



Royal Berkshire
NHS Foundation Trust

I am a carer

What you need to know when
the person you care for goes
into hospital

- Agreeing a care plan
- Communicating needs
- Understanding consent
- Refreshment, sleeping & car parking facilities

Useful names and numbers

Consultant's name: _____

Name of ward: _____

Ward Manager's name: _____

Ward telephone number: _____

Patient telephone (direct): _____

GP's name and number: _____

District Community Nurse: _____

Care Manager: _____

Other useful contacts: _____

A carer is “a person of any age who provides unpaid practical or emotional support to someone who is in need, because of their age, physical / learning disability or illness, including mental health”. (Unpaid carers include those in receipt of Carers’ Allowance.)

We all wish the patient to get the best treatment, and that their stay in hospital is as relaxed as possible. This is more likely to happen when the carer and hospital staff work in partnership, respecting each other’s roles.

This leaflet describes:

- What you, the carer, can expect when the person you care for goes into hospital
- How you can work with the hospital to get the best for the person you care for (referred to as ‘the patient’ in this leaflet).

Information in this booklet is in a question and answer format. If you have any questions that are not covered, please speak to the ward manager or nurse in charge or contact Patient Relations on 0118 322 8338, email talktous@royalberkshire.nhs.uk.

On admission

Will the hospital recognise my role as a carer?

- If you are next of kin, the hospital will probably acknowledge your role as a carer.
- If you are not next of kin, explain to the ward staff about the care you provide. If you are the main carer, ask to be a point of contact, **in addition to the next of kin.**
- If there is more than one family carer, the ward staff need to have just one key contact. This person can then share information with the other carers.

Do I have the authority to speak on behalf of the patient?

- If the person is an adult and can understand what is happening, the hospital staff will keep their information confidential and expect them to make their own decisions about the care they receive.
- If their mental capacity is not clear, explain your concerns to the ward staff as soon as possible. Staff should only ask patients to sign consent forms for treatment or referral to outside agencies if they are capable of understanding the details.
- Please speak to our Learning Disability Liaison Nurse or our Adult Safeguarding Nurse if you have concerns about consent. Their telephone numbers are on page 12.
- If you are a 'Shared Lives carer' or are not a close relative of the patient, staff may not be able to recognise your role. If social workers or recognised voluntary organisations have played a part in setting up a 'shared lives' relationship, they may be able to provide a reference as to your role as a carer.
- Tell the hospital staff if you hold power of attorney. You may need to show them a copy of the registered document. If you have been

the main contact with the GP or Social Services, it makes it easier for staff to see how important you are to the patient.

- If you are a carer and the patient agrees that you may speak for them, the staff would need the patient to verbally relay this (or indicate it by whatever means they can).

What should I expect from hospital staff?

The staff should:

- Recognise your role and experience in caring for the patient and your knowledge of them.
- Understand that some patients may have challenging behaviour and need predictability (the hospital Safeguarding Team can provide advice to staff and carers regarding these issues). Please discuss any concerns with the ward staff.
- Agree what care you will provide and document this on the patient's care plan.
- Understand that the situation is stressful for you and for the patient.
- Make you feel comfortable on the ward.
- Introduce you to any staff treating the patient.
- Involve you in discussions about care and keep you informed (unless the patient has mental capacity and does not want this to happen).
- Give jargon-free, simple, clear explanations.
- Allow enough time and privacy to discuss the health of the patient.
- Be courteous at all times.
- Welcome carers to visit at all times (we are signed up to John's Campaign <https://johnscampaign.org.uk/#/about>).

What should hospital staff expect from me?

You should:

- Introduce yourself to staff because it helps them to put a name to a face.
- Give relevant information about the patient to help ward staff to provide individualised care.
- Give your telephone number.
- Be polite and courteous, however stressed you are.
- Respect the hospital rules, such as washing hands and numbers of visitors.
- Accept that the person you want to speak to may not always be available.

What relevant information should I give the ward staff?

If relevant, please ensure that you or the patient has completed their 'Information about me' folder or '8 important things about ME' form.

These contain information that will help staff care for the patient. Both resources outline the following for hospital staff:

- The name the patient likes to be known by.
- Their level of independence and mobility.
- Their comprehension / memory problems.
- Their continence state.
- Any sight or hearing problems.
- Any medication the patient regularly takes.
- Any dietary requirements.

What information can I expect from hospital staff?

- If you are the main carer, the staff will normally give you factual information, such as ward details, name of consultant and updates. Please remember, however, that hospitals are bound by very strict patient confidentiality, which means they cannot give out some information:
 - if they believe that it is in the best interest of the patient; or
 - if the patient has indicated that they do not want information passed on.
- If you are not the main carer, please ask for information from the person who is. If this is not possible, then ask the hospital staff whether they can tell you.
- If you are the main carer or next of kin and you have concerns about care or treatment, please tell the ward manager / nurse in charge as soon as possible.

How can I manage all the information I get?

- Maybe take a friend or family member with you to key meetings as it is sometimes difficult to remember what has been said or agreed.
- If you do not understand something, do not be afraid to ask again or for the staff to write it down.
- It is difficult to remember all the questions you want to ask. Write them down before you visit.

What is the Safeguarding Team?

The Trust has a Safeguarding Team of specialist nurses who can help patients and their carers.

The Learning Disability Liaison Nurse can:

- Arrange a familiarising pre-visit to the hospital.
- Smooth admission, e.g. by arranging a different entrance to the hospital to avoid crowds.
- Liaise with community learning disability teams about discharge.

The Adult Safeguarding Nurse can:

- Advise and assist if you are concerned about harm, neglect or abuse to the patient.
- Liaise with the community safeguarding teams.

The Mental Health Co-ordinator can:

- Offer support, information and highlight services available.
- Provide guidance to carers about the Mental Health Act.

Consent and caring responsibilities

How can I find out about consent?

- The NHS Website gives information and advice on consent for adults, children and teenagers, patients receiving end of life care and those lacking capacity. Visit www.nhs.uk/conditions/consent-to-treatment/.
- The website also has a lot of useful information for carers. Visit www.nhs.uk/CarersDirect/.

What is the Mental Capacity Act?

- The Mental Capacity Act came into force in 2007 and it sets out what should happen when someone lacks capacity to make their own decisions.
- The Mental Capacity Act aims to protect people who lack capacity and have restrictions placed on them by hospital staff. “Restrictions” means the ward staff keep the patient under very close supervision and prevent them from leaving the ward. The protection is called a Deprivation of Liberty Safeguard (DoLS). When this happens, the Trust has to notify the patient’s local authority and the patient is assessed by health professionals from outside the Trust to ensure that the patient gets appropriate care. The local authority will grant a Deprivation of Liberty Safeguard, depending on the assessment.
- You can get more information from the Office of the Public Guardian/HM Courts & Tribunals Service website. Visit www.justice.gov.uk/courts/rcj-rolls-building/court-of-protection.
- The Alzheimer’s Society also has information about Deprivation of Liberty Safeguards on its website at www.alzheimers.org.uk/.

How do I know what my responsibilities are while the patient is in hospital?

Many carers feel they must stay with the patient to comfort and reassure them, but also to ensure and the staff understand and meet the patient’s safety and other needs. Many carers worry that staff are not really aware of the condition of the patient. They worry that very busy staff will not communicate with the patient properly. They fear this will mean inadequate care, particularly with regard to food, mobility and toileting arrangements.

If you want a respite from caring while the patient is in hospital, you should feel confident that the staff have all the information about the patient to care for them effectively. If the patient is unable to

communicate for themselves, please complete the 'Information about me' folder, as staff will consult it. Carers should be aware that Carers Allowance often stops during hospital stays. Attendance Allowance can stop too.

If you wish to participate in the care of the patient while they are in hospital, discuss this with the nursing staff on the ward. Make it clear what you wish to do. If the staff agree to your help, make sure they record it in the care plan. **And don't forget you can and should ask the ward staff for any help with specific tasks.**

You should be involved in discharge planning meetings so you can say what care you are able and willing to provide. Please ask to be involved if this is not the case.

If you are providing care, you are entitled to:

- A free car parking permit.
- Free tea and coffee;
- Meals from the trolley;

If no one offers you these, speak to one of the nurses or ask to speak to the ward sister / manager, matron or Patient Relations.

There is public parking on Levels 0, 1, 2 and 3 of the multi storey car park and disabled parking spaces on Levels 0 and 2 as well as a number of other sites around the hospital.

Will I be able to stay overnight?

- There are very limited full facilities for carers to stay overnight in the hospital. The ward staff have details of these.
- If it is not possible for you to use one of these rooms, staff should offer you an easy chair and blankets and pillows, to make you as comfortable as possible in the ward area. Speak to the nurse in charge of the ward if you wish to stay on the ward overnight.

- Alternatively, there may be housing association accommodation available very close to the hospital at a small charge per night (single room). Contact 0118 975 7888 and explain that you are a relative or carer of a patient at the Royal Berkshire Hospital.

Leaving hospital

Will I be consulted before the patient is either moved to another ward or hospital, or discharged home?

- Staff may not consult you over change of wards although they should tell you as early as possible. They should, however, consult you well in advance of any proposed change of hospital or discharge, and you should be involved in the assessment for this.
- Each hospital has its own discharge policy. You and the patient should be able to get a copy of this from the ward manager or the hospital's Patient Relations Team.

What if I feel I could not cope when the patient comes back home?

Before discharge from hospital, there will be an assessment of the patient's needs and sometimes a home visit to see how they cope with everyday tasks. If you feel unable to cope, please explain this to a senior nurse on the ward early in the patient's care so that there is time to make suitable arrangements.

What will staff give me upon discharge?

Staff may provide medication, prescriptions, discharge/aftercare information leaflets, and often a copy of a letter for the patient's GP. As the carer it is a good idea to check that you have understood what is being given and how to use it before the patient leaves the ward.

The nurses will be happy to discuss this to you and explain any instructions.

Caring for the carer

What about me?

- The admission to hospital of the person you care for can be a difficult time for a carer. Many feel that they are suddenly sidelined and worry that the standard of care will drop. Talk to ward staff if this is worrying you.
- The person you care for may seem to treat you differently when they are in hospital and seem rather distant or grumpy or angry that you are 'leaving them' in hospital. This is very common. However, it is distressing and it can make you feel 'guilty'.
- All of this can and does take its toll on your own health. Try to make sure that you eat and sleep regularly and that you have some time away from the hospital to clear your mind. This may be a good time for you to see your GP for a check-up.
- If you feel you would like to talk to someone, there are a number of people who may be able to help. Speak to Patient Relations, the hospital chaplains or telephone the Berkshire Carers Hub helpline. All their numbers are listed in the following section.
- If you have clinical concerns for the person you care for while they are in hospital, talk to the nurse in charge or contact Call for Concern[®], the patient safety service, on 0777 475 1352.

What is a carers' assessment

As a carer, it is important that you get the right help and support. Local Authorities have a legal duty under the Care Act to provide an assessment, and to give you information and advice about organisations within the Local Authority that can support you.

It is an opportunity for you to talk about the things that could make caring easier. This could be providing additional services for the person you are looking after, or services for you as a carer. It may also include respite care.

You can still have a carer's assessment even if the person you care for refuses help or an assessment themselves.

To find out about getting an assessment, you can:

- Speak to a member of the nursing staff or ask to speak to one of the safeguarding team.
- You can contact your local social services team (see page 14).
- Contact the Carers Trust or Berkshire Carers Hub (see overleaf).

Useful Trust telephone numbers

Patient Relations Team	0118 322 8338
Call for Concern	0777 475 1352
Learning Disability Liaison Nurse	0118 322 8159
Adult Safeguarding Nurse	0118 322 7482
Mental Health Co-ordinator	0118 322 6889
MS Nurse	0118 322 5369
Parkinson's Nurse	0118 322 8487/6855
Hospital Chaplains	0118 322 7105
Hospital Palliative Care Team	0118 322 7826
Royal Berkshire Hospital (switchboard)	0118 322 5111

Support organisations

<p><u>Carers Trust</u> www.carers.org/ info@carers.org / support@carers.org (A 'Triangle of Care' guide is available from the Carers Trust)</p>	<p><u>Alzheimer's Society</u> 0118 959 6482 www.alzheimers.org.uk berkshire@alzheimers.org.uk</p>
<p><u>Berkshire Carers Hub</u> Helpline: 0118 324 7333 ask@berkshirecarershub.org www.berkshirecarershub.org/ Bracknell carers tel: 01344 266 088 or email info@signal4carers.org.uk. Wokingham carers tel: 0118 974 6000. Windsor, Ascot and Maidenhead carers can contact Signal 4 WAM Carers on 01628 947974 or email: waminfo@signal4carers.org.uk</p>	<p><u>Mencap</u> Helpline: 0808 808 1111 0118 966 2518 (Reading) 01635 41464 (West Berkshire) 0300 777 8539 (Wokingham/Bracknell) www.mencap.org.uk</p>
<p><u>Berkshire Autistic Society</u> 0118 959 4594 www.autismberkshire.org.uk/</p>	<p><u>Parkinson's UK</u> Helpline: 0808 800 0303 www.parkinsons.org.uk/</p>
<p><u>MS Society</u> Helpline: 0808 800 8000 0118 931 1017 / 0118 986 2591 (Reading, Wokingham & District) 01628 635 396 (East Berkshire) www.mssociety.org.uk/ helpline@mssociety.org.uk</p>	

Crossroads (Care Scheme)

Bracknell	01344 860677
Newbury	01635 30008
Reading	0118 945 4209
Wokingham	0118 979 5324

Social Services

Reading Borough Council

0118 937 3747 / 0118 937 6545 (young carers)

www.reading.gov.uk/carers

West Berkshire Council

0845 6014726 / 01635 42400

<http://info.westberks.gov.uk/index.aspx?articleid=29942>

Wokingham Borough Council

0118 974 6000 / 6863

www.wokingham.gov.uk/care-and-support-for-adults/support-for-carers/

Bracknell Forest Council

01344 351 500 / 352 000

www.bracknell-forest.gov.uk/adultcarers

Oxfordshire County Council

0845 050 7666

www.oxfordshire.gov.uk/cms/content/carers-assessment

For information about benefits and support available for disabled people and their carers, visit the government website at www.gov.uk/browse/benefits/disability.

Rights and responsibilities for unpaid carers

Carer's name: _____

As the carer of a patient in the Royal Berkshire Hospital:

I have been given additional permission to (tick as appropriate):

- Provide assistance with washing and dressing.
- Provide assistance with feeding.
- Be actively involved in team meeting discussions, and planning the discharge (where appropriate) about the person I care for.
- Provide support to the person I care for when having investigations in the hospital.

Carers' responsibilities:

- I will inform staff if I am entering or leaving the ward (particularly out of 'daylight' hours).
- I understand that I may be asked to provide evidence of any Power of Attorney deputyship or any Advance Decision the person I care for has made.
- I understand that, at times, I may be asked to leave the ward or bay if there is a clinical necessity.
- I agree that, if I am assisting with feeding, washing or mobilising that staff may work alongside me to fulfil their clinical responsibility.

Carers providing care are entitled to:

- Free car parking permit.
- Free tea & coffee.
- Meals from trolley.

Valid from: _____ to _____

Authorised by: _____ [ward manager or consultant]

Carer given a copy of the Trust's 'Supporting Carers Survey'

Booklet authorised by: Caroline Ainslie (Executive Director of Nursing)
Patient Information, August 2019