

LauraLynn

Ireland's
Children's
Hospice

Family 
Handbook



LauraLynn

IRELAND'S CHILDREN'S HOSPICE

WELCOME TO LAURALYNN

Formerly known as The Children's Sunshine Home, we have been in operation in the Foxrock since 1925 with a history of innovative care for children throughout the years. We are a voluntary Healthcare Service, governed by a Voluntary Board of Management. Our aim is to provide integrated, seamless and co-ordinated services for the benefit of children through planning, commissioning, monitoring and evaluation of our services.

We, as a service are deeply committed to providing a quality service for each child and supporting you in any way we can.

Care for the child and support for the family is at the heart of everything we do. We are here to support you and your child, we can only do this by working in partnership together. We are only one part of the team in the wider healthcare environment and we will endeavour to assist in any way we can to ensure a cohesive and seamless service is provided to you.

The handbook contains summary information relating to the most common questions posed by families and we hope that this will act as a reference guide to you and answer any questions you may have.

Once again we welcome you to LauraLynn and hope that we can support you as long as is beneficial to you and your child.



Philomena Dunne
Chief Executive Officer

Contents

Introduction	3
Statement of Purpose and Function	4
Team	5
Key Admission Criteria	6
Overview of Our Services	7
A-Z Guidelines for your child's stay	8
Reminder to Parents	13
A Parent's Experience	14



INTRODUCTION

How can we help you?

Working in partnership with families, we can offer support for your baby/child and family. On contacting the service, a member of our team will meet with you to discuss your needs.

We can support you in some or all of the following:

- Assistance in identifying and accessing support within your community
- Practical support from birth
- Respite Care – including day/overnight
- 24 hour crisis care and telephone contact
- Transitional care from hospital to home
- Parent training and support
- Home support

Our Philosophy of Care

Our philosophy of care is to treat your child as an individual with dignity and respect and to enable them to enjoy an appropriate quality of life. Each family is central to the care of their child.

Our Values

- Family
- Life
- Care

Mission Statement

LauraLynn cares for children with life limiting conditions and their families by providing high quality transitional care, respite and crisis care, home support and end of life care.

Vision

All children who need us can access us.



*"Making the most of
short & precious lives"*

STATEMENT OF PURPOSE AND FUNCTION

LauraLynn provides:

- Quality Care for children with life limiting conditions
- A high standard of care which is responsive to the individual needs of children and young people
- A service that promotes and protects the rights of children availing of our services in a manner that respects their dignity and their rights to make choices (where possible)
- A culture within the organisation which strives to maximise each child's quality of life
- Family centred services
- A partnership approach with families, HSE and any other services you avail of
- Competent and qualified professionally trained staff who are sensitive to the needs and requirements of the children and their families
- Services that are well managed through efficient, effective and accountable use of available resources
- Monitoring and evaluation processes that aim towards continual improvement of the services to children and families



Children's Rights in Ireland

Children's Rights are human rights for all children and young people under 18 years of age. Human rights cover all areas of life and all people. Their purpose is to make sure everyone can lead a fulfilled life with respect, dignity and freedom. The United Nations is the main body that governs Human Rights. On November, 20th, 1989, after 10 years of discussion, a separate set of rights was created for children and young people, called the UN Convention of the Rights of the Child (UNCRC). The Human Rights Treaty sets out what governments must do to ensure children and young people everywhere have a good life. It describes all the things that children need in order to get the most from life. On September, 28th, 1992 the Irish State ratified the UNCRC and therefore committed itself to promote, protect and fulfil the rights of children in Ireland.

MULTI-DISCIPLINARY TEAM

Clinical Psychologist

Clinical Psychologist provides support to families as they adjust to the changes and challenge that go hand in hand with the experience of living and caring for a child with complex needs.

Consultant Paediatrician

A paediatrician is a medical doctor specialising in children's development and illnesses. The paediatrician at LauraLynn works with other members of the multi-disciplinary team to assess and manage any medical issues which may arise during your child's stay. Your child will remain under the care of their hospital team at all stages. When necessary, our paediatrician will liaise with your child's medical team within the acute hospital to ensure a seamless service is in place.

Occupational Therapy

Occupational Therapy provides skilled intervention to improve quality of life by facilitating meaningful enjoyments in daily life such as play, music and art.

GP Services

Medical cover/support is provided to compliment, not replace, your current services. GP services are provided on an as-needs basis while your child is in our care.

Dietician

The role of the dietician is to assess and monitor a child's nutritional wellbeing. Where appropriate, advice is given to you on how to achieve and maintain a healthy weight.

Nursing Team

The nursing management and leadership team supports Staff Nurses and Health Care Assistants to provide optimum nursing care. The team works closely with the other disciplines to ensure effective, safe and individualised delivery of care for your child.

Physiotherapist

The physiotherapist works to promote a child's physical development, enabling them to have a good quality of life and reach their full potential.

Social Worker

The Social Worker works in partnership with children and their families to offer support, advice and assistance to them. The role includes working with other healthcare professionals and liaising with statutory and voluntary services. Also involved in the role is assessment, counselling, and practical support. A key component of the role is advocating on behalf of each child that attends the service.

Chaplain

The chaplain offers pastoral and spiritual care to all irrespective of their religion or faith or none.

Volunteers

Volunteers give their time and talents freely for the benefit of others. They work within the policies and procedures of LauraLynn. Volunteers are appointed to enhance the capacity of paid staff, not as a substitute for them.

- * From time to time other therapeutic services may be offered to the benefit of the children and family.
- * All therapies and clinicians are provided to compliment, not replace, your current services.

KEY ADMISSION CRITERION

Children medically diagnosed with life limiting conditions will be admitted to LauraLynn

CATEGORY	DESCRIPTION	SERVICES OFFERED
Medically complex newborn babies	<ul style="list-style-type: none"> Babies with less than one year life expectancy 	<ul style="list-style-type: none"> Planned transitional care with a defined discharge date Respite (home support) Crisis Care End-of-life care
Medical trauma cases	<ul style="list-style-type: none"> Traumatic Brain Injury Critical cardiac conditions Progressive Neurological Conditions 	<ul style="list-style-type: none"> Transitional Care (0-12) Respite (0-17) Crisis Care (0-17) End-of-life care (0-17)
End-of-life care	<ul style="list-style-type: none"> Progressive Neurological Conditions Cystic Fibrosis Oncology Heart Defects 	<ul style="list-style-type: none"> Home Support Centre based terminal care

OVERVIEW OF SUPPORT

Palliative Care

Palliative Care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family.

Respite Services

Respite Services provide short-term planned breaks for your child and family. Respite can be for day and/or overnight.

Transitional Care Services

Transitional Care provides an opportunity for you to adjust to the transfer of your child from the hospital to home. This placement is for a fixed period of time during which we will work with you to ensure that supports are in place and that you are empowered to care for your child at home. If appropriate, respite services are available following discharge from transitional care.

Crisis Care

Crisis Care provides immediate placement for your child in the event of an emergency within your family where no other care options are available. You can contact the service at any time, day or night if in crisis to ensure that a 'life-line' is available to you, if required. Following crisis admissions a member of our team will liaise with you as a follow up.

End of Life Care

This refers to the care for a child in the last few weeks of their life. We aim to ensure maximum physical comfort for the child and emotional support for the child and family.

Home Support

LauraLynn at home will provide additional support in the family home, for a period of time, to compliment any care you may already receive. We aim to provide high quality nursing support in the home and ensure effective communication of your child's integrated care needs to the extended team in LauraLynn.



A-Z GUIDELINES FOR YOUR CHILD'S STAY

A

Admission

To ensure a smooth admission to respite, please arrive at time allocated, a Staff Nurse will meet with you on admission to discuss any changes in your child's care plan, handover and check medications, equipment, clothing and contact numbers. In the event of any person other than parents bringing your child to respite admission details are to be confirmed prior to the admission by parent.

B

Bedroom

Each child will be allocated a single, en-suite bedroom in LauraLynn House or a mutli-bed room in Hazel House.

Birth Certificate

A copy of your child's birth certificate must be submitted prior to admission.

C

Care Plan

Before your child's stay we will ask you to complete a Care Plan, which will help us get to know your child and ensure continuity of care. This Care Plan will be updated, as required, on each admission.

Child Protection

LauraLynn is fully committed to safe-guarding and promoting the wellbeing of all children with whom we provide a service. As part of our Child Protection Policy we vet all staff, including volunteers and students, ensuring that the children in our care are protected from abuse of any kind.

Clothing

ALL items of clothing and personal belongings must be labelled. Please ensure clothes are suitable for your child, i.e. soft, non-restrictive. The service cannot take responsibility for lost items. If you notice that a piece of clothing has been lost or misplaced, it should be brought to the attention of a staff member, as soon as possible.

Complaints

If you are unhappy with our service, we would like to hear from you. Please take the time to tell a member of staff and we will investigate it and try to put the matter right and/or give you an explanation. Information on our Complaints Policy can be found at reception; alternatively you can request a copy from a staff member.

Car Park

Areas are designated for family and wheelchair parking.

D

Dining Room Facilities

Our subsidised dining room is available for use by staff, volunteers and families. Please ask a member of staff for further details.

Discharge

A specific time will be allocated for discharge. In the event of any person other than parents collecting your child prior written notification must be given to staff.

E

Equipment

Any equipment your child brings with them for use during his/her stay must be clearly labelled with your child's name. In keeping with our infection control policy, please ensure all equipment is clean and in good working order. In the interests of health and safety, we will not be in a position to accept soiled or broken equipment.

F

Family Accommodation

Family accommodation is available; please contact a member of staff. Guidelines for use of accommodation will be issued along with access card. Please leave rooms as you find them

Family Notice Board

Notice boards and information screens are in place within LauraLynn House to assist with communications.

Fire Safety

All visitors are requested to observe the nearest fire exit. In the unlikely event of an incident arising, all visitors must follow the directions of the Fire Warden.

G

Garden Areas

For general use, please enjoy this facility and for everyone's comfort and enjoyment, please leave it as you would like to find it.

H

Hospital Appointments

Should you require support or advice please discuss with Staff Nurse on duty.

I

Infection Control

In the interests of good infection control, please use alcohol hand gels provided on entering and exiting the building. Please ensure that you observe good hygiene procedures such as hand washing while visiting. Unfortunately for the health and safety of your child, and other infection control reasons, we may have to cancel your child's respite on occasions. This will be discussed with you should the need arise.



K

Key Worker

A member of the team will be assigned and will maintain regular contact with you. They will ensure your child's care plan is up to date and support you in any aspects of your child's care.

L

Laundry

We do not launder clothing for children in respite/transitional care; however we will accommodate if an item is particularly soiled, or if your child is with us for an extended period.

M

Medications

A green prescription sheet will be given to you prior to your first admission, with instructions for your GP re completion. In the event of changes to the medications, the green prescription sheet must be updated by your GP. Staff nurses wear a red apron when administering medication. We ask that they are not disturbed when they are wearing a red apron.

O

Outings

From time to time staff may bring children on outings, health permitting and with parents permission.

P

Personal Possessions

It is strongly recommended that your child only bring those personal possessions most important for their stay at LauraLynn. It is advised that children do not wear delicate items of jewellery during their time here; items such as these are best kept and enjoyed at home.

Parent to Parent Support

From time to time parents request to speak to another parent in a similar situation to themselves. Should you like to speak with another parent we can arrange this for you.

Playgrounds

Children must be supervised at all times when using these areas. One playground is adapted for children with special needs. Please ask a member of staff for assistance.

Policies/Procedures

To run an organisation such as ours in an efficient and seamless manner, we must have policies and procedures in place for dealing with certain circumstances. If you require further information on any of the policies, please contact a member of the team.

Privacy

Privacy is an important feature of our service and we try to maintain all matters confidential to families. Please respect the privacy of other children and their families by not asking for information from staff.

R

Review

A review of your child's placement will take place on an annual basis. If the placement does not meet your child's needs, we will support you in accessing appropriate services.

S

Security

Security alarms are activated each evening. We would ask you to respect the need to allow children to sleep; therefore we encourage visits to finish before 8pm. All families/visitors must inform the Nurse on Duty before exiting the building after this time so alarms can be deactivated.

The gates at the entrance to LauraLynn are automated and close at night. Should you need to access LauraLynn outside of these times, there is a bell on the gate to alert staff.

Smoking

LauraLynn operates a "No Smoking Policy" in all buildings and on grounds. We ask if you smoke to use the designated smoking shelter situated in the grounds as all other areas are prohibited, in keeping with Health & Safety & Fire Regulations. Breaches of this will result in a fine being imposed.

You are asked not to discard used cigarette butts or other litter in the grounds – please place in the designated disposal unit at the smoking shelter.

Students

LauraLynn is an education centre for health care students, for example medical and nursing. From time to time students will be working in LauraLynn under the supervision of permanent staff.

T

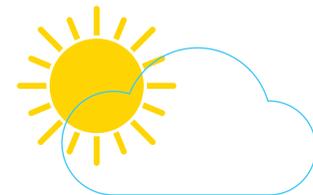
Telephone Enquiries

Immediate family members/designate may telephone the unit to ask the Staff Nurse about your child at any time. If there is no answer on ringing, please leave a message and someone will return your call. There may be times when staff are busy caring for children, resulting in a slight delay in returning your call. Please understand and be patient. Please ask the Staff Nurse what is the best time to call.

In order to ensure we can contact you should an emergency arise, we ask that you are contactable on a 24 hour basis.

CONTACT NUMBERS

Main Reception: 01 289 3151
LauraLynn House: 01 268 6666
Hazel House: 01 289 8799



Toys Guidelines

Toys are wonderful and very welcome, although an excess of stuffed, cuddly toys are not conducive to a healthy, dust-free environment. This is in keeping with infection control and prevention of harm. Bearing in mind the levels of equipment surrounding each child, we ask that toys be kept to a minimum, parents may be asked to take large items or quantities home for safe keeping.

V

Vaccinations

Prior to admission to the Children's Sunshine Home all children must have the most up-to-date vaccinations available to them, including the Hepatitis B vaccine. A record of vaccinations must be given to the nurse in charge before first admission.

Visitors

During your child's stay please identify, in writing, what visitors, if any, will be calling to see your child. Please let us know, in advance, if any of these visitors can bring your child off site, otherwise, for child protection purposes, we will have to refuse and this could cause embarrassment.

Visiting Guidelines

For your child's protection, security and Health & Safety, all visitors MUST sign in and out at the designated entrance. All visitors must report to the Nurse-on-Duty upon entering the building.

- Recommended visiting hours are from 10.00am to 8.00pm
- Extended families and friends are asked not to visit during meal times 12noon–2pm lunch & 4pm–6pm dinner
- Visiting to be limited to a reasonable number of people, 2 or 3 maximum, for each child
- Only visitors approved by the parents/guardians are permitted to visit
- Visitors under 12 years of age must be supervised by an adult at all times

We ask that all visitors respect the children and staff and behave in an appropriate manner. If staff members are of the opinion that visitors are causing disruption, they will be asked to leave. The service has the right to refuse/ restrict visitors.

Y

Your Opinion

Your opinion is important to us. If you have any suggestions that would make your child's stay more comfortable, or how we can improve our services, please let us know.

Z

Zero Tolerance

LauraLynn considers aggressive behaviour to be abusive or threatening comments, bad language, physical contact and aggressive gestures. We operate 'zero tolerance' with respect to the protection of all staff and children. This means that no abuse of staff or children is acceptable, whether verbal or physical. Any person acting in an aggressive, threatening or abusive manner will be asked to leave the premises immediately.

REMINDER TO PARENTS

1 We ask that parents (guardians) comply with sanitary and infection control rules of the service:

- keep quiet and order in the service
- implement recommendations of the medical personnel
- take care of hospice property

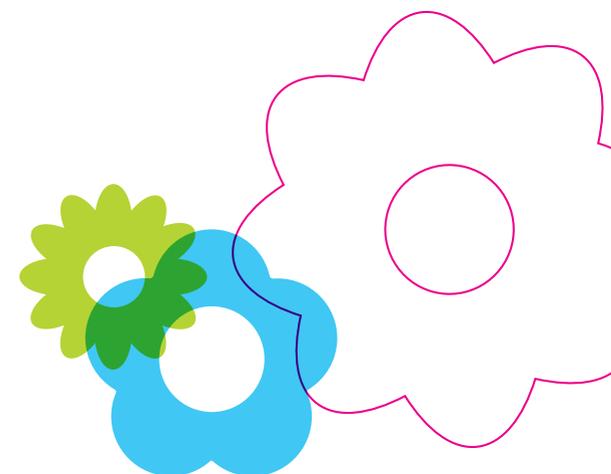
2 To address questions about household matters (laundering, food storage etc) refer to the nurse on duty

3 In LauraLynn the following is prohibited

- to drink alcoholic beverages
- to be in a state of alcohol intoxication
- to smoke in the facility
- to stay after 8pm unless agreed with Nurse Manager

Families Responsibilities

- We ask you to inform us of any changes in health conditions of your child and other needs relating to the care of your child.
- We encourage you to participate in planning and implementing care for your child according to your wishes and personal values.
- Please treat our staff with the same respect as you are treated
- In the absence of LauraLynn staff, it is your responsibility to monitor the well-being and maintain the health of your child at home



PARENT'S EXPERIENCE

Sandra, mother of Conor

I am the mum of a little boy called Conor, who avails of respite. Conor is now ten years old and it has now been six years since we started to use this wonderful respite. I can remember when Conor started school, the social worker there suggested The Children's Sunshine Home (now LauraLynn LL), as she thought it might be of benefit to me and my family. At the time I also had a one year old daughter. I do not have my family living near me and none of them ever felt confident enough to take Conor to give us a break.

Shirley came to see me in my home and explained to me how respite worked. She suggested that we could maybe start off by leaving Conor for a few hours and that all Conor's needs would be met as they would be at home. I was very reluctant to take it a step further. I felt I was meant to do this alone and that it was unfair of me to get someone else to look after Conor. Over the first three years of Conor's life, I had got so used to not having a break and never having anyone to mind him. At the same time as a parent, I felt very overwhelmed by the responsibility of the situation. I did not want to do it alone any more and felt that LL could give me that much needed break.

I went to visit Shirley at a later date in LL. I brought Conor with me; this gave me a better insight into the service. Even to see the building, the bright dining room, and the cosy bedrooms and meet the friendly staff and to see the other children in the physio room made me feel more comfortable about the whole thing. Conor now stays for three nights at one time. I always feel I can phone anytime to check on him. For me it has meant that I do get that break and we can do normal family things with my other children. I don't feel trapped by the situation any more, and it has made me a better parent for all my children.

Roisin, mother of Alice

Four months ago, we were offered respite for our 18 month old daughter Alice. At the time we had very mixed feelings about whether or not to avail of it. Alice has rarely slept a full night because of her condition which meant we were absolutely exhausted. With two other kids, their busy lives and routines – I found it so hard to juggle everything. One of our main concerns was *"What if she didn't settle and the staff didn't know her little ways and habits therefore making her more upset and stressed"*. We had heard that all the staff were trained to deal with kids with similar needs to Alice but in my heart I felt that they didn't know her like us. She didn't know them and maybe they wouldn't have the time to just cuddle her.

The second thing that really bothered us was that we felt very guilty. We felt like we were, in some way, abandoning her. We wondered how on earth we could even consider going away for a holiday, even for a couple of nights, without her. Spending quality time with her five year old sister and doing things with her such as going to the cinema can be impossible when you have a disabled child. Finding a babysitter was just as difficult due to Alice's illness. Some people quite openly admitted to us that they were actually afraid to mind her in case something happened.

We eventually decided to give LL a go and see how Alice got on. I will never forget dropping her up that day. She was scheduled to stay for two nights. To say that the weekend was one of the worst in my life is an understatement. I spent the entire weekend crying. I decided there and then I was going to collect her. Thank goodness I got talking to a wonderful nurse called Erina, she talked me through all the benefits of Alice staying. She pointed out how in the long run we would all benefit. Her sister would get to spend quality time with us and do things that are normal to most five year olds. She explained how we would all eventually get used to it and settle into a routine and we would definitely benefit all round just by getting some well-deserved sleep. I listened to Erina and will be forever grateful to her because that very same night another nurse noticed that Alice was apparently showing signs of seizure activity which were so subtle that we hadn't noticed anything out of the ordinary. She advised us to get it checked out, within one week of the observation Alice had an E.E.G. and is on seizure medication ever since.

We have all got used to Alice going on her little holidays now so much. If we didn't have LL to help us and give us a break we would be lost. The team of nurses and carers are fantastic. I can't praise them enough and Alice is happy to stay. Her sister got to have a sun holiday with us for a full week and got to do all the things that little girls enjoy such as Aqua Parks etc. We had taken Alice on holidays before and it's always ended in disaster. On our last holiday Alice ended up in hospital for three days with breathing difficulties.

On my last visit to LL, Ann Booth showed me around the new LauraLynn House where Alice and other kids will be moving to. I was so impressed with LauraLynn House and the facilities to cater for families, whereby parents can choose to stay overnight to help settle their child in. My only regret is that the facility wasn't available when Alice started going. It means that you can be on hand to show the nursing staff your child's daily and night time routine and that in itself gives you great peace of mind.

If you are blessed enough like us to be offered some respite I strongly recommend that you grab it with both hands. Respite now-a-days, as we all know is very hard to come by, and in some cases non-existent. From our experience I cannot praise them nor thank them enough. They are a superb bunch of people with the necessary experience and love in a home-away-from-home.



CONTACT NUMBERS & EMAIL ADDRESSES OF ORGANISATIONS THAT MAY BE OF HELP TO FAMILIES USING OUR SERVICES.

Inclusion Ireland

T 01 855 9891 inclusionireland.ie

Our Lady's Children's Hospital, Crumlin

T 01 409 6100 olhsc.ie

Anam Cara

T 01 404 5378 anamcara.ie

AMNCH, Tallaght

T 01 414 2896 amnch.ie

Carers Association

T 057 932 2920 carersireland.com

Central Remedial Clinic

T 01 805 7400 crc.ie

Children in Hospital Ireland

T 1890 252 682 childreninhospital.ie

CUH, Temple Street

T 01 878 4344 cuh.ie

Dept of Social Protection

T 1890 500 0000 welfare.ie

Enable Ireland

T 01 261 5900 enableireland.ie

Jack and Jill Foundation

T 045 894 538 jackandjill.ie

EPIC National Independent Advocacy Service for Children

T 01 872 7661 epiconline.ie

LauraLynn Ireland's Children's Hospice

Children's Sunshine Home

Leopardstown Road, Foxrock, Dublin 18.

T 01 289 3151 F 01 289 9972

E admin@lauralynn.ie lauralynn.ie

Registered Charity Number: CHY2633