



Irish Cancer Society

The Real Cost of Cancer

Research conducted by Kantar 2019

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Foreword

When thinking about cancer, people tend to focus on the treatment options and chances of surviving the disease.

Not the families right across the country crushed by debt, struggling to make ends meet and facing an uncertain financial future.

Not a parent having to make the choice between paying for medication for themselves and putting food on the table for their children.

Not the debt collectors working on behalf of hospitals, chasing cancer patients at their lowest physical and emotional point.

Not those sitting in a cold house during chemo because the heating bills are just too high.

Thanks to the hundreds of people across the country who've faced cancer and took the time to tell us their own story, this report lays bare the range of costs patients take on. Often, it is shocking, and the personal testimonies illustrate this. These families come from different backgrounds, are different ages and have different incomes. But they all have one thing in common - cancer.

Thankfully, more and more people are surviving this disease. But while treatments have improved, not enough attention has been given to its devastating financial impact. Patients and families are facing a lasting, and often crushing, financial burden. The uncomfortable truth is that financial hardship often goes hand in hand with cancer and can stay long after treatment is finished.

This report shows that the average cost to someone dealing with cancer is €756 a month. This can rise in some cases to over €1,000. Costs include wigs, medication, car parking and counselling, plus many more items that are needed when you have cancer. There are also Government charges such as in-patient fees, prescription charges and medication not covered by the the Drug Payment Scheme, which all contribute to the volley of costs being borne by people with cancer.

At the same time, people are faced with a loss in income of over €1,500 a month on average. This is as a result of having to leave their job, take reduced hours, close their business or take significant time off work. While things have improved for some people since the Irish Cancer Society first examined this issue in 2015, there are many, many others for whom the financial cost of cancer continues to devastate their emotional and mental well-being.

Things need to change.

We need the Government to stop the endless charges it levies on cancer patients. We need better access to medical cards and a greater appreciation of the huge financial strain of having cancer. The double whammy of increased costs and loss of income needs to be taken into account when considering what cancer patients can reasonably bear. The Irish Cancer Society will continue to push Government so that a more compassionate and understanding approach is taken.

We at the Irish Cancer Society are also determined to do more ourselves. We will make sure that people with cancer know about what entitlements and supports are available to them. We will also reach out to utilities providers, financial institutions and representative bodies to push for more a compassionate approach to dealing with cancer patients and survivors.

The reality is that having cancer is hard enough without being as worried about the next bill as getting better. The Irish Cancer Society is optimistic that by shining a light on the real cost of cancer, we are taking the first steps towards a future that is better for everyone.



Averil Power

Averil Power
Chief Executive
Irish Cancer Society

Summary

The findings of this national survey of cancer patients and their carers into the financial cost associated with a cancer diagnosis reveal that the average additional cost is €756 per month, with many facing outgoings of up to €1,000 per month.

Our research demonstrates the broad range of areas in which cancer patients face new or extra financial challenges.

Income and challenges in the workplace

- The average drop in the income of cancer patients was €1,527 per month, according to the survey, or €18,323 per annum
- One in three changed their employment status
- One in four changed their approach to work
- 45% of carers' employment was affected

Cost of medicines, consultants and parking at the hospital

- The average cost of medicines and medical expenses was just over €261 per month
- 1 in 10 incurred costs from hospital stays; the average was €288 per month which could not be claimed back
- Over a quarter paid consultants' fees at an average cost of €135 per month
- Similar amounts were spent on physiotherapy and other specialties; GP charges were an additional €81 per month
- The average costs associated with visiting hospital for appointments or treatment, such as petrol, parking and eating in the hospital was €291 per month





Additional bills at home

- One in two had additional heating, electricity and telecoms bills
- A quarter had increased food and drink costs
- One in eight also had additional childcare costs
- Over half spent more on personal care and clothing as a result of having cancer

Medical card and health insurance

- Two in five patients had a medical card at the time of their diagnosis
- Half received a medical card following diagnosis
- 17% of those who applied for a medical card were not successful
- 62% had private health insurance

Irish Cancer Society

Reflections and Recommendations

From the day they are diagnosed, cancer patients are faced with relentless and overwhelming costs and Government charges.

This report shows us that the financial cost of having cancer has a devastating effect on individuals and families already struggling to come to terms with the disease itself.

Most people know that having cancer is physically hard, but many people don't realise that it also causes real financial hardship.

We are calling for action so that no one is more worried about bills mounting up than they are about getting better.

To address the significant medical costs many face, we recommend

- A reduction in the monthly Drug Payment Scheme threshold to €100 per month for a family and €72 a month for single people
- The abolition of prescription charges for medical card holders
- The abolition of the €80 inpatient charge, which is paid by patients at every chemotherapy or radiotherapy appointment
- An immediate end to the HSE practice of referring unpaid inpatient charges to debt collectors and legal agencies.



To deal with some of the costs associated with appointments, we recommend

- Reduced car parking charges for cancer patients at public hospitals
- Hospitals that currently offer free or discounted parking to cancer patients are encouraged to freeze charges
- Easy-to-find information from the HSE on free or reduced rates in cancer hospitals

On the issue of medical cards, we recommend

- Automatic access to a medical card for all cancer patients (currently only under-18s)
- Clearer guidelines and processes for cancer patients applying for medical cards and for HSE-PCRS staff
- Give automatic, life-long medical cards for people with a terminal cancer diagnosis

To support families and individuals in dealing with increased day-to-day living costs

- We will develop and provide information that helps cancer patients and their families understand and access the support and entitlements available to them;
- We will reach out to utilities providers, financial institutions and representative bodies to push for more a compassionate approach to dealing with cancer patients and survivors

To reduce the impact of large one-off expenses, we are calling for

- All cancer patients to have equal access to the provision of bras, prostheses and wigs;
- The extension of fertility preservation treatment to cancer patients who are required to preserve their fertility after treatment. Currently, cancer patients can only avail of this before treatment;
- An increase in funding for the Housing Adaptation Grant Scheme, which will help cancer patients have a better quality of life in the family home.

To assist those who face a loss in income as a result of their diagnosis

- We will investigate the barriers facing cancer patients and survivors in returning to work and make recommendations for change;
- We will develop and publicise guidelines on best-practice for patients returning to the workplace and their employers.

To support carers of cancer patients

- We will work closely with carers of cancer patients and their representative groups;
- We will develop information and supports specific to the needs of carers.

The recommendations illustrate the wide range of organisations and sectors that need to work together to reverse the devastating impact of the real cost of cancer.

We believe if implemented these recommendations can make a real difference.

We conclude with a call to action to join us, and fight for change so that no one experiences the devastating financial impact of cancer being faced by families around Ireland today.

You can join the campaign and track our progress on www.cancer.ie/realcost



Methodology

In May 2019, the Irish Cancer Society commissioned Kantar (formerly Millward Brown) to conduct a survey among cancer patients and carers about the specific topic of the financial impact of cancer.

The key objectives of the research were to: Understand the factors contributing to the financial impact of cancer, such as additional costs and effect on earnings.

1. Calculate this impact - by measuring the different elements of this cost and any loss of income.
2. Explore who is most affected and the factors influencing the differences in the financial impact of cancer.

The Irish Cancer Society will use this information to present policy solutions and recommendations and to instigate campaigns that deliver real change for patients faced with huge, continuous financial pressure.

The Research

The research was conducted between May and June 2019 using a quantitative approach via an online survey, allowing participants to provide the details in their own time and privacy. The Irish Cancer Society hosted the survey, designed in conjunction with Kantar on www.cancer.ie.

We also included a question on our national face-to-face omnibus to inform respondents of the survey and if they wished to take part were guided to the Irish Cancer Society website.

At the end of the research period 514 people had participated in the survey. There was a mix of patients and carers, and from those currently going through treatment and those who are no longer having treatment. Over half (57%) had been diagnosed within

the past 3 years, since 2016. One in five (21%) had also had a previous diagnosis.

Once data was collated and analysed we reviewed the types of cancer of most recent diagnosis and discovered that aside 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 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, to take account of this.

Survey participants identifying as having breast cancer was higher than the national incidence rate, while the number of participants with prostate cancer was lower. 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 to this report.



The Financial Impact of Cancer

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

It manages to find its way into almost every aspect of your world and disrupts family life as you know it.

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

The financial cost of cancer is often not considered at the time of diagnosis.

Many of those who took part in our research commented that it was only after their treatment they properly assessed the financial toll cancer took on them. Most people are distracted by the day-to-day medical, physical and emotional impact of their diagnosis.

Our research showed that everyone, from every part of the country, at every age and from different socio-economic groups 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 change their working arrangements upon diagnosis and throughout the course of their treatment.

One in three respondents changed their employment status since their cancer diagnosis. Three in four had their employment circumstances changed in some way post-diagnosis.

Overall the cost of cancer is immense and we have made a conservative estimate of €756 per month, rising to over €1,000 per month in some cases.

“A life-altering experience”

Over three in five of those working have had their income reduced as a result of their cancer diagnosis with annual income reducing by over €18,323, equating to about €1,527 per month.

“Like a bomb went off. It cost a lot of money, has left me weak and in need of assistance, and destroyed my career, earning power and employment options”

“It's caused severe stress on us daily. Going from two excellent long-term full-time careers to social welfare. We even lost our house to the bank and I have missed appointments as we had no petrol to go”

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 55.

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, 47% had a medical card, with just under half of this number receiving a card since diagnosis. 9% had a GP card, while 61% had a Drug Payment Scheme (DPS) card for prescription medicines.

Just under two in three people (62%) had private health insurance at the time of the survey. A further 11% had private health insurance in the past. Over two in five had both a medical card and private health insurance.

Strikingly, 9% 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

Private Health Insurance only

44%

Medical Card only

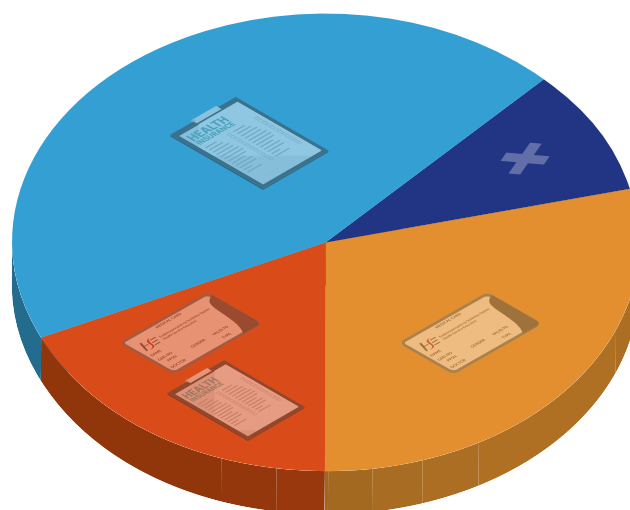
29%

Medical Card & Private Health Insurance

18%

Neither

9%



Overview of Costs Associated with Cancer

The costs associated with a cancer diagnosis are wide-ranging and often unexpected.

Aside from the obvious costs of medical expenses and the significant outlay which many dealing with side-effects must face, there is a plethora of new or increased expenses cancer patients and their families must endure.

Medical expenses which cannot be claimed back:

- Over-the-counter medication
- Prescription medication
- GP visits
- Consultant appointments
- Additional dental care
- Specified dietary supplements
- Hospital stays
- Specialist dressings
- Physiotherapy or other specialist medical care
- Treatment abroad
- Excess charges on Private Health Insurance
- Inpatient and emergency department charges
- Nursing care provided in home

Added costs during treatment and appointments:

- Cost of travel to and from appointments, including petrol, taxi fares and public transport costs
- Car parking charges at appointments
- Cost of eating out while at appointments
- Accommodation when attending appointments and hospital



Increases in day to day living expenses:

- Household heating and electricity bills
- Phone call/mobile/texts/data/broadband expenses/subscription services
- Household food and drink bills
- Pay for additional domestic support
- Childcare costs



One-off purchases such as:

- Wigs, hair pieces, head coverings
- Household modifications or adaptations, for example, a ramp or stair lift
- Fabric supports
- Specific support clothing
- Specialist equipment for your home, for example, a commode
- Specialist dental work and dental care
- New clothes
- Fabric support dressings
- Compression garments
- Support clothing



Patients also suggested the following costs:

- Counselling
- Childcare
- Transport
- Additional food expenses
- Legal fees and expenses
- General household expenses
- Prostheses

Additional personal care costs included:

- Skin care and moisturisers
- Mouthwashes, toothpastes
- Additional clothing
- Specialist shampoos, bath care, soaps
- Entertainment - including books, streaming services, TV
- Other toiletries
- Other personal care and clothing
- Liners/caps for wigs
- Specific support clothing
- Tailored make-up/cosmetics
- Fabric supports
- Absorption pads



Associated Medical Costs

As an initial indicator of the costs faced by cancer patients, we asked survey participants about their overall medical expenditure each month. Over six in ten people (61%) said that they had medical expenses specific to their treatment and, on average, spent €158 a month on medication.

Our research found that eight in ten people experienced side effects while having treatment for cancer and more than two in three 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 Drug 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, the average cost of managing side effects is €67 extra per month.

We asked cancer patients, survivors and carers to consider a number of medical expenses they might have. For those that did have expenses (80%), we asked them to estimate the average costs per month. These results are detailed in the table opposite.

We found that, on average, the cost of medical expenses (which can't be claimed back) are in the region of €261 per month.

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

While a small proportion incur considerable expenses, such as treatment abroad and specialist nursing care in the 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.

Costs for	Affects	Costs on average per month
OTC medication	56%	€53 pm
Prescription medication	45%	€111 pm
GP visits	37%	€81 pm
Consultants visits	29%	€135 pm
Additional dental care	17%	€74 pm
Dietary supplements	16%	€59 pm
Hospital stays	10%	€288 pm
Specialist dressings,	15%	€40 pm
Physiotherapy or other specialist medical care	13%	€113 pm
Excess on Private Health Insurance	17%	€142 pm
Paid hospital charges	13%	€124 pm
Treatment abroad*	3%	€587 pm
Nursing care provided in home*	2%	€359 pm
Other medical care*	8%	€127 pm

Costs Associated with Appointments

Some of the biggest costs patients deal with are when they are undergoing treatment.

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

"It really gobbled up my savings. Not only was the treatment costly but as I live in Sligo and had to travel to Dublin for treatment and for follow up appointments I had to take a job or build up my savings"

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

- 84% incurred travel costs at an average of €164 per month
- 83% incurred parking costs at an average of €64 per month
- 63% had additional costs for eating out of home while attending appointments at an average of €85 per month
- 17% also mentioned accommodation costs associated with attending appointments at an average of €210 per month.

Taking into account these frequently incurred expenses of travel, parking and eating out, the overall average cost associated with attending appointments is €291 per month per person.

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

This includes inpatient charges, which the Irish Cancer Society has spent the past three years working to abolish.

"[I'm] just 17 days into being diagnosed [after] same day admission to hospital. It's complete turmoil and as it goes on the financial burden is sinking in. Not sure what my income is going to be. My husband is using his annual leave to be with me and that's going to run out.

I'm a hundred miles away from home and will be totally alone when he goes back to work. The cost of accommodation in Dublin is beyond our budget. This only adds to what's already going on in my head."

Additionally, it appears the cost of car parking charges, which the Society has pressured Government and the HSE to reduce and produce new guidelines on, has risen slightly. 83% of patients faced these charges.



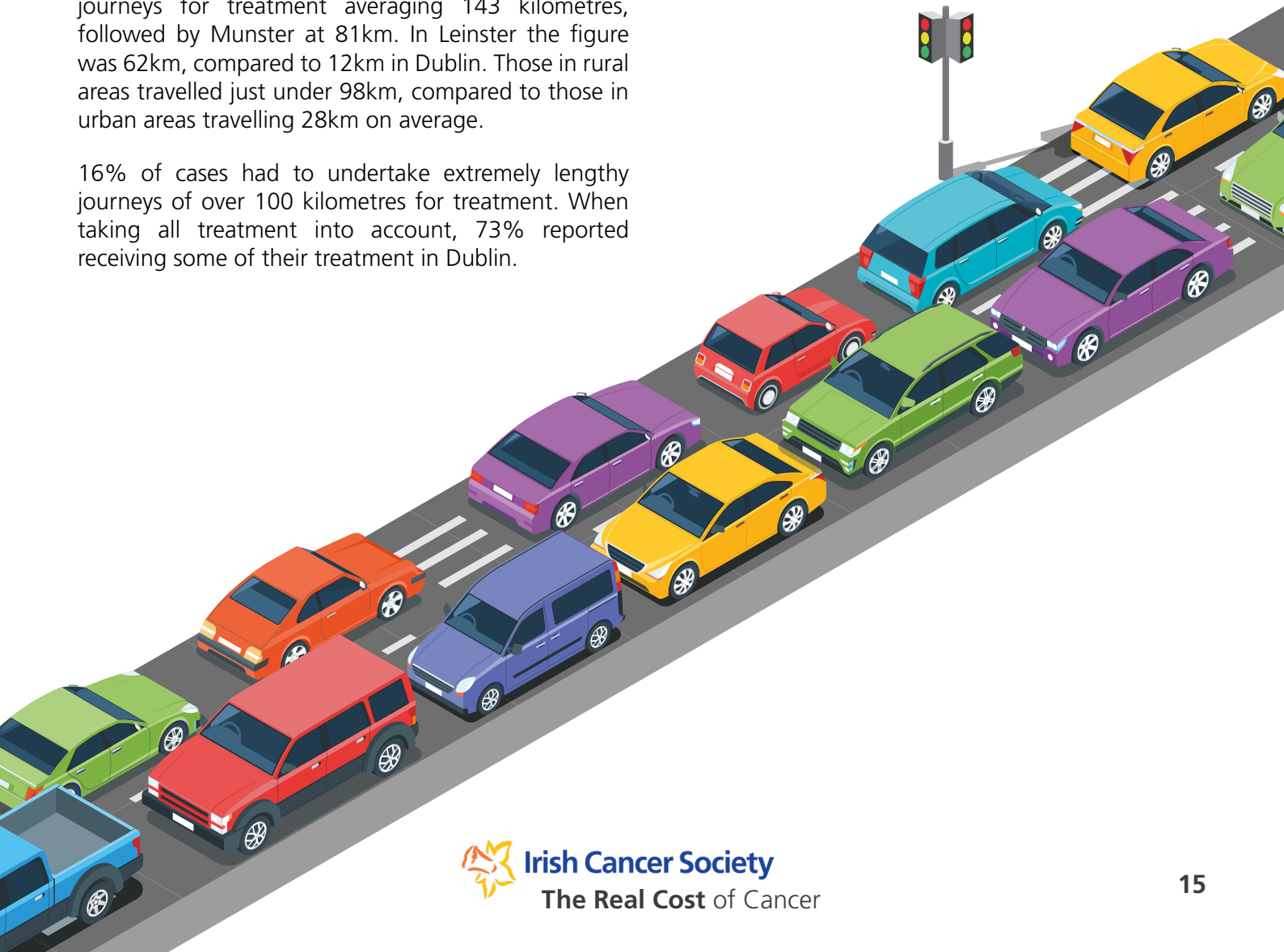


Charges were highest for those living in Dublin at €76 per month and the rest of Leinster at €68 per month, with the remainder still paying somewhere between €40 and €50 per month on parking.

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 hit those in Leinster (outside of Dublin) hardest at €192 per month, followed by Connaught/ Ulster at €171 per month, Munster at €150 per month and finally those from Dublin at €130 per month.

Patients living in Connaught/ Ulster reported the longest journeys for treatment averaging 143 kilometres, followed by Munster at 81km. In Leinster the figure was 62km, compared to 12km in Dublin. Those in rural areas travelled just under 98km, compared to those in urban areas travelling 28km on average.

16% of cases had to undertake extremely lengthy journeys of over 100 kilometres for treatment. When taking all treatment into account, 73% reported receiving some of their treatment in Dublin.



Impact on Day-to-Day Living Costs

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

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

- 49% experience higher heating and electricity bills;
- 37% spend more on phone bills;
- 25% spend more on food and drinks as appetites and nutritional needs change;
- 8% of families had additional childcare and babysitting costs;
- 11% had additional costs for subscriptions such as Netflix;
- Others also had additional outlays for household support (19%), such as cleaners and gardeners.



While 7 in 10 families spent more on these household expenses, more than 1 in 5 actually cut these expenses because they could no longer afford them, causing anxiety and frustration.

“All the extra costs especially the petrol and extra heating costs. I used my credit card which has resulted in me maxing out my card. So every month as well as the expense I have interest on the credit card”

Those in Munster are most likely to experience increases in these types of household costs overall. This is driven by increased household bills and higher food and drink costs.

Those aged 65+ and from wealthier backgrounds are most likely to pay for additional domestic support such as cleaners or gardeners.



Personal Care Items

Other day to day living costs were experienced in the areas of personal care and clothing items.

4 in 5 people 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
- Absorption pads
- Liners/caps for wigs
- Specific support clothing
- Specific make-up, cosmetics
- Fabric supports
- Other toiletries
- Other costs such as entertainment, books or TV

Adding this all up, it is estimated that this increased expenditure costs in the region of €235, although it varies from person to person.



One-off Expenses

Over 72% 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 40% of all women with cancer, equating to a fifth of all survey participants.

Over half of respondents purchased new clothes, for reasons like weight gain or weight loss or sensitivity to certain materials.

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

One in five also mentioned additional dental care and treatment. The average cost recorded by our survey respondents was €622. In some cases, cancer patients require significant dental interventions.

Cancer patients may 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 six respondents spent over €1,900 making these changes.

A further 9% told us that they had to purchase specialist equipment like commodes, at an average cost of over €243.

Other expenses revealed in response to the survey included new beds and furniture, walking sticks and digital thermometers. In some cases patients are paying for prosthetics and there was also the substantial cost of IVF treatment for others, something which the state provides no funding towards currently.



One in six people mentioned additional costly items following their cancer treatment which included:

- Counselling
- Medical treatment
- Food
- Travel
- Child care
- Legal fees

For those encountering these additional costs, the average spend was in the region of €1,200, although it differed greatly depending on the additional cost they had to pay for.



One-off costs such as:	Affects	Average One-off Costs
New clothes	54%	€276
Wigs, hair pieces, head coverings	24%	€500
Specialist dental work and dental care	14%	€622
Modifications to home	6%	€1934
Specialist equipment for home	9%	€243
Other one-off costs	6%	€1,014
Dietary supplements	16%	€59 pm
Hospital stays	10%	€288 pm
Specialist dressings	15%	€40 pm
Physiotherapy or other specialist medical care	13%	€113 pm
Excess on Private Health Insurance	17%	€142 pm
Paid hospital charges	13%	€124 pm
Treatment abroad*	3%	€587 pm
Nursing care provided in home*	2%	€359 pm
Other medical care*	8%	€127 pm

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 one in three of those who participated in the survey had changed their employment status since their cancer diagnosis.

- One in four are retired now, compared to one in five at the time of diagnosis;
- 9% are unemployed now but only 3% were unemployed at the time of diagnosis;
- The number of people working full-time fell from 22% to 15%.

Over 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 Munster and also those aged 50+.

Almost three in five (59%) felt supported by their employer if they decided to change their work status. For those that did change their working situation, almost four in five (79%) said it was their own decision.

The impact of cancer was also felt by carers with nearly one in two (45%) changing their employment status. Meanwhile, over one in three took unpaid leave or worked fewer hours (37%).

Two in five respondents had reduced their salary by over €20,000, with an average reduction in excess of €18,323 per annum, equating to around €1,527 per month for those experiencing a reduction in income.

This reduction in salary is higher among men who are from Dublin.

Three in four (75%) changed their working practices in some way, with 45% stopping working and 24% 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 15% had income protection in place at the time of diagnosis; meanwhile 12% tried to get income protection since diagnosis with only one in ten of these being successful.

“I was not able to return to full time employment for the first 6 months after completing treatment, so my salary was vastly reduced. I subsequently changed jobs 18 months later and reduced [my income] by 15k per annum.

My health has never returned to where it was originally, so I have 30 - 50 sick days per annum which affects my salary”



Other Financial Implications

There are many factors that can either mitigate or aggravate the financial impact of cancer on any one individual or household.

Possession of a medical card, private health insurance or a GP visit card can be a vital support for patients in managing the cost of cancer, but for those who fall between the gaps, the cost of cancer can be especially difficult to deal with.

One in two people who responded to the survey had a medical or GP card. Just under half of those with medical cards were awarded it after their diagnosis. About one in five of those without a medical card had applied for one but had not been successful.

Three in five said they have a Drug Payment Scheme card. This is higher for males in Dublin.

While one in three found the application process for the medical card was relatively straightforward, the average length of time from application to receipt of the medical card was between one to three 3 months (44%). Almost 7 in 10 were waiting for more than a month to receive their medical card.

Over 7 in 10 had private health insurance at some stage, but only 62% currently have health insurance, with 11% of cancer patients or carers no longer paying the premiums.

Despite encouragement to shop around, the vast majority (86%) have not changed providers mainly because they were happy with the current provider (48%), but also because they were worried their premiums would increase or they would be refused cover based on their cancer diagnosis.

15% of patients tried to take out life assurance since their diagnosis, but almost three in four were unsuccessful.

“Having been self-employed for [my] entire working life to survive financially on just disability allowance was difficult”

“I don't have money to pay all the bills, I don't qualify for a medical card and I've no help to fill out the other forms so I'm left in the dark”

“[I] attempted to arrange Life Assurance through a broker but the premiums for someone with my medical history were just too high as I don't have a very high paying job. Possibly in the future if I remain cancer-free then I will be able to”

“My husband died without life insurance so a major impact”

Impact on Family Life

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

When asked how much has cancer treatment interfered with their family life, over one in four people registered this impact at 7 or more out of 10.

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



“It has impacted the whole family. From having to find alternative childcare for a grandchild who we were not able to look after anymore, family members having to forfeit holidays to accompany [me to] appointments, having to update windows and fabric of house to cope with the reduced body temperature, increased wear and tear on [the] car and massive travel costs, it’s greatly impacted our lives”

“It has changed our lives completely, but we now value each day that comes. Ok, financially we would have been better off but what is money when it comes to one’s health? We were fortunate as we had no mortgage and just general out going expenses to meet”

“The financial strain led to serious resentment from my husband and the breakup of our marriage in the end”

“Very difficult making it on social welfare and the stigma of going to their office twice after surgery and then at treatment time. My employer told me to draw my pension fund. It was a stressful time as my child was only 3 at time of diagnosis”

Source of Advice

Cancer patients reported that establishing what financial supports are available to them and their families can be complex and the system is difficult to navigate.

A quarter said the hospital provided information on social welfare benefits but that this mainly focused around medical card and illness benefits.



Received info I was not aware of on:	%
Medical Card Entitlement	40
Illness benefit	26
Reductions and refunds of medical expenses	24
Sick pay entitlements	22
Applying for social welfare payments	19
Disability allowance	17
Nursing supports	16
Living at home supports	14
Carers Allowance	11
Invalidity pension	10
Carers Benefit	9
Supplementary welfare allowance	8
Other	8

“Being self-employed it was extremely difficult to access social welfare support. I closed my business, paid off my creditors and had nothing left. It took 5 months for my wife’s carers allowance application to be approved and even though it was backdated, that 5 months was a real struggle as we had very little income and very high expenses.

But for the generosity of friends, family and neighbours, we would not have been able to provide food for our children. The financial impact after a cancer diagnosis is immediate and significant. In particular the repetitive form-filling for social welfare benefits was overwhelming”

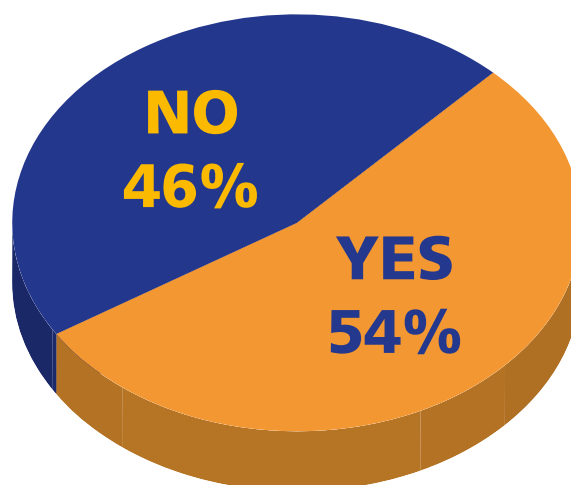
Support Services

Received information on support services when diagnosed

While more than one in two 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. A quarter specifically mentioned the Irish Cancer Society Daffodil Centres in hospitals.

The one in two who received information on support services noted the types of information they received as follows:



If YES, I received info I was not aware of on:	%
Cancer information booklets and factsheets	55
Irish Cancer Society Website	38
Irish Cancer Society	26
Local cancer support groups	24
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Support from the Irish Cancer Society

The Irish Cancer Society 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 freefone 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 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 ([@IrishCancerSociety](https://www.facebook.com/IrishCancerSociety)) and follow us on Twitter ([@IrishCancerSoc](https://twitter.com/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 the centre. Do check to see if there is an Irish Cancer Society's Daffodil Centres 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 the Irish Cancer Society's Daffodil Centre.



Patient Travel & Financial Support

Patient Travel & Financial Support provides practical support to cancer patients and their families through the following three supports available to patients;

- The Volunteer Driver Service is a free, volunteer delivered transport support for patients attending public hospitals for chemotherapy treatments. Diagnosed patients can access the service through their healthcare professional (social worker or oncology nurse) in a public hospital.
- Travel2Care is a transport assistance grant made available by the National Cancer Control Programme to patients travelling over 50km one way to one of the following hospitals for either tests (Form A) or treatment (Form B); Beaumont Hospital; Mater Misericordiae University Hospital; St James's Hospital; St Vincent's University Hospital; Cork University Hospital; University Hospital Waterford; Galway University Hospital; University Hospital Limerick; Letterkenny General Hospital; Our Lady's Children's Hospital Crumlin; St Luke's Hospital, Dublin; Whitfield Clinic (public patients travelling over 50kms for radiotherapy treatment); Altnagelvin Hospital. Form A (travelling for tests) is available on the Irish Cancer Society's website and Form B (travelling for treatment) is available through your healthcare professional
- The Children's Fund is an Irish Cancer Society grant available to children in their 1st, 2nd and 3rd year of cancer treatment. This grant can be accessed through healthcare professionals in any treatment hospital.

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.

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:



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Irish Cancer Society

The Real Cost of Cancer

TECHNICAL APPENDICES
RESEARCH CONDUCTED BY KANTAR 2019

Details on Methodology

As part of the analysis of this research, we have identified the need to apply specific techniques at two stages of the process.

These are as follows:

- Weighting by type of cancer
- Calculation of overall additional expenditure

In this technical appendices we have outlined the approach taken in both instances.



Taking account of type of Cancer

Weighting by type of cancer

The survey was open to anyone with cancer now or in the past, or their carers, to complete; we enforced no restrictions on the criteria other than this.

As part of the survey we asked about the type of cancer they (or the person they cared for) was last diagnosed with. We provided a list of the most widespread cancers, but allowed the opportunity to provide details of other cancers. At the end of the research period, we reviewed the types of cancers experienced by the survey participants and compared this to the known incidence of cancers taken from the National Cancer Registry (NCRI) 2016-2018.

We noted that most cancers were represented at a level which was fairly consistent with the level expected for invasive cancers, within a few percentage (to a maximum of 5% pts).

However, there were two notable exceptions.

These two exceptions were those with breast cancer and those with prostate cancer, two of the most widely diagnosed invasive cancers.

In the case of breast cancer we found that a third (36%) of those completing the survey were doing so in relation to breast cancer. This compared to the NCRI database, which indicated that 14% of all invasive cancers were breast cancer.

We found those referencing prostate cancer accounted for only 7% of our sample compared to 16% reported in the NCRI database.

We believe that this has occurred for a combination of reasons

- 1) More women completed this particular survey compared to men
- 2) Generally, women are more inclined to complete this type of survey and share personal information
- 3) Breast cancer has extensive support networks in Ireland compared to some other cancers and word of mouth may have played a part.

Solution

In order to offset this disparity, we applied weights to the data for those with breast cancer to adjust it down to represent 14% and we up weighted the results for prostate cancer sufferers to represent 16%. The remaining types of cancer were adjusted as a group to represent the remaining 70%. This weighted data has been used throughout the accompanying report.

Type of Cancer	Incidence in Survey %	Incidence in NCRI database %
Mouth & pharynx	2%	2%
Oesophagus	1%	2%
Stomach	1%	3%
Colorectal	8%	12%
Pancreas	1%	2%
Lung	5%	11%
Melanoma skin	2%	5%
Breast	36%	14%
Cervix	1%	1%
Corpus uteri (cervical)	5%	2%
Ovary	2%	2%
Prostate	7%	16%
Testis	2%	1%
Kidney	2%	3%
Bladder	1%	2%
Brain & Central nervous system	4%	2%
Hodgkin's lymphoma	3%	1%
Non-Hodgkin's lymphoma	4%	4%
Multiple myeloma	1%	12%
Leukaemia	4%	2%

Calculating the cost of additional expenditure

Calculation of overall additional expenditure

The main objective of this research is to gather information on the direct costs associated with cancer diagnosis and treatment and the affect this has on work commitments and ultimately income.

In conjunction with the Irish Cancer Society it was agreed that the 2019 surveys should align with the 2015 survey as much as possible. We updated some of the questions with regards to the changes in employment and employment circumstances, but in the main the questionnaire remained in line with the 2015 set of questions.

At the start of the survey we ask some general questions about cost of medicines and also about the cost of managing any side effects in order to get survey participants thinking about costs overall.

Once we had gathered information about their own situation, we then put to them a series of questions about additional expenditure, grouped together by type of cost.

We approached this by firstly asking them if they had experienced a specific cost. If they had, we asked them (through automatic routing) how much that aspect had cost them. For regular expenses we asked for them to supply this cost for an average month, but in other instances, where appropriate, we asked for the total or one-off cost.

The next step we took was to ascertain the proportion of the overall sample who had experienced additional

costs and we found that everyone, 100% of those in the survey, had experienced some cost.

With these findings we then set about to measure the average impact across all those who had provided us with this information.

We did this by taking each individual cost, under the headings below and estimated overall how many people had been affected by these costs; for example, we found that 80% had been affected by any of the medical costs and 94% had been impacted by costs during treatment. We then took the average costs experienced across this type of cost and adjusted it to take account of the incidence level so that it was averaged across all participants.

Incidence in Survey

Costs for	Affects	Average Estimated Cost
Medical Expenses	80%	€261 pm
Costs during treatment	94%	€291 pm
Day to day living expenses	70%	€138 pm
On-off purchases	72%	€569 once-off
Personal care costs	80%	€235 once-off
Additional costs	12%	€144 once-off
Overall Estimated Costs	All	€756 pm

In order to provide an overall cost we calculated the annual cost by multiplying the monthly costs and then added the one-off or total costs for the likes of personal care items and other one-off purchases such as wigs/head pieces, and so on. From this we were able to deduce that on average the cost per month was €756.

This does not include any impact on income levels, only direct additional costs.

However, in order to come up with the above figures we made some assumptions about the cost that were provided and these are outlined in the following page.

As an example, the table here outlines the different costs associated with medical expenses. The list of items is quite extensive, but we also allowed for participants to add details of other costs as they felt necessary.

We were able to calculate from our analysis that 80% experienced at least some of these costs; some may have experienced only one, others more than one. We then calculated the average costs provided for each element.

We analysed the feedback provided in order to come up with a reasonable average cost and following this we made the following adjustments:

- Some costs were experienced by only a few people, but were very expensive when they were incurred, such as Treatment abroad and Nursing care provided in home. In order to be reflective of the usual experience of cancer patients and carers we excluded these rare costs from our overall calculation as they had considerable impact on the overall calculations, given their expensive nature
- On reviewing the reason for other medical care costs we believe that these are covered by other aspects of our survey and cost calculation so in order to avoid duplication we have excluded 'other costs' throughout our calculations.

From this we calculated the overall cost of medical expenses to be €261 per month.

This has resulted in a more conservative estimate, but we feel it is reflective of the experience of most of the survey participants.

We have taken account of the proportion of the participants who have experienced each different element of these additional costs and have averaged the costs they incurred.

We have removed any extreme costs that have an extreme influence on the average costs.

We have excluded the amounts under other costs in each section as these mainly are covered in other sections of the survey.

If all costs were included, then the average cost would be in the region of €1200-1400 per month. We recommend that the average costs of €756 per month is more reflective of the experience of most cancer patients and their carers.

Incidence in Survey

Costs for Medical Expenses	Affects	Costs on average per month
OTC medication	56%	€53 pm
Prescription medication	45%	€111 pm
GP visits	37%	€81 pm
Consultants visits	29%	€135 pm
Additional dental care	17%	€74 pm
Dietary supplements	16%	€59 pm
Hospital stays	10%	€288 pm
Specialist dressings	15%	€40 pm
Excess charges on Private Health Insurance	17%	€142 pm
Paid hospital charges	€13	€124
Physiotherapy or other specialist medical care	13%	€113 pm
Treatment abroad*	3%	€587 pm
Nursing care provided in home*	2%	€359 pm
Other medical care*	8%	€127 pm

