



Data Storage, Use and Sharing

Zoë's Place is an independent registered Charity providing palliative, respite and end of life care to babies and infants aged from birth to 5 years suffering from life-limiting or life-threatening conditions. Compassionate care is at the heart of our philosophy and this will be provided to all who access our facilities irrespective of their religious beliefs, colour, race, culture or gender. There is no cost to the families for this service.

For more information see our website <https://zoes-place.org.uk>

This Privacy Notice explains how we use and share your information. We will continually review and update this Privacy Notice to reflect changes in our services and feedback from service users, as well as to comply with changes in the law.

Why do we hold information about your child?

It is a legal requirement. The Health and Social Care Act (2012) states that we have to keep records on the care and treatment we deliver to the children we care for.

How do we store the information and for how long do we keep it?

The information is primarily recorded on paper documents and some electronic records. We will be changing over to a fully electronic system within the next 12 months

We will not keep the information longer than is necessary in accordance with the General Data Protection Regulation (GDPR). The period the information is kept, reviewed, archived and destroyed is until the child's 25th birthday, however we also adhere to the Records Management Code of Practice for Health and Social Care 2016 set down by NHS Digital.

Who do we share the information with?

The information with the parents and main carer consent, will be shared internally between teams if necessary and also externally with other professionals who may be involved in the care, e.g. GP's, Health Visitors, District Nurses and Community Palliative Care teams. The sharing of this information means that everyone caring for your child is fully informed about their medical history, including medication and allergies. This improves communication and the co-ordination of services/care based on their individual needs. When you attend the hospice you will be asked for your consent to share this information.

How the records are used

By accessing the services of our Hospice, we will ask your consent to use your information for the following reasons:-

- To provide you with high quality, safe and effective patient care.
- Work effectively with others providing you with healthcare.

We may also need to use records about you to:

- Check the quality of health care (such as clinical audit), Internal training / Service Improvement
- Help investigate any concerns or complaints you or your family have about your child's healthcare.
- National & Regional Statutory reporting
- Statistical purposes.
- We may also ask you to complete an anonymous questionnaire about the care you have received from us.

We use anonymous information, wherever possible, but on occasions we may use personal identifiable information for research and auditing. However, **this information will only be used with your explicit consent**, unless the law requires us to pass on the information.

At any time you have the right to refuse/withdraw consent (opt out), in full or in part to information sharing. If you wish to discuss this further please discuss this with your Head of Care, Gina Harris.

How we make sure it is safe and secure

We will use your information in accordance with the GDPR and Zoë's Place Hospice Policies and Procedures. All staff receive training in handling personal data. All computers are password protected and all laptops encrypted. Any electronic record can only be accessed by approved staff. The information you provide will only be seen, accessed or shared by those staff involved in your child's care.

Feedback

We'd like to know if you find this information useful, if there is anything missing that you wanted to know, or anything you didn't understand. Please speak to a member of staff. Further information can be provided by the Head of Care, Gina Harris.