

Privacy Notice for Patients, Service Users and their Next of Kin

Why we collect your data

The personal information we process is provided to us for one of the following reasons:

- You have been referred to one of our clinical services (this information will usually be provided initially by another health provider such as your GP).
- You have referred yourself to one of our services and provided your contact and personal information.
- You are a family member or next of kin of a service user or patient using our services.
- We have been contacted for Out-of-Hours Advice and are not currently known to any of Trinity's services.

The term Trinity Hospice & Palliative Care Services (Trinity Hospice) includes anyone accessing the services of the Linden Centre & Brian House Children's Hospice.

Your rights

A Caldicott Guardian is a senior person responsible for protecting the confidentiality of people's health and care information and making sure it is used properly.

Under data protection law, you have rights we need to make you aware of. If you wish to contact us about any of the rights described, please do so. For more information please email trinity.caldicottguardian@nhs.net or write to Caldicott Guardian, Trinity Hospice & Palliative Care Services, Low Moor Road, Bispham, Blackpool, FY2 OBG.

[More information regarding the role of the Caldicott Guardian can be viewed by following this link.](#)

Access to your information

You have the right to ask for a copy of the personal information Trinity Hospice holds about you and to correct any inaccuracies in that information.

Please direct any requests to access personal data to trinity.caldicottguardian@nhs.net or write to Caldicott Guardian, Trinity Hospice & Palliative Care Services, Low Moor Road, Bispham, Blackpool, FY2 OBG.

When requesting clinical information, the Caldicott Guardian will review the information before it is disclosed to ensure that no information is shared inappropriately.

We will aim to respond to your request within one month however if it is a complex request we will keep you informed of any potential delay.

[You can read more about subject access requests on the ICO website by clicking this link. \(Information Commissioner's Office ICO\)](#)

There may be rare occasions when we are asked to disclose information to the police or other statutory agencies, such as social services in cases where criminal or safeguarding concerns have been raised. We will consider this on a case-by-case basis and aim to minimise data that is shared while still supporting the prevention or detection of crime or potential abuse. All requests of this nature will be dealt with by Trinity's Caldicott Guardian.

Your right to rectification

You have the right to ask us to rectify information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.

When you ask us to rectify any information we hold about you we will take reasonable steps to investigate whether the data is already accurate or needs to be amended.

We will then contact you to confirm the data has been corrected, deleted or added to. If we believe the data is accurate and therefore disagree with your request we will write to you to inform you of our decision and rationale.

If your request relates to clinical information recorded we are not allowed to delete certain notes from your clinical record however in these instances we will make a note that you disagree with the content.

We will action your request within one month.

[The ICO offers additional guidance about this which you can access here.](#)

Your right to erasure

You have the right to ask us to erase your personal information in certain circumstances. However this excludes where we have a legal obligation to keep hold of your data, such as healthcare regulations.

When making a request to be erased from our systems we will confirm that this has been carried out or advise you of the legal reason for not proceeding with your request.

[The ICO provides additional guidance on this and you can read more about it here.](#)

Your right to restriction of processing

You have the right to ask us to restrict the processing of your information in certain circumstances for example if you are concerned about the accuracy of data or how it is being used.

We will action your request within one month.

[The ICO provides additional guidance on this and you can read more about this right here.](#)

Your right to object to data portability

We would always attempt to accommodate requests to access your data in a portable version, Healthcare records can be shared with consent in an electronic format or via sending paper notes if systems are incompatible. However, we will consider on a case-by-case basis and do our best to respond where we can.

You are not required to pay any charge for exercising your rights. We have one calendar month to respond to you.

Please note that we may ask for proof of identification before processing any request.

Where we work with other providers

This privacy notice does not cover how any partner organisations process personal information; this includes any external links connected to our website. We encourage you to read the privacy notices on the other websites you visit. We do work with partner organisations to ensure that appropriate data sharing agreements or appropriate terms and conditions are in place to ensure that they are equally compliant in keeping your data as safe as we do.

Raising Concerns

We work to high standards when it comes to processing your personal information. If you have queries or concerns about Trinity Hospice's handling of your data or that of anyone working on our behalf, please contact us at trinity.caldicottguardian@nhs.net or write to Caldicott Guardian, Trinity Hospice & Palliative Care Services, Low Moor Road, Bispham, Blackpool, FY2 OBG.

If you remain dissatisfied with any immediate response to a particular situation, we will escalate this using our complaints policy.

Where is your data held

Your personal data is held on secure servers operated by both Trinity Hospice and agencies contracted by us. We do not transfer your data outside the European Economic Area (EEA) and we comply with the protection offered to you under the

GDPR and the Privacy and Electronic Communications Regulations 2003 EC Directive (PECR).

Data Security

All the information about you is confidential and is only accessed by those who need to use it. Personal data is collected and stored securely subject to stringent security measures and is protected against misuse. We have policies and procedures in place to ensure that all information we hold on you is treated with care and held securely. When we use external data processing services, we do so only under strict contractual terms to mirror the security policies that we have in place.

The information we collect

The information we collect will depend entirely on our relationship with you.

As clinical and fundraising information is collected for entirely different purposes, we do not pass information between the different systems in order to protect your confidentiality unless you have given consent for us to do so. The only exception to this is when a patient dies we will inform our fundraising team with the sole purpose of ensuring that any supporters who have died while receiving care with Trinity Hospice are not contacted inappropriately causing distress to the family.

If you are a patient or service user

Purpose and lawful basis for processing

If you are referred to Trinity Hospice clinical services, the purpose of collecting your personal and sensitive health information is to provide you with appropriate and safe healthcare. We may from time to time also ask you for additional information for the purposes of audit or research.

We do have a legal obligation to maintain healthcare records as set out in Regulation 17 of the Health and Social Care Act 2008, Regulations 2014, and as such, we need to capture information about you and your care to provide you with safe and effective treatment.

When starting to use our services, a member of the clinical team will seek your consent to share this information with other healthcare professionals involved in your care. We will seek additional consent in the event of your participation in any additional activities outside of this purpose, for example the use of photographs for teaching materials. We may also ask your consent to use any photographs for marketing purposes and this will be done very explicitly, no photographs or data will be used for this purpose without your consent.

What we need

If you are a patient or service user we will need to collect information about you, your condition and others involved in your care in order for us to be able provide the best possible care to you. We are careful to only record information that is directly relevant to your care.

The Data Protection legislation splits data into categories including personal and sensitive data, we will collect both kinds of data from you as set out below.

Personal information

The personal information we hold about you may include the following:

- Name, address, date of birth.
- Telephone numbers.
- Next of kin / emergency contact.

Sensitive Personal Information (special category data)

The sensitive personal information we hold about you may include the following:

- Details of your current or former physical or mental health. This may include information about any health care you have received or need, including about clinic and hospital visits and medicines administered.
- Details of services you have received from us.
- Information relevant to your continued care from other people who care for you or know you well, such as other health professionals and relatives.
- Details of your race and/or ethnicity.
- Details about any disabilities.
- Details about your language preferences.
- Details of your religion.
- Details of any relevant genetic data or biometric data relating to you.
- Data concerning your gender & sexual orientation.

The confidentiality of your medical information is of paramount important to us, therefore we make every effort to prevent unauthorised access to and use of information relating to your current or former physical and mental health.

Why we need it

We are obliged by Health Care legislation to keep ongoing records of the treatment provided to you. It is also an important tool to be able to share plans and progress between the team members involved in your care.

What we do with it

We gather health information about you from a number of sources including:

- Directly from you
- From the person referring you to our service
- From other people involved in your care
- From your next of kin

We keep your data primarily on a patient information system called EMIS which is a product used by many NHS providers and allows us the capability to share appropriate information, with your consent, with other users of the system involved in your care.

Some services also keep paper notes for the day-to-day elements of care and/or key information about those important to you in case the computer systems are not available.

All clinical notes are reviewed and updated by the clinical team looking after you.

How long we keep it

We will keep your clinical record for a minimum of 8 years after your discharge from the service, or for 25 years if you are a child using our service. When records are no longer required for direct care we ensure that access to these records is restricted.

Your notes may be kept for longer in very particular circumstances such as involvement in a clinical trial but in these instances specific consent would be obtained.

We are required under UK law to keep your information and data for the full retention periods as specified by the NHS Records management code of practice for health and social care and national archives requirements. More information on records retention can be found online at <https://www.nhs.uk/information-governance/guidance/records-management-code/>

We may from time to time offer you the opportunity to become involved with research projects linked to Trinity Hospice, in these cases your direct consent will be obtained and the care of your data will be outlined as part of the project as it may differ from project to project.

The NHS is operating a National data opt-out scheme by which you can opt out of your data being used for research or planning purposes. Trinity Hospice is compliant with the scheme.

How the NHS and care services use your information

Whenever you use a health or care service, such as attending your GP 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.

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. 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. 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.

Our organisation is compliant with the national data opt-out policy.

If you are a family member or next of kin

We collect the details of family members and next of kin for patients or service users in our care. We do this under the grounds of Legitimate Interest of the person in our care to provide the best possible support to them and their loved ones. There is also the Legitimate Interest of the family members who require support as a carer in their own right or become bereaved who may choose to receive support from our bereavement services. We may from time to time also ask you for additional information for the purposes of audit or research.

What we need

Names and contact details of your next of kin or emergency contact. We may also complete a family tree of your immediate family or people important to you.

Why we need it

As a Hospice we provide holistic care to palliative care patients and also support for families and carers. As such it is important to understand family dynamics, who information is to be shared with and also identify who may need to be referred for additional support within our carer support or bereavement services.

What we do with it

We record this information as part of the clinical record of the patient. If you are referred for carer or bereavement support you will be registered as a patient / client in your own right and the details given in the section about patient data above will also apply.

We will use the data to invite you to a service of remembrance or advise you of other services that may be of benefit to you following the death of a loved one if you consent to us doing this.

We will not pass your data on to our fundraising department unless you consent for us to do this. Once you have provided consent it is important that you know you can change your mind and ask that this information is no longer shared by emailing trinity.governance@nhs.net or write to the Quality & Clinical Governance Lead, Trinity Hospice & Palliative Care Services, Low Moor Road, Bispham, Blackpool, FY2 OBG.

How long we keep it

As your data forms part of the clinical record, it will be kept for a minimum of 8 years after the patient is discharged or 25 years if they are a child. When records are no longer required for direct care we ensure that access to these records is restricted.

Out-of-Hours Advice and Access to Health Records

What does this mean?

Our hospice provides out-of-hours advice to patients and healthcare professionals involved in their care. To give safe, effective, and timely guidance, our clinical team may need to access your shared health record. This helps us understand your medical history, current treatment, and preferences.

When might this happen?

- If you contact us directly for advice about your care.
- If a healthcare professional (such as your GP, district nurse, or hospital team) contacts us for advice about your care.

Why do we access your records?

- To ensure accurate advice and continuity of care.
- To confirm important clinical details when responding to healthcare professionals.
- To support urgent decision-making for palliative or end-of-life care.

Our Legal Basis for Using Your Information

Under UK GDPR:

- Article 6(1)(e) – We process your data because it is necessary to perform a task in the public interest (providing healthcare).
- Article 9(2)(h) – We process your health information because it is necessary for the provision of health or social care or treatment.

Confidentiality and Security

- Our staff are bound by professional confidentiality obligations.
- We only access the minimum information needed.
- All access is logged and audited.

Your Rights

- Patients have the right to object to your information being accessed for direct care purposes.
- If you choose to opt out, please let us know. We will record your preference and inform healthcare professionals who contact us for advice that we cannot access your record.
- Please note: Opting out may affect our ability to provide timely and accurate advice.

Frequently Asked Questions

Do I need to give consent every time?

No. For direct care, consent is usually implied because you expect those involved in your care to share relevant information.

Who can see my record?

Only staff directly involved in your care and advice requests.

What happens if I opt out?

We will respect your choice and inform any healthcare professional who contacts us that we cannot access your record. This may limit the advice we can give.

How do I opt out?

Contact our hospice team by phone or email. We will update your record and confirm your preference.