



ST CATHERINE'S HOSPICE

*Information and
advice for carers*



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At St Catherine's Hospice we understand that when someone you love is ill, it affects everyone. We are committed to providing people with high quality care and we know that although caring for someone you love can be very rewarding, it can also leave you in need of some support yourself.

As a carer you have a vital role in providing your loved one with the care they need, so we will work with you and alongside you to make sure you feel involved, supported and listened to when it comes to their care.

This booklet aims to answer some common questions that carers often have and to provide you with information about the people and places that can offer you the help you need.

What does being a carer mean?

The title 'carer' refers to someone who is responsible for providing or arranging care for a person who cannot care for themselves. Although you might not feel like the word represents your relationship to the person you care for, identifying yourself as a carer will help you to gain access to help and support from lots of organisations including St Catherine's, your GP and local council.

Getting support is important, particularly when you are caring for someone, as you may face the following challenges:

- Stress and worry
- Social isolation/loneliness
- Money worries
- Physical health problems
- Depression
- Frustration and anger
- Low self-esteem

How can St Catherine's help?

The Patient and Family Support Team (PFST) can provide emotional and practical support to anyone with a friend, family member or loved one who is being cared for by the hospice.

We offer:

Counselling and emotional support

Whether you are a carer, family member or patient, our counsellors, student counsellors and support visitors can work with you on an individual basis. Coping with the change in your role and the impact your relatives' illness can have on your relationship can be very distressing and leave you feeling isolated. Our trained, skilled listeners will help you to share any concerns or

worries in confidence and aim to give you the strength to cope with any challenges you may face during your time caring, and if you become bereaved.

Home visits

Our team may be able to visit you at home if you are unable to attend an appointment at the hospice. If this is the case, please speak with us.

Helping practically

Our Welfare Advisor will provide advice and support for you and your family about a range of financial and practical issues that may arise when you are caring for someone.

This could include advice on benefits, grants, disabled parking badges, making wills and appointing a Lasting Power of Attorney. If you would like to see or speak to our Welfare Advisor, please telephone 01293 447345.

Spiritual care

When people close to you become ill, this can raise questions and anxieties of a spiritual nature; perhaps challenging your sense of meaning, purpose and value, or your priorities and beliefs. Our Spiritual Care Team is available to anyone who might appreciate the company of someone who can listen and will help you explore any difficult questions that may arise.

Spiritual support is available to people whatever their faith and members of the team will always respect your own beliefs and religious practices. If you would like more information about how to access this support, please telephone 01293 447343 and ask to speak to our Spiritual Care Lead.

Other help available to carers

There are a number of other organisations which can offer you support, from offering financial advice to discounted gym memberships. Here are some suggestions, but please ask a member of the PFST team or other members of the hospice team if you would like any more information.

Financial help

There are a number of ways that you can get help, support and benefits that you are entitled to. Here are some useful contact details:

St Catherine's Hospice Welfare Advisor: 01293 447345

Carers Advice Line: 0808 808 7777

Age UK Money Advice Service: 0800 169 2081

You might also want to look online at www.gov.uk/carers-allowance/overview or www.ageuk.org.uk/money-matters to see if you are entitled to Carers Allowance. If you are, both websites have information on how to make a claim and what you might expect to receive.

www.turn2us.org.uk can help you calculate your benefit entitlement.

Things you can do

Statutory Carers Assessment

Carers are entitled to a Statutory Carers Assessment. A Carers Assessment is an opportunity to discuss with your local council what support or services you need. The assessment will look at how caring affects your life, including your physical, mental and emotional needs, and whether you are able and willing to continue caring.

To request an assessment in West Sussex contact Carers Support West Sussex (CSWS) on 0300 028 8888. The CSWS information and advice line is open Monday to Friday 9am - 5pm and 9am - 7pm on Wednesdays.

To request an assessment in Surrey, contact Surrey's Carer Support Service on 0303 040 1234, **Text:** 07714 075993. Surrey's Carer Support Service can help with advice, information, advocacy, and training to support you in your caring role. You can also contact East Surrey Carers' Support Association in Redhill on 01883 745057.

The person you are caring for may also be entitled to a Community Care Assessment. To find out if they are eligible for an assessment, contact Adult Social Care Point on 01243 642121 (available 9am - 5pm Monday to Friday, with an out of hours message).

Make use of an Independent Advocacy Service

As you are caring for someone, you are entitled to an Independent Advocacy Service. This service is provided by an advocate, independent of Social Services and the NHS, and who is not part of your family or one of your friends.

An advocate can support you by finding helpful information or going to meetings or interviews with you. For example, you may want your advocate to write letters on your behalf, or speak for you in situations where you do not feel able to speak for yourself.

An advocate's role also includes arguing your case when you need them to and making sure the correct procedures are followed by your Health and Social Care Services. Being independent means they are there to represent your wishes without giving their personal opinion and without representing the views of the NHS or the Local Authority. Many local councils fund local advocacy services and some hospitals do too.

To find out if there are any in your area, contact your local council.

Appoint a Lasting Power of Attorney

A Lasting Power of Attorney is a legal document that allows a person to appoint one or more people (attorneys) to help them make decisions or to make decisions on their behalf. There are two types of Lasting Power of Attorney:

- Health and welfare
- Property and financial affairs

For more information go to www.gov.uk/power-of-attorney/overview

The website gives you the option to make a Lasting Power of Attorney online, print off forms to complete, or to request forms by post. Alternatively, you can call the Office of the Public Guardian on 0300 456 0300.

The Prevention Assessment Team

The Prevention Assessment Teams (PAT) include staff from West Sussex County Council, Sussex Community NHS Trust, Guild Care and Age UK West Sussex. The team's aim is to help local people maintain their independence, health and wellbeing in their own homes.

PATs normally work with people who do not receive other specialist health or social care services. PATs can provide information and advice and access to practical and emotional support either over the phone or with a home visit.

To find out more about how they can help you and the person you care for, please contact the Northern Prevention Assessment Team (covering Crawley, Horsham and Mid Sussex) on 01403 229510. The phone line is open Monday to Friday.

If you are based in Surrey, please contact Adult Social Care on 0300 200 1005.

You might also like to contact organisations such as Age UK, British Red Cross and Carers UK for general support and advice.

Find out about your rights at work

If you tell your employer you are a carer, they might be able to offer you extra support and you may learn of colleagues who are in a similar situation. Contact the ACAS helpline on 0300 123 1100 (Monday to Friday, 8am - 8pm and Saturday, 9am - 1pm) to find out about your rights at work.

The Carers UK website also has information and resources to help you manage your caring role whilst working. You can access the resources at www.employersforcarers.org/resources/other-resources-for-employees

Taking care of yourself

When you are a carer you will be spending a lot of your time focusing on someone else and it can feel unnatural to think about yourself and your own needs. However, it's important that you look after your own wellbeing as paying attention to what you need can be very positive for you and the person you care for. Here are some ways that you can do this:

- **Try to stay healthy** – it's important to make sure you eat well, take exercise and have a rest when you need it
- **Share your feelings** – speak to someone you trust, whether it's a friend, family member or a healthcare professional
- **Learn a relaxation technique** – there are lots of tools that you can access via apps, websites or face-to-face, such as mindfulness, meditation or adult colouring
- **Take a break** – even if it is just sitting down with a cup of tea, give yourself permission to do this
- **Make time for yourself** – do something you enjoy, whether it's pottering in the garden, listening to music or reading a magazine or book
- **Be realistic about what you can do** – you cannot do everything. Try and accept support when it is offered. Many people will want to help but they might not know how. Give them specific things and suggest times to visit and they will usually feel pleased you have asked for their help
- **Make sure you are kept informed** – this will help you feel able to make decisions that are best for you and the person you are caring for. You could also think about the things that can free up some of your time, such as:
 - Paying someone else to do your weekly chores (you may be entitled to receive benefits towards this)
 - Arranging alternative care arrangements
 - Ordering your shopping online for home delivery

- Completing the online Caring with Confidence course via NHS Choices. For more information about the course please call: 0300 123 1053

You might also like to talk to your GP

As well as helping you to stay healthy and offering advice and information to help you feel confident when you are caring for someone, GP's can refer you to Social Services and local voluntary agencies who can support you.

GP's can also work with you to make it as easy as possible to access their care.

Speak to your GP to see if they can:

- Visit you or the person you care for at home, especially if your caring responsibilities make it difficult for you to attend surgery appointments
- Arrange appointments for you and the person you care for at the same time to avoid having to visit twice
- Arrange for repeat prescriptions to be delivered to your local pharmacy to save you picking them up - Some pharmacies can also deliver prescriptions to your home
- Provide you with supporting letters and information to enable you and the person you care for to access benefits such as Attendance Allowance, or to show your Local Housing Department or the Blue Badge scheme

Your GP may also be able to help by providing information and advice on:

- Medical conditions and treatments for the person you care for to help you feel more confident in your role as a carer
- Services provided by the NHS, such as continence services and patient transport to hospital appointments
- Prescription schemes to join the gym

Useful emergency contacts

A fully charged mobile is useful when you are out and about. You might also like to add In Case of Emergency (ICE) contact details into your phone.

Also think about:

- **Carers Emergency Respite Service:** You might worry about what will happen to the person you are caring for if you suddenly become ill or are involved in an accident. The Carers Emergency Respite Service covers Sussex and is intended to provide you with peace of mind by making sure that home-based care can be put in place for a short time in an emergency. To find out more, please contact Crossroads Care South Central on **01903 790270** (9am - 5pm Monday to Friday)
- **Carers Emergency Card:** This card will show your name, a unique identification number and an emergency phone number. If you have an accident, emergency or are taken seriously ill, the card can be used to alert a 24 hour emergency call centre that the person you will need help and support. For more information about the Carers Emergency Card, visit the Carers UK website at www.carersuk.org
- **Technology-based equipment:** Carers Support can help you access simple home technology equipment to suit your needs. You might want to consider items such as key safes or wellbeing alarms. You can find out more by calling 0300 028 8888

Resources for young carers

You are a young carer if you aged 18 or under and help look after a relative. There is specific support available for you, including:

Action for Children

Helps young people reach their potential.

Website: www.actionforchildren.org.uk

Matter

A space for young adult carers aged 16 to 25 to connect, share advice and access trusted support.

Website: matter.carers.org

Shine: Young adult carers' network

One-to-one or group support for carers aged 18 to 25. Shine also helps with employment and advice about how to access funds and benefits.

Website: www.carerssupport.org.uk/yac/shine

email: youngcarers@westsussex.gov.uk, **telephone:** 0300 028 8888

Surrey Young Carers

Supports young carers 5-18 and young adult carers 18-24 years by offering advice and support.

Website: www.surrey-youngcarers.org.uk, **email:** Syc@actionforcarers.org.uk
telephone: 01483 568269.

The Children's Society Young Carers

Reaches out to young carers from all communities through national and local programmes and helps voluntary and statutory services to support young carers.

Website: www.youngcarer.com, **Young Carer telephone:** 01962 711511 or
The Children's Society main switchboard: 0300 303 7000.

Other useful resources

Sussex based resources

Crossroads Care South Central (*Covers West Sussex*)

Support for carers, including: respite, emergency respite and children's services.

Website: www.crossroadscare-sc.org, **email:** admin@crossroadscare-sc.org
and **telephone:** 01903 790270 (9am - 5pm Monday to Friday).

Carers Support

Practical information and emotional support, including:

- Carers support workers
- Emotional support
- Information for carers
- Support groups
- Events and activities.

Website: www.carerssupport.org.uk, **email:** info@carerssupport.org.uk and
telephone: 0300 028 8888

Surrey based resources

Action For Carers

Provide practical Surrey wide services to carers and signpost carers to people and places who can offer them other essential, specialist support

Website: <http://www.actionforcarers.org.uk>, **email:** info@actionforcarers.org.uk
and **telephone:** 01483 302748.

Surrey Carers Moving and Handling Service

Has a dedicated Moving and Handling team who work in the community to help carers learn how to limit the risk to their own health whilst moving and handling someone they care for. To request help from this team please visit <http://www.actionforcarers.org.uk/getting-help/moving-and-handling/> and complete the referral form.

Crossroads Care Surrey

Offers home based care to people facing the end of life to give carers a respite break.

Website: <http://www.crossroadscaresurrey.org.uk>, **email:** enquiries@crossroadscaresurrey.org.uk and **telephone:** 01372 869970.

General resources

Age UK

Advice for carers, including caring for someone with dementia and computer training courses for older people.

Website: www.ageuk.org.uk/work-and-learning/technology-and-internet

Brigitte Trust

Practical help and emotional support, including: respite, transport to hospital appointments, shopping, trips out and bereavement support.

Website: www.brigitte-trust.org, **telephone:** 01306 881816

Carers Trust

Access to breaks, information and advice on topics such as money, benefits, and education and training.

Website: www.carers.org, **telephone:** 0844 800 4361

Carers UK

Expert advice, information and support to carers as well as a practical carers guide.

Website: www.carersuk.org, **telephone:** 0207 378 4999

Dementia UK

Advice and support for caring for someone with dementia.

Website: www.dementiauk.org

Disability Rights UK

Information, products and services for disabled people.

Website: www.disabilityrightsuk.org

Macmillan Cancer Relief

Advice on looking after someone with cancer, including coping with emotions, organising your finances and working while caring for someone.

Website: www.macmillan.org.uk/information-and-support/audience/looking-after-someone-with-cancer.html

Marie Curie

Information covering everything from day-to-day caring to looking after your own needs. Visit the website to watch a series of films aimed at carers.

Website: www.mariecurie.org.uk/help/being-there

Motor Neurone Association (MND)

Help and advice for carers looking after someone affected by Motor Neurone Disease.

Website: www.mndassociation.org/for-carers

NHS Guide to Care and Support

A guide for carers, people who have care and support needs and people who are planning for their future care needs. It covers care service and advice, money and your rights.

Website: www.nhs.uk/conditions/social-care-and-support-guide/Pages/what-is-social-care.aspx

NHS Mobility Equipment Advice

What you should look out for when choosing mobility equipment, wheelchairs and scooters.

Website: www.nhs.uk/conditions/social-care-and-support-guide/pages/mobility-equipment-wheelchairs-scooters.aspx

UK Online Centres

Free computer courses throughout the UK.

Website: www.ukonlinecentres.com

If it would be helpful to have this booklet in another format or language please call St Catherine's on 01293 447333.

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St Catherine's Hospice is regulated by the Care Quality Commission. To view our most recent report, please visit: www.cqc.org.uk/location/1-143117253 or call 03000 616 161.

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