



LauraLynn Children's Hospice – Palliative Care Services Privacy Statement Service Users - Children

1. Who we are

LauraLynn, Ireland's Children's Hospice provides specialist palliative and supportive care services to meet the needs of children with life limiting conditions and their families in Ireland.

Our LauraLynn Model of Care describes our supports within five pillars of children's hospice care: Direct Care, Family Support, Symptom Management, End-of-Life Care and Bereavement Support.

The aim of our Model of Care is to ensure that the right child receives the right care, at the right time, in the right place, by the right team. www.lauralynn.ie/model-of-care

This Privacy Statement refers to our commitment to our compliance to data protection legislation including the Irish Data Protection Acts and the EU General Data Protection Regulation.

Throughout this document "we", "us", "our" and "ours" refers to LauraLynn, Ireland's Children's Hospice. Our registered address is Leopardstown Road, Foxrock, Dublin 18-Eircode: D18XO63.

2. How to contact Our Data Protection Officer

There are many ways you can contact us, including: by phone, email, and post.

Email	dpo@lauralynn.ie
Phone	Data Protection Officer 0353 1 2893151
Our postal address	Data Protection Officer, LauraLynn, Ireland's Children's Hospice Leopardstown Road, Foxrock, Dublin 18-Eircode: D18XO63

3. The information we collect about you

Personal data means data relating to a living individual who is or can be identified either from the data or from the data in conjunction with other information that is in, or is likely to come into, the possession of the data controller, who is LauraLynn Ireland's Children's Hospice.

Personal data will be obtained in a lawful, fair and transparent manner for a specified purpose and will not be disclosed to any third party, except in a manner compatible with that purpose.

All medical information under GDPR is deemed a special category of personal information and we will endeavour to ensure your information is treated with the utmost respect and confidentiality where we safeguard your data while held by use.

LauraLynn staff, including doctors, nurses and the team of healthcare staff caring for you, keep records about your health and any care or treatment you may receive from us. It is important for us to have a complete picture as this information enables us to provide the right care to meet your individual needs.



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Only where necessary we process data for the following groups of individuals (current and former): For further information please refer to individual privacy statements www.lauralynn.ie/privacy-and-security

- Children
- Parents
- Guardians
- Grandparents
- Siblings

4. Legal Basis for processing your data

Consent

Where you have explicitly agreed to us processing your child's information for a specific reason such as collecting your child's data, including special category data including health data, religious affiliation beliefs, cultural identity for the provision of treatment and service or the use of photographs and or videos for inclusion on social media platforms, in publications, and or on our website for awareness of our services and for fundraising campaigns and family events.

Where consent is relied upon as a basis for processing of any personal data, you will be presented with an option to agree or disagree with the collection, use or disclosure of personal data. Once consent is obtained, it can be withdrawn at any stage.

Contract

Where you have entered into a service with us and the processing is necessary to perform this service as outlined in the Palliative Care Services Terms & Conditions.

Compliance

We are required to comply with the Children's Healthcare Act, Children's First Act, Social Welfare Consolidation Act and may be required to share your personal data with the following sectors:

- We may disclose your information related to the enforcement of a criminal law or a law imposing a penalty or sanction, or for the protection of public interest
- In certain circumstances disclose your information to prevent or lessen a serious and/or imminent threat to somebody's life, health, safety, to public health or public safety
- We may, for the purposes of investigation of a complaint under the Data Protection Acts, be required by the Data Protection Commission to provide any documentation it considers necessary



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- We may, for the purposes of investigation be required by the Health Information and Quality Authority to provide any documentation it considers necessary

Legitimate interest

Processing is necessary for the purposes of legitimate interest pursued by us to safeguard the safety and security of our service and its users. Using CCTV, access controls to property, night security and monitoring network and information security to assist in indicating possible criminal acts or threats to security in such instances processing is necessary for the purposes legitimate interest pursued by us to safeguard the safety and security of all individuals including our service users.

Processing is necessary to prevent fraud. Processing of minimal personal data is necessary to operate our services in LauraLynn generally and manage and administer our appointments with you.

From time to time, we may conduct satisfaction surveys. Where we do so we rely on the lawful processing of legitimate interest to enhance our service delivery. Under the data protection section, you will be presented with an option to opt out of such surveys. A withdrawal option will be provided in all survey communication thereafter.

5. When and how we collect information about you

Your information is collected in a number of different ways.

This might be through a referral made by your Consultant, GP or another healthcare professional you have seen, or perhaps directly from you or your family, in person, over the telephone, during the completion of your holistic needs assessment or during your first attendance at our service. During your treatment we may receive information from those third parties named above and where you have been informed and agreed for this information to be shared with us. Health specific data will be collected by the clinical staff taking care of you and will be held in your medical record (this can be paper and/or electronic).

The types of personal data we collect and process are outlined below:

Types of Personal Data (i.e. any information relating to an identified or identifiable person)	
Demographic Data	date of birth, gender, number of family members
Contact Details	Name, address, contact phone number, next of kin details, name of siblings
Digital Identifiers	LLIN – LauraLynn Identification Number. Photos with the provision of explicit consent we may process films, photographs, video recordings



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Special Categories Data	Through explicit consent we collect information regarding cultural identity, medication details, allergies, dietary preferences, body size, body weight, genetic information, skin/hair/eye colour, distinguished features, religious beliefs, HNA, medical report, medical notes, individual diseases & diagnoses, treatment history, examination results, prescriptions, medical provisions for travel or accommodation, daily notes, incident details, data on medical or paramedical care
Opinions and Assessments	Incident details
Any other types of data not listed above	CCTV
Government Identifiers	PPS No

6. Protecting your data

We collect this data in a transparent way and only with the full knowledge of interested parties. Once this information is available to us, the following rules apply:

Our data will be:

- Accurate and kept up to date
- Collected fairly and for lawful purposes only
- Processed by us on the basis of explicit consent with the Terms & Conditions, legal compliance or legitimate interest
- Protected against any unauthorised access or illegal processing by internal or external parties.

Our data will not be:

- Communicated to any unauthorised internal or external parties
- Stored for longer than required for the purpose obtained
- Transferred to organisations, states or countries outside the European Economic Area without adequate safeguards being put in place as required under Data Protection Law.

Our commitment to protect your data:

- Restrict and monitor access to sensitive data
- Develop transparent data collection procedures
- Train employees in data protection and security measures
- Build secure networks to protect online data from cyber attacks
- Establish clear procedures for reporting privacy breaches or data misuse
- Establish data protection practices (document shredding, secure locks, data encryption, frequent backups, access authorisation etc.).



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7. Purpose for processing your data

We use your information to manage and deliver your care (Direct Care) to ensure that

- The right decisions are made about your care;
- Your treatment is safe and effective; and
- We can coordinate with other organisations that may be involved in your care.

This is important because having accurate and up-to-date information will assist us in providing you with the best possible care.

In addition to using the data to provide for your care, this data is also routinely used to improve services and plan for the future (Indirect Care).

Therefore, your data may be used in:

- Evaluating and improving service user safety
- Reviewing the care provided to ensure it is of the highest standard possible, improving individual diagnosis and care. This can be carried out by multiple quality improvement methods e.g. clinical audit and/or retrospective chart reviews. Such activities are part of normal health care delivery. Any data collected will be anonymised and no identifiable details will be included.
- Findings from research involving anonymised (non-identifiable) data may be shared outside of the organisation in order to enhance understanding of how to improve quality and access to care on the part of funders, care providers and the public, as in the case of organisational reports, presentations at conferences, academic publications, and in our engagement with media.
- Training healthcare professionals
- Ensuring that our services can be planned to meet the future demand
- Preparing statistics on service performance and monitoring how we spend public money
- Supporting the health of the general public e.g. Influenza, winter vomiting bug
- To comply with all relevant law
- To manage your safety and security while you are on our premises
- To facilitate the prevention, detection and investigation of crime and the apprehension or prosecution of offenders
- To investigate, exercise or defend legal claims or other claims of a similar nature.

8. Who we share your information with

We may disclose your personal data to external third parties in connection with specific purposes and compliance, including:

- Other health care organisations that are involved in your care.
- Services such as Primary Consultant, Public Health, GPs, community services and transportation
- Third parties who provide services to us (Solicitors, Auditors (internal and external), IT service providers,) Digital Asset Management, Social Media platforms, Marketing, Print & Design agencies other contractors as and when required



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- Authorities and bodies where required or permitted by law, e.g. HIQA, HSE, Director of Public Health of certain diseases, TULSA, An Garda Síochána
- Insurance Companies

9. How long will we hold your information

We will only retain personal data for as long as necessary for the purposes for which it was collected as required by law or regulatory guidance to which we are subject or to defend any legal actions.

10. Implications of not providing information

Where lawful basis is a statutory or contractual requirement, if a service user individual is obliged to provide their personal data, such as health data in order for us to provide care treatment, failure to provide this information may result in us being unable to provide this service.

11. Processing your information outside the EEA

Some of the third parties we share your data with may reside outside the European Economic Area (which currently comprises the Member states of the European Union plus Norway, Iceland and Liechtenstein). If we do this, your information will be treated to the same standards adopted in Ireland and include the following data protection transfer mechanisms:

- Model Clauses (also known as Standard Contractual Clauses) are standard clauses in our contracts with our service providers to ensure that any personal data leaving the EEA will be transferred in compliance with EU data-protection law. Copies of our current Model Clauses are available on request.
- Transfers to countries outside the EEA which have an adequate level of protection as approved by the European Commission (such as the United Kingdom).
- Transfers permitted in specific situations where a derogation applies as set out in Article 49 of the GDPR. For example, where it is necessary to transfer information to a non-EEA country to perform our contract with you.

12. How to exercise your information rights (including the right to object)

Erasure

When do I have the right to all my personal data being deleted by LauraLynn:

You have the right to have your personal data deleted without undue delay if?

- The personal data is no longer necessary in relation to the purpose(s) for which it was collected/processed
- You are withdrawing consent and where there is no other legal ground for the processing
- You object to the processing and there are no overriding legitimate grounds for the processing
- The personal data has been unlawfully processed



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- The personal data must be erased so that we are in compliance with legal obligation

What happens if LauraLynn has made my personal data public?

If we have made your personal data public, we, taking account of available technology and the cost of implementation, will take reasonable steps, including technical measures, to inform those who are processing your personal data that you have requested the erasure.

What happens if LauraLynn has disclosed my personal data to third parties?

Where we have disclosed your personal data in question to third parties, we will inform them of your request for erasure where possible. We will also confirm to you details of relevant third parties to whom the data has been disclosed where appropriate.

Data portability

When can I receive my personal data in machine-readable format from LauraLynn?

You will receive your personal data concerning you in a structured, commonly used and machine-readable format if:

- processing is based on consent or contract
- processing is carried out by automated means.

Would LauraLynn transfer the personal data to another service provider if I requested this?

We can transfer this data to another service provider selected by you on your written instruction where it is technically feasible taking into account the available technology and the feasible cost of transfer proportionate to the service we provide to you.

Under what circumstances can LauraLynn refuse?

You will not be able to obtain, or have transferred in machine-readable format, your personal data if we are processing this data in the public interest or in the exercise of official authority vested in us.

Will LauraLynn provide me with my personal data if the file contains the personal data of others?

We will only provide you with your personal data, ensuring we protect the rights and freedoms of others. Where personal data of another person may be on the same file(s) as yours, we will redact the full details of the other person.

Contact us at (dpo@lauralynn.ie).

Automated individual decision making

What are my rights in respect of automated decision making?

LauraLynn does not have any automated decision-making processes. Where any such processes are introduced, we will provide you with the relevant information required under the "General Data Protection Regulation".



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Object

Have I already been informed about my right to object?

We have informed you of your right to object prior to us collecting any of your personal data as stated in our privacy statement.

When can I object to LauraLynn processing my personal data?

You can object on grounds relating to your situation.

LauraLynn will stop processing your personal data unless:

- we can demonstrate compelling legitimate grounds for the processing, which override your interests, rights and freedoms
- the processing is for the establishment, exercise or defence of legal claims.

Restrict processing

When can I restrict processing?

You may have processing of your personal data restricted:

- While we are verifying the accuracy of your personal data which you have contested
- If you choose restricted processing over erasure where processing is unlawful
- If we no longer need the personal data for its original purpose but are required to hold the personal data for defence of legal claims
- Where you have objected to the processing (where it was necessary for the performance of a public interest task or purpose of legitimate interests), and we are considering whether our legitimate grounds override.

What if LauraLynn has provided my personal data to third parties?

Where we have disclosed your personal data in question to third parties, we will inform them about the restriction on the processing, unless it is impossible or involves disproportionate effort to do so.

How will I know if the restriction is lifted by LauraLynn and/or relevant third parties?

We will inform you on an individual basis when a restriction on processing has been lifted. Contact us at (dpo@lauralynn.ie).

Rectification

What can I do if LauraLynn is holding incorrect personal data about me?

Where you suspect that data we hold about you is inaccurate, we will on demand rectify any inaccuracies without undue delay and provide confirmation of same.



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What happens if LauraLynn has disclosed my personal data to third parties?

Where we have disclosed inaccurate personal data to third parties, we will inform them and request confirmation that rectification has occurred. We will also provide you with details of the third parties to whom your personal data has been disclosed.

Contact us at (dpo@lauralynn.ie).

Withdraw consent

Under what circumstances could I withdraw consent?

You can withdraw consent if we are processing your personal data based on your consent.

When can I withdraw consent?

You can withdraw consent at any time.

If I withdraw consent what happens to my current data?

Any processing based on your consent will cease upon the withdrawal of that consent. Your withdrawal will not affect any processing of personal data prior to your withdrawal of consent, or any processing which is not based on your consent.

Contact us at (dpo@lauralynn.ie).

Lodge a complaint

Can I lodge a complaint with the Data Protection Commission?

You can lodge a complaint with the Data Protection Commission in respect of any processing by or on behalf of LauraLynn of personal data relating to you.

How do I lodge a complaint?

Making a complaint is simple and free. All you need to do is write to the Data Protection Commission giving details about the matter. You should clearly identify the organisation or individual you are complaining about. You should also outline the steps you have taken to have your concerns dealt with by the organisation, and what sort of response you received from them. Please also provide copies of any letters between you and the organisation, as well as supporting evidence/material.

Contact details to lodge a complaint:

Contact	Data Protection Commission
Telephone	+353 57 8685800/+353 76 1104800
Email	info@dataprotection.ie
Address	Office of the Data Protection Commission Canal House Station Road Portarlinton R32 AP23 Co Laois



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What happens after I make the complaint?

The Data Protection Commission will then take the matter up with LauraLynn on your behalf.

Access your data

When do I have the right to access my personal data from LauraLynn?

Where LauraLynn process any personal data relating to you, you have the right to obtain confirmation of same from us and to have access to your data.

What information will LauraLynn provide to me?

If we are processing your personal data, you are entitled to access a copy of all such personal data processed by us subject to a verification process to ensure we are communicating with the correct person. We will provide any of the following information:

- why we are processing your personal data
- the types of personal data concerned
- the third parties or categories of third parties to whom the personal data have been or will be disclosed. We will inform you if any of the third parties are outside the European Economic Area (EEA) or international organisations
- how your personal data is safeguarded where we provide your personal data outside the European Economic Area or to an international organisation
- the length of time we will hold your data or if not possible, the criteria used to determine that period
- your rights to:
 - request any changes to inaccurate personal data held by us
 - have your personal data deleted on all our systems
 - restriction of processing of personal data concerning you
 - to object to such processing
 - data portability
- your right to lodge a complaint with the Data Protection Commission info@dataprotection.ie
- where we have collected your personal data from a third party, we will provide you with the information as to our source of your personal data
- any automated decision-making, including profiling, which includes your personal data. We will provide you with meaningful information about the logic involved, as well as the significance and the envisaged consequences of such processing for you.

How long will it take to receive my personal data from LauraLynn?

We will provide you with a copy of the personal data we are currently processing within one month of request. In rare situations if we are unable to provide you with the data within one month we will notify you, within one month of your valid request, explaining the reason for the delay and will commit to delivery within a further two months.



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How much will it cost me to receive my personal data?

We will not charge for providing your personal data.

Can I request additional copies of my personal data?

If you require additional copies, we will charge €20 to cover our administrative costs.

Can I receive my personal data electronically?

You can request your personal data by electronic means and we will provide your personal data in a commonly used electronic form, if technically feasible.

What will LauraLynn do if another person's personal data is shared with my personal data?

We will only provide you with your personal data, ensuring we protect the rights and freedoms of others. Where personal data of another person may be on the same file(s) as yours, we will redact the full details of the other person.

Contact us at (**dpo@lauralynn.ie**).

13. Changes to this notice

Where changes to this Privacy Statement occur, the updated version will be published on our website at [www.lauralynn.ie] and where appropriate/possible communicated directly to individuals through a communication channel we deem appropriate.