about support they can offer, and in some areas, dementia specialist Admiral Nurses can liaise with the hospital's Dementia Team to ensure consistent care during the hospital stay and good communication with families and carers.

If the person with dementia is unable to articulate their needs clearly, particularly when they're unwell, it can be useful to complete a Care Passport. This provides information about the person to help guide the care and support they receive in hospital.

Two commonly used Care Passports are 'This is Me,' produced by Alzheimer's Society, and 'Reach Out to Me', part of the national hospital Butterfly Scheme.

If the person with dementia has an Advance Care Plan or ReSPECT form, you should also give these to the hospital. An Advance Care Plan is a document showing the person's wishes for their care, and the ReSPECT form is a document stating their wishes regarding emergency treatment. Please see Sources of support at the end of this leaflet for more information.

There are some things you can do to help a person with dementia prepare for being in hospital:

- ask them what information might help to reassure them (for example, how often you can visit, how long they will be staying etc)
- involve them in packing their hospital bag. Discuss what clothes and belongings they'd like to take, such as books, magazines, smartphone, music device 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
- remember to pack glasses, hearing aids and dentures
- pack an up-to-date record of the person's medication and allergies along with their Care Passport

Unplanned hospital stay
Sometimes a person with dementia may be admitted to hospital in an emergency. This could be unsettling as they may not fully understand why they need to

go to hospital. It may be useful to keep a list of things to pack in their hospital bag in this situation (described above).

On arrival (admission)

On arrival, make sure the hospital staff know that the person has dementia. Give them a copy of the Care Passport and ask for it to be kept with the person's hospital notes. It will help explain the person's care needs and preferences if they're unable to express these themselves and their family carer is not available.

If applicable, also give the hospital staff the ReSPECT form or Advance Care Plan to help guide decision-making should the person become more seriously unwell.

Ask if the hospital has an Admiral Nurse or Dementia Team that can support people with dementia and their family during their stay.

During the stay

It's important that the person with dementia receives emotional support while in hospital, but staff may not have time to spend long periods with them. Carers, family and friends can help with this during visits, giving the reassurance of seeing a familiar face or hearing a familiar voice.

Between visits, or if you're unable to visit, you might be able to phone or video call them. The ward may have devices for patients to use.

Try to build a good relationship with ward staff so you can communicate regularly with those providing day-to-day care. If they seem very busy, try to arrange an update meeting with them. If you're unable to visit in person, regular phone calls with ward staff can be helpful.

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, which welcomes unrestricted visiting for family carers of people with dementia. However, when there are concerns related to infectious diseases like norovirus or Covid-19, visiting may be more restricted.

Many hospitals are members of the Dementia Friendly Hospital Charter: a national initiative to improve the care patients with

dementia receive, and ensure carers and families are involved. You can ask the hospital staff about this.

Activities

The person with dementia may benefit from having some 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, jigsaw puzzles
- family photo books
- comfort objects like a blanket or cushion
- games or films

The Admiral Nurse or Dementia Team may be able to provide resources for some of these activities on the ward or in the day room.

Walking

Walking is a good form of exercise and many people with dementia like to be able to walk around. They may feel agitated or angry if they're prevented from walking.

Ask the staff if it's safe and possible for the person to walk around the ward or visit the day room. They may be able leave the ward with a visitor to go the hospital coffee shop or grounds. Some hospitals have dementia-friendly gardens for this purpose.

Eating and drinking

When people are ill and in hospital, their appetite may be reduced. Tell hospital staff the person's food and drink preferences, and record these in their Care Passport.

Picture menus may be available to show what the food looks like, and snack menus are often available if the person doesn't like to eat main meals. If they have difficulty using cutlery, finger food may also be available.

Some hospitals allow carers to visit at mealtimes to sit and sometimes eat with the person with dementia to encourage them. They may 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. Their food may need to be softer and their drinks a little thicker to aid swallowing.

If there are concerns around the person's food intake in hospital, the Dietician Team can offer support. It's helpful to know the person's weight so this can be monitored.

Please see Sources of support 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 be a sign that someone is unwell. It's a common condition in hospital, and people with dementia are more prone to it.

People who have delirium can behave in ways that are unusual for them. They 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, see things that are not really there, or believe things that are not true.

The treatment for delirium is to treat the underlying cause, such as an infection or dehydration. 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 for our leaflet on delirium.

Pain

If a person with dementia is in pain, they may become distressed, so it's important to manage pain effectively.

It can be difficult to tell if someone is in pain if they're unable to communicate clearly and if the ward staff don't know them very well, so if you feel the person with dementia is in pain, it's important to discuss this with staff.

Their Care Passport should state how the person may communicate that they are in pain. For example:

- restlessness
- vocal sounds
- grimacing
- holding the affected area

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

Concerns and complaints

Most people receiving hospital care feel well looked after. However, if you have concerns about the person's care, talk to their named nurse in the first instance. If you're 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 what you would like them to do to improve the situation and resolve your complaint. It’s 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 speak with the hospital’s Patient Advice and Liaison Service (PALS). They can support patients and families in discussions with hospital staff to help resolve problems and concerns.

Making decisions

When a person is in hospital, important questions can arise relating to their health and finances. If the person with dementia still has capacity to make decisions, they can do so themselves. However, if they lack capacity at that time, other arrangements may be necessary. Please see Sources of support for our leaflet about capacity.

The person may have appointed a Lasting Power of Attorney (LPA) for England and Wales, Power of Attorney (PoA) for Scotland, or Enduring Power of Attorney (EPA) for Northern Ireland. These allow another person to make certain medical or financial decisions for them if they’re no longer able to make those decisions themselves.

The person may have completed a ReSPECT form or Advance Care Plan to guide decision-making in the event of them lacking capacity for certain decisions. They may also have a legally binding Advance Decision or Advance Directive which allows them to refuse in advance specific medical procedures or treatments.

If the person no longer has capacity to appoint an attorney or make an Advance Decision, you can apply to the Court of Protection to become their deputy. However, this process is expensive and can take a long time.

If there are no legal arrangements in place, the decision-maker will

need to make a ‘best interests decision’ following consultation with the person with dementia and their family.

At the end of life

If someone is nearing the end of their life in hospital, they and their carers will usually be supported by the Palliative Care Team. This is a team of specialist staff who aim to make sure that patients are as comfortable as possible and receive quality end-of-life care tailored to their needs and preferences. The patient and their family should be involved in any decision-making. They can help with the discharge plan, or arrange transfer to a hospice, community hospital or care home.

Leaving hospital (discharge)

When someone is ready to leave hospital there will be a discharge planning process. It’s important to talk with the hospital staff about discharge planning in advance and raise any concerns. The process may involve input from:

- ward doctors and nurses
- your Admiral Nurse
- Dementia Team
- Physiotherapy
- Occupational Therapy

- Speech and Language Therapy
- Mental Health Team
- Adult Social Care
- Discharge Co-ordinator

It may help to make a list of the names of people you have spoken to and their contact details.

A Carer's Assessment should be carried out to see whether family carers need support once the person is discharged. The person may also need a financial assessment, looking into their finances and checking their eligibility for different types of funding. Please see Sources of support for our leaflet on the Carer's Assessment.

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 hospital Social Care Team should develop a discharge plan that considers the person's needs, where they will be living and who will be providing care or support. This will be reviewed in the community after discharge to ensure that it continues to meet the person's needs, and adjusted if those needs change in the future.

The discharge process may be different depending on where you live.

Our Admiral Nurses can help

If you have any questions or concerns about dementia, you can call the dementia specialist Admiral Nurses on our Helpline for free.

Call **0800 888 6678** or email **helpline@dementiauk.org**

Opening hours:
Monday-Friday, 9am-9pm
Saturday-Sunday, 9am-5pm

Sources of support

Admiral Nurse Dementia Helpline
0800 888 6678 or by email on helpline@dementiauk.org

Patient Advice and Liaison Service (PALS)
What is PALS (Patient Advice and Liaison Service)?
nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/

The Butterfly Scheme
butterflyscheme.org.uk

Dementia UK leaflets

Advance Care Planning
dementiauk.org/advance-care-planning

Capacity and decision making
dementiauk.org/capacity

The Carer's Assessment
dementiauk.org/the-carers-assessment

Dealing with restlessness
dementiauk.org/dealing-with-restlessness

Delirium
dementiauk.org/delirium

Eating and drinking
dementiauk.org/eating-and-drinking

False beliefs and delusions in dementia
dementiauk.org/false-beliefs

Lasting Power of Attorney
dementiauk.org/lasting-power

Pain in dementia
dementiauk.org/pain

Understanding dying
dementiauk.org/understanding-dying

Making the home safe and comfortable for a person with dementia
dementiauk.org/safe-comfortable-home

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email **feedback@dementiauk.org**

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit **dementiauk.org/donate** or call **0300 365 5500**.

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Dementia UK
Helping families face dementia

If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

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Saturday and Sunday, 9am – 5pm

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

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Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).