

## 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 Data Protection Act 1998.

The General Data Protection Regulation (GDPR) is a legal framework that applies across the 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.](#)

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 GDPR.

We process your personal data for a number of legitimate interests, including delivering care. Taking into account your interests, rights and freedoms, legitimate interests allow us to process your personal information in order to assess and provide care and support. We require certain personal information about you, including data about your health, without which we are not able to provide our services to you.

Some types of data under GDPR merit 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 process such special categories of personal data for the provision of health or social care or treatment or the management of health.

There may be circumstances whereby we need to process your personal data in order to protect your vital interests: in accordance with your expressed wishes, where known. Under specific circumstances, and where required by law, personal data may be shared under legal obligation, for example with statutory agencies. Special category data may be shared for the purpose of safeguarding of children and of individuals at risk.

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. This Privacy Notice is an important part of those rights, to be transparent with individuals about the collection and use of their personal data.

**The right to access:** You may request access to your personal information

**The right to rectification:** You may ask us to make valid changes

**The right to erasure:** You may request that we erase your personal information

**The right to restriction:** You may request that we restrict processing of your personal information (for example while a query is resolved concerning your data)

**The right to portability:** You may obtain and re-use any of your personal information for your own purposes across different services.

**The right to objection:** You may object to any processing of your personal information

**Rights in relation to automated decision making and profiling:** this is your right to not 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).

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.

Although we will endeavour to find a resolution, you may feel you wish to escalate a matter. You also have the right to lodge a complaint with the Information Commissioner's Office, who is the UK's independent authority responsible for upholding information rights in the public interest.

### **How long will your personal information be kept?**

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 have to 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.

### **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](mailto:gdpr@helenanddouglas.org.uk)
- **Telephone:** 01865 794749
- **Post:** 14a Magdalen Road, Oxford OX4 1RW
- **Caldicott Guardian:** [Andrea Lambert \(Director of Clinical Services\)](#)

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.

### **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.