

Cliona's Foundation 2025 Impact Report

cliona's
For families with a
seriously sick child



Contents

EXECUTIVE SUMMARY	1
WELCOME TO CLIONA'S FOUNDATION	3
THE EMOTIONAL TOLL	5
CASE STUDY 1	6
FINANCIAL STRESS AND INCREASING DEBT	7
CASE STUDY 2	8
LEAVING THE WORKFORCE, SOCIAL ISOLATION AND REDUCED INCOME	9
CASE STUDY 3	10
THE IMPACT CLIONA'S MAKES	11
ADDRESSING THE CRISIS	12
MOVING FORWARD TOGETHER.....	13



*The Beasley Family, Listowel
on Ballybunion Beach*

Executive Summary

Since its establishment in 2008, Cliona's Foundation has distributed more than €3.25 million and has helped more than 1,600 families across 31 counties. Over these years, the funds have been used in various vital ways to alleviate some of the non-medical related financial stress that comes with caring for a seriously sick child- transport and car park costs, utility bills, accommodation, food, rent, to name only a few.

However, despite our efforts, our 2024 survey confirms that families continue to struggle with escalating non-medical related costs.

Survey findings highlight that costs far outstrip any, if available, support from the state, and that many families are being forced into further debt to bridge the gap. Incurring additional debt creates a further layer of anxiety for families already struggling to come to terms with their new reality.

Our survey also underscores the profound emotional toll on relationships that caring for a sick child can have. It confirms that in many cases the emotional toll on relationships have caused them to fall apart. In other cases, relationships are being pushed to breaking point as a combination of financial pressure and social exclusion that comes from withdrawing from the workplace or social gatherings, which slowly erodes the fabric of relationships.

However our survey findings also offer hope. It is a validation of the work that Cliona's Foundation have been doing for almost 20 years, with many survey respondents celebrating the transformative effect support from Cliona's Foundation has had on their family situation. Over the course of 2024, we successfully disbursed €540,000 to over 216 families. Respondents have highlighted improvements in mental health, in their happiness levels, and in their ability to cope.

The needs continue to outpace the available resources. Since 2018 after the publication of our report "Too Dear To Visit" we have been calling on the government to establish a grant system that would recognise the particular challenges that come with looking after a seriously sick child.

Such a fund needs to be adequately resourced, predictable and sustainable. Cliona's Foundation have also proposed an innovative model of funding that would see the state provide 'match-funding' (where the state would match the funds raised by Cliona's foundation) through a fund administered and managed by Cliona's Foundation, allowing greater efficiencies and ensuring the expertise and knowledge accumulated over almost 2 decades is maximized.

Every year 400 families in Ireland receive the devastating news that their child has a serious illness or condition that will fundamentally change the day-to-day life of that family. Sadly, approximately 400 children will succumb to these illnesses annually. During the course of that illness, these changes are costly and are having profound impacts on families, their mental wellbeing, and their relationships.

But yet, most of these impacts are unheard and unseen, and families are left to struggle through, dependent on what small support they can secure from the state, or from Cliona's foundation.

Greater government intervention is essential. We will continue to lobby the government for systemic change that will ensure ongoing support for families, while continuing to work with people across Ireland, to raise the funds that will allow families to give their child the attention and care they so badly need.

Impact to Date

Grants Distributed

€3.25M

over 17 years



Families Supported

1,677

from 2007 to June 2025

Families in 2024

213 ↑ **96%**

2020 - 110 families

Welcome to Cliona's Foundation 2024 Impact Report

This year's report is a reflection of the challenges faced by families across Ireland who are caring for seriously ill children and of the critical support we've been privileged to provide.

It is also a clear call to the government to recognise the particular challenges that these families face, to take action and put in place supports that are:

ADEQUATE *to the scale of the financial challenges faced by families*

APPROPRIATE *to the particular context and needs of individual families*

PREDICTABLE *so that families can enjoy certainty that support will be provided on an ongoing basis.*

Through our work, we've witnessed first hand the immense physical, emotional, and financial strain that these families endure. The findings this year underscore an alarming trend: the cost of care continues to rise, with families not only grappling with medical expenses but also the hidden costs—travel, accommodation, and loss of income—that can overwhelm even the most resilient households.

In 2024, we saw an increase in the number of families seeking help, signaling a growing need for our assistance. Many shared stories of isolation, financial hardship, and the emotional toll of navigating complex care systems. Yet, amidst these challenges, we also saw incredible resilience and determination—a testament to the strength of these families.

Thanks to the support of people across Ireland, Cliona's Foundation has been able to offer vital financial relief, alleviating some of the burdens and allowing families to focus on what truly matters: the care and well-being of their children.

This report delves into the key findings of the year, highlighting the pressing issues faced by families, the impact of our work, and the collective power of your support. Together, we are not only helping families in the present but also advocating for systemic change to create a more compassionate and supportive Ireland.

As we look forward, we remain steadfast in our mission to ensure no family faces these challenges alone. Thank you for standing with us in this journey of hope and impact.

Our Vision

“All families caring for a seriously sick child will be supported financially”.

Our Mission

“To provide immediate financial support to families caring for a seriously sick child across the Island of Ireland”.



Lily and Tom Dempsey with their carer in their home in Co. Wexford

Over the course of 2024 Cliona's Foundation conducted a comprehensive survey across families supported by the Foundation. The objective was to provide clear evidence of the often unseen challenges that families caring for seriously ill children face, and the impact of those challenges on their lives.

The findings were distressing, but not surprising.

Childhood Illness in Ireland: The Reality

Childhood illness can place an immense emotional and financial burden on families



4,000 Children
face serious or life-limiting illnesses



€15,300 p.a
is the average additional cost that families dealing with these challenges incur



400 Children
tragically lose their fight every year



20% families
required a loan from a financial institution to fund the additional expenses



78% Parents
Are forced to stop or reduce their paid work to care for their seriously sick child



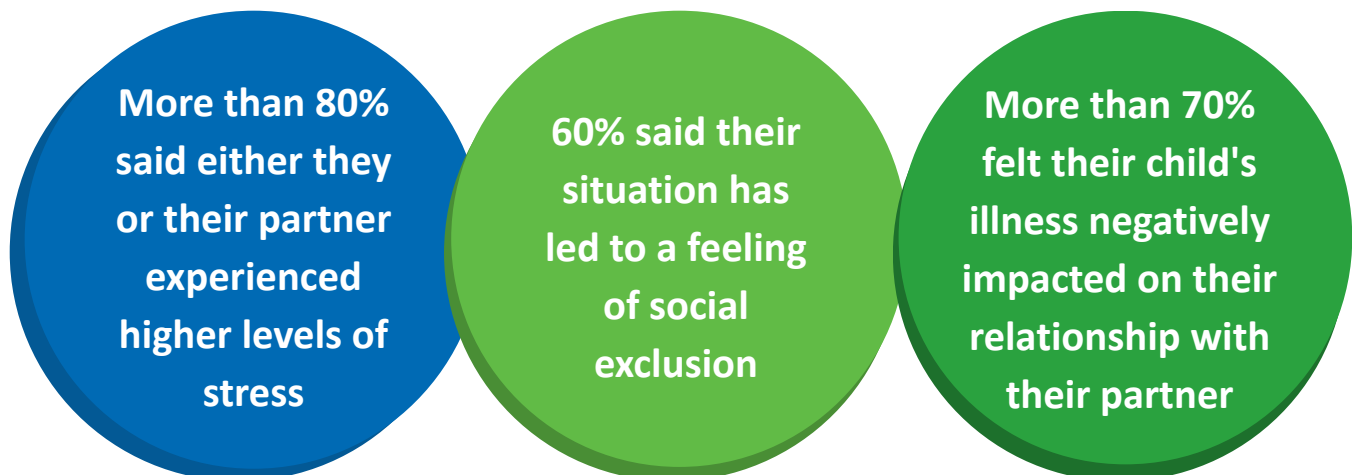
52% families
had to borrow from friends or family

The Emotional Toll

Caring for a seriously ill child extends far beyond hospital visits and medical treatments. It is an emotional journey that affects and takes its toll on every member of the family . Our 2024 survey confirmed the extraordinary emotional toll that families experience as they adapt and respond to a new reality.

“The stress of caring makes you irritable and you take things out on those closest to you.”

Our survey shows that:



These statistics are not just numbers—they represent families living in a constant state of anxiety, uncertainty, and exhaustion, often unseen, and rarely highlighted.¹

The emotional toll is compounded by a chronic lack of sleep, fear of prognosis, disruption of routine, and the endless coordination of care. Parents are often forced to become medical experts, caregivers, and advocates, all while grieving the normality they previously had.

The emotional strain is not limited to romantic relationships. Sibling relationships often suffer due to the unintentional imbalance of attention. At Cliona’s Foundation we refer to these siblings as “the shadow children” Our survey findings show that almost 40% of families reported a rise in anxiety among siblings.

Relationship health can be fundamental to family resilience. As such, Cliona's Foundation will be increasing its efforts to connect families with support networks and counseling services.

At Cliona's Foundation, we recognise the silent suffering of the 4000 families living and caring for children with serious illness.

Our support aims not only to ease financial burdens, but to acknowledge the profound emotional trauma families endure—and to help them feel seen, heard, and supported.

Case Study 1 – “The Emotional Toll”



Anna* – aged 8 – Ewings Sarcoma

I admit to being very exhausted now and your help will allow me to get away for a night to catch up on sleep so that I can be at my best for Anna. Using the money towards travel expenses from home to Crumlin. Anna's dad and I share care for her on a 24-hour basis while she's in Crumlin and I travel home when he stays with her. Anna and I live in Co Louth, her dad lives in Co Derry. I am her main carer. Anna has been in the care of St Johns Ward since May 2024. Your very generous financial support will help with the travel expenses.



Financial stress and increasing debt

The emotional strain involved in caring for a seriously sick child is exacerbated by the increasing costs of non-medical expenses. It is estimated that to care for a seriously sick child costs between €10, 000 and €15, 000 each year². While inflation rates have stabilised and reduced since the exceptional high of 2023, the cost of living in Ireland remains high³ and compounds an already very challenging situation for families.

State support to families looking after a seriously sick child is in most cases insufficient, means-tested or non-existent and is forcing many families into debt.



RIP Sarah Crowe
Aged 12
22rd March 2016

Our survey findings revealed:



38% of families with seriously sick children received no state support since their child's diagnosis

83% of families that do receive state support indicated that the level of support is completely inadequate, and is pushing families into debt.

52% of families were forced to borrow from friends or families to meet the additional costs, with almost 20% of families accessing loans from a financial institution to fund the additional expenses.

² Irish Cancer Society 2021
³ <https://www.irishtimes.com/business/2025/04/30/food-prices-continue-to-climb-according-to-inflation-data/>

“Social Protection payments do eventually come through if one is entitled to them but there is always a delay and worry until the claims are decided”.

Case Study 2 - “Financial Stress and Increasing Debt”

Lily* - aged 4 - Leukemia

Month to month expenses for normal family life as I am at home full time now on carer's benefit and was working outside the home prior to Lily's illness. The money will be put aside and used to keep our family life as normal as possible in a year where they have had enough upheaval. We dropped half our income due to Lily's illness. It gives huge relief from the financial worry. It gives a cushion for unforeseen costs that can't be deferred, for example our car has just gone in for repairs after a breakdown at the weekend. It means life continuing as normal as possible and being able to afford to be at home with Lily. While the journey is still intense it buys me more time at home with him. It buys the family stability because if one of us is in the hospital the other can be at home.



Rita and
Shona
Dempsey,
Wexford

Leaving the workforce - social isolation and reduced income

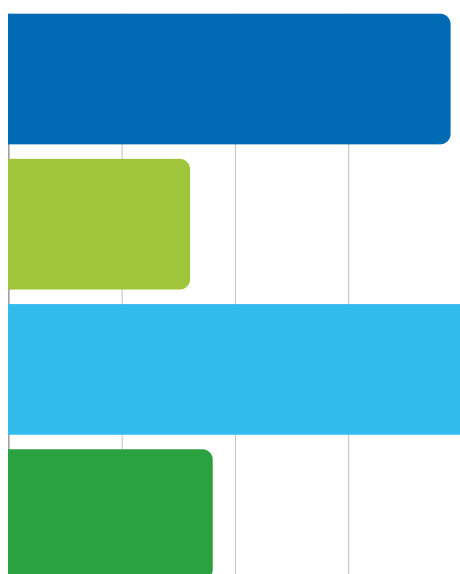
To look after a sick child often requires a total reconfiguration of how parents organise their family's lives. More often than not, this includes either leaving the workforce completely, or reducing work hours significantly. The resultant drop in income occurs precisely at a time when needs are increasing. Withdrawing from the social environment of the workplace also compounds the sense of social isolation.

Reduced income is forcing families to make difficult decisions as to how to prioritise their expenditure.



*Padraig (RIP) and
Maeve Beasley
Listowel, Co.Kerry*

Our survey shows that:



78% of respondents have had to quit their job completely to care for their sick child.

In **32% of cases** in 2 income households a second partner/parent also have to leave their employment.

86% of families have cut back on family outings or the needs of other siblings.

36% of families have experienced difficulty in paying household bills as a consequence of additional expenses and reduced income.

“Both myself and my partner gave up work temporarily for 8 months due to the level of travel, hospitalization and care that was required by our child. I changed jobs to a less demanding role due to the time flexibility needed for appointments as well as the stress associated with the diagnosis. We have no social life for fear of bringing infection into the home from crowded locations like bars etc. Also for the foreseeable future we cannot even have a night away together as we are responsible for the child’s medical needs so one of us must be with him every day/night.”

Case Study 3 - Leaving the workforce- social isolation and reduced income”



Henry* - aged 8 - diagnosis of MPSI

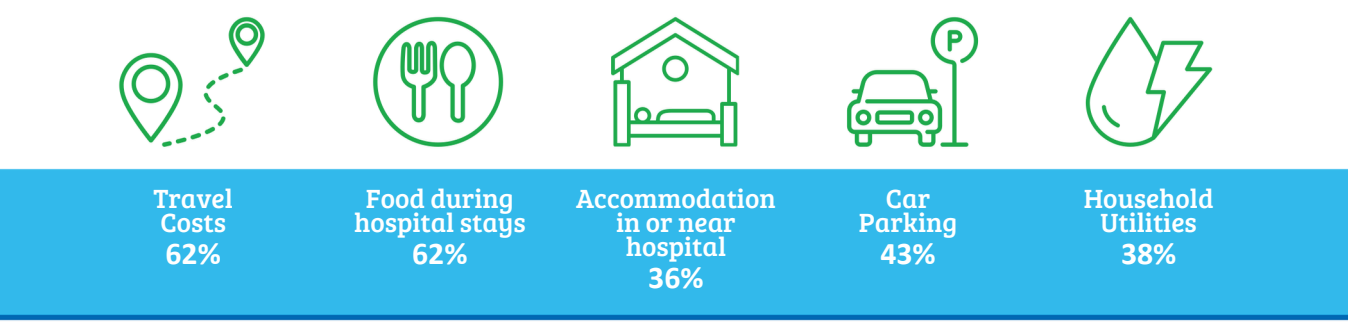
We will use the grant for bills, as funds have been low. We have been in hospital for 5 weeks. The cost of food and travel have left our bank balance empty. Tyres in car had to be replaced costing us €1000 and we needed to borrow money to pay for them. This grant has had a massive impact. Will help get back to normal once hospital visits are over. My husband and I had to miss numerous days off work which led to more financial stress.

The Impact Cliona's Foundation Makes

In 2024, Cliona's Foundation provided €542,000 in direct financial support to 216 families across Ireland.

The grants we provide reflect the wide spectrum of needs families are faced with at this difficult time.

The primary uses for the financial support provided were the following:



The financial support was not limited to these five areas. It was also used for:



We believe it is the families themselves who know best as to where the financial support will have the greatest impact on their household.

But beyond financial aid, we provide something priceless: relief. Families told us that even modest grants lifted the crushing weight of worry. They could pay a bill, sleep a little easier, and feel less alone.

” Cliona's relieved us of the financial pressure we found ourselves under in an already impossible situation. It allowed us to breath and focus on what is most important to us - our son and of course his health. ”

Our model is based on compassion, trust, and dignity. We believe in empowering families—not over burdening them with excessive paperwork or red tape at a time when they are already under extraordinary strain.

The Impact Cliona's Foundation Makes

In 2024, Cliona's Foundation provided €542,000 in direct financial support to 216 families across Ireland.

The grants we provide reflect the wide spectrum of needs families are faced with at this difficult time.



we believe it is the families themselves who know best as to where the financial support will have the greatest impact on their household.

But beyond financial aid, we provide something priceless: relief. Families told us that even modest grants lifted the crushing weight of worry. They could pay a bill, sleep a little easier, and feel less alone.

Cliona's relieved us of the financial pressure we found ourselves under in an already impossible situation. It allowed us to breath and focus on what is most important to us - our son and of course his health.

Our model is based on compassion, trust, and dignity. We believe in empowering families—not over burdening them with excessive paperwork or red tape at a time when they are already under extraordinary strain.

Addressing the Crisis A Call for Systemic Change

No charity can shoulder this burden alone. To truly support these families, we continue to advocate for lasting change that will establish a funding model that will allow Cliona's Foundation to assist more families in more ways in a sustainable way.

We are calling on the government to establish a dedicated fund to support the 4000 families living with a child with serious illness, and the more than 400 families each year that will receive the life-changing news of a diagnosis of a serious illness or condition for their child.

The establishment of a state supported fund will allow for funds to be mobilised and distributed in manner that is:

ADEQUATE

our survey findings confirmed that state support to families with seriously ill children is insufficient for their needs. We need state funding that reflects the true cost of care. In this regard, we have proposed the establishment of a fund administered by Cliona's Foundation, to which the government would match the funds raised by Cliona's to significantly increase the amount of the grant, reach and impact of the Foundation.

APPROPRIATE

funds should be targeted to where the needs are greatest, and made available for a wider range of supports including counselling, a suite of wellness services. This should be family led, as the experts in identifying the most urgent need.

PREDICTABLE

funding needs to be provided in a way that is predictable and sustainable, to allow families the certainty with which to plan and budget for the future.

Moving Forward Together

At Cliona's Foundation, we are inspired everyday by the courage of the families we serve.
Their strength drives our mission forward.

But we cannot do it alone

We need your voice, your support, and your action. Whether as a donor, policymaker, or advocate, you can help ensure no family in Ireland faces this journey unsupported.

Our Vision For The Future

To provide as much financial and emotional support as needed.



Financial Support

- ▶ Cash Support
- ▶ Ongoing support packages from partner companies (in the form of gift cards) for vital expenses like food, fuel, accommodation, and travel costs
- ▶ Provide Financial Advisory services, such as budgeting and mortgage assistance, through a network of qualified financial advisors



Emotional Support

- ▶ Family Counselling
- ▶ Bereavement Counselling
- ▶ Sibling Support
- ▶ Establishment of a national volunteer network of qualified psychologist and counsellors to support families through this traumatic time

Together, we can ease the hidden costs of illness. We can protect families from emotional collapse. We can build a compassionate Ireland that truly leaves no one behind.



LOCATION of FAMILIES we have ASSISTED over the past 17 years.

Cliona's

For families with a seriously sick child



TOTAL OF **1,677** FAMILIES
JUNE 2025