

## Privacy and your information - 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 as it explains how we use information about you, how we keep it safe and confidential, when it might be shared and how you can access your hospice records.

### Why we collect information about you

We receive information about you from you, 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 ("**Records**"). 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

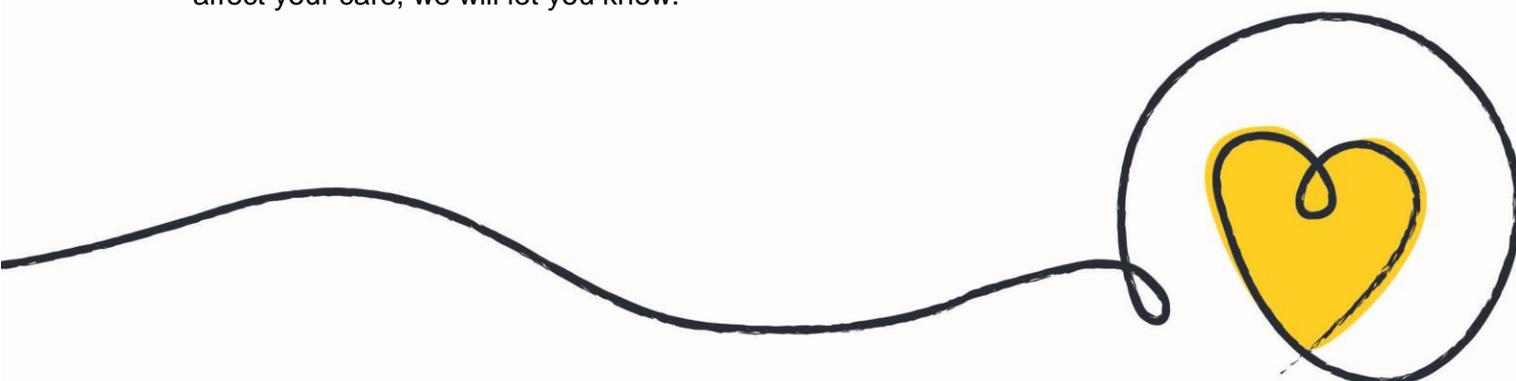
It is important that the hospice team has up to date and accurate Records about you. This helps us ensure that you receive the best possible care. It also means that your concerns can be investigated properly if you have a complaint about your care.

### How your Records may be shared with other professionals to help 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 in health and social care who are working with our team.

Often it is necessary to share relevant information from your Records with health or social care professionals in other services who are directly involved in your care. Such professionals may include your GP or district nurse, hospital teams, ambulance staff or social care services.

In these circumstances, we only share relevant information from your Records for medical purposes and if these people have a genuine need for it, or if we are under a legal obligation to do so. If you give us any specific instructions not to share your Records in this way, we will respect this to the extent we are not prohibited from doing so by any legal obligation, although this may affect your care. If it will affect your care, we will let you know.



## How your Records may be shared with your family or friends

We will not share information from your Records with your family or friends without your consent. However we find that often people do like those close to them to be kept informed. Please tell us if there are particular people who you would like us to share your Records with in this way. Equally, please let us know if there are people with whom we should never share your Records.

## 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), may also ask to view relevant information from your Records and/or seek feedback from you about the service we provide. If you don't want us to share relevant information from your Records with the CQC or you don't want to provide feedback to the CQC, the CQC 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 (i) to help teach health or social care professionals or (ii) 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 you 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.

However and 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 diseases (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 your details in your Records change.



### **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 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 below
- 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.

### **How can you or someone else get access to your Records?**

The Data Protection Act 1998 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 printed out.

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, should contact the **Service Information Co-ordinator** by post or by calling 01293 447439. We will probably 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. If your Record, or the deceased person's record, is less than 40 days old there is no charge. For older Records/records we may charge up a fee of up to £50 to help us cover our administrative costs.



## **Other records at St Catherine's**

All St Catherine's care is free. This is thanks largely 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](#), 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 1998.

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 1998, the data controller is St Catherine's Hospice Limited of Malthouse Road, Crawley, West Sussex, RH10 6BH.

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 [privacy@stch.org.uk](mailto:privacy@stch.org.uk) or St Catherine's Hospice, Malthouse Road, Crawley, West Sussex, RH10 6BH. 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](http://www.ico.org.uk) or by calling 0303 123 1113.

