

Too Dear to Visit:

The hidden cost
of caring for
a child with a
life limiting illness.

Academic Review Report

SEPTEMBER
2018

Cliona's

For families with a
seriously sick child



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This academic review report was commissioned by the Board of Cliona's Foundation.

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Thanks are also extended to the beneficiary families who participated in the survey.

Finally, thanks to the Board members and staff of Cliona's Foundation.

Notes on the Authors.

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He has a particular interest in the consequences of population ageing on health and social care. He has carried out advisory work and research on health care reform in the new democracies in Central and Eastern Europe and the former Soviet Union, in Bangladesh, Malawi, Tanzania and in South Africa. He has published widely on health economics and financing, is author of two guidebooks on health insurance and of a textbook on health economics. He is a former President of the Association of Schools of Public Health in the European Region and chairs the steering committee of the WHO European Observatory on Health Systems and Policy.

Dr. Julie Ling is currently the CEO of the European Association for Palliative Care. Originally a nurse, Julie has 30 years of palliative care experience in both adult and children palliative care.

Acknowledgements

Executive Summary

Background.

Many children with life-limiting conditions have non-malignant illnesses and an uncertain prognosis. Parents, usually mothers, willingly become full-time carers for their child. Taking on this caring role frequently impacts directly on the family finances through loss of employment, income or opportunities. Caring also impacts indirectly through increased expenses related to the care needs of their child such as attendance at hospital appointments including travel and parking and other non-care related expenses. Cliona's Foundation is a national charity that provides assistance directly to families of children with life-limiting or chronic complex care needs across Ireland to help with the non-medical expenses related to caring for their child.

This report documents the foundation and development of Cliona's Foundation and reports on the work of the organisation over the last 10 years. Information relating to other sources of funding available to parents are explored. Data are presented on the families who have, to date, been in receipt of assistance from Cliona's Foundation.

Going Forward.

Cliona's Foundation believes that no family should have to face any added financial stress when they are already struggling to cope with the devastation and trauma of a seriously ill child. The charity is committed to increasing its assistance to families during the coming years and will strive to help more families than ever. The foundation will continue to review its approach with the beneficiary families and their children and will modify its assistance if and as required.

The current supports from government are often inadequate, poorly targeted on the needs of families of children with life limiting conditions, slow and difficult to access. If government support more fully closed the funding gap for families it would be possible to focus the support from Cliona's Foundation on meeting urgent and unexpected needs.

The report sets out three key recommendations:

1. Requirement to establish a national database on families caring for children with a life-limiting condition.
2. Government to establish a new '*looking after a child with life limiting illness*' grant for families with a child suffering from a life-limiting condition.
3. Cliona's Foundation to tailor its support services to meet the unique needs of the families including partnerships with services companies to provide a range of assistance to the families.

Finally, Cliona's Foundation is endeavouring to strengthen its Board of Directors over the coming months and to broaden its sources of funding & assistance so as to more fully meet the needs of families of children with life-limiting conditions.

Foreword

As parents of a sick child we knew all too well about the stress and upset of having a sick child. We strongly believe that no family in these circumstances should have to face the additional 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 condition.

When a child is diagnosed or born with a life-limiting condition it presents an immense challenge for the whole family. Caring for a sick child impacts on all aspects of family life placing some families under increased financial pressure. Families need all the support and help they can get to care for their child through ill-health including help in meeting non-medical expenses. At Cliona's Foundation we endeavour to help as many families as possible by providing assistance directly to families who are caring for a child with a life-limiting condition.

The intention of this document is to report on the work of Cliona's Foundation with families caring for seriously sick children, to describe the work that has been undertaken over the last 10 years and to highlight challenges and opportunities for the future development of Cliona's Foundation in this area.



Terry Ring Brendan Ring

Terry and Brendan Ring
Founders of Cliona's Foundation
Limerick

Cliona's
For families with a
seriously sick child



Glossary of Terms

CHILD

Person below the age of 16 years.

HSE

Health Service Executive.

LIFE-LIMITING CONDITION.

A life-limiting condition in children is defined as a condition for which there is no reasonable hope of cure and from which children will die.

LIFE-THREATENING CONDITION.

A life-threatening condition in children is those for which curative treatment may be feasible but can fail, such as cancer.

PALLIATIVE CARE FOR CHILDREN.

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a): Palliative care for children is the active total care of

the child's body, mind and spirit, and also involves giving support to the family. It begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes (WHO, 2012). Children's Palliative Care is an active and total approach to care, from the point of diagnosis or recognition, 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/young person and support for the family. It includes the management of distressing symptoms; provision of short breaks; and care through death and bereavement (ACT, 2009)

RESPITE CARE.

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

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 with certain age ranges or diagnostic categories). Some of these non-governmental organisations are either partially or in some cases fully funded by the state.

INTRODUCTION TO CLIONA'S FOUNDATION.

Introduction.

This section of the report focuses on the work of Cliona's Foundation. The Foundation is a registered Irish Charity founded in 2007 that provides assistance for a range of non-medical costs to families who have a child with a life-limiting condition, whether as a result of an illness or an accident. As access and availability to state funding is challenging for families, Cliona's foundation aims to support families who are experiencing severe hardship and who have exhausted all other avenues of possible financial support.

Cliona's Foundation was founded by Brendan and Terry Ring in memory 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 a lot of time in different hospitals throughout Ireland with Cliona as she underwent different medical treatments for her brain tumour. During this time they came into contact with many families struggling to meet the additional costs associated with their child's illness or condition.

The role and function of Cliona's Foundation.

Cliona's Foundation is unique in that it focuses on providing support directly to families specifically for non-medical costs. The aim is to ease the financial burden on families caring for a child with a life-limiting condition. In particular Cliona's Foundation focuses its services on helping families who have children undergoing long-term medical treatment for a life-limiting condition or complex critical illness. Funds raised by Cliona's Foundation are not used to pay for the child's medical care; rather, donations are made to help families with the "hidden" costs of caring. These include items like accommodation, food, travel costs, parking and other miscellaneous costs incurred by the families of children with life-limiting or complex critical illness attending hospitals or other medical facilities for visits and for treatments.

REPORT: Aims and Objectives.

This report aims to highlight the work of Cliona's Foundation by:

- Reporting on the activity of the organisation in its first 10 years.
- Identifying key national and international literature on caring for a child with a life-limiting or chronic complex conditions.
- Identifying supports available to families.
- Discussing the social and economic impact of caring for a child with a life-limiting condition.
- And, identifying the challenges and opportunities for Cliona's Foundation in the coming years.

The majority of families in receipt of assistance from Cliona's Foundation have or are caring for a child with a life-limiting condition therefore this is the term that will be used throughout the report, however some families who have received grants are caring for a child with a chronic complex condition. Cliona's Foundation assesses each application on its individual merits.

Vision, Mission and Values.

Cliona's Foundation Company Limited by Guarantee ("Cliona's Foundation") is a registered charity, (Company Registration Number 464037, Charity number CHY 18127, CRA Number 20068899) set up by Brendan & Terry Ring following the death of their daughter Cliona from an inoperable brain tumour. As they made the many trips to hospitals all over Ireland with Cliona, the couple were struck by the many families with whom they came in contact, who had a critically ill child like themselves and these families were on the brink of financial meltdown because of the mounting non-medical expenses piling up. Brendan and Terry took action and set up Cliona's Foundation in honour of their only daughter.

VISION.

No family will suffer financially when caring for a seriously ill child.

MISSION.

To provide financial assistance for families of children with a life-limiting condition.

ETHOS AND VALUES.

The ethos and values of Cliona's Foundation are delivered through the following set of principles:

- **Respect.**

Cliona's Foundation respects the needs and dignity of all its stakeholders with a special empathy for the beneficiaries and their families.

- **Honesty.**

Cliona's Foundation is honest and truthful in all its dealings with every stakeholder and anyone interacting or engaging with the organisation. We will answer all reasonable questions on any aspect of the organisation and its activities.

- **Accountability.**

Cliona's Foundation is accountable for all its activities and all funding received from donors and fundraising activities. A full governance, activity calendar and financial management system are in place to ensure this accountability.

- **Transparency.**

Cliona's Foundation is committed to full transparency in all its fundraising and activities. There are a number of ways for anyone interested to contact the organisation and receive a timely response to your query /request.

- **Partnership.**

Cliona's Foundation is committed to working in partnership with other like-minded organisations.

Foundation Patron - Miriam O'Callaghan

FINANCIAL SUPPORT FOR THE FAMILIES OF CHILDREN WITH LIFE-LIMITING CONDITIONS.

Chapter Summary.

For the families of children with life-limiting conditions, accessing financial support and allowances can be very stressful. Being entitled to such funding does not always translate into it being granted. The bureaucracy surrounding the application process can be stressful and prolonged, with parents in some cases reporting that their child has died before the allowances are granted. There are some voluntary organisations that are able to provide some support and financial assistance but unlike Cliona's Foundation they are either limited by geography or diagnosis.

2.1 Introduction.

In Ireland various agencies provide a range of financial assistance to families of children with life-limiting conditions and complex chronic conditions. However entitlement and access to these varies according to the child's diagnosis and their geographical location. Each state benefit has specific qualifying criteria and requires parents to complete a range of application forms and processes. In the first part of this section grants and allowances available to some of the parents of children with life-limiting conditions are described.

2.2. State services & allowances.

In Ireland there are universal services and payments for all children and there are also services and payments specifically for people with disabilities. These apply for children either born with or have acquired or congenital disabilities (Citizens Information, 2017).

2.2.1 Tax allowances.

Support available for all families with children includes child benefit and relevant tax credits. For the parents of a child who is incapacitated or disabled it is possible to claim an additional tax credit, the Incapacitated Child Tax Credit can be claimed for children with disabilities. A further tax allowance can be claimed if parents have a Primary Medical Certificate which confirms that your child has a permanent disability. One of the advantages of seeking a Primary Medical Certificate is that it can be used when purchasing a car and provides tax relief on Vehicle Registration Tax, Annual Motor tax and also provides tax relief on fuel consumption up to 600 gallons per year. Tax relief on medical expenses associated with their child's care can also be claimed by the parents.

2.2.2 Medical Card.

Medical cards are issued by the Health Service Executive (HSE) and allow the holder to receive a range of health services free of charge. Medical cards are available to some families of children with life-limiting conditions but are dependent on the family circumstances and means testing. If a family is not eligible for a medical card, a child may get an individual discretionary medical card if they have particular medical expenses. Since July 2015, all children with a cancer diagnosis are entitled to a medical card for five years (HSE, 2015). Other work is ongoing within the HSE to identify childhood conditions where a medical card should automatically be awarded (Department of Health, 2014). All children under the age of six are entitled to a GP visit card that entitles them to free GP care but not to free prescriptions and not free access to other community health services

2.2.3 Allowances for children with disabilities.

There are a range of allowances provided by the state for the parents of children with disabilities. Various eligibility criteria apply to each individual allowance.

2.2.3.1 Domiciliary care allowance.

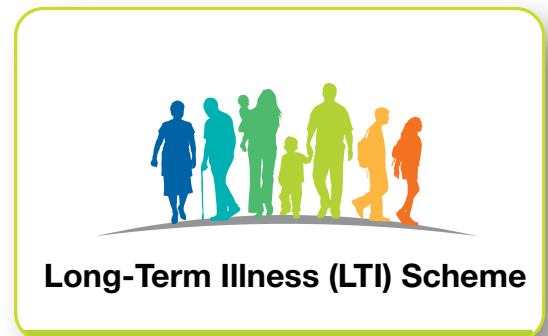
The Domiciliary Care Allowance is provided by the Department of Social Protection to the families of children under the age of 16 with severe disability who are cared for in the family home. Parents are required to satisfy the habitual residence condition before being awarded the Domiciliary Care Allowance.

2.2.3.2 Long Term Illness Card.

The long term illness card scheme is available to those suffering with specific conditions (Figure 1)(HSE,2015a) who are not medical card holders. Benefits include a range of free medications and treatments. This scheme is not means tested or dependent on income and children can have both a medical card/GP visit card and a long term illness card.

**FIGURE 1 -
Conditions considered under the Long Term Illness Card Scheme**

Acute Leukaemia
Intellectual disability
Cerebral palsy
Mental illness (in a person under 16)
Cystic Fibrosis
Multiple Sclerosis
Diabetes insipidus
Muscular Dystrophies
Diabetes mellitus
Parkinsonism
Epilepsy
Phenylketonuria
Haemophilia
Spina bifida
Hydrocephalus
Conditions arising from Thalidomide



2.2.4 Carer's allowance.

Carer's allowance is a means-tested allowance payable to carers who live with and look after people who need full time care. If your child is under 16 years of age and you care for your child, you qualify for Carer's Allowance. If you are in receipt of Domiciliary Care Allowance this is not taken into consideration when applying for Carer's Allowance.

2.2.5 Carer's support grant (formerly Respite care grant).

Parents who qualify for the Domiciliary Care Allowance are also eligible for the annual Respite Care Grant. This payment is made to carers to enable them and the person they are caring for to take a break. This grant can be used at the carer's discretion.

2.2.6 Carer's Benefit.

Carer's Benefit is a payment made to insured people who leave the workforce to care for a person in need of full-time care and attention. It is paid for a maximum of 104 weeks in total for the care of any individual.

2.2.7 Assessment under the Disability Act, 2005.

Parents can also apply for an assessment of need for their child under the Disability Act 2005. At present this is only available to children aged under five. Other grants are available to adapt homes and help with a child's education. Services vary according to the geographical location of the family home and the nature of a child's disability. Not all of the services are relevant to every child.

2.2.8 Assistance with the cost of equipment.

The HSE will provide assistance with aids and appliances, for example wheelchairs, if the child or family has a medical card. If a child has a Long Term Illness Card, the family may also get help with the costs of medical or surgical appliances. For families who do not qualify for a medical card, some help may be available from the HSE if the medical or surgical appliances are part of hospital. Equipment for people with disabilities in most circumstances is supplied free to medical cardholders. People with a Long Term Illness Card may get equipment essential for the primary condition, free of charge. Those without a medical card may be able to claim back the VAT.

The following grants are also available but are mutually exclusive:

Housing Adaptation Grant for People with a Disability up to €30,000 for houses more than 1 year old and €14,000 for houses under 1 year old.

Mobility Aids Grant Scheme is means tested. Maximum grant €6,000.

2.3 Voluntary organisations providing support for families of children with life-limiting conditions.

Limited support for families is available through local and national charities. In many cases this support is for specific purposes and can be for children with specific diagnoses. For example, Aoibheann's Pink Tie provides grants to families of children who are undergoing treatment for cancer in Our Lady's Children's Hospital, Crumlin.

2.4 Summary of financial support for families of children with life-limiting conditions.

For the families of children with life-limiting conditions, accessing financial support and allowances can be very stressful. Being entitled to such funding does not always translate into it being granted. The bureaucracy surrounding the application process can be stressful and prolonged, with parents in some cases reporting that their child has died before the allowances are granted. There are some voluntary organisations that are able to provide some support and financial assistance but unlike Cliona's Foundation they are either limited by geography or diagnosis.

Audit of Cliona's Foundation

INTRODUCTION.

At Cliona's Foundation information on all applications for assistance are logged. In the following section findings of an audit of all successful applicants are presented.

CHAPTER SUMMARY.

Cliona's Foundation is providing much needed financial support to families struggling to care for children who have a life-limiting medical condition. Since 2007 they have distributed almost €700,000 to families caring for their seriously-ill children in 29 counties across Ireland, to help with non-medical costs.

Over half of the funds distributed help with the travel and accommodation associated with the caring of their child. A further €110,000+ helps families to deal with reduced income and various household bills that arise on top of the costs of caring for their child.

The feedback from the families highlights the impact and relief that the assistance from Cliona's Foundation provides for them. The testaments from the families provide a great insight into just how important the funding is in providing them with some welcome relief in their ongoing caring for a seriously-ill child.

Methodology.

An audit of all successful grant application forms submitted to Cliona's Foundation was undertaken. All data were anonymised to protect confidentiality. Records were scrutinised and data collected on age, sex and diagnosis of the child. The allocation of grants made to families was also analysed and the geographical location of grant recipients was noted.

Results.

Cliona's Foundation was formally established in March 2008 and all records of successful applicants for grants until December 2016 were included. Cliona's Foundation awarded financial assistance for non-medical expenses to 389 children with life-limiting or chronic complex care needs during this period. **Note:** by mid 2018 over 500 families have been assisted across Ireland.

Diagnosis.

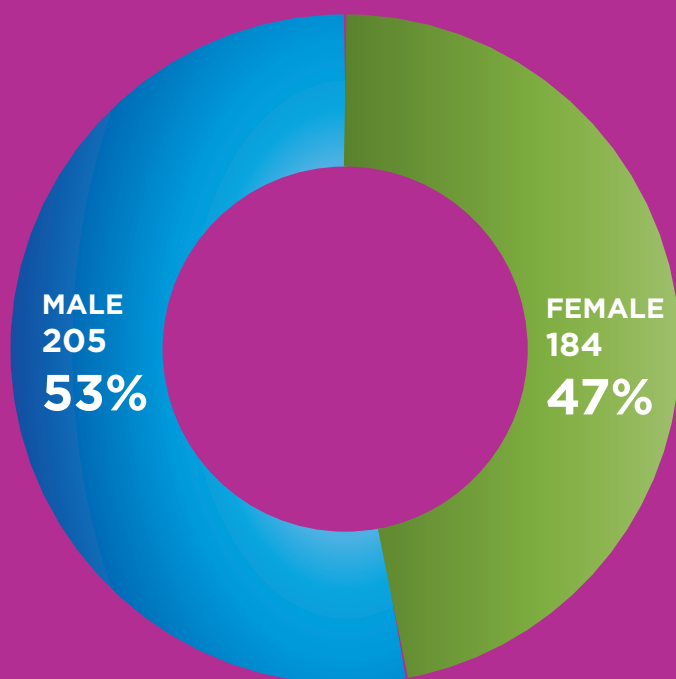
In line with Cliona's Foundation policy the majority of grants were awarded to the families of children with life-limiting conditions. Eighty-eight percent (88%) of the grants awarded were to families of children with a life-limiting condition. In other cases the children had conditions requiring high levels of treatment and care.

Sex and Age.

Cliona's Foundation currently awards grants to the families of children up to 16 years of age. During the audit period (2008-16) grants were awarded to 184 girls and 205 boys.

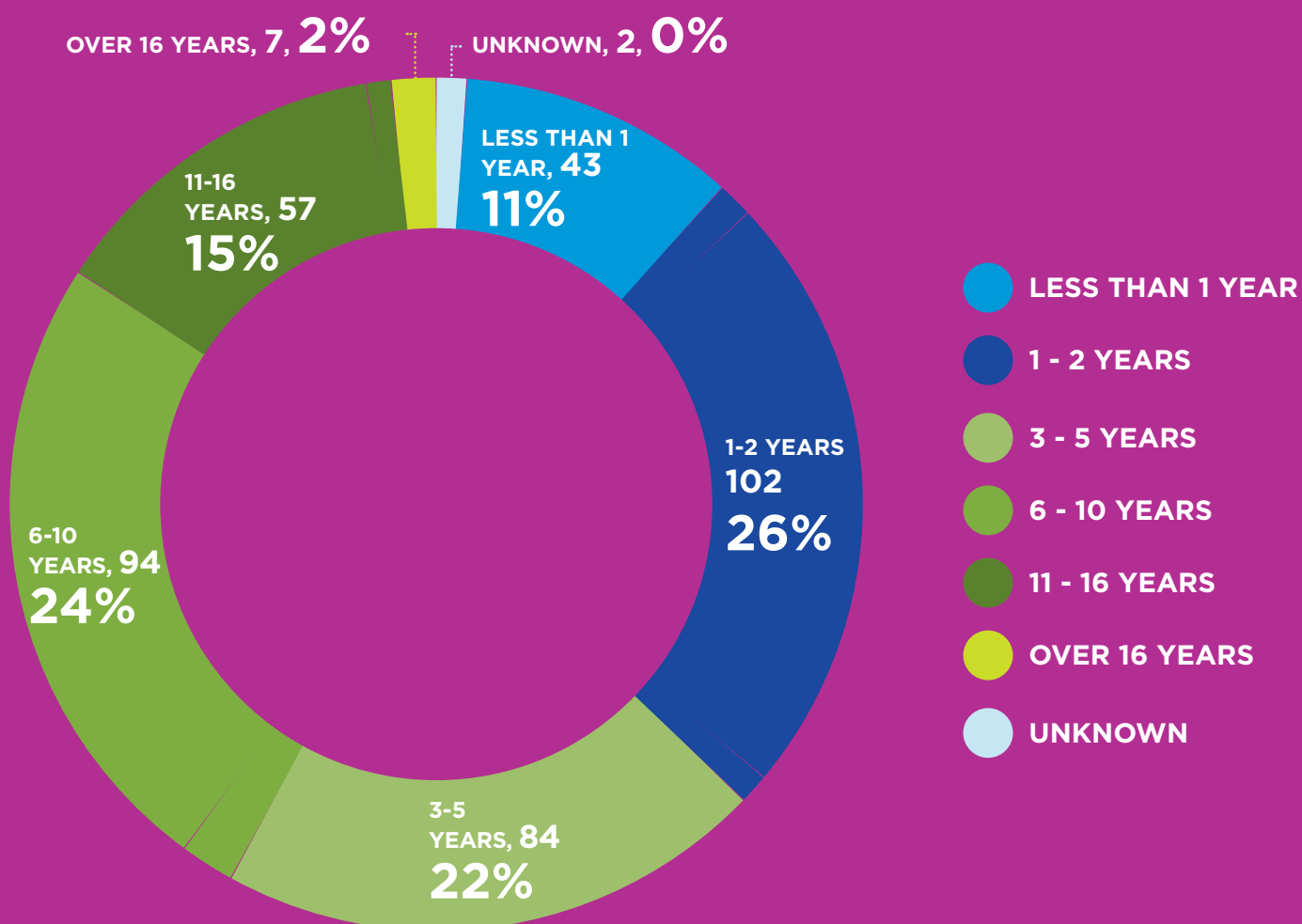
Section 3

BREAKDOWN OF AWARDEES - Male /Female [n=389].



BREAKDOWN OF AWARDEES - Ages of Children [n=389].

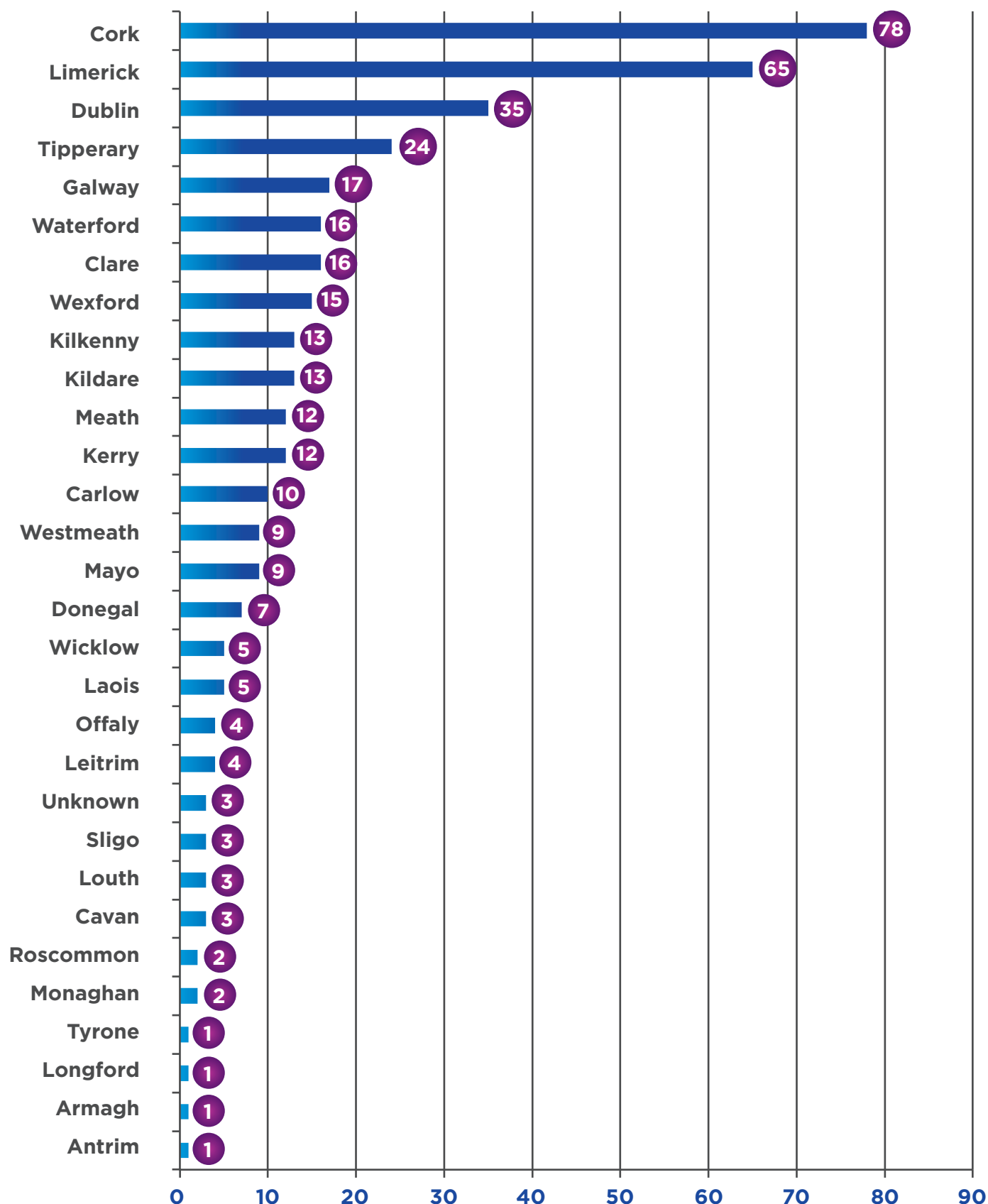
The age breakdown is summarised in the following chart and the largest cohort is the 1-2 year old with 102 awardees.



LOCATION.

As a charity based in Limerick, initially Cliona's Foundation focused its grant awards on those living in Munster. Since 2012, grants have been awarded to families throughout Ireland, and, to the end of 2016 families from 29 of the 32 counties have received financial support from Cliona's Foundation.

Location of Awardees [n=389].



GRANT UTILISATION.

The families receiving the financial assistance, i.e. 'grant' from Cliona's Foundation use the assistance given for a wide variety of costs and bills. These are summarised into five main categories shown in the Table 1.

TABLE 1:
Usage Categories.

Grant Used for:	Numbers	Grant Amount
Travel and Accommodation Costs - includes overseas for treatment	220	€381,352
Equipment (For home, car etc.)	59	€102,272
Family Assistance	64	€110,939
Respite - includes nursing support, home care	22	€38,136
Other -Gifts for child etc.	24	€41,602
Total	389	€674,300

Cliona's Foundation Family Feedback.

Families benefitting from the services of Cliona's Foundation are not routinely followed up but many chose to give feedback on their experience and what the support has meant to them and their family. Of the 389 children whose family received a grant from Cliona's Foundation, sadly over 60 are known to have subsequently died.

Beneficiary families frequently contact with Cliona's Foundation to express their thanks for the help and to update on the condition of their child. Some examples of this feedback include:

- 1. "Bills were the last thing on our mind when our son was in hospital and we spent many weeks in the Ronald McDonald house. Thanks to Cliona's Foundation for saving our young family and on the day the cheque was received seeing tears turn to smiles was beautiful."* – **Family from Limerick**
- 2. "You have no idea how much this means to us and how helpful it will be. It as an incredible surprise to see it in the post this Friday when we got home with our son for the 1st time in more than 6 months. I had to quit my job to be able to stay with him in hospital and now take him to his check-ups and rehabilitation appointments."* – **Family from Kildare**
- 3. You will never know how much it means to us being in Crumlin 5 ¹/₂ months with our son. It was bad enough him being so sick, but all the added expenses of just trying to maintain our home too along with living in Dublin and even just trying to have money for travelling up and down and eating was near impossible. The cheque we received was a godsend and came a the right time for us as we were at breaking point."* – **Family from Wexford**
- 4. You have no idea what this means to us & it will help us in a huge way. When our daughter got sick my husband had to give up his job as we have 3 other kids, all under 7. This money will help us so much in just our basic day to day life, the food shopping & the diesel costs to Dublin for appointments."* – **Family from Sligo**

Summary of Findings

Cliona's Foundation is providing much needed financial support to families struggling to care for children who have a life-limiting medical condition. Since 2007 they have distributed almost €700,000 to families caring for their seriously-ill children in 29 counties across Ireland, to help with non-medical costs.

Over half of the funds distributed help with the travel and accommodation associated with the caring of their child. A further €110,000+ helps families to deal with reduced income and various household bills that arise on top of the costs of caring for their child.

The feedback from the families highlights the impact and relief that the assistance from Cliona's Foundation provides for them. The testimonials from the families provide a great insight into just how important the funding is in providing them with some welcome relief in their ongoing caring for a seriously-ill child.

“ We cannot
repay you for
your **kindness**
but I am
praying every
day that God
will bless you a
thousand folds ”



Review of international evidence and evidence from Ireland.

Chapter Summary.

In this section, a literature review explores the childhood mortality, prevalence of life-limiting conditions in children and the impact of caring for a child with a life-limiting condition on the parents, siblings and family as a whole. The literature review examines Irish and overseas evidence with much of the reference material from the international sphere.

The financial impact of caring is described including the effect of caring on employment and consequent income reduction. The financial burden on parents is evident and many families are estimated to be spending upwards of €10,000, and above, per annum caring for their child with a life-limiting condition. Non-medical costs clearly add to the stress and anxiety experienced by parents who struggle to meet the care needs of their sick child. The loss of employment opportunity & consequent reduced income, combined with non-medical costs are creating a significant funding problem for many families.

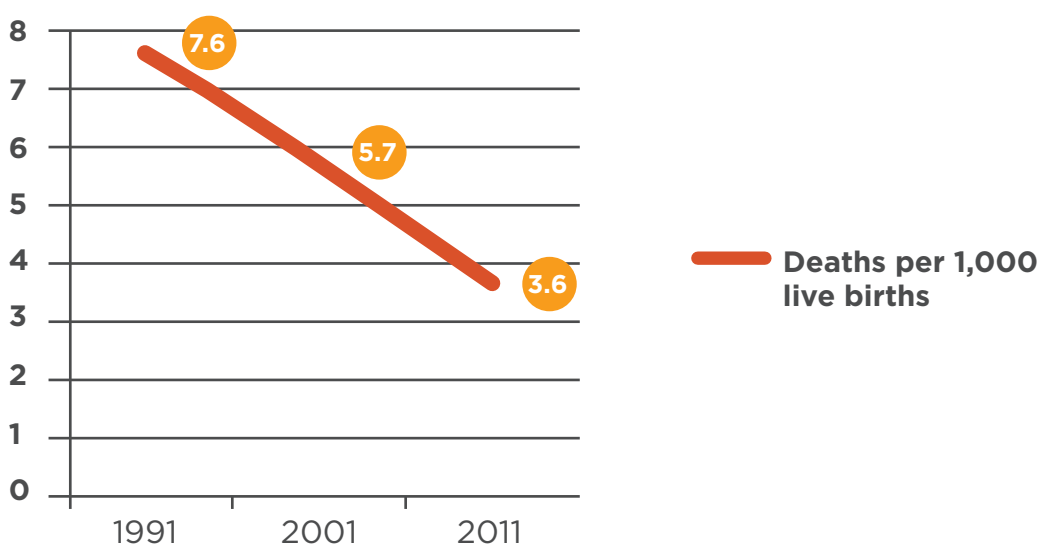
Introduction.

For parents caring for a child with a life-limiting or a chronic complex condition the care of their child is a full time job which impacts on all aspects of family life. In particular providing care can place strain on parents socially, psychologically, emotionally and financially. In this section findings of a literature review are presented to highlight the challenges that parents of children with life-limiting conditions face.

Child mortality.

Infant mortality continues to fall (Figure 2) and death in childhood in Ireland remains relatively rare (Department of Children and Youth Affairs, 2012).

FIGURE 2:
Irish Infant Mortality (Department of Children and Youth Affairs, 2012)



It is estimated that there is an average of 322 childhood deaths from life-limiting conditions each year in Ireland (Figure 3.)(Lauralynn & IHF, 2013).

FIGURE 3:

Average number of childhood deaths and deaths from life-limiting conditions (Lauralynn & IHF, 2013)

Year	Number of deaths	Number of deaths due to life-limiting conditions
2005	417	292
2006	421	321
2007	413	306
2008	462	347
2009	403	316
2010	423	348
2011	393	NA
Average annual	419	322

In 2011, 393 children died in Ireland with an overall mortality rate of 3.4 per 10,000 children (Table 2.) The largest single cause of childhood death is congenital malformations and conditions in the perinatal period. This confirms the findings of an earlier study which found that between 1996 and 2001 that 83% of all childhood deaths occur up to the age of one year with the majority (67%) occurring in the first days, and weeks of life (Department of Health and Children & Irish Hospice Foundation, 2005).

TABLE 2:
Number of deaths of children, by age and cause of death (CSO, 2011)

	Under 1 Number	1-4 Number	5-9 Number	10-14 Number	15-17 Number	All Children Number
TOTAL	258	34	28	20	53	393

MAIN CAUSE OF DEATH

Malignant neoplasm	2	2	8	9	7	28
Certain conditions in the perinatal period	93	-	-	-	-	93
Congenital malformations	111	4	5	2	2	124
Sudden infant death syndrome	13	3	-	-	-	16
Injury and poisoning	1	4	3	1	18	27
Other	38	21	12	8	26	105

Improvements in technology and healthcare have impacted positively on the reduction in infant mortality but have also resulted in many children surviving who are dependent on technology or who have life-limiting conditions.

Life-limiting conditions in children.

Life-limiting conditions affecting children and young people can be defined broadly into four categories (Appendix 1) (ACT, 2009). Categorisation is challenging as not all conditions described in each category result in death during childhood. Diagnosis is only part of the process: the spectrum and severity of the disease and subsequent complications, as well as the needs of, and impact on the child and family, also need to be taken into account (Together for Short Lives, 2015). There is a huge overlap between children with complex disabilities and those with life-limiting conditions requiring palliative care.

Prevalence of children with life-limiting conditions in Ireland.

In 2005, a children's palliative care needs assessment estimated that there are approximately 1400 children living with a life-limiting condition in Ireland (Department of Health and Children/Irish Hospice Foundation, 2005). This figure was based on a prevalence rate of 12:10,000 children. In the absence of robust evidence, this figure was based on calculation's using UK data. More recently, international literature suggests this figure is a severe under-estimate and suggest that prevalence rate of 32-44:10,000 children (Fraser *et al*, 2012). Application of 32:10,000 to Irish child statistics from the Central Statistics Office results in an estimated 3840 children living with a life-limiting condition in Ireland (Ling *et al*, 2015).

The overlap between life-limiting conditions and disabilities.

According to the National Physical and Sensory Disability Database, 6% of all children in Ireland are registered as having a disability. In 2011, this equated to 8034 children registered as having a physical/sensory disability with one in three of these children reported to have multiple disabilities. There is an overlap between children with disabilities and those with life-limiting conditions (Craft and Killen, 2007).

Children with life-limiting conditions often have an unpredictable disease trajectory (ACT, 2009). As a result of advances in medicine and technology many children with life-limiting conditions are living longer. Many parents report having been told several times that their child will die only for them to survive for often months or sometimes years (Ling, 2012). In the majority of cases, parents take on the role of primary carer willingly and without knowing the duration of this commitment (Steele, 2005). For many parents, caring becomes a full-time job (Eaton, 2008).

Parents as carers.

Initially, parents often struggle to come to terms with their child's diagnosis and prognosis. However despite initial concerns, parents become adept at providing 'hands-on' care to their child. Many parents develop nursing skills, sometimes carrying out highly technical care usually provided by trained nurses (Kirk, 2000; Nichol & Begley, 2012). Heaton *et al* (2005) reported on the time-consuming nature of the technical care that parents administer. Parents often feel ill-equipped to deal with meeting the special needs of their child (Lemacks, 2013) and this can be exacerbated by the need for life-long hospital appointments and admissions. Parents often become the experts in the care of their own child, however taking on this caring role impacts on all aspects of family life (Steele, 2005). Taking on the role of carer can often result in excessive physical burden (Department of Health and Children/IHF, 2005; Thomas & Price, 2012) and can lead to social isolation (Yantzi *et al*, 2006; Thomas & Price, 2012).

The impact of caring for a child with a life-limiting condition on family life.

Multiple research has highlighted the impact of caring for a child with a life-limiting condition on family life and the burden this places on families (Eaton, 2008; Thomas & Price, 2012; Ling, 2012; Lemacks *et al*, 2013). Taking on the role of primary carer for their child impacts on all aspects of quality of life for parents (Lemacks *et al*, 2013) including sleep, work, finances and relationships (Heaton *et al*, 2005). Caring has also been reported to impact on physical and mental health of parents including significant fear, anxiety and depression (Lemacks *et al*, 2013)

In many instances, the family home require adaptations to provide a caring environment (Kirk, 2002) and space may be utilised to store the equipment often necessary to care for their child (e.g. oxygen and suction machines and wheelchairs).

Impact on siblings.

Long-term care of a child at home also impacts on well siblings often conferring a '*different type of childhood*' (Heaton *et al*, 2005). Well siblings may not only receive less attention from their parents but in some cases siblings are involved helping to provide care (Heaton *et al*, 2005). In some cases, younger siblings may be placed with extended family members to allow parents time with their sick child particularly if their sick sibling is hospitalised requiring their parent to stay at the hospital. In some cases siblings may be placed with wider family members for extended periods of time.

Well siblings of children with life-limiting conditions also report feeling less important than their sick sibling (Knapp & Contro, 2009). Changes in family dynamics impact on the whole family and parental concerns regarding family finance adversely impact on well siblings. Some work has been undertaken internationally exploring the economic impact of caring for a child long term (Lowson *et al*, 2007) which suggests that the financial impact of caring for a sick child puts strain on many families. These findings have been confirmed by others (Steele, 2005; Knapp & Contro, 2009). It has been suggested that the needs of parents in their roles as long-term care givers as well as the unique needs of siblings of children with complex chronic conditions should be recognised with appropriate referrals to community agencies that are able to secure financial support through both statutory and voluntary means (Elias & Murphy, 2012).

The financial impact of caring for a child with a life-limiting condition.

Families who have children with long-term conditions are frequently faced with considerable economic stress and burden that often increases over time as their child's condition becomes more severe or complex (Redmond & Richardson, 2003). Stress as a result of caring responsibilities on parental relationships is reported by several authors (Stein *et al*, 1989; Steele, 2005; Yantzi *et al*, 2006; McConkey *et al*, 2007; Rodriguez & King, 2009) and can be exacerbated by other factors related to the care of a sick child such as strained family finances and limited employment opportunities due to caring responsibilities (Stein *et al*, 1989; McConkey *et al*, 2007). An Australian study of families of children with life-limiting conditions reports that nearly all caregivers are concerned about financial pressure with 52% expressing considerable concern about their finances. Respondents reported that the combination of the financial costs of caring, coupled with an inability to work posed a major difficulty for families (Remedios *et al*, 2015).

Research with parents of children with cancer found that negative financial effects on parents of caring for their child also included debts that were accrued over the course of treatment (Dockerty, 2003). Out of pocket expenses including travel, lodging and meals away from home add to costs. Parents also report many hidden costs directly and indirectly associated with caring for their sick child (Steele & Davies, 2006) incurred by families and in some cases medications and medical supplies also need to be purchased (Dockerty *et al*, 2003). This care is all set within the context of a family environment that is characterised by low support and high conflict (Deeley *et al*, 1998). Parents describe their inability to maintain a social life not only due to the care needs of their child (Steele, 2005; Rodriguez & King, 2009) but also due to the associated costs (Steele & Davies, 2005).

A study in Ireland in association with the Jack and Jill Foundation (McNamara, 2015) explored the costs to families who were caring for children with life limiting conditions. Even where the child was eligible for free health care, many families considered the services to be inadequate, and paid privately for additional care. For example, some parents were paying €500 per annum for additional physiotherapy (McNamara, 2015).

Parental employment opportunities.

Parents, most frequently mothers, become the main carer of their child often giving up paid employment to do so (McGarvey & Hart, 2008), regardless of their earning power (Dockerty *et al*, 2003). In Ireland many women, who traditionally would have provided support, are now working outside of the home and are required to do so in order to meet the increasing living costs (Kennedy, 2001; Daly, 2004). This is an added stress when employment is curtailed or simply no longer possible due to the caring responsibilities for their child. The migration of family members in Ireland is now more common this also impacts on the ability of the wider family system to provide support to the family in caring for the sick child.

Employment can often be detrimentally impacted for families of children with life-limiting conditions who are required to attend medical appointments. Remedios *et al*, (2015) point out that these are rarely available outside of traditional working hours. Due to their caring commitments, parents may lose jobs, change jobs or decide that one parent needs to give up work in order to stay home with their child. These decisions result in drastic changes to family life.

McNamara (2015) found that many families faced serious falls in family income, due to taking time off work, stopping work to care for the child, working shorter hours and changing jobs to allow more time for caring. The average loss of family income was nearly €24,000 per annum, representing around one third of income prior to caring for the child.

Generally families of children with life-limiting conditions spend about 1/3 of their post-tax income on the additional costs of caring for their child. The economic burden on families is huge and research shows that the percentage of income being spent, i.e. 33%, is pretty consistent across different income levels (McNamara, 2015).

The average post-tax income for a household in Ireland in 2016 was €34,704 according the CSO (CSO, 2016) indicating that families caring for a child with a life-limiting condition can be spending amounts up to and over €10,000 per annum [i.e. 1/3 of €34,703.]

Non-medical expenses.

Several authors report on non-medical costs incurred by the parents of children with life-limiting conditions (Redmond & Richardson, 2003; Department of Health and Children/Irish Hospice Foundation, 2005; Remedios et al, 2015).

These include:

- Travel to appointment
- Parking
- Hotel and accommodation
- Meals
- Fuel for travel
- Time away from work
- Special equipment
- Home adaptations
- Special childcare arrangements

McNamara (2015) found that these costs were highly variable. Additional out-of-pocket expenses (such as travel, additional phone and energy costs) that were not reimbursed had an average cost per year of around €1,400, but in some cases it was over €5,000.

A UK 2014 Report on families with severely disabled children states that more than a quarter of families in the survey have £300 or more extra costs relating to their child's disability or health condition every month. (Counting the Costs, 2014) The £300 is equivalent to around €350 per month or €4,100 per annum in an Irish context.

Similar patterns have been reported by those who received financial assistance from Cliona's Foundation – in many cases there were large increases in non-medical expenses, and for some people the costs of travel and subsistence were high. On hospital visits, out-of-pocket expenses ranged widely depending on how far parents had to travel, including overseas for specialised treatment. The average daily out-of-pocket was €145 but could be as low as €20 (local hospital) and up to €500 per day for travelling abroad. An extended stay in hospital, for example, of 55 days at €145 per day adds up to €7,975 in a year.




Summary

Summary of Section 4.

In this section, a literature review explores the childhood mortality, prevalence of life-limiting conditions in children and the impact of caring for a child with a life-limiting condition on the parents, siblings and family as a whole. The literature review examines Irish and overseas evidence with much of the reference material from the international sphere.

The financial impact of caring is described including the effect of caring on employment and consequent income reduction. The financial burden on parents is evident and many families are estimated to be spending upwards of €10,000, and above, per annum caring for their child with a life-limiting condition. Non-medical costs clearly add to the stress and anxiety experienced by parents who struggle to meet the care needs of their sick child. The loss of employment opportunity & consequent reduced income, combined with non-medical costs are creating a significant funding problem for many families.





“ When our **daughter** got sick my husband had to give up his job ”

Meeting future need

It is estimated that approximately 4,000 children are living with a life-limiting condition in Ireland. Research in this paper has highlighted that the families of children with life-limiting conditions spend about 1/3 of their post-tax income on the costs of caring for their child. The average post-tax income in Ireland in 2016 was €34,704 indicating that many families caring for a child with a life-limiting condition are spending upwards of €10,000 to €11,000 per annum and certainly at the critical times of the illness. The total burden faced by families at a national level is into several millions of euro each year. The research also highlights that travel and related costs can range from €1,400 to €8,000 in a year and are a major part of the spending by the individual families.

Not all families of children with life-limiting conditions require the help of Cliona's Foundation. For families who are in need of support, and who meet their criteria, Cliona's Foundation aims to help families make ends meet. Much of the funding assistance so far has gone towards non-medical costs for families, especially travel and subsistence. Support per individual family has been around €1,500, the average cost per year for additional costs as found in McNamara (2015). Helping with these non-medical costs is particularly important given the reduction in family incomes that is frequently present in these situations. While some of the financial pressures are offset for qualifying families from payment of carers' allowances and other benefits, it is the case that families frequently face additional non-medical costs along with lower household income.

The goal of Cliona's Foundation is to help families caring for a child with a life-limiting condition that require assistance with non-medical costs anywhere in Ireland. An important feature of their support is the possibility of being flexible to meet the widely varying needs for assistance. The total amount required each year to help all the families (that need it) across Ireland is significant and beyond the capacity of any one charity. Looking to the future, a care-support model for families of children with life-limiting conditions that combines new public funding with complementary support services from charities such as Cliona's Foundation is needed. This could go some way towards ensuring that all the families who require support will receive it in a timely manner.

Recommendations

1. **Further research needed on the number of children with life-limiting conditions and the associated care costs.**

The research has again highlighted the lack of detailed information on the prevalence of life-limiting conditions in Ireland. It also highlights the lack of detailed information on the extent of non-medical costs for families caring for a child with a life-limiting condition in Ireland.

A national database of families with seriously sick children with life-limiting conditions should be established as soon as possible. This has been called for before and would ideally be co-ordinated by the Department of Health in conjunction with the key children's hospitals, hospice facilities and relevant charities. The objective of the research is to work confidentially with the families to develop a national database for life-limiting conditions in Ireland. This would provide comprehensive data on the number of children, the nature of their medical conditions, the nature of the family situations, and the main difficulties faced by these families. A key objective is that the new research would examine the type and extent of non-medical costs for families caring for their children and therefore serve to increase the knowledge about these costs and signpost ways for additional or improved interventions.

Specific shortfalls in services and funding supports can be identified and addressed suitably when examined against the findings of this new national research.

2. **Government support for families of children with life-limiting conditions with a new grant.**

The strain on families caring for a child with a life-limiting condition is often intolerable. The additional financial costs plus the hardship of reduced income creates stress. These families are already trying to cope with the emotional and psychological stress of caring for their child and should not have to deal with the additional financial stresses. In many cases the available government supports fall well short of what is needed to restore lost income and to pay additional costs, but in addition the current supports are generic and eligibility criteria can make it difficult to access them in a timely way. The applications processes are slow, often difficult and put further stress on families.

Stress on families would be reduced significantly with a single assessment process for government financial support for families caring for a child with life limiting conditions. This should provide for the additional costs to families, including non-medical costs such as travel and subsistence, and provide compensation for the loss of income from leaving work to provide care.

There is a need for a new ‘looking after a child with life limiting illness’ grant for those families who find themselves with a child in this situation. The proposed new grant would be operated by the HSE with a straightforward application process. Ideally, it would be a simple flat rate per month from HSE that would remove the large and untimely distress, with a very simple application process and decisions (e.g. a tick box from a paediatrician or some such) that springs into action seamlessly. It is critical that the application time period is as short as possible, i.e. weeks rather than months, to help the families during their time of crisis. Based on the non-medical costs identified in this report, a ‘looking after a child with life limiting illness’ grant ranging up to €800 per month, with a quick turnaround, is proposed.

One option would be to ask a charity, such as Cliona’s Foundation, to operate the new grant scheme, perhaps as a pilot scheme initially. Charities like Cliona’s have direct experience in working with these families in these situations and this experience will ensure a fast and efficient establishment and operation of the new grant service.

3. The future role for Cliona’s Foundation and other charities.

Cliona’s Foundation has made a huge contribution with limited resources, with supports that are targeted to those with needs that are not adequately met by government welfare payments and supports. The research here is showing that it has been able to close only a small part of the funding gap experienced by families, but has been particularly effective in meeting needs that are specific to individual families, and ones that can be difficult to anticipate. In addition it has been able to move quickly to provide support at a time of maximum stress to families, and before the full range of government support has been provided.

Unless a substantial part of the government support (recommendation no. 2 here) for families with children with life limiting conditions is channelled through charities, they will continue to meet only a small, but important part of the overall need. **They should focus on providing support in very flexible ways, focussed on meeting the varied and urgent needs of families, often in the early period following diagnosis of the life limiting condition.**

They will often be the best mechanism to support families who are faced with high and unexpected costs of travel and subsistence while supporting a child who is undergoing treatment. For example, Cliona’s could develop partnerships with providers of a range of goods and services such as accommodation, fuel, food & beverage, insurance companies etc., and use its delivery systems to give assistance to families in a timely manner. Cliona’s can help the families receive the right mix of assistance and support, e.g. to help them when they are travelling back & forth to hospital with their seriously sick child. These tailored support services will be designed to be complementary to the proposed new grant above and the other public supports available.

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Appendix 1

Categories of life-limiting conditions in children {Together for Short Lives, 2015}

CATEGORY 1.

Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails. Children in long-term remission or following successful curative treatment are not included. (Example: cancer; irreversible organ failure of heart or kidneys)

CATEGORY 2.

Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. (Example: cystic fibrosis; Duchenne Muscular Dystrophy)

CATEGORY 3.

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (Example: Batten's Disease, mucopolysaccharidoses)

CATEGORY 4.

Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (Example: severe cerebral palsy; multiple disabilities such as brain or spinal cord insult; high risk of an unpredictable life-threatening event or episode).



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