

Your information and what you need to know

A guide to your rights and
your health record



St Elizabeth
Hospice

Registered Charity No. 289154

Introduction

This leaflet explains how St Elizabeth Hospice uses and safeguards information collected about you and your care. It outlines who may have access to the information and how you can arrange to see it.

What is your health record?

Your doctor and other health professionals caring for you keep records about your health, treatment and care. When you are first contacted by St Elizabeth Hospice a record will be started and this will be added to as your treatment continues. It is called a health record and it helps to ensure you receive the best possible care from us.

Will other information about me be recorded?

Often patients require care, support and information in addition to the medical management of their actual illness. All patients are offered a Holistic Needs Assessment at various points during their illness such as at referral to St Elizabeth Hospice and when significant changes in their condition occur. Details discussed during these assessments will also be recorded on your health record.

What is a Holistic Needs Assessment?

A Holistic Needs Assessment is a discussion with staff from the Hospice about your physical, emotional and social needs. It provides an opportunity for you to talk about any worries or concerns you may have. For instance you may wish to raise important issues such as how you are feeling, anxiety about your illness, money worries or relationship concerns. The focus is on you as a whole, not just your illness and your doctor or nurse will ask for information from you about your current situation. However, you decide how much information you want to share.

It will help clarify your needs and ensure, with your agreement, that you are referred to the relevant services that may be of help for you. Alternatively, if you prefer, you will be given written information about these services. If you would like one of the Hospice staff to speak to your family or friends or provide them with written information this can be arranged, so please ask.

Do I have to have a Holistic Needs Assessment?

A Holistic Needs Assessment is offered to all patients to pinpoint what help is available. However you do not have to have an assessment if you do not want one.

What information is included on your health record?

Your health record contains information provided by us, by you or by other people involved in your care and treatment. This information may be stored either on computer or it may be written down on paper (a manual record).

The records may include:

- Basic details about you, such as your name, address, date of birth, NHS number, GP and next of kin
- Contacts we have had with you such as clinics, appointments, admissions, support, home visits, phone conversations
- Notes and reports about your health and any treatment and care you need/receive including notes from your Holistic Needs Assessment
- Results of investigations, such as X rays, scans, laboratory reports and tests
- Photographs, videos or tape recordings of phone conversations.
- Relevant information sent to and from other health professionals, relatives or carers

How is your health record used?

The main purpose is to create an accurate and up-to-date guide which will be used to provide you with the appropriate healthcare and treatment. People who may see the information include:

- Your doctor, nurse or any of the other St Elizabeth Hospice staff involved in your care e.g. therapist, support worker
- Administrative staff supporting the clinical team

If you agree, your relatives and carers will be kept up to date with the progress of your treatment.

Your information may also be used for NHS purposes and passed on to other partner organisations so we can all work together for your benefit.

How is your health record used to help partner organisations?

We may share your information with our partner organisations.

The main partner organisations are:

- General Practitioners (GPs)
- Ambulance Services
- The Department of Health
- The East of England Strategic Health Authority
- Hospitals
- Community Services

If we need to share your information with other agencies, it will be subject to strict controls and data sharing agreements describing how and which bits of your information may be used. Wherever possible we will remove details that identify you.

Your information could be used for:

- Teaching and training staff, education services
- Social Services
- Local Authorities
- NHS Common Service Agencies such as dentists, ophthalmic services etc
- Voluntary or private sector providers
- Helping staff to review the care they give to make sure it is of the highest standard
- Helping with research into better methods of healthcare

How do we keep your health record secure and confidential?

We have a duty to store all health records in secure environments where access is strictly controlled. Secure networks are used for computerised records.

How can you see the record we hold about you?

The Data Protection Act 1998 allows you to have access to your health records, held either on computer or on paper, and to have explained what is contained in them.

If you are receiving treatment you can discuss your records informally with your St Elizabeth Hospice doctor or other healthcare professional during the consultation or treatment session.

If you want to see your health records which are held at St Elizabeth Hospice, at any other time, or would like a copy of them, you can make a request in writing (this includes email) to the Chief Executive (details overleaf). This is known as a Subject Access Request (SAR).

If you are unable to make a written request, the request can be made verbally.

What happens if you make a request?

When we receive a written request the Chief Executive will write and ask you to give us further details and proof of identity.

We are then required to give you access to your record within 21 days of receiving the completed form.

If the request is granted, you will be offered an appointment with the Medical Director and / or Chief Executive to go through the record.

Following the meeting, you or your representative will be provided with the copy of the relevant part or parts of the health record requested.

If you do not wish to attend the meeting, the relevant part of the health record will be posted or can be collected by you or your representative within 21 days.

If you think there is a mistake in your record, you should write and tell us so that it can be amended.

Can somebody else see your record?

Yes requests to access health records can also be made by

- Anyone authorised by the patient
- A person appointed by the court to manage the patient's affairs
- Following the death of a patient, their representative or any person who may have a claim arising out of the patient's needs

Where requests are made by another individual we will ensure the patient has given consent to release the information.

Are there any reasons why I couldn't see my health record?

In exceptional cases information from your health record may be withheld:

- If your doctor believes it is likely to cause you serious harm to your mental or physical health or to that of any other person
- If the information has been provided by a third person who has not consented to the disclosure

What happens if the request is denied?

- If access to all or part of a health record is denied, we will record the reasons and inform the requester in writing.
- If you or your representative are not happy with the decision a formal complaint can be made to St Elizabeth Hospice

Will we charge you to see the health record (where no copy is required)?

There is no charge if the records have been added to in the 40 days before receipt of your written request.

After that a charge of up to £10 may apply.

Will we charge you to have copies of your health record?

Yes there may be a charge to cover our administrator's time

- Up to £10 for records held on computer
- Up to £50 for health records held on computer and/or on paper (including X-ray film)

For further information or to make a request please contact:

St Elizabeth Hospice
565 Foxhall Road
Ipswich
IP3 8LX

Tel: 01473 727776

Email: enquiries@stelizabethhospice.org.uk

If you would like to access your or a patient's records please complete the form below and send to:

**St Elizabeth Hospice
565 Foxhall Road
Ipswich
IP3 8LX**

I would like to access my records

First name: _____

Last name: _____

Date of birth: _____ Sex: _____

Current address: _____

_____ Postcode: _____

Telephone no.: _____

Name of patient: _____

Relationship to patient: _____

About St Elizabeth Hospice

St Elizabeth Hospice improves the life for people living with a progressive illness.

Our work is centred around an individual's needs, providing specialist support, wherever it is required, whether at home, in the community or at the Hospice.

The Hospice is an independent charity which provides its services free of charge.

St Elizabeth Hospice
565 Foxhall Road Ipswich IP3 8LX
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