

SUPPORTING FAMILIES WITH CHILDREN IN HOSPITAL  
ON THE ISLAND OF IRELAND

# The Financial Reality of Having a Child in Hospital



The findings in this report were presented at the **Working Together for Families In Hospital** Virtual Conference - 11 May 2022

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Children's Heartbeat Trust and Children in Hospital Ireland



# Introduction

When a child requires prolonged or frequent hospital care, it places a significant burden on the physical, mental, and financial wellbeing of the entire family unit. There are limited supports available for families during this intensely challenging time. Parents with a child in hospital incur significant additional costs, including increased spending on travel, accommodation, and food. Further expenses include additional phone and technology costs, as well as spending more on clothing and laundry services.

There are also new costs associated with caring for siblings, including paying for additional childcare and entertainment. **Mental health supports for parents and siblings are another hidden cost, with research indicating significant demand for services from this cohort.**

Parents not only wish to but are now required to be **almost constantly present** with their child in hospital and form a key part of the child's care team. This restricts their ability to participate in paid employment, compounding the financial difficulties they experience.

The non-medical financial costs experienced by parents with children in hospital weakens the financial stability of the family unit, with adverse consequences for the rights and wellbeing of the sick child, their parents, and their siblings.



## The Rights of the Child

As affirmed by the United Nations Convention on the Rights of the Child, children have specific guaranteed rights. These rights do not change or cannot be diluted because a child is sick. Equally, the rights, responsibilities, and duties of parents, as the primary caregiver, should not be diminished.

The best interests of the child must be a primary consideration for state institutions when taking any action which impacts on children – when conflicting choices are available, the state is obliged to opt for the approach which best promotes the interests of the child.

The UN Committee on the Rights of the Child has recognised the important role of parents, as the primary caregiver and as a key advocate for the rights of the child. The Committee

has called for increased support for families through the provision of financial assistance and mental health supports for parents and siblings.

The European Association for Children in Hospital (EACH) Charter identifies specific supports which should be provided for parents, including paid parental leave, free hospital accommodation, and that they should not be negatively impacted financially when their child is in hospital.

Child Rights

**The best interests of the child must be a primary consideration.**



# Stress

How families manage the stress of having a child in hospital is determined by several factors including the quality of emotional and practical support, and the degree of financial burden. It is not without reason that the expression "when a child is ill, the whole family is ill" exists. When a parent is distressed this stress can be passed onto the child, often non-verbally. Clinical observations indicate that high levels of parental stress can sometimes impede recovery and development. The added stress of financial difficulties due to the cost of having a child in hospital can take stress to an unbearable level with family wide consequences.

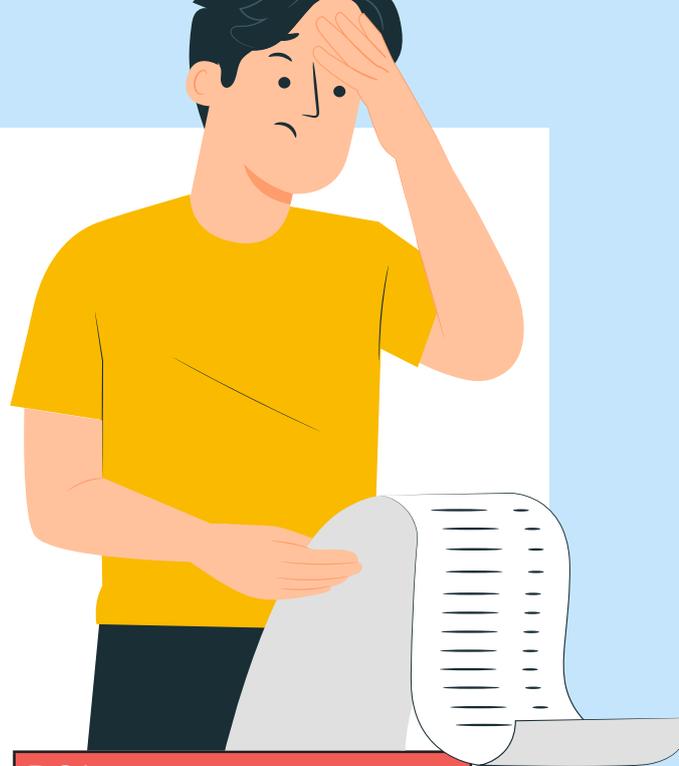
Research shows that a caring, responsive adult is the most effective mediator of stress in a child. Parents with a child in hospital are pressurized and sometimes so anxious that they struggle to respond in ways that they would normally choose. Quite simply, they are often burnt out. In addition to any siblings, the child in hospital is likely to benefit exponentially from parental stress being reduced in any way. Reducing the financial burden is one such way. These children deserve no less.

**On top of all the other challenges that come with having a child in hospital, adding financial pressure can push a parent towards toxic stress.**

An illustration of a man in a red sweater and blue shirt, looking stressed and struggling to carry two large, dark grey circular weights on his shoulders. Each weight contains stacks of gold coins and two coins with the pound (£) and euro (€) symbols. A black banner with the text 'FINANCIAL PRESSURE' in white capital letters is stretched across the weights. The background is a solid yellow color.

**FINANCIAL PRESSURE**

# Supports for parents on the island of Ireland



## GOVERNMENT SUPPORTS

Across the island, the financial supports available from government bodies are limited, with significant challenges faced by parents attempting to access them. There can be long waiting periods for applications to be processed. Furthermore, the entitlement to these payments can be removed in some cases when a child requires a prolonged stay. The reason stated for the removal of payments is the belief that it is the hospital, not the parents, who incurs the financial cost of caring for the child. This fails to recognise the reality that parents are incurring significant additional costs specifically due to their child being in hospital.

These payments are not suitable for responding to the emergency situation that parents find themselves in. The welfare system in either jurisdiction is not adequately equipped to respond effectively to the unique needs of parents with a child in hospital.

### ROI

Carer's Allowance/Benefit
Domiciliary Care Allowance
Incapacitated Child Tax Credit

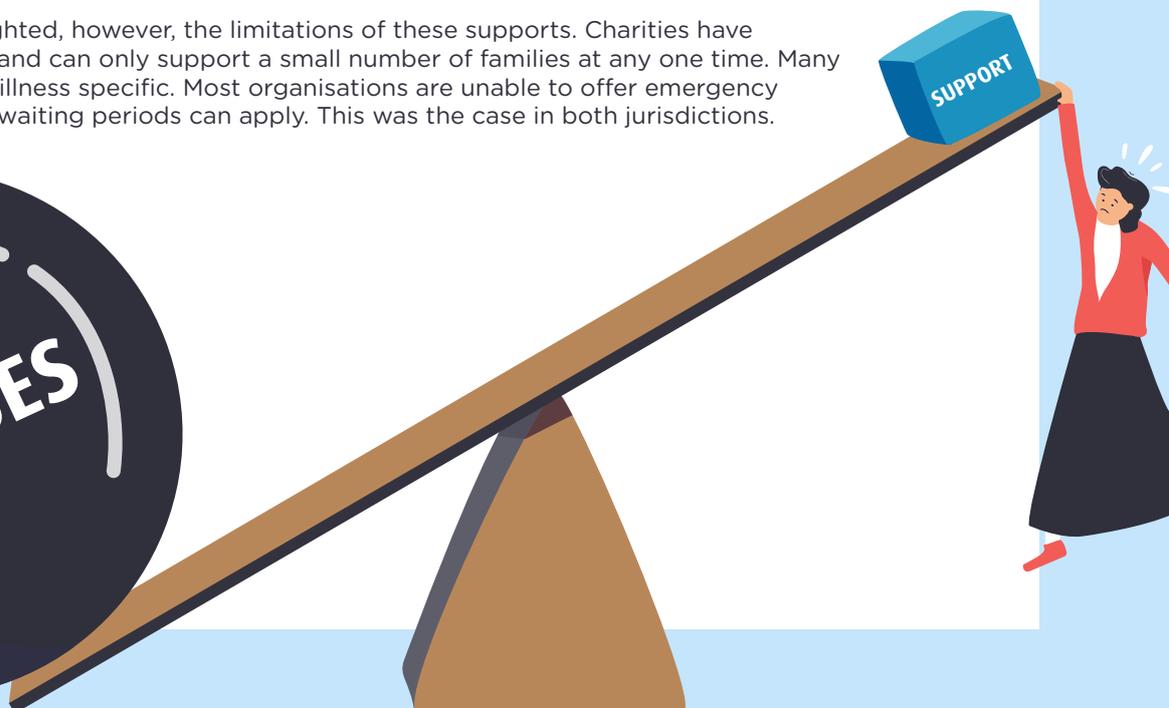
### NI

Disability Living Allowance (DLA)
Carer's Allowance
Universal Credit

## CHARITABLE SUPPORTS

Charities have an important role to play in supporting parents. As part of this report, a survey of childhood illness organisations was carried out. A range of assistance is provided, including financial supports, accommodation near the hospital, access to specific equipment and the provision of counselling and other family support services.

The survey highlighted, however, the limitations of these supports. Charities have limited resources and can only support a small number of families at any one time. Many supports are also illness specific. Most organisations are unable to offer emergency funding and long waiting periods can apply. This was the case in both jurisdictions.



# Approaches to supporting parents in other jurisdictions



Several European countries have made significant steps to financially support parents with children in hospital. According to a survey carried out by EACH, parents in 12 European countries are legally entitled to some form of paid parental leave when their child is in hospital. This is generally funded by the state through the social insurance system.

In Portugal, parents on leave can continue to receive up to 65% of their salary. For those with a child in hospital or who have chronic conditions there is no time limit on the paid leave entitlement. In Finland, 70% of a parent's salary is paid for up to 60 days, with a similar level of support offered in the Netherlands. Despite these supports, responses to a 2022 survey carried out by CIH indicate that parents in these countries are still negatively impacted financially by the same non-medical costs as families on the island of Ireland.

On the island of Ireland, parents do not have a legal entitlement to paid leave and can only access it at the discretion of their employer.

In 2021, the Scottish government launched the **Young Patients Family Fund**. The fund provides financial support for the families of inpatients from birth up to the age of 18 and covers costs such as food, travel and overnight accommodation where necessary. Claims can be made on a weekly basis when a child is in hospital or for up to three months after discharge.

**In Portugal, parents on leave can continue to receive up to 65% of their salary.**

**In Finland, 70% of a parent's salary is paid for up to 60 days.**



**IN 2021, THE SCOTTISH GOVERNMENT LAUNCHED THE YOUNG PATIENTS FAMILY FUND.**

## All-Island Recommendations

- **Develop a scheme to assist families with the additional costs and the loss of income arising from the hospital care of a child**
- **Provide paid parental leave specifically for parents whose child requires prolonged and/or frequent hospital care**
- **Invest in counselling and mental health supports for children in hospital, their parents, and their siblings throughout their illness journey**

# SUPPORTING FAMILIES WITH CHILDREN IN HOSPITAL ON THE ISLAND OF IRELAND

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