



## 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 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.

## 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 and requires or needs palliative care.
- There is a strong possibility of the child dying before the age of 18.

Please note, parental consent 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.

\*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.

## 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.

## Together for Short Lives: Categories of Life Limiting Conditions

<b>Category 1</b>	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.
<b>Category 2</b>	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.
<b>Category 3</b>	3 Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.
<b>Category 4</b>	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.

*Figure 1: A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions 3rd Edition, Together for Short Lives, February 2013*

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 their elements, including 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 unfortunately, children with non-progressive disabilities may not meet the referral criteria. For children that may fall within ACT/TFSL Category 4 we use the Helen & Douglas House evidence based guide to vulnerability factors for a child with a static neurological condition (See Referral Form).

**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
2. Expected outcome of disease directed treatment and burden of treatment
3. Symptom burden
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.
<b>Key:</b>	 <b>curative</b>  <b>palliative</b>

## How to make a referral to LauraLynn?

The person making the referral ("the referrer") will need to be responsible for ensuring that parents/guardians and paediatrician complete and sign the form **before** it is returned to LauraLynn.

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.

## What happens once a referral has been made?

Once a referral has been received, the Referrals Panel will review the form and decide if it is a suitable referral.

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 in order to make a fully informed decision.

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.

**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.**

**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](mailto:referrals@lauralynn.ie)  
T: 01-2686680  
F: 01-2899972  
W: [www.lauralynn.ie](http://www.lauralynn.ie)



**LauraLynn**  
IRELAND'S CHILDREN'S HOSPICE