

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.

Please read this statement to understand how your personal information will be used.

Who we are

Helen & Douglas House is a registered charity caring for children and young people with life-shortening and life-threatening conditions, their families and carers, through specialist hospice care.

We aim to enable these young people to live as well and as fully as possible to the end of their lives, and to support their needs and wishes at the time of their death. We do this by providing specialist palliative care through medical and nursing expertise, emotional and practical support. We also support families and carers alongside these young people, and into bereavement.

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

As an organisation Helen & Douglas House is registered with the Information Commissioner in accordance with the Data Protection Act 1998.

The General Data Protection Regulation (GDPR) is a legal framework that applies across the European Union and that takes effect from 25 May 2018. The GDPR relates to people's fundamental rights and freedoms concerning the control, processing and protection of personal data (identifiable to an individual).

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

Privacy Notices, like this, describe how your personal information is treated in line with the requirements of the GDPR. This Privacy Notice relates to you as a *service user* of Helen & Douglas House.

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?

This Privacy Notice relates to your personal information as a **service user** of Helen & Douglas House i.e. as a patient or as family member/carer, or other person, who may receive support from us.

If you provide us with personal data of people other than yourself (e.g. family members), please ensure they are also aware of this privacy information.

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 could 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 (in-so-far as these data support and safeguard your personalised care and decision-making). We will also ask for names and contact details of those who have parental and/or caring responsibility for you. 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.

In the event that a funding contribution for your care at Helen & Douglas House is made via a Direct Payment from a Personal Budget (from NHS and/or social care), we will process relevant personal details for the purposes of invoicing and receipt of payment.

Personal information for your care and support may be recorded in a number of formats including 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 from Helen & Douglas House,
- our assessment of your eligibility for care and support by Helen & Douglas House (including records from other health and social care professionals),
- the decision to be accepted onto the caseload of Helen & Douglas House,
- 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 Helen & Douglas House services, including our duties at end-of-life.

If you are family member or carer of a patient, or have a significant relationship with the patient, we may contact you for the purposes of discussing any related support needs that you may have (in addition to those of the patient themselves).

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 identities (unless permitted otherwise).

In the event that you may be asked, and agree, to be part of 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.

How long will your personal information be kept?

As a minimum, we will keep information about you securely for the required statutory periods, as set out by the Department of Health and Social Care in England within the *Records Management Code of Practice for Health and Social Care 2016* published by the Information Governance Alliance. 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.

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 – as defined by the GDPR. These are outlined below in ***bold italics***.

By agreeing to be assessed and to receive care and support from Helen & Douglas House, you are engaging in a contract with us to provide such services. 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 GDPR, the establishment and performance of a ***“contract”*** with you is the primary lawful basis upon which we process your personal information.

Some types of data under GDPR merit higher protection (*special categories of personal data*) and can only be processed for specific purposes. This includes ***health data***. It also includes information about your ***racial or ethnic origin***, and your ***religious (or other) beliefs*** that you may provide to us. We process such *special categories of personal data* for the ***“provision of health or social care or treatment or the management of health or social care systems and services”***.

Whilst it is anticipated that your personal information will be managed within the framework of the contract, there may be circumstances whereby we need to process your personal data in order to protect your ***“vital interests”*** (and in accordance with your expressed wishes, where known).

Under specific circumstances, and where required by law, personal data may be shared under ***“legal obligation”*** e.g. with statutory agencies.

As part of our ***“legitimate interests”*** we may use 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.

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.

Your rights to your data

The GDPR sets out specific rights that people have to their data.

The information contained in this Privacy Notice is an important part of those rights – describing the personal data that we collect, how it will be used, and on what lawful basis.

The accuracy of your personal information is important to us, and we will aim to check key data during our contacts with you as part of our standard practices. You may also request access to your personal information and ask us to make valid changes.

The GDPR also permits you certain other rights:

- to request that we erase your personal information,
- to request that we restrict processing of your personal information (e.g. while a query is resolved concerning your data),

- to object to any processing of your personal information, and
- not to be subject to an individual decision based solely on automated processing (please note, Helen & Douglas House does not make such solely automated decisions about its service users).

Such requests (e.g. to erase or cease processing your personal information) may have implications for the further care or support that we would be able to give you, and we ask that you raise any concerns you have about the use of your personal data with us at the earliest opportunity. Contact details are provided below.

Should you need to do so, you also have the right to lodge a complaint with the supervisory authority for data protection – which in the UK is the Information Commissioner’s Office.

Contacting Helen & Douglas House

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
- Telephone: 01865 794749
- Post: 14a Magdalen Road, Oxford OX4 1RW

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.