



Royal Berkshire
NHS Foundation Trust

Information for carers

Help and advice for carers / care partners of
patients using the Royal Berkshire NHS
Foundation Trust

[www.royalberkshire.nhs.uk/patients-and-
visitors/accessibility/carers-support](http://www.royalberkshire.nhs.uk/patients-and-visitors/accessibility/carers-support)



We want everyone to get the best treatment in hospital and at the Royal Berkshire NHS Foundation Trust we understand this can be a stressful time for families and carers in particular. *We want to work in partnership with you.* We want to make carers visible. In this booklet we will outline how we intend to do that, what you can do to help us and how we can all deliver the best patient experience.

If you need access to alternative communication methods, such as an interpreter, video call, sign language or Makaton, please speak to the ward manager or contact the Patient Advice and Liaison Service (PALS) on 0118 322 8338 or email: PALS@royalberkshire.nhs.uk

If you are an unpaid carer or next of kin but cannot visit as regularly as you need or want to, speak to the ward manager. Sometimes, people can agree a 'code' with ward staff so they are able to receive full updates via a phone call.

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Definition of a carer

A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid (they may be in receipt of carer's allowance).

On admission

Will the hospital recognise my role as a carer?

- **Yes.** We are working hard to make our hospital 'Carer Aware' and a carer friendly hospital.
- It is not necessary to be Next of Kin for us to recognise your role as an unpaid carer. If you have Power of Attorney for Health, please let us know.
- If there is more than one family member caring for a patient, the ward staff will need to have just one key contact. This person can then share information with the other carers / family members. It is important that the family can agree who this person will be and inform the ward staff of their name and contact details.

Can I speak on behalf of the patient?

- If the patient is an adult and can understand what is happening, and the implications of their decisions, the hospital staff will keep their information confidential and expect them to make their own decisions about the care they receive.
- If the patient is anxious, needs support to process information or for whatever reason they want you to be included in decision making, asking questions and understanding information – they will need to tell clinical staff they want you, as their carer, to be involved.
- If the patients' 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 all the details.
- Please speak to one of our learning disability liaison nurses or our adult safeguarding nurse if you have concerns about **consent**. Ward staff can call them for you, or, their telephone numbers are at the end of this booklet.
- Tell the hospital staff if you hold Power of Attorney. Health and financial power of attorney roles are different. You may need to show staff a copy of the registered Health document. If you have been the main contact with the GP or Social Services, it makes it easier for staff to understand how important you are to the patient.
- See also the section on mental capacity on page 8.

What should I expect from hospital staff?

The staff should:


- Introduce themselves by saying “*Hello my name is...*” We have signed up to the “Hello my name is” campaign (www.hellomynameis.org.uk/).
- Welcome carers at all times (we are signed up to John’s Campaign <https://johnscampaign.org.uk>). Visiting times for other family or friends will vary according to current guidance.
- Recognise your role and experience in caring for the patient and your knowledge of their needs.
- Understand that some patients may have a change in behaviour if they become distressed and they will need predictability where possible. Please discuss any concerns with the ward staff.
- Agree what care you can provide and document this on the patient’s record.
- Complete a **Carers Passport** with you and give you a **Carers ID card** so that all staff are aware of your role.
- Understand that the situation is stressful for you and for the patient.
- Make you feel comfortable on the ward.
- 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 patient’s health.
- Signpost you to advice on getting further support, a carer’s assessment and other information and advice following
- Be courteous at all times.

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, but you are welcome to make an appointment.
- Not photograph or film staff, other patients / visitors or clinical areas in our hospital. It is not allowed and is a breach of confidentiality.

Our **Carers' Charter** outlines all of these expectations and is available on all ward areas. A copy is also available on the hospital website: <https://www.royalberkshire.nhs.uk/patients-and-visitors/accessible-information-standard-and-reasonable-adjustments/carers-support>:



Carers' Charter

The Royal Berkshire NHS Foundation Trust is committed to recognising the valuable role of Carers and working with them as partners to deliver excellent patient care



A Carer is anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid. NHS England, Commitment to Carers


Our Carers' Charter is based on our Trust CARE values and outlines what you can expect from us and how you can help us

What you can expect from us:

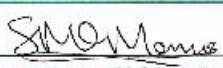
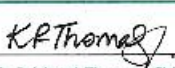
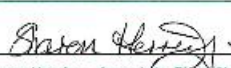
- C** Carers will be identified as early as possible and you will be central to the care planning, delivery of care and discharge for the person you care for (with their consent).
- A** Acknowledgement of the vital contribution and lived experience of Carers. We will ensure you are aware of your rights to a Carers Assessment.
- R** Respect and recognise the knowledge you have gained about the person you care for. Reassurance that we will care for your loved one as you would reasonably expect us to.
- E** Ensure you are aware of support available to you by signposting you to support organisations that are relevant to your Carer needs.

What we expect from you:

- C** Complete a Carer feedback survey (scan the QR code) so we can learn from your experience and, if necessary, make improvements.
- A** Always speak to us if you have any concerns. You may need to arrange an appointment to speak with a specific member of staff, but there will always be someone available to listen.
- R** Recognise the pressures our staff are working under while trying to deliver excellent care to every patient, and show them respect; even if you are feeling under a lot of stress.
- E** Ensure you tell us if you need additional support in your role as a Carer; we can signpost you to help and support.



SCAN ME

Signed:   

Steve McManus, Chief Executive Officer
Katie Prichard-Thomas, Chief Nurse
Sharon Herring, Associate Chief Nurse, Patient Experience

Compassionate Aspirational Resourceful Excellent

April 2024

What information should I give the ward staff?

If relevant, please ensure that you or the patient has completed an '*Information about me*' or '*8 things about me*' document or '*hospital passport*' form. This can contain information that will help staff care for the patient. Important information for staff to know will include:

- 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 or information about their likes/ dislikes, e.g. – do they have sugar in their tea? Do they only drink coffee? Perhaps they don't drink either!
- Something about their life – what did they work at? Do they like gardening or football?

If you don't have one of these documents but think it would be helpful to the person whom you care for, please ask a member of staff.

If the patient has an Advanced Care Plan or ReSPECT form completed it is important you share that with staff also.

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 rules, 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 the main carer or next of kin and you have concerns about care or treatment, please talk to the ward manager / nurse in charge as soon as possible. If you have tried this, but still have concerns about the patient's clinical condition, please contact **Call4Concern on 0777 475 1352**. This service will connect you to one of the Critical Care Outreach nursing team.

How can I manage all the information I get?

- If it is possible, 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 ask the staff to write it down.
- It is difficult to remember all the questions you want to ask. Write them down before you visit. Be comfortable to ask for time to make notes in the meeting so you can write down the information you have been given.
- If staff use language you do not understand, feel confident to ask them to explain it a different way.

Who are the Safeguarding Team?

The Trust has a Safeguarding Team of specialist nurses who can help patients and their carers. Contact details can be found at the end of this booklet

The Learning Disability Liaison Nurses 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/

What is mental capacity?

The mental capacity act applies to any one over the age of 16.

Mental capacity is the ability to make decisions for yourself. People who cannot do this are said to 'lack capacity'.

This might be due to illness, injury, a learning disability or mental health problems that affect the way their brain works.

It can be a temporary or permanent loss of capacity.

To have capacity a person must be able to:

- Understand the information that is relevant to the decision they want to make;
- Retain the information long enough to be able to make the decision;
- Weigh up the information available to make an informed decision;
- Communicate their decision by any possible means, including talking, using sign language, or through simple muscle movements such as blinking an eye or squeezing a hand.

People should be assessed on whether they have the ability to make a particular decision at a particular time.

The mental capacity of some people will fluctuate, e.g. there might be times when they are able to think more clearly and so make a valid decision about the particular options being put to them.

What is DoLS?

The Deprivation of Liberty Safeguards (DoLS) are part of the Mental Capacity Act 2005. DoLS protects people aged 18 years and over who lack mental capacity or are not able to make a decision about their care or treatment.

If you need any more information about mental capacity or DoLS, please ask to speak to the ward manager, matron or a member of the Safeguarding Team.

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

We understand that many carers feel they must stay with the patient to comfort and reassure them, but also to ensure the staff understand and meet the patient's safety and other needs. We know many carers worry that staff might not really be aware of the condition of the patient and worry that very busy staff will not communicate with the patient properly. However, if you need 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 a patient passport document and staff will consult it. There are many different versions of this available on the internet or download our **hospital passport** from this web page www.royalberkshire.nhs.uk/patients-and-visitors/accessibility .

Carers should be aware that carer's allowance may stop during hospital stays. Attendance allowance can stop too. For more information on this, please have a look at: www.gov.uk/carers-allowance

If you do wish to participate in the care of the patient while they are in hospital, please discuss this with the nursing staff on the ward. Make it clear what you are willing and able to do – and document it on the **Carers Passport**. ***And don't forget you should ask the ward staff for help with specific tasks that you are not able to manage on your own.***

You should be involved in discharge planning meetings so you can say what care you are willing and able to provide. If you have never had a carer's assessment, you should know you are legally entitled to one. Contact your local carers support organisation, to find out how they can support you to access a carer's assessment. Their contact details are at the end of this booklet.

If you are providing care to a patient while they are in our hospital we will offer you:

- Free car parking permit
- Free tea or coffee;
- Meal voucher

If no one offers you these, speak to one of the nurses or ask to speak to the ward manager or matron. These will be offered to one carer and will be managed by the Nurse in Charge upon completion of a Carers Passport.

Will I be able to stay overnight?

There are some limited facilities for carers to stay overnight in the hospital. Please speak to the ward manager who will have details of what is available in that area. Staff should offer you an easy chair with blankets and pillow, to make you as comfortable as possible in the ward area. Speak to the nurse in charge of the ward if you need to stay on the ward overnight. From time to time there may be additional restrictions and these will be updated on the Trust website:

<https://www.royalberkshire.nhs.uk/patients-and-visitors/visitor-guidelines#:~:text=General%20visitors%20between%202pm%20and,Berkshire%20Cancer%20Centre>

Leaving hospital

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

Staff may not be able to consult you over change of wards though 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. If you need further support with planning for the patient to come home speak to the ward staff or discharge team as soon as possible. Their contact details are at the end of this booklet. The sooner your concerns are raised, the better you can be supported.

What if I feel I might 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. You are entitled to a carer's assessment from your local authority and you should request this. Details of local authorities are listed at the end of this booklet. You can get support with the carer's assessment from your local carer support provider. If you feel unable to provide the care that will be needed, you must inform staff of this as soon as possible.

What will staff give me upon discharge?

Staff may provide medication, prescriptions, discharge/aftercare leaflets, and often a copy of a letter for the patient's GP. As the carer it is important to check that you have understood what is being given and how to use it before the patient leaves the ward. If there is information you feel you need to understand better before you take the patient home, it is important that you tell us and we will explain it.

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. Talk to ward staff if this is worrying you, but please be assured your loved one will be well cared for while in hospital.

The person you care for may seem to treat you differently when they are in hospital and may be distressed that you are 'leaving them' in hospital. This is very common. However, it is upsetting, and it can make you feel 'guilty' which is something you should not ever feel.

All of this can 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. If you have your own health concerns, this may be a good time for you to see your GP for a check-up. Make sure your GP knows you are a carer and has you registered as such.

If you feel you would like to talk to someone, there are a number of people who may be able to help. You could speak to PALS, the Carers Lead Nurse, the Patient Experience Team, the hospital chaplains or contact your local carers support provider. 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 4 Concern, the patient safety service, on 0777 475 1352. All other contact details are listed on the following pages.

What is a carer's 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 (2014) to provide a **carer's assessment**, and to give you information and advice about organisations within the local authority that can support you. This assessment is purely for **your** needs, and not those of the patient. Their needs will be assessed separately. 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 access to 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, contact your local carer support provider for more information, advice and signposting.

When caring ends

Looking after someone may be a large and significant part of your life, but often your caring role will change over time, and may come to an end. The reasons may vary considerably.

The person you are looking after may have recovered or their needs have changed. We can provide support if you are dealing with:

- **bereavement** – if you have sadly lost the person for whom you cared
- **residential care** – if their needs have escalated and you can no longer care for them at home

- **end of life planning** – you may need support to help you consider what to do and how to cope when someone you're caring for is approaching the end of their life
- **life after caring** – you may wonder what you can do next and where you can apply your skills. We can provide ideas and support for your next steps.

For more advice and support around this time please be sure to speak to your GP and look up Carers UK www.carersuk.org/help-and-advice/practical-support/when-caring-ends/bereavement

Useful Trust telephone numbers / contact details

Carers Lead Nurse	07824 343236 (<i>non urgent voicemail service</i>) Email: karen.oleary@royalberkshire.nhs.uk
Call 4 Concern	0777 475 1352
Chaplaincy Team	0118 322 7105
Dementia Nurse Specialist	0118 322 3216
Discharge Team:	hospitaldischargeteam@berkshire.nhs.uk
Learning Disability Liaison Nurses	0118 322 8159
Mental Health Co-ordinator	0118 322 6889
Multiple Sclerosis Nurse Specialist	0118 322 5369
Palliative Care Team	0118 322 7826
Patient Experience Team	0118 322 7446
Parkinson's Nurse Specialist	0118 322 8487 / 6855
Safeguarding Team	0118 322 7482
Royal Berkshire Hospital (switchboard)	0118 322 5111
Patient Advice and Liaison Service (PALS)	0118 322 8338

Local and national support organisations

Some organisations that may be useful for you to know about so you can get more support.

Age UK Berkshire (lead contact for all carers age 19+)	Tel: 0118 959 4242 Email: carers@ageukberkshire.org.uk or info@ageukberkshire.org.uk Website: www.ageukberkshire.org.uk
Berkshire Youth (for carers age 18 and under in Wokingham)	Tel: admin@berkshireyouth.co.uk Email: admin@berkshireyouth.co.uk Website: www.berkshireyouth.co.uk
Bracknell Forest Council	Tel: 01344 352000 Website: www.bracknell-forest.gov.uk/health-and-social-care/care-and-support/support-carers/carers-assessment/why-you-may-want-assessment
Crossroads Care	Bracknell Tel: 01344 860677 Newbury Tel: 01635 30008 Reading Tel: 0118 945 4209 Wokingham Tel: 0118 979 5324

Oxfordshire County Council	Tel: 0845 050 7666 Website: www.oxfordshire.gov.uk/cms/content/carers-assessment
Promise Inclusion (<i>carers of children and adults with a learning disability and / or autism in Wokingham</i>)	Tel: 0300 777853 Email: admin@promiseinclusion.org Website: www.promiseinclusion.org
Reading Borough Council	Tel: 0118 937 3747 Website: www.reading.gov.uk/carers
West Berkshire Council	Tel: 0845 6014726 Website: http://info.westberks.gov.uk/index.aspx?articleid=29942
Wokingham Borough Council	Tel: 0118 974 6000 / 6863 Website: www.wokingham.gov.uk/care-and-support-for-adults/support-for-carers/
Age UK Berkshire	Tel: 0118 959 4242 Email: info@ageukberkshire.org.uk Website: https://www.ageuk.org.uk/berkshire/
Age UK Reading	Tel: 0118 950 2480 Email: info@ageukreading.org.uk Website: https://www.ageuk.org.uk/reading/
Alzheimer's Society	Dementia Connect Support Line 0333 150 3456 (an interpreting service is also available on this number – the caller needs to be able to give their name, telephone number and language required in English and then someone will call them back in the language required). Email: dswbershire@alzheimers.org.uk Website: www.alzheimers.org.uk
Autism Berkshire	Tel: 0118 959 4594 Website: www.autismberkshire.org.uk/
Drug and Alcohol	Drug and Alcohol Service Reading , Website: www.changegrowlive.org , Tel: 0118 955 7333 Email: Reading.admin@cgl.org.uk
Sight loss	Berkshire Vision Website: https://berkshirevision.org.uk Tel: 0118 987 2803 Email: info@berkshirevision.org.uk
Hearing Loss	Reading Deaf Centre Website: https://readingdeafcentre.co.uk/
Macmillan Cancer Support	Website: www.macmillan.org.uk Macmillan Cancer Information & Support Centre Berkshire Cancer Care, Royal Berkshire Hospital. Tel: 0118 322 8700

	Email: Macmillan.Information@royalberkshire.nhs.uk
Carers UK	Information & Support Helpline: 0808 808 7777 Monday-Friday, 9am-6pm Email: advice@carersuk.org
The Reading & West Berks Carers Partnership	<p><i>Caring for a child or adult with a Learning Disability in Reading?</i> Reading Mencap, Information & Advice and Carers Assessments in Reading. 21 Alexandra Road, Reading, RG1 5PE Tel: 0118 926 3600: Email: carers@readingmencap.org.uk Website: www.readingmencap.org.uk</p> <p><i>Caring for someone 50+ years in Reading?</i> Age UK Reading, Information & Advice and Carers Assessments in Reading. Walford Hall, Carey Street, Reading, RG1 7JS Tel: 07716 418 941: Email: carers@ageukreading.org.uk Website: www.ageuk.org.uk/reading/</p> <p><i>Caring for someone 50+ years in West Berkshire?</i> Age UK Berkshire: Information & Advice in West Berkshire. Unit 119, Broad Street Mall, Reading RG1 7QA Tel: 0118 959 4242 E-mail: info@ageukberkshire.org.uk Website: https://www.ageuk.org.uk/berkshire/</p> <p><i>For all other carers in Reading & West Berkshire:</i> CommuniCare: Information & Advice and, in Reading, Carers Assessments as well. 233 Kings Road, Reading, RG1 4LS Tel: 0118 926 3941 Email: office@communicare.org.uk Website: www.communicare.org.uk</p>
Mencap	<p>There are local Mencaps in every local authority area in Berkshire.</p> <p>Reading Mencap: Website: www.readingmencap.org.uk Email: carers@readingmencap.org.uk</p> <p>West Berkshire Mencap: Website: www.wbmencap.org Tel: 01635 41464</p> <p>Promise Inclusion (formerly Wokingham, Bracknell & Districts Mencap) Tel: 0300 7778539 Email: admin@promiseinclusion.org Website: www.promiseinclusion.org</p>
Talking Therapies	<p>Website: https://talkingtherapies.berkshirehealthcare.nhs.uk/ Tel: 0300 365 2000 (Press option 4) Email: talkingtherapies@berkshire.nhs.uk</p>

Parenting Special Children	Specialist support for Berkshire families with children and young people with special needs. 11 Glebe Road, Reading RG2 7AG. Tel: 0118 986 3532 Web Address: www.parentingspecialchildren.co.uk
Stroke Recovery Service	Reading & Wokingham Stroke Recovery Service Tel: 0118 321 9349 Dave Riley Email: ReadingWokingham@stroke.org.uk
Bracknell Carers Support	Tel: 01344 266 088 Email: info@signal4carers.org.uk
Carers Trust	Website: www.carers.org/ Email: support@carers.org
Parkinson's UK	Helpline: 0808 800 0303 Website: www.parkinsons.org.uk/
MS Society	Helpline: 0808 800 8000 Tel: 0118 931 1017 / 0118 986 2591 (Reading, Wokingham & District) Tel: 01628 635 396 (East Berkshire) Website: www.mssociety.org.uk Email: helpline@mssociety.org.uk
Young Carers	West Berkshire Tel: 01635 503090 Email: EarlyRHub@westberks.gov.uk Reading Tel: 0118 937 6545
Parent Carer Forums <i>Groups of parent carers of children and young people with Special Educational Needs & Disabilities. Their aim is to make sure services in the area meet the needs of disabled children and their families.</i>	Tel: 07516185380 Email: fran.morgan.rff@gmail.com Reading Website: www.readingfamiliesforum.co.uk/ Wokingham - SEND Voices Wokingham Email: info@sendvoiceswokingham.org.uk Website: www.sendvoiceswokingham.org.uk West Berkshire - website: www.wbpcf.org.uk
Social Prescribers	West Berkshire: Contact your GP for more details Reading: https://rva.org.uk/social-prescribing/ Wokingham: https://involve.community/social-prescribing/

All about me / This is me booklet – free printable resources

Here are links to free printable templates to documents that tell us all about the patient's life, likes and dislikes.

- **Dementia:** www.alzheimers.org.uk/sites/default/files/2020-03/this_is_me_1553.pdf

- **Autism:** <https://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport>
- **Learning Disabilities:** www.royalberkshire.nhs.uk/patients-and-visitors/accessibility

Notes and questions

This image shows a single sheet of white paper with horizontal green ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT Patient Experience Team, May 2025

Next review due: May 2027