

# PRIVACY NOTICE ON PERSONAL INFORMATION AND YOUR CARE



## 1. WHO WE ARE

- 1.1 The Hospice of St Francis (Berkhamsted) Ltd. is a charity. We are bound by the data protection legislation and the regulations enforced by the Care Quality Commission and the Information Commissioner. This means that we need to make it easy for members of the public to see, whether they are involved with the Charity or not, how and why we collect and protect data about them. The law calls this a privacy notice. This part of our privacy notice concerns the information we collect and protect if you or a member of your family has care and support from The Hospice of St Francis.
- 1.2 If at any time you or your family have any questions about how we are keeping and using personal information that you have given to us, please do not hesitate to ask the nurse, doctor or therapist from the Hospice who are caring for you.

Or you can contact our **Data Protection Co-ordinator** at The Hospice of St. Francis (Berkhamsted) Ltd, Spring Garden Lane, Off Shootersway, Northchurch, BERKHAMSTED, Hertfordshire HP4 3GW.

Email: [DPC@stfrancis.org.uk](mailto:DPC@stfrancis.org.uk)

Telephone: 01442 869550 Ext 522

## 2. WHY WE COLLECT INFORMATION ABOUT YOU

- 2.1 All healthcare organisations in the UK have regulatory and legal duties to:
- Maintain full and accurate records of the care provided to you;
  - Keep records about you confidential, secure and accurate;
  - Provide information in a format that is accessible to you (e.g. in large type if you are partially sighted);
  - Share information about you with other healthcare professionals, within the context of the Data Protection Act (1998), the General Data Protection Regulation (2018) and the Caldicott Principles, where this sharing of information is in your best interests.
- 2.2 This means that we ask for information that personally identifies you, including your name, address, postcode, date of birth and contact details. We will ask for your NHS

number if you have one. We will also be given by your doctor, nurse or the NHS team caring for you, information about your needs, and/or your diagnosis and treatment dependent upon the reason you have been referred to us.

- 2.3 We will ask you for information so that we can assess your needs and check that the care you need from us is the care that you get. The information we ask for to provide bereavement care for example will be different from the information we ask for if you come to stay at the Hospice.

### **3. HOW INFORMATION ABOUT YOU IS USED**

- 3.1 The Hospice of St Francis will collect, protect and use the information that you give us in four different ways:

#### **Identifiable**

This is the term for the information described in section 3 – those details that personally identify a person. We add to your records every time we are in contact with you, to make sure that everyone from The Hospice of St Francis providing care has the most up to date information and knows from looking at your records and talking to you on the day, what you need.

For the same reasons we may also share that information with the people from other organisations who are caring for you. This reduces duplication and should reduce the need for you to tell each professional the same information, the time spent with you can be focused on your care.

We will talk to you and look at your care records if you have concerns, or complaints too because this information enables us to investigate and resolve them.

#### **Pseudonymised**

We can make improvements in the care that we provide by looking in detail at a group of number of people who came to us for the same type of care. We do this by using a coded reference number so that we can look at the care we provided whilst at the same time, using a coded number does withhold all the personally identifiable information.

#### **Anonymised**

We can make improvements in the care that we provide by aggregating data – like the number of referrals or the number of people needing different types of care. We do this by removing all the personally identifying details and looking at overall numbers.

## **Aggregated**

We can make improvements in the care that we provide by analysing information using statistical methods to show general trends, themes or patterns and comparing the results to other similar organisations to compare our performance.

- 3.2 We use pseudonomised, anonymised and aggregated data for audit and research and for training purposes.
- 3.3 The Charity Trustees use pseudonomised, anonymised and aggregated data to govern the Charity.
- 3.4 In summary, we use information about you to:
  - Give us the information to safely provide any treatment or advice we provide
  - Help us to plan and review your care together with you, any family members you want to be involved and other professionals who are providing care to you at the same time
  - Make sure your care and treatment is safe and effective,
  - Make sure any advice we provide is appropriate and relevant to you
  - Ensure everyone involved in your care is kept up to date with accurate information
  - Enable us to make improvements to our services, conform to legal and regulatory standards and govern the Charity
  - Investigate any concerns or complaints you might have, either about your care or the standards of any health or social care professionals looking after you.

## **4. HOW WE PROTECT INFORMATION ABOUT YOU**

- 4.1 Personally identifiable information about you is stored in the same place as information about your care. It can be recorded and stored in a paper file kept in locked cabinets and/or on an electronic care records system which is encrypted for security. Every time a member of the team at The Hospice of St Francis makes an entry on your file it must be signed and dated by the staff member. There is an equivalent security mechanism on electronic records.
- 4.2 The Hospice of St Francis uses paper files and an electronic records system called SystemOne that is also used by other healthcare providers. This means that if you have consented to share, your District Nurse, GP and other health professionals who are treating you can see the care that each organisation is providing and changes or updates made when any of these professionals see you. The

Hospice of St Francis is part of *My Care Record*, an approach to improving care by joining up health and care information. Health and care professionals from other services will be able to view information from the records we hold about you when it is needed for your care. Please see [www.mycarerecord.org.uk](http://www.mycarerecord.org.uk) for more information.

- 4.3 We use strict controls called role based access. These controls mean that only those staff who are directly responsible for your care can see information on your paper file or electronic care record.
- 4.4 You can ask to see and review the care records we hold about you at any time. You can ask any member of staff at The Hospice of St Francis or you can contact the [Data Protection Co-ordinator](#). Their contact details are in section one of this notice. We will respond as quickly as possible, however it may need up to 30 days depending upon the amount of information we hold about you, to respond to this request.
- 4.5 Except for the reasons set out in section three of this notice, we cannot share information about you that identifies you for any reason, unless:
- You ask us to do so;
  - We ask and you give us specific permission;
  - We have to do this by law;
- 4.6 We have special permission because we believe that the reasons for sharing are so important that they override our obligation of confidentiality (e.g. to prevent someone from being seriously harmed). We will check with you first, before sharing personally identifiable information about you with other people or organisations who are also caring for you.
- 4.7 **The simple rule is ‘Nothing about me without my permission’.**
- 4.8 If we are undertaking research and would like to include your experience in the research study, we must consult with you first and explain the study. We cannot include your experience in the research study unless we have your explicit permission.
- 4.9 If you have given power of attorney to someone else or for any reason your mental capacity affects your ability to decide, we will consult with the appointed person or your next of kin.
- 4.10 All staff at the Hospice are bound by their contract of employment to abide by the Data Protection Act and maintain confidentiality. We provide regular training, advice and support to ensure that staff are kept up to date with any changes to the duty of confidentiality.
- 4.11 Any breach of confidentiality is a disciplinary matter that can result in dismissal.

- 4.12 The Hospice of St Francis fully implements the two roles defined in the legislation to govern the protection of personally identifiable information. They are the Senior Information Risk Owner (SIRO) and the Caldicott Guardian. These roles are held by two different senior people who attend the Charity Board and are responsible for ensuring the Charity protects the confidentiality of personally identifiable information and enables only appropriate and lawful information to be shared.
- 4.13 Further information about the role of the SIRO and the Caldicott Guardian and who they are is available on our website.
- 4.14 The Hospice of St Francis (Berkhamsted) Ltd. is a Data Controller and under the terms of the Data Protection Act 1998 and the General Data Protection Regulation (2018) we are legally held responsible by the Information Commissioners Office for ensuring that all personal confidential data that we collect and use i.e. hold, obtain, record, use or share about you is done in compliance with this legislation.
- 4.15 All data controllers must notify the Information Commissioner's Office (ICO) of all personal information processing activities. Our ICO Data Protection Register number is Z2330224 and our entry can be found in the Data Protection Register on the Information Commissioner's Office website.
- 4.16 All health and social care organisations are required to provide annual evidence of compliance with the laws, regulation and standards of data protection through the Information Governance Toolkit. The toolkit has to be reviewed and resubmitted annually.
- 4.17 We comply with the schedules set out in the Records Management Code of Practice for Health and Social Care 2016 to govern the retention and appropriate secure destruction of personally identifiable information.
- 4.18 We never sell any information about you.
- 4.19 Our clinical teams do not share your personal information with other Hospice teams for example, our fundraising supporter database. If you have been kind enough to donate to us in the past or volunteer with us, these Hospice teams will not know you have become a patient and will continue to keep you informed about the Hospice's work. If you would rather this did not happen, please let us know by contacting the [Data Protection Co-ordinator](#) (DPC).
- 4.20 We have a [Data Protection Co-ordinator \(DPC\)](#) who has an overview of how we collect, protect and use information who welcomes any suggestions for improving our procedures. The DPC's contact details are in Section One of this notice.

4.21 We encourage people to bring concerns to attention if they think that our collection or use of information is unfair, misleading or inappropriate by telling a member of the team caring for them, contacting the DPC or asking to see our Caldicott Guardian.

## 5. How the NHS and care services use your information

The Hospice of St Francis is one of many organisations working in the health and care system to improve care for patients and the public.

Whenever you use a health or care service, such as attending Accident & Emergency or using Community Care services, important information about you is collected in a patient record for that service. Collecting this information helps to ensure you get the best possible care and treatment.

The information collected about you when you use these services can also be used and provided to other organisations for purposes beyond your individual care, for instance to help with:

- improving the quality and standards of care provided
- research into the development of new treatments
- preventing illness and diseases
- monitoring safety
- planning services

This may only take place when there is a clear legal basis to use this information. All these uses help to provide better health and care for you, your family and future generations. Confidential patient information about your health and care is **only used** like this where allowed by law.

The Hospice is contracted to Integrated Care Boards and we are required to share data for research and planning purposes but data is pseudonymised by their system on receipt of the information.

Most of the time, anonymised data is used for research and planning so that you cannot be identified in which case your confidential patient information isn't needed. You have a choice about whether you want your confidential patient information to be used in this way. The Hospice of St Francis has put processes in place to be compliant with the NHS National Opt-out Policy which applies your choice to any confidential patient information we use or share for purposes beyond your individual care. If you are happy with this use of information you do not need to do anything. If you do choose to opt out your confidential patient information will still be used to support your individual care.

To find out more or to register your choice to opt out, please visit [www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters). On this web page you will:

- See what is meant by confidential patient information
- Find examples of when confidential patient information is used for individual care and examples of when it is used for purposes beyond individual care
- Find out more about the benefits of sharing data
- Understand more about who uses the data
- Find out how your data is protected
- Be able to access the system to view, set or change your opt-out setting

- Find the contact telephone number if you want to know any more or to set/change your opt-out by phone
- See the situations where the opt-out will not apply

You can also find out more about how patient information is used at:

<https://www.hra.nhs.uk/information-about-patients/> (which covers health and care research);  
and

<https://understandingpatientdata.org.uk/what-you-need-know> (which covers how and why patient information is used, the safeguards and how decisions are made)

You can change your mind about your choice at any time.

Data being used or shared for purposes beyond individual care does not include your data being shared with insurance companies or used for marketing purposes and data would only be used in this way with your specific agreement.

## **6.0 ADDITIONAL LEGAL OBLIGATIONS TO COLLECT AND USE INFORMATION**

**6.1** There are some circumstances where other laws supersede the data protection legislation.

- The Police and Criminal Evidence Act and our Terrorism Legislation - There is an overriding public interest e.g. in order to safeguard an individual or to prevent a serious crime;
- There is a legal requirement that will allow us to use or provide information e.g. a formal Court order or subpoena;
- We are required to do so by the Secretary of State for Health
- Emergency planning reasons such as protecting the health and safety of others. Typically these relate to severe weather, outbreaks of diseases e.g. seasonal flu, and major transport incidents.

**6.2** You have legal rights, including a right to have your information processed fairly and lawfully and a right to access any identifiable information that we hold about you:

- You have the right to have the information provided to you in a way you can understand (and explained where necessary, e.g. abbreviations). Where you agree, the access right may be met by enabling you to view the record without obtaining

- You have the right to privacy and to expect The Hospice of St Francis to keep your information confidential and secure.
- You have the right to request that your confidential information is not used beyond your own care and treatment and to have your objections considered.
- You have the right to object to information sharing at any time by telling a member of the team at The Hospice of St Francis caring for you. If there are any consequences to withdrawing consent these will be fully explained and discussed with you first by a Doctor, Nurse Consultant or our Caldicott Guardian first.
- You have the right to apply to see the information that we hold about you. You can ask any member of staff at The Hospice of St Francis or you can contact the [Data Protection Co-ordinator](#). Their contact details are in section one of this notice.
- You have the right to obtain a copy of your record in permanent form
- You can also raise a concern directly with the Information Commissioners Office.

## **7.0 REVIEWS AND CHANGES TO THIS PRIVACY NOTICE**

- 7.1 Legislation is updated, to make sure our Privacy notice is current we review the contents on an annual basis. This Privacy Notice was last reviewed in February 2023.