

Anonymised information

Some information we have to share for statistical purposes and in these instances we take strict measures to ensure you cannot be identified.

Information may also be used for approved research projects. In most instances the information will be made anonymous so that you cannot be identified. If this is not possible, we will seek your permission or request approval from the Health Research Authority Confidentiality Advisory Group.

Can the fundraising team access my clinical information?

No, the fundraising team hold a completely separate database for people who donate to St. Gemma's. They cannot see or access clinical information.

If you or your family make a donation to the Hospice you will automatically be added to the donor database. Periodically, we will send information about our important work, details of future events and ways you can support us. You can opt out of receiving mailings at any time.

Your rights

You have the right to confidentiality under the Data Protection Act 1998*, the Human Rights Act 1998 and the common law duty of confidentiality.

*The Data Protection Act 1998 requires every organisation that processes information to register as a Data Controller with the Information Commissioners Office (ICO), unless they are exempt. St Gemma's Hospice is registered with the ICO as a data controller under registration reference Z6029123.

You have the right to ask for a copy of all records about you. You can apply to the Hospice through the Medical Director, there may be a fee for this.



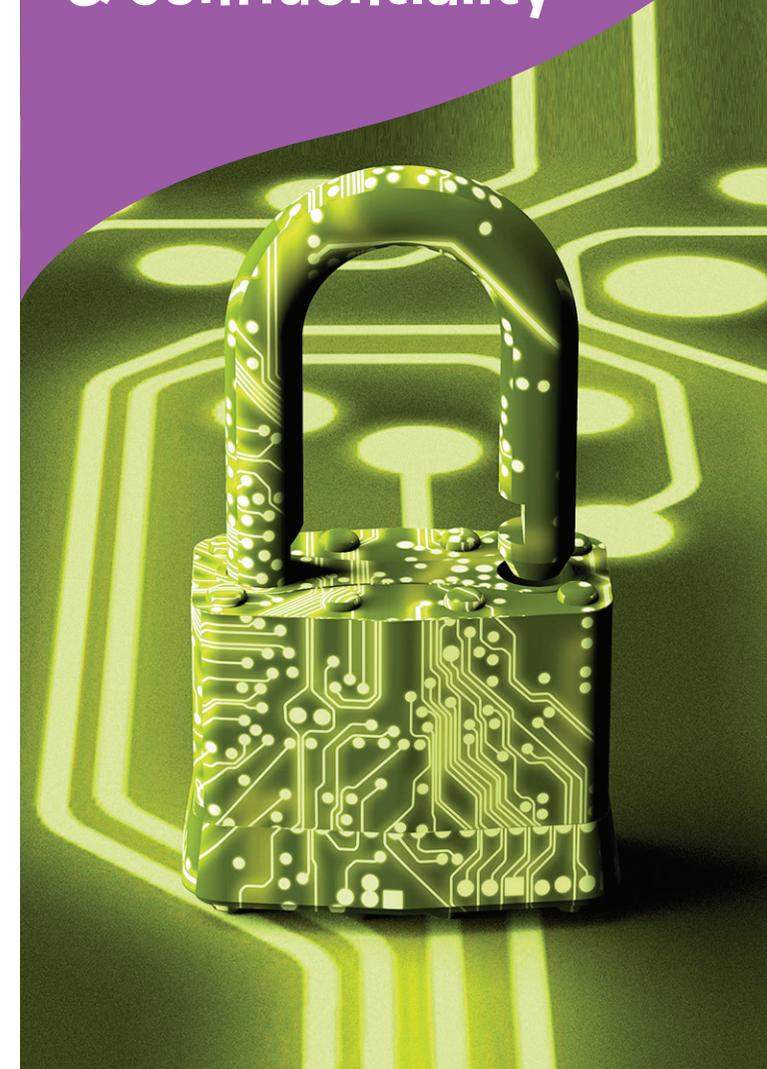
For further details on information and records please contact:

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A large print version of this booklet is available from the Hospice -
Please contact 0113 218 5557

Your health records & confidentiality



www.twitter.com/stgemmahospice



www.facebook.com/st.g.hospice

Better information,
better health



Why do we collect information about you?

At St Gemma's Hospice, we collect and hold information about you to enable us to give you the correct care and treatment. The information is held on computer, paper record or both. It forms part of your care record and is held securely as required by the Data Protection Act 1998.*

What sort of information do we hold?

We record information about you and the care you have received. For example:

- 🔒 Your name, address, date of birth, next of kin
- 🔒 Your symptoms, previous illnesses and diagnosis
- 🔒 Results of investigations such as X-Rays and laboratory tests
- 🔒 Contact we have had with you such as home visits, attendance to our day services, admissions to the Hospice
- 🔒 Relevant information from those who care for you and know you well, such as health professionals and relatives

What do we use this information for?

- 🔒 To provide appropriate care, by giving the staff caring for you access to up to date and accurate information
- 🔒 To share with other professionals who become involved in your care such as District Nurses and your GP
- 🔒 To help staff review and improve the quality of your care
- 🔒 To train and educate staff
- 🔒 To help us when investigating queries or complaints
- 🔒 To manage and plan future care services
- 🔒 To support palliative care research that has been approved by the local ethics committee
- 🔒 To contact your next of kin

Accessing NHS records

St Gemma's is a local, independent charity and we are not part of the NHS, but we do work very closely with all NHS services in Leeds. We are also part of the NHS records system. This allows us to share information securely with your GP and other care professionals. In accordance with NHS guidance, the Hospice has an appointed Caldicott Guardian; a senior member of staff responsible for protecting patient confidentiality and enabling appropriate sharing.

How do we keep your records confidential?

Everyone working for St Gemma's follows strict policies around confidentiality and storage of information.

We have a duty to:

- 🔒 Maintain full and accurate records of the care we provide to you
- 🔒 Keep records about you confidential, secure and accurate
- 🔒 Provide information in a format that is accessible to you (for example in large type if you are partially sighted)

All electronic records can only be accessed by staff members who have a 'smart card.' A smart card is like a bank card with a chip and PIN. An electronic record is maintained of those individuals who have accessed your records.

Sharing information about you?

The sharing of sensitive personal information is strictly controlled by law. We will consult you before information about you is shared to ensure we act with your consent. If you are unable to consent for any reason, we will only share information where it is in your best interests to do so.

With your consent, information may be shared with:

- 🔒 other professionals involved in your care
- 🔒 your relatives, partners or friends who act as a carer for you
- 🔒 social services and local authorities
- 🔒 voluntary sector providers
- 🔒 regulators

We are sometimes asked for medical reports by solicitors. In these cases, we will always obtain your written consent for us to disclose the information.

There may be times when we need to share information **without your consent** e.g.:

- 🔒 Where there is a risk of harm to you or other people
- 🔒 Where we have been instructed to do so by a Court
- 🔒 To control infectious diseases
- 🔒 Where we believe that the reasons for sharing are so important that they override our obligation of confidentiality (for example, to support the investigation and prosecution of offenders or to prevent a serious crime)
- 🔒 Where we are legally required to do so

Staff will ask you if you are happy to share information with St Gemma's and other health and social professionals directly involved in your care – referred to as 'sharing out.' The other option is that only St Gemma's can view your record, known as 'sharing in.' Sharing out is the preferred option as this allows your GP, district nurses and others directly involved in your care to see what care has been provided by St Gemma's. If you choose not to make your records shareable please be aware that clinical teams caring for you may lack important clinical details that could compromise your care.

What if I cannot make the decision myself?

If you are no longer able to make decisions for yourself, for example this may be because you are too unwell or your condition has affected your memory, we will share information with either your next of kin or designated power of attorney for health and welfare.