Carers are invited to be with patients

Information for carers
Not everyone realises that “in looking after somebody” they have become a carer.

A carer is someone who, informally and without payment, cares for a friend, family member, neighbour, or in fact anybody who could not manage without their help. This could be due to age, physical or mental health issues, substance misuse or disability.

In this context, being a carer does not refer to professional carers who are paid to care and who may, as part of their job, accompany someone to hospital, as for example, agency workers or care home staff may do.

Carers come from all walks of life, can be all ages and are in different caring situations; often they have other commitments such as work, family and study. We value the important role that carers play and know that being a carer can sometimes be difficult, demanding, both physically and emotionally, and isolating. We also appreciate and understand that carers have a lot of knowledge about the uniqueness of the person they care for and their condition, and that it is important to listen to carers and involve them in decisions about the patient’s care.

This leaflet provides information which we hope will be useful for you to know if you are a family member or carer of a patient in one of our hospitals and wish to stay with them to support their care; it also provides information on the ways in which we can support carers and contains links to other organisations and useful resources which you may find useful.

We’d like to tell you about six initiatives for carers in the Trust.
1. Carers’ Charter

We have developed a Carers’ Charter that outlines our commitment to work closely with families and carers and is available to you as a separate document.

The Charter identifies you as the nominated carer of a patient and aims to help us understand the needs of patients and carers better. It has been created by healthcare professionals, family members, carers and patients working collaboratively together to help us achieve this ambition.

2. John’s Campaign

The Trust supports John’s Campaign which is a national campaign that asks for the families and carers of patients to be invited to stay with them in hospital for as many hours are needed and as they are able to give. John’s Campaign supports care for people who have conditions, such as dementia, where families and carers have the knowledge and skill to work in partnership with ward staff to ensure patients receive care that works best for them.
3. Information for Carers Webpage

Our ‘Information for Carers’ webpage contains the information in this leaflet along with the links listed below.

To view the page go to the ‘Patients & Visitors’ section of the Leeds Teaching Hospitals website (http://www.leedsth.nhs.uk) and select ‘Information for Carers’.

4. Dementia Carer Support Worker

Carers Leeds offers a specific service to carers of people with dementia or memory problems in the Leeds Teaching Hospitals NHS Trust. We have a specialist Dementia Carer Support Worker based at St James’s University Hospital who covers all the sites in the Leeds Teaching Hospitals Trust ie. Leeds General Infirmary, St. James’s, Chapel Allerton, Seacroft and Wharfedale hospitals. Much of the work focuses on involving carers in discharge planning and ensuring carers are informed about services available to them in the community.

For more information about Dementia Carer Support in Leeds Teaching Hospitals contact:

Lorraine Lumb
Email: lorraine.lumb@carersleeds.org.uk
Tel: 0785 448 1024
5. Hospital Liaison Support Worker

Carers Leeds also has a Hospital Liaison Support Worker whose role is to help people, who pay for their own care, find care homes and care packages to support discharge. This role does not just relate to patients with dementia.

For more information contact:
Clare McNeill
Email: clare.mcneill@carersleeds.org.uk
Tel: 0749 526 3821

6. Hospital 2 Home (Support for Carers)

Age UK Leeds offers help for older people who have had a short stay in St James’s Hospital to facilitate discharge, get settled in at home and prevent readmission.

Carers Leeds works in partnership with this scheme to ensure that carers identified within this project are offered support and are linked in with the Carers Leeds service.

Carers are offered a visit at home from a Carer Support Worker who makes sure that the carers needs are recognised and that the carer is getting all the help they need to make the home situation safe and sustainable.

April Lee, Carer Support Worker says “All my referrals come from the Hospital to Home team from Age UK Leeds who work within St James’s Hospital. When I receive these referrals I will get in touch with a carer within 24 hours during a working week. I introduce unpaid carers to our service and
the support we can offer on an ongoing basis from support groups, newsletters, events and training. Depending on the illness of the person they care for we can then offer one to one support with a specialist team such as Dementia or Mental Health. All other carers will be supported by our outreach or office team depending on the carers ability to leave the cared for person for any time.

**We also have an advice line:**
**Tel:** 0113 380 4300

**And a drop in service within our Headrow office in Leeds:**
**Monday - Friday:** 9:00am - 4.30pm

**For more information about Hospital 2 Home contact:**
April Lee
**Email:** april.lee@carersleeds.org.uk
**Tel:** 0113 380 8919
Frequently Asked Questions

We get asked lots of questions about being a carer; here are just a few of them with some brief answers.

What does working in partnership with ward staff mean?
Working closely with carers helps staff to understand the needs of individual patients better and can improve the care we offer. Working in partnership involves staff listening and responding to people like you who often know our patients and their needs better than we do.

Will I still give medication?
Your knowledge of the patient’s medication is important, and ward staff will welcome your contribution in deciding the best and most appropriate way for the patient to receive medication whilst on the ward. Sometimes you will be asked to carry on as usual and at other times it may be more appropriate for ward staff to take on this role.

As a family member or carer, will I be expected to stay on the ward to provide care?
No, as supporters of John’s Campaign we are offering you an opportunity to have a discussion with nursing staff if you would like to stay with a patient in hospital. We invite you to ask us about arrangements that would work well for you and improve the care for a patient. Please be aware we may not be able to achieve everything you ask for; however we promise to consider your requests and to let you know why if we are not able to fulfil them. You will not be expected or asked to provide care at any point.
Is there anything I need to think about if I stay on the ward?
The Carers Charter describes what we would like you to consider if you stay with us and this includes being sensitive to the privacy and dignity needs of other patients on the ward. We would also ask you to be aware of the need for ward staff to deliver care and to work with them to understand when they will need you to leave the bedside to allow this to happen. The ward staff will go through the Carers’ Charter with you in more detail and you will be able to use this discussion to ask any questions you may have.

Will I be able to stay at mealtimes if the wards prefer these times to be free of visitors?
Mealtimes are protected on our wards to make sure that patients are supported in receiving the nutrition they need without distraction. Whilst visitors are usually discouraged at these times, as a carer we would welcome you to be present during mealtimes as we recognise the contribution you make in assisting our staff with this important aspect of care.

Will I be able to stay overnight?
It may be possible for you to stay overnight and staff on the ward will be able to advise you on this. Where it is possible for you to stay, it will be necessary for staff to review this arrangement on a day by day basis. This is because changes in ward circumstances can affect what is manageable. These changes may include taking account of other patients on the ward and their needs.

Will there be somewhere to sleep if I stay overnight?
Ward staff will do what is possible to make you as comfortable as they can, however they will not be able to provide an
empty bed overnight on the ward as these can be needed at any time for patients.

The ward staff will discuss what they are able to offer. In some situations, it may be possible to offer a camp bed or a comfortable chair and a blanket may be provided. It may be necessary for sleeping arrangements to be offered in a nearby room on the ward away from the bedside, to ensure privacy and dignity can be maintained for our patients.

Will I be able to have food if I stay?
We are unable to provide food for relatives and carers of our patients who wish to stay with us. Ward staff will be very happy to direct you to the closest catering facilities available, which include 24/7 vending facilities on all our hospital sites.

Will I be able to use bathroom facilities if I stay?
Depending on the layout of the ward, in some cases it may be possible for staff to offer you this option. The ward staff will be able to discuss what is possible with you. Due to the risk of infection and to maintain the safety of our patients and yourself, if no separate facility is available on the ward for you to use, we ask that you use the nearest public facilities. The ward staff will direct you towards these. We ask for your consideration in not using patient facilities.

Will I be able to request free parking?
Unfortunately, the Trust is not able to accommodate free parking for carers and family members due to the demand for parking spaces on hospital sites.
Information on hospital parking charges may be found at:
www.leedsth.nhs.uk/patient-and-visitor-information/patient-information/getting-to-hospital/

The Trust does however support free parking for relatives visiting patients who are approaching the end of life. Please approach ward staff if it would be helpful to have this support made available to you.

Will other family members or carers be able to stay as well?
We are happy for family and carers to spend time with our patients to support better care, however, we ask that this is limited to one person at a time outside open visiting hours. During visiting times, we ask that our usual practices are followed, which limit visitors to two per bedside at any one time. This helps to reduce the infection risk to our patients, prevents them over tiring and allows our staff to continue to deliver care when the environment is busier. We ask that if there are more visitors who wish to attend that visiting is rotated between you to keep within these limits. Your understanding, which will contribute greatly to the smooth running of the ward, is very much appreciated.

Are staff able to decline requests to stay?
Yes, where ward staff feel it would not be possible to meet the needs of patients, they may decline a request for a carer to stay. Where this is necessary it may be possible for the staff to provide you with additional support and updated information, for example by regular phone calls.
Where can I smoke?

We are a smoke-free Trust and as such there is a strict no-smoking policy in the hospital buildings. Smoking outside should be in designated shelters.

What should I do if I have any concerns whilst I am on the ward?

We know that coming into hospital can be a stressful time for patients and carers. We welcome you talking to us to help us to deliver the best care and support for you and the patient. We ask that you discuss any concerns you have with the nursing staff. If the nurse in charge or ward sister are unavailable to resolve your concerns, it is possible to raise concerns via our Patient Advice Liaison Service PALS.

They can be contacted on:

Tel: (0113) 206 261
Email: patientexperience.leedsth@nhs.net
We also welcome your feedback and comments through the Friends and Family Test which provide invaluable information from patients, family and carers about what we are doing right, and what we could improve on.

Friends and Family Test cards look like this and can be answered by a carer on behalf of a patient.

**Sit Up, Get Dressed, Keep Moving Campaign**

We encourage patients to get out of bed, wear their own clothes and be as mobile as possible as part of the ‘Sit Up, Get Dressed, Keep Moving Campaign’. Carers can help by bringing comfortable daytime clothing and shoes for their relative or friend.

When patients are up, dressed and moving about they feel more positive and are less likely to lose muscle strength. We know that for every 10 days of bed rest in hospital, the equivalent of 10 years of muscle ageing occurs in people over 80 years old, and building this muscle strength back up takes twice as long it does to deteriorate. This can lead to people having to stay in hospital longer or losing their independence. And it’s not just older people who lose muscle strength, it can happen to all age groups albeit at different levels.

**Alison Raycraft, Lead Nurse for Older People, says:**

“Little things like this can have a huge impact not only on someone’s independence and confidence, but also their mental health and wellbeing too. Our patients who get themselves dressed and up and about tell us that they feel much better and many are able to go home sooner too, which is fantastic.”
Looking after yourself

It is important that you take care of your own wellbeing, especially when you are busy looking after someone else’s health. Being healthy is not only important for you, but it also helps the person you care for too.

Finding time for yourself can be difficult when you are a carer, but just finding a few minutes to look at some of the information available from a variety of organisations could help make a difference to you.

Online Resources for Carers

You can register for free online resources provided by Leeds City Council and Carers UK here:


This includes:

- **About Me**: building resilience for carers: an e-learning resource that helps carers identify and build networks of support and promotes their self-care.

- **Jointly**: our care co-ordination app for people sharing care.

- **The role of good nutrition when caring for someone**: an e-learning course that aims to help carers understand the role of nutrition both for themselves as well as the person they are looking after.

- **Upfront Guide to Caring**: a simple assessment tool to guide people new to caring or seeking support for the first time to navigate the Carers UK website.
• **Looking after someone:** Carers Rights Guide: which helps carers understand their rights as a carer and where to go for financial or practical help.

• **Being Heard:** a self-advocacy guide for carers: which helps carers develop the skills to self-advocate.

• **Information and support resources for carers**

**Useful Links**

**Carers Leeds**  
http://www.carersleeds.org.uk/  
Carers Leeds is an independent charity based in Leeds that gives support, advice and information to unpaid carers aged 16 and over.

**Carers UK**  
https://www.carersuk.org/  
Carers UK is a national charity that gives advice, information and support to carers.

**NHS Choices - Your guide to care and support**  
https://www.nhs.uk/conditions/social-care-and-support/  
Contains information for carers and people who have or will have care and support needs
Carers Trust
https://carers.org/
Carers Trust is a charity working to improve support, services and recognition for unpaid carers.

Carers Direct Helpline
Tel: 0300 123 1053
https://www.nhs.uk/conditions/social-care-and-support/carers-direct-helpline/
You can call the Carers Direct helpline if you need help with your caring role and want to talk to someone about what options are available to you. The website also contains information on how you can contact them if you are deaf, hard of hearing, speech-impaired or if English is not your first language.

Leeds Directory
Tel: 0113 391 8333
http://leedsdirectory.org/service-provider/carers-leeds/
Leeds Directory is a source of information on a wide range of services and organisations which can be accessed online or via their telephone help line.

A Practical Guide to Healthy Caring
A guide for carers, especially those over 65 and new to caring.
Leeds Commitment to Carers
http://www.carersleeds.org.uk/leeds-commitment-to-carers/
Leeds Teaching Hospitals NHS Trust has signed up to the Leeds Commitment to carers. More information can be found on their website.

Leeds City Council - Information and advice for carers

John’s Campaign
http://johnscampaign.org.uk/#/
A campaign that asks carers of people with dementia be welcomed and invited to stay with the person they care for if they so wish. Leeds Teaching Hospitals has extended this campaign to include all carers, whether the person they care for has dementia or not.
Counselling Directory
https://www.counselling-directory.org.uk/
A nationwide directory of professional counsellors and psychotherapists.

Information for carers of people with various needs

Action on Hearing Loss
http://www.actiononhearingloss.org.uk/
“From day-to-day-care, to practical information, to campaigning for a fairer world for people with hearing loss, and funding research to find a cure, we’re taking action on hearing loss.”

Age UK
https://www.ageuk.org.uk/
“Age UK’s vision is for a world where everyone can love later life. We do this by inspiring, supporting and enabling in a number of ways.”

Alzheimer’s Society
http://alzheimers.org.uk/
Alzheimer’s Society is a national charity for people with dementia and their carers.
DALES (Deaf Across Leeds Enablement Service)
http://www.dales-bid.org.uk/
DALES provides a range of support services for deaf, hard of hearing and deaf blind adults living in Leeds.

Dementia UK
https://www.dementiauk.org/
Dementia UK provides specialist dementia support for families through their Admiral Nurse service.

LEEP1
http://www.leep1.co.uk/
LEEP1 is a Leeds based self-advocacy group for people with learning disabilities.

Mencap
https://www.mencap.org.uk/
Mencap is a leading UK charity for people with learning disabilities and their families.

Royal Association for Deaf People (RAD)
https://royaldeaf.org.uk/
RAD is a charity providing a wide range of services for Deaf people.
Royal National Institute for Blind People (RNIB)
http://www.rnib.org.uk/
The RNIB is the UK’s leading charity supporting blind and partially sighted people.

Young Carers

Willow Young Carers Service
http://www.barnardos.org.uk/willow.htm
Willow is a support service for young carers aged 5-18 years old living in Leeds and is run by Barnardo’s charity.

NHS Choices - Young Carers Rights
https://www.nhs.uk/conditions/social-care-and-support/young-carers-rights/
Contains lots of useful information for young carers.

Carers Trust - About Young Carers
https://carers.org/about-us/about-young-carers
Information and support for young carers from the national charity the Carers Trust.
The Children’s Society - Young Carers
The Children’s Society campaign for change, promote best practice with central and local government, and work in partnership with key workers to support young carers.

Sibs
https://www.sibs.org.uk/
Sibs is a charity for siblings of disabled children and adults.

Working Carers

Supporting Working Carers Report
Report produced by Think Local Act Personal.

Top Tips for Supporting Working Carers
Top tips for employers on supporting working carers.