



Cliona's Foundation
PRACTICAL FINANCIAL ADVICE



FOR PARENTS /GUARDIANS COPING WITH A CHILD WITH A LIFE-LIMITING CONDITION

www.clionas.ie | Telephone 061 331 333 | CHY 18127

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.

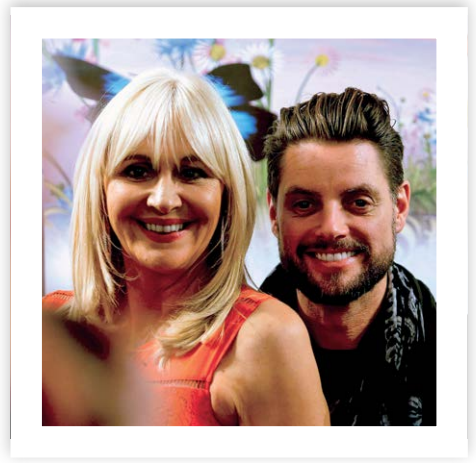
Cliona's Foundation is a registered Irish charity founded in 2007 providing financial assistance for a range of non-medical expenses to families who have a child, with a life-limiting condition.

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. 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 the range of extra non-medical costs.



Founders: Brendan & Terry Ring



Patron: Miriam O'Callaghan with
Foundation Ambassador Keith Duffy

Introduction

This booklet provides advice on dealing with non-medical expenses to parents and families who have a child with a life-limiting condition. It also introduces the services of Cliona's Foundation.

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.

1. 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.
2. 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 much more.

3. 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, e.g. Domiciliary Care Allowance.

4. If you are a PAYE worker you may be entitled to claim relief on certain additional expenses if you have a child with a life threatening illness. These include travel, overnight accommodation and are in addition to the normal health expenses you pay for the child. Check out www.revenue.ie



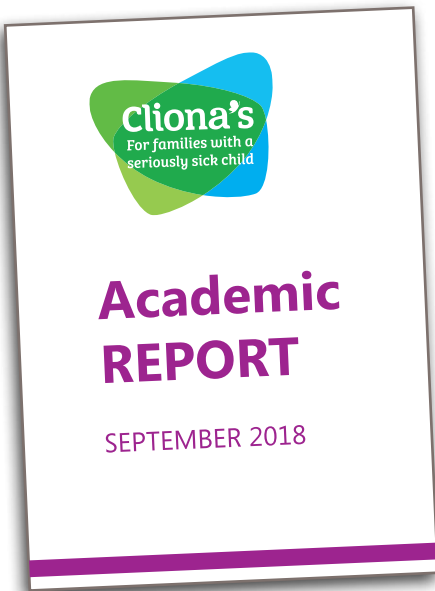
**400 CHILDREN ARE DIAGNOSED
WITH LIFE-LIMITING CONDITIONS
IN IRELAND EACH YEAR.**

An Overview of Non-Medical Expenses

Additional costs come in all types and forms. For example, some families have to pay for accommodation so they are close to their child, or avail of take away food due to its convenience. The parking fees, petrol/diesel costs, taxis and certain equipment or modifications to your home that your child requires can all add up to astonishing amounts of money.

In many cases, one or both parents may be unable to work or have to reduce their time at work during their child's chronic illness as they may need round the clock care. The caring for other children in the family while parents are in the hospital can also result in extra childcare costs.

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, for example. Such modifications also require financial assistance.



Cliona's Foundation finalised an **Academic Report** on the subject of non-medical costs in 2017-2018. The research shows that average daily costs for families can be €145 or higher.

Many families are faced with annual bills of up to €10,000 in meeting the full range of non-medical expenses, especially where there are prolonged spells of treatment in hospital or other medical facilities.

THE NON-MEDICAL COSTS COUPLED WITH REDUCED INCOME CREATES A FINANCIAL CRISIS THAT ADDS TO THE REST OF THE STRESSES WHEN CARING FOR A VERY SICK CHILD.

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 causes 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 Supervisor who should be able to clarify any concerns you may have.



**TO-DATE, CLIONA'S FOUNDATION HAS HELPED OVER 500 FAMILIES
ALL OVER IRELAND.**

- Keep receipts so you can keep track of your finances and to prove your financial struggles to the relevant awarding authority.
- 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 officer/Social Worker 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 the best options.



Advice from Parents

It is essential to know there are other parents out there going through the same ordeal as you are. Do not be afraid to talk to other parents about what you are going through and the struggles you may be experiencing. Parents can provide very valuable information and advice to you on what supports are available and how to access them. Below are some experiences and advice from parents whose children are undergoing/or have undergone 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.



CLONAS FOUNDATION PROVIDES FINANCIAL SUPPORT WHERE OFTEN THERE IS NO OTHER SUPPORTS AVAILABLE.

Siobhan's Story

As the mother of a Down Syndrome daughter, 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.



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 to pay, 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.

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 from birth to age 16 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.clionas.ie**
2. Post the application to our office at Roselawn House, University Business Complex, National Technology Park, Limerick along with a letter of support on headed paper from your child's Consultant or Social Worker.
3. We will then be in touch with you in due course once the application has been received.



Options for Donating to Cliona's Foundation

Complete and return this form to:

Cliona's Foundation, Roselawn House, University Business Complex,
National Technology Park, Limerick.

Mr Mrs Ms *please tick ✓*

Name: _____

Email: _____

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

OR

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:

Make a payment direct to our Bank Account:

Cliona's Foundation

IBAN: IE1 3BOFI 904165 82777066

BIC: BOFIIIE2D

Call 061 331 333 to make a donation with your card.

You can also donate online at www.clionas.ie

At Cliona's Foundation we understand that everybody is not in a position to make a large donation. If you would 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

NOTE: If you are a PAYE or self assessed tax payer and donate €250 or over within a year, Cliona's Foundation can get more from your donation at no extra cost to you. A donation of €250 can result in Cliona's Foundation receiving an extra 31%.

Your Notes & Questions:

A series of 20 horizontal dotted lines for writing notes and questions.



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061 400658 | www.cube.irish

We at Cliona's Foundation wish you all the very best during this difficult time. Caring for a very sick child is a journey that we have a lot of experience with.

YOU DON'T HAVE TO DO IT ALONE.



Charity No. CHY 18127

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University Business Complex
National Technology Park
Limerick

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