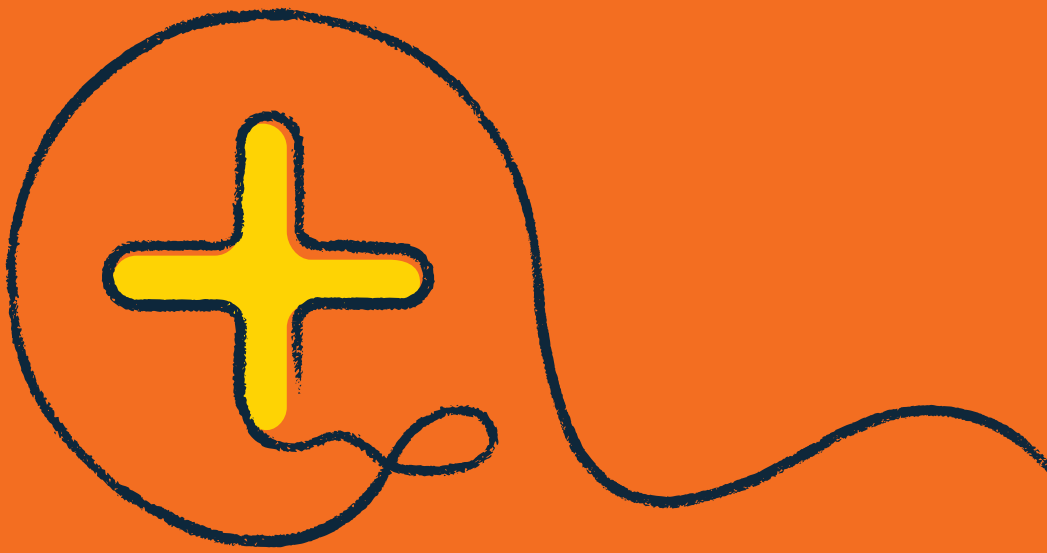
ST CATHERINE'S HOSPICE

Your information: what you need to know



Content

A guide for people we support

YOUR INFORMATION

What you need to know about your records at St Catherine's Hospice

St Catherine's Hospice is a local charity supporting people who are living with life limiting illness. Our care and support extends to family, friends and carers. Please read this leaflet carefully, and share it with your family and carers.

This leaflet explains:

- what information we collect about you and your family and carers
- how this information is used and who we might share it with
- how we keep it safe and treat it confidentially
- how to gain access to a copy of your record

Why we collect information about you

We receive information about you from you, from your family and from other people involved in your care (e.g. your GP or hospital doctors and nurses). We use this information to keep records about you and your care. These records are stored electronically or on paper and may include:

- personal details like name, address, date of birth, legal representative
- contacts we have with you like appointments and telephone calls
- notes and reports about your health, treatment and care
- results of x rays and laboratory tests
- relevant information from people who care for you or know you well
- things you tell us about your wishes and preferences.

How your records are used to help you

It is important that the hospice team has up to date and accurate records about you. This helps us make sure that you receive the best possible care. It also means that your concerns can be investigated properly if you have a complaint about your care.

We use implied consent to contact you regarding your care via SMS messaging. If you would prefer an alternative method of contact we can email, telephone or write to you. Please make us aware of your preferred method of contact. If you would like to opt out of communications altogether please let us know. There are some circumstances where we may still contact you if it is vital for your care. You can discuss this and update your preferred contact methods with us at any time.

Sharing your records with other professionals

So that we can provide the most appropriate care to you, members of the St Catherine's team looking after you may share relevant information from your records with each other. This team may include doctors, nurses, therapists, pharmacists, administration staff and people providing emotional and spiritual support. It may also include students or trainees in medicine or health and social care who are working with our team.

We share relevant information with other health care professionals outside of the hospice who are also involved in your care.

This may include your GP, district nurse, hospital teams, ambulance staff or social care services. This helps us provide seamless care for you between the partner organisations caring for you. This information sharing may be via the electronic patient record systems used by the hospice and partner organisations. If you give us specific instructions not to share information about you in this way, we will respect as much as we can without it affecting the level of care we can provide to you. We will discuss with you any implications of not sharing your data and work out the best option for you, your care and the organisation.

Using the information you give us

The information you give us about you and your family or carers might be shared with our fundraising and communications teams so that we can provide you with information about the hospice that we think will be of interest to you. You have the right to opt out of receiving this type of communication at any time.

Other reasons for sharing your records

Your records help us to review the care we provide and to make sure that it is of the highest possible standard. This includes routine audits of our care or investigating and responding to complaints or incidents. Our regulatory body, the Care Quality Commission (CQC), or NHS organisations who commission services from us, may also ask to view relevant information from your records and/or seek feedback from you about the service we provide. If you do not want us to share relevant information from your records with these organisations or you do not want to provide feedback, they will respect your wishes where it is possible to carry out their checks without looking at relevant information from your records and/or contacting you for feedback.

Some relevant information in your records may also be shared with other professionals or other organisations. This might be to help teach health or social care professionals, or to provide statistical information to national organisations with interests in health care or health care research. When relevant information from your records is shared in this way, we remove or disguise any personal or identifiable information about you wherever possible. If it is not possible to do this, we will ask for your consent. Your wishes will be respected, and if you do not want us to share your records in this way it will not affect your care.

Occasionally, we are required by law to share your records and may therefore be prevented from respecting your wishes not to share your records. This includes when:

- our regulator, the CQC, is carrying out an audit
- we find an infectious disease (like meningitis or measles) which may put other people in danger
- a formal court order has been made
- other organisations like the police or social services need it to prevent serious crime or where there is a child or adult at risk of abuse or neglect.

How you can help us

You can help us by giving us the right details about yourself and by letting us know if you have any particular wishes about sharing your records. You can also help by letting us know when any of the details in your records change.

Sharing your information with your family or friends

It is really important that we know which family members and/or friends to involve in your care and who we can share information with. These people do not need to be related to you but they should be able to tell us your wishes in case you are unable to do so yourself. It is also important that before you give us their details (such as their name, address and contact number) that they are happy for you to share that information with us and for us to contact them. Sharing this leaflet with them is probably the best way to do this.

How we keep your records safe and confidential, and for how long

We take our obligations to keep your records safe very seriously. Everyone working for us, or who has received your records from us, has a legal duty to keep your records confidential. They are monitored by the Caldicott Guardian, a senior clinician responsible for ensuring that people's rights to confidentiality are respected.

We keep your records for as long as the law requires us to do so. A person's health records are usually held for up to 10 years after their death.

Your Records help us to review the care we provide and to make sure that it is of the highest possible standard."

Your rights

You have the right to:

- know how we will use your records - that is what this leaflet aims to tell you
- access your records - please see section overleaf
- object to us making use of your records
- ask us to restrict or change the way we use your records; we are obliged to agree if it is possible to do so
- include any corrections you want to make in your records.

The National Data Opt Out (introduced by the NHS in March 2020) means that patients can opt out of their identifiable health and care information being used for reasons other than their individual care and treatment. St Catherine's Hospice is compliant with the National Data Opt Out. You can find out more about the National Data Opt Out here: **https://www.nhs.uk/your-nhs-data-matters/**

How can you or someone else get access to your records?

The Data Protection Act 2018 gives you, or someone acting for you, the right to see or have a copy of your records. We can arrange for you to view your record on a hospice computer with a doctor or nurse or for a paper copy to be provided.

According to the Access to Health Records Act 1990, other people are allowed to view relevant information from your records after your death - but only if they are your personal representative, an executor named in your will, or someone who has a legal reason to access your records.

Anyone wanting to access their own records, or access the record of someone who has died can email clinicalsystemsteam@stch.org.uk or write to us at:

St Catherine's Hospice, Grace Holland Avenue, Pease Pottage, West Sussex, RH11 9SL or call us on: 01293 447333

We will ask for a form to be completed with details of the request and which parts of the record are required. We may ask for proof of identity (like a passport) and if someone claims to be acting on your behalf we will contact you to confirm the request. There is no charge for these requests.

Other records at St Catherine's

All St Catherine's care is free. This is largely thanks to the generous support of fundraisers and donors who help us raise several million pounds each year to run the hospice. This means we also collect information about people who contribute to our fundraising, play our lottery or give items to our shops via Gift Aid. Again, we keep all this information confidentially. If you do contribute to our fundraising, play our lottery or give items to our shops via Gift Aid, please see our Privacy Statement at **www.stch.org.uk/privacy-statement** as this leaflet does not apply to such information.

Legal information

You also have a right to seek compensation from us for any damages caused by us breaching the Data Protection Act 2018.

If you are aged under 16, you must get your parent/guardian's permission before you provide any personal information to us.

For the purpose of the Data Protection Act 2018, the data controller is St Catherine's Hospice Limited of Grace Holland Avenue, Pease Pottage, West Sussex, RH11 9SL. The legal basis for us processing your data is that of 'legitimate interest' and in some circumstances that it is necessary for the performance of a contract.

Where we share relevant information from your records in accordance with this leaflet and such persons are based outside the European Economic Area (EEA), relevant information from your records will have to be transferred outside the EEA.

Further information, contacting us and complaints

For further information on all these issues please talk to a member of the St Catherine's team who can put you in touch with the Caldicott Guardian.

Questions, comments and requests regarding this leaflet are welcomed and should be addressed to:

qualityteam@stch.org.uk

or

St Catherine's Hospice,
Grace Holland Avenue,
Pease Pottage,
West Sussex, RH11 9SL

You also have the right to complain to the Information Commissioner's Office if you believe we have not handled your records in an appropriate manner. The ICO can be contacted at:

www.ico.org.uk or by calling 0303 123 1113

If it would be helpful to have this leaflet in another format or language please call the main hospice switchboard on 01293 447333.

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