



Tŷ Hafan Privacy Notice – Children and their families

As a specialist paediatric palliative care provider, Tŷ Hafan needs to collect and process personal information about the children in our care and their families. This privacy notice explains what we collect and how we use, store and share that personal information.

We keep our privacy notice under regular review to make sure it is up to date and accurate and may change the terms of this privacy notice from time to time.

If you have any questions regarding this notice, please write to:
Data Protection Officer, Tŷ Hafan, Hayes Road, Sully CF64 5XX or email dataprotection@tyhafan.org

Who we are

Tŷ Hafan, the hospice for children in Wales is a registered charity (No: 1047912) and charitable company limited by guarantee (No: 307406), registered in Wales.

What personal information we collect

- Personal data about the child and their immediate family and/or legal guardians including names, addresses, contact details and dates of birth.
- Special category data about the child which will include medical history, any legal orders, details regarding parental responsibility/guardianship, religious or spiritual beliefs and ethnic background.
- Special category data about family members (if appropriate) which could include health information, religious or spiritual beliefs and ethnic background.

How we collect this information

We collect information directly from the child, parents or guardians, and siblings. We also receive information from health, education and social care professionals such as hospital consultants, GPs, school nurses and social workers.

How we use this personal information

We can only use personal information if we have a lawful reason to do so. The lawful reasons include where:

- It is in our legitimate interest
- It is our legal obligation
- We have explicit consent, or
- It is in the vital interests of the data subject or another person

We use a child or family member's personal information for the following reasons:

1. Care Services

- Assess whether a child is eligible for Tŷ Hafan's services
- Develop care plans for both the child and family members
- Provide care services for the child
- Provide support and therapeutic services for family members
- Arrange short break stays
- Provide emergency care
- Support with the management of complex symptoms
- Provide end of life care for the child
- Maintain records and notes relating to the care and support provision
- Ensure we have accurate and up-to-date information for safe and effective care
- Provide information about support group events
- Support referrals to other services
- Provide updates on the child's progress to families and to relevant professionals caring for the child.

Our lawful basis for this processing is legitimate interest. A legitimate interest is where we have a genuine reason to process personal data and the processing does not harm any of the rights and freedoms of an individual.

2. Research and Clinical case studies

- Research (either anonymised or with consent)
- Clinical case studies (either anonymised or with consent)

Where the personal information is not anonymised, our lawful basis is consent

3. Audits and Complaints

- Care quality audits and reviews
- Complaints investigations

Our lawful basis for this processing is legal obligation.

4. Fundraising and marketing campaigns

Some children and their families want to tell their stories or take part in marketing activities to help Tŷ Hafan with fundraising initiatives and awareness-building. This can include inclusion in videos and photos which are released to media outlets or used on the internet. No information will be used for these purposes without consent. We will

also have a full discussion with family members to make sure there is a clear understanding of how their information will be used. Any consent given can be withdrawn at any time.

Our lawful basis for this processing is consent.

We will send fundraising and marketing communications to family members based on their individual contact preferences. Contact preferences can be changed by using the unsubscribe link on a relevant email or contacting us directly: call 029 2053 2255, email supportercare@tyhafan.org or write to us at Supporter Care, Tŷ Hafan, Hayes Road, Sully CF64 5XX.

Further information relating to our processing of supporter information can be found on our website <https://www.tyhafan.org/data-protection/>

Our lawful basis for sending email, text or telephone communications is consent.
Our lawful basis for sending postal communications is legitimate interest.

5. Importing into our supporter database

We copy the names and contact details (address, phone and email) of a child's family from our care services database to our supporter database. We do this to ensure that our income generation and supporter care teams can identify and communicate appropriately with family members who have chosen to financially support Tŷ Hafan.

Our lawful basis for this processing is legitimate interest.

Sharing of information

Information about a child or family member may be shared with various members of Ty Hafan's care service team depending on the care provided. It may also be shared with students who are working at Ty Hafan as part of their professional courses.

We may also share information with other professionals on a need-to-know basis.

These include:

- **Health or social care professionals** - We will share information with other health or social care professionals involved in the child's care to ensure medical records are up-to-date and accurate. Such professionals may include GPs, consultants, NHS hospital paediatric teams, ambulance crews, social workers or school nurses/teachers. Please note that information shared may also include personal or medical information about family members or legal guardians where it is relevant to the child's care.

It is possible to object to this data sharing but as an objection may seriously affect the care and services that we can provide, we will ensure that any potential consequences are discussed and fully explained.

- **Emergency services** - We may need to share information with emergency services in the case of a medical emergency or if it is a matter of safeguarding or child protection.
- **Legal or regulatory bodies** - We may be required by law to share information relating to the child and/or family members if, for example, we receive a formal court or police order. We may also need to comply with requests for information from Health Inspectorate Wales who is the regulator of healthcare in Wales or with relevant professional bodies.

When we need to share information, we ensure it is transferred securely with confidentiality maintained.

If a child is dying or has died at the hospice, we will inform other families who are visiting or in residence at that time as we may need to offer support to them, but no personal details about the child are shared. We will ensure that the family at the focus of such care are advised of our preference to share non child specific information with other relevant families, taking account of any specific concerns or pre-existing relationships that could impact on a family's desire for confidentiality.

Confidentiality and appropriate use of information

Our Caldicott Guardian is responsible for protecting the confidentiality of the child and family's health and care information, making sure it is used properly and only shared with those professionals who need to see it.

How we protect personal information

We take all reasonable care and precautions to protect personal information and use a combination of both physical and technical measures.

Our employees receive data protection training to ensure any personal data is handled and processed appropriately. Information is retained in secure electronic and paper records and access is restricted to appropriate staff. Our computer network is guarded by firewalls and kept in a secure environment on servers located within the European Union.

Our hospice site has CCTV installed. This is for security reasons and the footage is only held for a maximum of 30 days unless we are required to disclose the images for legal reasons.

If you do not want to provide us with your personal information

If you choose not to provide us with your personal information, you object to our processing of your personal information, or you choose to withdraw any consent that you may have provided for processing, we will respect such requests in accordance

with our legal obligations. This may mean, however, that you may not be able to make use of our services.

How long we keep personal information for

We will not keep your information longer than is necessary. It is kept in line with national guidelines or requirements according to the purpose for which it is collected.

Individual rights

Under data protection law, individuals have several rights regarding their personal information including but not limited to:

- The right to request a copy of the personal information we have collated
- The right to request we correct any incomplete or inaccurate information
- The right to withdraw any given consent
- The right to request that we stop using or erase the information we hold (Please note that we may not be able to comply with this request if there are legal reasons which require us to retain the information).

To exercise any of these rights under data protection law, please contact Data Protection Officer, Tŷ Hafan, Hayes Road, Sully CF64 5XX or email dataprotection@tyhafan.org.

How to make a complaint

To make a complaint about the processing of your data, please contact us at the address above. If you are not satisfied with our response, you can complain to the Information Commissioner's Office (ICO) by calling their helpline on 0303 123 1113 or via their website <https://ico.org.uk/concerns/>.

Changes to this Privacy Notice

This Privacy Notice was last updated on 24/10/2022.