



Irish Cancer Society

Real Cost of Childhood and Adolescent Cancer

Research conducted by Core Research, 2021

Contents



Foreword	4
Acknowledgements	5
Introduction	6
Costs experienced by parents/guardians	8
Costs experienced by adult survivors	18
Discussion and Recommendations	20
References	24



Foreword



Cancer is devastating at any age but when a child or an adolescent is diagnosed with the disease, it throws the world off its axis. The terror and disorientation is felt not only by the immediate family, but also by their support network and the communities in which they live, work and go to school.

Survival is naturally the foremost concern of families, but it is the scale of the financial misery layered on top of such a life-changing diagnosis that is the shocking finding from the Real Cost of Childhood and Adolescent Cancer research. The financial burden of a child or adolescent being diagnosed with cancer is an almost unbearable weight on top of an already hugely heavy emotional and psychological load being borne by families.

With profound thanks to the families who shared their experiences of the financial burden they faced, this report illustrates the breadth and depth of the expenses parents incur, as well as the loss in income they experience as they drop everything to care for their sick child.

Behind each of the facts and figures from this research are real families. The testimonies from families, and the deep desire for change across the cancer community, must serve as a wake-up call that families are being let down. More structured support from diagnosis through to survivorship, or end of life, is needed.

This report builds on our knowledge in this area and shows that 8 in 10 of all parent/guardian respondents reported an average reduction in personal income of €1,280 per month. This level of income loss is hugely significant to any person no matter their stage of life but it is particularly challenging when you have a family to support.

Added to the crippling impact of income loss is the punishingly high costs associated with a childhood cancer diagnosis. Four in 5 of all parent/guardian

respondents reported an increase in costs, with the median increase being €2,250 since the child was diagnosed. These costs include medication, dietary supplements, wigs, fabric supports, dressings, play therapy, and mental health support.

Many of these costs are felt almost immediately in out of pocket expenses, others will be felt later as families dip into savings, if they are lucky enough to have some.

For families who cannot afford to pay these increased costs, their child is forced to go without the support they so vitally need. This stark inequity between Ireland's most vulnerable needs urgent action to ensure all children and adolescents with cancer have every support they need.

Adult survivors of childhood cancers also face extra costs due to late effects of their treatment. For some, it can mean regular check-ups or purchasing and maintaining prostheses. For others it may be enhanced barriers or challenges in accessing health insurance or life assurance.

While there are some supports available from Government, the Real Cost of Childhood and Adolescent Cancer report and parents themselves are telling us that it is simply not enough. The time for change is now.

The Irish Cancer Society will continue to push for a more compassionate and supportive approach across relevant policy areas, so that families can focus on their much-loved child and not on how to pay the next bill.

The Irish Cancer Society is also determined to do more through our own services. For instance, our free Volunteer Driving Service will shortly start to transport children and adolescents with cancer to treatment and this will help reduce costs for families. We will increase awareness and uptake of our free counselling and play therapy, and make it available to any family member who needs it.

We will improve access to the Irish Cancer Society's Children's Fund so more families benefit from our financial support.

We will also work directly with families to help them to access the supports and services they need.

The scale of the problem illustrated in this report highlights the need for urgent solutions.

The Irish Cancer Society is hopeful that by working in collaboration with all stakeholders and by taking this first step of publishing the Real Cost of Childhood and Adolescent Cancer, that the awful financial reality faced by families across the country today, won't be the reality for families in the future.

Averil Power.

Acknowledgements

Thank you to all the people who responded to the survey and who participated in the online community.

We would also like to acknowledge the support of the Steering Committee, which included the Childhood Cancer Foundation, CanCare4Living, CanTeen, Siobhan Broderick and Dr Aifric O'Kane (Senior Clinical Psychologist, Paediatric Psychology) in reviewing the survey text, information sheets and reviewing the findings and recommendations of the research.

We would also like to thank all organisations and individuals who shared information about the survey online.

Introduction

Each year, over 200 children and adolescents (up to the age of 19) are diagnosed with cancer. Cancer has a devastating and wide ranging impact on children, adolescents and their families. Some of these impacts extend to adulthood.

The devastating impacts of cancer go beyond the initial diagnosis, treatment and health impacts. We know that cancer also has a profound effect on a person and their family's financial health and wellbeing. The Irish Cancer Society and Kantar looked into the [Real Cost of Cancer in 2019](#). Our research demonstrated that people affected by cancer can face a reduced income and increased medical costs, additional household bills, day-to-day living expenses, parking charges, etc.¹

Working alongside Core Research, the Irish Cancer Society wanted to understand the Real Cost of Childhood and Adolescent (CA) Cancer and the unmet needs of parents/guardians of children under the age of 18 with cancer, and of adult survivors of CA cancer.

The following document outlines the costs of cancer as experienced by parents/guardians and adult survivors.

The Research

The Real Cost of Childhood and Adolescent research took place in two parts:

- Survey: The survey was designed to capture responses from parents/guardians of a child with cancer, and from adult survivors of childhood cancer. The purpose of the survey was to measure the main financial impacts of a cancer diagnosis.

- Online qualitative community: The online community was designed to gain insight into the lived experience of and challenges faced by parents/guardians and adult survivors.

	Survey	Online Community
	111 respondents Respondents answered questions about the costs of a childhood or adolescent cancer diagnosis.	18 participants Participants engaged in a series of tasks and group discussions on their experience.
Parent/guardian of a child under 18 who is currently receiving treatment for cancer	36	5
Parent/guardian of a child (who was under the age of 18 at the time) who has finished cancer treatment since January 2015	64	11
Adult survivors	11	2



Costs experienced by parents/guardians

Even before taking costs associated with treatment and care into account, most parents report giving up work, changing their working status, or taking unpaid leave in order to care for their child throughout their treatment. The loss of income increases the challenges in meeting expenses incurred throughout the child's treatment. Often, this can leave families facing an uncertain financial future, and can result in stress and worry for parents.

Based on the survey responses, the average length of time a child has been in treatment (current and past) is 2 years and 4 months.

Income reduces as a result of a child's diagnosis

A childhood or adolescent cancer diagnosis has a clear impact on parents' working status. 8 in 10 parents/guardians surveyed were working at the time of their child's diagnosis. As a result of their child's diagnosis, 2 in 3 respondents stated that their working status changed. Of those, 7 in 10 responded that they are now looking after the family home compared to before their child's diagnosis.

As a result of their child's diagnosis, 2 in 5 respondents reported they took 'unpaid leave', whilst 1 in 4 had 'certified sick leave.'

8 in 10 of all parent/guardian respondents reported a reduction in personal income as a result of their child's diagnosis.

Parents/guardians reported a median personal income loss of €1,000 per month, with an average loss of €1,280*.



"For us, the major impact was not the expenses, it was the loss of income."

"The other expense is having to give up your job and while carer's benefits help it's not enough."

"I had to give up my job, which left us with my husband as the only income. Thankfully, he managed to keep his job only taking holidays when needed for hospital stays and appointments."

"After taking leave I ended up taking redundancy while my daughter was in treatment. I went back to work when she had recovered but I'm at a significantly reduced salary (-50%)."

"It's had a huge impact even though my daughter is finished treatment. I am only working very few hours. We have essentially being reduced to a one income family."

"I wasn't working and my husband had to take unpaid leave from work when our son was diagnosed."

Parents/guardians experience additional expenses

Medical costs represent the biggest overall expense for families dealing with a cancer diagnosis. Costs include paying for medication, counselling appointments and play therapy sessions. While some supports are available in these areas (e.g. specific charity funding, medical cards), parents/guardians mentioned the need for greater access to supports than is provided. Specifically, people need greater access to affordable and accessible mental health supports.

Overall, 4 in 5 of all parent/guardian respondents reported an **increase in costs** related to additional expenses, including medications, dietary supplements, wigs/head pieces, fabric supports/dressings, play therapy, and mental health supports. For these respondents, the median increase in costs for this group was €2,250 and the average costs were €4,178. These costs do not include costs associated with accessing appointments for their child's treatment, such as transport, car parking, etc.



* This is after data had been cleaned. Overall, when not controlling for outliers, parents/guardians reported a median personal income loss of €1,150 per month, with an average loss of €3,670.

Medication is a significant expense

To gain perspective on the breadth of expenditure since the time of diagnosis, the following table provides information based on responses from people whose child had **finished** cancer treatment (n=64).

	Proportion of respondents	Average	Median
Over-the-counter medication	44%	€397	€450
Prescription medication	38%	€754	€500
Specified dietary supplements	27%	€659	€500
Physiotherapy or other specialist medical care	25%	€997	€500
GP visits	14%	€362	€500
Hospital stays	13%	€1,141	€1,250
Specialist dressings, etc.	11%	€287	€100
Excess on private health insurance premium	9%	€790	€625
Other medical care	9%	€970	€600
Consultant's visits	6%	€675	€700
Hospital charges – inpatient charges, emergency department charges	3%	€400	€400
None of the above	33%		

All children under the age of 18 who have been diagnosed with cancer in the last 5 years are eligible for a medical card.ⁱⁱ The medical card entitles these children and adolescents to free inpatient (in public hospitals), outpatient and GP services, as well as free prescription drugs (although a prescription charge applies up to a maximum of €15 per month).ⁱⁱⁱ Parents/guardians who responded to the survey highlighted many upfront payments as a result of their child's cancer diagnosis. Furthermore, some additional health care expenses for

a child under the age of 18, for which people are out of pocket initially, can be claimed back through tax relief.^{iv}



"Thank god we have a medical card as we would not manage paying medicines."

One-off costs, and medical and mental health expenses integral to a child's care place a huge burden on families

Before a diagnosis there are many costs that families would never consider are associated with their child having cancer. However, quickly these very necessary

expenses become apparent. It includes one-off costs such as wigs, hair pieces and head coverings as children face hair loss as a result of treatment, fabric supports, as well as mental health supports like play therapy which allow children to "play out" their thoughts, feelings and problems just as in certain types of adult therapy.

The following table gives an overview of expenses incurred by people whose child has **finished** cancer treatment (n=64).

	Proportion of respondents	Average	Median
Wigs, hair pieces, head coverings, etc	34%	€388	€150
Play therapy	22%	€1,180	€800
Fabric supports, dressings, etc.	20%	€197	€100
Other one-off costs	20%	€2,595	€2,000
Extra academic tuition for your child diagnosed with cancer	16%	€840	€700
Modification in home, for example, a ramp; downstairs bathroom	8%	€9,000	€3,000
Specialist equipment, (e.g. wheelchair)	6%	€895	€540
Special needs assistant for your child diagnosed with cancer	3%	€500	€500
None of these	33%	-	-

Almost **1 in 4** of all parents/guardians reported having incurred costs for play therapy since their child's diagnosis.

The high cost of play therapy may serve as a barrier to accessing this much needed support. Some families reported that they received some support from charities in accessing play therapy but that once the allocated sessions had been used they had to consider paying out of pocket. One parent commented that the sessions were 'essential to our [child's] and family's health & survival.'

"They needed help of a play therapist which was 50 euro each visit and once a week... we could see it was helping them deal with life a bit better but it was such a worry as how we were going to keep paying for it."

"We could access everything but what we were offered for free wasn't anywhere near enough. My youngest child needed 20 sessions of play therapy."

Mental health supports are necessary but costly

Some parents/guardians explained that not only did their child need support, but the wider family unit also had a need to access mental health support. In the online community, many participants articulated the difficulty in accessing these supports communicating that even if they had some access to free sessions, more were generally needed. Based on the research, the average cost of mental health supports range from €50-70 per session.

Roughly **2 in 5** of all survey respondents reported that they **spent money to access mental health/psychological support**.

The following table gives an overview of expenses incurred by parents/guardians.

	Average	Median
Child is currently receiving treatment for cancer	€1,236	€1,000
Child has finished cancer treatment	€1,769	€1,250

"I believe that parents and children should be given access to mental health services as a priority. With the costs of everything, it isn't something everyone can afford."

"Our biggest expense was counselling - the whole family needed counselling and we had to pay for most of it ourselves. At one stage we were paying €180 a week as 3 people were in counselling at the same time. so €720 a month. We had no idea our family would need so much counselling."

Costs associated with attending appointments are a significant burden for families

Almost all families experienced costs related to getting to and from appointments. These costs include transportation, parking, eating out, accommodation, and items such as tolls and car servicing, etc.

Travel emerged as key non-medical related expenses. These costs added up faster than anticipated with multiple trips and a lot of time spent away from home in order to access treatment. As these costs build up rapidly, many noted that they significantly added to the financial burden associated with diagnosis.

2 in 3 parents/guardians reported they had to travel over 30 kilometres to the Comprehensive Care Centre; roughly half lived further than 30 kilometres from their child's nearest Shared Care Centre.

For almost all parents/guardians who took the survey, there were monthly costs associated with attending the Comprehensive Cancer Centre and/or Shared Care Centres. These costs include transport, parking charges, food, accommodation, other (e.g. tolls, car servicing, etc.). The median cost per month is €398, while the average is €989.

Costs in context

Using the median monthly travel-related costs reported by all parents/guardians, over the course of a year a person could spend €4,776 in costs associated with attending their child's appointments.



The table below represents responses from all 100 parents/guardians who participated in the survey and represent monthly costs.

	Child is currently receiving treatment for cancer	Average	Median	Child has finished receiving treatment	Average	Median
Travel costs going to and from appointments e.g. petrol, fares, taxis, etc	94%	€279	€120	97%	€463	€200
Parking costs while at appointments, etc	89%	€66	€30	91%	€201	€50
Cost of eating out while at appointments	94%	€118	€70	92%	€365	€200
Accommodation costs	28%	€88	€90	42%	€503	€175
Other travel-related costs associated with appointments (tolls, car servicing etc.)	6%	€202	€202	19%	€458	€180
None of these	0%	-	-	3%	-	-



"To this day we are still attending appointments in Dublin, my child will need medical care for the rest of their life. No additional costs are met with regard to travel. We never stayed over whilst my child was on treatment because we couldn't afford it. I used to sleep in the car park with my child for 20mins so I could make the journey home. Once treatment is finished you are literally thrown out of the system."

"I feel tax relief of 100% on travel would be a big help and if this was applied retrospectively, e.g. to the last seven years [...] it would be a big help."

1 in 5 survey respondents reported travelling abroad for their child's active treatment. Controlling for outliers, the average costs reported are €3,175 with median costs of €2,500. Some financial support came from private and charity fundraising in addition to the Travel Abroad Scheme.

Childcare, too, was reported to be a burden for parents, both financially and emotionally. 35% of respondents reported spending more on childcare for their children while a child was being treated for cancer. In the online community, parents/guardians described the effect on their wellbeing, often feeling guilty that they think they are neglecting their other children.

Parents/guardians have reported a number of upfront costs, which they have to bear related to their child's care and treatment. There are currently some provisions for parents/guardians of children with cancer to claim tax relief on costs associated with bringing a child to and from care, e.g. travel to bring your child to hospital, travel to visit your child in hospital, provided the visit is necessary, overnight accommodation and travelling abroad).⁹ Related to travel to hospitals, based on the 2019 rate, parents/guardians can claim 18c per kilometre. Assuming a 60 kilometre round-trip, based on respondents' reported proximity to a Comprehensive Cancer Centre or Shared Care Centre, a person can expect approximately €10.80 in tax relief. Similarly, parents/guardians can apply for some tax relief on accommodation costs. Car parking is not subject to such relief.



"Parking, this is probably the toughest thing. To get parking in the hospital you had to be there before 8am and then the parking is just so expensive. Think we spent €120 a month, petrol €150 a month."

"Our other 3 children needed someone else to pick them up and feed them after school which was very tough on them."

"We stayed in Crumlin for about a month in total so that involved childcare for kids and my husband driving up and down each day to visit."

The majority of people had access to some form of social entitlements

While their child is in treatment, some parents/guardians were able to avail of some benefits and entitlements.

In responding to the survey, over 9 in 10 parents/guardians who received information on benefits and entitlements got this information from a social worker at a hospital/shared care centre.

Approximately **8 in 10** parents/guardians had access to **Domiciliary Care Allowance**. Approximately **6 in 10** parents/guardians reported their child had a **medical card**. Fewer people reported receiving other benefits and entitlements such as Carer's Benefit (38%), Carer's Allowance (36%) or funding from a charity (28%).

However, some parents/guardians stated in the online community that they were unaware of the supports available to them through charitable organisations or else felt too ashamed to ask for help.



" [...] carers allowance and Domiciliary Allowance was such a life saver for us alongside private fundraising our family did to help us survive financially."

"I was the main earner in the household and had to give up my job overnight. My husband's income covers the mortgage and bills. The social welfare payments cover childcare 2 days per week for my other child and household food."

Some parents had to rely on loans or fundraising

To meet costs following their child's diagnosis, almost 3 in 10 of all parent/guardian respondents had to organise some form of fundraising activity to cover medical and non-medical expenses associated with their child's treatment. 1 in 5 took out a personal loan to meet additional costs.

Parents met some unexpected expenses in addition to other financial burdens

In addition to the already significant financial requirements levied on families, other unforeseen costs had to be met. Children who undergo treatment can experience weight fluctuations, meaning they require new clothing as well as clothing altered to suit Hickman Lines. An unexpected amount of money is also spent on support clothing and hospital clothes such as pyjamas.

Additional food costs arose due to some children craving particular foods as well as their nutritional requirements once they return home. Parents/guardians, too, must eat while away from home and were unaware that they would not be given food in hospitals and would have to spend additional money on their sustenance.

Furthermore, families experience increased data and mobile phone bills, particularly as WiFi was reported as unreliable in hospitals. This is in part due to children using online entertainment resources in hospital (due to lack of energy), as well as parents/guardians keeping in touch with family at home. Many were unaware that phone data is generally capped and not unlimited, creating the need for purchasing additional data.

“Due to weight loss and then weight gain we were constantly buying clothes. We probably spent €200 the first month and €100 a month after that.”

“Food bill doubled due to trying to eat better quality and fresh food also meeting needs of cravings and eating in hospital and convenience such as take away etc.”

“Unexpected expense was mobile WiFi - the WiFi in the hospital wasn't reliable so we bought portable WiFi. That was €30 and then spending €30 a month”

“Our son wanted to watch Netflix all the time and we were surprised to learn that unlimited data is actually limited. My husband had to buy extra data every week at one point.”

Cancer brings significant opportunity costs

People will prioritise the care of their child with cancer. As income drops and other costs increase, families must make sacrifices or alter their plans. For instance, many have had to shelve long-term financial plans due to the need to dip into savings, halt pension contributions etc. in order to afford the costs associated with their child's diagnosis.

“Digging into savings was a necessity but gives a more unstable sense of security for the future.”

“My fear is that if we had to deal with another situation like this our savings are depleted so we would be in trouble.”

“I'm certain that my pension has been affected due to no and reduced contributions over the last few years. My income level will take time to reestablish if ever. We spent our savings so this takes from that feeling of security.”

“No long term financial plan - I live one day at a time, week to week, constantly budgeting... No retirement plan, No savings - all used up, No prospect of same in the near future - fear, anxiety, stress, not been able to sleep at night relating to same.”

People had to try to meet their major fixed expenses, too, such as bills and mortgages, deferring payments in some situations.

“We tried to negotiate with our mortgage company who added to our stress, we reduced our mortgage repayments, feel into arrears, drained all our savings...”

“We still had to take the decision to pay interest only on our mortgage for 6 months. Dealing with the bank was extremely stressful at an already stressful time.”

“Difficulty paying bills - having to constantly budget, bills mounting up - ongoing battle - is so draining [...]. I worry too much about finances & making ends meet!”

There is a massive impact on other children in the household too, particularly as they had to stop extra-curricular activities.

“Normal life just came to a stop after our [child's] diagnosis... things like our other kid's extra curricular activities stopped.”

“I feel guilty because my children paid the price with the sacrifices they had to make. We could no longer afford gymnastics, basketball or dancing, so their life changed drastically...”

Some reported having to use savings for their children's higher education on meeting more immediate expenses, which has led them to adjust their plans.

“We had to start from scratch again for college funds... I'm back working full time, something I had never planned. Emotionally, we are holding our breaths, waiting for the what if's”

“Our eldest daughter is already talking about college she wants to go into medicine we are worried about how we can do it, We no longer have savings we live week to week on [other parent's] wage...”

Costs experienced by adult survivors

Eleven adult survivors responded to the survey and two participated in the online community. Given the small number of participants in the research overall, the findings are summarised thematically. The findings below are not representative of the entire community of adult survivors, but rather demonstrate some of the lived experience of some adults who had cancer while under the age of 18. It is important to acknowledge that each experience is unique. For instance, some will have additional medical needs throughout their life, while others will not.

For adult survivors there are a range of material and opportunity costs associated with their cancer diagnosis. Some reported ongoing costs related to attending appointments or in purchasing/maintaining prosthetics. Others reported little lasting financial impact. The main issues raised by this group are:

- Ongoing medical costs
- Ongoing health impacts
- Impact on access to finance and premiums
- Effects on career or education

Treatment for childhood/adolescent cancer can lead to late effects which require additional care in adulthood. Some adult survivor participants reported ongoing medical costs associated with their diagnosis, including attending appointments or paying for prostheses. Another participant mentioned that as a result of the treatment they were given as a child, they may face the risk of added medical complications. This is something they will need to be monitored for.

“*Cost of maintenance of prosthetic is annual fee and a new prosthetic costs 1000 euro lasts between 3 and 10 years.*”

“I have annual appointments for check-ups and this results in the cost of getting bloods done with my GP the week before the appointment, time off work to get the bloods done, and for the actual consultation. The last few years I have required onward referrals, for further follow-up with other consultants and this has meant additional costs (fuel, parking, etc) and time out of work for each additional appointment.”

“The type of radiotherapy that was used when I received my treatment [...] has created some long term medical issues, namely damaged arteries.”

Some survivors discussed challenges associated with accessing financial services and supports, or in trying to manage their higher premiums for insurance, for instance. Others reported increased difficulty in accessing life assurance or taking out personal loans. These experiences appeared to contribute to a sense of stress or financial insecurity for these participants.

“*I have two young children but cannot get life assurance because of my medical history.*”

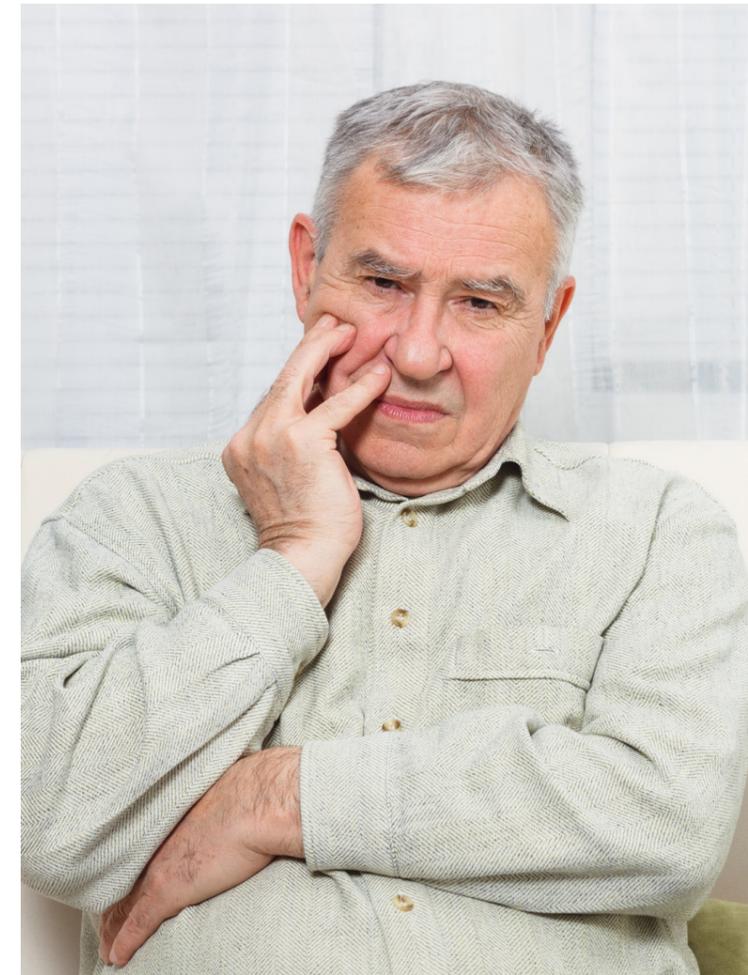
“Cost of a high level of health insurance so to cover the cost of being able to access private appointments with specialist if needed and getting a percentage of the cost back. I have been refused a medical card on 2 occasions.”

“I do believe survivors should be given life time medical cards to help financially. Getting loans mortgage etc. are all a little bit more complicated, but not inhibitive.”

For some adult survivors, their childhood diagnosis had lasting impacts on their career or educational prospects. For instance, not being able to attend full time education or that their ability to work and finance themselves had been a challenge. This appeared to be limiting both in terms of financial capacity as well as the ability to ‘live a normal life’.

“*My parents still provide all my care even though I’m now [of adult age]. I have just gotten my 1st job 6 weeks ago as it has been tough to find work after I graduated...*”

“Was not able to receive a full education.”



Discussion and Recommendations

Costs associated with a childhood and adolescent cancer diagnosis are burdensome, and have far reaching impacts. While the health and wellbeing of the child with cancer is the consistent focus, it is important that we do not ignore the other problems which arise as a result.

While survival rates for childhood and adolescent cancer have improved, survivors can experience health impacts due to their treatment over the course of their adult life.

Parents/guardians reported that they need a range of informational, peer and financial supports. Crucially, parents/guardians called out the need for the State to ensure that people can more easily access income replacements and allowances (for instance by removing means testing), easier access to medical cards, and other financial supports such as tax relief on travel costs.

Parent/guardians need support at a difficult time in their life, evident in the findings from this research. Families can experience financial hardship as a result of a cancer diagnosis.^{vi} Some of the financial impacts of a CA cancer diagnosis have been well documented, and the Real Cost of Childhood and Adolescent Cancer findings are consistent with a broader picture. Some of the biggest costs associated with CA cancer treatment include travel costs to and from treatment, loss of income (reduction or termination of working hours), out of pocket expenses for treatment, medication and medical supplies.^{vii} Families can face a prolonged economic hardship as a result of a CA diagnosis, and this can have impacts on their financial security, quality of life and well-being.^{viii} Self-employed parents face a loss in income, too.^{ix} Mothers/female guardians are more likely to be affected by the economic burden and/or change in employment status.^x

Adult survivors also experience adverse financial and socio-economic impacts. In research conducted in Ireland in 2018, some survivors reported that the expiry of medical card and 'employment barriers' contributed

to the residual financial burden of a CA cancer diagnosis.^{xi} Survivors of childhood cancer have expressed that practical supports, for example access to a medical card beyond 5 years following their diagnosis, could be somewhat helpful in addressing the financial burdens they face.^{xii} A 2020 report by Barrett et al. outlined that adult survivors can endure anxiety linked to their health and experience higher rates of psychological challenges,^{xiii} prescriptions for anti-depressants, and hospitalisation for mental disorder, compared to the general population.^{xiv} While these findings did not show up in the Real Cost of Childhood and Adolescent Cancer research, we recognise these as part of the diverse and often acute needs of all survivors. While the Real Cost of Childhood and Adolescent Cancer research has identified some challenging areas for adult survivors, additional research is required to understand the wider extent of a cancer diagnosis on a person's medical, material and opportunity costs in adulthood.

For the family overall, a cancer diagnosis can lead to a need to access mental health services. While the person who has been diagnosed with cancer should have access to psychological services and mental health evaluation over the course of their lifetime, so too should their family. Siblings of someone who had cancer in childhood also have unmet medical need, in part due to feeling forgotten.^{xv} Given the many decisions parents have to make while their child is in treatment, they can experience economic, occupational and sometimes marital difficulties.^{xvi} Furthermore, parents can carry fear for their child's health throughout their life.^{xvii}

Families should not have to worry about the additional financial burdens when a child has cancer. Nor should parents/guardians feel embarrassed to access supports or guilt that they feel financial stress while their child is ill.

Ireland can lead the way and set the standard for the health, socio-economic and psychological care of children/adolescents with cancer, survivors and their families. The Irish Cancer Society will take action to alleviate some of the burden on families and

survivors. We call on the Government to make similar commitments and meet our actions to support parents/guardians and adult survivors.

Recommendations for Government

Provide access to psycho-social support services as a matter of priority

- Establish and fund a CAYA specific public psycho-oncology support hub-and-spoke service, with adequate staffing capacity and infrastructure to meet needs across Ireland. The service should cover the entire cancer care pathway, from diagnosis to survivorship, and to end-of-life for those who need it. The service should also be available to parents/guardians and siblings who are impacted by a child/adolescent's cancer diagnosis.

Alleviate and reduce the medical costs for children/adolescents and adult survivors

- Abolish prescription charges for medical card holders
- Provide a lifelong medical card to survivors of childhood and adolescent cancer.
- Ensure that medical card applications for children with cancer are processed quickly, so that parents do not face high costs while waiting for a card to be issued. All cancer patients under-18 who have been diagnosed in the past five years are entitled to a medical card.

- Take action to more widely promote the eligibility of all cancer patients under 18 for a medical card. Despite cancer patients under 18 being eligible for a medical card within five years of diagnosis, uptake reported by the parents/guardians surveyed was lower than anticipated at only 6 in 10. This suggests a need for improved awareness of what is a vital lifeline for many.

Support families and survivors in meeting burdensome expenses

- Provide a dedicated grant to parents/guardians of children with cancer, or for adolescents aged 16-17 who are responsible for their own care, to cover non-medical expenses as a result of their treatment needs.
- A grant should be provided to all cancer patients to have equal access to the provision of prostheses and wigs.
- We welcome the Government's Budget 2022 decision to extend Carers' Allowance and Domiciliary Care Allowance to parents/guardians whose child is treated in hospital for up to 6 months. We call on the Government to extend entitlements for Domiciliary Care Allowance to parents/guardians of 16 and 17 year olds.

Support with transport for accessing care

- Waive car parking charges for people attending appointments related to their cancer treatment or for maintenance appointments and/or appointments related to side-effects of cancer treatment.

Actions for the Irish Cancer Society

Alleviate some of the financial burden reported by parents/guardians

- The Irish Cancer Society will immediately review its Children's Fund payment to ensure that it is easier to access and to ensure that it can better support families with the significant costs that result from a childhood cancer diagnosis.
- We will work directly with families to help them to access the supports and services they need. This will be supported by the establishment of an Irish Cancer Society nursing presence in CHI Crumlin.
- We will increase awareness and uptake of our free counselling and play therapy, and make it available to any family member who needs it.
- The Irish Cancer Society's Volunteer Driving Service will become available to children and adolescents travelling to CHI Crumlin for treatment, starting on a phased basis, and will be extended to cover Shared Care Centres around the country over the course of 2022.

Meet some of the informational and support needs

- The Irish Cancer Society will publish a booklet on the financial support available from the Irish Cancer Society and from Government.
- The Irish Cancer Society will continue to work in partnership with Children's Health Ireland to develop an on-site support for families, where they can get information, direct access to help and support, general advice from a paediatric oncology nurse and much more.

- We will increase awareness of the support to families available from oncology nurses on our Support Line 1800 200 700.
- The Irish Cancer Society facilitates [peer-to-peer](#) support for parents whose children have been diagnosed with cancer. We will endeavour to ensure that parents/guardians are aware of this resource to facilitate connecting with each other.
- The Irish Cancer Society will introduce enhanced support, including form filling and sign-posting, to help cancer survivors access banking, insurance and other financial services.

Advocate for medical card entitlement for adult survivors to meet medical need

- We will advocate for life-long medical cards for survivors of childhood cancer, a particularly important resource for people who have late effects due to treatment.

Raise awareness of the lifelong impacts of childhood and adolescent cancer

- The Irish Cancer Society is in the process of completing research on Access to Financial Services and Products, to understand whether or not challenges exist for cancer survivors in accessing financial services, and how to address any challenges.
- We will also consider ways in which to engage with adult survivors of childhood cancer to learn more about their needs and advocate on their behalf.



References

- i. Irish Cancer Society. 2019. "The Real Cost of Cancer." Available [here](#)
- ii. Citizens Information. 2021. "Medical cards." Updated 23 February. Available [here](#)
- iii. Irish Cancer Society. 2021. "Benefits and Entitlements for Families." Updated 7 October. Available [here](#)
- iv. Revenue. 2020. "Health Expenses." Published 1 May. Available [here](#)
- v. Revenue. 2020.
- vi. Kelada, L., Wakefield, C. E., Vetsch, J., Schofield, D., Sansom-Daly, U. M., Hetherington, K., O'Brien, T., Cohn, R. J., Anazodo, A., Viney, R., Zeppel, M. J. B. 2020. "Financial toxicity of childhood cancer and changes to parents' employment after treatment completion." *Pediatric Blood & Cancer* Volume 67, Issue 7; Santacroce, S. J., Kneipp, A. M. 2019. "A Conceptual Model of Financial Toxicity in Pediatric Oncology." *Journal of Pediatric Oncology Nursing* 2019, Vol. 36(1) 6–16
- vii. Kelada et al. 2020; Miedema, B., Easley, J., Fortin, O., Hamilton, R., Mathews, M. 2008. "The economic impact on families when a child is diagnosed with cancer." *Curr Oncol.* 2008 Aug; 15(4): 173–178.
- viii. Erdmann, Friederike, Feychting, M., Mogensen, H., Schiegelow, Zeeb, H. 2019. "Social Inequalities Along the Childhood Cancer Continuum: An Overview of Evidence and a Conceptual Framework to Identify Underlying Mechanisms and Pathways." *Front Public Health.* 2019 Apr 18;7:84; Miedema et al. 2008.
- ix. Miedema et al. 2008
- x. Roser, K., Erdmann, F., Michel, G., Falck Winther, J., Mader, L. 2019. "The impact of childhood cancer on parents' socio-economic situation-A systematic review." *Psychooncology.* 2019 Jun;28(6):1207-1226. doi: 10.1002/pon.5088. Epub 2019 May 8; Kelada et al. 2020; Miedema et al. 2008; Erdmann et al. 2019.
- xi. Barrett P, Mullen L, McCarthy C. 2018. "Survivorship after childhood cancer – health needs assessment 2018." National Cancer Control Programme; Dublin.
- xii. Barrett et al. 2018.
- xiii. Fidler, M., M., Ziff, O. J., Wang, S., Cave, J., Janardhanan, P., Winter, D. L., Kelly, J., Mehta, S., Jenkinson, H., Frobisher, C., Reulen, R. A. & Hawkins, M. M. 2015. "Aspects of mental health dysfunction among survivors of childhood cancer." *Br J Cancer.* Volume 113, Issue 7.
- xiv. Barrett, P. M., Mullen, L., McCarthy, T. 2020. "Enduring psychological impact of childhood cancer on survivors and their families in Ireland: A national qualitative study." *European Journal of Cancer Care.* Volume 29, Issue 5.
- xv. Barrett et al. 2020.
- xvi. Ljungman, L., Cervall, M., Grönqvist, H., Ljótsson, B., Ljungman, G. & von Essen, L. 2014. "Long-Term Positive and Negative Psychological Late Effects for Parents of Childhood Cancer Survivors: A Systematic Review." *PLoS One.* Volume 9, Issue 7
- xvii. Ljungman et al. 2014.

To find out more about our services:

Visit us at www.cancer.ie

Call our Support Line **1800 200 700**

Email us on supportline@irishcancer.ie

Follow us:



[Fb.com/IrishCancerSociety](https://www.facebook.com/IrishCancerSociety)



[@IrishCancerSoc](https://twitter.com/IrishCancerSoc)



[@IrishCancerSociety](https://www.instagram.com/IrishCancerSociety)