Patients, families and carers

Why do we collect personal information about patients, families and carers and how do we use it?

Personal information about patients, including information about other health and social care professionals and family and friends involved in providing support and care, is essential in enabling us to provide the care required and to ensure that the needs of patients and their family members and carers (ie close friends) are at the centre of all the care we provide. The lawful basis for collecting and using information to provide care to our patients, families and carers is "public task" ie the information is fundamentally necessary for us to provide our care. The fact that we are providing health and social care permits us to handle sensitive personal data. This lawful basis permits us to:

- Co-ordinate the care that we offer – both within our Dorothy House team and externally
- Offer wider Dorothy House support to a patient's family members, including in bereavement
- Provide information to the NHS and other commissioners with whom we hold service contracts
- Audit, evaluate and develop our services.

Different levels of information are held depending on the extent of Dorothy House input.

What personal information do we collect about our patients, families and carers?

Based on the data processing reasons outlined above, we may collect all or some of the types of information below to help us provide the best care possible:

Basic details including name, postal/email address, telephone number, date of birth/death.

Demographic, equality and diversity data

Medical information including NHS number, detailed medical records, prescribed medications; investigation results and information from other professionals involved in care, patient/client service activity.

Other information includes personal and social history and documentation of consultations. Interactions with family members/carers are usually recorded within the patient's record, but if a family member or carer is receiving more involved support from Dorothy House then a record will be created in their own right as a 'client' record – we will ensure that they are aware of this.

Some people will only attend group sessions, using our 'Open Access', but we are still providing a health and social care service. We therefore create a record for each person who attends one of our groups and we will update this with attendances and any relevant clinical notes.

Where do we store patient, family and carer's information and for how long?

Patient and 'client' data is stored on our electronic patient record system called SystmOne. This is a secure clinical database used by many other health and social care providers including GPs in our area. SystmOne data is hosted off-site within the European Economic Area (EEA) which gives a high level of security as all data processed within the EEA is covered by the General Data Protection Regulations.

Under current data protection legislation, all organisations involved in a patient's care have a duty to ensure that information held about them is accurate, up to date and kept secure at all times. Access to records can be audited and can always be traced back because users log in using unique identifiers and secure access methods.

Currently, SystmOne is not able either to archive or delete patient records as it is a system shared across many health and social care organisations. However, when a record of a patient who has died or has been discharged is accessed after 52 weeks from date of death or discharge, a reason must be provided and the system tracks access to these records.

Access within the Dorothy House team is on a need-to-know basis. Where volunteers are providing care and support they are regarded as part of the Dorothy House team. All staff and volunteers with access to confidential personal information receive information governance training.

Using cameras or other recording equipment during treatment and care

At Dorothy House Hospice Care (Dorothy House) we promote the **open and honest** recording of consultations or conversations with healthcare professionals.

Where this is done with everybody's agreement, we believe this benefits the patient and the healthcare professional by:

- enabling patients to remember important advice, particularly where there are language barriers
- providing a copy of the consultations when patients may have been distressed
- giving patients more time to process information
- helping patients and their family members where patients may be experiencing memory loss or have some cognitive impairment
- including patients' family members in their care and decision making
- helping patients to remember if the information is particularly complex.
- helping to set family member's mind at ease about the care received or even help identify poor care or abuse.

To achieve this, we will work with you to ensure that:

- any recording is done openly and honestly with the express permission of the patient
- the recording process itself does not interfere with the consultation process or the treatment or care being administered
- the patient understands that a note will be made in their health record stating that they have recorded the consultation or care being provided
- the patient is reminded of the private and confidential nature of the recording and that it is their responsibility to keep it safe and secure
- any recording is only made for **personal use**
- you are aware that the misuse of a recording may result in criminal or civil proceedings
- you understand that the patient is entitled to see their notes
- we can consider providing the patient with a written record summary, and or a verbatim record (if practical) of their consultation for their own personal use if this is helpful.

We are aware that patients and families may be considering covertly recording a consultation. Using a hidden camera or other recording equipment is a big decision. It can affect people's privacy and dignity. And it can have legal consequences as well. It may also be interpreted as a sign that trust is lacking or that the patient may be considering a complaint or legal action.

Both legally, and as a matter of courtesy, you should seek the health professionals' agreement before recording a consultation/treatment. **We strongly discourage covert recording.**

If you are worried about yours or somebody's treatment and/or care, you should first raise these concerns with us. We take proactive steps to investigate and address any issues regarding your treatment and care. You can do this by using our complaints procedure.

You can also raise concerns with the Care Quality Commission (CQC). They have very helpful guidance on this subject. Using cameras or other recording equipment to check somebody's care.

It is important to note that the CQC state that an organisation should not ever refuse to treat someone or care for them properly because recording equipment or similar technology is being used.

Sharing personal information about patients and clients with third parties

Dorothy House works as part of a health and social care system in our community. To provide the safest, highest quality, most integrated patient and client care we can, sharing of health and social care information is encouraged, whilst confidentiality is prioritised. This may include digital innovations that will support the delivery of your care. We believe that you would expect us to share relevant health and social care information with other services/organisations involved in your care, or those who you have agreed should become involved and you will inform us if you do not wish for this to happen. We do not generally share information about clients, or those who only attend our 'Open Access' groups, but for patients, we would anticipate sharing information with; as part of your care are

- Community care professionals eg GPs, District Nurses, multi-disciplinary teams, Specialist Nurses, Community Matrons
- Hospitals
- Public/private health and social care providers.

Although we would always aim to share only the minimum information required, when sharing is via SystmOne, this is not always technically possible. However, we can ensure that individual elements of information are not shared, so please tell us if there are particular areas that you wish to remain confidential. Patients do have the right to totally opt out of Dorothy House sharing their electronic patient record with other health and social care providers.

Very rarely we may be required to share confidential personal information without consent if we are required to do so by statutory law, such as with safeguarding concerns.

We are required to share information for commissioning, service planning and regulatory purposes with

- Clinical commissioners of local services
- Care Quality Commission and other regulatory bodies.

We will ask, specifically, for your consent (lawful basis) if personal data is to be used if:

- Referring our patients/clients on to other service providers (non-health/social care)
- Requested by solicitors or insurance companies.

In order for us to raise awareness of our work it is extremely useful to be able to use stories and photographs/video of our patients and their families. We will only ever do this with your specific consent (lawful basis).

Updated February 2026