



Carers of people living with dementia

Information leaflet

Introduction

At Surrey and Sussex Healthcare NHS Trust we understand the importance of carers' involvement in our patients' lives. As the carer of a person with dementia, we recognise that you will need support while that person is in hospital and appreciate that this can be a stressful time for you. We want to work in partnership with you while you and the person you care for are with us. We define a carer as anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem including dementia would not be able to cope without their support.

We want to deliver the best possible patient care and to ensure that people living with dementia or who are experiencing memory problems are given the support they need, with dignity, respect and compassion. This leaflet is designed to give information which will be useful to you, including the services available and the people who are here to help you at the East Surrey Hospital.

Dementia information

If you would like more information specifically about dementia and other memory problems please ask the staff to contact the Consultant Admiral Nurse; who is available to provide support to you while the person you care for is in hospital and to answer any questions you may have about dementia.

Admission to Hospital

When a person is admitted to hospital it can be a difficult and confusing time, especially for people living with dementia. At East Surrey Hospital we aim to help the patient feel as comfortable as possible in these unfamiliar surroundings. We also have many staff within the ward or department who have undertaken additional training aimed at providing the right support for people with dementia.

Valuing the role of carers and how you can help

The unfamiliar surroundings of a hospital ward can naturally be unsettling for a person with dementia. Your role is important; it can be helpful to bring familiar objects such as copies of photographs of family members or a much-loved pet placed. These can be very reassuring for a person with

dementia in an unfamiliar environment. Photos can also provide staff with a talking point or something to focus on if the patient is feeling distressed or anxious. In some cases a notebook may be handy so staff and visitors can write messages, reminders and details of when they are next visiting.

Other ways you can help

Please inform the nurse in charge if you would like to continue to provide support to the person you care for. The ward staff will remain responsible for the care and treatment of the patient just as they would for all other patients on the ward. Carers can:

- Provide support throughout the admissions
- Assist at mealtimes and choose meals for their loved one
- Attend the appointments offered by the ward and provide information and history about the person you support establishing a positive working relationship from the start.
- The Trust has an 'Open Visiting' policy allowing you to visit to provide support at any time. Your in-depth knowledge of the person in hospital is extremely valuable to the whole team and we value and appreciate your input.
- Ensure dentures, glasses and hearing aids are available and in good working order.
- Help staff by informing them of the best way to communicate with the person in hospital.
- Personalise the immediate environment. Familiar items such as photo albums, a blanket from home, or activity the person can enjoy will alleviate anxiety commonly experienced in the unfamiliar hospital environment.
- Notify staff if you notice a change in usual behaviour. For example, tell staff if the person is not as alert as usual, or is displaying behaviour that is not typical of the way they normally behave.
- Ward staff may ask you to bring the patient's own clothes in, as a Trust we encourage the national and hospital's "PJ Paralysis" campaign: as patient feels better we encourage patients to get dressed in their own clothes.



The Butterfly Scheme

In this hospital we use the Butterfly Scheme for people with dementia or delirium. It aims to alert staff to the specific care approach needed to ensure that patients receive appropriate care and so reduce the person's stress levels and increase their safety and well-being. A blue butterfly is used where someone has a confirmed diagnosis of dementia and an outline of a butterfly is used where there are memory problems that may be an undiagnosed dementia or delirium. These are placed by the bed and in the notes alerting staff. You can choose not to have the butterfly by the bed if you prefer. If you require more information please speak to a member of staff.

Reach Out To Me

We encourage people with memory problems or their carers to complete a Reach Out to Me document. This helps make sure that hospital staff can give the best care that is tailored to the person you care for. Components of the Reach out to me document include information on preferences, routines and topics of conversation. You may have completed a similar document before (This is me or Mycarematters information); if so we will be happy to make a copy of it and ensure staff read it.



mycarematters

You may choose to create a Mycarematters profile online. We currently ask that you print it out and provide us with a paper copy, but it has the advantage of being able to be updated and reprinted whenever necessary. This is a free service. Go to www.mycarematters.org and follow the prompts, or if you prefer to create a Mycarematters profile by hand, ask us for a blank Mycarematters chart. We are able in some wards to display your Mycarematters profile behind the bed, if you wish.

Carers Passport

At East Surrey Hospital we encourage those carers who wish to continue caring to come and help when the person they care for while in hospital. The Carer's Passport aims to support carers to do this and gives them some additional benefits such as discounted parking and meals in the canteen. Please let ward staff know that you are a carer.

Open visiting and John's Campaign

Most of the wards at East Surrey allow open visiting (flexible visiting throughout the day). However, be aware that at times the wards may be busier with staff providing personal care and ward rounds taking place. Also please follow staff advice regarding visiting during outbreaks of infections when the ward may have to limit or stop visiting. Please see additional information regarding visiting on the Supporting patients: Open visiting guidelines.

As a Trust that has open visiting we have signed up to John's Campaign. This promotes the important role of carers and gives carers the right to continue to support the person with dementia while they are in hospital.



Who is on the ward?

It is important for you to know that the ward team is here to help you and answer some of the questions you might have.

Ward Sister and nursing team:

On the ward, the Ward Sister and nursing team will be your first point of contact. Do not hesitate to talk to the Nurse in Charge if you would like to know more about the care and treatment of the person you care for.

- **Ward Doctor / Consultant:**
You can also talk to one of the doctors on the ward if you would like to know more about treatment. A suitable time can be made with the Ward Clerk
- **Hospital mental health liaison team and old age consultant psychiatrist:** The Mental Health liaison service is a team of specialist mental health professionals whose role it is to ensure any person who is hospital has access to quality mental health assessment and treatment.
- **Ward dementia champion**
Each ward should have a Dementia Champion. This person should be able to give you guidance, advice and information. The dementia champion is usually identified on the ward but if you would like to know who it is then please ask a member of staff.
- **Matron**
This is a senior nurse leader who supervises a group of wards. If you wish to have a more in depth discussion, or if you have any concern or suggestions to voice, they might be the one to talk to. Their contact details can be obtained from the nurse in charge.
- **Consultant Admiral Nurse**
Is available Monday to Friday to all the clinical areas at East Surrey Hospital. The Consultant Admiral Nurse supported by Dementia UK can offer support and information to patients, staff, families and carers regarding different aspects of dementia care throughout the admission and provide guidance on local support available.



Dementia volunteers (Butterfly volunteers)

Work alongside clinical staff to offer an extra dimension to care by providing social support for patients with dementia and their carers.

The volunteers have received some training and are equipped to respond appropriately to the needs of people living with dementia. They will help with activities, at meal times or just sit with someone to provide comfort and reassurance.

Increased confusion during admission

As the hospital environment is very different from the person's usual surroundings there may be a higher chance of the person you care for becoming more confused and disorientated. This can lead to 'acute confusion' also known as delirium and can happen when a person is unwell in addition to their symptoms of dementia. Delirium or acute confusion can develop suddenly and is caused by things such as medication, surgery and pre-existing and new medical problems. It tends to improve when the things that causes it improves. For more information on delirium acute confusion please speak to the medical team or ward staff; we have also produced a leaflet with information on delirium for patients and families and carers.

Keeping someone safe (Mental Capacity Act and Deprivation of Liberty)

Some people with dementia in hospital may be unable to make their own decisions about their care or treatment because they lack the mental capacity to make specific decisions, or want to leave the ward. To ensure the person with dementia receives the right care, protection and is safe we would assess for mental capacity on specific decisions. Having mental capacity means being able to understand and retain information and to make a decision based on the information presented.

Sometimes, caring for and treating people who need extra support may mean restricting their freedom. For instance, it might be necessary to stop a person leaving the ward or hospital. If there are restrictions like this, it may be considered that the person is being deprived of their liberty. Deprivation of Liberty Act in the person's best interest and for the minimum possible time. If the ward team feels it is in the best interests of the person you care for we will inform you.

Eating and drinking

Sometimes people with dementia can experience difficulties with eating and drinking and this can make it very stressful for both them and their carer at mealtimes. It is important to remember that dementia affects different people in different ways, so you might have to try out various approaches before you find one that works. Some of the reasons why people with dementia have difficulty eating and drinking are:

- they forget that they have already eaten or think that they have eaten a meal when they have not
- they have difficulty remembering how to prepare food
- their tastes change – people with dementia often prefer sweeter or spicier foods
- they may develop difficulties with, or have a problem with, the chewing or the consistency of the food – as a person's illness progresses they can develop problems with swallowing
- they will often lose their appetite

Supporting Nutrition (Dietitian Support, Finger Food Boxes, Social Dining)

We know that as someone's dementia progresses they may struggle with large main meals. Our dietitians can advise on suitable options and our speech and language therapists can assess a person's swallowing and offer advice on type and consistency of food. The ward can also offer finger food snack boxes that patients can have as an alternative or supplement their diet. The finger food boxes provide high calorie snacks. The ward kitchen always has available toast, jam, biscuits, cereals and custard and rice pudding pots.

On the wards we also aim to encourage social dining; this is when groups of patients are invited to sit at a table in the bay with other patients. We know that eating in these social situations is beneficial for some patients. Please note we are only able to offer this when we have sufficient nursing, therapy and/or volunteers.

Planning for discharge

As the person's health improves, discussions will commence about how best to support their on-going care needs from hospital. If it is felt that the individual will need some form of support on discharge, a referral will be made to the discharge team. A social worker will be allocated to the person and they will meet with them and their carers to make an assessment of the care/support required.

Dementia is a condition which can affect a person's insight, capacity and ability to make decisions. This can result in differing views between people with dementia and those caring for them. While the person with dementia has capacity they must be supported to make their own decisions and articulate their views. However, if they lack capacity, best interest principles will be applied. Balancing the needs and views of carers and those of the person with dementia is essential to successful discharge planning.

Things you may not know

By law, carers are entitled to a carers' assessment by their local authority. This should help carers understand what financial and emotional support is available and also offer details around different community-based support resources offering extra help and support. This includes charities and organisations outside of the hospital who may be able to assist you and your family.

If you would like this assessment, please tell the nurse in charge of the ward who will complete a referral for you or you can contact the correct social care team for your location (Surrey, Sussex, London borough of Croydon) to request a carer's assessment.

Carers: looking after yourself

When you are caring for someone with dementia, it can be easy to ignore your needs and forget that you matter too. If you are caring for someone with dementia, be prepared for the fact that you will need support at some point. You will probably need a lot of different types of help and support, ranging from practical care to give you time off from being a carer, to having someone to talk to about your feelings and concerns. Don't forget, our staff are always happy to discuss your concerns and answer any questions that you may have or ask to speak to the Consultant Admiral Nurse.

Friends and Family Test

We collect feedback from patients and carers using this questionnaire. We greatly value all comments and will use them to strive to improve the experience of our patients and carers. Please fill in a survey and return to the hospital ward or a member of staff before you are discharged from the ward.

Further help and support for carers can be found at:

Local support

<p>If you live in Surrey Contact Action for Carers Surrey</p> <p>0303 040 1234 carersupport@actionforcarers.org.uk</p>	
<p>If you live in Sussex Contact Carers Support West Sussex</p> <p>0300 028 8888 info@carerssupport.org.uk</p>	

National Support Services

Alzheimer’s Society

A national charity providing support to people with all types of dementia and their carers. The society provides: a helpline, day care, support services, carers groups, social events, advice and help with claiming benefits and a monthly e-newsletter with articles about research and tips from other carers. Call **020 7423 3500** for details of your local branch
Visit www.alzheimers.org.uk

Dementia UK Helpline

The helpline is available from 09:15 - 16:45pm Monday to Friday and 18.00 – 21.00 on Wednesdays and Thursday evenings.
Or email direct@dementiauk.org
Call **0800 888 6678**
Visit www.dementiauk.org

Age UK

A UK-wide charity which can provide: information and advice, subsidised holidays, insurance, legal and financial advice and wills, day care, carers groups, and community dementia support workers.
Call 0800 169 2081
Visit www.ageuk.org.uk for more information about local services

Cinnamon Trust

A charity that helps older people to be with their pets for longer, including dog walking and long term accommodation for owners who have died or moved into residential care.
09.00 – 17.00 Monday to Friday
Call **01736 757900**
Visit: www.cinnamon.org.uk

SASH supports the following:



The right to stay with people with dementia



Join Dementia Research (www.joindementiaresearch.nihr.ac.uk) is a nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies.

Anyone, with or without dementia, can register as a volunteer or [sign-up for someone else](#), providing it's in their best interest.

Signing up is the first step in becoming involved in supporting vital research studies across the nation.

Contact us

Corporate Nursing
East Surrey Hospital
Redhill Surrey RH1 5RH
Tel: 01737 768511

www.surreyandsussex.nhs.uk

Patient Advice and Liaison Service (PALS)

Telephone: 01737 231 958

Email: pals@sash.nhs.uk

Write to: PALS, East Surrey Hospital
Redhill, Surrey RH1 5RH

You can also ask a member of staff to contact PALS on your behalf.

This information can be made available in other languages and formats, including in larger text. Contact 01737 231 958 for help.

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Last updated: March 2018

Document name: People living with dementia or memory problems Carers guide