

Referral Process



LauraLynn
IRELAND'S CHILDREN'S HOSPICE

What does LauraLynn do?

Lauralynn, Ireland's Children's Hospice provides palliative care to children (from 0-18) with life-limiting conditions and their families. We focus on enhancing quality of life which includes physical comfort and wellbeing, as well as the emotional, social and spiritual aspects of care. We offer an inclusive service that embraces all the family and all faiths, beliefs and cultures. We provide support from diagnosis (which maybe before a child's birth) to end of life and throughout bereavement with a range of nursing, practical, emotional and medical care. Care can be delivered in our hospice, at hospital, in the community or in the family home, depending on the child and family's preference.

The WHO defines palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment treatment of pain and other problems, physical, psychological and spiritual”ⁱ

Who can be referred to LauraLynn?

Our core criteria are that the child should:

- Be under 18* at the time of referral.
- Have a medically diagnosed life-limiting condition and fall within one of the ACT/TFSL categories (see below) and
- Have palliative care needs and would benefit from the support available from LauraLynn Hospice.
- There is a strong possibility of the child dying before the age of 18.

*Young people referred at 16 years of age and over are considered individually depending on whether they are entering the final phase of their life and there are no alternative services available to match their choice of place of care.

Limited life expectancy in a child is defined as being the result of any condition, on its own or in conjunction with others, which makes it unlikely that the child will live beyond their (late) teenage years. Due to the nature of life limiting conditions, our criteria are flexible and we always consider children and families on an individual basis.

Together for Short Lives: Categories of Life Limiting Conditions

Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver, kidney.
Category 2	Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.
Category 3	Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.
Category 4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.
Category 5	Unborn children with major health problems who may not live through birth, infants who may survive for only a few hours/days, infants with birth anomalies that may threaten vital functions, and infants for whom intensive care has been appropriately applied but developed an incurable diseases.

Figure 1: Together for Short Lives: Categories of Life-Limiting Conditions 2018

Children with Complex Neurodisability

Whilst we very much recognise the burden of care faced by families with relatively stable diseases involving complex neuro-disability, LauraLynn focuses on providing care to children and families most likely to benefit from all elements of the hospice service, including direct care, symptom management, emotional and practical support, end of life care and bereavement care.

Please note that the physical dependency of a child does not always correlate with their prognosis (i.e. may be highly dependent but stable) and children with non-progressive disabilities may not meet the referral criteria.

When referring children with complex neuro-disability, the onus is on the referrer to demonstrate palliative care needs.

Our referral form includes a section to complete which helps the referrer to illustrate additional vulnerabilities. The inclusion of medical reports, symptom management plans, emergency care plans and prescriptions are welcomed as supporting documentation.

In order to help us further identify which children may have palliative care needs, we consider the following:

1. Trajectory of disease/condition and impact on daily activities, for example
 - a. Frequency and/or prolonged hospitalisation
 - b. Deterioration in condition which highlights the life-limiting or threatening nature of diagnosis, such as, loss of independent mobility in boy with Duchenne Muscular Dystrophy, Progressive respiratory failure in child with Cystic Fibrosis:
 - c. Increasing dependence on medical technology.
2. Expected outcome of disease directed treatment and burden of treatment
3. Symptom burden
 - a. Eg severe pain/discomfort without reversible cause
 - b. Progressive feed intolerance or gut failure.
4. Preferences of child, parents or healthcare professional
5. Estimated life expectancy

“Surprise Questions” may also be beneficial to ascertain if a child is life-limited and may require palliative care support:

- **Diagnosis or recognition**

Would you be surprised if this baby / child died as a result of this condition or problem?

- **Death before adulthood**

Would you be surprised if this baby/ child died before adulthood (18th birthday)?

- **Increasing instability**

Would you be surprised if this baby / child died in the next few months to years?

Would you be surprised if this child died in the next five years?

- **Critical illness or end of life**

Would you be surprised if this baby / child dies in the next few days / weeks?

If your answer is ‘NO I would not be surprised’ to any of these questions you should be thinking about palliative care for this child or young person.

Palliative care and other health care services, aimed at prolonging life, may be delivered alongside each other, in varying proportions.







Relationship between palliative care and treatments aimed at cure or prolonging life	
	As the illness progresses the emphasis gradually shifts from curative to palliative treatment.
	Highly technical invasive treatments may be used both to prolong life and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	No cure is possible and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes.
Key:	 curative  palliative

Figure 2: Oxford Textbook of Palliative Care for Children; 2012.

When can a referral be made?

Referrals can be from the point of diagnosis of a life limiting condition; or even antenatally.

Referrals may also be made for children who do not have a clear diagnosis, but whose medical history suggests that their life expectancy is likely to be reduced.

Please do not feel that a child must be nearing end of life before referring, but do recognise that the family must be able to accept that their child's life expectancy will be limited in order to feel comfortable in a hospice environment.

Who can make a referral to LauraLynn?

Anyone, including parents, involved in the care of a child can refer to LauraLynn.

How to make a referral to LauraLynn?

The person making the referral ("the referrer") should complete the LauraLynn referral form.

Please note, parental permission is required for the referral to be made, together with consent to obtain medical information about the child (or young person) from a paediatrician and/or GP.

The referrer should inform the family that they are making a referral to LauraLynn, and that LauraLynn will contact the family and may seek further information from the referrer.

The referral form must be completed *in full* before being returned to LauraLynn at the address below. Referrals cannot be accepted unless all sections are completed and signed. Incomplete forms will be returned to Referrer.

The data included in the referral form will be held in line with Data Protection Legislation.

It is helpful if medical reports, clinic letters are included with the referral form.

What happens once a referral has been made?

Once a referral has been received, it will be considered by the multi-disciplinary clinical care forum. This committee meets weekly.

In the case of urgent referrals for end-of-life care, referrals are considered outside of this forum and accepted within hours.

In some circumstances, a member of the care team here in LauraLynn may need to visit the child and family to gather more information, in order to make a fully informed decision. We may also seek further information from a relevant health care professional before a decision to accept is made.

A letter will be sent to the parents/guardians, referrer, paediatrician and GP informing them of the decision to either ACCEPT or DECLINE the referral. We aim to inform parents and referrers of our decision within 2 weeks of receipt of a completed referral form.

On acceptance to the service the family will be contacted by a member of the clinical team to arrange a Holistic Needs Assessment. This assessment allows exploration of the family's priorities, identification of goals and planning of service provision.

All support offered is reviewed annually, so we can continue to offer the most appropriate care and ensure our resources are used fairly and in line with the needs of all the children and families using our service. Some children's health needs may stabilise and may no longer meet the criteria for services from LauraLynn Children's Hospice.

LauraLynn, Ireland's Children's Hospice does not offer long term residential care for children.

For further information on the referral criteria or process, please contact the following:

LauraLynn, Ireland's Children's Hospice
Leopardstown Road
Foxrock
Dublin 18
D18 X063

E: referrals@lauralynn.ie
T: 01-2686680
F: 01-2899972
W: www.lauralynn.ie



ⁱ World Health Organisation (2020). Global Atlas of Palliative Care, 2nd edition 2020. [Global Atlas of Palliative Care, 2nd Ed 2020 \(thewhpc.org\)](https://www.thewhpc.org/)