



Cliona's Foundation
PRACTICAL FINANCIAL ADVICE



*Providing financial assistance
for critically ill children*

Patron: Miriam O'Callaghan

**FOR PARENTS COPING WITH A CHILD WITH
A LIFE LIMITING ILLNESS**

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About Cliona's Foundation

"Thank you for your kindness and all the good work you do. Your little girl's name has touched many people's lives."

- Received on a thank you note from a parent to Cliona's Foundation

Cliona's Foundation is a registered Irish charity founded in 2007 providing financial assistance for a range of non-medical expenses to families who have a child, with a life limiting illness, whether as a result of an illness or an accident.

Cliona's Foundation aims to support those families who are experiencing severe financial hardship and who have exhausted all other avenues of financial support (very often there is no State funding available to these families).

Cliona's Foundation was founded by Brendan and Terry Ring in honour of their daughter Cliona, who died as a result of an inoperable brain tumour. In the eight years that followed Cliona's diagnosis, Brendan and Terry spent an enormous amount of time in different hospitals, throughout Ireland with Cliona as she underwent different medical treatments for her brain tumour. During this time, Brendan and Terry witnessed many families struggling to meet all of the additional expenses which arise when you have a child with a life limiting illness.

As parents of a sick child they knew all too well about the stress and upset that goes hand in hand with having a sick child. They strongly believe that no family in these tragic circumstances should have to face the added burden of trying to find money to pay for a range of extra non-medical costs that arise on a daily basis when a child has a life limiting illness.



Brendan & Terry Ring

Cliona's Foundation Founders.

Introduction

This booklet sets out an array of different non-medical expenses that can arise at a time when a family is already trying to deal with having a child with a life limiting illness.

When a child is diagnosed with a serious illness or disability, it may be difficult to take in all the information your doctors tell you. Very often, particularly if the illness or disability is complex, a number of different medical specialists will be assigned to your child's case. This can lead to a lot of confusion and information overload.



It is important to carry a notepad and pen to document what you may be told by each doctor. This makes it easier to list the questions you may have about your child's condition. What may be obvious to doctors may not be obvious to you, so always make sure to ask whatever questions you have, however big or small.



Many parents are surprised at the additional costs outside of any medical bills that occur when caring for a sick child. In most cases, a social worker is required to help access information such as meals being subsidised in hospital canteens, accommodation for parents, parking, transport issues and many more.



A social worker can apply for a medical card on your behalf. If your child is disabled and requires a Primary Medical Cert, this can be obtained through the social worker also. There may be other allowances the family are entitled to i.e. Domiciliary Care Allowance.



It is estimated that 400 children every year in Ireland are diagnosed with critical illness.

An Overview of Non-Medical Expenses

There are a number of non medical expenses that occur when looking after a child with a life limiting condition. For example, some families need to pay for accommodation so that they can remain close to their child. Also they need money for food and other expenses like petrol.

The parking fees, petrol/diesel, taxis and certain equipment or modifications to your home that your child requires can all add up to astonishing amounts of money.

In extreme cases, one or both parents may be unable to work during their child's chronic illness as they may need round the clock care.

Since the foundation of the charity, requests for assistance have covered the following:

Travel	Average Daily Costs
Parking	€17.00
Petrol/Diesel	€15.50
Taxis	€20.00
Train Fares (Return)	€30.00

Total Costs	€82.50
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Sustenance	Average Daily Costs
Lunch	€7.00
Snacks	€5.00
Take away	€14.00
Treats	€4.00

Total Costs	€30.00
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Miscellaneous	Average Daily Costs
Hospital Accommodation	€9.00
Laundry	€10.00
Childcare	€30.00
Phone	€7.00
Long-Stay Accommodation	€50.00

Survey

Out of a random sample of seven families surveyed, financial assistance was used by the families for the following:

Families struggling with day-to-day living expenses							
Expenses associated with hospitalisation or treatment abroad							
To supplement loss of earnings due to extended time off work							
Adapting or modifying a vehicle or home to accommodate special needs							
Financial support for travel expenses							
Relocation to a more suitable property							
For equipment not covered by the HSE, Medical card or Long Term Illness Supplement.							
To create a suitable and safe play area for the child							

An Overview of Non-Medical Expenses (contd.)

Cost implications on a monthly basis i.e. physiotherapy or Occupational Therapy can add day-to-day financial extras. In some cases, only one parent can be working where there may have been 2 earners in the family and a number of siblings who also need to be looked after.

When caring for a child with a life limiting illness, house modifications may need to be undertaken as the child is continuing to grow and thus, the child would be getting heavier to carry up a stairs. Such a modification requires financial assistance which we will outline later in this booklet.



To date Cliona's Foundation have helped over 200 families all over Ireland with financial assistance.

For larger families:

Average €65 per day for childcare

Average €100/month for after-school care costs

Average €80/month for modifications and home safety

Advice from Health Care Professionals

Medical staff are acutely aware of the added stress that non-medical costs may have on top of the emotional stress that families have dealing with a sick child. Below are some tips from Irish nurses who have considerable experience helping worried families.



Parents find the transition from ICU to a ward situation can be quite difficult because they are leaving an environment where their child has been looked after on a One-to-One basis, as they are now on a ward where a nurse would have a number of other children to look after.



On a ward, you have children who will not be as ill as your child; they may be running around and having fun, which may cause more distress.



Hospitals can be very confusing places. You may meet lots of medical staff and sometimes you can get conflicting information within a short space of time. If you find yourself in this situation, speak with the Ward Manager who should be able to clarify any concerns you may have.



Keep receipts so you can keep track of your finances and to prove your financial struggles to the relevant awarding authority.



Some parents find it convenient to make larger portions of meals one night and freeze them so they can be simply heated and eaten throughout the following week.



Most hospitals provide some form of bedding and overnight accommodation so you can be with your child rather than at a nearby hotel or B&B.



Talk to your Social Welfare Office sooner rather than later, so that you can get a better understanding on your entitlements.



Avoid impulse purchases and take advantage of coupons and store specials.



Research the possible dietary requirements your child may have, and shop around to find cheaper options.

Advice from Parents

It is essential to know there are other parents out there going through the same ordeal as you are. Below are some tips from parents whose children are undergoing ongoing hospitalisation.

Adam's Story

My son has spent most of his life in hospital due to severe Mowat Wilson Syndrome.

Most definitely in my son Adam's case, he is very sensitive to the emotions of those around him and he takes strength and happiness from those around him, which I think a lot of children do. If your child sees you upset they get upset, so as hard as it was, I made sure to keep my 'breakdowns' away from Adam. But it is important to have those moments to let out your emotions by means that suit you, whether it be to a family member, Counsellor, Church, or in private.

Siobhan's Story

As a mother of a very ill child who was born with a life limiting condition, I found you are asked on many occasions things like 'did you have a good pregnancy?', 'any illness in your pregnancy?', 'what did you eat?' etc. All these questions can make you really question yourself, making you wonder 'Did I do something wrong?' This is hard to go through. You have to try and trust in yourself. You know your body better than anyone else.



Cliona's Foundation provides financial aid where there is no other option or support for families



Dylan's Story

When you have a disabled child, it reaches out to people other than yourself; brothers & sisters, your partner, grandparents and close friends. These people are valuable assets for rebuilding emotional strength and making sure you have time to yourself. With doctor's appointments, hospital stays, affording necessary equipment and trying to spread your love to your other children, it's important to still be able to do the simple things like pop out for milk. The day-to-day stuff is still there, bills or work for example, and when all this is done, you suddenly can find you've lost yourself in it all. I try and tell myself that Dylan needs me happy and healthy. I am no good to him worn out or sick from not eating proper meals etc.

Sarah's Story

As a single mother living quite far away from a hospital, I often cannot afford to get the train down to see my daughter when she is in long-term care. I found myself blindsided by all these unexpected bills and fees and had to carry on with my job in order to afford them. The balance between the emotional stress of Sarah's illness and the financial stress caused by it is often unbearable. My advice would be to find your 'happy place' - for me it is her smile. When things are very tough, go to that 'happy place'.

How to get Help from Cliona's Foundation in Three Easy Steps.

Cliona's Foundation assists families all over Ireland with financial aid for non medical costs associated with looking after a child with a life limiting condition.

1. If you would like to apply for funding from the Foundation please complete our formal application form which can be downloaded at www.clionasfoundation.ie
2. Post the application to our office at Unit B3, Eastway Business Park, Ballysimon Road, Limerick along with a Letter of support on headed paper from your consultant.
3. We will then be in touch with you in due course once the application has been processed.



Donate to Cliona's Foundation

If you or somebody that you know has been touched by the information in this booklet and would like to donate to Cliona's Foundation please post this form along with your donation to:

Cliona's Foundation,
Unit B3, Eastway Business Park,
Ballysimon Road,
Limerick.

Mr ☐

Mrs ☐

Ms ☐

Name: _____

Address: _____

Phone: _____

Email: _____

I enclose a cheque/bank draft for _____ payable to
Cliona's Foundation.

I would like to make a donation using my credit card.

Please debit my Visa ☐ Debit Card ☐ MasterCard ☐

Card Number:

Security Code:

Expiry Date:

Signature: _____ Date:



Alternatively you can make a donation through our bank account:

Cliona's Foundation
Bank Of Ireland
Main street
Bruff
Co Limerick

Sort Code: 904165 **Bank A/C no:** 8277706

IBAN: IE13BOFI 904165 82777066

BIC: BOFIIIE2D

At Cliona's Foundation we understand that everybody is not in a position to make a large donation, but if you would still like to help Cliona's Foundation you can donate €2 using our text number.



Text: **CLIONA** to **50300**

***100% of text cost goes to Cliona's Foundation across most network providers.**

Some providers apply VAT which means a minimum of €1.63 will go to Cliona's Foundation.

Service Provider: LIKECHARITY.

Helpline: 01 443 3890

Would you like to be added to our mailing list?

Please tick as appropriate:

YES ☐

NO ☐



Contact Us

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Facebook: www.facebook.com/clionasfoundation.com



Twitter: <https://twitter.com/ClionasFDN>

Patron: Miriam O'Callaghan



*Miriam O'Callaghan
with Sarah Crowe*

We at Cliona's Foundation wish you all the very best during this difficult time. Caring for a sick child is a journey that we have a lot of experience with. You don't have to do it alone.



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