



LauraLynn

IRELAND'S CHILDREN'S HOSPICE

LauraLynn, Ireland's Children's Hospice **Model of Care**

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1

Foreward





It gives me great pride to introduce you to the LauraLynn Children's Hospice Model of Care, which marks a coming of age for our relatively new service.

It is unclear exactly how many children in Ireland are living with a life-limiting condition but extrapolating from UK statistic would suggest there are 3,840 children, 50% of whom have palliative care needs. Furthermore, at any one time, up to 720 children with a life-limiting condition would be classified as 'unstable, deteriorating or at end-of-life'. The needs of these children, and their families, form the central purpose of LauraLynn's Children's Hospice Service, and the drive behind the development of this model.

LauraLynn has become an important element of the spectrum of care for children with life-limiting conditions that comprises statutory, charitable and voluntary providers across the acute, primary and community care setting. Our model reinforces the interdependent nature of the work we do, which, at its heart, is interdisciplinary, inter-agency and in partnership with the child and family.

This Model of Care will act as a standard of care guide in LauraLynn and I hope it will inform policy and service development both internally and nationally in our health service. It will be dynamic - evolving in line with our growing understanding of children's hospice and palliative care and in response to the changing needs of children, their families and the healthcare system that surrounds them.

The model has been developed incorporating best practice in children's palliative and hospice care globally, as well as more than eight years' experience of our organisation and staff. I am very grateful for all the support and advice we have received in during its development; from UK children's hospices that facilitated site visits and shared their practice and learnings, to individuals who have carefully reviewed draft versions and provided greatly appreciated, constructive input.

The discipline of children's palliative care is still relatively young in Ireland but there is a growing recognition of its significance and contribution in enhancing the quality of life of children with life-limiting conditions and their families. There is so much more work that needs to be done to ensure that every child and family has the care they need when they need it.

I hope and believe that this Model of Care document will be a tool to further advance children's palliative care here in Ireland and help LauraLynn to both extend our community of care and ensure that we achieve our vision to make every day better for those in our care.

A handwritten signature in black ink that reads "Orla O'Brien".

Orla O'Brien
CEO



2

Executive
Summary

2.1 Children's Palliative Care

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. LauraLynn's palliative care services are underpinned by the following definition:

"Palliative care for children and young people with life limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social and spiritual elements, and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement." (Together for Short Lives 2018. A Guide to Children's Palliative Care 4th Ed.)

In Ireland, children's palliative care has been on the national agenda for nearly two decades, commencing with the national report on palliative care in 2001, followed by a National Needs Assessment in 2005 and in 2009 a National Policy on Caring for Children with Life-limiting Conditions was published by the Department for Health and Children. More recently, the national Paediatric Model of Care and the cross-party Slainte Healthcare Report (2017) both reference children's palliative care. Currently in Ireland, services are provided by both statutory, voluntary and private sector organisations across health and social care.

2.2 Children's Hospice Care

Children's hospices provide a range of interdisciplinary care and supports to children with life-limiting conditions including support for the entire family, short break care, practical help, advice and information, provision of specialist therapies, provision of information, education and training, bereavement support, 24-hr phone support, 24-hr access to emergency care and 24-hr end-of-life care. (TFSL, 2018). Children's hospice services may be provided in the home or in a purpose-built building.

LauraLynn, Ireland's Children's Hospice is the only children's hospice operating in the Republic of Ireland. As a relatively new service provider in the ever growing and evolving space of children's palliative and hospice care here in Ireland, LauraLynn aims to provide excellent care to all children with palliative care needs and their families. With the right resources and support to draw upon, the quality of life for children with life-limiting conditions, and their families can be enhanced.

2.3 LauraLynn Children's Hospice Model of Care

A model of care defines the way services are currently delivered. This document therefore provides a description of the care that is provided by LauraLynn and is considered to be a dynamic and evolving document. The LauraLynn Children's Hospice Model of Care is supported by the aforementioned Irish documents as well as international research, practice, guidelines and pathways.

The aim of the 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. The model describes the LauraLynn Children's Hospice Care Pathway from the referral criteria and process, to the range of supports offered based upon individual child and family holistic needs, along with the development of family-related outcomes or goals, through to the annual review and discharge process, including transition to adult services and for some children, to end of life care and bereavement.

2.4 The Five Pillars of Care

The LauraLynn Children's Hospice 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.

Direct Care includes short breaks / respite for children and their families either in the purpose built hospice or support in the family home. This care may be either planned or unplanned to support a crisis. Step-down care, supporting a child and family move from acute hospital to home, may also be provided in our hospice.

Family Support encompasses our comprehensive, therapist-led and targeted interventions for children and their families provided by our interdisciplinary health and social care professionals. LauraLynn Family Supports focus on the child and family's spiritual, social and occupational, psychological, emotional and physical well-being. The primary focus of all family supports is to maintain and enhance the quality of life for the child and family by building resilience, promoting well-being and reducing distress.

Symptom Management focuses on the assessment and interdisciplinary, multi-modal management of symptoms that may be present at any time along the trajectory of the child's condition. Our consultant-led medical team, clinical nurse specialists, along with the broader care team and family support team, strive to optimise quality of life and reduce possible suffering associated with the burden of physical, emotional, spiritual and social symptoms.

End of Life Care can be supported in LauraLynn House, in the family home, or in the hospital, thereby offering children and families a choice in location of care and in location of death. Our Butterfly Suite can be used after a child has died, regardless of where the death occurred.

Bereavement Supports are offered to all family members right from the initial referral, or diagnosis / recognition of a life-limiting condition, and continue after the child's death and beyond. Supports are holistic in addressing the social and emotional needs of bereaved family members, helping them through the grieving process whilst nurturing positive relationships, fostering resilience, self-esteem and emotional well-being.

LauraLynn acknowledges that no single organisation or service can provide the level of care required to meet the complex needs of these children and their families, right from the point of diagnosis or recognition of a life-limiting condition, living with the condition through to end of life care and bereavement. Therefore, our Hospice Care Team aims to support each child and family through effective communication, coordination and collaboration with other service providers and health care professionals, whilst keeping the child and family at the centre of everything we do.

In addition, effective workforce planning, recruitment and retention, including education and training as well as appropriate staff supports are essential to achieving this model.

LauraLynn recognises too the paucity of research in the area of children's hospice and palliative care, and therefore intends to undertake research to provide further evidence for this model, as well as the development of this evolving specialty in general.

Finally, LauraLynn recognises the critical importance of good quality, safety and risk management, with a strong emphasis on both leadership and accountability, and therefore, underpinning all components of this model are clear corporate and clinical governance structures.

3

Introduction
to Children's
Palliative Care



3.1 Defining Children's Palliative Care

Together for Short Lives (TFSL), previously ACT, in association with the Royal College of Paediatrics and Child Health defined palliative care for children as "an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child, and support for the whole family. It includes the management of distressing (acute and chronic) symptoms, provision of short breaks, care at the end of life and bereavement support" (ACT & RCPCH, 2003). Paediatric Palliative Care or Children's Palliative Care¹ is concerned with providing care to children with either life-limiting, life-threatening or life-shortening conditions who are considered unlikely to reach adulthood. Children's palliative care may start ante-natally and continue beyond a child's 18th birthday when supporting transition. It has been further defined by Craft & Killen, as being "the need to maintain quality of life, not just in the dying stages, but also in the weeks, months and years before death and is characterised by concern for symptom relief, promotion of general well-being, and psychological and social comfort for the child and family." (Craft & Killen, 2007).

3.2 Difference Between Palliative Care for Adults and for Children

The Department of Health and Children (2009) noted that the principles of palliative care for adults and children are similar, however, a number of differences exist that warrant an approach specifically for children with life-limiting conditions, and their families.

These differences include:

- Significantly smaller patient numbers in comparison to the adult population
- A wide range of life-limiting illnesses affecting children and the lengths of illnesses vary from days to years; there may also be a fluctuating and uncertain disease trajectory
- Children may have significant intellectual and physical disabilities associated with their conditions, which further complicate the palliative care approach
- Parents play an active part in decision making for their child as well as providing their ongoing care
- The death of a child is uncommon and there is increased risk of complicated grief and prolonged bereavement of family, including siblings
(Dept. Health & Children, 2009)

3.3 Terminology in Children's Palliative Care

There are several terms that refer to complex medical diagnoses that children may be born with or acquire during childhood. In general, life-limiting is used when there is no reasonable hope of cure and that the child's life is limited in scope. Whereas life-threatening is used when there is a possibility of cure or to describe a specific point in the disease trajectory where there is an immediate threat of death. Life-shortening may also be used to distinguish conditions that will reduce the lifespan of the child.²

¹ For the purpose of this document, the term Children's Palliative Care is used and child / children includes infants, children and young people, from birth to 18 years.

² The term, 'life-limiting condition' will be used throughout this document to include life-limiting, life-threatening and life-shortening conditions.

3.3.1 Four Groups of Life-limiting and Life-threatening Conditions

The types of life-limiting conditions that affect children and for which palliative care may be required were categorised by TFSL in the United Kingdom:

CATEGORY	
1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail.</p> <p>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.</p> <p><i>Examples: cancer, irreversible organ failure of heart, liver, kidney</i></p>
2	<p>Conditions where premature death is inevitable.</p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: Cystic fibrosis, Duchenne muscular dystrophy</i></p>
3	<p>Progressive conditions without curative treatment.</p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, Mucopolysaccharidoses</i></p>
4	<p>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</p> <p><i>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</i></p>

FIGURE 1: Four Groups of Life-Limiting and Life-Threatening Conditions (TFSL, 2018)

The aforementioned groups are widely used internationally to guide health care professionals, however in acknowledgement that recognising this cohort of children may remain difficult, Hain et al (2013) compiled a list of over 300 ICD10 diagnoses that have been judged by professionals working in paediatric palliative care to be life-limiting. International Classification of Diseases (ICD) codes are the preferred method of collecting data on childhood death (ImPACCT 2007).

3.4 Levels of Children's Palliative Care

For those children with life-limiting conditions that are identified as having palliative care needs, three levels of children's palliative care with increasing specialisation are recommended:

Level 1 – The palliative care approach, where palliative care principles should be appropriately applied by all healthcare professionals

Level 2 – General palliative care, where at an intermediate level, a proportion of children and families will benefit from the expertise of healthcare professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care

Level 3 – Specialist palliative care services are those whose core activity is the provision of palliative care.

(Craig et al, 2007)

Aligned with these levels of specialisation, Together for Short Lives (2018) recommends that "the elements of children's palliative care provided along the care pathway should be provided at all levels: universal, core, and specialist".

Universal Services cover a broad spectrum of children's palliative care that children with life-limiting conditions should receive from all health and social care professionals involved in their care

Core (Targeted) Services encompass the largest number of children's palliative care services and provide targeted and skilled support including nursing support, emotional and psychological support, short breaks, provision of specialist equipment, social and practical support, transport, coordination of services, play services, and therapies including physiotherapy

Specialist Support Services should include: specialist psychosocial support, including 24/7 availability at times of crisis and when the child dies, access to 24-hr specialist advice and expertise, effective management of symptoms to reduce pain and other distressing symptoms, outreach or home-based services, expert children's palliative care, support and advice available to the children and family 24/7/365, and medically supported short breaks (TFSL, 2018)

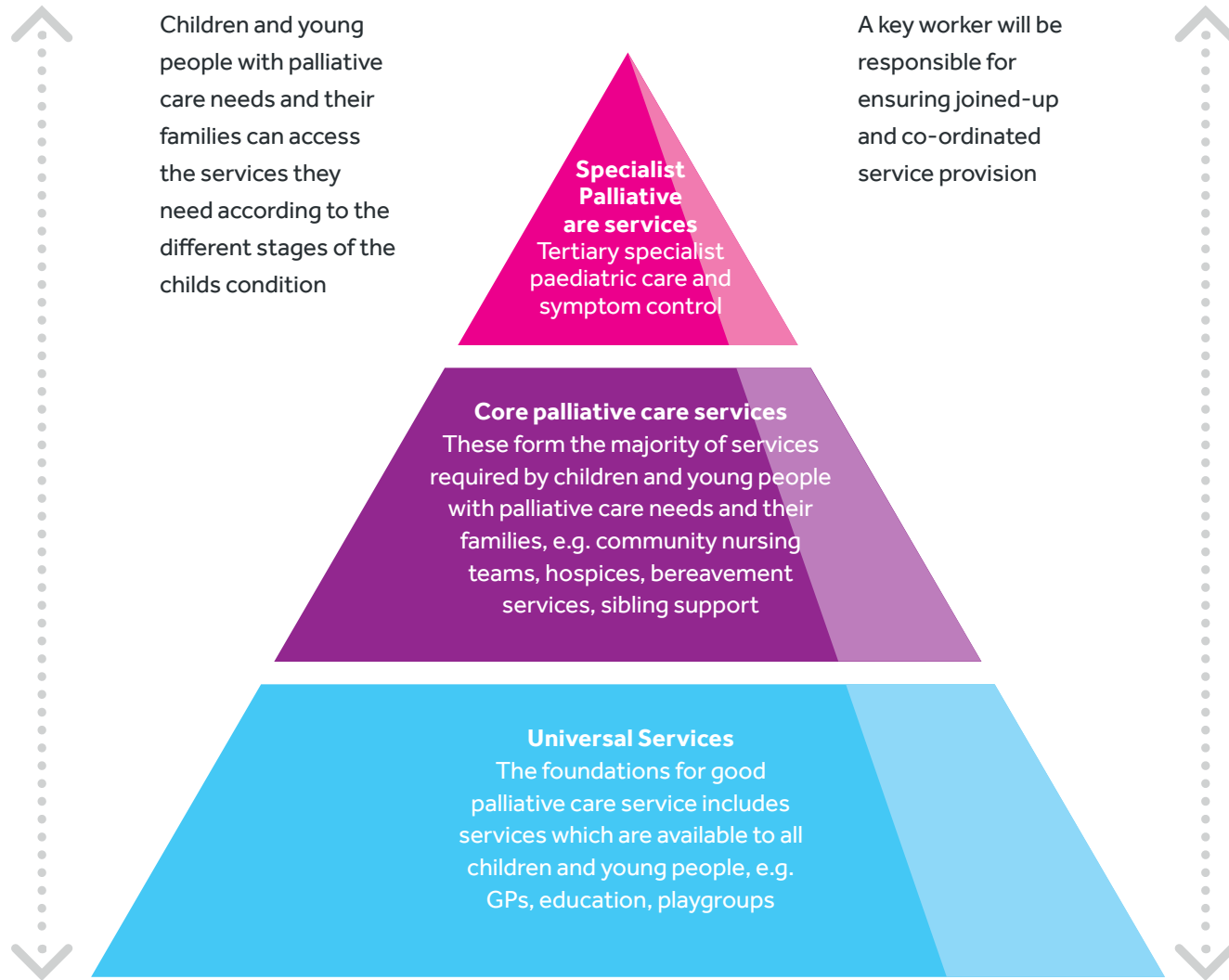


FIGURE 2: Different levels of palliative care services, which should form the basis of Children's Palliative Care (Craft & Killen, 2007)

3.5 Children's Palliative Care Interdisciplinary Team

Being cared for by an inter-disciplinary team helps to ensure necessary assessments are carried out and treatment can be provided to resolve any distressing symptoms. It is suggested therefore, that the interdisciplinary team, essential to support the running of a children's palliative care service, will include at a minimum:

- Medical staff (with additional experience in paediatric palliative medicine)
- Nurses (including those with special expertise in children's palliative care e.g. symptom management)
- Pharmacist
- Social worker
- Psychologist
- Play specialist / youth worker
- Experts in child and family support who have experience in end of life care

(NICE, 2016)

3.6 Children's Palliative Care Interventions

Children's palliative care, including specialist interventions, usually involves some or all of the following components; assessment of need, planning of care and delivery of care. The associated interventions are likely to fall into one or more of the following categories:

- Communication
- Advance care planning / emergency healthcare planning
- Co-ordination of care / key working
- Discharge planning, including rapid discharge to facilitate end of life care in the setting of choice for child and family
- Education (of child / family)
- Social support (for the child or family including siblings)
- Psychological support (for the child or family including siblings)
- Non-pharmacological symptom management techniques such as guided imagery, massage
- Pre-bereavement and bereavement support (for child and family including siblings)
- Pain management
- Symptom management other than pain
- Short break care away from home
- Short break care at home, school or other community
- End of life care (care in the last hours and days of life) including provision of 24 hours a day, 7 days a week, on call service
- Transition from children's services to adult services

4

Introduction to Children's Hospice Care



4.1 What is Children's Hospice Care

The world's first children's hospice was established in 1982 in England and since then there are over 50 children's hospices operating in the UK, with numerous other countries providing children's hospice services (USA, Canada, Australia, South Africa, China, Sweden, Denmark, Poland, Hungary, Austria and Ireland). LauraLynn, the Republic of Ireland's first and only children's hospice opened its doors in September 2011.

Whilst there is no one single model of children's hospice care, all children's hospices are focused on improving the quality of life of children who are not expected to live to reach adulthood, and that of their families. They provide flexible, practical and free support to the entire family, often over many years and at various stages of the child's illness. Children's hospices often provide an enhanced level and expertise of service, beyond universal services, and are therefore considered to be the providers of both core and specialist palliative care for children with life-limiting conditions and their families.

Delivered by an interdisciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the physical, emotional, social and spiritual needs of both the child and their family through a range of supports. Indeed, the philosophy underlying the highly individual and holistic care that children's hospices offer to families does much to inform and promote the development of children's palliative care.

4.2 Aims of Children's Hospice Care

The aims of children's hospice care are to:

- Provide high quality, child and family led care, based upon an assessment of their needs, in the preferred location of care
- Ensure all children and their families have equitable access to palliative care services that are flexible, planned, person-centred and takes account of their physical, emotional, social and spiritual needs
- Provide compassionate care and support in a friendly environment and to facilitate a supportive network for the child and family

4.3 Range of Children's Hospice Supports

By offering the option of supports in a comfortable, family-friendly and purpose-built accommodation, as well as in the family home, children's hospice services allow families to feel supported, refreshed and enabled to continue to care for their child. A child's needs may be assessed and reviewed by the expert team who specialise in children's palliative care, both in the family home and during a stay in the hospice building. The types of supports offered to children and their families may include, but are not limited to:

- Support for the entire family (including siblings, grandparents and extended family)
- Specialist short break care (respite)
- Practical help, advice and information
- Provision of specialist therapies, including physiotherapy, occupational therapy, play and music therapy
- Provision of information, support, education and training to carers
- Symptom management
- Bereavement support
- 24-hour telephone support
- 24-hour access to emergency care
- 24-hour end of life care



5

Children's
Palliative Care –
The Irish
Context

5.1 Irish Publications:

Children's palliative care in Ireland is referenced in a report by the National Advisory Committee on Palliative Care (2001) that advocates further research into the palliative care needs of children and their families. It notes that Children's palliative care should include the provision of respite / short breaks to children and their families.

Since then, a further five significant documents have been published in Ireland relating to children's palliative care and one report on the future of healthcare in general including specific reference to children's palliative care:

- A Palliative Care Needs Assessment for Children (2005) Dept. of Health & Children and Irish Hospice Foundation
- Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (2009) Department of Health & Children
- Respite Services for Children with Life-Limiting Conditions and their Families in Ireland – A National Needs Assessment (2013) Irish Hospice Foundation and LauraLynn, Ireland's Children's Hospice
- Evaluation of the Children's Palliative Care Programme (2016) Department of Health & Children, HSE and Irish Hospice Foundation
- Committee on the Future of Healthcare – Slaintecare Report (2017) Department of Health & Children

Additionally, the National Clinical Programme for Paediatrics and Neonatology (HSE & RCPI) published their Model of Care for Paediatric Healthcare Services in Ireland (2017) thus highlighting the importance of having a model of care for healthcare services provided to children in Ireland. Within this model is a chapter dedicated to Children's palliative care.

5.1.1 A Palliative Care Needs Assessment for Children (2005)

The 2005 Palliative Care Needs Assessment proposed four key principles upon which future service developments should be based:

Inclusiveness – All children regardless of culture, geographical location and age should be able to access appropriate care. All providers should have access to specialist palliative care as required

Partnership – The active participation of all stakeholders including the child should be facilitated. Parents should be incorporated as partners in the process of decision-making and in the planning of care

Comprehensiveness – Care should include a focus on psychological, emotional, educational and spiritual needs of a child and his or her family

Flexibility – Care should be adaptable to the individual and changing needs of the child and his or her family. High quality care for children with palliative needs should be provided regardless of location or diagnosis

It also recommended the following:

- Equity of service provision
- Home care and community support services
- Key worker for each child
- Readily available access to locally based respite (short breaks)
- Broader range of bereavement services

5.1.2 Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (2009)

Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (2009) works as a blue-print for children's palliative care services in Ireland, and makes several key recommendations that give clear direction to the development and delivery of services for children with life-limiting conditions in Ireland.

The policy acknowledges the significant role of the voluntary sector in responding to the healthcare needs of children with life-limiting conditions and recommends the on-going involvement of this sector in the planning and delivery of specialist palliative care services.

Respite is defined in the policy as "the provision of appropriately trained individual(s) to care for children with life limiting conditions, for a specific period of time, thus providing temporary relief to the usual care giver". It notes that as international experience has shown, the preferred model of care for children with life-limiting conditions is 'hospice@home' with nursing and interdisciplinary team input providing care and support. However, it further states that inpatient hospice beds, specifically for respite should be developed as part of children's palliative care.

5.1.3 Evaluation of the Children's Palliative Care Programme (2016)

An evaluation of the national children's palliative care programme (2016) prioritised service developments such as:

- Bereavement services
- In-home and out-of-home respite care for children with life-limiting conditions and complex care needs
- Proper provision of end of life care
- Access to out of hours care
- Transition from children's to adult services

5.1.4 Model of Care for Paediatric Healthcare Services in Ireland (2017)

The National Model of Care for Paediatric Healthcare Services in Ireland (2017), which has been approved for implementation by the HSE Leadership, states that current children's palliative care services are insufficient to meet the increasing needs. The proposed model of care is aimed at promoting equal access and also states that care should be flexible and adaptable to meet the individual and changing needs of the child. It again supports the 2009 National Policy position on respite, bereavement care and also working with voluntary agencies. It also notes that children should continue to access palliative care services from a number of healthcare providers in various settings and include hospice-at-home, home respite, inpatient hospice and specialist palliative care services.

5.1.5 Committee on the Future of Healthcare – Slaintecare Report (2017)

The Slaintecare Report is a vision for a new health service in Ireland. Importantly, it recommended additional funding for palliative care in Ireland, specifically referencing LauraLynn Children's Hospice, children's respite and palliative care services.

6

**Children's
Palliative Care –
The International
Context**



6.1 International Publications

In addition to the aforementioned Irish documents, a number of international organisations have developed and published guidelines for children's palliative care, which reflect current principles and best practice. Whilst it is not possible to summarise all relevant publications within this document, some of the key ones are noted here:

- A Guide to Children's Palliative Care (4th Edition) - Supporting babies, children and young people with life-limiting and life-threatening conditions and their families (2018) Together for Short Lives
- The Big Study: For Life-limited Children and their Families (2012) Together for Short Lives
- Core Standards for Paediatric Palliative Care (2007) European Association for Palliative Care, IMPaCCT
- United States Congress (2008), Children's Program for All-Inclusive Coordinated Care Act of (ChiPPAC) developed by Children's Hospice International
- Standards for Pediatric Palliative and Hospice Care for Children – Advancing Care for America's Children (2009) American Academy of Pediatrics; Committee on Bioethics and Committee on Hospital Care
- End of life care for infants, children and young people with life-limiting conditions: planning and management (2016) National Institute for Health & Care Excellence (NICE)
- Palliative Care for Children and Young People in Wales: Meeting future needs (2015) Welsh Institute for Health and Social Care - University of South Wales

6.2 Common Themes

Common throughout many of the publications are the best practice principles of an integrated approach to care, where all children with life-limiting conditions are considered for referral to palliative care services and that services should be both interdisciplinary and flexible, regardless of geographic location. This integrated approach also recognises that the concept of parallel planning is essential, whereby palliative care may be offered to children and their families alongside curative treatment, or treatment aimed at significantly prolonging life. In addition, the importance of short breaks, irrespective of location, both for the child as well as the family is a constant, as too is ensuring that services are needs-led and responsive to changes in the child and family's condition.

A young child with a missing tooth is lying on a bed, smiling. The child is wearing black pajamas with a colorful Halloween pattern featuring pumpkins, stars, and a ghost. The bed has a blue quilted blanket. A blue circle with the number 7 is on the left side of the image.

7

Children's
Palliative
Care Data

7.1 Prevalence Rates of Children Living with Life-Limiting Conditions

Ireland, similar to many other countries, does not have a national database identifying all children with life-limiting conditions and therefore much of the data relating to children's palliative care is inferred from UK studies.

At present it is estimated that 25% of our population is aged 0-17yrs and matching this with a prevalence rate of 32:10,000 per child population extrapolated from UK data it is suggested therefore that approximately 3,840 children in Ireland are living with a life-limiting condition and of these, approximately 370 children will die every year (Ling et Al. 2014). Furthermore, according to UK research and data, whilst prevalence of life-limiting and life-threatening conditions has increased for all age groups, it has increased most significantly for neonates and young adults (16-19 year olds) (Fraser et. Al 2015). Research is required to ascertain if this is applicable to the Irish population.

7.2 Estimating Prevalence Rates of Children with Palliative Care Needs

Although estimating the number of children and young people who actually require palliative care is further problematic because it is defined, not by organ system, but by the needs of an individual child and family (Wales Institute, 2015) it is suggested that, based upon expert opinion, at any given time, roughly 50% of children living with a life-limiting condition will have palliative care needs (TFSL, 2013). Therefore, based upon the 2016 Irish Census, (CSO, 2016) there are an estimated 1905 children in Ireland, living with a life-limiting condition, who may have palliative care needs.

7.3 Prevalence Rates of Children Requiring Specialist Palliative Care

To date there has been no published research in Ireland estimating the proportion of children with life-limiting conditions who are not clinically stable and therefore in greater need of input from services that may offer specialist children's palliative care. Fraser et Al (2015) carried out a study in Scotland that considered four clinical stages (stable, unstable, deteriorating and dying). From this research it would suggest that each year 14-19% of children and young people with a life-limiting condition were unstable (12-15%), deteriorating (1.6-2.2%) or dying (1.1-1.6%). Within an Irish context this would therefore suggest that anywhere from 538-730 children living with a life-limiting condition may be considered unstable, deteriorating or dying and benefit from additional and specialist palliative care services.

A young child with dark hair is sitting in a red, quilted stroller. The child is crying with their mouth wide open and eyes squeezed shut. They are wearing a dark blue shirt and a red and white patterned bib. A small blue toy is visible in their hands. The background shows a hospital or clinic setting with a person's hand on a metal cart to the left and a green floor mat to the right.

8

**Children's
Hospice
Care Data**

8.1 National Data for Children's Hospice Care

LauraLynn Children's Hospice is the only children's hospice in the Republic of Ireland and therefore data collected in LauraLynn may provide some evidence towards the need for children's hospice care in Ireland, but not necessarily to national prevalence rates; further research in this area is therefore required.

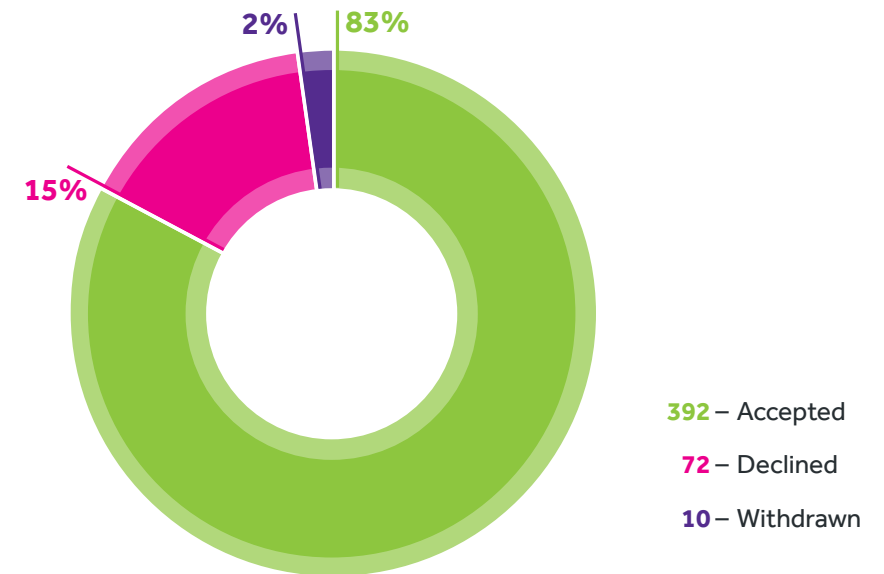
8.2 Referral Data

Since opening in September 2011 until December 2018, over 400 children have been referred to LauraLynn. With an acceptance rate of 80% to date, LauraLynn has supported over 323 children with life-limiting conditions and their families. Of these approximately 38% have died.

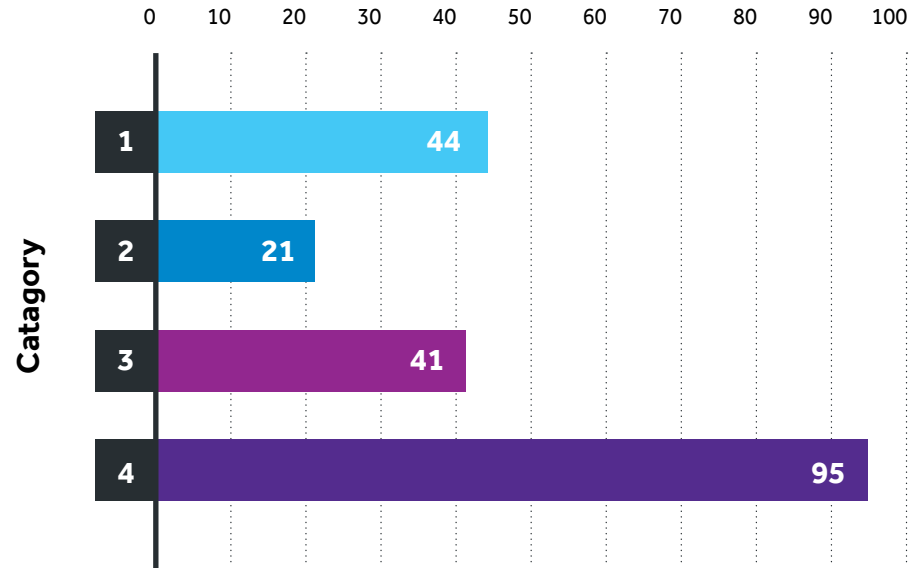
The following tables present some of the key data for LauraLynn over the period of January 2015 to December 2018. Of note:

- Over the last four years, approximately 66% of deaths have occurred in the same year as referral
- The majority of referrals come from Clinical Nurse Coordinators (previously Children's Outreach Nurses) or consultant paediatricians, with other referrals coming from a range of health care professionals both within the acute and community setting, as well as just over 9% coming from a parent or family member
- The majority of children and families referred to LauraLynn are from the Greater Dublin and Leinster region, but as of December 2018, there were children receiving supports from LauraLynn residing in 22 of the 26 counties in Ireland

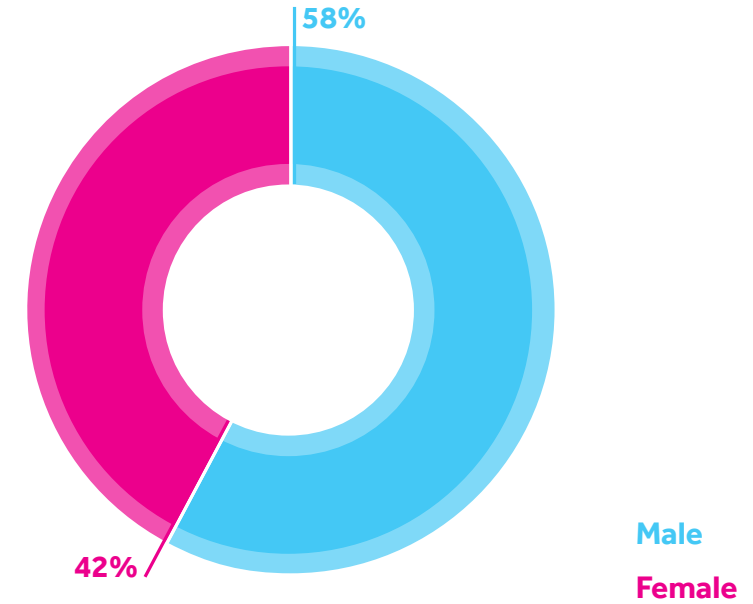
Total referrals September 2011 – December 2018: N = 474



Total Accepted from January 2015 – December 2018:
N = 201

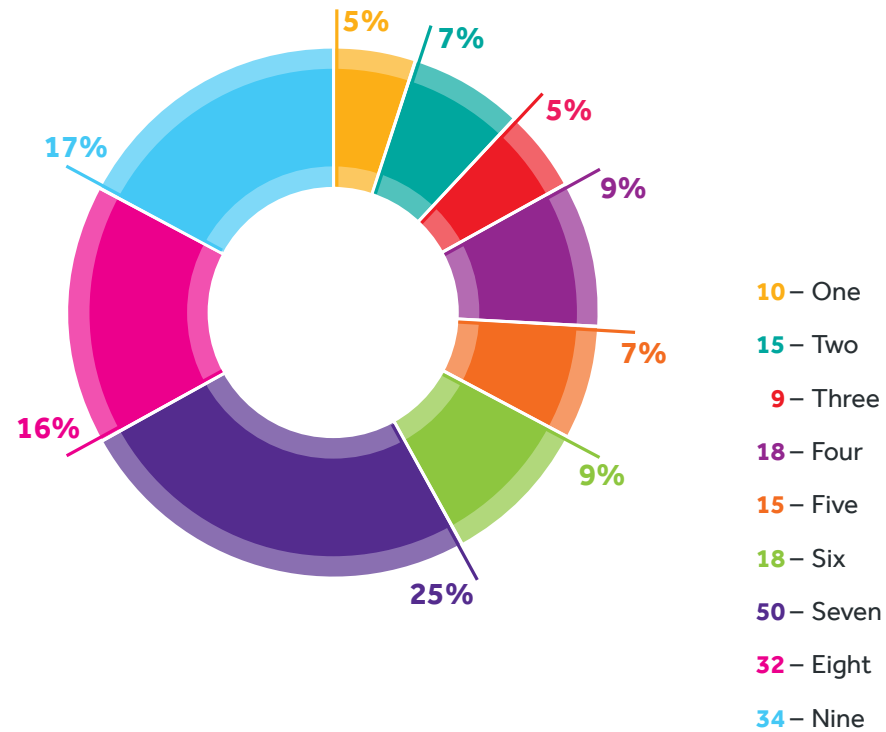


ACT/TFSL Category

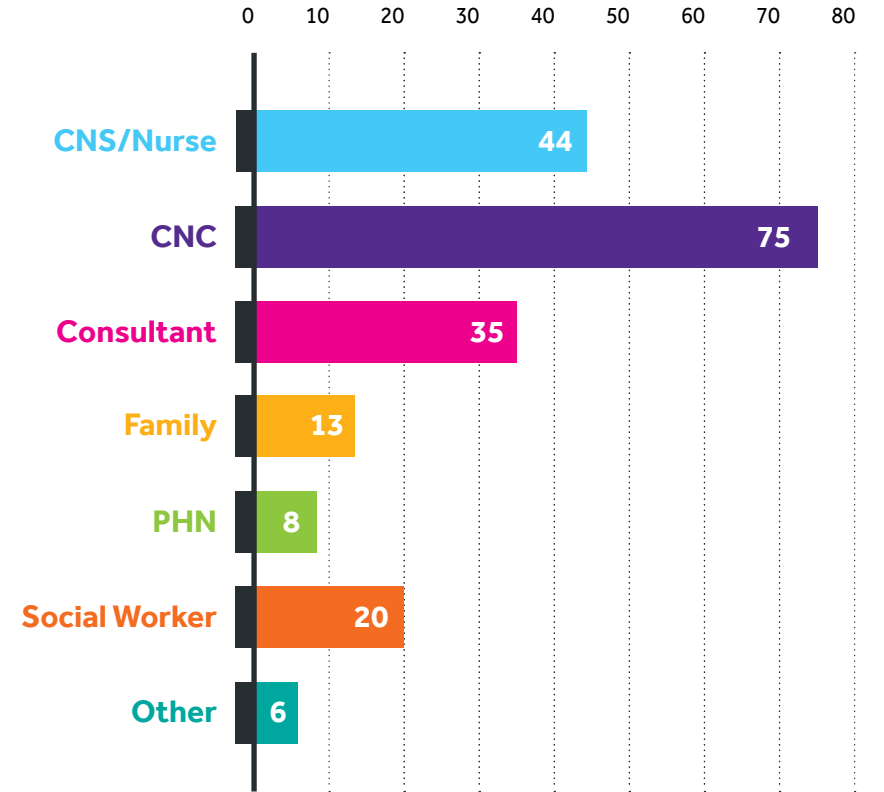


Gender

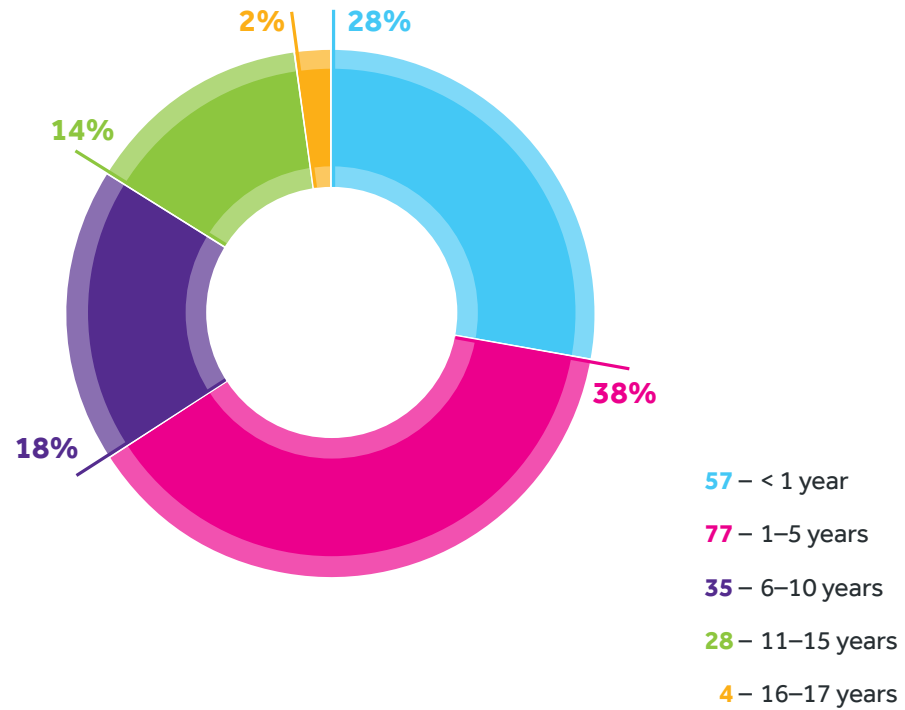
Total Accepted from January 2015 – December 2018: N = 201



CHO Area

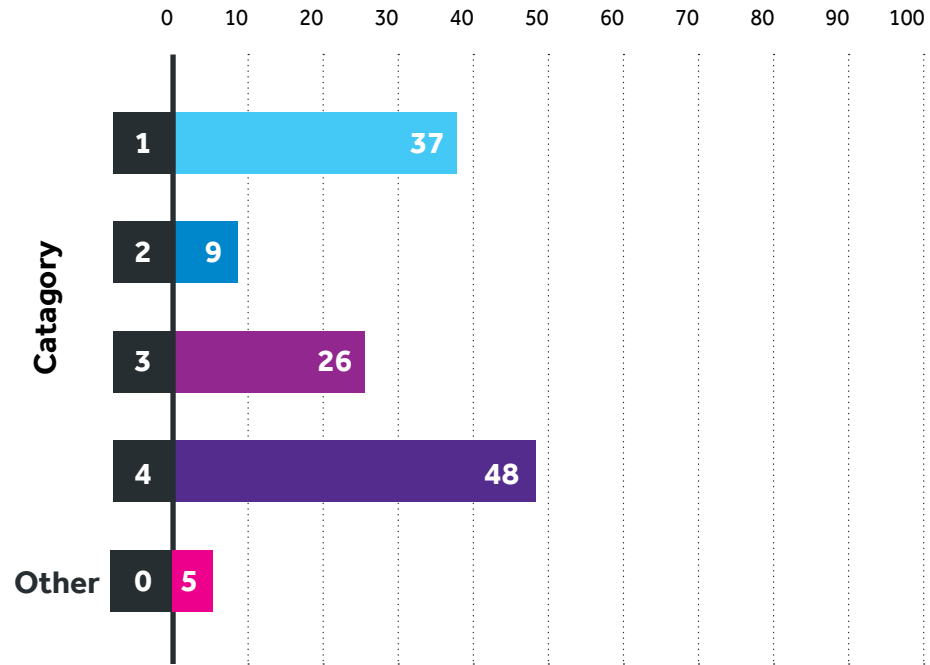


Source of Referral

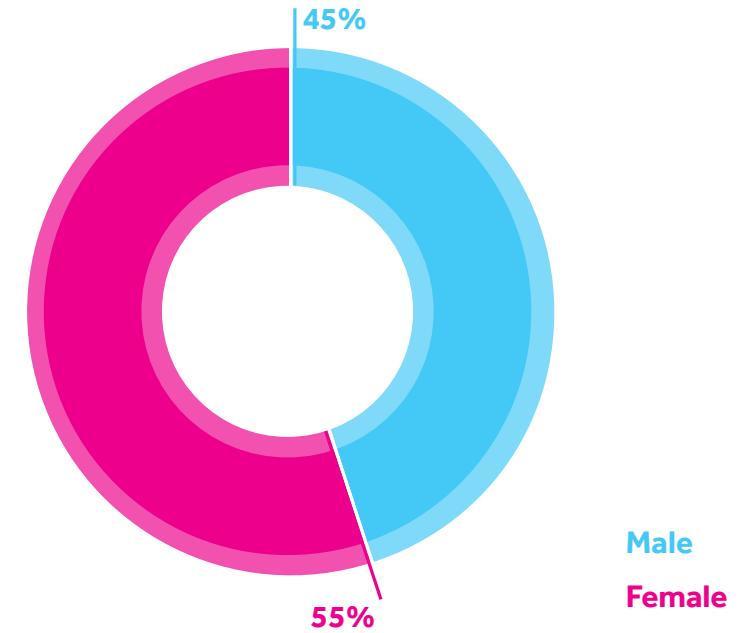
Total Accepted from January 2015 – December 2018: N = 201

Age at Referral

Total Number of Deaths from January 2015 – December 2018: N = 125

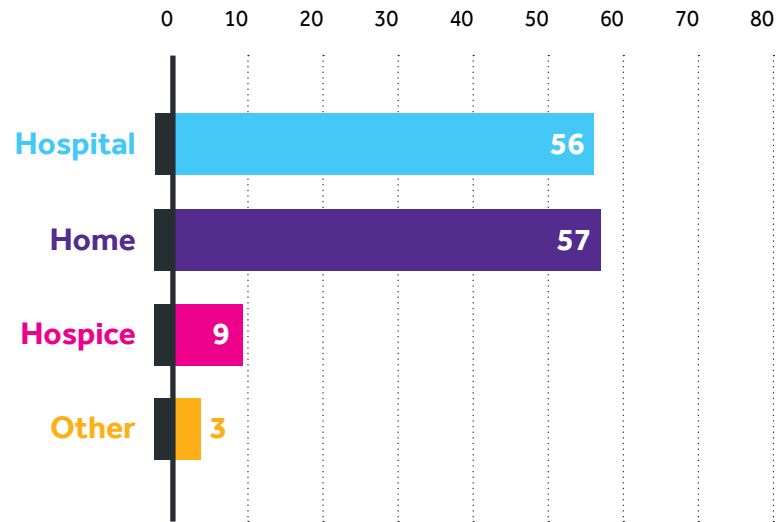


ACT / TFSL Category

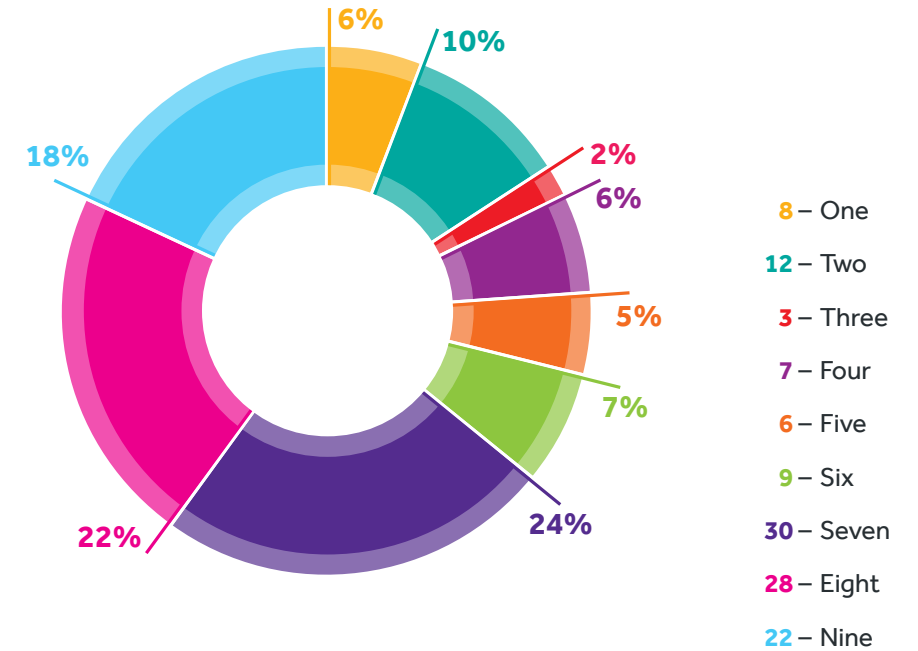


Gender

Total Number of Deaths from January 2015 – December 2018: N = 125

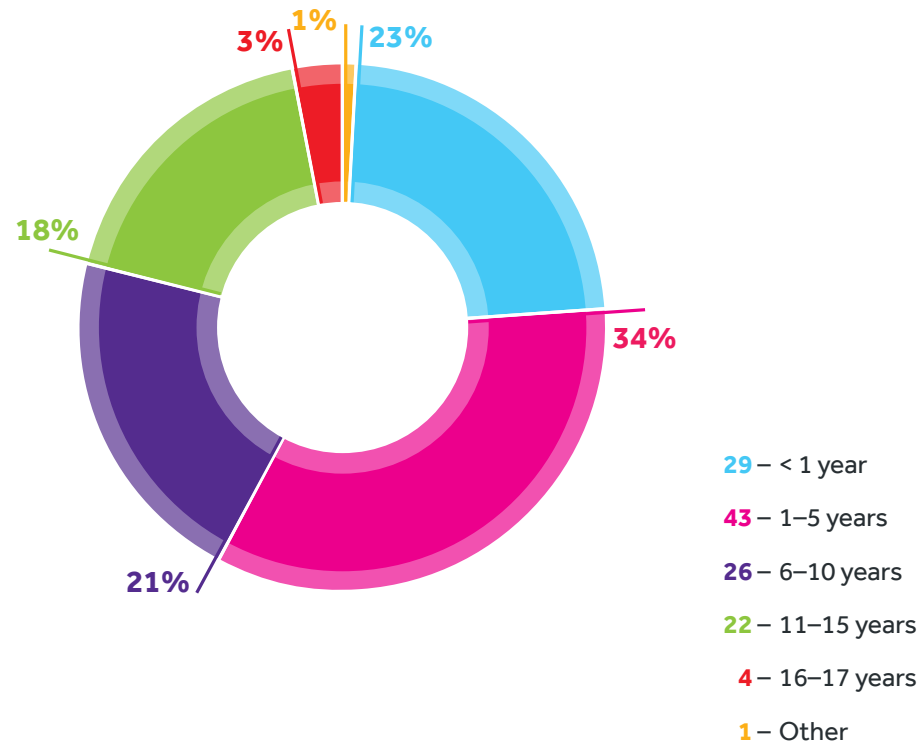


Location of Death

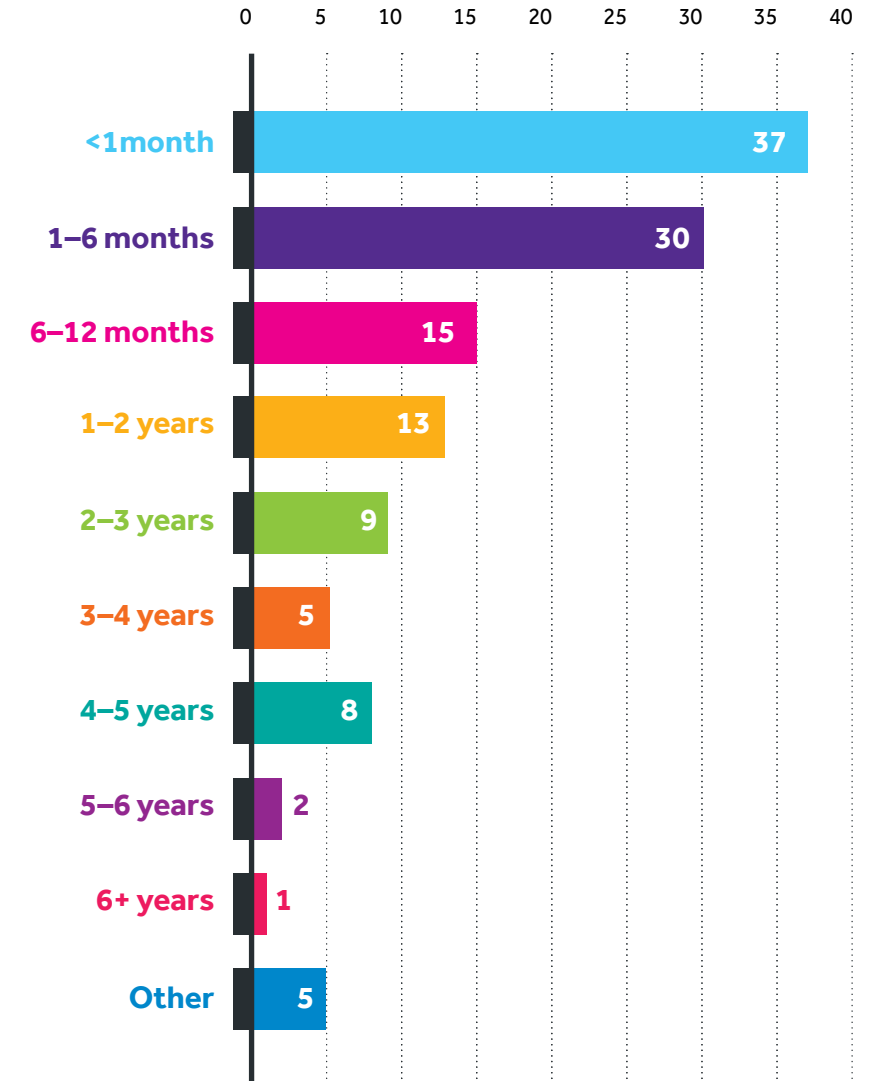


Deaths by CHO area

Total Number of Deaths from January 2015 – December 2018: N = 125



Age at Death



Length of Time in Service at Death

9

The LauraLynn
Children's Hospice
Model of Care



9.1 What is a Model of Care

A “model of care” broadly defines the way services are delivered and outlines best practice care. It aims to provide a descriptive picture of practice, which effectively represents how services are currently delivered. It should be dynamic and evolving in nature, so as to continuously reflect current service provision (ACI, 2013).

9.2 What is a Model of Care

In 2015 LauraLynn Children’s Hospice commenced a project to identify, define and document our children’s hospice and palliative care services. As part of this process, extensive review of research and current best practice was carried out. It was subsequently concluded that the most appropriate format to present findings is a model of care.

The following broadly represents the approach adopted:



FIGURE 3: Approach to Model of Care Design

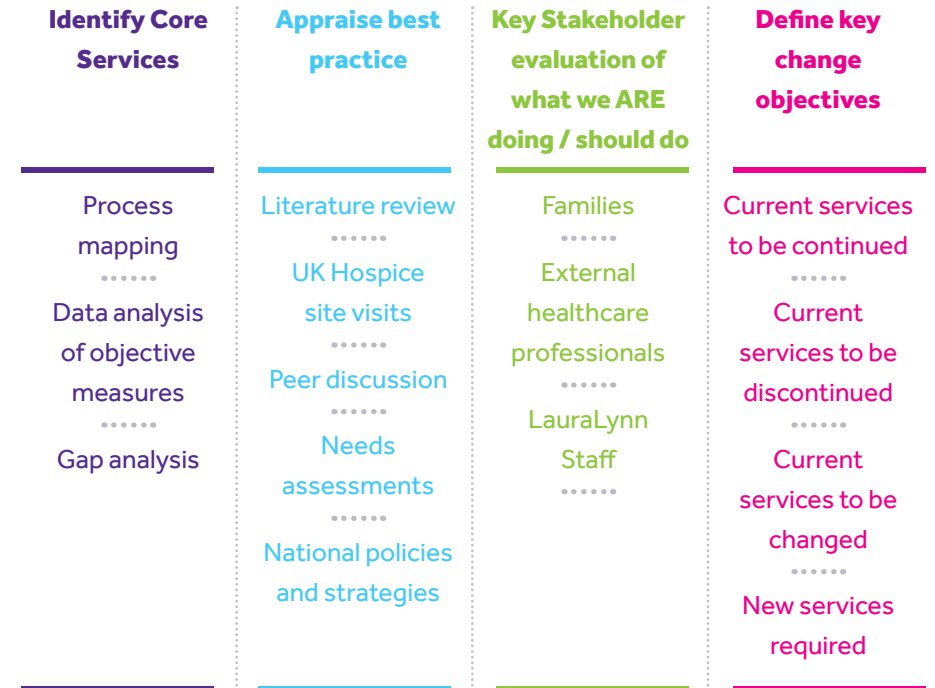


FIGURE 4: Key Processes Involved in Model of Care Design

9.3 The LauraLynn Children's Hospice Model of Care Aims – The 5 Rs

By having a clearly defined and articulated model of care, it will help ensure that LauraLynn staff, the children and their families, as well as other healthcare professionals, understand the nature of the service and are working towards a common set of goals.

The LauraLynn Children's Hospice Model of Care aims to ensure that:

The Right Child, receives the Right Care, at the Right Time, in the Right Place, by the Right Team

- LauraLynn's Referral Guidelines are clear and objective, to help to ensure the **Right Child** and family is supported
- Our Holistic Needs Assessment Process, Annual Reviews and Key Working Teams ensure that the **Right Care** is provided to each child and family
- Our links with external health care professionals, and key staff help identify those children and their families that may benefit from a hospice care pathway at the **Right Time**
- We offer our services in a range of locations, including our hospice building, the family home and the acute setting to ensure that a child and family's preferred care is achieved in the **Right Place**
- Our workforce recruitment and retention, along with our education, training and development plans ensures that all children and their families are being cared for by appropriately skilled and knowledgeable healthcare professionals – the **Right Team**



FIGURE 5: The LauraLynn Children's Hospice Model of Care Aims – The 5 Rs

10

The LauraLynn
Children's Hospice
Care Pathway



10.1 LauraLynn Children's Hospice Pathway

The LauraLynn pathway aims to best reflect the journey a child and family may travel when engaging with LauraLynn as well as all the elements of the model of care. The pathway recognises that supports may be available to the child and family through each different stage – Diagnosis / Recognition of Life-Limiting Condition, Living with the Condition, End of Life and Bereavement. (See [Appendix 1 LauraLynn Children's Hospice Care Pathway](#))

10.2 LauraLynn Children's Hospice Referral Process

LauraLynn believes that all children with palliative care needs should have access to our hospice supports, when and where they need it and that it is offered to the child and family, from the perinatal stage, through to the child's 18th birthday. Our referral criteria are designed to identify those children living with a life limiting condition who have palliative care needs. Whilst LauraLynn very much recognises the burden of care faced by families caring for children with relatively stable diseases and conditions, LauraLynn focuses on providing care to children and families most likely to benefit from the various pillars of care:

- [Section 13](#) Pillar One – Direct Care
- [Section 14](#) Pillar Two – Family Support
- [Section 15](#) Pillar Three – Symptom Management
- [Section 16](#) Pillar Four – End of Life Care
- [Section 17](#) Pillar Five – Bereavement Care

In order to ensure an effective and objective process, eligibility is assessed by an inter-disciplinary referral panel and is based upon medical diagnosis, clinical assessment and information specific to the child.

10.3 LauraLynn Children's Hospice Referral Criteria

The LauraLynn Referral Criteria state that the child must:

- Be under 18³ at the time of referral
- Have a medically diagnosed life-limiting condition (or diagnosed with a condition in the antenatal period) as per the ACT/TFSL categories
- Have identified palliative care needs

In addition, there must be a strong possibility of the child dying before adulthood.

The LauraLynn Children's Hospice Referral Form is available to download on www.lauralynn.ie or by contacting a Clinical Nurse Specialist

10.3.1 Additional Measures to Help Identify Palliative Care Needs

Further consideration is given to the following to best help identify which children may have palliative care needs:

- Trajectory of disease/condition and impact on daily activities
- Phase of illness – Stable, Unstable, Deteriorating, Dying
- Expected outcome of disease directed treatment and burden of treatment
- Symptom burden
- Expert opinion of healthcare professional
- Estimated life expectancy

(Harrop & Edwards, 2013)

³ Further consideration is given to children referred at 16 years of age or older, in relation to their phase of illness (Stable, Unstable, Deteriorating or Dying) and whether it is appropriate to be referred to LauraLynn or if other services are more suitable – in recognition of the fact that it may be more meaningful for the young person and family to start developing a relationship with a service that can continue to be fostered beyond 18 and to adulthood. Where possible, LauraLynn will endeavour to take into consideration the cognitive ability and personal wishes of the young person when deciding if LauraLynn is an appropriate service.

10.3.2 The Surprise Question

"Surprise Questions" may also be beneficial to ascertain if a child is life-limited and may require palliative care support. LauraLynn suggests that referring healthcare professionals consider the following:

- Diagnosis or recognition - Would you be surprised if this child died as a result of this condition or problem?
- Death before adulthood - Would you be surprised if this child died before adulthood (18th birthday)?
- Increasing instability - Would you be surprised if this 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 child dies in the next few days / weeks?

If the answer is 'NO I would not be surprised' to any of these questions it may be appropriate to make a referral to LauraLynn.

(Shaw et Al. 2014)

10.3.3 Additional Vulnerability Factors – Helen and Douglas House Tool

LauraLynn recognises that the physical dependency of a child does not always correlate with their prognosis (i.e. may be highly dependent but stable) and, therefore, children with non-progressive disabilities may not meet the referral criteria. For children that may fall within ACT/TFSL Category Four, LauraLynn uses the Helen & Douglas House Guide to Vulnerability Factors for a Child with a Static Neurological Condition, to assist in identifying if a child meets our referral criteria. This tool gives extra consideration to respiratory, feeding, seizure related and loco-motor factors, along with other neurological vulnerabilities. (Harrop & Brombley, 2012)

10.4 Who May Refer

Referrals are welcomed from all medical, nursing, health and social care professionals, as well as from parents and family members directly. In order to proceed with all routine referrals, consent must be obtained from the child's parent(s)/ guardian(s), and the primary paediatrician or GP. Referral forms must be completed in full before there will be reviewed by the Referral Panel. At any stage, the referrer may contact a LauraLynn Clinical Nurse Specialist to discuss a potential referral and seek guidance in our process.

10.5 When to Refer

Referrals can be made at any time from point of diagnosis or recognition of a life-limiting condition. 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. It is not necessary for a child to be nearing end of life before referring, but we ask that the referrer recognise that the family must be accepting of the referral and willing to explore that their child's life expectancy may be limited.

It may be appropriate to consider a referral in the following circumstances:

- Unpredictable or deteriorating health, including frequent unplanned hospital admissions or discussions around Advance Care Planning and Resuscitation Status.
- Support required around physical symptoms that are difficult to manage i.e. Pain, Seizures, Secretions.
- Significant disease progression i.e. changes in ability to cough, gag or swallow with subsequent increased reliance on suctioning and oxygen

(Harrop & Edwards, 2013)

10.6 LauraLynn Children's Hospice Referral Panel

Once a completed referral form has been received an acknowledgement letter will be sent to both the referrer and parent(s) of the child. A Clinical Nurse Specialist will then review the referral form to ensure all required and relevant information is available and will present the referral at the weekly Child and Family Review Meeting. All referrals are examined and discussed by the Referral Panel during these meetings.

The Referral Panel consists of:

- Consultant Paediatrician (Chairperson)
- GP (As required)
- Clinical Nurse Specialist(s)
- Assistant Director of Nursing
- LauraLynn@HOME Team Leader
- Family Support Team

10.6.1 Referral Decision Making Process

The Referral Panel reviews the referral, and identifies if additional information is required to make an objective decision. As our referral criteria are based upon the medical condition and needs of the child, often we will contact the primary medical team for additional supporting information to help us make a more informed decision. Whilst we aim to make our decision to accept or decline a referral in a timely manner, it may take some weeks for all relevant information to be obtained.

In circumstances where an immediate decision is not possible to make based upon the available information provided, and in order to ensure we can make an objective clinical assessment of the child's palliative care needs, a Clinical Nurse Specialist will arrange to meet with the child and parents to carry out a further clinical assessment. At all stages through the referral process healthcare professionals involved in the care of the child are encouraged to provide evidence to support the referral, and help us best identify a child's

palliative care needs. Following an assessment, the Clinical Nurse Specialist will again present the referral at the Child & Family Review Meeting, at which stage a decision will be made.

10.6.2 Accepted Referrals

When a child is accepted to our service, the Parent(s), Referrer, Primary Paediatrician and GP are all informed in writing of our decision, and a Clinical Nurse Specialist will contact the family by telephone to arrange carrying out a Holistic Needs Assessment (see [Section 11.2: The Holistic Needs Assessment](#)).

10.6.3 Declined Referrals

If a child does not meet the referral criteria, the Referral Panel will decline the referral. LauraLynn understands that this may be distressing for everyone involved, but a decision to decline is never taken lightly. Whenever we decline a referral we endeavour to explain our reasons and discuss them with the original referrer. A Clinical Nurse Specialist will, where appropriate, sensitively discuss our decision with the family too. A re-referral can be made at a later date if a child's health subsequently deteriorates.

In situations where a parent or referrer is not happy with the outcome, we may ask for additional information to be provided so that we can review our decision. At all times, decisions made regarding referrals to LauraLynn are confirmed by the chairperson of the Referral Panel and Child and Family Review Meeting.

10.6.4 Emergency / End of Life Referrals

Although the majority of our referrals are non-urgent, we aim to respond to emergency referrals at short notice. A clinical team may be involved in caring for a child who has very rapidly entered a clear deteriorating or end of life phase and we encourage the team to contact LauraLynn House and speak to a Clinical Nurse Specialist so that an immediate response can be organised. Where deemed necessary, a decision to accept may be made in conjunction with our Consultant Paediatrician and/or GP along with two members of the LauraLynn Senior Nursing Team.

Our response to emergency referrals will vary according to each individual situation, but may include:

- Same day assessment visit to hospital or a child's home
- Admission to LauraLynn House as soon as appropriate and possible
- Direct care being provided in the family home on the same day or as soon as appropriate
- Memory making supports being provided wherever the child is, on the same day or as soon as appropriate



11

Child and Family
Assessments

11.1 Assessing Needs

LauraLynn places the child at the centre of everything we do and our care supports the whole family. Our Hospice Care Team aims to work in partnership with children and their families to encourage that all decisions are in the child's best interest and will enhance their quality of life. Furthermore, we recognize that all care and supports provided should be based upon assessed needs. LauraLynn believes that the assessment process is not static and in practice occurs on a continuous basis, both informally and formally. As a service we are continually looking to ensure that a child and family's needs are reviewed and reassessed at frequent and appropriate intervals. We aim to ensure that all assessments are shared with the child and family and other healthcare professionals and agencies as appropriate.

11.2 The Holistic Needs Assessment (HNA)

We start building our relationship with children and families by talking about their needs. As soon as a child has been accepted to LauraLynn an assessment is conducted with each family to identify their own individual needs. Families are assisted too in developing specific family-related goals (outcomes). These in turn will help us measure the impact of our supports for each child and family.

The Holistic Needs Assessment (HNA) is a formal tool for assessing the holistic needs of each child and family. The purpose of the holistic needs assessment is to take a 'snap shot' of a child's needs and the broader needs of the family. The assessment follows a particular format and everyone is asked the same questions and in roughly the same order. This process helps to establish the family's expectations of LauraLynn, their own goals and aspirations as a family, and any areas of their life they identify as requiring support. Following acceptance to our service, a member of our Clinical Nurse Specialist Team will arrange to meet with the child and family and carry out the HNA. Our preference is to carry out this assessment in the family home, because it allows us to see the child and family in

their own home environment, where most of their living is done. It may also take place here in LauraLynn House or even in hospital, depending on the child and family wishes and individual circumstances.

11.2.1 HNA Domains

Our HNA looks at four domains – Physical, Social & Occupational, Psychological and Spiritual and is a comprehensive discussion, which gathers information on the needs of all family members to identify and understand family priorities to inform a personalised service. Undertaking the HNA is not simply a target to complete, rather it is a means of ensuring that the child and family's concerns or problems are in the first place identified so that attempts can be made to address them, and also that they are seen as a whole across each domain.

11.2.2 Benefits of the HNA

The HNA:

- Enables the child and family, in conjunction with the Hospice Care Team, to identify which aspects of hospice care they feel will best meet their needs at that time
- Gives structure to the child and family fully engaging in their care and facilitating their choices
- Facilitates effective assessment and care planning to identify individual concerns and need
- Enables us to track over time whether our interventions are having the intended outcomes and the families are achieving their goals
- Supports our engagement with families, to identify their hopes, expectations and fears for involvement with LauraLynn
- Helps us identify how LauraLynn could make a difference to them
- Facilitates LauraLynn to identify those families that are in greatest need and/or most immediate risk

- Helps LauraLynn to use resources effectively and ensure that we provide personalised care which reflects need
- Improves communication with the child and family and between professionals, reducing the need for replication of assessments
- Enables detailed discussions to take place with children and families about complex issues
- Helps us to demonstrate consistency, equity and transparency in our process.

11.2.3 Possible Issues Identified During a HNA

LauraLynn believes that the HNA may help to identify:

- Health needs of the child/young person
- Family dynamics and available support networks
- Emotional health and wellbeing
- Frequency of hospital admissions
- Family resilience
- Choices and preferences regarding location of care
- Hopes and wishes and advanced care planning

As the HNA takes note of all who contribute to the planning and delivery of care, we are better able to gauge what supports are available to the family and the quality of those supports. The assessment focuses on the well-being of the family more generally and whether anyone might benefit from support of one kind or another. We look also at relationships in the family and we illustrate this using a genogram or 'family tree'.

11.2.4 Completed HNAs

Once a HNA has been completed with the child and family, a Clinical Nurse Specialist presents it at the Child & Family Review Meeting. At this stage, our inter-disciplinary team discuss the various needs and goals identified, and look to see how LauraLynn may provide supports at a universal,

targeted or specialist level as required. Where the latter (specialist) support is identified, often an additional assessment may be carried out in order to ensure effective support.

As a team we consider if we have the appropriate resources to meet the identified outcomes:

- Do we have the appropriate environment and equipment?
- Do we have a workforce with necessary competence?

We are therefore cognisant that we may not always be in a position to directly and completely meet the identified needs of each child and family. Whilst we continuously endeavour to allocate our resources appropriately we will frequently signpost to, and work in partnership with, other services and healthcare professionals to help meet identified needs and desired outcomes.

A synopsis of the HNA is discussed with the child (as appropriate) and family and actions or care plans jointly agreed to address identified concerns and goals. LauraLynn will also endeavour to communicate the outcomes of the HNA, with the family's consent, with other relevant healthcare professionals involved in the care of the child and family, to help promote and ensure continuity of care and avoid duplication of care provision and needs assessment.

Following completion of HNA each child and family is linked with a named Clinical Nurse Specialist, who has responsibility to ensure that the child and family are introduced to LauraLynn in a supported, timely and appropriate manner. The Clinical Nurse Specialist will ensure that all other members of the Hospice Care Team are aware of the individual needs of the child and family and related goals.

11.3 Annual Reviews

The individualised supports offered to a child and family are formally reviewed at least annually or more frequently if circumstances change. This formal process is in addition to frequent check-ins by the Clinical Nurse Specialists, key-workers and members of the Nursing Care Team and serves to ensure that LauraLynn is meeting the family's expectations and needs, and that they are satisfied with the supports provided. It also allows us to formally review the complex palliative care needs of the child and additional family needs.

Our Medical Team and Clinical Nurse Specialists jointly review each child. Where appropriate they may meet with the family to ensure we continue to provide optimal care, symptom management, reaffirm advanced care plans, and in conjunction with the broader interdisciplinary care team, review the holistic needs of the child and family. During the annual review process we may contact the child's GP, Consultant Paediatrician and other relevant healthcare professionals for up to date information about each child.

This annual review process provides LauraLynn with the opportunity to measure the outcomes of our interventions and where appropriate re-evaluate our supports to ensure we provide each child and family with the most suitable universal, targeted and specialist service delivery. Depending on the individual child and family, a partial or full reassessment of their holistic needs may be carried out.

11.3.1 Discharge from LauraLynn Children's Hospice

As a hospice, we endeavour to support children living with a life limiting condition, that have palliative care needs and our annual review process also helps to ensure that we continue to be an appropriate service for each child and family. Many positive developments in treatment and care over the past few years have, in some instances, increased life expectancy and where

there is an improvement or recovery in a child's condition, we may be in a position to discharge children who no longer have palliative care needs. For those children, whose health is improving, we may consider a reduction in supports, moving towards discharge from the service if children's hospice care is no longer felt suitable. Where possible our Clinical Nurse Specialists will assist families in identifying alternative supports. Each child and family will have an individual discharge plan created, ensuring the family are well supported throughout the process. Generally, a child and family will have a phased discharge over a period of approximately six months. This may be extended up to a year, based upon the individual needs and circumstances of the child and family. All relevant healthcare professionals, including the child's GP, Consultant Paediatrician and initial referrer will be informed in writing of the decision to discharge following our annual review process.

As with our referral process, in situations where a family is not happy with our decision to discharge, we may ask for additional information to be provided so that we can review our decision. At all times, decisions made regarding discharges from LauraLynn are confirmed by the Consultant Paediatrician, as chairperson of the Child and Family Review Meeting.

11.3.2 Withdrawal from LauraLynn Children's Hospice

LauraLynn recognises that children and their families may choose themselves to no longer avail of supports from our hospice. In these situations, where a family choose to withdraw from our service, a Clinical Nurse Specialist will liaise with the child and family to formalise the discharge and will subsequently inform all relevant healthcare professionals of the child and family's decision.

11.3.3 Transition from LauraLynn Children's Hospice

Despite having a life-limiting condition and associated palliative care needs, a significant and growing number of children are living into adulthood because of improvements in the management of their condition. As children mature, their capacity to understand their condition and become involved in decision-making grows. During adolescence young people with capacity should be empowered to gradually take more responsibility for themselves. Parents are encouraged to support this process as it will enable young people to develop the skills necessary to function autonomously in adult services when their care is transferred at age 18. LauraLynn believes that transition should start in early adolescence and continue until the young person is engaging with adult services.

Transition can be defined as the purposeful, planned movement of adolescents and young adults with long-term physical and medical conditions from child-centred to adult-oriented health care systems (TFSL, 2015). LauraLynn is a children's service and young people are therefore discharged from our care on reaching the age of 18.

Graduating from LauraLynn is a great achievement for our children who have coped with ill-health and uncertainty. The process of moving to adult services should be gradual and planned and we are committed to supporting families through this process. We encourage young people and their families to view transition as part of the continuum of life and to take ownership of it from an early stage as it is all about planning for the future. Good preparation will help equip young people and their families for the next phase of their journey. Many agencies and services, apart from LauraLynn, are involved in caring for the young person, and each has a special role to play in ensuring a successful transition. LauraLynn therefore recognises that open communication and networking between services are key elements in the process.

In recognition of the important and complex nature of transition, LauraLynn has developed a Transition Pathway to help guide young people, families and our Hospice Care Team and ensure effective and timely transition.

12

The Five
Pillars of Care



As a children's hospice, our intention is that care provided is safe and effective, responsive to needs, is delivered in location of choice and by a caring and compassionate team. All care and supports provided to each child and family is free of charge and at no financial cost to the family. The interdisciplinary Hospice Care Team provides support to the child and the family to help meet these specific needs using our five pillars of children's hospice care:

- Section 13 Pillar One – Direct Care
- Section 14 Pillar Two – Family Support
- Section 15 Pillar Three – Symptom Management
- Section 16 Pillar Four – End of Life Care
- Section 17 Pillar Five – Bereavement Care

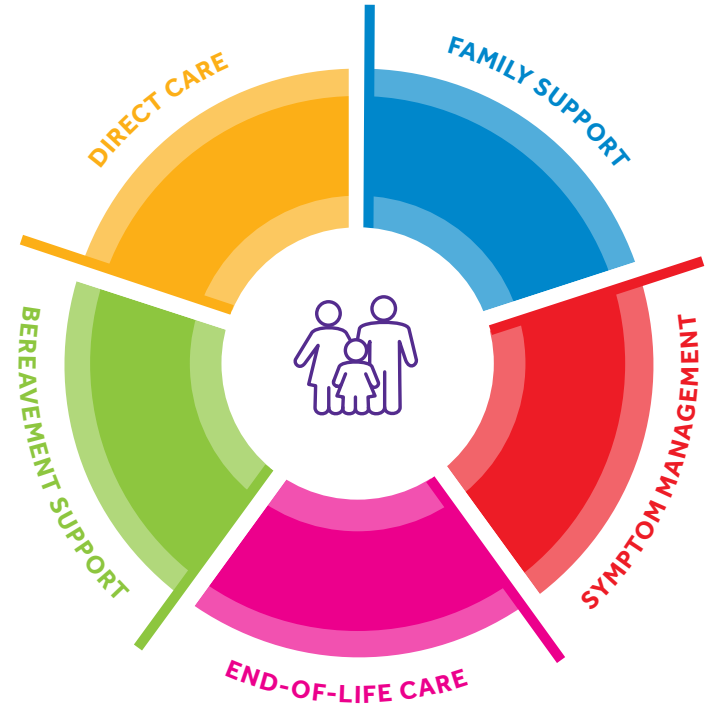


FIGURE 6: The Five Pillars of Care

The pillars are not chronological; children and their families do not start receiving services under one pillar and then move to the next, rather, the child and family's needs and identified goals, guide which pillar's supports will be offered, when they may be offered and importantly, pillars may be presented in tandem. Frequent re-evaluation helps the Hospice Care Team provide care that is child-centred, family-led, efficient, effective, and responsive.

13

Pillar One -
Direct Care



13.1 Direct Care in LauraLynn

Families caring for children with life-limiting conditions and palliative care needs are required to develop many clinical skills. Parents become expert caregivers to their child and for some it can be difficult finding others – friends, family, and healthcare providers, who are also competent to provide the required specialist care to their child.

Home is widely recognised as the preferred place of care for most children and can both minimise disruption to the child and family's usual activities and often promote a sense of being in control. Social networks and interpersonal relationships are more likely to be maintained in the home setting, however, LauraLynn recognises too that providing care at home may be an additional stressor for families.

In order to best support families, and in recognition that the impact of caring for a child with a life-limiting condition on the whole family is far reaching, the LauraLynn Children's Hospice Model of Care offers direct care and support to children and their families. This direct care most frequently occurs in the form of planned respite or specialist short break care⁴ and may take place in LauraLynn House as well as in the family home.

The provision of short break care is recognized as an essential component of care for children with life-limiting conditions and is an aspect of children's hospice care that is most commonly recognised. It is frequently cited as beneficial to both the child at the centre of care and their family. In acknowledgement of this need, planned short breaks are available for all children and their families.

⁴ For the purpose of this document, the terms respite and short break care may be used interchangeably, however, LauraLynn recognises that respite is generally considered for those episodes of care where the focus is on offering parents a break from providing care to their child, whereas short breaks, whilst they may offer an element of respite, also focus on supporting the child and extended family.

Whilst short break stays can be used to provide the parents with a much needed respite from the on-going care of their child, parents and siblings are also encouraged to stay as a family, and often breaks will be planned and purposeful in nature, focusing on aspects such as symptom management, enabling the entire family to avail of family support services, or simply for the family to spend some time together without the responsibility of providing care for their child.

13.2 Planned Direct Care

13.2.1 Planned Short Break Stays in LauraLynn House

Specialist short break stays in LauraLynn House are offered universally to all children and their families that have been accepted for service. Each child and family is offered an annual allocation of nights. The number of allocated nights varies depending on the number of families availing of our service, but currently is limited to approximately fifteen nights per calendar year. Families may choose themselves how they would best like to use their nights and are encouraged to book stays a few months in advance to ensure they can take full advantage of the services on offer from our interdisciplinary Hospice Care Team, as well as ensure availability. Planned stays may range from an overnight stay, to a longer week-long break. Extended stays may be considered depending on the individual child and family needs.

For many parents, learning to trust others with the care of their child can be very difficult and the Hospice Care Team respects this and allows them to adjust to stepping back a little at their own pace so that they can take a much needed break or enjoy being with their child for the "fun things" that often are taken for granted. Equally too, some families choose for their children to stay at LauraLynn House without them whilst they take a break or to spend time with siblings. In some situations parents may be required to stay with their child in LauraLynn House as the hospice care team get to know the often complex care needs of their child.

For those families that stay with their child in LauraLynn House, they can check in for a break together, safe in the knowledge that their child's clinical needs are in the hands of highly skilled healthcare professionals. Families may avail of our family accommodation bedrooms located close to the children's bedrooms. In addition, our Family Suite offers the option for parents to sleep in a bedroom adjoining their child's bedroom.

Opportunities for the Child

For the child, specialist short break stays provide opportunities to:

- Play and have fun in a safe and purpose-built environment - play and social activities within LauraLynn House allow children to be children without restrictions based on medical equipment or clinical needs
- Be included in age and developmentally appropriate activities
- Socialise and engage with children of similar abilities
- Have their individual care needs met in a safe, respectful and dignified manner
- Experience cognitive stimulation appropriate to their specific needs
- Participate in therapeutic experiences

Opportunities for the Family

For the family, specialist short break stays provide opportunities:

- For siblings to have fun and receive support in their own right
- To be together and to be supported in the care of their child
- For parents to spend quality time with healthy siblings, or recharging on their own
- To avail of a wide range of therapeutic family supports from our extensive interdisciplinary Hospice Care Team
- To avail of an often, much needed rest, while knowing their child is being cared for by experienced, caring and compassionate professionals
- To feel supported, refreshed and enabled to continue to care for their child at home
- To meet other families in similar circumstances

Opportunities for the Care Team

For the Hospice Care Team a specialist short break stay:

- Allows LauraLynn to get to know the individual needs and care routines of the child and family so they can best support them during an unplanned stay if required
- Enables LauraLynn to provide additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks provided by social care
- Provides an opportunity for the team to evaluate the child's health and care needs
- Provides an opportunity to address some aspects of symptom assessment and management as required
- Provides an opportunity to get to know the child and family when well, so that trusting relationships are developed prior to a deterioration in the child's clinical condition. This in turn will help to enhance the experience of the child, family and care team at end of life

13.2.2 Planned Short Break Support in the Home:

The LauraLynn@HOME Team may offer families the option of direct care in the home to allow families to take a break from, or to assist with, the on-going complex care needs of their child. Support visits are arranged a week in advance and may be one off, and for a period of 3-5 hours, or may be offered as a series of visits over a period of short weeks (e.g.2-4 weeks).

Often this type of support may be requested by a family that is waiting the commencement of a HSE funded home care package, if there is a change in the family support system, resulting in an increased demand or stress on the family or simply to support the family in attending a special occasion or spend time with siblings.

Some families may show an initial reluctance to avail of specialist short break stays in LauraLynn House, possibly due to anxiety at the prospect of others not being familiar with their child, or of leaving their child. Where this has been identified, LauraLynn@HOME may offer direct care in the home as a means to assess the individual care needs of the child, start the process of building a trusting and professional relationship with the family and act as a link between the child and family in the home and the care team in LauraLynn House, thus ensuring a continuum of care to reassure the child and family.

Support provided by LauraLynn@HOME should not be classified as an on-going care package and therefore differs from any home care package provided through statutory or other voluntary agencies.

13.2.3 Planned Short Break Support in the Hospital

From time to time, many of the children attending LauraLynn may have prolonged admissions to hospital. Where possible, LauraLynn will endeavour to support the child and family during this time, in recognition that it can be very stressful for both the child and family. A member of the Hospice Care Team may offer to spend time with the child to allow the parents / family member to take a break from the ward for short period of time. Additional emotional and practical support and advice may be given in relation to the child's condition and / or changing clinical needs.

13.3 Planned Symptom Management Stays in LauraLynn House

In certain circumstances, it may be appropriate to plan an admission to LauraLynn House for a child and family in order to facilitate optimal symptom assessment and management. All such stays are planned in advance and arranged in conjunction with our Consultant Paediatrician, Clinical Nurse Specialists and members of the Family Support Team as required. Symptom assessment and management stays are considered to be in addition to the annual allocation of

nights that each child and family is offered. Please refer to [Section 15: Symptom Management](#) for further information.

13.3.1 Planned Symptom Management Support in the Home

LauraLynn@HOME is available to support a child and family in optimising symptom assessment and management and will provide direct care in the home to support the work of the Symptom Management and Supportive Care Team. Please refer to [Section 15: Symptom Management](#) for further information.

13.4 Planned Step-down Care Stays in LauraLynn House

In addition to planned specialist short break stays, in some circumstances, it may be possible for a child to receive step-down care in LauraLynn House. Step-down care is aimed at enabling a more staged transfer from hospital to home. This may be offered when a child has been in the hospital for a prolonged period and is nearing discharge. Generally, this option is offered to those children who have had a recent deterioration in their condition or who may be considered more clinically unstable. He/she may be transferred to LauraLynn House to give the family time to adjust before they bring their child home, and where appropriate for the Hospice Care Team to provide additional support and education in the changing care needs of the child. It is hoped that the provision of step-down care in LauraLynn House may enable an earlier discharge from hospital. At all stages, step-down care is provided in a collaborative approach and arranged in close liaison with both the acute hospital as well as community supports. All step-down care stays are dependent on the appropriate resources being available for the child and family when they are discharged from LauraLynn House to home. Step-down care is needs led and dependent on the availability of suitable resources in LauraLynn House, and may use some of a child's annual allocation of nights.

13.4.1 Planned Step-Down Support in the Home

Planned support visits may be offered following a prolonged hospital admission or associated deterioration in a child's condition. The direct nursing care offered by LauraLynn@HOME enables the family to adapt to the child's changing care needs, particularly during periods of instability, and will also facilitate any additional education and training that they family may require in relation to the child's care plan, treatment options or medication regime. When LauraLynn@HOME offers step-down care it is for a defined period of time, with agreed hours of care, and provided in conjunction with other healthcare agencies as appropriate.

13.5 Crisis or Emergency (Unplanned) Stays in LauraLynn House

LauraLynn House aims to provide unplanned support to the child and family, which is not pre-booked in advance but arranged when the need arises, and at short notice. These unplanned stays are not taken out of a child and family's annual allocation of nights. We aim to respond to emergency requests within 24 hours and may offer initially up to 48 hours support. A stay may be further extended at the discretion of the service depending on both family circumstances and available resources. LauraLynn will also work closely with other relevant healthcare professionals and agencies and endeavour to ensure additional supports are available, as required, following an emergency stay in LauraLynn House.

Generally, a crisis admission is facilitated if:

- A parent or primary carer is not available to look after their child due to significant accident, illness or bereavement of a close family member or significant other
- If a child requires urgent symptom management that can be treated effectively and efficiently in LauraLynn House

13.6 Crisis or Emergency Support in the Home

LauraLynn@HOME endeavours to respond at short notice to family emergencies. If a crisis arises, families are encouraged to contact a Clinical Nurse Specialist, and in conjunction with supports in LauraLynn House, direct nursing care in the home may be possible. Whilst every situation is treated individually and based upon the assessed needs of the child and family, LauraLynn@HOME is not in a position to provide nursing care at short notice in response to unplanned gaps in routine home care packages.

13.7 End of Life Care in LauraLynn House

In addition to crisis / emergency stays identified above, LauraLynn House aims to always be an option for children that are approaching end of life. End of Life Care is a priority for LauraLynn House and is offered to families already known to the service, but also to families that may not yet have been referred; the latter requiring an urgent emergency / end of life referral. Children and their families may choose this option if either home or hospital is not the preferred location of care, or if there are concerns about being able to provide appropriate symptom management and support at home. As with all unplanned stays, this is needs led and consideration is given to the individual child and family circumstances and available resources. Please refer to [Section 16: End of Life Care](#) for further information.

13.7.1 End of Life Care in the Home

LauraLynn@HOME support families in the home by providing direct nursing care and practical support for their child, at end of life. All end of life care supports in the home are provided in close collaboration with the primary Paediatrician, G.P., Clinical Nurse Coordinator, Community Specialist Palliative Care team and relevant healthcare professionals. Please refer to [Section 16: End of Life Care](#) for further information.

13.8 Allocation of Direct Care Supports

Planned specialist short break stays at LauraLynn House are additional and complimentary to all other services provided by other agencies. All requests for planned stays are processed in a fair and transparent manner and reviewed at the weekly LauraLynn House Bed Management Meeting. This provides the Hospice Care Team an opportunity to assess if there are adequate resources (e.g. staffing skill-mix, clinical equipment, etc.) available to safely and effectively care for each child and allows the Hospice Care Team to consider the individual wishes of each child and family, whilst ensuring a fair allocation of nights.

13.8.1 Short Break Stay Cancellations

Where an unplanned / crisis / symptom management / end of life care admission is required, priority will be given over planned specialist short break stays. Every effort will be made to cause the least amount of disruption to other families, but at times this may result in the postponement or cancellation of another child and family's specialist short break stay. Decisions regarding the offering of unplanned stays are made in conjunction with members of the Senior Nursing Team along with the Consultant Paediatrician as appropriate.

13.9 Clinical Care in LauraLynn House

13.9.1 Staffing in LauraLynn House

As a children's hospice, individualised and expert nursing care is provided along with the appropriate medical support provided by our Consultant Paediatrician and GPs. Nurse staffing levels are managed to ensure that there are appropriately skilled and experienced team members allocated to each child during the day. This means that in addition to ensuring optimal care provision to meet the often complex needs of the child, any additional activities that they may wish take part in can be tailored to their personal preferences and choices and they will be supported to take part in any activities they wish.

Where appropriate, individual risk assessments are completed for those children with highly complex care needs and both staffing levels and skill-mix may be adjusted to ensure safe and effective care. Overnight, staffing levels are adjusted to reflect the individual care needs of each child and family staying in LauraLynn House. Through effective workforce planning and roster management, experienced, senior nurses are always on duty, with additional support available from a senior children's nurse manager.

13.9.2 Partnership in Care

During a stay in LauraLynn House all clinical care is provided by the care team along with the Family Support Team. Children and their families are encouraged to actively participate in making decisions about their care, and at all stages, care planning and provision is designed to be holistic and takes into account individual preferences and circumstances, and importantly, views the child and family themselves, as the experts in the care giving, along with the skills and knowledge of the expert hospice care team. Choice and consent are fundamental to care provision in LauraLynn and the Hospice Care Team take time to ensure both the child and family are involved in the process as much as possible.

13.9.3 Integrated Care Plan

Each child will have an individual, integrated care plan that details their specific clinical care requirements along with an account of their needs, routines, likes and dislikes. In order to best ensure that the care planning process is as comprehensive and inclusive as possible, all children and families that avail of stays in LauraLynn House are required to have an initial First Admission stay, prior to any subsequent stays being booked. During this two day stay, parents / primary care givers are required to stay for the duration so the both the child and family may meet with the wider hospice care team and importantly allow the Nursing Care Team to identify individual care needs and agree care plans. As with all elements of care, this is considered to be a process rather than once-off assessment. Care plans are reviewed at regular intervals; prior to any subsequent planned stay, as well as during times when there are changes in treatment options or the clinical condition of the child. During this First Admission stay, a member of the Medical Team will also meet with and assess the child and family. Whilst the child's primary paediatrician leads on the child's treatment plan and options, this ensures that the team are fully informed of current medication management and treatment plans and where appropriate allows the introduction of advanced care planning discussions.

13.9.4 Complex Care Needs

Due to their underlying medical condition or diagnosis, many of the children will have complex health care needs that require various nursing procedures and medication management regimes. The Nursing Care Team carry out all aspects of care as required, in accordance with robust, regularly updated, internal policies, procedures and guidelines. No clinical procedure is carried out unless the individual care team member has had the appropriate training and deemed to be competent.

Due to the specialist knowledge, skills and experience, along with extended training, the Nursing Care Team in LauraLynn may currently undertake and support the following:

- Enteral nutrition (gastrostomy, NG / NJ tube feeding, jejunostomy)
- Urinary catheter care and/or catheterization
- Stoma care
- Monitoring technologies (e.g. blood sugars, ketones)
- Tracheostomy care
- Oxygen therapy
- Suctioning (oral, naso-pharyngeal, via tracheostomy)
- Non-invasive & invasive ventilation (via tracheostomy)
- Subcutaneous medication via syringe drivers
- Complex medication management regimes
- Peritoneal dialysis

This list is not exhaustive, but highlights the major clinical procedures that staff may deal with routinely. If there are other specific clinical treatments that a child requires during a stay in LauraLynn House, the team will endeavour to support the child and family in the provision of same, where clinically safe and appropriate. There are certain clinical procedures that are currently not possible in LauraLynn House i.e. intravenous therapy, blood

transfusions, invasive ventilation via endotracheal tube. If however, such a clinical treatment is required, LauraLynn will look to transfer the child and family to the acute setting if required.

LauraLynn is not an acute hospital setting and transfer to hospital may also be required in the event of an unexpected, life-threatening situation, where it may be treated as an emergency and the ambulance service will be called. At all times, basic life support is available for all children and treatment carried out in accordance with the child and family's wishes. LauraLynn advocates advanced care planning and will always endeavour to work closely with children and their families, to identify specific wishes in relation to treatment plans. Resuscitation treatment agreements that have been completed with families by other health care agencies are reviewed by the LauraLynn Medical Team and will guide the supports provided by the wider Hospice Care Team.

The LauraLynn Clinical Education Team support the on-going training and education needs of the Hospice Care Team, ensuring that each staff member has the appropriate skills, knowledge and experience to undertake the clinical tasks required. Please refer to [Section 19.3: Education, Training and Development](#) for further information.

13.10 Clinical Care in the Home:

All care in the home is provided in a similar manner to that provided in LauraLynn House. Each child will have a full assessment to identify their care needs, taking extra consideration to how this is carried out in the home environment. Where appropriate, the child's LauraLynn House integrated care plan is used to support care in the home, but often additional or adapted care plans may be required to reflect the home environment. As with care provision in LauraLynn House, the LauraLynn@HOME Team adhere strictly to relevant policies, procedures and guidelines. Additional environmental, moving and handling, lone working and clinical risk assessments may be required to ensure the safety of both the child and family as well as that of the LauraLynn@HOME Team member. Whilst providing care in the home, LauraLynn aims to work closely with other healthcare professionals, services and agencies involved in the care of the child in order to maximise the support which can be offered and to create a seamless service which minimises disruption to the family and ensures the child receives safe and coordinated care.

14

Pillar Two –
Family Support



This pillar of care refers to LauraLynn services aimed at reducing distress and enhancing quality of life for children, their parents or carers, and siblings. Family Supports follow a clearly-defined pathway to ensure that care is integrated, targeted and equitable (McKiernan & Balfe, 2019). In the first place, main concerns and goals are identified through routine assessments, and arising from on-going dialogue with the child and family and other service providers. With consent, these are relayed in a timely way to a weekly forum convened by the service's interdisciplinary Family Support Team. Here, a form of 'triaging' is carried out by the team, which takes account of factors such as the type and severity of difficulties facing the child and family, the family's coping resources, and the availability of quality of supports within the wider professional and social networks. Based on the outcome of this process, family supports are offered that are tailored specifically to the identified needs and goals. Supports are informed by the clinical expertise of team members, relevant research, and best practice guidelines. Supports are delivered by individual team members (as when the clinical psychologist provides parental support, for example) or by some combination of team members (as when the music and occupational therapist provide in-home support focused on enhancing parent-child bonding). Whatever the mode of support, allocation of the team's resources takes account of the needs and preferences of the child and family, as well as the availability of resources within the team.

14.1 Levels of Family Support

A signature strength of the Family Support Team at LauraLynn is its integrated way of working. Inspired by frameworks developed in related contexts (e.g., NICE, 2016; Kazak, 2006; Jones et al., 2015), and underpinned by the shared values of collaboration, excellence and compassion, the Family Support Team provides personalised interdisciplinary services across four levels (see Table 1). At each level, supports are delivered within the family context and with due regard given to the child's development stage and point in the illness trajectory.

LEVEL	
1	To support the child and family's understanding of their experiences, information and guidance is made available through direct consultation, and via the service's website and leaflets. Supports of this kind are provided by various members of the Hospice Care Team, based on the awareness that distress is a normal reaction to the experience of life-limiting childhood illness.
2	To normalise and enhance coping, organised child and family support services are provided. These allow for families to meet with others in a similar situation, and they are focused on developing coping strategies. These kinds of supports are provided by the Family Support Team jointly with certain experienced members of the nursing and medical team. Underpinning this support is a knowledge of the nature of loss and grief and a strong capacity for empathic listening.
3	Where quality of life and daily functioning is impacted in a substantial way, child and family centred counselling and therapy services are provided. These are the remit of the Family Support Team, and are informed by advanced knowledge and skills. Academic qualifications and substantial clinical experience are central to this work.
4	High levels of distress and complex psychosocial needs are responded to by the service's specialist clinical psychologist, in consultation with relevant external agencies. Expert knowledge and skills in the area of mental health are key in this regard.

TABLE 1: Levels of Family Support

14.2 Examples of Family Supports

What follows is a description of specific supports available through the Family Support Team across each of the four levels. Services are delivered either onsite at LauraLynn House, in conjunction with members of the wider Hospice Care Team, or in the community (home) setting. In certain instances, in-home family supports are facilitated with backup from the service's community-based nursing and care team, known as LauraLynn@Home. (Note. Supports provided by members of the Family Support Team in the area of bereavement care are discussed separately; see [Pillar 5 – Bereavement Care](#).)

14.2.1 Provision of Information

At Level 1, the Hospice Care Team is available to provide information and reassurance to families and healthcare professionals. Whereas the Family Support Team are available during regular office hours, the Nursing Care Team at LauraLynn House is contactable 24 hours per day. A Clinical Nurse Specialist is available routinely from 07.45-18.00 Monday to Friday. At all stages, there is an experienced, senior children's nurse manager on-call (24hrs) to provide additional advice and support to both the Hospice Care Team as well as to families. In situations where no member of the care team is in a position to provide direct support and advice, efforts will be made to signpost towards those health care professionals and/or organisations that may be in a position to help.

14.2.2 LauraLynn House Facilities

Also at Level 1, families are welcome to arrange to come and visit LauraLynn House and avail of some of the outdoor facilities and LauraLynn House resources. Examples of resources which are open to children and families include our sensory garden and wheelchair-friendly playground, along with the landscaped gardens. In addition, families may choose to use certain indoor facilities, such as the multisensory therapy room or multi-sensory bathroom. Use of these facilities creates opportunities for children and families to familiarise themselves with LauraLynn House and to build trusting, therapeutic relationships with the Hospice Care Team.

14.2.3 Annual Family Events

At Level 2, throughout the year, LauraLynn host various family-oriented events, such as our Summer Family Fun Day and our Christmas Family Party events. These occasions provide families with a safe space to come together to socialise, network, create memories and simply participate in fun, child and family oriented activities that are designed to take into account the various developmental and clinical needs that children with life limiting conditions may have and ultimately provided shared family experiences. Along with creating some meaningful memories, it provides families with an opportunity to feel more comfortable in our children's hospice setting and familiarise themselves both with LauraLynn House as well as the Hospice Care Team.

14.2.4 Creative Arts Projects

Across Levels 2 and 3 are the creative arts projects. During a child's stay in LauraLynn House various members of the Hospice Care Team will provide creative art and sensory experiences and activities for children, such as baking, bath bomb masterclasses, princess ballet classes, film academy, wheelchair football, sensory stories, interactive stories, hand & foot massage, footprint crafts and many more. LauraLynn is always looking for new and innovative ways to interact with, and support children and their families and over the past two years, two creative arts projects have been designed specifically to meet the needs of families. These are described below.

LauraLynn at The Abbey Theatre — a collaborative arts project including LauraLynn Children's Hospice, The Abbey Theatre, The National Concert Hall Kids Classics and the National Art Gallery. This project is about developing an immersive and multisensory experience for children and their families and focuses on creating a unique stage production inspired by the personalities of the participating children. In addition to the Abbey Theatre resident artists' involvement, the team at the National Art Gallery work their magic with set design and creative wheelchair adaptation for the cast members and Kids Classics Musical Group compose and perform an original score.

LauraLynn at The Oscars — a combined therapeutic intervention of journaling, photography, scriptwriting and play therapy that culminate in a celebration day, thus providing children with additional opportunities to access and interact with siblings and friends. Parents are encouraged to promote creativity, provide validation to the children's ideas and concepts with the support of professionals from LauraLynn, RTE and Windmill Lane Productions.

While also providing supports at Levels 1 and 2, the Family Support Team offer a range of interdisciplinary Level 3 supports. These are described below.

14.2.5 Chaplaincy

The Chaplain's role is to take a leadership role in the delivery of spiritual and /or religious care within the context of a multidisciplinary team approach. This is achieved by creating a safe space for children and their families to develop their understanding the nature of spirituality, irrespective of whether this includes a religious component. Implicit in the work is a recognition that within palliative care there is opportunity for human development. Informing this is a deep understanding and appreciation on the part of the chaplain that spiritual and emotional pain often results from a loss of meaning and unmet spiritual needs. Responding to this, the chaplain engages pastorally with children and their families who are experiencing spiritual distress and pain, a process that often involves helping others to see this kind of suffering as part of the normal process of living with life-limiting childhood illness, functional disability, and awareness of impending death.

14.2.6 Music Therapy

Music therapy offers a space for each individual to find a means for self-expression, whatever their ability or method of communication. The music therapists at LauraLynn use music to facilitate and support these expressions and to encourage and reaffirm what each person offers. When working in the family and group contexts, this enables positive connections and interactions which are inclusive of all family members regardless of age or level of functioning.

14.2.7 Occupational Therapy

The occupational therapist in LauraLynn works with the child in the context of their family including parents and/ or siblings. The occupational therapist supports the quality of the child's life within their typical daily routine maintaining the child's personhood and supporting the family to be able to engage and interact with their child, particularly when functional needs are impacted by symptom burden.

14.2.8 Play Therapy

At LauraLynn, the Senior Play Therapist provides emotional and practical support for children and their families. Play Therapy is a form of psychotherapy providing children with the safe therapeutic space to explore and express their thoughts and feelings through play, art, sand, music, puppets, role play etc. Play is a child's natural means of communication and through play therapy the child is empowered to express their reality, coming to an inner resolution, building resilience and increasing coping skills. It is offered to both the child living with the life-limiting condition, as well as to siblings. Therapeutic / sensory play and play therapy is offered to children to foster increased self-esteem and sense of belonging.

14.2.9 Social Work

LauraLynn's Senior Social Worker supports individuals and families to navigate the demands of life-limiting illness and to negotiate different coping mechanisms and communication styles within their family system, particularly where conflict arises. The role also involves advocating for the child and family within the organisation and externally, acknowledging the impact of the child's illness on the family's ability to plan for the future, and on the bereavement process. Facilitating discussion of the child and families' preferences around place of care and place of death is an additional offering made by the social worker, as is supporting patients and families in managing the practical and financial stresses associated with illness and death.

14.2.10 Collaborative Family Support Work

Collaborative Family Support work in LauraLynn combines the disciplines of occupational therapy and music therapy to offer a family-centred intervention, which identifies and dynamically adapts to the changing needs of the child and family as they move through the stages of their child's condition. The intervention identifies and addresses the impact of these changing states on the whole family. Family sessions provide a framework built around creative mediums in which the family can come back from the medical focus of their child's needs and reconnect with each other in a more personal way. On a therapeutic level the relationship established between both therapists and the family also offers opportunity for emotional holding in which the family can safely explore and process their anticipatory grief and loss and be supported in adjusting and re-adjusting to their child's uncertain journey. Wherever possible moments of creativity and connection are captured through photos, family stories, song writing and audio/video recording to further validate this experience in the present moment and also provide precious memories which can be cherished as they move through their lives together.

In addition to inputting across Levels 1 through 3, the service's clinical psychologist provides specialist supports at Level 4, as required. More detail is provided below.

14.2.11 Clinical Psychology

The work of LauraLynn's Principal Specialist Clinical Psychologist is aimed at reducing psychological suffering and enhancing quality of life for children and their families. This is achieved through assessment and intervention. Examples of interventions delivered by the psychologist include psycho-education (e.g., increasing understanding of difficult feelings or states, like guilt, anger, anxiety and grief), talking therapy for individuals (e.g., cognitive behaviour therapy, Mindfulness-based therapy), couples therapy, parenting support (e.g., advising parents on how best to manage behavioural difficulties, or how best to plan difficult conversations with a child), and meditation training to help parents to regulate their mood. Interventions are delivered primarily onsite, though some consultations may be offered in the home, by telephone or Skype. In addition to direct work, the psychologist is tasked with indirect support of children and families through consultation and training with the Hospice Care Team. The clinical psychologist also undertakes research in the field of children's palliative care that is focused on enhancing family supports.

A close-up photograph of a carousel. In the foreground, a white horse with a blue and yellow saddle is mounted on a golden pole. To its right, a zebra with black and white stripes is also mounted. In the lower right corner, a peacock with a blue body and a large, colorful tail fan is visible. The background shows other carousel animals and the ornate structure of the ride, all slightly out of focus.

15

**Pillar Three –
Symptom
Management**

Research suggests that children with life-limiting conditions may have a high symptom load and that these symptoms may be poorly controlled and distressing for both the child and family. Providing effective symptom assessment and management is a cornerstone of children’s palliative care (TFSL, 2017).

The LauraLynn Children’s Hospice Model of Care advocates the effective evaluation of a child’s physical, psychological and social distress and the management of problematic symptoms to best improve the quality of life for the child and family, by both preventing and treating actual and potential symptoms. The comprehensive assessment of symptoms requires an interdisciplinary approach involving the child, family and wider healthcare professionals.

There are a number of challenges in the accurate assessment of symptoms; the varying developmental needs of children, difficulty in the recognition of symptoms, and lack of appropriate assessment tools. In addition, many children with palliative care needs have a disability, and many have severe to profound neurological impairment, which impacts their ability to communicate and our ability to understand how they may express pain or distress. A combination of assessment approaches which encompass objective and subjective measures, involving the child, parent and healthcare professional is crucial and knowing the child, knowing the population and knowing the science is essential too.

15.1 Common Symptoms in Children’s Palliative Care

The majority of symptoms experienced by children with life-limiting conditions may be classified as physical and grouped into the following:

- Pain
- Respiratory difficulties – e.g. breathlessness, cough, secretions, hiccups, haemoptysis, pleural effusions
- Gastrointestinal difficulties - e.g. mouth care, nausea and vomiting, constipation, diarrhoea, obstruction, anorexia, ascites
- Neurological difficulties – e.g. seizures, agitation, delirium, raised intracranial pressure, spinal cord compression, dystonia, muscle spasm
- Haematological issues - e.g. anaemia, thrombocytopenia, bleeding, thrombosis

In addition, behavioural symptoms such as hyperactivity, repetitive behaviours, anxiety, agitation or disturbed sleep may also be severe. Indeed, in recognition of fact that symptoms are rarely just physical, LauraLynn advocates for optimal management to include attention to the psychosocial, emotional and spiritual aspects where appropriate.

15.2 LauraLynn Symptom Management and Supportive Care Team

In LauraLynn symptom assessment and management is considered the responsibility of the entire interdisciplinary Hospice Care Team and always carried out in collaboration with the individual child and family along with the child’s primary paediatrician and other relevant healthcare professionals. Good symptom management is a highly skilled task, requiring excellent assessment, sound clinical judgement and specialist knowledge. Our Symptom Management and Supportive Care Team is led by our Consultant Paediatrician, who in conjunction with our team of Clinical Nurse Specialists, and additional support

from our GPs, aim to provide a responsive and effective specialist symptom assessment and management service. All members of the team have additional training and experience in children's palliative care and the provision of specialist and supportive care.

The team works closely and collaboratively with all staff in LauraLynn as well as external healthcare professionals to assess and produce individualised symptom management plans, written specifically for each child as required, aimed at optimising quality of life and reducing the distress and the burden of symptoms for both the child and family. In addition to specific and individualised plans, the team act as a resource for both staff and families, at any stage during a stay in LauraLynn House.

15.3 Core Principles of Good Symptom Management

Despite the wide variety of diagnoses and conditions of the children attending LauraLynn, the Hospice Care Team are in a good position to become familiar with many of these conditions, and more importantly, of the manifestations of the conditions for each child, and apply the same principles for expert and specialist management across the various conditions, diseases and diagnoses. Throughout the entire process of symptom management, the team adheres to the following core principles:

- Assessment that is holistic and interdisciplinary in approach
- A thorough evaluation of symptoms, considering potential causes, and exploring the impact on quality of life
- Review of previous treatments, and consideration to what has worked well previously
- Effective communication with the child and family, ensuring the use of simple terms, without medical jargon, explaining possible reasons for symptoms and treatment options and at all times ensuring the child and family are actively involved
- Keeping medication management as simple as possible as well as

prescribing prophylactically and pre-empting side-effects

- Consideration given to non-pharmacological options and at all stages the input of the interdisciplinary team is encouraged and options such as distraction therapy, relaxation techniques, music and play therapy are utilised as appropriate
- Frequent (re)evaluation of interventions and treatment plans adjusted accordingly
- Advice and support is always sought from other healthcare professionals as required

(Craig et Al, 2007; NICE, 2016)

15.4 Prioritising Need

The Clinical Nurse Specialists support all children and families in LauraLynn, but priority is given to those children who may be unstable, deteriorating or at end of life. The team works closely with the interdisciplinary team to best identify those children in most need. Depending on individual children identified, the Clinical Nurse Specialist may be required to link with the family and undertake an initial assessment in the family home.

- For children who are considered stable, symptoms may be well controlled and all that is required is for the family to know how to access additional support in the event of a change
- Those children considered unstable, may require frequent and regular review due to the unpredictability of their condition and the increased risk of symptoms worsening quickly. At this stage additional support and advice from the team is offered
- Children that are deteriorating are considered with a view to anticipating their future needs, in order to provide additional support and to underpin the supports already in place

15.5 Planned Symptom Management Stays in LauraLynn House

When it is deemed necessary or beneficial, a symptom management stay in LauraLynn House can be arranged. This allows for continual and interdisciplinary assessment over a number of days. Where children are admitted with complex symptom management requirements, daily or twice-daily 'huddles' are organised to allow the team come together and discuss how best the child and family can be supported from a holistic perspective.

The Family Support Team ensures a total approach to care allowing for the consideration of the complex interplay of physical, environmental and psychological factors. For example, in addition to pharmacological interventions, physiotherapy and occupational therapy assessment of sleep, positioning and equipment may also be of benefit in improving the quality of life of the child and family.

At the end of a stay, the family are provided with a symptom management plan and clear documentation around medication management as required. A symptom management report is shared with all relevant external healthcare professionals including the primary Paediatrician and GP. In addition, the Clinical Nurse Specialist continues to link with families on an individual basis and liaise with LauraLynn's consultant paediatrician as required. Additional advice and support is available for families at home, through the nursing care team in LauraLynn House.

A Clinical Nurse Specialist is available from 07.45-18.00 Monday to Friday, in addition to an experienced children's nurse manager who can offer 24-hour telephone advice to the Nursing Care Team, regarding the clinical care and symptom management of children known to the service.

15.5.1 Symptom Management in the Home

Symptom management is often an evolving and on-going process that may require specialist input throughout a child's illness. LauraLynn therefore endeavours to support families when caring for their child at home and the LauraLynn@HOME Team often work in conjunction with the Symptom Management and Supportive Care Team in this regard. Prior to a planned Symptom Management stay in LauraLynn House, the LauraLynn@HOME team may visit at home and provide direct and targeted care for an agreed number of hours to help in the initial assessment of a child's symptoms. Whilst recognising the child and family as the experts, the LauraLynn@HOME team are able to directly observe the symptoms and the impact they may be having at home. The visits also help to ensure optimal continuity of care between the home and LauraLynn House as any additional care needs may be recognised in advance of admission to the hospice.

Subsequent to a symptom management stay, or in some circumstances following an acute hospital admission, a child and family may also be offered a period of targeted support from LauraLynn@HOME. These visits enable the team to:

- Feedback to the Clinical Nurse Specialists and provide an objective evaluation of any symptom management plan
- Provide expert nursing care for the child, along with additional support to the family with any new care plans, treatment options or medication regime
- Assess the emotional and psychosocial needs of the family and provide information and advice as appropriate and refer on to other healthcare professionals for additional supports



16

**Pillar Four –
End of Life Care**

A core pillar of the LauraLynn Children's Hospice Model of Care is caring for the dying child and family. End of life care is a continuum of palliative care and focuses on preparing for the death and managing the end stage of a terminal condition and includes care during and around the time of death, and immediately afterwards. It comprises the management of pain and other distressing symptoms and the provision of psychological, social, spiritual and practical support for the child and family. The end of life phase is said to begin when a judgement is made that death is imminent. It may be the judgement of a healthcare professional or team responsible for the care of the child, but it may also be the family who first recognises its onset. In some instances it may occur very suddenly, with little time for planning, and in other situations it may be very predictable and expected. It is usually limited to a short number of days, but with children, may often vary in length.

16.1 Location of Care at End of Life

Good end of life care should enable the child and family to have a choice about their location of care and ultimately, location of death. International research and national policy has suggested that home is the preferred location of care for children at end of life, but this is changing and the literature is starting to reflect this. The place chosen by a child and family, who have been fully informed, is by definition the best place and in recognition that home is not always preferred, possible or prudent, this model of care aims to offer the family the choice about place of death for their child and offers support in LauraLynn House or at home. Our Hospice Care Team works in close collaboration with the child and family, primary medical team, community services (e.g. Community Specialist Palliative Care Team, G.P., Public Health Nurse, Clinical Nurse Coordinators), along with other voluntary services to ensure the child and family's wishes are met where possible and every effort is made to ensure the family has open access to supports both in LauraLynn House and in the family home if that is what they wish.

16.2 Best Practice at End of Life

In keeping with best practice and recommended guidelines, when providing end of life care, LauraLynn aims to empower families and give them control over events at the end of life, and will endeavour to:

- Keep the child and family central to all discussions regarding decision making and care planning at end of life
- Ensure the full involvement of the interdisciplinary team as appropriate
- Ensure sufficient time is given to the child and family to make decisions and to assure them that they are not alone in the decision making process, rather part of the interdisciplinary care team
- Review identified wishes regularly as they may change
- Ensure siblings and extended family members – like grandparents, are always considered and provided for

- Promote continuity of care and minimise changes to staff caring for the child and family
- Always give consideration to parallel planning in recognition that the child's condition may change and not follow predicted trajectory

(NICE, 2016; TFSL 2012, 2018)

LauraLynn recognises that caring for children at end of life can be an intensely emotional time and good communication is essential to ensuring effective care provision. From the onset of recognition that a child is dying, the child and family's needs are assessed and a plan of care is developed. The Symptom Management and Supportive Care Team take a lead with planning, monitoring and evaluating all individualised end of life care plans, and as with all complex situations will ensure that a holistic, interdisciplinary approach is taken, including the full Hospice Care Team as well as relevant other healthcare professionals.

16.3 Advanced Care Planning

Effective symptom management for children is essential to ensure comfort but also to enhance their quality of life. This is as important at the end of life as it is throughout the journey, and anticipatory planning for end of life is vital in managing what is likely to happen. LauraLynn believes that children and parents should be given appropriate and timely information and be offered the opportunity to take the lead on decisions pertaining to their child's care.

Where possible, a child and family's wishes for care at end of life are discussed prior to the child being recognised as dying. Advanced care planning is an important part of caring for children with life-limiting conditions, and in particular for those children that are considered more unstable and / or deteriorating. Families may benefit from having the opportunity to discuss possible care related options and for preferences to be documented in advance so that professionals may know what the child and family's wishes are as the end of life approaches. Revisions and re-discussions are also facilitated as appropriate.

Ideally, end of life discussions should be led by a healthcare professional that a child and family have come to trust, who is perceived as confident, caring, experienced, and readily available. The Hospice Care Team can facilitate advanced care planning and end of life discussions over multiple visits to LauraLynn House or in the family home. This supports the child and family to explore wishes for living as well as for dying in a safe and supportive space.

The Hospice Care Team utilise advanced communication skills when talking to families about the care and support they can expect when the child dies. The team discuss the possible emotional, spiritual and psychosocial impact, as well as allow the child's and family's beliefs, values and wishes to be considered. When offering advanced care planning, the Hospice Care Team can discuss with the child and family where they would prefer to be cared for and where they would prefer to die, and carry out a realistic evaluation of the different options, taking into account:

- Individual wishes
- Religious, spiritual and cultural values
- The views of relevant and experienced healthcare professionals both within LauraLynn as well as those of external professionals
- Safety and practical issues

In addition to preferred location of care and death, and detailed symptom management and treatment plans, advanced care planning discussions may include the practical arrangements that will be needed after the death of a child.

This may cover matters such as:

- The care of the body
- Any relevant legal considerations
- The involvement of the coroner
- Registration of the death
- Funeral arrangements
- Transport requirements
- Post-mortem examination (if this is to be performed)

16.4 End of Life Care in LauraLynn House

Our Consultant Paediatrician or G.P. and Clinical Nurse Specialists coordinate all end of life care admissions to LauraLynn House with support from other members of the Hospice Care Team as required. Due to the complex nature of care at end of life, admissions are always carried out in collaboration with the child's primary paediatrician and / or GP and any other relevant acute or community healthcare teams in recognition of the fact that no single organisation or service can provide the level of care required to meet the complex needs of the child and family at end of life.

16.4.1 End of Life Care Transfer from Acute Setting

For children that are being transferred from the acute setting, LauraLynn advocates interagency and interdisciplinary discharge planning. A Clinical Nurse Specialist may visit the child and family in the hospital to start planning for the transfer and help identify any additional equipment, medication and even transport arrangements. Whilst transfers may take place at any time of day, efforts are made to ensure our Consultant Paediatrician is available and if required, on site, to receive care of the child and family, along with the Clinical Nurse Specialists and extended Hospice Care Team, into LauraLynn House. Ideally, when a child and family are transferred from an acute hospital, they are accompanied on transfer by a member of the nursing and medical team from the hospital, thus allowing a safe transfer and smooth transition and hand over of care.

LauraLynn will endeavour to facilitate the transfer of children from intensive care units to LauraLynn House for the controlled withdrawal of intensive and life-supporting treatments such as mechanical ventilation.

16.4.2 Interdisciplinary End of Life Care

When caring for a child at end of life, following an initial assessment and evaluation of care requirements, twice daily "huddles" occur to discuss the child and families' needs including symptom management, psychosocial, emotional and spiritual needs. The Family Support Team work closely to ensure that the holistic needs of the entire family are met, and may include meeting extended family members such as grandparents and cousins.

Along with "huddles" and in recognition of the emotional burden caring for a child and family at end of life may have, additional staff supports are offered to the Hospice Care Team. Our Psychologist, Social Worker and Chaplain encourage and facilitate frequent individual and team debriefings as required, to ensure staff are well supported.

In addition to our standard bedrooms and family accommodation, a family suite is available at end of life which allows parents to sleep in an interconnecting room to that of their child, remaining physically close at all times with on-going nursing support. The family suite allows for continuing clinical care, with clinical equipment such as piped oxygen and over-head hoisting fully available, yet providing the child and family with a more comfortable, private and peaceful surrounding.

Throughout a child's stay in LauraLynn House, extended family members as well as close friends, health and social care professionals, teachers and indeed anyone who has been a part of the child's journey, are welcomed to visit, with the child and family's expressed consent. The Hospice Care Team work closely with families to ensure that they feel supported in welcoming visitors, but also mindful so as not to be over-burden at such an emotional and sensitive time. Families are encouraged to personalise and decorate their bedroom to create a home-from-home environment, in which they feel as safe and comfortable as possible.

16.5 End of Life Care in the Home

When the family home has been chosen as the preferred place for a child to die, LauraLynn will work in collaboration with other healthcare professionals and agencies, such as Clinical Nurse Coordinators, Community Specialist Palliative Care Teams, GPs, PHNs and hospital teams, to help provide responsive, direct nursing care and practical support in the home. The LauraLynn@HOME Team are routinely available from 08.00-18.00 Monday to Friday, with any additional requirements outside of these hours provided on an individual basis, and in conjunction with the nursing care team in LauraLynn House.

As with end of life care in LauraLynn House, a member of the Symptom Management and Supportive Care team will endeavour to meet with the child and family and carry out an initial assessment and evaluation of care requirements. The Clinical Nurse Specialists may act as a resource in giving specialist advice in order to support the child being cared for at home. Together with all relevant healthcare professionals, the Clinical Nurse Specialist and LauraLynn@HOME Team support the end of life care planning process and where required, provide clear accessible care plans, advice on symptom management and medication management as needed to support the child and family. In addition to expert nursing care, the Clinical Nurse Specialists and LauraLynn@HOME Team may provide practical and emotional support to the child and family, referring on to other members of the LauraLynn Family Support team as required.

16.6 End of Life Care in Hospital

When the acute setting / hospital is the preferred location of care for a child and family at end of life, or for practical considerations, the family home or LauraLynn House is not an option, LauraLynn may offer support to both the family as well as hospital teams as required, by providing practical advice and support and visits from the LauraLynn@HOME Team to supplement the care being delivered. In addition, input from our Family Support Team is offered to compliment the emotional, spiritual and psychosocial support already being provided.

LauraLynn actively encourages hospital teams to contact a LauraLynn Clinical Nurse Specialist at any stage to identify what supports may be possible.

16.7 LauraLynn House Butterfly Suite

Following the death of a child, families are offered the use of the Butterfly suite in LauraLynn House, a self-contained suite with a temperature-controlled bedroom (cool room), adjoining sitting room with kitchenette, and bathroom.

LauraLynn understand that families value the opportunity to take their time saying goodbye. The Butterfly Suite allows the family a protected space and time to remain with and care for their child after death in peaceful surroundings, for a few days. Whilst research is limited, families appear to find this aspect of supportive care after the death of a child, immensely valuable. Family and friends are welcomed and the life of the child is celebrated. At all stages, LauraLynn endeavours to ensure every family's cultural differences and spiritual beliefs are respected. Our Chaplain has a variety of resources and contacts to assist the Hospice Care Team in providing care in the most appropriate way for individual families. Importantly, the use of the Butterfly Suite is not dependent on the location of death and may be used if a child already known to LauraLynn has died in LauraLynn House, at home, or in hospital. A member of the Hospice Care

Team remains allocated to support the family during this time so that they may be a point of stability. In a compassionate, professional and experienced manner they spend as much time with the family as they need, actively listening, talking and caring for all family members. The Hospice Care Team may also provide important practical support such as help with planning the funeral and dealing with the many potentially overwhelming tasks, which have to be undertaken following the death of a child.

Some families may choose to not use the Butterfly Suite, and instead may prefer to care for their child after death, at home. In these situations LauraLynn can support the family in the practical arrangements to facilitate this (e.g. transport arrangements) and offer the family the use of a portable cooling blanket to aid them in caring for their child in the home. For families that may choose neither option, LauraLynn will work closely with them to achieve whatever wishes they do have.

16.8 Memory Making at End of Life

LauraLynn recognises creating memories is an essential component of end of life care. It allows for legacy building as well as supporting children and families in bereavement. Memory and legacy making can facilitate continuing bonds with the child after death.

Various members of our Hospice Care Team specialise in crafting beautiful artworks (e.g. framed family trees, Picture Words, hand and foot moulds) and offering creative ways to both allow families to create memories and to continue the bond with their child in a meaningful way through the visual nature of the artwork, at this very sensitive and difficult time. It can be an opportunity for families to release emotion and create objects, which will remind them of their child. Often work that is commenced with the child and family prior to the death of the child may be continued with the family as part of our bereavement supports.

Such memory making is facilitated in LauraLynn House, as well as in the family home or if appropriate in hospital, and is provided to compliment the various family supports offered prior to a child's death as some of our therapists may also have created specific legacies with children and their families.

16.9 LauraLynn Butterflies

When the death of a child occurs at LauraLynn House, at home or in the hospital, butterflies are used as a symbol to mark the child's death. Metal-crafted butterflies are placed at discrete locations in the grounds of LauraLynn House as a sign of respect for the child, and to inform staff that a death has occurred. These butterflies remain throughout the grounds until after the child's funeral or burial / cremation service.

17

Pillar Five -
Bereavement
Care



At LauraLynn, bereavement care is set in a culture of compassion so that families receive high quality bereavement and end-of-life care that is appropriate to their needs and wishes, and in accordance with their religious, secular, ethnic, social and cultural values. Underpinning this is a clear and transparent ethos of bereavement care, and a recognition that it is the responsibility of all staff to embody compassion. Governance policies and guidelines for bereavement care and care pathways have been developed to ensure best practice and so that care is provided within the framework of national standards (NSBC, 2016; Jones et al., 2015) professional codes of practice, and the organisation's strategy. Systems are monitored and evaluated by a Bereavement Coordinator supported by a Bereavement Committee and a Bereavement Specialist Team to ensure that bereavement care and end-of-life care is organised around the needs of children and their families. Finally, staff access to education and training opportunities in the delivery of compassionate bereavement and end-of-life care is promoted, in accordance with their roles and responsibilities.

17.1 LauraLynn Children's Hospice Bereavement Committee

The Bereavement Committee is an interdisciplinary group tasked with ensuring high standards of bereavement care for children with life-limiting illnesses and their families from the point of entry to the services, to end of life, and in the grieving period that follows.

17.2 Aims of LauraLynn Bereavement Supports

LauraLynn bereavement supports aim to:

- Support families in developing an understanding of bereavement.
- Create a space that allows for processing of intense feelings.
- Offer guidance that allows families to reorganise roles, relationships and routines within the family.
- Intervene in cases where mental health difficulties arise from the experience of loss.
- Nurture personal growth in the context of major loss.
- Sign-post community-based bereavement supports.

17.3 Levels of Bereavement Support

LauraLynn bereavement supports operate through an interdisciplinary approach focusing on the child and family's spiritual, social, psychological, emotional and physical well-being. Formal supports (e.g., bereavement counselling) and informal supports (e.g. compassionate communication in the course of routine clinical care) are delivered by the Hospice Care Team from point of admission to discharge.

Depending on the assessed or perceived level of need, and according to the skills, knowledge and expertise of the Hospice Care Team member, different forms of support are provided. Consistent with established bereavement care frameworks (e.g., Jones et al., 2015), supports are delivered by members of the Bereavement Specialist Team, and the wider Hospice Care Team, across four levels, as identified in Table 2.

LEVEL	
1	All staff are responsible for delivering information, guidance and practical support
2	Staff with additional expertise implement psychological techniques such as problem solving with family members affected by grief
3	Counselling and specific psychological interventions such as facilitating group bereavement programmes are delivered by trained and accredited professionals.
4	High levels of distress and complicated grief reactions are responded to by the service's specialist clinical psychologist, in conjunction with relevant external agencies.

TABLE 2: Levels of Bereavement Support

Irrespective of the level of bereavement interventions offered, what is common is the goal of supporting families in their experience of loss, from anticipating a death to end of life, death and thereafter.

17.4 Types of Supports Available

Whilst the bereavement supports offered by LauraLynn are continuously evolving, based upon identified needs, the following are types of supports currently offered and available to all bereaved families across 4 levels:

17.4.1 Structured Events and Supports:

At Level 1, a range of events are scheduled throughout the year, such as the Annual Memorial Service, Grandparents Support Morning, Wellness Morning (for bereavement mothers and female relatives), golf outings for fathers, Autumn Memorial Walk, and anniversary cards.

17.4.2 Legacy and Memory Making

Across Levels 1 through 3, memory and legacy making is offered at any time during the child's life and death. It allows families to engage with their child in a meaningful way. Ultimately, a tangible output is created that is supportive of the family's long-term grieving. Memory Making may involve arts and crafts, as well as therapeutic inputs for children and their families. It is facilitated at LauraLynn House, at home, or in hospital.

17.4.3 Time to Grieve Programme

Also at Level 3, the Time to Grieve programme is an innovative therapeutic intervention for grieving parents at LauraLynn. The programme takes a holistic approach to supporting the emotional and spiritual needs of families within 12 months of the death of their child, incorporating psycho-education on the nature of grief and adjustment, memorialising the child, group reflection, emotional expression through music (playing and listening), and reflection supported by spoken word. The group is co-facilitated by the social worker, chaplain and clinical psychologist with a musical offering.

17.5 Bereavement Specialist Services

Examples of supports offered by members of the bereavement specialist team include the following:

- At Level 3, the chaplain offers spiritual, pastoral, religious and cultural support and is available to officiate at Services of Farewell for children who have died in LauraLynn House.
- The social worker offers face-to-face individual and group (Level 3) supports to families prior to, at the time of, and following the death of a child (onsite and in the home, according to need). In the context of bereavement supports, the aim of the social worker also involves liaising with the hospice care team and external agencies and providing information to families on entitlements and other supports, as appropriate.
- Our therapists offers both directive and non-directive Level 3 supports to children and families who are anticipating or who have experienced a loss. These are offered through the mediums of play and music to support a child with the emotional aspects of their loss.
- Across Levels 1 through 4, the specialist clinical psychologist provides talking therapy to individuals, couples and families who are anticipating a death or have experienced a loss. The focus of the psychologist's work is on supporting people with the psychological and emotional aspects of grief. Psychological supports are offered as part of standard supports offered to all families following the death of a child (for example, group bereavement interventions). Talking therapy sessions are typically provided onsite, though telephone or Skype consultations can also be facilitated.

17.6 Accessing Supports Following the Death of a Child

In the weeks following the death of a child, a member of the Hospice Care Team follows up with the family by telephone. At three months following the death, a letter is sent out to bereaved families, formally informing them to avail of bereavement specialist supports. In the months thereafter, invitations are sent regarding various other bereavement supports (named above). At any time, families are welcome to make contact with a member of the Hospice Care Team to request bereavement support.

18

Coordination,
Collaboration
and Partnership



LauraLynn Children's Hospice recognizes that children with life-limiting conditions and in particular those with palliative care needs, may see many health and social care professionals in the acute and community settings. Furthermore, LauraLynn acknowledge that in order to provide integrated, seamless, effective and efficient supports, communication and coordination between services is essential. LauraLynn hopes that such a collaborative approach will facilitate smooth transitions between hospital, hospice and home.

LauraLynn works in partnership with other services so that children and families have increased choice and flexibility over their place of care and place of death. This includes how and where they may access psychosocial and family supports, along with access to short breaks in LauraLynn House.

In partnership with children and their families, LauraLynn will share the findings from the individual holistic needs assessments, and the supports to be offered to help meet identified goals and family-related outcome measures. Where possible, LauraLynn offers an interagency approach to identifying concerns, assessing needs, and agreeing actions and outcomes. The aim is to empower families by providing them with support, resources and information, tailored to meet their individual needs, recognising that this is done across a range of service providers and organisations, rather than by LauraLynn alone.

18.1 Formal Connections

LauraLynn is a member of various local, regional and national networks, working groups, associations and committees. The following are some of the key groups that LauraLynn participates in. This list is not exclusive:

- National Perinatal Palliative Care Working Group
- National Integrated Care Pathway for children with Neuromuscular Diseases Working Group
- National Paediatric Transition Working Group
- Senior Children's Nursing Network
- Irish Childhood Bereavement Network
- Specialist Palliative Care Directors' of Nursing Network
- Strategic Advisory Group for Children's Palliative Care
- Irish Association for Palliative Care
- All Ireland Institute for Hospice and Palliative Care
- Hospice Chaplains' Association
- U.K. and Ireland Children's Hospice Network of Occupational Therapists and Physiotherapists
- Together for Short Lives

18.2 LauraLynn Children's Hospice and Children's Health Ireland (CHI) Partnership

LauraLynn is continuously looking to further establish formal connections and partnerships with key stakeholders and service providers both in the acute and community setting to help us best achieve our model of care and to enable better collaboration, coordination and partnership. With that in mind, LauraLynn is establishing two key posts with Children's Health Ireland.

18.2.1 Clinical Nurse Specialist in Children's Palliative Care

A new Clinical Nurse Specialist post has been developed between Children's Health Ireland (CHI) at Crumlin and LauraLynn Children's Hospice. The post holder will work as a member of the Specialist Children's Palliative Care Team in CHI at Crumlin with additional responsibility to strengthening professional relationships between both organisations.

It is proposed that the Clinical Nurse Specialist will work 0.8 Whole Time Equivalent (WTE) in CHI at Crumlin and 0.2 WTE in LauraLynn to allow attendance at the weekly LauraLynn Child and Family meetings and at other Hospice Team meetings as required. The Clinical Nurse Specialist will also work with the broader team to identify gaps in the provision of care to children with palliative care needs and to design and develop shared care pathways between both organisations.

In addition, LauraLynn will facilitate a LauraLynn Clinical Nurse Specialist to attend regular team meetings in CHI at Crumlin, to include, but not be limited to the weekly Neurology and Oncology psycho-social meetings.

18.2.2 Senior Pharmacist

Following a review of medication management practices at LauraLynn in 2017, it was recommended that the addition of a part-time pharmacist post to the LauraLynn Hospice Care Team would help improve medication management processes and minimise the risk of medication-related incidents. The appointment of a pharmacist to LauraLynn aligns with palliative care best practice guidelines which recommend that pharmacists should form an integral part of the multi-disciplinary teams of specialist palliative care units (Dept. of Health and Children, 2001; NICE, 2016).

LauraLynn has worked closely with CHI at Crumlin to develop a shared post with the aims of:

- Providing a clinical pharmacy service and medicines information support to the medical and nursing team in LauraLynn
- Reviewing and implementing medication safety strategies and initiatives, ensuring that the organisation is meeting legal and best practice requirements in relation to medicines management
- Reviewing current inpatient prescription charts and advising on alternatives to include consideration of e-prescribing tools
- Developing and delivering training to the nursing staff on medicines management
- Providing medicines information for children's palliative care via the existing Palliative Medicines Information service and develop the paediatric remit of this service

In addition, there is a paucity of research in the pharmacological management of problematic symptoms in children's palliative care. This post will support collaborative research in the most effective pharmacological interventions in this population.

18.3 LauraLynn Children's Hospice Research Partnership

LauraLynn has signed a Memorandum of Understanding with University College Dublin that supports a three year collaboration (commenced in November 2018), which will facilitate specialised research into the understudied healthcare field of children's palliative care.

18.3.1 Aims of Research Partnership

The aims of the collaboration are:

- To create and support teaching and research opportunities in both organisations
- To enhance and facilitate service-based research in children's palliative care
- To support the research and teaching strategies of both organisations
- To foster national and international cooperation and collaboration

18.4 Informal Networking

At a more local and informal level, LauraLynn Clinical Nurse Specialists and other members of the Hospice Care Team meet and communicate frequently with various other healthcare professionals that are involved in providing care and supports to children and their families attending LauraLynn; both in the acute and community setting. A member of the LauraLynn Clinical Nurse Specialist team will attend various inter-agency and interdisciplinary meetings, in particular relating to:

- Acute hospital discharge
- Symptom management
- End of life care
- Community supports

The aim is to ensure effective and timely communication amongst all professionals, and where possible to avoid and minimise duplication of service provision as well as over-burdening a family with multiple professionals. Often, where there are quite complex and changing needs, particularly relating to symptom management and / or end of life care, an anonymised, group email will be set-up amongst all relevant professionals to achieve prompt and clear communication.

18.5 Collaborative Learning and Networking

LauraLynn hosts an annual Professionals Open Day to encourage and support networking opportunities. The event aims to acknowledge the vast depths of our professional colleagues' knowledge and to offer them an insight into the complexity and workings of a children's hospice from the expert practitioners within the Hospice Care Team.

18.6 Ireland's International Children's Palliative Care Conference

LauraLynn is a key member of the planning committee for Ireland's International Children's Palliative Care Conference. Along with numerous other health care agencies, LauraLynn supports with the funding, organising and chairing of the event. LauraLynn recognises the value in sharing research and other projects at conferences, and also learning from the projects being undertaken by other professionals.

19

Workforce



LauraLynn aims to pursue excellence in care provision and service delivery, offering the best possible care to all children and families. We recognise that the recruitment and retention of highly skilled, experienced and motivated staff is essential to achieve this, in particular due to the often-complex nature of the children and the needs of their families. A flexible, compassionate, committed and highly skilled workforce is key to providing this care.

19.1 LauraLynn Children's Hospice Care Team

As the number of children with complex nursing and palliative care needs is steadily increasing, we need to ensure that our Hospice Care Team reflect this both in terms of skills and numbers. The Hospice Care Team in LauraLynn is made up of individuals from a variety of professional backgrounds to ensure the care provided is holistic, responsive and of a high quality. LauraLynn recognises that high staff to child and family ratios may be required so that the individual needs of children and their families can be met. (Please refer to [Appendix 3: LauraLynn Children's Hospice Care Team Structure](#))

19.1.1 LauraLynn House Nursing Care Team

The LauraLynn House Nursing Care Team consists of registered children's, general and intellectual disability nurses, along with health care assistants and nursery nurses. The Staff Nurses and Health Care assistants / Nursery Nurses provide direct care to each child and family that stay in LauraLynn House and are supported by Clinical Nurse Managers who provide additional clinical support and leadership, to ensure safe and effective care is always provided. As a team they act as keyworkers to individual families and work closely with the extended Hospice Care Team. The LauraLynn House Nursing Care Team is rostered on 24 / 7 over two shifts.

19.1.2 LauraLynn@HOME Team

The LauraLynn@HOME Team consists of registered children's and general nurses who under the guidance and management of the Team Leader, provide direct care to children and their families in the home and where appropriate in hospital. LauraLynn@HOME routinely work from 07.45-18.00 Monday to Friday, but depending on the circumstances may be able to provide care outside of these times. The team develop and maintain strong communication channels and links with external professionals to enhance and maintain continuity of care.

19.1.3 Chaplain

The Chaplain in LauraLynn is Chairperson of the Bereavement Committee and in addition offers pastoral care by being available and present to children and their families through empathic and compassionate listening, irrespective of the person's faith or none. The Chaplain also offers spiritual care that engages with transcendent and existential issues such as suffering, end of life, spiritual pain and death, where clarification, meaning and purpose of these may be addressed.

19.1.4 Clinical Nurse Specialist – Children's Palliative Care

In LauraLynn the Clinical Nurse Specialist supports the child and family along the LauraLynn Pathway, from point of referral through to bereavement. Acting as a point of contact for a caseload of children and families, our Clinical Nurse Specialist Team ensure a coordinated and seamless service through close liaison with other members of the Hospice Care Team as well as relevant external health care professionals and agencies. The Clinical Nurse Specialist will take a lead with assessing the holistic needs of the child and family as well as developing and managing symptom management and end of life care plans. They will also provide comprehensive education

and training around treatment as required. A key role too is monitoring and evaluating the effectiveness of the targeted supports offered to families, ensuring LauraLynn is continuously working to support assessed needs and identified goals.

19.1.5 Dietitian

Children with complex medical needs commonly encounter adverse feeding and nutritional symptoms throughout the course of their conditions, and these are often a defining feature. While many children require tube feeding in the latter stages of illness, many others will have longstanding gastrostomy or jejunostomy tubes. Texture of diet often has to be altered for safety and/or nutrition. The Dietitian in LauraLynn is highly qualified to provide the child and family with support plans relating to the frequent nutritional complications that arise, such as weight loss, reflux, vomiting, constipation, diarrhoea and aspiration. Furthermore, nutrition and hydration are significant issues at end of life and our Dietitian works with the extended Hospice Care Team in managing such concerns.

19.1.6 Head of Clinical Education

The Head of Clinical Education and has the overall responsibility to devise, co-ordinate, deliver and evaluate in-service education to support current and future members of the Hospice Care Team and respond to the educational needs of children's palliative care nationally.

19.1.7 Music Therapist

Music therapy offers a space for each individual to find a means for self-expression, whatever their ability or method of communication. The Music Therapist in LauraLynn uses music to facilitate and support these expressions and to encourage and reaffirm what each person offers. When working in the family and group contexts this enables positive connections and interactions which are inclusive of all family members regardless of age or level of functioning.

19.1.8 Occupational Therapist

The Occupational Therapist in LauraLynn works with the child in the context of their family including parents and/ or siblings. The Occupational Therapist supports the quality of the child's life within their typical daily routine maintaining the child's personhood and supporting the family to be able to engage and interact with their child, in particular where extensive symptoms or deterioration in functional needs apply constraints.

19.1.9 Physiotherapist

At LauraLynn, Physiotherapists are involved in promoting quality of life, comfort and enjoyment for children and families in collaboration with other members of the team. They provide guidance and interventions such as:

- Mobility, moving and handling
- Individualised night positioning to promote comfort and restful sleep while protecting the airway and providing postural support
- Assessment and treatment of breathing problems

Our Physiotherapists also work closely with the Clinical Nurse Specialists during end of life care to help prevent and treat distressing symptoms.

19.1.10 Play Therapist

In LauraLynn the Play Therapist provides emotional and practical support for children and their families. Play Therapy is a form of psychotherapy providing children with the safe therapeutic space to explore and express their thoughts and feelings through play, art, sand, music, puppets, role play etc. Play is a child's natural means of communication and through Play Therapy the child is empowered to express their reality, coming to an inner resolution, building resilience and increasing coping skills. It is offered to both the child living with the life-limiting condition, as well as to siblings. Therapeutic / sensory play and play therapy is offered to children to foster increased self-esteem and sense of belonging. From a bereavement perspective, the Play Therapist may address children's grief through the

power of play, as well as providing guidance and insights to parents to positively empower them in caring for their children's emotional needs.

19.1.11 Psychologist

In LauraLynn the Clinical Psychologist's work is aimed at reducing psychological suffering and maintaining / enhancing quality of life for children and their families by assessing, treating and, where possible, preventing psychological difficulties. After the death of a child, the Clinical Psychologist provides counselling to support families in their grief. Part of the psychologist's work is undertaken directly with children and families. The psychologist is tasked too, with offering consultation and training to the Hospice Care Team in relation to the delivery of care. The Clinical Psychologist also undertakes research in the field of children's palliative care and is the Clinical Lead for Research in LauraLynn.

19.1.12 Practice Development Manager / Clinical Placement Coordinator

Practice Development is a continuous process of improvement towards increased effectiveness in patient centred care. The Practice Development Manager supports the Nursing Care Team to develop their knowledge and skills to transform the culture and context of care. The role of the Clinical Placement Coordinator supports the facilitation of learning and assessment of competence among nursing undergraduate students in the practice setting (NMBI, 2016).

19.1.13 Social Worker

In LauraLynn the role of Social Worker involves assessing the psychosocial needs of children and their families who avail of our service. Our Social Worker will support families in identifying both their practical and emotional needs and providing support in coping with loss and change. This includes assessing bereavement needs and providing support prior to death and into bereavement. Often the Social Worker will engage with relevant external agencies to facilitate meeting identified needs and care plans for families.

A key role too is working with other team members in supporting emotional debriefing sessions for staff particularly following traumatic deaths.

19.1.14 LauraLynn Medical Team

The Medical Team consists of our Consultant Paediatrician, with a special interest in Neurodisability and Paediatric Palliative Care, and our two General Practitioners; all of whom have completed additional training in paediatric palliative medicine. Along with providing routine medical support to the Nursing Care Team, together they lead on all specialist symptom management, supportive and end of life care. At all times, the individual child's primary paediatrician and family are kept central to the decision making and treatment planning process. Our consultant also provides expert advice to other hospital and community teams upon request, and is Executive Lead for Research and Education and chairs the Senior Clinician Review group.

19.2 Effective Components of Workforce Development

LauraLynn believes the components of effective workforce development that can help, support, develop and motivate a highly skilled hospice care team are:

- A robust performance management and development system
- An education and training system that ensures individual and organisation needs are met
- A supervision and support system to help identify and support the impact of the emotional and psychological challenges of working in the area of children's hospice and palliative care
- Competence framework and values based recruitment, induction and orientation processes
- Communication systems to ensure all staff are kept informed of strategic and operational developments that may impact their working environment or role requirements

19.2.1 Performance Management and Development System

LauraLynn is committed to supporting its staff to live the values of LauraLynn in order to deliver high quality, effective and safe supports. Central to that is the requirement to engage with staff so that their voice is heard thereby enabling a highly motivated workforce where training and development needs are met. The Performance Achievement (PA) process facilitates this.

- Performance Achievement Reviews (PARs) enable staff to set goals, monitor performance and provide feedback throughout the performance review cycle and to develop staff competencies and capabilities
- The Performance Review Cycle (PRC) is the architecture of the PAR system for planning and reviewing an individual's performance and development with them, aligning individual goals and objectives with those of the organisation. It is carried out on a regular and consistent basis, and includes 2-3 key meetings annually between a manager and his / her direct report(s) as part of the cycle. It is a process that requires participation, respect, and frequent honest discussion and feedback on issues like role, responsibilities, objectives, resources, risks to success, and performance. It provides agreement on, and a record of, performance objectives and expectations and can be used to inform the reward, capability and disciplinary processes. It also informs local and strategic staff development planning

19.3 Education, Training, Learning and Development

It is the policy of LauraLynn Children's Hospice to provide the highest quality care to all the children that avail of our service. To fulfil these responsibilities LauraLynn aims to ensure all staff and volunteers are appropriately educated, trained and competent.

All care in LauraLynn, as per the five pillars, is planned and delivered through the collaborative efforts of the LauraLynn Hospice Care Team. To that end the Hospice Care Team is supported by the LauraLynn Learning and Development Team who deliver an on-going programme of education, training and development throughout the year.

The Learning and Development Team plan, schedule and co-ordinate internal education courses, masterclasses and workshops to meet the needs of the Hospice Care Team. They liaise with internal and external trainers / facilitators to plan and schedule training sessions and ensure that all trainers / facilitators are qualified (where required) and competent subject experts to deliver training.

19.3.1 Mandatory Training:

LauraLynn strives to ensure that all staff and volunteers are appropriately educated, trained and competent to ensure that effective services are provided and that any training or education needs are identified and addressed. Staff are required to undertake certain training and education to:

- Comply with legal obligations
- Carry out duties safely and efficiently
- Reduce and address areas of risk
- Maintain competence to the required standards identified by external bodies

In keeping with relevant statutory and compulsory training the following Mandatory Training schedule is in place for the LauraLynn Hospice Care Team:

Children First	To provide staff with training to ensure they are aware of their role to safe-guard and protect the well-being of all children
Fire Awareness	To raise awareness of fire hazards and learn how to act safely in the event of an emergency fire situation
Manual & People Handling	To assist in the development of the knowledge and skills required for safe manual and people handling
Infection Control	To understand the principles of standard infection control and universal precautions
CPR / Basic Life Support	To provide participants with the requisite knowledge and skills for Basic Life Support
Clinical Holding / Management of Actual or Potential Aggression (MAPA)	To provide staff with training to safely hold a child during clinical assessment and treatment procedures, as well as principles of the Management of Actual or Potential Aggression
Therapeutic Handling	To provide staff with an understanding of the potential problems children with life-limiting conditions may experience, in relation to handling, moving and positioning
Food Handling	To provide staff with an understanding of Food Safety, HACCP and Allergy management guidelines in food
Clamping	To provide staff with a working knowledge of how to safely secure children and their wheelchairs for transport

TABLE 3: LauraLynn Mandatory Training

Mandatory training requirements and records are reviewed annually to ensure that all staff are provided with the appropriate training to safely meet the needs of the children and families they provide care to.

19.3.2 Children's Palliative Care Education and Training

In order to ensure that children with life-limiting conditions receive appropriate care, both basic and on-going education and training of staff working in children's hospice and palliative care is essential. This is underpinned by the National Policy for Children's Palliative Care (2009), which advocates a 'culture of professional learning'. In LauraLynn, our education programmes are aligned to the HSE Palliative Care Competencies (Ryan et al., 2014):

DOMAIN OF COMPETENCE	
1	Principles of palliative care
2	Communication
3	Optimising comfort and quality of life
4	Care planning and collaborative practice
5	Loss, grief and bereavement
6	Professional and ethical practice in the context of palliative care

TABLE 4: HSE Palliative Care Competencies (2014)

19.3.3 Education and Training in Practice

At LauraLynn, we aim to generate a culture of learning to support the attainment of competency in knowledge, skills and attitudes for all healthcare professionals who provide care for children with life-limiting and palliative care needs and their families. The aim is to develop inter-professional learning that is facilitated through reflection, practical demonstrations, group work and lectures.

The learning and development opportunities in LauraLynn are captured in Figure 7 – Modern Workplace Learning at LauraLynn. These include the formal courses such as the Induction programme for new staff, masterclasses delivered by an expert, and Open Days for Professionals.

Social collaboration supports learning through shared activities with colleagues, this includes clinical debriefing after a child has died, Knowledge Exchange / Share & Learn, CEO briefings and formal and informal preceptorship.

Modern Workplace Learning at LauraLynn

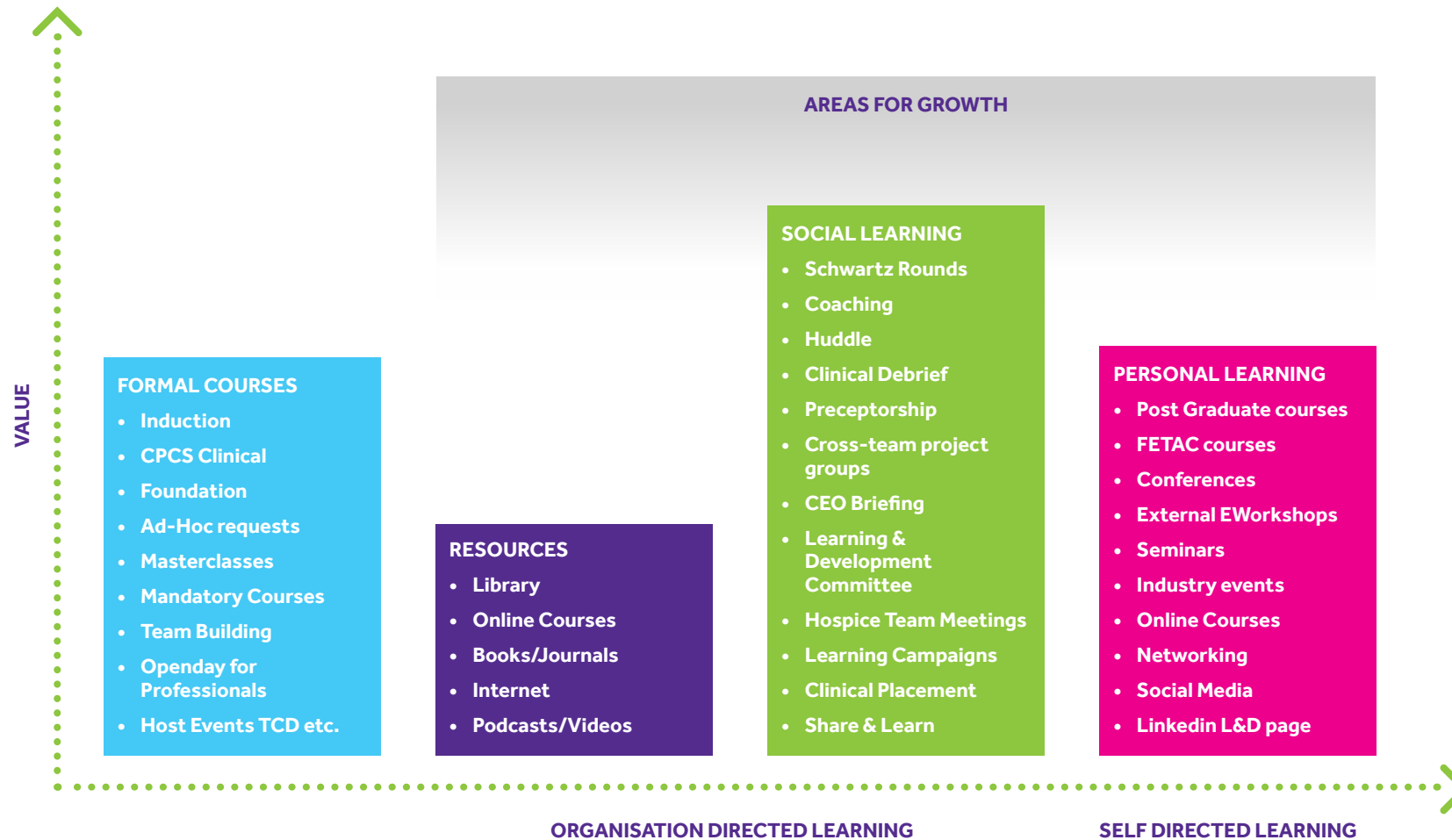


FIGURE 7: Modern Workplace Learning at LauraLynn

In the modern workplace the personal commitment to identifying goals of learning are supported by completing formal academic courses, networking and through social media. To actualise this personal commitment to learning and development, education and training is closely associated with an individual's Performance Achievement Review (PAR) which allows staff to set performance objectives with their manager that both support the individual and the strategic or organisational goals.

These all enhance the staff member to maintain and extend their knowledge, skills and attitudes to ensure we have the 'Right Team' who are appropriately-skilled and knowledgeable health and social care professionals to provide care for the children and their families who avail of our service.

Please refer to [Appendix 2: LauraLynn Clinical Nurse Education Pathway](#) for further information on the formal education and training that is provided to the Nursing Care Team.

19.3.4 PaedPal TASK

LauraLynn recognises that caring for children with palliative care needs places exceptional demands on health care professionals. It is therefore essential to understand the professional development requirements of nurses within this evolving specialty. There are few formal mechanisms to allow nurses to self-check and appraise their evolving knowledge/competencies within children's palliative care.

The Paediatric Palliative care Tool for Appraising Skills and Knowledge (PaedPAL TASK) has been designed by LauraLynn based on published competencies for children's palliative care nursing. This (PaedPAL TASK) supports nurses in identifying their practice knowledge, strengths and deficits, with the ultimate goal of focusing nurses to plan their own individual professional learning goals.

The creation of a dedicated appraisal tool allows nurses in LauraLynn to translate the conceptual requirements for competence in clinical practice

into a reflective appraisal document. This unique PaedPAL TASK provides a mechanism to encourage nurses to formally assess and challenge their existing knowledge with a view to documenting and recognising personal requirements for professional development.

The aim is that this tool is used in conjunction with and as a support to all the informal and formal training and education provided in LauraLynn. It is not used as part of the performance achievement system, but rather it is envisaged that it acts as a structured guide to the individual nurse.

19.3.5 Graduate Education and Training in LauraLynn

LauraLynn is a recognised teaching site for undergraduate training for both medical and nursing students:

- Undergraduate Medical Students from Trinity College Dublin are provided education and training in relation to principles of children's hospice and palliative care during their fourth year.
- Trinity College Dublin undergraduate Nursing Students (Combined General and Children's Programme) may undertake a specialist placement in LauraLynn House

In addition to the aforementioned training, Post-Graduate and Masters Students undertaking courses in Children's Palliative and Complex Care / Palliative Care are offered placements in LauraLynn and will spend time working with various members of the Hospice Care Team both in LauraLynn House as well as in the family home where appropriate. All placements are arranged directly with the Clinical Placement Coordinator and are offered subject to the scheduling and resources of the various clinical areas.

19.4 Recruitment

LauraLynn uses a Competency Based Approach to recruitment and selection, to help identify candidates who are most suited to the role in terms of their knowledge, skills and abilities. In addition, a Values Based Recruitment (VBR) approach is used to help select potential employees on the basis of their individual values and behaviours. The purpose of including VBR is to ensure that the future and current LauraLynn workforce is selected against the values of the organisation so that we have the right people, with the right skills and values, to deliver excellent care and experience for children and their families.

19.5 Induction

LauraLynn recognises that its staff are fundamental to its success. To enable all staff to become effective and efficient in their role as quickly as possible, it is essential that all staff new to the service, or the role, receive a timely induction. LauraLynn places critical importance on thorough induction procedures, which make new staff feel welcome, valued and settled in their new role. This then forms the basis from which staff can quickly get up to speed, perform their duties effectively and begin to make a contribution to their team, the department and LauraLynn.

The aims of the induction process are to:

- Promote an environment of effective health, safety and welfare
- Promote an emphasis on service user focus
- Obtain effective output and an acceptable standard of performance from the new employee in the shortest time possible
- Establish quickly in the mind of a new employee a favourable attitude towards the organisation so that they are more likely to stay
- Ensure that initial stages of employment are smooth for a new employee

The induction process also allows the line manager to communicate LauraLynn policies, values and standards to new employees. It helps to put new employees at ease at an early stage and to secure their commitment to delivering the best possible service.

New employees who are offered employment are required to serve a 6-month probationary period. The objective of the probationary period is to monitor the new employee's progress in the job with a view to determining their suitability for continued employment.

19.6 Staff Supports

LauraLynn offers a range of supports to the Hospice Care Team in recognition of the importance of maintaining their own health and well-being. These supports range from mental health and emotional supports, to individual opportunities for personal and professional development. LauraLynn endeavours to promote a positive working environment, with the aim of providing a great place to work with the Hospice Care Team feel valued, and proud of the work they do. Figure 8 shows the range of staff supports available.

MENTAL & EMOTIONAL WELLBEING

Mindfulness
 Emotional Debriefing
 Schwartz Rounds
 Positive Psychology Programme
 Support Contact Person
 Employee Assistance Programme (EAP)
 HR Consultation
 Individual Psychological Consultation
 Wellbeing at Work Programme

PROFESSIONAL & PERSONAL DEVELOPMENT

Coaching & Mentoring
 Clinical & Emotional Debriefing
 Academic Qualifications
 Professional Courses/Conferences
 Learning & Development Helpdesk
 Clinical Supervision
 Clinical Practice Development Performance
 Achievement Cycle Coffee & Culture Club
 Online Training
 LinkedIn L&D page
 Library
 Learning Campaigns
 Tailored Training Solutions
 Knowledge Exchange / Share & Learn

WHAT ARE SCHWARTZ ROUNDS™?

Schwartz Rounds™ are tightly structured monthly meetings for multi professional groups of staff working in healthcare organisations. They are a forum for staff to discuss and reflect on the emotional aspects of providing care.

WHAT IS THE WELLBEING AT WORK PROGRAMME?

The wellbeing at work programme offers supports in the 5 key pillars of physical and mental wellbeing – Nutrition, Sleep, Physical Activity, and Mental Health & Working Environment.

WORK ENVIRONMENT

Gardens and Quiet Space
 Free Car Parking
 Subsidised Staff Restaurant
 Occupational Health
 Flu Vaccination Clinic
 Cycle to Work Scheme
 Healthcare Services Credit
 Union Pension Plan

COMMUNICATION

CEO Briefings
 Team Meetings
 Notice Boards
 Staff Satisfaction Surveys
 Daily Huddles

FIGURE 8: Staff Supports available at LauraLynn

19.7 LauraLynn Children's Hospice Volunteer Programme

19.7.1 LauraLynn House Volunteers

The Volunteer Programme in LauraLynn House is a constantly developing service to meet the needs of the children and families. Volunteers are currently supporting the Hospice Care Team and the children and families in a variety of roles both directly and indirectly:

Activity Assistants	Activity Assistants are active in LauraLynn House seven days a week. Volunteers support the staff to create a fun environment for the children during their stay. They assist with play, arts & crafts, sensory activities, storytelling and other activities
Domestic Aid	Volunteers come in twice a week to iron bed sheets and clothes for the children during their stay in LauraLynn House
Music	We have a team of volunteer musicians that visit us on a weekly basis to allow the children experience live music during their stay. Our musicians cover a wide variety of genres including classical, pop and folk
Complimentary Therapy	This is a developing area within LauraLynn. We currently have three Pet Therapy Dogs, hairdresser, yoga instructors and we aspire to offering other therapies to our families including reiki, massage, reflexology and aromatherapy
Drivers	Our volunteer drivers provide a much-needed service for families without their own adapted vehicles. Our drivers provide transport to families for their stays in LauraLynn House. They also bring children on excursions and hospital appointments during their stay with us if required
Events	All LauraLynn events are supported by our Volunteer Team. They assist with our family camps, family fun days, parties, fundraising and special events throughout the year
Maintenance	We have a small team of volunteers that assist our Facilities Team on a regular basis. From odd jobs to larger projects, they are kept extremely busy
Administration	The administration team provide support to all departments in LauraLynn. They assist with data entry, mail outs, archiving, filing and fundraising support

TABLE 5: LauraLynn House Volunteer Programme

19.7.2 Fundraising Volunteers

LauraLynn Children's Hospice was founded on the back of tremendous and selfless work of volunteers. Years of fundraising by key volunteers are one of the main reasons why LauraLynn exists today. Fundraising volunteers still play a vital role in the on-going development of LauraLynn and we rely on volunteers across the length of breath of the country to volunteer their time hosting fundraising events to ensure we can keep our doors open.

19.7.3 Volunteer Training

All registered volunteers must complete a series of training sessions over the course of their time with us. Volunteers are required to complete training depending on their role assigned. Training Sessions for volunteers include, but is not limited to the following:

- Induction
- Child protection
- Infection control
- Manual handling
- Fire awareness
- Communication
- Role specific training
- CPR (as required)

20

Research



The paucity of evidence in children’s palliative and hospice care is a potential problem that may serve as a barrier to the future sustainability of children’s palliative care services. In keeping with the organisation’s recognition of the need for additional research in this area, LauraLynn has devised a research strategy that will operate across three areas (See Figure 9 right). A three year Memorandum of Understanding (refer to [Section 18.3: LauraLynn research Partnership](#)) has been signed between LauraLynn and University College Dublin to help support the LauraLynn Research Strategy and the Board Sub-Committee – Research and Ethics, provides additional advice and governance to all Hospice Care Team members undertaking research, as well as to external professionals carrying out research in LauraLynn.

20.1 LauraLynn Children’s Hospice Research Strategy

The objective of Area 1 is to build on the existing infrastructure for research in order to create a platform from which Areas 2 and 3 can be launched. Areas 2 and 3 are overlapping and involve, on the one hand, undertaking research projects that are specifically tailored to support LauraLynn’s strategic development and, on the other, raising the profile of LauraLynn and children’s palliative care. In conjunction with universities and other service providers where possible, the LauraLynn research strategy will enable the Hospice Care Team to build a much-needed evidence base for the care and support provided by the LauraLynn Children’s Hospice Model of Care. LauraLynn will endeavour to disseminate all research findings through both conference papers and presentations as well as through publications.

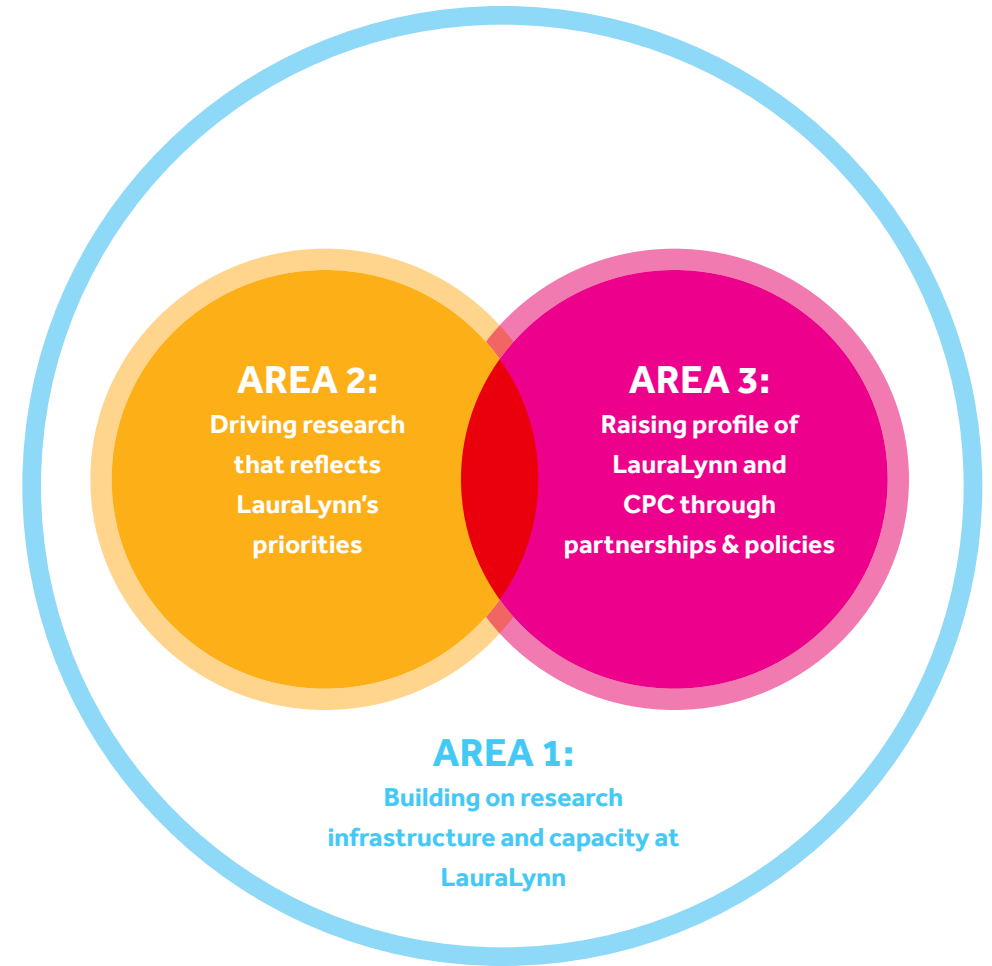


FIGURE 9: Research Strategy

21

Family
Engagement



LauraLynn aims to offer a caring and supportive service which responds to the needs of all children and their families. Trusting, open and honest relationships between the Hospice Care Team and the child and family are critical aspects of children's hospice care. All family members are encouraged to feedback to the Hospice Care Team any thoughts or suggestions in relation to the care and supports they receive.

21.1 Child and Family Feedback

All members of the Hospice Care Team are encouraged to seek feedback and to pass on any received to line managers and to share at team meetings as appropriate. Children and families can give feedback in the following ways:

- Speak to a member of the Hospice Care Team during a stay or home visit
- Contact a member of Hospice Care Team by telephone to discuss and suggestions or concerns
- Discuss any suggestions or concerns during a key-working call with a Clinical Nurse Specialist / Hospice Care Team member
- Complete a Compliments, Comments & Complaints form and post in confidential letter box – available at entrance to LauraLynn House and in Family Accommodation
- Write to a Nurse Manager or Executive Team member

21.2 LauraLynn Family Engagement Committee

The LauraLynn Family Engagement Sub Committee of the Board of Directors has been established to represent families' interests and views and in recognition of the valuable input they may provide. It consists of key members of the Hospice Care Team along with members of the Executive Management Team. Family Representatives on the committee are appointed on a rotating membership basis, and both current and bereaved family members are invited to nominate themselves.

21.2.1 Family Engagement Committee Objectives

The objectives of the Family Engagement Committee are:

- To provide an effective representative body for families (parents, siblings, grandparents, guardians, carers)
- To communicate and engage effectively with the Board of Directors, CEO and staff
- To develop and foster communications within all strands of the service
- To allow for greater openness for communication and put forward suggestions, issues and concerns for the improvement of the service in an open and constructive manner
- To agree on the key actions and deliverables of the sub-committee and to review and monitor the implementation of these actions within the agreed timeframe

21.3 Communicating with Families

Families are kept informed of all new developments through a variety of communication methods:

- Face to face / by telephone – all staff are encouraged to update and inform children and families in person, during any visits to LauraLynn House or home visits, or during routine key-working calls
- By email – all families are encouraged to provide LauraLynn with an email address to allow us to keep in contact regularly. The LauraLynn Family eZine is sent to all families 3-4 times a year
- By post – for those families who have opted out of email communication, LauraLynn will maintain communication and update families by post

22

LauraLynn
Children's Hospice
Facilities



22.1 LauraLynn House

LauraLynn House was first opened in September 2011 and is an architecturally-designed, two-story, low-energy, sustainable building spread over 1,300 square metres. LauraLynn House is a specialised care setting dedicated to children with palliative care needs and their families and whilst it is designed to comply with health and safety and infection control regulations LauraLynn House has also been designed to:

- Feel warm and welcoming
- Include clinical equipment and facilities to meet the needs of children with complex needs, including technology-dependent children
- Be fully accessible

LauraLynn House has a large reception area, with separate family meeting room / reflective space. Surrounding the centrally located Hospice Care Team Interactive Zone, there are seven en-suite children's bedrooms and one family suite comprising of an en-suite child's bedroom with adjoining parents' bedroom. The multi-sensory bathroom and the medication and clinical supplies room are located bedside the bedrooms. In addition, there are various office spaces to host members of the Nursing and Medical Team. Offices for the interdisciplinary Family Support Team are located in an adjacent building. Alongside the large living room there is a specially designed play therapy room, multisensory room and kitchen. Throughout the building, every effort has been made to both ensure full accessibility with overhead tracking hoists for safe moving and handling, along with doors to the landscaped gardens that surround LauraLynn House.

22.1.1 Children's Bedrooms

Each of the 8 children's bedrooms are equipped with piped oxygen and suction units as well as overhead tracking hoist facilities for safe moving and handling. A range of specialised beds and postural management equipment (sleep systems) is also available for each room, and each bedroom is also fitted with OneView interactive bedside entertainment units with access to LauraLynn's electronic health records (EHR) system.

Further planning and consideration has been made to ensure we can safely and effectively meet the health and care needs of the children:

- Low windows and under floor heating in all children's areas
- Emergency call bells throughout the house
- Assisted bathroom with Jacuzzi bath and wide range of bathing aids
- Separate, lockable medicine cabinet in each child's bedroom
- Separate, restricted access medication and clinical equipment / supplies room
- Additional access to oxygen concentrators, oxygen cylinders
- Access to essential clinical equipment, such as suction machines, syringe drivers, oxygen saturation monitors, blood glucose & ketone monitors

22.1.2 LauraLynn House Family Accommodation

The family accommodation facilities, situated on the second floor include a self-catering kitchen, separate living room and four en-suite family rooms (two twin rooms and two triple rooms; with additional camp beds available). The family accommodation is fully accessible by lift and stairs.

22.1.3 LauraLynn House Multisensory Rooms

LauraLynn House has a multisensory room with heated waterbed, built in music system, ceiling star lights and soft flooring and walls and provides a safe space for children to relax or enjoy some one-to-one time with a therapist, or simply have fun with siblings. The sensory bathroom has a height-adjustable Jacuzzi bath, built-in music system and ceiling star lights and offers therapeutic benefits for the children. Parents and siblings are more than welcome to join their child for a bath.

22.1.4 Music in LauraLynn House

Whilst music therapy is offered as a targeted intervention, there is also a wide range of musical instruments available and the Hospice Care Team offer music and singing activities as part of the range of opportunities for the children and families to enjoy. Often too, musical groups, bands and choirs are invited in to LauraLynn House to perform for children and their families.

22.1.5 LauraLynn House Specialist Equipment

LauraLynn House has an extensive range of sensory and play equipment to meet children's play and recreational needs. There is a wide range of arts and craft supplies with additional furnishings to ensure all children, irrespective of their sensory and physical abilities may partake in developmentally appropriate activities. There are various Acheeva learning stations that provide full support in supine, prone or side-lying to protect body shape and respiratory function for children that may not be able to remain in their chair for long periods, and as an alternative to a bed, as well as activity stations that are height adjustable and designed to fit with wheelchair users. Specialist entertainment and educational technology provided by LifeLites charity, such as Eyegaze, Mobile Magic Carpet, iPads, Soundbeam and Beamz offers children opportunities to benefit from the power of assistive technologies to learn, to be creative, to communicate and to take control. Overhead tracking hoist facilities are also available in individual therapy rooms as well as in the main living room.

22.1.6 LauraLynn House Quiet Space

For those children, siblings or parents that may enjoy some time out in a more quiet space, our Reflective Space has been specifically designed to be warm, comfortable and relaxing, and our Rainbow Den allows children and families to take a break from the living room and avail of the wide range of computers and gaming consoles.

22.1.7 LauraLynn House Butterfly Suite

Our butterfly suite is located within LauraLynn House and is available to support families in the immediate period following their child's death. For further information please refer to [Section 16.9: LauraLynn Butterfly Suite](#).

22.2 LauraLynn Outdoor Facilities

LauraLynn has four designated safe, secure and well-maintained outdoor recreational areas:

- The adapted playground is accessible to children with physical disabilities offering wheelchair swings and roundabout while a second playground offers play opportunities for mobile children and siblings
- The accessible sensory garden contains a quiet corner with memorial fountain, a play area, chess game, musical instruments, seating and pathway through sensory flowerbeds
- An internal beach themed courtyard with seating areas is also available for small groups/activities
- Throughout the rest of the grounds, there is ample car parking facilities for staff, families and visitors. There are walkways throughout the garden areas and benches for resting at frequent intervals. The grounds also host an additional sensory trail that includes natural scents, textures and visual components for children with sensory impairments

22.3 LauraLynn Restaurant

The LauraLynn Restaurant is open daily and is available to all relatives, staff, volunteers, students and visitors to the hospice. Freshly cooked meals are prepared each day with an emphasis on healthy, nutritious ingredients. Soup, sandwiches, tea and coffee are available throughout the day.

Cooked meals are available Monday – Sunday at the following times:

Breakfast 8.30 am to 11.30 am

Lunch 12.30 am to 2.30 pm

Tea 5:00 pm to 6:00 pm

Meals are free of charge to families staying in LauraLynn House and extended family members and other visitors may purchase meals in the restaurant. Free tea and coffee making facilities are available to all.

22.4 Infection Control

LauraLynn takes infection control seriously. All staff, volunteers and visitors to LauraLynn House have a vital part to play in preventing the spread of infections and are asked to clean their hands using the hand-washing sinks and alcohol gel dispensers provided on entering at reception, and throughout the building. All visitors should pay particular attention to any advice they are given by the Hospice Care Team or Household staff.

23

Governance



23.1 Clinical Governance

Clinical Governance focuses upon experiences and learning, in order to improve upon clinical outcomes, improve the working environment, assess and where possible, anticipate risk in order to eliminate or reduce risk or harm. LauraLynn espouses to excellent clinical governance to demonstrate accountability for and ensure continuous improvement in the quality of care that is provided to children and their families. LauraLynn ensures that the principles of clinical governance underpin the work of the Hospice Care Team.

23.2 Quality Improvement

Quality improvement in LauraLynn is about finding effective ways to deliver safe, effective, high quality care for children and their families. The views, experiences and outcomes for children and their families are paramount to quality improvement. LauraLynn therefore focuses on how to best identify the changing needs of children and their families and identifying methods to improve their experience and outcomes. From this, LauraLynn is able to learn, develop and improve the supports provided.

23.3 Quality Risk and Safety Committee

The Quality, Risk and Safety Committee provides scrutiny and challenge with regard to all aspects of quality, risk management and health and safety, throughout LauraLynn, including; infection control, clinical governance, and audit, in order to provide assurance and make appropriate reports or recommendations to the Board of Directors. The Committee is chaired by a member of the board, and strives to embed high standards of care and ultimately to ensure continuous quality improvement in all aspects of service provision. The committee meets every two months and considers regular updates and reports regarding the following:

- Risk Management
- Complaints, Comments & Compliments

- Clinical and Non Clinical Audit
- Quality Improvement Initiative programmes
- Health and Safety
- Senior Clinician Review Group
- Facilities
- Medicines Management
- Prevention and Control of HCAI's
- Child and Protection and Welfare
- Clinical Education and Training
- Policies, Procedures and Guidelines

In addition to the QRS Committee meetings, quality of care is also formally monitored through regular meetings:

- Executive Management Team Meeting (fortnightly)
- Risk Management Meeting (fortnightly)
- Medication Monitoring and Management Meeting (weekly)
- Senior Clinician Review Group Meeting (monthly)
- Hospice Care Team Meeting (monthly)
- Child and Family Review Meeting (weekly)
- Psychosocial Family Support Team Meeting (weekly)

23.4 Risk Management

An effective quality improvement environment requires a culture that is open and positive and all staff are encouraged to report any concerns, incidents and risks as well as excellent practice. LauraLynn has a robust Risk Management System in place in order to provide a high quality, safe environment to children and their families, and an environment and culture that is safe for staff, volunteers and visitors. The risk management process is both proactive and responsive in its applications and incorporates the identification, assessment, management and on-going review of risks on an organisational and individual level, as well as evaluating their potential consequences and determining the most effective

methods of responding to them. LauraLynn aims to empower all staff to assume responsibility for contributing to effective risk management, systematically leading to a risk management culture in the service. All concerns, incidents or risks are reported to and reviewed by the fortnightly Risk Review Meeting and escalated to the Quality Risk and Safety Committee as appropriate.

23.5 Audit

LauraLynn has an annual audit programme, which ensures that, as an organisation, we are continually improving our clinical services. The Audit Committee has been established to ensure that best practice principles and standards of audit are applied to all aspects of the service with the ultimate goal of improved care to children and families receiving services. Current audits undertaken include:

- Clinical Hygiene
- Medication Management
- Hand Hygiene
- Child Protection
- Healthcare Record Management
- Non-clinical Audit Environmental Hygiene
- Health & Safety
- Hand Hygiene Facilities Measurement Tool
- Hand Hygiene Sanitary Assembly Specifications (HACCP)

23.6 Senior Clinician Review Group

The Senior Clinician's Review Group is tasked with providing oversight of behaviours, processes, protocols and application thereof that impact, or have potential to impact in a substantive way, on clinical practice at LauraLynn. The group is populated by a cross-section of senior clinicians who are experts by experience in their respective fields and the deliberations and actions of the review group are informed by evidence and research based practices and guidelines. The group is chaired by the Consultant Paediatrician and reports to the CEO via the Quality, Risk and Safety Committee.

The objectives of the Group are to:

- Allow dynamic and timely response to challenging and emerging clinical situations
- Highlight, review, and provide practical written or verbal guidance on matters that arise in clinical practice and which may present obstacles to effective and safe delivery of quality care

23.7 Feedback

Staff are encouraged to seek feedback from children and their families on their experience and any aspects of the care provided as well as the building and facilities. LauraLynn aims to accomplish this by:

- Regular communication by Clinical Nurse Specialists and Key Working teams
- Pre and post short break stay phone check-ins as well as during stays
- annual Child and Family Reviews
- Feedback forms following specific projects (e.g. family camps, Christmas party)
- Comments, Complaints and Compliments Boxes
- Family Engagement Committee

LauraLynn seeks to respond to feedback in a proactive way in order to ensure we maintain the highest standards of quality care provision.

23.8 Quality and Safety Walk-Abouts

LauraLynn utilises Quality and Safety Walk-Abouts to allow Board members to have a structured conversation regarding safety and quality with members of the Hospice Care Team. The Walk-Abouts are intended to provide staff with the opportunity to give immediate feedback and ideas, both in terms of identifying potential risks as well as highlighting good practice. Following a Walk-About, any issues or concerns are fed back to the Executive Management Team member along with local manager, and an action plan is developed to address them.

23.9 Policies, Procedures and Guidelines

LauraLynn has a range of organisational policies, procedures and guidelines, which are reviewed regularly to reflect changing requirements and support high quality clinical practice. Each document has a lead author and an agreed review date.

23.10 Clinical Leadership

Effective clinical and managerial leadership is essential and at all stages there are easily identifiable and clear lines of responsibility and accountability. LauraLynn has a clear and agreed Hospice Care Team structure with all staff reporting to the Assistant Director of Nursing and in turn to the Director of Nursing for professional leadership and clinical accountability. The Assistant Director of Nursing is also responsible for ensuring that the Hospice Care Team is adequately staffed, trained, qualified and experienced to provide the supports identified in this model of care and also tasked with ensuring the Hospice Care Team is appropriately supported by the organisation. Both the Consultant Paediatrician and Director of Nursing are members of the Executive Management Team and report directly to the Chief Executive Officer.

23.11 Corporate Governance

LauraLynn Children's Hospice is a registered charity, limited by guarantee, governed by a Board of Directors and managed by the Chief Executive Officer and Executive Management Team.

The non-executive Board of Directors are drawn from diverse backgrounds and possess a wide range of skills and experience. Each Director is appointed for a period of three years having been recommended by the Nominations Committee and is eligible for re-appointment for two further consecutive three-year periods (nine years in total). The Board meets at least six times each year and has responsibility for all the business of the organisation.

The Board is supported by a Board committee structure, which deals effectively with specific aspects of the business of the organisation.

The Board sub-committees in place are:

- Quality, Risk & Safety Committee
- Finance & Operations Committee
- Financial Audit Committee
- Nominations, Corporate Governance & Remunerations Committee
- Fundraising Committee
- Research & Ethics Committee
- Family Engagement Committee

All new Board Members and Trustees are inducted into the organisation, receiving a Code of Conduct for Board Members Booklet which includes our Conflict of Interest Policy. The Board delegates the day-to-day management of the organisation to the Executive Management Team, which comprises of the Chief Executive Officer and the following senior managers:

- Consultant Paediatrician
- Director of Nursing
- Head of Communications and Marketing
- Head of Finance
- Head of Fundraising
- Head of Human Resources
- Head of Operations
- Quality, Risk and Safety Manager

LauraLynn takes the commitment and trust of our donors, funders and the public very seriously and we honour it by providing clear and transparent information about how we raise our money, how we account for it and how we spend it.

Our voluntary Board of Directors and Trustees are ultimately responsible for our governance, strategic direction, ethos and values. Additionally, The Board are responsible for ensuring that the organisation operates an appropriate system of financial control and complies with relevant laws and regulations.

LauraLynn Children's Hospice is registered with the Charities Regulatory Authority and supports the implementation of the Charities Act 2009. We are

compliant with our HSE Annual Compliance Statement and The Governance Code for Community, Voluntary and Charitable Organisations. We are signed up to all ICTR fundraising regulations and adhere to the data protection laws. We have achieved the Standard of Recommended Practice (SORP) for financial management, which means that LauraLynn operates to the triple lock standards of transparent reporting, good fundraising and good governance.

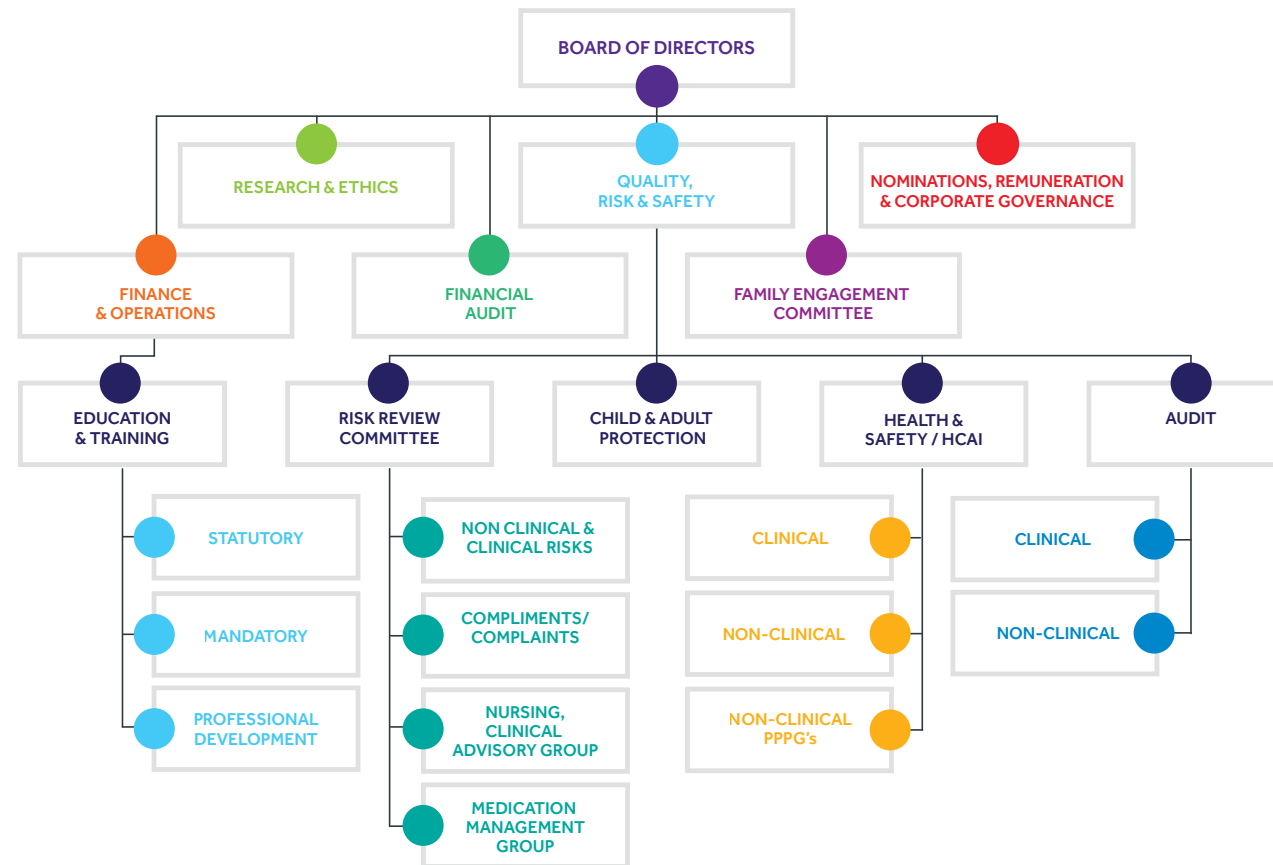


FIGURE 10: LauraLynn Board of Directors and Committee Structure

23.12 General Data Protection Regulation (GDPR) in LauraLynn

LauraLynn recognises the importance of safe data management and adheres to the core principles of GDPR. Appropriate controls are in place to ensure the effective management of all data held, for the children and families that are availing of services in LauraLynn, as well as data pertaining to staff. In addition strict controls are in place in relation to information held on all donors.

23.13 Safeguarding Arrangements

The LauraLynn Child Protection and Adult Vulnerability Committee is chaired by the Senior Social Worker and reports to the Quality, Risk and Safety Board Sub-Committee. LauraLynn is fully compliant with all HSE requirements and has a designated lead for Child Protection and an additional two deputies for all related concerns. LauraLynn accepts and recognises its responsibilities to inform itself of the issues that cause harm and to establish and maintain a safe, person-centred environment for those children and families that LauraLynn supports. LauraLynn is committed to promoting an atmosphere of inclusion, openness and transparency and greatly welcomes feedback from the people who use our services, their families, carers, our staff and volunteers so that it can continuously try to improve services. LauraLynn strives to safeguard those who use its services by adhering to its Policy on Child Protection & Welfare which is in line with the Children's First National Guidance for the Protection & Welfare of Children (2015). LauraLynn has zero tolerance towards abuse and will not tolerate any form of abuse wherever it occurs or whoever is responsible.

As per the Child Protection & Welfare policy, all staff are required to attend mandatory Child Protection training on a two-yearly basis and a variety of procedures are in place to mitigate against and reduce possible risks:

- Pre-employment checks including Garda Vetting
- Professional standards for healthcare staff
- Professional registration for healthcare staff
- Code of behaviour for all staff
- Trust in care policy
- Child protection and welfare policy
- Personal care policy
- Restrictive practice policy
- Manual Handling policy
- Positioning Care Plans
- Incident Reporting
- Staff supervision and training
- Care plans in place and updated
- Supervision/accompaniment in place for visitors and members of public
- Restricted access – badges only
- Child protection reporting process and forms in place

A young man with short brown hair, wearing a grey and white striped shirt, is seated in a wheelchair. He is looking towards a woman with blonde hair, wearing a black and white striped shirt, who is smiling at him. They are sitting at a white table. A man in a grey shirt is leaning over the table, looking at something in his hands. The background shows a clinical or hospital setting with other people and equipment.

24

Glossary

Advance Care Planning

Advance care planning is a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the person's condition with loss of capacity to make decisions and communicate these to others .

Bereavement

The term bereavement, takes account of the unique individual grief experience of the bereaved person, through the anticipation of death and the subsequent adjustment to living following the death, of someone significant.

Child

A child is defined as a young person aged up to their 18th birthday.

Children's Hospice Services

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the needs of both child and family - physical, emotional, social and spiritual - through a range of services. These include:

- 24 hour end of life care
- Support for the entire family (including siblings, grandparents and the extended family)
- Bereavement support
- 24 hour access to emergency care
- Specialist short break care
- 24 hour telephone support

- Practical help, advice and information
- Provision of specialist therapies, including physiotherapy as well as play and music therapy
- Provision of information, support, education and training where needed to carers

Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose built building.

Children's Palliative Care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Coroner

The coroner is a doctor or lawyer responsible for investigating deaths in particular situations and can also arrange for a post-mortem examination of the body, if necessary.

End of Life

End of life 'The phase 'end of life' ends in death. Definition of its beginning is variable according to individual child/young person and professional perspectives. In some cases it may be the child/young person or family who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient.

End of life Care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition, this includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and their family. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement. This is not confined to specialist services but includes those services provided by any health or social care professional in any setting.

Family

The term 'family' includes parents, other family members involved in the care of the young person, or other carers who are acting in the role of parents. Family may also include informal carers and all those who matter to the child/young person. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets).

Hospice at Home

Hospice at Home is an integral component of children's palliative care. Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment, especially in the last weeks and days of life. Hospice at home works in partnership with parents and families and provides hands on expert nursing care on a 24-hour basis, along with other elements of palliative care including:

- Emotional, psychological and social support.
- Access to specialist colleagues in other disciplines, such as physiotherapy, as required.
- Provision of information, support, education and training where needed to all carers both lay and professional.

- Close collaboration and communication with the primary care team, the child's acute hospital specialists if appropriate and other agencies
- Specialist respite care.
- 24 hour end-of life care.
- Bereavement support.

Key Working

Key working or care co-ordination is a service, involving two or more agencies that provide disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, interagency collaboration at strategic and practice levels and a named key worker for the child and their family.

Key Worker

The role of the key worker is defined as a person who takes on the role of coordinating the patients care, ensuring a point of access for the patient and promoting continuity. In addition the key worker facilitates accessing information and advice for those involved in the ongoing care, including the patient, their family and all members of the multidisciplinary team. The role allows families to have an identified person to contact for advice and support from the point of their illness diagnosis throughout the treatment and on to bereavement care where needed.

Life-Limiting / Life-Shortening Conditions

Life-limiting /life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-Threatening Conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

Needs-Led

Need-led is the term used to describe how services should be provided on the basis of the needs of the child and family and not as a result of assessing the resources that are available. To deliver a needs-led service it is important to assess and thoroughly understand the needs of the children and families first.

Palliative Care

Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

Parents

The term 'parents' is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

Phases of Illness

Four main phases of illness can be identified to help reflect the type and level of care needed:

- Stable: symptoms controlled, needs met by current care plan, family situation stable
- Deteriorating: symptoms gradually or steadily worsening over weeks, or development of new but expected problems over days/weeks, with need for adaptation of care plan and regular review, with worsening family distress and/or social/practical burden (note that rapidly or unpredictably deteriorating would fall into the next category)
- Unstable: new severe problem(s) or rapid increase in existing severe problem(s) over days, and urgent or semi-urgent change in intervention(s) needed to meet needs
- Dying: death anticipated in a matter of days, requiring frequent, usually daily, review

Throughout the course of a disease a child will experience several phases. There is no sequential order of the phases and a child can be in the same phase several times during their disease trajectory. Phases can vary in length from days to weeks to months.

Quality of Life

WHO defines Quality of life is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.

Respite Care

The provision by appropriately trained individual(s) of care for children with life-limiting conditions for a specified period of time, thus providing temporary relief to the usual care-giver.

Short Break Care

Short break care has three main functions:

- To provide the child or young person an opportunity to enjoy social interaction and leisure facilities
- To support the family in the care of their child in the home or an alternative community environment such as a children's hospice.
- To provide opportunities for siblings to have fun and receive support in their own right. Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person

Specialist Short Break Care

Specialist short break care refers to a setting of care, a programme of care or a service that provides additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks provided by social care. It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist short break care provides the support required to meet the child's holistic care needs and enables children and families to be able access short break services. Specialist short breaks will often address some aspects of symptom management. Specialist short breaks should also meet the functions described under general short breaks.

Specialist Palliative Care

Specialist palliative care services are those whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs which require a greater degree of training, staff and other resources. Specialist palliative care services because of the nature of the needs they are designed to meet are analogous to secondary or tertiary health care services.

Supportive Care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to improve the quality of life for people with life-threatening illness. It recognises that people need some forms of care that are not directed towards cure from the time that the possibility of a life-threatening condition is raised.

Symptom Management

Symptom management is the management of common symptoms associated with life-limiting conditions. It is often used to refer to symptoms that are primarily physical, but in palliative care symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate.

Technology Dependent Children

Technology dependent children are those who need both a medical device to compensate for the loss of a vital bodily function and substantial and on-going nursing care to avert death or further disability.

Terminal Care

Refers to care given at the end of life when the child is dying. Terminal care may take place in hospital, at home or in a hospice and is a continuum of palliative care.

Transition

Transition is the term used when the child is moving from childhood into adulthood. The transfer of service provision around this time should be well planned and ensure as little disruption to the young person and their family as possible.

Young Person

The term young person describes a person from their 13th – 19th birthday.

Voluntary Body/Organisation

A not-for-profit service and/or support organisation outside of the statutory sector. Voluntary organisations may operate on a national or local basis and some have particular eligibility criteria (e.g. provide services for children within certain age ranges or diagnostic categories). Some of these non-governmental organisations are either partially or in some cases fully funded by the state.



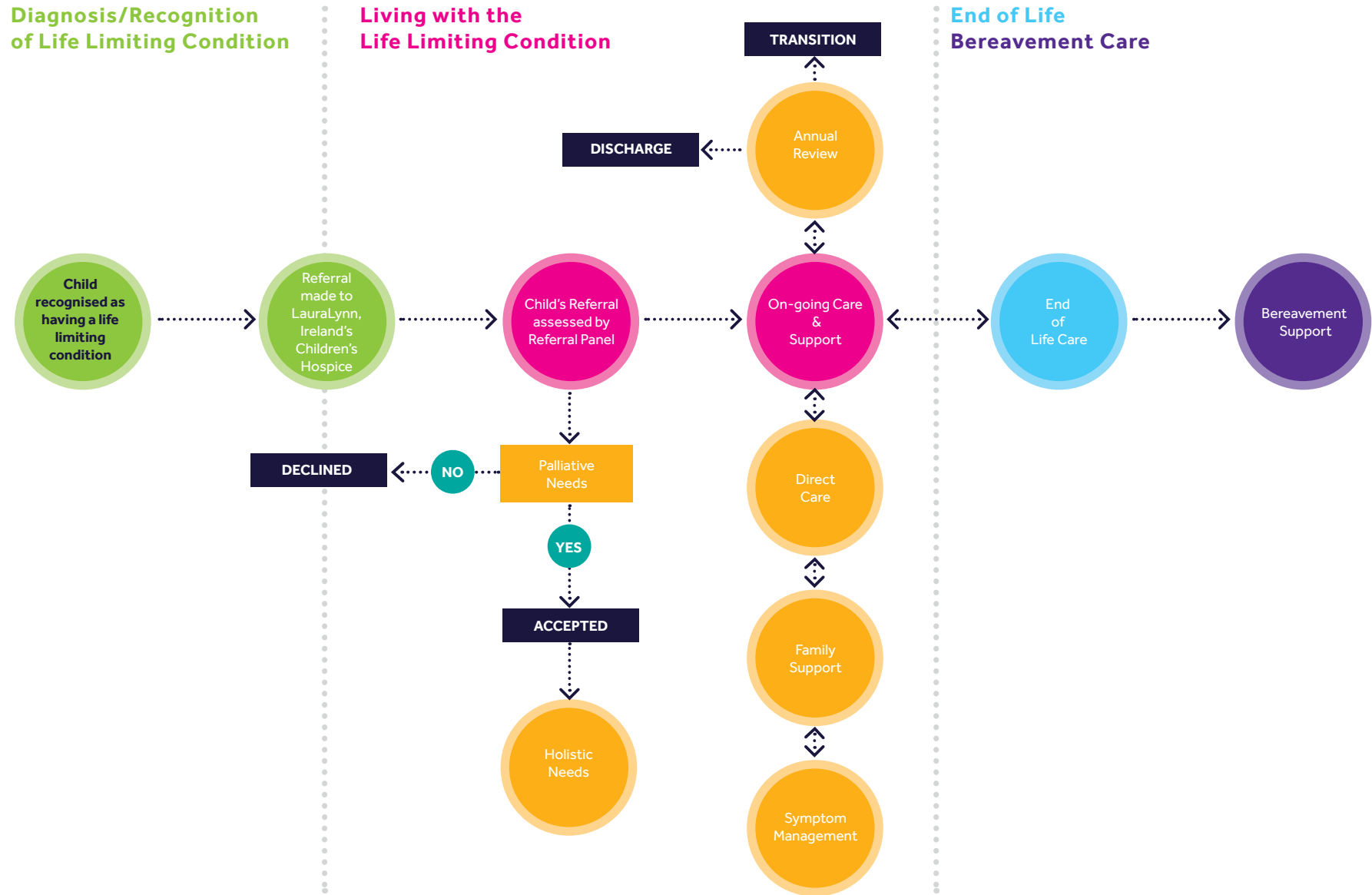
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References

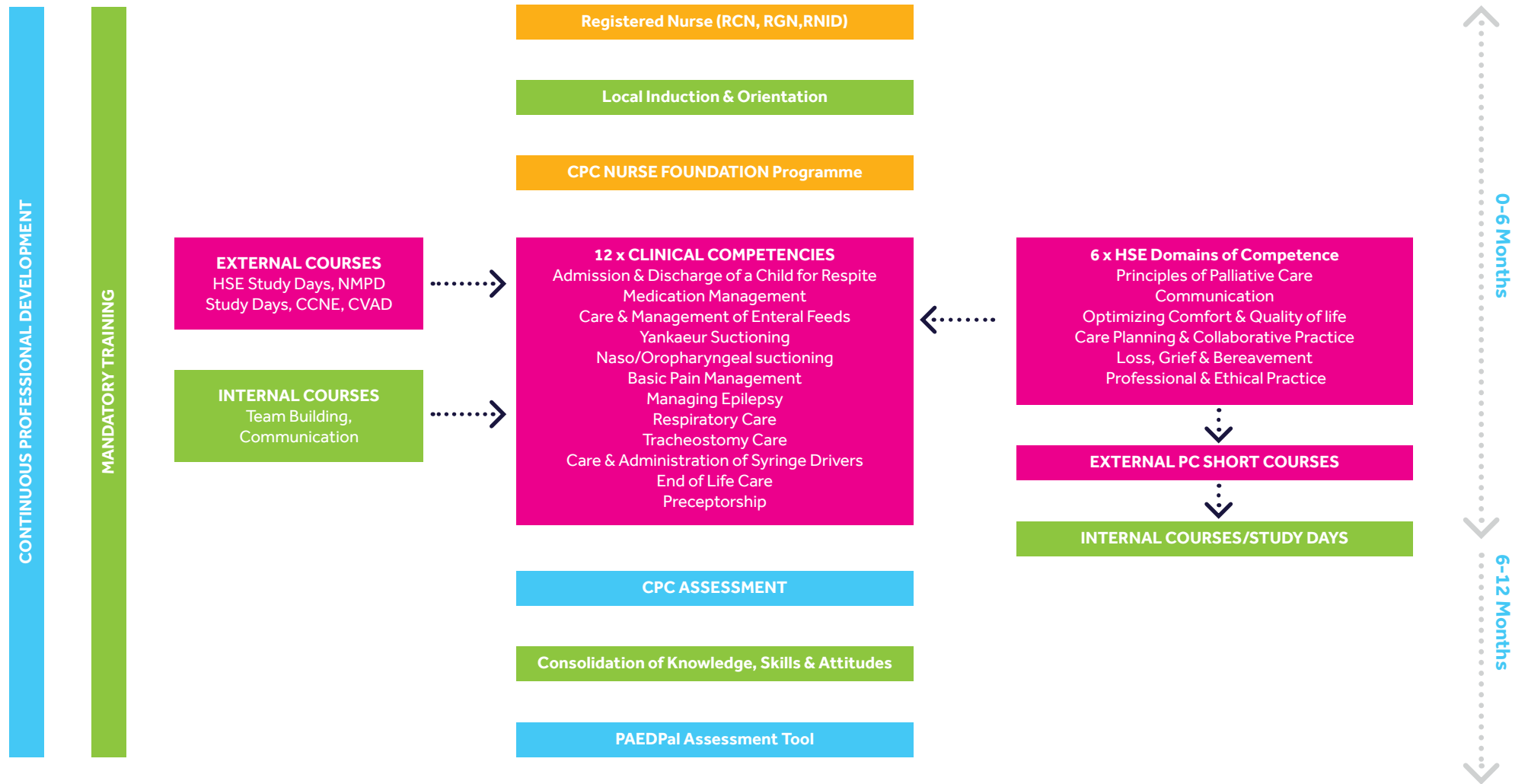
- Agency for Clinical Innovation. (2013). A practical guide on how to develop a Model of Care at the Agency for Clinical Innovation. Chatswood; Australia.
- Association for Children with Life Threatening or Terminal Conditions and Their Families and Royal College of Paediatrics and Child Health Child Health (2003). A Guide to the development of Children's Palliative Care Services 2nd Ed. Bristol: ACT & London: RCPCH, UK
- Chambers, L (2013). The Language of Children's Palliative Care: Discussion Paper. TFSL, Bristol.
- Craft, A & Killen, S (2007). Palliative Care Services for Children and Young People in England: An Independent Review for the Secretary of State for Health. DH England, London.
- Craig et Al. (2007). IMPaCCT: Standards of Paediatric Palliative Care in Europe. European Journal for Palliative Care. 14(3).
- Department of Health and Children (2001) Report of the National Advisory Committee on Palliative Care. Stationary Office, Dublin.
- Department of Health and Children & Irish Hospice Foundation (2005). A Palliative Care Needs Assessment for Children. Stationary Office, Dublin.
- Department for Health and Children (2009). Palliative Care for Children with Life-Limiting Conditions in Ireland: A National Policy. Stationary Office, Dublin.
- Department of Health & Children and Irish Hospice Foundation (2016). Evaluation of Children's Palliative Care Programme (CPCP). Dublin.
- Fraser et Al. (2012). Rising National Prevalence of Life Limiting Conditions in Children in England. Paediatrics, 129:e923.
- Fraser et Al. (2015). Children in Scotland Requiring Palliative Care: Identifying Numbers and Needs (The ChiSP Study). University of York.
- Hain et Al, (2013) Paediatric Palliative Care: Development and Pilot Study of a "Directory" of Life-Limiting Conditions. BMJ Pall Care, 12:43.
- Harrop, E and Brombley, K (2012). Vulnerability Factors considered for acceptance of Children with Cerebral Palsy or other static neurological conditions to Children's Hospice services. Helen & Douglas House, Oxford.
- Harrop, E & Edwards, C (2013). How and When to Refer a Child for Specialist Palliative Care. Arch. Dis.Child.Educ. Practic Edition, 98(202-208).
- Houses of the Oireachtas (2017). Houses of the Oireachtas Committee on the Future of Healthcare: Sláintecare Report.
- Hunt, A, Coad, J et Al. (2013). The BIG Study for Life-Limited Children and their Families: Final Research Report. TFSL, Bristol.
- Irish Childhood Bereavement Network (2015). Standards for Supporting Bereaved Children and Young People: A Framework for Development. ICBN, Dublin.
- Irish Hospice foundation & LauraLynn Children's Hospice (2013). Respite Services for Children with Life Limiting Conditions and their Families: A National Needs Assessment. Dublin.
- Ling et Al. (2014) Children with Life-Limiting Conditions: Establishing Accurate Prevalence Figures for Ireland. National Development Committee for Children's Palliative Care, Dublin.
- National Clinical Programme for Paediatrics & Neonatology (2017) A National Model of Care for Paediatric Health Services in Ireland. RCPI, Dublin.

- National Clinical Programme for Palliative Care (2014). Glossary of Terms. HSE, Dublin.
- National Clinical Programme for Palliative Care (2014). Palliative Care Needs Assessment Guidance. HSE, Dublin.
- National Institute for health and Care Excellence (2016). Guideline on End of Life Care for Infants, Children and Young People with Life-Limiting Conditions: Planning and Management. NICE, London (N961).
- Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive.
- Shaw KL et Al. (2014) The Spectrum of Children's Palliative Care Needs: A Classification Framework for Children with Life-Limiting or Life-Threatening Conditions. *BMJ Supportive & Palliative Care*, March, 5.
- Together for Short Lives (2012). A Guide to End of Life care: Care of Children and Young People before Death, at the End of Death and after Death. TFSL, Bristol.
- Together for Short Lives (2013). A Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions. 3rd Ed. TFSL, Bristol.
- Together for Short Lives. (2014). A Family Companion to the Together for Short Lives Core Care Pathway for Children with Life-limiting and Life-threatening Conditions. TFSL, Bristol.
- Together for Short Lives. (2015). Stepping Up: A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions. TFSL, Bristol.
- Together for Short Lives. (2017). A Guide to Supporting Children and Young People with Life-limiting and Life-threatening Conditions and their Families: Providing a Children's Palliative Care Approach. TFSL, Bristol.
- Together for Short Lives (2018). A guide for Children's Palliative Care: Supporting Babies, Children and Young People with Life-Limiting and Life-Threatening Conditions and their Families. 4th Ed. TFSL, Bristol.
- Welsh Institute for Health and Social Care (2015). Palliative Care for Children and Young People in Wales: Meeting Future Needs. University of South Wales, Cardiff.
- McKiernan A, Balfe J. (2019). Integrated psychosocial care of children with advanced cancer and their families. *Cancer Professional*; 13(3): 15-16.
- Kazak A. (2006) Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice and collaboration in pediatric family systems medicine. *Families Systems Health*.
- Jones A, Deane C, Keegan O. (2015) The development of a framework to support bereaved children and young people: the Irish Childhood Bereavement Care Pyramid. *Bereavement Care*.
- Bereavement Care Standards Development Group (2016). National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death. BCSDG.

LauraLynn Children's Hospice Care Pathway



LauraLynn Clinical Nurse Education Pathway



LauraLynn Children's Hospice Care Team Chart

