

Privacy Notice

Overview

We value the patients and service users that we care for, as well as our supporters, staff and volunteers. That is why we are committed to protecting your privacy. This notice is intended to let you know the basis on how and why Douglas Macmillan Hospice (DMH) also known as Dougie Mac, uses the information you provide to us or that we obtain about you; it is intended to advise you what to expect regarding personal information collected. We are committed to protecting your privacy and will only use collected personal information in line with all applicable laws, including Data Protection Act 2018 and the UK General Data Protection Regulation (UK GDPR).

For ease, we have layered this notice depending on your relationship with us, so that you can find the information that is most relevant to you. The notice is posted on our website, on noticeboards and can be produced as a hard copy upon request.

We keep our privacy policy under regular review and may update it from time to time, so please do check it regularly.

This privacy notice was updated in January 2024.

Who are we?

Douglas Macmillan Hospice, also known as Dougie Mac, is based in Stoke-on-Trent, North Staffordshire and the surrounding villages. We provide hospice care for children, young adults and adults who have been diagnosed with life-limiting or incurable illness and we offer support to their families. Our registered charity number is 1071613.

We require relevant and appropriate information to carry out activities regarding your relationship with us and provide you with an excellent service. We strive to keep our information systems fit for purpose and aim to hold accurate personal information that is up to date; any information found to be inaccurate will be corrected. Please keep us informed if your personal information changes so that we can update our records.

We are registered as a data controller with the ICO; our registration reference is Z5056068. Our Data Protection Officer is Mrs Karen McKenzie, and our Caldicott Guardian is Dr Emer McKenna. If you have any questions about our privacy notice or how we use your information, please contact us:

- By Phone - 01782 344300
- By Email - post@dmhospice.org.uk
- By post or in person -
Douglas Macmillan Hospice
Barlaston Road
Stoke-on-Trent
ST3 3NZ

Your rights

Under the Data Protection Act 2018 and UK GDPR, you have a number of rights which you can exercise. Please note that there may be times when not all rights may apply and your request cannot be fulfilled; this could be due to your individual circumstances or legal obligations. We will advise you though if this is the case. These rights include:

Right to be informed – You have the right to know why and what we are doing with the collection of your data. This information should be contained within this privacy notice, and may also be provided to you at the point of collecting your personal information.

Right of access – Also known as a ‘Subject Access Request’. You have the right to ask us and obtain copies of your personal information. We will respond to your request within one month (unless the request is unfounded or excessive, or adversely affects the rights and freedoms of other people). You can submit your request on our [webform](#) or ask a Dougie Mac representative.

Right to rectification - You have the right to have inaccurate personal data rectified as well as to complete information that you think it incomplete.

Right to erasure – In certain circumstances, you have the right to ask us to erase your personal information. There are times though when this right does not apply and we are required to retain your information to comply with legal obligation or health care. We will let you know if that is the case.

Right to restriction of processing - You have the right to ask us to limit the ways in which we use and process your personal information. There are times though when this right doesn’t apply; we will let you know if this is the case.

Right to object to processing - You have the right to object to the processing of your personal information

Right to data portability - You have the right to ask that we transfer your information to another service or organisation.

Right not to be subject to automated decision making including profiling – You have the right to object to us using your personal information for profiling or making automated decisions

Right to withdraw – You have the right to withdraw your consent for when we are processing your data based upon consent.

Complaints

Should you have any concerns about the way we process your data, you have the right to complain. Please contact us first so that we can attempt to resolve any concerns. If you are not satisfied then you can also complain to the Information Commissioner's Office about how we have used your information. The ICO's contact details are:

- Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
 - Helpline number: 0303 123 1113
 - Website: ico.org.uk
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PATIENTS, FAMILIES, CARERS & SERVICE USERS

This part of the privacy notice is intended specifically for Dougie Mac patient/service users, as well as families/next of kin or carers of a patient, including parents or guardians of a child (under 16 years of age) in our care.

A patient/service user is anyone who has been referred to the hospice and is or has received support or care from one of our services. This also includes people who have made enquiries or who have been referred to us but not yet receiving care.

Carers, families/next of kin or friends of a patient/service user are people who a patient/service user identify as important. They may also access our services and visit a patient/service user at the hospices.

1. Why do we collect your information

To access our services and provide you with care we may need to collect a variety of personal information. We collect your data to:

- enable care services to be carried out and to help make decisions about care and treatments
- provide holistic support
- provide end of life carer support
- manage and respond to an enquiry or request
- investigate any concerns or complaints you may have, either about your care or services provided

2. What information is collected and why

The type of information we collect and use about you will vary depending on your relationship with Dougie Mac.

For patient/service users, as well as carers, families/next of kin who also receive support or treatment from us, this might include:

- your name, address, contact number and email, next of kin and family information, and your doctor's contact details, so that we provide relevant treatment, can contact you about your care and appointments, and ensure we know who to contact in the event of an emergency.
- information about your health and wellbeing, for example your NHS Numbers to aid us in the administration or prescription of medications.
- details of physical and mental health, your medical history, your ethnicity, and religion to help us understand the needs of our patients and provide appropriate services.

If you have been referred to us, the above information may come from your doctor, health professional or other care providers who have referred them to our services. If the service user is a child, then they can only be referred to us if the parent or legal guardian has provided consent for the referral.

Information may also be used for research as well as for quality and improvement purposes. This data is usually anonymised (so no identifiable information is used) however if we did require your personal information for these purposes, we would require your consent.

For carers or patient/service user's next of kin: we may be provided with your information by one of our patients that have named you as their next of kin. This may include your name and contact details so that we can get in touch or if you are needed in an emergency.

We will collect your personal information if you choose to access any of our services, for example complementary therapy or bereavement services. We will require your consent if you wish to access these services, at which point you will be a service user.

For visitors (including contractors and those attending outpatient appointments at the hospices) you will be required to sign in on tablet devices at the reception areas; this enables relevant staff to know you have arrived for appointments as well as for safety purposes. The information we may collect includes your name and who you are visiting/have an appointment with.

You may appear in video footage from Closed Circuit Television (CCTV) which we have in operation both in and around both of our hospice sites for security purposes.

3. How and when we collect your information

We will collect personal information from you when you enquire about or access our care services. This information could be collected verbally, in writing or electronically, and could be collected over the phone, from face to face meeting, or through our website. Your personal information is recorded and may be stored on our clinical records systems and may be accessed and updated every time you interact with us. At times, your personal information may be provided to us by family members/guardians who have contacted us, or by other healthcare professionals. We may also collect personal information from you if you submit feedback or a complaint.

Additional consent will be sought for other activities, such as digital photography/videography used for marketing purposes, use of other software to support us in the delivery of care services, such as

Bookwhen (booking system) and the Family platform used within Children's Services, or when carers/next of kin access other hospice services, including holistic support.

4. Where we store our information

We use a system called SystmOne to process patient information for our Adult services. SystmOne is currently used by a wide range of healthcare providers and the NHS, which enables the sharing of your health information with other clinicians and organisations involved in your care. We use a system called The Care Database to process information for our Children and Young Adult services; this system is also widely used by other hospices.

Patients who have previously received care from Adult team at Douglas Macmillan Hospice may have their patient data stored in a system called Crosscare. This system will remain in place whilst our adult services fully migrates to SystmOne. We have no current plans to migrate our data held at Children and Young Adult services to SystmOne.

We may also temporarily hold data on internal IT systems or in cloud environments used by our organisation.

5. Lawful basis for processing your information

In line with Data Protection Act 2018 and UK GDPR, we will process your personal information fairly, lawfully and transparently; we will only process personal information if there is a lawful basis. Wherever possible we will use your consent preferences over our legitimate interest to enable us to lawfully communicate with you. Consent will be gained at the earliest point upon accessing our services.

When accessing our services, we will need to collect personal and medical information about you and your care in order to provide you with safe and effective treatment. We have a legal obligation to manage your personal records and maintain healthcare records, in accordance with the Health and Social Care Act 2012. We may also process your sensitive personal information (such as medical information, ethnicity, religion) in order to deliver health and care services (UK GDPR Article 9 (2) (h)) as well as in the public interest (UK GDPR Article 9 (2) (i)).

We will also collect and process your personal information if we believe it is in our and/or your legitimate interests; using your personal information in order to provide care support and services in the most appropriate way (Article 6 (1) (f) of the UK GDPR)

We may also process your information because we are legally obligated to, for vital interests or to perform a task in the public interest, such as to support national LeDer reporting.

6. Keeping your information secure

We are committed to protecting your personal information. We comply with all relevant legislation to ensure the safe handling of your data and ensure your personal information is protected.

Access to personal information is controlled and will only be accessed or shared appropriately by staff and volunteers involved in your care. All computers are password protected. Access to databases, software and electronic records are restricted through the use of log ins/password control and/or NHS Smartcard (chip and pin).

We use anti-virus software and fire walls to protect against cyber-attacks.

All staff and volunteers who handle personal data receive mandatory data protection and information security training. If we need to share your information, we will ensure it is done so using secure channels.

Everyone working for Dougie Mac has a legal duty to keep information about you confidential; this duty is enforced by common law, statute, codes of conduct and contracts of employment.

We operate strict physical security at all our sites and undertake audits to make sure our security controls are effective and reliable. If information needs to be taken outside our premises, we take extra precautions to keep it as safe as we can.

When we use third party organisations to process information on our behalf we ask them to demonstrate compliance with our security requirements, adherence to any instructions we give them and compliance with relevant data protection legislation for the duration of their relationship with Dougie Mac. We have contractual agreements with these organisations which clearly define their obligations about what information they hold and how they use it.

7. Storing or transferring your data outside of the EEA

Dougie Mac is based in the UK and we endeavour to store all our data in the UK or within the European Economic Area (EEA). We do not transfer or store your personal data to any third countries.

Some organisations which provide services to us may transfer personal data outside the EEA for processing purposes, but we will only allow them to do so if your data is adequately protected and in line with legal requirements. This includes, for example, ensuring that appropriate safeguards in relation to international transfers of data are included in contracts.

8. Using and sharing your information

We use your collected information to provide you with effective and appropriate care from our services. Your contact details may be used to communicate with you about your healthcare and appointments in various formats, e.g. by letter, text or phone. We may also need to contact your next of kin in the event of an emergency.

We may share your information with other health and social care staff if we think it is in your best interests. For example, this may be information we give to your doctor about the care we have given you; it may be to a hospital or another health or social care service, where we think that you would benefit from their involvement. We will speak to you about any referrals that we think you need and the reasons for them.

To give the best care we can, sometimes we will also need to share information about you with others. We may share your information with a range of Health and Social Care organisations and regulatory bodies, for example the Care Quality Commission (CQC).

We may also have to share your information, subject to data sharing agreements on how it will be used, with the following organisations:

- NHS (hospital) Trusts;
- community services;
- general practitioners (GPs), dentists, ophthalmic services; and
- ambulance services.
- social services;
- education services;
- local authorities;
- voluntary sector providers;
- private sector providers;
- Fire and Rescue Services and
- Police & Judicial Services .

You may be contacted by any one of these organisations; they must tell you why they have contacted you. Information sharing is regulated by specific rules and law.

You have the right to refuse/withdraw consent to information sharing at any time. We will fully explain the possible consequences to you, which could include delays in you receiving care.

We will not sell or lease your information to any third party.

Your personal information may be used to update other hospice databases, for example when a patient/service user who has accessed our care services dies we will update the supporter database (Donorflex) so as to avoid inappropriately causing distress to family members. Your data will not be used by Dougie Mac for marketing purposes (unless you give consent).

We only share your personal information with our trusted partners, our data processors, to process data on our behalf which is necessary to deliver the service we provide as a hospice; we have contracts in place that require third parties to keep your personal information secure and not to use it for any other purpose.

There may be circumstances when we are required by law to share your personal information, for example to ensure we are safeguarding our children and families, or sharing CCTV images with authorised bodies, for example the Police, as part of an investigation.

8. National Data Opt-Out

The national data opt-out applies to CQC-registered adult social care providers in England and only applies where a service user is receiving social care that is provided, arranged or funded (in part or whole) by Local Authorities or the NHS in England. The national data opt-out gives everyone the ability to stop health and adult social care organisations from sharing their confidential patient information for reasons other than providing their individual care and treatment and only applies where the data processing relies upon Regulation 5 of the Control of Patient Information Regulations 2002.

Individuals can view or change their national data opt-out choice at any time by using the online service at www.nhs.uk/your-nhs-data-matters or by calling 0300 303 5678 (Monday to Friday, 9am to 5pm).

We review all of our data processing on an annual basis to assess if the national data opt-out applies. This is recorded in our Record of Processing Activities. All new processing is assessed to see if the national data opt-out applies.

If any data processing falls within scope of the National Data Opt-Out we use Message Exchange for Social Care and Health (MESH) to check if any of our service users have opted out of their data being used for this purpose.

9. How long we keep your information for

Clinical records are retained in accordance with the national guidance for health and social care records. Your information may also be retained on our systems after you have been discharged from the Hospice, so that your clinical record can be accessed by and inform other health professionals for your future care.

All other personal information will not be kept longer than is necessary/required, and/or will be kept as long as we are legally bound to. Information is retained and handled in compliance with our own Retention Policy; when no longer needed the information will be destroyed securely.

CCTV images are stored for 30 days; some footage may be kept for longer depending on circumstances such as an investigation but will be securely destroyed following investigation.

10. Safeguarding

We are committed to preserving confidentiality regarding identity, however, there may be occasions when we are required to inform Local Authority Safeguarding Teams and/or the Police where there may be experience or risk of abuse and neglect and any acts outside the law. Although we would usually seek peoples consent before taking this action, we may sometimes have to do this without consent in accordance with local and national safeguarding policy and procedures.