



Information for carers

Help and advice for relatives and friends supporting people using Gloucestershire Health and Care NHS Foundation Trust services

The team supporting the person you care for is:

Your named contact in the team is:

The contact phone number is:

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This booklet is for carers, families and friends of people who have contact with the services provided by Gloucestershire Health and Care NHS Foundation Trust (GHC).

When someone you care for has health problems, it can be worrying and stressful. If you would like someone to talk to, there are a number of people who may be able to help.

You can speak to the Named Nurse or Community Key Worker. The Team Manager or other members of staff in the team can also help.

You can also speak to:

GHC Patient Advice and Liaison Service (PALS)

 **0300 421 8313**

 experience@ghc.nhs.uk

GHC Spiritual Care and Chaplaincy Team

 **01452 894 540**

 SpiritualCare@ghc.nhs.uk

Gloucestershire Carers Hub

 **0300 111 9000**

 carers@peopleplus.co.uk

Who is a carer?

“ A carer is a person who provides unpaid help and support on a regular basis to a partner, child, relative, friend or neighbour, who is frail or has a physical or mental illness, disability or substance misuse issues. The carer is not employed to provide this help but does so to improve the quality of that person’s life ”

In GHC we use the term ‘carer’ to distinguish those who are carrying out the role described here.

We understand that many parents, relatives and friends who support patients and service users as part of your relationship may not identify yourselves using this term - but we hope that the information is of use however you see your role.

Carers are very important to us. Our aim is to work well with you in a way that reflects our core values:

working together

always improving

respectful and kind

making a difference

Young carers

This guide has been designed for adult and parent carers. However, young people can also be involved in caring, and can really benefit from having specialist support, advice and involvement in care planning.

Young carers are defined as those aged under 18, while those aged 16-25 are young adult carers. Young carers care, unpaid, for a family or friend with an illness or disability, mental health condition, or an addiction. This care can include emotional as well as practical support. It can have an impact on their own health, wellbeing, education and quality of life.

Under the Children Act 1989 and Children and Families Act 2014, young carers are entitled to an assessment, looking at the impact of caring, whether they wish to continue caring – and if it's appropriate for them.

Gloucestershire Young Carers offers a wide range of support to young carers and young adult carers:

 **01452 733 060**

 mail@glosyoungcarers.org.uk

 www.glosyoungcarers.org.uk

You can also ask a member of staff for young carer information.

Your rights as a carer

Carers make a huge contribution to society, and have certain rights. These include employment rights and the right to request a Carers' Assessment.

Carers' Assessments

As a carer, you have a legal right to an assessment of your needs under the Care Act 2014.

A Carers' Assessment is not a test of your ability to care. It recognises your crucial role, and that supporting your emotional, physical and mental wellbeing is essential.

Depending on your needs and eligibility, an assessment may result in:

- A payment for you to spend on something that makes caring easier
- Some practical help for you, for example respite care
- Information and guidance about other ways your needs might be met

If you think this would be helpful or want to know more, staff can help you by putting you in touch with Gloucestershire Carers Hub, who will talk to you about.

- your needs and what you think will support you
- what services locally are available to help you
- how to access the services you are eligible for

Gloucestershire Carers Hub staff can help you decide whether you would like a formal carers assessment.

You do not need to have a Carers' Assessment to be able to access much of the carer support available locally, free of charge.

This might include:

- information and guidance about support in the community
- emotional and wellbeing support for you
- courses and education about caring and looking after yourself
- contact with other carers in similar situations who know what you are going through and can share their experience
- Information about benefits and help to manage debt can also be very useful.

You don't need to live with the person you are supporting, or be caring full time, to speak to Gloucestershire Carers Hub – you may be trying to juggle work and caring, and this is what is having a big impact on you.

You can also contact Gloucestershire Carers Hub yourself at any time, they do not require a referral from a professional to support you. Their contact details are at the front of this booklet.

Your employment rights

If you are a carer juggling work with your caring role, then you also have employment rights. These include the right to request flexible working and the right to take unpaid time off during emergencies without affecting your employment. The Equality Act 2010 ensures that people have protection from discrimination in employment, in education and when receiving services. A carer cannot be discriminated against on the basis of their association with a disabled person.

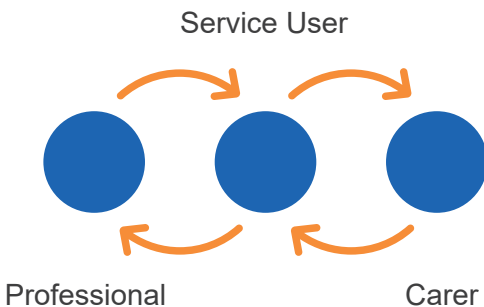
The Triangle of Care

GHC is a member of the Triangle of Care programme.

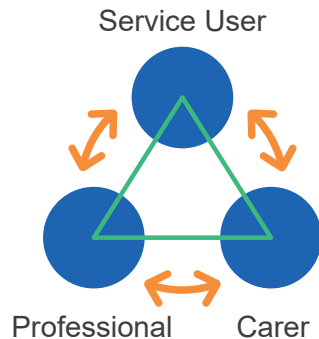


It represents the way health services aim to work with carers – a triangular relationship in which the carer, service user and professional are equal partners in a therapeutic alliance. It promotes safety, supports communication and sustains wellbeing.

From this



To this



Inclusion and support for carers from us

As the carer of someone receiving our services, you should be given the opportunity to talk to us about:

- the person you care for – please feel confident to tell us information you think it is important we should know
- your own needs in your caring role

Carer support within GHC should routinely be offered to you. What is on offer will depend on which service your friend or family member is using, but common examples of this support are:

- information on health conditions and disabilities and what to expect in future
- inclusion in discussions and meetings about treatment options, condition management and discharge planning
- advice about how you can best support the friend or relative who is using our service.

Our teams support people experiencing different types of health problems and who have varying levels of need. The different services we offer also work in different ways. You can find more information from the team working with the person you care for, in the pocket at the back of this booklet.

Asking for information

Sometimes it can be difficult to know how to ask for the information you need. The following questions might be helpful for you to use when talking to staff.

- What tests and assessments will you do?
- Are you able to tell me what the diagnosis/current problem is?
- Will medication help? Are there any side effects? Who can I talk to for more information about this?
- Are there any other treatments and services that might be useful / available?
- What is the treatment plan? Am I able to have a copy of the plan?
- How often will the person I care for be seen?
- What should I do if I think my friend or relative's condition is becoming worse?
- Where can I get further information about the condition and the services available?
- How will I be involved in planning care?
- What support is there for me as a carer?

It is important that, when we meet with you, the information provided is what you need to know, and explained at the right time. As a carer, you will have questions about the diagnosis, treatment and progress of your friend or relative at different stages of their contact with us.

In some meetings, for example care reviews, there will be a written record of the discussion. When the contact is less formal, you can also ask us to write down the information and provide you with any supplementary information, such as leaflets or information sheets, that might be useful to you.

Carer information sessions and support groups

Carer education and support groups provide:

- Time to talk, share experiences and support each other
- Visiting speakers on health issues and services
- Increased understanding of health problems and how they may be managed
- Education for carers on looking after their own wellbeing
- Information on carers' rights

These may be provided by the team, depending on which service your friend or family member has contact with - ask the care co-ordinator if this is part of what the team offers. You can also access carer education and support programmes run by local carer organisations.

Preparing for and dealing with an emergency

Advance planning

Planning is key to coping with a crisis, so it's important to think in advance about an action plan. You and the person you care for might like to make a plan about what they want to happen if there is an emergency.

Often, as part of their care, teams will help your friend or relative to plan what will happen if they become unwell again. If carers are part of that plan, they should be involved and have a copy of it so they know what's expected and who to contact.

Your friend or relative can also make a plan for themselves about what they want to happen in future, if they want and are able to. They may like to involve you in this.

The plan can be in any format. There are some Advance Care Planning tools available from staff, but it does not need to be on a special form. The important thing is that staff know about it. Service users, friends and family can talk through and record preferences about treatment, and other future support that might be necessary, and these can be stored in the clinical records so staff are aware of them if a situation arises.

Carers often recognise early signs that someone's health is deteriorating. You should not worry that you will be seen as "making a fuss" – you are the person who may be most aware of a developing problem and staff should respect your opinion.

If you are requesting help, the following list can help you prepare what to say:

- **Situation:** Who is calling and why? Be clear about the situation.
- **Background:** How has this come about and what has happened?
- **Assessment:** What are the problems that you are worried about?
- **Recommendations:** What do you feel would help?
- **Decision:** Make a note of what was agreed and who will do what.

The Carers Emergency Scheme

The Carers Emergency Scheme is designed to plan emergency support for adults who need essential care, in the eventuality that you as their carer unexpectedly cannot carry that out. Gloucestershire Carers Hub are able to provide information about setting this up and advise that carers speak to them before there is an emergency, so the plan is already in place.

Useful numbers

Don't be afraid to call if you need help.

**If you feel in immediate danger,
dial 999 and ask for the police.**

NHS 111: Confidential health advice and information on non-emergency situations or where advice or reassurance is required.

 **111**


Gloucestershire Social Care Services:

 **01452 426 868** - Adult Helpdesk

 **01452 426 565** - Children and Families Services

 **01452 614 194** - Out of hours (emergency only)

Gloucestershire Police:

 **101** - For non-emergency advice please telephone

Samaritans

 **116 123**

Shelterline - Housing advice.

 **0808 800 4444**

Refuge - For women experiencing domestic violence.

 **0808 200 0247**

Respect - For men experiencing domestic abuse.

 **0808 801 0327**

Confidentiality and information sharing

Our Carers' Charter sets out how we should involve you in the care of the person you care for.

Staff have a legal duty to keep personal information confidential. For a variety of reasons, service users sometimes do not consent for staff to share information with carers, and if they are able to make that decision staff need to respect it.

However, it is good practice for staff to revisit this decision with service users, to ask them if it applies to all information or just some things, and to remind the service user of the positives of carer involvement.

If the person you care for has agreed that information **can be shared** with you, planned care or treatment should be discussed with you. **If not**, you can still receive **general factual information** both verbally and written, as well as support for yourself in your caring role.

As the carer you should be helped to understand:

- the present situation
- any confidentiality restrictions put in place by the service user
- the service user's treatment plan and its aims

- any written care plan, crisis plan or recovery programme
- the role of the professionals involved in the service user's care
- how to access help, including out of hours services

As the carer you should have:

- the opportunity to speak to a professional on your own and share information that you consider relevant and important
- rights to your own confidentiality when talking to a professional
- encouragement to feel a valued member of the care team
- confidence to voice your views and any concerns you may have
- support in your caring role
- access to an assessment of your own needs and your own written support plan

Communication and ‘consent to share’

Effective, seamless care is based on all those involved with someone having access to the right information. The person receiving support, and/or others may be put at risk if this information is not provided.

Where information is shared with others, they also have a duty of care to ensure that this information is protected.

We often need to ‘share’ information about service users with a range of people. These may include family, friends, neighbours, and staff in organisations such as social services, housing, schools or voluntary and community groups.

It is important that the person’s views and wishes about what can be shared, and with whom, are recorded. This is called ‘Consent to Share Information’ and there is a distinction to be made between general information about their wellbeing, information about the service, and sensitive, confidential information about their current mental health and progress.

The standard position regarding sharing information with families and carers is that clinicians are expected to do this unless the person withholds their consent. This is because sharing information and communicating effectively:

- Helps families and carers to support the person better, and promotes their recovery and wellbeing
- Creates relationships and communication channels that can improve shared understanding between teams and families, harnesses carer expertise and reduces the risk of relapse or harm for the person
- Supports carers and families to maintain their own wellbeing, and reduce isolation, anxiety and exclusion.

Staff should discuss with service users how we share information with family, friends and carers, and ask them about:

- How they would like to be involved
- What the family know already
- Information that can't be shared, or concerns the service user may have about families having information

Service users should know that clinicians will usually try to speak to involved families and carers about their own perspective of the situation, and the family's support needs for themselves. Clinicians will agree with the service user about personal information that can be shared with carers in advance through the consent to share process.

Adult service users, and those young people deemed to be ‘Gillick competent’, have a right to confidentiality. [‘Gillick competence’ is a term used in medical law to decide whether a child (under 16 years of age) is able to consent to their own medical treatment, without the need for parental permission or knowledge. The standard is based on the 1985 decision of the House of Lords in *Gillick v West Norfolk and Wisbech Area Health Authority*. The case is binding in England and Wales.] In principle, younger children also have the right to confidentiality but the parent(s) with legally defined parental responsibility are able to make decisions on their behalf.

Information sharing with anyone not directly involved in the Service User’s care, must be done in line with the principles outlined in **Confidentiality: NHS code of Practice**



www.gov.uk/government/publications/confidentiality-nhs-code-of-practice

Carers have their own right to confidentiality, and can ask for information they provide to be kept confidential from the service user. Where a carer shares confidential information about themselves, this should be stored in a separate Carer record.

GHC has further information on this in its guide **Commonsense Confidentiality – a guide for staff, carers, family and friends**. Please ask staff if you would like a copy.

Taking care of yourself

It's important to look after yourself and stay well in order to cope in a demanding caring role. It can be stressful for you if the person you care for is upset or angry, or you find yourself in a role you did not choose. It's not surprising that many carers experience mental and physical health problems due to the demands of caring.

The following tips are about looking after yourself. Some come from other carers and others are from research about carers' health:

- If you are feeling stressed, anxious, low or depressed, speak to your GP about some help for you. This may be through the surgery or from a range of workshops and counselling services the GP can refer you to. You can also refer yourself to **GHC's Let's Talk Service** for some psychological support. Let's Talk is a free service provided by the NHS for people aged 18 and above. They offer courses, one-to-one support by telephone or face-to-face therapy depending on your needs.

The contact number for Let's Talk is:

 **0800 073 2200.**

You can learn more about the service at:

 www.letstalkglos.nhs.uk

- If you need to talk through your caring role, carer organisations offer one-to-one and group support
- Try to maintain your physical and mental health by taking some exercise and eating as well as you can
- If you are offered health checks try to take them up. Carers are at a higher risk of having health problems diagnosed later in life because they may miss health checks
- Connect with others - this does not always need to be face-to-face to be effective
- Be compassionate towards yourself - demands on you may be very high, so focus on what you have achieved rather than feeling guilty about what you have not
- If it's hard for you to say no or set boundaries, investigate 'assertiveness techniques' online, from books on prescription, or a course

Gloucestershire Carers Hub has a range of things on offer for carers to help you take care of yourself, including regular get-togethers, activities and courses.

You can find out more on their website:

 www.gloucestershirecarershub.co.uk

UK carers organisation Mobilise offers online support groups and advice.

 www.mobiliseonline.co.uk

Short breaks for parents/carers of young people

If you are a parent/carer of a child or young person with a disability, short breaks for them can include day, evening, overnight, weekend and holiday activities and give young people the opportunity to have fun and relax with friends. Making short breaks possible can range from supporting children and young people to join children's activities and services in their communities to providing specialist services, or a mixture of both.

Gloucestershire Special Educational Needs and Disabilities Information Advice and Support Service (SENDIASS) can advise or signpost parent carers about breaks for young people:

 **0800 158 3603**

or use the contact form on:

 www.sendiassglos.org/contact-us

POhWER

 **0300 456 2370**

 pohwer@pohwer.net

You can also text the word 'pohwer' with your name and number to:

 **81025**

Advocacy services

Advocacy services provide support to ensure disadvantaged people are treated fairly and have equal rights.

In Gloucestershire, POhWER provides advocacy services, including:

- Independent Care Act Advocacy
- Independent Mental Capacity Advocacy
- Independent Mental Health Advocacy
- Independent Health Complaints Advocacy
- Independent advocacy to eligible individuals wishing to complain about their experience of adult social care.

GP Carers' Register

Many GP practices have an established process and protocol for identifying carers within their practice. However, you should check and inform your GP practice if you are a child or adult caring for someone at home or elsewhere who has a physical or mental illness, has a learning disability, suffers alcohol or drug addiction problems or who is disabled, elderly or frail.



Once you are registered as a carer many GP practices offer some or all of the following:

- Free annual flu vaccinations
- Joint appointments for patients and carers
- Back-to-back appointments for patients and their carer
- Home appointments for carers who are housebound
- Health check for carers, sometimes also linked to an advice clinic
- Sharing of relevant information with a carer regarding the illness, treatment and prognosis of the cared-for with appropriate agreement
- One or more ‘emergency’ appointment slots ‘free’ each day for carers
- A nominated staff member who telephones older or vulnerable patients who are carers on a regular basis
- A nominated staff member as a carer lead
- A dedicated carer’s noticeboard and carer’s link on their website for information
- Link entries on their register to a referral for a carers’ Assessment and/or referral to relevant organisation or agency for advice and support
- To link registration to an invitation to a local carers’ support group

Sources of information, advice and support

GHC Patient Advice and Liaison Service (PALS)

 **0300 421 8313**

 experience@ghc.nhs.uk

GHC Spiritual Care and Chaplaincy Team

 **01452 894 540**

 SpiritualCare@ghc.nhs.uk

Gloucestershire Carers Hub

 **0300 111 9000**

 carers@peopleplus.co.uk

 www.gloucestershirecarershub.co.uk

Gloucestershire Young Carers

 **01452 733 060**

 mail@glosyoungcarers.org.uk

 www.glosyoungcarers.org.uk

Gloucestershire Domestic Abuse Support Service

 **01452 726 570**

 support@gdass.org.uk

 www.gdass.org.uk

Your rights as a carer


British Institute of Human Rights - Carers Guide:

 www.bihar.org.uk/carersguide

Equality Act 2010. What do I need to know as a carer?:

 www.gov.uk/government/publications/individuals-what-do-i-need-to-know-as-a-carer

Carers UK – factsheet for young carers/parent carers:

 www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/young-carers-and-carers-of-children-under-18


Abbreviations used in this booklet

GHC	Gloucestershire Health and Care NHS Foundation Trust
PALS	Patient Advice and Liaison Service
SENDIASS	Special Educational Needs and Disabilities Information Advice and Support Service

Your experience

Your views are important to us. If you need advice or have feedback on a community hospital in Gloucestershire or on our community health and adult social care services, you can contact one of the advisors from our service experience team. All enquiries are completely confidential.

You can contact us between 9:00am and 5:00pm, Monday to Friday.

 **0300 421 8313** (answerphone available outside office hours)

 experience@ghc.nhs.uk

 www.ghc.nhs.uk/get-in-touch/give-us-views

Service Experience Team

Gloucestershire Health and Care NHS Foundation Trust, Edward Jenner Court, 1010 Pioneer Avenue, Gloucester Business Park, Brockworth, Gloucester, GL3 4AW

For general enquiries or if you would like further information, additional copies or would like to receive this leaflet in another language, large print or on audio format, please contact the Trust Communications Team at Edward Jenner Court, 1010 Pioneer Avenue, Gloucester Business Park, Brockworth, Gloucester, GL3 4AW. You can email us at ghccomms@ghc.nhs.uk or call us on **0300 421 8100**.