

What needs to be done?

Recommendations



On the Front Line...

- Abolish parking charges – in the short term, establish consistency across the country.
- Subsidise food – as standard across all children's hospitals and paediatric wards.
- Negotiate with private contractors of hospital canteens to ensure that the service meets the needs of families in terms of opening hours and flexibility in regard to these.
- Abolish charges for hospital-provided accommodation for parents
- Provide better access to mental health and counselling support for parents and siblings of children in hospital.
- Provide greater funding for hospital discretionary funds, which are an invaluable support to parents in a crisis situation.
- Ensure improved systems of information for parents so that they can be aware of services and supports available within the hospital and from statutory authorities
- Make provision for a Citizens Information or DEASP information stand, with a staff member, to be available in children's hospitals on a daily basis (in regional hospitals, at least weekly)

Structured Support...

- Introduce a non means-tested, recognised scheme of assistance towards the non-medical cost of having a child in hospital. This would provide help with costs such as:
 - ▷ Food
 - ▷ Transport
 - ▷ Accommodation
 - ▷ Childcare for other children
 - ▷ Loss of earnings
- The Domiciliary Care Allowance system in place to assist parents of children in need of long-term care at home is not suitable for supporting parents with the costs of having a child in hospital.

This payment:

- ▷ Is not designed to support parents who have a child in hospital
- ▷ Cannot be accessed until there has been a diagnosis – this could take a number of years
- ▷ Cannot be paid until the child is at home. A child could spend six months or more in hospital before discharge during which there is no entitlement to a payment.

In addition, when the child who is receiving DCA is admitted to hospital, the allowance (and other associated supports) is cut off after 13 weeks, despite the fact that parents still need to care for the child in hospital every day.

- State should oblige employers to offer more paid leave to parents of children in hospital. This would assist parents in taking an active role in their child's care.



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Childhood Illness

Financial Stress

Financial Impact Survey 2019:
Tackling the hidden costs of childhood illness

Summary of Findings

Children in Hospital Ireland

Methodology

Research conducted between July and December 2019

- Desk Research and Policy Analysis
- On line Survey – quantitative and qualitative questions
- Interviews – parents, NGO professionals, social workers in three hospitals



Response

- Over 300 surveys returned
- Interviews with six social workers, seven NGO staff and ten parents

What the Policies Say

Charter of the European Association for Children in Hospital Ireland
Article 3(2) states that 'Parents should not need to incur additional costs or suffer loss of income'

UN Convention on the Rights of the Child

Article 3 states that, in all actions taken by public and private authorities, 'the best interests of the child shall be a primary consideration'. Article 18 says that families are entitled to state support in fulfilling their duties towards their children

Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People, 2014–2020

This Policy Framework says that the state intends to ensure that parents are 'equipped and supported to raise their families, to play their role as their children's primary carers, to promote the best possible outcomes for their children and to meet all challenges that may arise'.

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Findings

Travel

- ▷ 89% of families travelled by private car to hospital. Most cited the reason for this as the **difficulty of bringing a sick child on public transport**. For some, the journey to hospital involved three hours travelling each way.

Parking

- ▷ While not the biggest financial concern, it is **one of the biggest sources of frustration**.
- ▷ **Discrepancies in charges between different hospitals** – varying concessions which some parents may not even know about or know how to access.

Accommodation

- ▷ **94%** of parents have stayed overnight.
- ▷ Charges for hospital-provided **parents' accommodation vary from €18 to €30 per night**.
- ▷ Charges for accommodation provided by voluntary groups range from €0 to €10 per night. However, there is only a **limited supply** of such accommodation.
- ▷ **10%** of families had to **stay at a hotel**.
- ▷ Only one parent can stay in a child's room in a hospital, the other parent would have to find accommodation
- ▷ **Parents cannot stay in room if child is in intensive care**, which means they must find accommodation elsewhere.

Food

- ▷ An average of €47 spent by a parent for one day in hospital.
- ▷ Hospital canteens do not have flexible opening hours.
- ▷ Parents of children in isolation cannot use shared kitchen areas – increasing their costs.

Childcare Costs

- ▷ **81%** of respondents had **other children** at home.
- ▷ 28% of parents **relied on paid childminding/crèche** services for children at home.
- ▷ 25% relied on their partner to mind other children (which meant that this parent could not be readily available to support the parent staying with the child the hospital).
- ▷ 34% relied on other family members to mind other children.
- ▷ **Additional costs for other children** of, on average, €41 per week as a result of having a child in hospital (outings and activities).

Mental Health Support

- ▷ 21% of parents had **sought mental health support** as a result of having a child in hospital.
- ▷ 24% said that they **could not afford to access counseling** or similar form of support.

Impact on Family Income

- ▷ 78% had **lost income** as a result of having a child in hospital.
- ▷ 19% said they had **given up work** to look after their child.
- ▷ 11% had **reduced their hours**.
- ▷ 13% were taking a **temporary leave of absence**.
- ▷ 16% had used up much or all of their **annual leave**.

Financial Support

Statutory Support Schemes

- ▷ Those on **higher incomes were more likely** to successfully access the **non means-tested schemes**
- ▷ 51% found applying for **state support was 'very difficult'**. Issues included:
 - Complex forms.
 - Long wait times.
 - Poor communication from Department of Employment and Social Protection
 - Perceived inadequacies in the means test.
 - Pressure of dealing with sick child leaves little room for dealing with technical forms.
- ▷ The difficulties varied according to geographic region.

Charitable Support

- ▷ Those that did access support from a patient group found it **invaluable at a time of crisis**. This charitable support included:
 - Free or subsidised accommodation
 - Financial once off grant for expenses
 - Meal vouchers

How Families Covered the Costs

- ▷ 24% **borrowed money** from friends or family to pay hospital-related bills.
- ▷ 13% took out **loans**.
- ▷ 17% incurred debt through **overdrafts and using credit cards**.
- ▷ 37% used their **personal savings** to deal with their expenses.



Impact on Families



58% said they had seen a 'strong negative impact' or an 'extreme negative impact' on their financial well-being

Higher levels of impact recorded in those in lower-income brackets

71% worried 'fairly often' or 'very often' about their finances

Being so far from Dublin and on my own, means that I don't see my [other] kids for weeks

The €60 each per week it would cost [for counselling] is not realistic for us at this time

It can cost parents €108 per day in non-medical costs

'[Parents are] already paying for their place back home. They're paying for accommodation in Dublin and mortgage or rent back home ... We're asking families to live in two places' (Social Worker)

'You kind of know [your child] is getting the help they need and that you're doing everything to get them sorted out medically. So because of that, in a way, the money is the biggest stress. It's the money that has you thinking 'how am I going to do this, how am I going to do that'... your part in it is making sure the money is there for them to get what they need ... the more difficult thing to manage is making sure we have the money day to day to look after all the other costs we have when we're up at the hospital'. (Parent)

[My partner] wasn't in a good headspace; he was on high alert all the time and wasn't able to perform to the best of his ability. The stress for him of having to stay in [work] to support us when really all he wanted was to be with us. (Parent)