

## Helen & Douglas House: Service User Privacy Notice

At Helen & Douglas House we are committed to ensuring your privacy and the security of your personal information. We promise to respect any of your personal data that is shared with us, and to keep it safe. We aim to be clear where and when we collect your data and not do anything with it that you wouldn't reasonably expect us to.

This Privacy Notice relates to your personal information as someone who receives support from Helen & Douglas House. You may be a young person, parent, family member/carer, or other person closely involved in a young person's care. If you provide us with personal data of people other than yourself, please ensure they are also aware of this privacy notice.

### Who we are

Helen & Douglas House is a registered charity providing palliative, end of life and bereavement care to life limited children, young adults and their families. We aim to enable these young people to live as full a life as possible, to ensure their holistic needs are met and promote their wishes at the time of their death. Our medical and nursing experts provide specialist practical and emotional care and extend their support to families and carers alongside these young people.

Whilst Helen & Douglas House is an independent charity, we work closely with other service providers, professionals and commissioners in health and social care to plan and provide support tailored to individual needs. These partnerships may include public sector, commercial and voluntary sector organisations. We also work closely with statutory agencies such as Social Services where required, for example in relation to safeguarding.

We are funded mainly through charitable donations, raised through fundraising. We also generate income directly from our shops and other trading activities. A relatively small proportion of our costs is currently provided through government funding – via national and local commissioning agreements.

- Our Registered Charity Number is 1085951.
- Helen & Douglas House is regulated by the Care Quality Commission (CQC).

### Data Protection

Helen & Douglas House is registered with the Information Commissioner in accordance with the UK GDPR and Data Protection Act 2018.

The General Data Protection Regulation (GDPR) is a legal framework that applies across the UK and European Union and came into effect on 25 May 2018. The GDPR relates to people's rights and freedoms concerning the control, processing and protection of person identifiable data.

The Information Commissioner's Office (ICO) is the UK's data protection authority. More information about the GDPR can be found on the ICO web site.

Under the definitions of the GDPR, Helen & Douglas House is both a data controller and a data processor. This means that we determine the purpose and means of the processing of personal data, as well as undertaking processing.

## What information do we collect and how do we use it?

For the purposes of providing, you with care and support, we need to collect, process and share certain personal information about you and your health. This includes the sharing of personal data with health and social care professionals, and also with commissioners in respect of care management and funding.

Depending on the service(s) you access, the personal data that we may collect about you may include:

name and contact details; date of birth; gender; NHS number; medical condition/diagnosis and medical history; spiritual, religious and other beliefs; family, social, ethnic and cultural contexts.

We will also ask for names and contact details of those who have parental and/or caring responsibility for you or your next of kin.

Other information that we collect in relation to you includes: details of the key professionals from other organisations who are involved in your care; details of your care packages and other services you access.

Personal information for your care and support may be recorded in a number of formats including paper and electronic notes, images and photographs. Such information will not be used for purposes other than those specified in this Privacy Notice – unless by your consent or other lawful permission.

We collect, store, process, share and delete personal information as part of

- your referral to receive care and support;
- our assessment of your eligibility for care and support (including records from other health and social care professionals);
- the decision to be accepted onto the caseload;
- the planning, coordination and provision of care and support – by Helen & Douglas House and by other organisations involved in your care;
- commissioning and funding discussions with the NHS and Local Authorities, and associated reporting and payments;
- our statutory duties to safeguard your, and others', health and wellbeing;
- your discharge from our services, including our duties at end-of-life.
- the administration and storage of your records whilst using our services

If you are a family member or carer of a patient, we may contact you for the purposes of discussing any related support needs that you may have in your own right.

We may also retain and process information for the purposes of scientific or historical research or statistical purposes. Research proposals will be subject to strict codes of practice to safeguard the individuals' interests, including anonymisation of identity; unless permitted otherwise.

If you are asked and provide permission to take part in an identifiable case study, this will be via a separate and explicit consent process. Case studies may be used for purposes that include marketing, education and training, and reporting about our service.

## The lawful reasons by which we process your personal data

We are only allowed to process personal data if our requirements meet specified legal bases defined by the UK GDPR.

The personal data that is used is limited to the information we need and is processed mainly using the legal basis to perform the tasks or services we have agreed with you or as needed for legal requirements.

Additionally, there will be instances where we will process information using our legitimate interests where, for example in promoting what we do, but only where this is of interest to you. Our legitimate interests will include the use of your personal information to contact you for specific additional reasons, as would be expected within an existing and relevant relationship with this organisation and its service offering. This may include: contacting someone who has a significant relationship with a patient, such as a family member/carer, to discuss any support needs that they might have; or discussing participation in a case study.

We require certain personal information about you, including data about your health, without which we are not able to provide our services to you. Under UK GDPR this type of data merits higher protection and can only be processed for specific purposes; this includes health data, information about your racial or ethnic origin, and your religious/ spiritual beliefs that you may provide.

We rely upon the following legal basis to process this data:

- Consent – where necessary we will seek your or your parent / guardians' explicit consent to use the data
- Legally permitted exemptions defined under UK GDPR article 9 and Data Protection Act 2018 Schedule 1. For example, where the data processed is necessary for the:
  - purposes of carrying out the obligations in the field of social security and social protection law GDPR article 9,2 (b); or
  - purposes necessary to protect the vital interests of the data subject GDPR article 9,2 (c); or
  - purposes of preventive or occupational medicine, medical diagnosis, the provision of health or social care or treatment GDPR article 9,2 (h)
- where required by law, personal data may be shared under legal obligation, for example with statutory agencies

We will also seek your consent where the processing activity is not part of the agreed services.

The GDPR permits processing of personal information for archiving purposes in the public interest, scientific or historical research processes or statistical purposes, whilst respecting the rights and interests of the individual.

## How long will your personal information be kept?

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.

Healthcare information about patients and other service users will be kept for eight years from the date of discharge or death, or in the case of children, until their 25th birthday, whichever is longer. Records will be retained until their 26<sup>th</sup> birthday if a young person was 17 at conclusion of treatment, or eight years after death, whichever is longer. There may be exceptions to these timeframes, such as

incident records which we must keep for 25 years.

We may also securely archive your records for longer periods for the purposes of research or statistical analysis, or where the Code of Practice suggests that this is advisable.

## **Keeping your information safe and secure**

Helen & Douglas House is committed to keeping personal information secure to protect it from being inappropriately or accidentally accessed, used, shared or destroyed, and against it being lost.

In addition, we limit access to your personal information to those employees, agents, contractors 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.

To prevent unauthorised access or disclosure, we have put in place suitable physical, electronic and managerial procedures to safeguard and secure the information we collect.

## **Do we sell or share personal details?**

Access to your personal information is only allowed when required by law or is required as part of fulfilling our service obligations.

Internally the team looking after your child may share relevant information from their Records with each other. This team may include doctors, nurses, therapists, pharmacists, administration staff and people providing emotional and practical family support. It may also include students or trainees in medicine or health and social care who are working with our team.

As a healthcare provider we also work closely and share data with other service providers, professionals and commissioners in health and social care to plan and provide support tailored to individual needs. These partnerships may include public sector, commercial and voluntary sector organisations. We also work closely with statutory agencies such as Social Services where required, for example in relation to safeguarding.

We make use of third-party service providers to help us fulfil our services and where we do, the third party is required to take appropriate security measures to protect your personal information in line with our policies. We do not allow our third-party service providers to use your personal data for their own purposes and we only permit them to process your personal data for specified purposes and in accordance with our instructions.

We use third party providers to:

- host and administer our electronic patient record database
- to help us with communications or manage marketing promotions or events you have expressed an interest.
- host and administer our website
- to host our databases in areas care, retail shops, fundraising and marketing
- for our IT security and systems
- for any legal advice and guidance in matters related to care, data protection and employees

If you would like to know more specific details about where we share your data or the third parties please contact us at [\*\*gdpr@helenanddouglas.org.uk\*\*](mailto:gdpr@helenanddouglas.org.uk)

## International Data Transfers

We are a UK based charity and following Brexit we will continue to store and process personal information mainly in the UK or EEA. Please note though that your data may be exported to as well as stored and processed in countries outside of the country in which you reside, including, without limitation the United States.

For data subjects residing in the UK or EEA, this means that your personal information may be exported, stored, and processed outside of the UK or EEA. Whenever we transfer your personal data out of the UK or EEA, we ensure a similar degree of data privacy and protection is afforded to it by ensuring at least one of the following safeguards is implemented:

- we will only transfer your personal data to countries that have been deemed to provide an adequate level of protection for personal data by the UK and European Commission
- where we use service providers who are not in territories approved by the UK or EU commission, we will look to implement additional safeguards such as a detailed review of security measures and the use Standard Contractual Clauses (SCCs) approved by the UK and or European Commission

## Marketing

Helen and Douglas House as a Charity are funded mainly through charitable donations, raised through fundraising so are reliant on the generosity and support of our supporters and fundraising activities to supplement the funding for the services we provide.

We undertake various marketing or fundraising activities but only where we believe you will be interested to help us or where we have your agreement.

For further details on our marketing and fundraising please read our Marketing Communications and Events Section under the Supporter and Customer Privacy Notice.  
[www.helenanddouglas.org.uk/supporter/](http://www.helenanddouglas.org.uk/supporter/)

## Your rights to your data

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 working relationship with us.

Under certain circumstances, you have rights under UK GDPR and Data Protection Act 2018 (DPA) and the EU General Data Protection Regulation 2016/679 (GDPR) in relation to your personal information.

You may have the right to:

- be informed of how we will use your data as provided by this Policy
- access the information held about you. Your right of access can be exercised in accordance with data protection law;
- object to us processing or ask us to restrict the processing of your personal information for any of the purposes listed in this Policy, at any time

- ask us to update and correct any out-of-date or incorrect personal information that we hold about you free of charge
- ask us to erase or delete your personal information (in certain circumstances). We will do our best to respond to such requests, but these are subject to certain limitations such as legal requirements
- Request a transfer of your personal information (again in certain circumstances).

If you wish to exercise any of the above rights or to review, verify, correct or question anything detailed in this policy or are unhappy with any aspect of how we use your data please contact us at:

Write to us at - Helen & Douglas House, 14A Magdalen Road, Oxford, OX4 1RW

Email us at – [\*\*gdpr@helenanddouglas.org.uk\*\*](mailto:gdpr@helenanddouglas.org.uk)

Call us on – 01865 794749

We will respond to your request promptly and look to resolve any query within 30 days and free of charge. However, we reserve the right to refuse or charge an administrative fee for the furthering of any of the above requests if they are done so in a frivolous, vexatious or excessive manner. We will always notify you if such a charge is being applied

You also have the right to make a complaint at any time and we appreciate the chance to deal with your concerns in the first instance. To register a complaint please email us at: [\*\*gdpr@helenanddouglas.org.uk\*\*](mailto:gdpr@helenanddouglas.org.uk)

If you are unsatisfied by our reply then you have the right to lodge a complaint to the Information Commissioner's Office (ICO), the UK supervisory authority for data protection issues. You can contact the Information Commissioner's Office by telephone on 0303 123 1113, or by using the live chat service which is available through the Information Commissioner's website [www.ico.org.uk](http://www.ico.org.uk).

## **National Data Opt-Out:**

The national data opt-out was introduced on 25 May 2018, enabling individuals to opt-out from the use of their data for research or planning purposes. Helen & Douglas House will not share your data or information for research purposes and will only share your data for reasons outlined in this policy and for the purposes of providing individual or direct care.

For more information on the national data opt-out, please visit [www.digital.nhs.uk/services/national-data-opt-out](http://www.digital.nhs.uk/services/national-data-opt-out).

You can find details here for how you can view and manage your choices.

## Contacting Helen & Douglas House

We have appointed external expertise as our data protection officer (DPO). They can be contacted by email at [gdpr@helenanddouglas.org.uk](mailto:gdpr@helenanddouglas.org.uk)

In the event that you need to contact us regarding any matters of data protection, you may do this via:

- Email: [gdpr@helenanddouglas.org.uk](mailto:gdpr@helenanddouglas.org.uk)
- Telephone: 01865 794749
- Post: 14a Magdalen Road, Oxford OX4 1RW
- Caldicott Guardian: Sally Hayes (Director of Nursing and Care)

We hope that this Privacy Notice is helpful in explaining our use of your personal information, and the rights that you have under the General Data Protection Regulation. The accuracy and security of your data is important to us; please contact us if you have any questions.

## Privacy Policy Changes

Provided that compliance is maintained in regard to the UK GDPR or Data Protection Act 2018, we reserve the right to amend and modify this privacy statement for any reason and at any time. This policy was last updated in April 2023

## Other privacy resources

[Cookies Policy](#)

[General User Privacy Notice](#)

[Recruitment Privacy Notice](#)

## Accessibility

If you, or someone you know, wish to receive this privacy notice in a different format, such as large print, braille, audio recording, or translated into a different language, please contact us by email, telephone or post using the details above.