

Information resource for family, carers and friends and for people living with dementia

Values underpinning NHS dementia care

We believe that people living with dementia are entitled to person centred care that recognises and respects their individual care needs. 'Person-centredness' is a term that is becoming increasingly familiar within health and social care; it is being used to describe a standard of care that ensures the patient/client is at the centre of care delivery. It is underpinned by values, beliefs and respect for people, their individual rights, mutual respect, understanding, and shared decision making with the person and their family or carers. Some of the outcomes for care are a greater involvement and satisfaction with care, and an enhanced feeling of well-being.

Care in hospital wards

Someone with dementia may be admitted to a general or specialist hospital ward either as part of a planned procedure, such as a cataract operation, or unplanned, following an accident, such as a fall.

Hospital environments can be disorientating and frightening for a person with dementia and may make them more disorientated than usual.

Many conditions, such as infected leg ulcers, constipation, chest, or urine infections, can cause additional disorientation and distress that often reduce once treated and the person resettled into a familiar home environment. When disorientation is severe it is known as a delirium. However, this is a treatable medical condition.

- Problems with sight can increase disorientation
- Hearing difficulties can increase disorientation and feelings of isolation
- Problems with teeth, gums or dentures can result in discomfort and stress and poor food and fluid intake

Top tips for carers

This covers some of the issues that friends, family and carers should consider when a person with dementia goes into hospital and gives tips on how the person can be reassured and supported during their stay.

- Let staff know that the person you care for has dementia, and what type, if you know
- Ask to speak to the Registered Nurse who will be in charge of the person's care
- East Sussex Healthcare NHS Trust (ESHT) have implemented the Butterfly Scheme[®] that supports people with dementia whilst in hospital. Please ask staff for an information sheet
- If the person has reduced communication, is using a Care Passport, Life History such as 'REACH Out to Me' or 'This is Me'* document will assist all staff to know the person better e.g. how they communicate their needs
- If you hold a legally appointed Lasting Power of Attorney (LPA) please let staff know and bring the original of the legal document with you

- Ask that you be included in all decisions regarding the person's care, and/or provide the contact details of the most appropriate person to be contacted (such as the Lasting Power of Attorney)
- Please bring in toiletries, day clothes and comfortable shoes (this helps orientation to time as well as mobilisation) and hearing aid batteries if required
- If the person has difficulty eating and drinking, someone will help them at mealtimes, or ask if you can assist (if you are able to)
- ESHT have signed up to 'Johns Campaign', a scheme that encourages open visiting and supports overnight stays for the carers or family of people with dementia
- If a person needs to walk around a lot or is prone to becoming restless, let staff know and help them to identify ways of helping the person
- Bring in some familiar objects such as photographs or books that will help the person with dementia feel less isolated. Use a message pad or notebook to let the person know where you are and when you will be back
- The staff will discuss with you what will happen when it is getting nearer to the time for the person with dementia to leave hospital, so that you are prepared and know what support is available
- A Carers Card will enable you to obtain a discount on parking charges. This can be obtained through an Adult Social Care assessment or from Care for the Carers

You may want to make an appointment to speak to Adult Social Care. Adult Social Care can advise on a range of matters, such as:

- Problems getting to and from the hospital to visit
- Benefits and Community Health Assessment (CHC) for ongoing support either at home, residential or nursing care funding assessment
- Difficulties experienced by carers, friends or family, such as illness, disability, stress or other commitments that may affect their ability to visit or continue to care for the person

Documentation and the Care Passport or 'REACH Out to Me'

Within ESHT we use the Butterfly Scheme[®] that supports people with dementia whilst in hospital. The Butterfly Scheme[®] have produced a document 'REACH Out to Me' that can be used to record personal and life history information and supports person centred care. Additionally, it provides a snapshot of the person with dementia, giving information about them as an individual, such as needs, preferences, likes, dislikes and interests.

- If the person who has reduced communication is using a Care Passport, or a Life History such as 'REACH Out to Me' or 'This is Me'* document, this will assist all staff to know the person better e.g. how they communicate their needs. The 'REACH Out to Me' can be found on the ESHT website or please ask the ward staff for a copy, they can also provide more information about the Butterfly Scheme[®].

The information you can complete should include on the 'REACH Out to Me':

- The name by which the person wishes to be known
- Brief details of their normal routines, including whether they need reminders or support with washing, dressing, going to the toilet, eating and drinking or taking medication
- Information about foods they particularly like or dislike, or any difficulties they have when eating
- Illness or pain that may bother them and how they may express that
- Any cultural or religious needs
- Information about sleeping patterns

- Whether the person likes to be active or inactive - for example, if they walk about, and what can calm them if they are agitated or distressed
- Whether the person has an advance decision or a personal welfare/health and wellbeing Lasting Power of Attorney (LPA)

You can ask the Registered Nurse or Therapists to include information that will be helpful to offering care in the best way so the multi-disciplinary team (MDT) can provide person-centred care.

It may be helpful if you 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 will also help staff to communicate and gain more insight into 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 and particular interests. This makes it easier to start or keep a conversation going

How you can help recovery

- Bring in toiletries, clothing and well-fitting shoes for the daytime and rehabilitation activities
- Please make sure that clothes are discreetly labelled, in case they are mislaid
- Clean spectacles and check on hearing aid batteries
- Think of enjoyable pastimes or items to occupy the person's time and make a rummage or memory box for the person while they are in hospital

Providing reassurance

Familiar objects, such as photographs on the bedside table of family members or a much-loved pet, can be very reassuring for a person with dementia on an unfamiliar hospital ward. They can also provide staff with a good talking point. If the person still reads, you could provide a notebook, so that staff and visitors can write messages, reminders, and details of when they are next visiting.

Familiar faces may also bring the person comfort and reassurance. Because of this, flexible visiting times can be achieved on the ward – please discuss with the Registered Nurses on the ward including the ward manager or matron.

Unavoidable noise and bustle on the ward can add to the person's disorientation and heighten 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 to get away from the bustle when you visit.

There may also be occasions when the person with dementia states, or demonstrates, that they do not want care given at the time offered e.g. morning wash or shave. Therefore, this may be

delayed until later in the day or evening when the ward is quieter and less distracting or overly stimulating.

Eating and drinking

Eating and drinking can be more difficult for a person with dementia, and this can be exacerbated by the busy hospital environment. Please make staff aware of any difficulties that the person has plus any strategies that may help with eating and drinking, and if the person has any previous dietitian or speech and language therapy (SaLT) advice please share this with the ward staff. Some people with dementia benefit from reminders and prompts at mealtime and staff may be grateful for any assistance you can offer in helping the person to eat, so please discuss with the nurse in charge who will also be able to share ward menus. It may be possible to bring in certain food and drink from home to support the person, again please discuss this with the ward staff.

Extra snacks, nourishing drinks, and specific food options such as “finger foods” and modified texture foods (such as soft and pureed options) are available from the catering team as needed. Drinks are available 24 hours a day, please let the ward staff know if the person has a favourite drink or preferred cup. Some wards within ESHT use a system called “red tray and red jug” as a way of identifying patients who have increased need for assistance with eating and drinking or require modification in the consistency of their food and drink. This is done with the use of specially designated coloured meal trays and jug lids. For more information about this please speak to the ward staff.

If the person is not eating well or is losing weight, the ward staff will conduct nutritional screening which will identify whether any dietary changes are recommended. This could include following a higher energy / higher protein fortified diet with extra nourishing drinks and / or snacks. If more intensive support is required, the ward staff can refer the person to the dietitians who will co-ordinate a nutritional care plan with both nursing and catering staff. If dietetic support is needed on discharge from hospital, the hospital dietitians will contact the community dietitians for follow up.

Difficulties with swallowing food and drinks can be a problem for people who have dementia. If new problems occur during the hospital stay, the ward staff will refer to SaLT who might provide new swallowing guidance. Please look out for and follow any new guidance provided to help with safer swallowing. If SaLT support is needed on discharge from hospital, the hospital SaLTs will contact the community team for follow up.

Medication

Doctors and nurses will discuss the person's medication, and any changes, with the person with dementia and their carer or relatives.

We aim to reduce, and if possible, avoid giving tranquillising or sedative medications as this may make the person more disorientated and dependent. Occasionally, such medications may be used as a short-term measure. If you have any concerns, please discuss these with the doctor.

Please ask the Registered Nurse to talk through medications with you before discharge.

If you have any concerns with the person's treatment or care whilst in hospital, it would be helpful to keep brief notes and discuss these first with the Registered Nurse, ward manager or the Matron.

You may prefer to contact the Patient Advice and Liaison Service (PALS) based at the hospital. PALS acts on behalf of patients and families liaising with hospital staff to help resolve concerns quickly.

Discharge

Leaving hospital will be planned, and carers or family should receive notice in advance. However, we recognise that the hospital is a very challenging place for a person with dementia; therefore, our aim is to minimise the impact of a hospital stay by planning for discharge as soon as possible after admission. Your support in working with the staff is invaluable.

Carers - looking after yourself. Where you can get support as a carer

It is all too easy to ignore your own needs when caring for someone with dementia and forget that you matter too. It is important to take steps to safeguard your own health and well-being, so that you can continue to cope and retain your confidence.

Every carer needs support and people with whom they can discuss their feelings. You may get the support you need from friends and family, from understanding professionals or from a local support group where you can chat to others who have had similar experiences and who really understand what it is like.

Care for the Carers is a very supportive organisation and you may find a referral to their service helpful at this time. Please see below or ask ward staff for details.

Help that is available

The Trust has a Dementia Care Team who are available to talk to. They are contactable through ward staff, via switchboard or on the numbers below.

Care at home

If a person is disorientated, has memory, self-care problems or has dementia and may need support, under The Care Act 2014, the local authority social services department should carry out a community care assessment.

Why request a community care assessment?

The 'community care assessment', also referred to as a 'care assessment' or a 'needs assessment', enables social services to find out what the person's care needs are, and to decide which services could help to meet those needs. This could be care in the person's own home, such as:

- Equipment and adaptations
- Aids
- Home care
- Short break services (respite)
- Day care

Alternatively, it could be that the person's needs would be best met through care in a care home.

How is an assessment arranged?

The assessment can be arranged through:

- the person's GP, consultant or another professional making a referral to the local authority for assessment

- the person who is seeking support and care contacting the local authority for an assessment, or another person (such as a friend or relative) doing so on their behalf

Try to discover what help is available in caring for the person with dementia **before you might need it**. That way when you do need to access services, you will know who to turn to. The Alzheimer's Society can provide information on all dementias, can help you to access services and provide a listening ear.

Ask for an assessment of the needs of the person you are caring for if one has not already been carried out. Your needs as a carer should be considered in any assessment. The Care Act 2014 gives carers the right to a separate assessment of their needs. Ask Adult Social Care about this. Adult Social Care can advise on further support available for caring at home or assessment for residential or nursing care either now or in the future.

If the person has received specific advice and input from a specialist (for example, a dietician) whilst on the ward, you might want to make sure that follow-up care is being arranged. Ask the Registered Nurse for names and contact numbers for further review once the person is back in the community e.g., own GP (see Contact numbers on last page).

At the end of life

End of Life care is considered to be within the last year of life. The NHS utilises several guidelines and National Standards to support care at end of life. These guide staff to provide quality care that is aimed at ensuring the person can have a dignified death, is comfortable, pain free and that any other symptoms are controlled and there are no unnecessary and intrusive investigations or treatments, including resuscitation, being carried out. The NHS encourages people with dementia and their families/carers to start planning well in advance for end-of-life care – often several years in advance or even soon after diagnosis

If the person is dying in hospital, those important to the patient may wish to stay with them outside visiting hours - open visiting, free car parking and accommodation are all available if needed. Please discuss these arrangements with staff.

East Sussex Healthcare NHS Trust would like to express appreciation for you working in partnership with our staff to ensure that we can provide dedicated, person-centred care.

With acknowledgement and thanks - this information has been adapted by members of the East Sussex Healthcare NHS Trust Dementia Steering Group from the Alzheimer's Society factsheet, Care on a hospital ward and Wakefield Memory Assessment Service, Carers Information Pack.

Useful contact details

ESHT Dementia Care Team:

Eastbourne 0300 131 5515, Conquest 0300 131 4898

Patient Advice and Liaison Service (PALS):

Hastings, Rother area 0300 131 5309, Eastbourne area 0300 131 478

PALS can also be contacted via email: esh-tr.palsh@nhs.net

Memory Assessment Service:

If you're worried about your memory, or a friend, family member contact your GP. Your doctor may do some basic tests with you and might refer you to the memory assessment service

Adult Social Care and Health - East Sussex County Council:

Phone: 0345 60 80 191

8am to 8pm, 7 days a week (including bank holidays). Calls are charged at a local rate

Out of hours emergencies: phone 0345 60 80 191 and select option 2 to connect to our Emergency Duty Service

Care for the Carers - East Sussex:

Phone: 01323 738390, Text: 07860 077300

Email: info@cftc.org.uk

For a directory of dementia services available within East Sussex and more information:

Website: <https://1space.eastsussex.gov.uk/>

Important information

The information in this leaflet is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

Your comments

We are always interested to hear your views about our leaflets. If you have any comments, please contact the Patient Experience Team – Tel: 0300 131 4731 (direct dial) or by email at: esh-tr.patientexperience@nhs.net

Hand hygiene

The Trust is committed to maintaining a clean, safe environment. Hand hygiene is very important in controlling infection. Alcohol gel is widely available at the patient bedside for staff use and at the entrance of each clinical area for visitors to clean their hands before and after entering.

Other formats

If you require any of the Trust leaflets in alternative formats, such as large print or alternative languages, please contact the Equality and Human Rights Department.

Tel: 0300 131 4434 Email: esh-tr.AccessibleInformation@nhs.net

Reference

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The following clinicians have been consulted and agreed this patient information: Dr Aktham Nahhas, Consultant, Clinical Lead for Dementia Care

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