

# **The Norfolk Hospice**

## **Privacy Statement – patients, families, and clients**

### **WHAT IS THE PURPOSE OF THIS DOCUMENT?**

The Norfolk Hospice (TNH) is committed to protecting the privacy and security of your personal information.

This privacy notice describes how we collect and use personal information about you and your family during and after your care with us, in accordance with the UK General Data Protection Regulation (GDPR).

It applies to all patients, families and clients who use our services.

The Norfolk Hospice is a “data controller”. This means that we are responsible for deciding how we hold and use personal information about you. We are required under data protection legislation to notify you of the information contained in this privacy notice.

This notice applies to current and former patients, families and clients. We may update this notice at any time but if we do so, we will provide access to an updated copy of this notice as soon as reasonably practical.

It is important that you read and retain this notice, together with any other privacy notice we may provide on specific occasions when we are collecting or processing personal information about you, so that you are aware of how and why we are using such information and what your rights are under the data protection legislation.

### **DATA PROTECTION PRINCIPLES**

We will comply with data protection law and principles, which means that your data will be:

- Used lawfully, fairly and in a transparent way.
- Collected only for specified, explicit and legitimate purposes and not used in any way that is incompatible with those purposes.
- Adequate, relevant and limited to what is necessary.
- Accurate and kept up to date.
- Kept only as long as necessary for the purposes we have told you about.
- Kept securely.

## **THE KIND OF INFORMATION WE HOLD ABOUT YOU**

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

There are “special categories” of more sensitive personal data which require a higher level of protection, such as information about a person’s health or sexual orientation.

We will collect, store, and use the following categories of personal information about you:

### **Patient’s Personal Information Retained**

- Personal contact details such as name, title, addresses, telephone numbers, and personal email addresses
- Date of birth
- Gender
- NHS number
- Marital status and dependants
- Next of kin and emergency contact (first contact) information
- Employment records (including job titles, work history) if patient happy to share, and if disease may be industrial caused
- Complaints and grievance information (but this is not stored as part of your clinical record)
- Photographs of wounds or, with explicit consent, other photos such as for fundraising or for raising the profile of TNH work
- DNACPR documentation, recording whether agreed with resuscitation decision
- Preferred Place of Care and Preferred Place of Death
- Home key safe details (usually as an alert on SystemOne record)
- Safeguarding risks (usually as an alert on EMIS records)
- Informing the authorities of notifiable diseases you may have at the time
- Any details discussed with the coroner
- Additional support needs, such as mental health, sensory impairment and mobility requirements
- Which services are accessed

- Appointment attendance details, schedule and ongoing plan
- Inter-practice communications pertaining to the circumstances of your care

We may also collect, store and use the following “special categories” of more sensitive personal information:

- Information about your race or ethnicity, religious beliefs, sexual orientation and political opinions
- Information about your health, including any medical condition, health and sickness records, including medical condition, current and historical diagnoses, health and sickness records, previous encounters with other GPs, consultants, community nurses and medical institution staff, medical test results
- Detailed records of medical encounters between yourself and healthcare professionals
- Medications currently and historically taken
- Record of capacity to give consent (Mental Capacity Act 2005)
- Allergies and intolerances
- Safeguarding risks pertaining to mental health or criminal convictions

## Use of this personal information

- Making a decision about your current and future healthcare such as a referral, transfer, change of medication, equipment order
- Informing ongoing healthcare practice to meet your specific needs
- Reviewing your condition prior to an encounter to ensure continuity of care
- Informing other clinicians and services involved in your care about your condition, treatment and requirements
- To contact yourself, or your approved contacts if you lack capacity for these discussions, about current and future care objectives or to inform about a schedule alteration concerning these objectives
- To conduct data analytics studies and research to review and improve ongoing hospice and palliative care standards
- Gathering evidence for possible grievance, disciplinary or complaint proceedings
- Dealing with legal disputes involving you, or other employees, workers and contractors, including accidents on site (RIDDOR)

- Ascertaining the most appropriate services to be offered
- Complying with health and safety obligations, including access and nutritional needs
- Equal opportunities monitoring and equality of access improvements
- To book ambulance or volunteer transport for movement between your home and the hospice site

## **Next of Kin / First Contacts / Carers Personal Information Retained**

- Personal contact details such as name, title, addresses, telephone numbers and personal email addresses of the patient states you are one of their main contacts
- Marital status and dependents
- Complaints and grievance information, but only if you are involved in the process and this would be kept separate to your clinical records
- Additional support needs such as mental health, sensory impairment and mobility requirements
- Which services are accessed (bereavement, spiritual care) and records of activity
- Communications with health care professionals and administrative support staff

We may also collect, store and use the following “special categories” of more sensitive personal information:

- Record of capacity to give consent (Mental Capacity Act 2005) especially if you lack capacity and the hospice is speaking to ‘patient representatives’ to make a best interests decision
- Safeguarding risks pertaining to mental health or criminal convictions

Use of this personal information:

- To contact your approved contacts about current and future care objectives or to inform about a schedule alteration concerning these objectives if you, the patient, lacks capacity and your next of kin is the first contact or have a Lasting Power of Attorney, or where this is not in place the Welfare Deputyship.
- To alert them to changes in the patient’s condition, such as deterioration or death
- To complete and forward consented referrals to support services

- Conducting service performance reviews, managing performance and determining performance requirements
- Gathering evidence for possible grievance, disciplinary or complaint proceedings but would be kept separate from patient's clinical records and their own clinical record
- Dealing with legal disputes involving them or other employees, worker and contractors, including accidents on site
- Ascertaining the most appropriate services to be offered
- Complying with health and safety obligations
- Equal opportunities monitoring and equity of access improvements
- Informing the authorities of notifiable diseases they may have at the time

### **Bereavement/Spiritual Care Clients Personal Information Retained**

- Personal contact details such as name, title, addresses, telephone numbers, and personal email addresses
- Date of birth
- Gender
- Marital status and dependents
- Next of kin and emergency contact information
- Photographs with explicit consent such as for fundraising or raising the profile of TNH work
- Records of contacts with support volunteers and groups
- Personal details of the associated patient including name, diagnosis, date and place of death and address

We may also collect, store and use the following "special categories" of more sensitive personal information:

- Information about their race or ethnicity, religious beliefs, sexual orientation and political opinions (only if the client chooses to share this with us and we feel it would help us support them)
- Information about their health, including any medical condition, health and sickness records

### Use of this personal information

- Inviting them to participate in any groups or events relating to spiritual or bereavement support
- Forwarding remembrance and condolence communications.
- To provide context to bereavement volunteers in order to inform the nature of the care provided to them and best meet their individual needs
- Gathering evidence for possible grievance, disciplinary or complaints proceedings but would be kept separate from patient's clinical records and their own clinical record
- Inviting them to participate in service feedback surveys and groups
- Complying with health and safety obligations
- Equal opportunities monitoring and equity of access improvements
- Informing the authorities of notifiable diseases they may have at the time

## **HOW IS YOUR PERSONAL INFORMATION COLLECTED?**

We collect personal information about patients, families and clients through the admission and referral process, either directly from you or from existing medical records which you have consented to us having access to

## **HOW WE WILL USE INFORMATION ABOUT YOU**

We will only use your personal information when the law allows us to. Most commonly, we will use your personal information in the following circumstances:

- Where we need to keep you safe, e.g. when there is a safe-guarding risk to you
- Where we need to comply with a legal obligation
- Where it is necessary for our legitimate interests (or those of a third party) and your interests and fundamental rights do not override those interests

We may also use your personal information in the following situations, which are likely to be rare:

- Where we need to protect your interests (or someone else's interests).
- Where it is needed in the public interest.

## **If you fail to provide personal information**

If you fail to provide certain information when requested, we may not be able to perform the care we would like to or we may be prevented from complying with our legal obligations, such as making sure you have the ability to make important decisions, or to be cared for in the best place.

## **Change of purpose**

We will only use your personal information for the purposes for which we collected it, unless we reasonably consider that we need to use it for another reason and that reason is compatible with the original purpose. If we need to use your personal information for an unrelated purpose, we will notify you and we will explain the legal basis which allows us to do so.

Please note that we may process your personal information without your knowledge or consent, in compliance with the above rules, where this is required or permitted by law.

## **DATA SHARING**

We will share your clinical records with other health and social care staff to ensure you have safe and effective care at all times, both within the hospice building and in the community.

We require third parties to respect the security of your data and to treat it in accordance with the law.

## **Why might you share my personal information with third parties?**

- We will share your personal information with third parties where required by law, where it is necessary to administer your care safely or where we have another legitimate reason in doing so. We may also need to share your personal information with a regulator or to otherwise comply with the law. This may include making returns to the Care Quality Commission, or local safeguarding teams.
- Active promotion of research, development and service evaluation improves the quality of our services in the future. You may be offered the opportunity to participate within such areas and we would gain your consent prior to undertaking anything that would be used in this manner. The appropriate safeguards to your information are applied at all times. You are under no obligation to participate and may choose whether you are involved or not.

## **Which third-party service providers process my personal information?**

“Third parties” includes other service providers involved in your care. This can include NHS services such as hospital or community teams, social care services, care homes, GPs, district nursing teams, etc. – it very much depends on which services can help you most.

## **How secure is my information with third-party service providers and other entities in our group?**

All our third-party service providers and other entities in the group are required to take appropriate security measures to protect your personal information in line with our policies. We only permit third-party service providers to process your personal data for specified purposes and in accordance with our instructions. They will also require your consent to access your health records.

## **Transferring information outside the UK**

We do not envisage that your personal information will be transferred outside the UK, however we will notify you in writing if this position changes.

## **DATA SECURITY**

We have put in place measures to protect the security of your information. Details of these measures are available upon request.

Third parties will only process your personal information on our instructions and where they have agreed to treat the information confidentially and to keep it secure.

We have put in place appropriate security measures to prevent your personal information from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. In addition, we limit access to your personal information to those employees, volunteers and other third parties who have a business need to know. They will only process your personal information on our instructions and they are subject to a duty of confidentiality. Details of these measures may be obtained from the CEO.

We have put in place procedures to deal with any suspected data security breach and will notify you and any applicable regulator of a suspected breach where we are legally required to do so.

## **DATA RETENTION**

### **How long will you use my information for?**

We will only retain your personal information for as long as necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, accounting, or reporting requirements. For health care records this is usually 8 years from our final contact with you. Retention depends on the sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure of your personal data, the purposes for which we process your personal data and whether we can achieve those purposes through other means, and the applicable legal requirements.

## **RIGHTS OF ACCESS, CORRECTION, ERASURE, AND RESTRICTION**

### **Your duty to inform us of changes**

It is important that the personal information we hold about you is accurate and current. Please keep us informed if your personal information changes during your relationship with us.

### **Your rights in connection with personal information**

Under certain circumstances, by law you have the right to:

- **Request access** to your personal information (commonly known as a “data subject access request”). This enables you to receive a copy of the personal information we hold about you and to check that we are lawfully processing it.
- **Request correction** of the personal information that we hold about you. This enables you to have any incomplete or inaccurate information we hold about you corrected.
- **Request erasure** of your personal information. This enables you to ask us to delete or remove personal information where there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your personal information where you have exercised your right to object to processing (see below).
- **Object to processing** of your personal information where we are relying on a legitimate interest (or those of a third party) and there is something about your particular situation which makes you want to object to processing on this ground. You also have the right to object where we are processing your personal information for direct marketing purposes.
- **Request the restriction of processing** of your personal information. This enables you to ask us to suspend the processing of personal information about you, for example if you want us to establish its accuracy or the reason for processing it.
- **Request the transfer** of your personal information to another party.
- **Be informed** about the collection and use of your personal data.

If you want to review, verify, correct or request erasure of your personal information, object to the processing of your personal data, or request that we transfer a copy of your personal information to another party, please contact the CEO, in writing.

### **No fee usually required**

You will not have to pay a fee to access your personal information (or to exercise any of the other rights). However, we may charge a reasonable fee if your request for access is clearly unfounded or excessive. Alternatively, we may refuse to comply with the request in such circumstances.

## **What we may need from you**

We may need to request specific information from you to help us confirm your identity and ensure your right to access the information (or to exercise any of your other rights). This is another appropriate security measure to ensure that personal information is not disclosed to any person who has no right to receive it.

## **RIGHT TO WITHDRAW CONSENT**

In the limited circumstances where you may have provided your consent to the collection, processing and transfer of your personal information for a specific purpose, you have the right to withdraw your consent for that specific processing at any time. To withdraw your consent, please contact the CEO. Once we have received notification that you have withdrawn your consent, we will no longer process your information for the purpose or purposes you originally agreed to, unless we have another legitimate basis for doing so in law.

## **DATA PROTECTION OFFICER**

If you have any questions about this privacy notice or how we handle your personal information, please contact the Data Protection Officer. You have the right to make a complaint at any time to the Information Commissioner's Office (ICO), the UK supervisory authority for data protection issues.

## **CHANGES TO THIS PRIVACY NOTICE**

We reserve the right to update this privacy notice at any time, and we will provide access to the new privacy notice when we make any substantial updates. We may also notify you in other ways from time to time about the processing of your personal information.

**If you have any questions about this privacy notice, please contact the CEO.**