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Foreword

There is a massive physical and psychological impact on a person who is diagnosed and treated for cancer, and often, for their family too. Thanks to the courage of the many people who have shared their story, we now know much more about the impact on them of being a cancer patient.

What has been less known and little recognised however has been the financial impact of being treated for cancer in Ireland. The Irish Cancer Society decided to find out. We have been told that for some patients, the stress of managing the financial cost of a cancer journey has been as big as, and has contributed to, the stress of having cancer.

The Irish Cancer Society has established, via a survey conducted for us by Millward Brown, that the average cost to the patient and their family of going through the cancer journey is €862 per month, rising to €1,200 a month in some cases, that is before taking into account the loss of income that some experience. This very high figure means that cancer patients are having to deal with a very considerable financial burden at the same time as managing the medical and psychological burden of having cancer.

One patient told us that for her, the stress of managing the cost was greater than the stress of having cancer.

A medical card or private health insurance does not support these costs as most expenses are extras not covered by health insurance, a medical card or social welfare.

Additional home heating costs, travel to and from hospital, hospital parking charges, childcare costs, over-the-counter medicines, prescription drugs and charges, physiotherapy, specialist medical equipment and dental care are high on the list of the necessities which many cancer patients must pay for but which are not covered by insurance or state support.

For those working, the associated loss in income can be as high as €1,400 per month on average.

This issue cannot be ignored. Cancer patients are receiving excellent medical care in our hospitals and more patients than ever are surviving cancer. However the very high financial burden being borne by the cancer patient must be alleviated. While we are not suggesting how this would be done, we would like this urgent and important issue to be addressed in the 2016-2025 National Cancer Strategy.

Kathleen O’Meara
Head of Advocacy and Communications
Summary

The findings of this nationwide survey of cancer patients and their carers into the true cost to them of being treated for cancer has revealed that the average additional cost is €862 per month, with many facing costs of up to €1,200 per month.

In addition the survey found that:

Drop in income:
- The average drop in the income of cancer patients was €1,400 per month, according to the survey, or €16,750 per annum
- A third of working patients give up work
- A quarter reduce their hours

Medical card and health insurance:
- Three in five patients had a medical card at the time of their diagnosis
- Half receive a medical card following diagnosis
- 23% of those who applied for a medical card were not successful
- 57% had private health insurance

Cost of medicines, consultants and parking at the hospital:
- The average cost of medicines and medical expenses was just over €300 per month
- 1 in 7 incurred costs from hospital stays; the average was €482 per month and could not be claimed back
- Over a quarter paid consultants’ fees at an average cost of €144 per month,
- Similar amounts were spent on physiotherapy and other specialties; GP’s charges were an additional €88 per month
- The average costs associated with visiting hospital for appointments or treatment, such as petrol, parking and eating in the hospital was €287 per month

Additional bills at home:
- More than half had additional heating, electricity and telecoms bills
- One in eight also had additional childcare costs
- A quarter paid for additional domestic support such as cleaners or gardeners
- 87% spent more on personal care and clothing as a result of having cancer.
Methodology

In May 2015, the Irish Cancer Society commissioned Millward Brown to conduct a survey of cancer patients and carers about the specific topic of the financial impact of cancer.

The key objectives of the research were to:
1. Understand the factors contributing to financial impact of cancer, such as additional costs and effect on earnings.
2. Calculate this impact - by measuring the different elements of this cost and any loss of income.
3. Explore who is most affected and the factors influencing the differences in the financial impact of cancer.

This will provide the Irish Cancer Society with an up-to-date financial effect of cancer across Irish society, and as advocates of those who have cancer and their families, to help shape future strategy and offer solutions.

The Research

The research was conducted during June to August 2015 in a two phased approach. Initially, 8 qualitative in-depth interviews were conducted with people living with a cancer diagnosis, who were currently going through or had undergone treatment in the recent past. This approach helped us to understand the day-to-day challenges faced by these patients and the broad range of financial implications which come with cancer diagnosis and treatment. This initial qualitative phase was conducted in June 2015.

The second phase of the research was required to capture robust data on affected expenditure and income figures, from a broad range of cancer patients and carers, on the specifics of the financial impact of cancer. The approach taken was a self-reporting questionnaire via an online or postal survey, allowing participants to provide the details in their own time and privacy. The Irish Cancer Society hosted the survey, designed in conjunction with Millward Brown, on the www.cancer.ie website and also offered the option of a pen and paper postal survey.

A PR and social media campaign was launched, combined with contacting over 11,000 people in the Irish Cancer Society database and a further 1,000 via the Millward Brown national omnibus survey in July 2015. The survey remained on the Irish Cancer Society website until August 2015.

At the end of the research period 409 people had participated in the survey, all of these submissions through the website, as there were no requests for the postal option. There was a mix of patients and carers, and from those currently going through treatment and those who had being diagnosed up to 30 years ago. Almost three quarters (73%) had been diagnosed within the past 5 years, since 2011. Almost one in five (18%) had also had a previous diagnosis.

Once data was collated and analysed we reviewed the types of cancer diagnosis and discovered that apart from two exceptions, reported levels of cancer types were in line with those expected based on the NCRI incidence of invasive cancers.

The two exceptions were in the case of breast cancer and prostate cancer, the two cancers with the highest incidence in Ireland. As the survey was self selecting we anticipated some differences and have weighted the final results, in accordance with best practice to take account of this.

The number completing the survey in relation to breast cancer was higher than expected and in relation to those with prostate cancer was lower than expected. We took account of this by weighting the data for those specific groups. Full details of the weighting procedures are included in the technical appendices which can be made available upon request.
The Financial Impact of Cancer

“When I got the diagnosis of cancer… it was like someone crept into the house and stole our happiness”

Dealing with a cancer diagnosis is one of the most difficult things that can happen in anyone’s life.

It impacts upon every facet of you and your family’s daily life.

The main priority in this complex and demanding situation should be dealing with your diagnosis and, when appropriate, a treatment plan.

The financial cost of a cancer diagnosis is often not considered upon diagnosis.

Many of those who took part in our research commented that they had never considered or calculated the financial toll cancer took on them. Most people are distracted by the day-to-day medical, physical and emotional impact.

“IT made life more difficult at what was the most difficult time of our lives”

Our research showed that everyone, from every part of the country, at every age, from different socio-economic groups, for those with and without medical cards and those who have private health insurance or not, have experienced the financial impact of cancer.

The financial impact can take two specific forms:

- Additional costs
- Reduction in income

Additional costs appear in many ways, such as the cost of medication, managing side effects, additional medical expenses, increased day-to-day living costs, costs associated with treatment, changes in personal care costs, and one-off household purchases.

Meanwhile, many have had to alter their working arrangements upon diagnosis and throughout the course of their treatment.

A third of respondents changed their employment status since their cancer diagnosis, while almost two thirds of those in employment have changed their working circumstances in some way.

Overall the cost of cancer is immense and we have made a conservative estimate in the region of €862 per month, rising to over €1200 per month in some cases.

Three in five of those working have had their income reduced as a result of their cancer diagnosis with annual income reducing by over €16,500, equating to about €1,400 per month.

“Our research showed that everyone, from every part of the country, at every age, from different socio-economic groups, for those with and without medical cards and those who have private health insurance or not, have experienced the financial impact of cancer.”

“The biggest financial impact would be my loss of earnings from having to leave my job. I haven’t been able to go back to my job yet because there is something every month, treatment wise”
Everyone is Affected

Our research shows that people from all walks of life are affected by the real cost of cancer.

We engaged with patients and carers, across every county in Ireland, in both rural and urban locations.

We reached people across all age ranges, from young to old, and included the experiences of childhood cancer patients whose parents submitted responses on their behalf. The average age of our respondents was 51.

The research took into account the experiences of carers and patients, including those with a current diagnosis and survivors.

Among those who took part in the survey, 59% had a medical card, with half of this number receiving a card since diagnosis. Just 2% had a GP card, while 57% had a DPS card (Drug Payment Scheme) for prescription medicines.

Just under three in five (57%) currently have private health insurance with a further 14% having held private health insurance in the past. A quarter of respondents had both a medical card and private health insurance.

Strikingly, one in 14 (7%) had neither a medical card nor private health insurance, which leaves them with little to no financial support for their medical costs.

Those who have Medical Card & Private Health Insurance

- Medical Card only: 7%
- Medical Card & Private Health Insurance: 36%
- Private Health Insurance only: 33%
- Neither: 24%
Overview of Costs Associated with Cancer

The costs associated with cancer diagnosis are wide-ranging and often not immediately apparent.

Along with the obvious costs of medical expenses and the significant outlay which many dealing with side-effects endure, we asked specifically about the following:

**Medical Expenses not claimed back including:**
- Over-the-counter medication
- Prescription medication
- GP visits
- Consultants visits
- Additional dental care
- Specified dietary supplements
- Hospital stays
- Specialist dressings
- Physiotherapy or other specialist medical care
- Treatment abroad
- Nursing care provided in home

**Added costs during treatment & appointments:**
- Travel costs going to and from appointments, such as, petrol, taxi fares and public transport costs
- Parking costs while at appointments
- Cost of eating out while on appointments

**Increase in day to day living expenses:**
- Household heating and electricity bills
- Phone call/mobile/texts/data/broadband expenses
- Household food and drink bills
- Pay for additional domestic support
- Childcare costs

<table>
<thead>
<tr>
<th>Costs for</th>
<th>Affects</th>
<th>Average Estimated Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Expenses</td>
<td>77%</td>
<td>€303 pm</td>
</tr>
<tr>
<td>Costs during treatment</td>
<td>94%</td>
<td>€287 pm</td>
</tr>
<tr>
<td>Day to day living expenses</td>
<td>77%</td>
<td>€217 pm</td>
</tr>
<tr>
<td>On-off purchases</td>
<td>41%</td>
<td>€274 once-off</td>
</tr>
<tr>
<td>Personal care costs</td>
<td>87%</td>
<td>€389 once-off</td>
</tr>
<tr>
<td>Additional costs</td>
<td>14%</td>
<td>€212 once-off</td>
</tr>
<tr>
<td><strong>Overall Estimated Costs</strong></td>
<td><strong>All</strong></td>
<td><strong>€862 per month</strong></td>
</tr>
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</table>

One off purchases such as:
- Wigs, hair pieces, head coverings
- Household modifications or adaptions, for example, a ramp or stair lift
- Specialist equipment for your home, for example, a commode
- Specialist dental work and dental care

**Additional personal care costs included:**
- Skin care and moisturisers
- Mouthwashes, toothpastes
- Clothing for comfort, coverage
- Specialist shampoos, bath care, soaps
- Liners/caps for wigs
- Specific support clothing
- Specific make-up/cosmetics
- Fabric supports
- Other toiletries
- Other costs such as entertainment

**Patients also suggested the following costs:**
- Counselling
- Medical supplies (bandages, pads, compression stockings)
- Alternative therapies
- Increased insurance cover
- Vitamins
- Pets in kennels
- Accommodation costs
Associated Medical Costs

As an initial indicator of the costs faced by cancer patients, we asked survey participants about their overall medical expenditure for a month. Over half (56%) stated that they had medical expenses and on average were spending €155 a month on medication.

Our research found that 8 in 10 people had experienced side effects while being treated for cancer and 62% covered the cost of dealing with these side effects themselves. This includes the use of over-the-counter (OTC) medication, a vital necessity for many but one that is not covered under the Drugs Payment Scheme. Likewise, medical card holders don’t receive support in paying for OTC medication.

Aside from the physical, emotional and psychological toll of these side effects, on average, they cost €69 extra per month.

We asked cancer patients, survivors and carers to consider a number of medical expenses they might have and, for those that did (77%), we asked them to estimate the average costs per month. These results are detailed in the table opposite.

We have estimated that on average the cost of medical expenses (which can’t be claimed back) would be in the region of €303 per month.

This costs is based on average spend and the proportion of people experiencing each costs.

While a small proportion incur considerable expenses, such as treatments abroad and specialist nursing care in home, we have excluded these (and the generalised option of ‘other medical costs’ which are covered elsewhere in more detail) from our calculations* as they are not typical for most people. This has resulted in a more conservative estimate.

<table>
<thead>
<tr>
<th>Costs for</th>
<th>Affects</th>
<th>Costs on average per month</th>
</tr>
</thead>
<tbody>
<tr>
<td>OTC medication</td>
<td>51%</td>
<td>€110 pm</td>
</tr>
<tr>
<td>Prescription medication</td>
<td>43%</td>
<td>€136 pm</td>
</tr>
<tr>
<td>GP visits</td>
<td>35%</td>
<td>€88 pm</td>
</tr>
<tr>
<td>Consultants visits</td>
<td>28%</td>
<td>€144 pm</td>
</tr>
<tr>
<td>Additional dental care</td>
<td>15%</td>
<td>€92 pm</td>
</tr>
<tr>
<td>Dietary supplements</td>
<td>14%</td>
<td>€72 pm</td>
</tr>
<tr>
<td>Hospital stays</td>
<td>14%</td>
<td>€482 pm</td>
</tr>
<tr>
<td>Specialist dressings,</td>
<td>11%</td>
<td>€95 pm</td>
</tr>
<tr>
<td>Physiotherapy or other</td>
<td>11%</td>
<td>€141 pm</td>
</tr>
<tr>
<td>Specialist medical care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment abroad*</td>
<td>4%</td>
<td>€1,978 pm</td>
</tr>
<tr>
<td>Nursing care provided in home*</td>
<td>1%</td>
<td>€593 pm</td>
</tr>
<tr>
<td>Other medical care*</td>
<td>12%</td>
<td>€396 pm</td>
</tr>
</tbody>
</table>

Some of those facing these more extreme costs, such as treatment abroad, were reportedly paying out between €2,000 and €9,000 per month.

While the number of cases facing these specific expenses is small, the financial burden is staggeringly high.
Costs Associated with Appointments

Some of the most significant costs associated with cancer occur when a patient is undergoing treatment.

The associated costs of attending appointments quickly add up and the likes of parking, eating out and travel, in many cases, significantly add to the burden caused by the real cost of cancer.

Ninety-four per cent of those surveyed said that they incurred some costs while going through treatment or attending appointments:

- 86% incurred travel costs at an average of €166 per month
- 80% incurred parking costs at an average of €62 per month
- 68% had additional costs for eating out of home while attending appointments at an average of €86 per month
- 20% also mentioned other costs associated with attending appointments at an average of €179 per month. These additional costs include overnight accommodation required for appointments, childminding and babysitting, amongst others

Taking into account these frequently incurred expenses of travel, parking and eating out, the overall average cost associated with attending appointments is €287 per month per person.

Much of this severe financial strain comes about in the form of hidden costs, not normally associated with illness, but that are levied on cancer patients on an ongoing basis.

While travel costs affected people from across the country, there was a slightly higher incidence among those from rural rather than urban areas. Highest travel expenses were felt by those in Leinster outside of Dublin at €194 per month, followed by Connaught/Ulster at €177 per month, Munster at €168 per month and finally those from Dublin at €117 per month.

Patients living in Munster reported the longest journeys for treatment averaging 70 kilometres, followed by Connaught/Ulster at 62km. In Leinster the figure was 44km, compared to 22km in Dublin. Those in rural areas travelled just under 60km, compared to those in urban areas travelling 28km on average.

1 in 10 cases had to undertake extremely lengthy journeys of over 100 kilometres for treatment. When taking all treatment into account, 71% reported receiving some of their treatment in Dublin.

Focusing specifically on parking costs, these were highest for those living in Dublin at €78 per month and rest of Leinster at €64 per month, with the remainder still paying somewhere between €40 and €50 per month on parking.
Impact on Day-to-Day Living Costs

Increased everyday household expenses account for some of the financial hardship experienced by three quarters of cancer patients and their families.

Our survey found that for people who have additional household expenditure as a result of their cancer diagnosis:

- 55% experience higher heating and electricity bills;
- 54% spend more on phone bills;
- 38% spend more on food and drinks as appetites and nutritional needs change;
- Others also had additional outlays for household support (26%), such as cleaners and gardeners;
- 12% of families had additional childcare and babysitting costs.

While 75% of families spent more on the household expenses above, the remaining 25% actually cut these expenses because they could no longer afford them, causing much anxiety and distress.

We asked how this made them feel and this is what we were told:

- "Insufficient and unable to provide for family"
- "It just added to the stress of a very scary and worrying time in our lives"
- "Like I couldn't provide for my four children or myself. I felt ashamed"

Those from more middle class backgrounds (social grades ABC1) are mostly likely to pay for additional domestic support such as cleaners or gardeners.

Personal Care Items

Other day to day living costs were in the areas of personal care and clothing items, where amounts spent may feel small but mount up over time when you consider what is involved. In fact 87% said they experienced increased expenditure in personal care items due to cancer diagnosis, on the following types of items:

- skin care / moisturisers
- mouthwashes, toothpastes
- clothing for comfort, coverage
- specialist shampoos, bath care, soaps
- liners/caps for wigs
- specific support clothing
- specific make-up/cosmetics
- fabric supports
- other toiletries
- other costs such as entertainment, books or TV

Tallying these up altogether it is estimated that this would cost in the region of €390 in total for personal care items although it varies from person to person.

Those in Dublin are most likely to experience increases in these types of household costs overall. Residents of Connaught/Ulster are the second most likely to experience an increase, in this case driven by increased childcare costs while they travel longer distances.
One-off Expenses

Over 40% of people who completed the survey said they paid for one-off expenses that included wigs, modifications to their home, counselling and dental treatment. The cost of these items was considerable.

There are specific one-off costs typically associated with cancer treatment, such as buying wigs and hair pieces - a cost incurred by 38% of all female cancer sufferers, equating to a fifth of those participating in the survey.

The average cost of these wigs, hair pieces and head coverings was over €500 overall with many opting to have more than one to allow for cleaning and having different options.

One in ten also mentioned additional dental care and treatment. The average cost recorded by our survey respondents was about €650, indicating substantial dental intervention.

Many cancer patients need to make modifications to their home such as ramps or stair lifts when they are going through or have completed treatment. Our survey revealed that one in ten respondents spend an average of almost €900 making these changes.

A further 10% told us that they had to purchase specialist equipment like commodes, at an average cost of over €200.

Other expenses revealed in responses to the survey included new beds and furniture, walking sticks, hand sanitisers and digital thermometers. In some cases patients are paying for prosthetics and there was also the substantial cost of IVF treatment for others.

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<tr>
<th>One-off costs such as:</th>
<th>Affects</th>
<th>Average One off Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wigs, hair pieces, head coverings</td>
<td>21%</td>
<td>€511</td>
</tr>
<tr>
<td>Specialist dental work and dental care</td>
<td>10%</td>
<td>€653</td>
</tr>
<tr>
<td>Modifications to home</td>
<td>9%</td>
<td>€891</td>
</tr>
<tr>
<td>Specialist equipment for home</td>
<td>10%</td>
<td>€215</td>
</tr>
<tr>
<td>Other one of costs</td>
<td>10%</td>
<td></td>
</tr>
</tbody>
</table>

One in seven people mentioned additional costly items following their cancer treatment which included:
- Counselling
- Alternative therapies
- Vitamins
- Increased insurance cover
- Pets in kennels
- Accommodation costs

For those encountering these additional costs, the average spend was in the region of €1,500, although it differed greatly depending on the additional cost they had to pay out.
A break from the reality of cancer

Another expenditure mentioned by some people was to have a ‘treat’ to help take a ‘break from the reality of cancer’ - particularly those with partners and families.

This was done to either provide respite from the treatment of cancer, to have something to look forward to, or just to escape for a while.

Over half of cancer households (54%) said they had chosen to treat themselves following cancer diagnosis or treatment, with one in five of these mentioning trips to the cinema, eating out or day trips, amongst other activities.

However, for two in three of these (66%), they embarked on some sort of holiday, such as a short break or weekend away, a hotel or spa break, holiday abroad or in Ireland or visiting family members, at an average cost of over €1,000.

Many felt the break was well worth it in the overall scheme of things.
Impact on Income

Cancer patients and their families are not just facing increased costs, many have to manage on a reduced household income as well.

As many as a third of those who participated in the survey had changed their employment status since their cancer diagnosis.

- One in 5 are retired now, compared to one in 10 at the time of diagnosis;
- 13% are unemployed now but only 6% were unemployed at the time of diagnosis;
- The number of people working full time fell from 44% to 29%.

Three in five of all workers said their incomes decreased as they could not work as much as before their cancer diagnosis. This was highest among those in Dublin and also those aged under 40.

Three in ten of these had reduced their salary by over €20,000, with an average reduction in excess of €16,750 per annum, equating to around €1,400 per month for those experiencing a reduction in income.

This reduction in salary is highest among those who are from east coast (Dublin/Leinster), those who are currently caring for someone with cancer and those from a higher social class (AB).

Almost two thirds (64%) changed their working practices in some way, with 38% stopping working and 27% reducing their hours as a result of their cancer diagnosis.

Some also mentioned taking annual leave instead of sick time to cover surgery, treatment and appointments so they would continue to get paid.

Only 12% had income protection in place at the time of diagnosis; meanwhile 10% tried to get income protection since diagnosis with only one in ten of these being successful.

“Of all patients/carers experienced %

<table>
<thead>
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<th>Event</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Took leave of absence</td>
<td>25</td>
</tr>
<tr>
<td>Worked fewer hours</td>
<td>22</td>
</tr>
<tr>
<td>Changed approach to work</td>
<td>19</td>
</tr>
<tr>
<td>Resigned from job</td>
<td>12</td>
</tr>
<tr>
<td>Took annual leave to cover sick leave</td>
<td>11</td>
</tr>
<tr>
<td>Reduction in salary</td>
<td>10</td>
</tr>
<tr>
<td>Changed jobs or employers</td>
<td>7</td>
</tr>
<tr>
<td>Turned down a new role or promotion</td>
<td>7</td>
</tr>
<tr>
<td>Been made redundant</td>
<td>3</td>
</tr>
<tr>
<td>Took force majeure leave</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>36</td>
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</table>

“The biggest financial impact would be my loss of earnings from having to leave my job, I haven’t been able to go back to my job yet because, in terms of treatment, there is something every month.”

“The company I work for don’t pay sick leave, it’s a small office. But I had holidays to take or I would work extra hours to cover my time off. When I went in for my surgery I told work that I was going to take a few weeks off at least and see what happens. I really thought I would be back in work after that, people told me to slow down, they thought I was mad. Eventually I had to leave work and signed on sick leave with the social welfare. It’s not the same as your weekly wage though.”
Other Financial Implications

There are many factors that can affect the financial impact of cancer on any one individual or household. These include whether the individual has private health insurance, a medical card, a GP visit card or a Drugs Payment Scheme card.

Three in five people who responded to the survey had a medical or GP card. Half of those with medical cards were awarded it since their diagnosis. About a quarter of those without a medical card had applied for one but had not been approved. Cancer patients used the ‘other comments’ box in the survey to express the wide-ranging problems they encountered when applying for medical cards.

Over half (57%) said they have a Drug Payment Scheme card. This is higher for people from higher social groups, those in Dublin and aged 35-49.

Over 7 in 10 had private health insurance at some stage, but only 57% currently have health insurance, with 14% of cancer patients/carers no longer paying the premiums.

Despite encouragement to shop around, the vast majority (89%) have not changed providers mainly because they were happy with the current provider, but also because they were worried their premiums would increase or they would be refused cover based on their cancer diagnosis.

12% had tried to take out Life Assurance since their diagnosis with the vast majority (83%) not being successful. Excerpts from their feedback on application for Life Assurance is included below:

“I have a medical card now but they kept losing the form…they said the form was misplaced or lost. I am a nurse and this always seems to be the case. We had to apply 3 times before we got the medical card and our GP costs were not covered until we got the medical card”

“Called two insurance providers who both said they had three simple questions which they would start with. One of the questions was “have you ever been diagnosed with cancer?” once the answer was yes I was told they were sorry but I was not eligible for cover!”

“The cost went up from €13.50 per month to €117 per month and hence I couldn’t afford that amount of money anymore”

“I would have to be 5 years cancer free before I would be considered for life assurance”
Impact on Family Life

We received lots of feedback on the impact of cancer on family life and in relation to children.

When asked “how much has your cancer treatment interfered with your family life”, two thirds registered this impact at a considerable 7 or more out of 10.

Some of the specific comments made in relation to family life are included here:

“My husband had to take a less well paid job as he worked away & had to come home to look after myself & the children”

“I’ve a child with special needs so need a trained carer to mind her if I’m at hospital”

“As my child lost his full leg we had an ambient room built, our outstanding bill on this was €24,000. Prior to this, we survived by buying hand rails for bathrooms and stairs and seat for bath”

“It made it very difficult to plan ahead and to cope with unforeseen or emergency expenditure. Children missed out on a lot growing up - holidays, school trips etc. because the money wasn’t there to pay for them. We were living hand to mouth”

“It’s harder to say no to a child on chemotherapy”
Cancer patients reported that establishing what financial supports are available to them and their families can be complex and then system is difficult to navigate.

A third said the hospital provided information on social welfare benefits but that this mainly focused around medical card and carers allowance, with some mentions of other benefits.

“At my diagnosis I didn’t know what my social welfare entitlements were but as time went on, I had to find out what was going on and what I was entitled to. We don’t qualify for a medical card, we had our own private health insurance. But I spoke to a few different people in the HSE and one told me I probably would qualify for a medical card and someone else told me I wouldn’t. I got the forms and the form was so complex and convoluted that I gave up. I did qualify for the drugs payment card. That was a blessing, thanks be to God, because there was a drug I need to take for three days after the chemotherapy and that cost €1,800 on top of steroids and anti-sickness tablets. The drugs card was very helpful for that. We still had to pay the first €144 a month.”

<table>
<thead>
<tr>
<th>Received information on:</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Card Entitlement</td>
<td>43</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>27</td>
</tr>
<tr>
<td>Applying for social welfare payments</td>
<td>21</td>
</tr>
<tr>
<td>Sick pay entitlements</td>
<td>21</td>
</tr>
<tr>
<td>Disability allowance</td>
<td>19</td>
</tr>
<tr>
<td>Illness benefit</td>
<td>17</td>
</tr>
<tr>
<td>Reductions and refunds of medical expenses</td>
<td>10</td>
</tr>
<tr>
<td>Supplementary welfare allowance</td>
<td>10</td>
</tr>
<tr>
<td>Invalidity pension</td>
<td>9</td>
</tr>
<tr>
<td>Nursing supports</td>
<td>6</td>
</tr>
<tr>
<td>Living at home supports</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>19</td>
</tr>
</tbody>
</table>
Support Services

While well over half received information on support services, four in ten received no such information.

The Irish Cancer Society booklets and website were a good source of information for patients and carers alike. Three in ten specifically mentioned the Irish Cancer Society Daffodil Centres in hospitals:

<table>
<thead>
<tr>
<th>Received information on:</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Cancer information booklets and factsheets</td>
<td>79</td>
</tr>
<tr>
<td>Irish Cancer Society website</td>
<td>64</td>
</tr>
<tr>
<td>Local cancer support groups</td>
<td>40</td>
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<tr>
<td>Irish Cancer Society Daffodil Centres</td>
<td>29</td>
</tr>
<tr>
<td>Counselling</td>
<td>22</td>
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<tr>
<td>Useful organisations</td>
<td>14</td>
</tr>
<tr>
<td>Survivors supporting survivors</td>
<td>12</td>
</tr>
<tr>
<td>Citizens information</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
</tbody>
</table>
Conclusion – The Real Cost of Cancer

The findings of the Real Cost of Cancer survey illustrate that everyone who is diagnosed with cancer is impacted financially in some way.

The Irish Cancer Society wants to ensure that cancer patients and their families are supported in all aspects of their cancer journey and this includes making sure appropriate financial supports are in place.

The research shows that many cancer patients are facing financial stress, sometimes hardship, by having to deal with massive extra costs, as well as a huge drop in income for many patients at a time when they are going through the severe physical, emotional and psychological impact of a very serious illness. The financial burden being carried by cancer patients is immense.

The Irish Cancer Society will explore the implications of the findings from this research and aim to develop detailed policy solutions that will alleviate the pressure being felt by families across the country.

We want Government, the Health Service Executive and the National Cancer Control Programme to acknowledge the scale of the cost of cancer and to design appropriate and accessible supports to the financial crisis faced by cancer patients in Ireland.

To find out more about our services:

- Visit us at www.cancer.ie
- Call our Cancer Nurseline 1800 200 700
- Email us at cancernurseline@irishcancer.ie
- Follow us on:
  - Facebook https://www.facebook.com/IrishCancerSociety
  - Twitter https://twitter.com/IrishCancerSoc
Support from the Irish Cancer Society

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

Cancer Nurseline
The Cancer Nurseline 1800 200 700 is a freephone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services.

The Nurseline can also put you in contact with various support groups that are available. It is open Monday to Thursday from 9am to 6pm, and every Friday from 9am to 5pm.

- The website www.cancer.ie provides information on all aspects of cancer
- All queries or concerns about cancer can be emailed to the Nurseline at cancernurseline@irishcancer.ie
- The online community on www.cancer.ie is a discussion space on our website to share your stories and experiences with others
- Find us on Facebook and follow us on Twitter (@IrishCancerSoc).

The Irish Cancer Society’s Daffodil Centres
The Irish Cancer Society’s Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Nurseline. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge. The Irish Cancer Society’s Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit a centre. Do check to see if there is an Irish Cancer Society’s Daffodil Centre in your hospital.

Survivor Support
Being diagnosed with cancer can be one of the hardest situations you can face in your lifetime. Our Survivor Support is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. All of the volunteers have had a cancer diagnosis and have been carefully selected and trained to give you support, practical information and reassurance when you need it most. You can speak to someone who really knows what you are going through. If you would like to make contact with a volunteer, please call the Cancer Nurseline on 1800 200 700 or visit a Irish Cancer Society’s Daffodil Centre.

Counselling
Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the Cancer Nurseline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Cancer information booklets and factsheets
The booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. They are all available free of charge from the Irish Cancer Society’s website www.cancer.ie or picked up at the Irish Cancer Society’s Daffodil Centres.