



The Medical & Financial Impact of a Cancer Diagnosis

Submission by the Irish Cancer Society to the Expert Panel on
Medical Need for Medical Card Eligibility

30th June 2014

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Opening statement

This year in Ireland, more than 30,000 people will hear the words “you have cancer”, and with these words, their lives will change forever.

They will start on a journey which, for a growing number, will see them restored to full health. During their treatment, however, they will need complex and demanding medical care. Cancer creates an urgent and in some cases massive medical need.

A lot of other things may happen to the patient, as a result of having cancer.

They may have to give up work, even if they work for themselves. They may have to have their children cared for while they go for treatment. They may have to travel long distances. They may have to pay for some drugs. They may need to visit their GP a lot more than before. They may need to go to the A & E Department if they fall ill. They may not be able to pay their mortgage, putting them under more stress. They may need to buy expensive wigs. They may need to have very costly dental treatment. They may need physiotherapy. They may have lifelong conditions to manage as a result of their treatment.

The full consequences of being treated for cancer are not widely understood, outside the community of cancer survivors and those who support them, including the Irish Cancer Society. There is no doubt that the pressure on cancer patients is increasing.

That is why we are making this submission. As the voice of cancer patients in Ireland, we ask that cancer be included as a condition which bestows automatic eligibility to a medical card.

We ask that positive consideration be given to our submission.

John McCormack,
Chief Executive,
Irish Cancer Society.

Overview

Cancer is a very serious condition for any individual that can have fatal consequences. An average of 19,200 invasive cancers (excluding non-melanoma skin) were diagnosed every year between 2009 and 2011, equivalent to an incidence rate of 425 cases per 100,000 per year¹.

No barrier should exist for people who have cancer to be able to access diagnosis and treatment in hospital and to access community based services. When people are diagnosed they require the highest standard of treatment, care and follow-up. The Irish Cancer Society firmly believes that all those with a diagnosis of cancer should have access to a medical card for the duration of their treatment, including cancer patients whose cancer has returned and for those who have progressed to needing palliative care.

The Society is asking the Expert Panel on medical cards to give particular consideration to the impact of cancer on people lives and on their working lives.

Cancer is the second leading cause of death in Ireland after diseases of the circulatory system². Cancer is not a single disease with a single type of treatment. There are over 200 different types of cancer, each with a specific name, treatment and chance of being cured. There are about 22 cancer types mainly diagnosed in Ireland³. The five most common cancers are (non-melanoma) skin cancer, prostate, breast, bowel and lung.

62,000 years of life were lost to cancer in 2010, more than to any other cause.⁴

Whilst over 34,000 people will be diagnosed with cancer in 2014 according to the National Cancer Registry Ireland (NCRI), not all cases are life-threatening or require treatment. Just over 8,500 of these cases will be a non-melanoma skin cancer (this is mostly non-invasive, rarely fatal and is cured by surgical removal) and a fifth will be non-invasive. Unfortunately for the remaining 19,200 cases there will be multiple hospital appointments, interventions and follow-up for life in some cases, and for several years in other cases.

Estimates from the NCRI suggest that there are more than 134,000 people living with a diagnosis of cancer in Ireland, 59,500 men and 75,000 women.⁵

The emotional impact of a cancer diagnosis cannot be underestimated. At the outset the patient receives a large amount of medical information from their oncologist and choices about course of treatment, prognosis, outcomes etc. The Society repeatedly hears from cancer patients that at the outset of diagnosis they simply didn't have the physical or

¹ 'Cancer in Ireland 1994-2011': Annual report of the National Cancer Registry (NCRI) 2014

² NCRI

³ 'Cancer in Ireland' NCRI Annual Report 2011

⁴ 'Cancer in Ireland 1994-2011' NCRI 2014

⁵ 'The Financial Impact of a Cancer Diagnosis' NCRI 2010

emotional resources to consider applying for a medical card. When they did start the application process they found it stressful and burdensome. For cancer patients to have the assurance that they would receive a medical card upon diagnosis would alleviate a lot of financial and emotional distress for them.

“And it’s at a time in your life when you are most vulnerable. It’s at a time of your life where worry should be, if possible, taken off you. Even if it’s only for a short period of time the time of your treatment is a time when you most need to have your mind focused. And your mind needs to be focused on making yourself better, not worrying about the finances.”

- A cancer patient⁶

Indeed, a study done by leading cancer charity, Macmillan Cancer Support in the UK, found many patients claimed that financial concerns were second only to pain as a cause of stress⁷.

Treatment is the most expensive time for a cancer patient. Generally they are unable to work. They may be hospitalised or unwell so may need childcare assistance. They have hospital bills, transport costs, drug costs, medical equipment costs etc. Additionally, often spouses have to take time off work in order to care for the patient during this time.

For these reasons we are asking the Expert Panel to prioritise cancer as one of the medical conditions that entitle a person to a discretionary medical card, irrespective of their means.

Given cancer’s position as the second leading cause of death in Ireland and the complex, individualised nature of cancer treatment the Irish Cancer Society firmly believes that cancer should be top of the priority list when considering what medical conditions would benefit most from medical card eligibility.

Medical Impact

Cancer is a unique disease as every cancer diagnosis is individual and the course of treatment can be varied and complex. In this regard it differs significantly to many of the other fatal diseases.

⁶ ‘The Financial Impact of a Cancer Diagnosis’ NCRI 2010

⁷ ‘Macmillan Cancer Relief study into the benefits advice for people with cancer.’ Quinn 2002

Treatment for a cancer patient regularly involves surgery, chemotherapy, biological therapies, immunotherapy, hormonal therapy and radiation therapy. Most people will have more than one treatment type with many having three or more treatment modalities which may be given over varying lengths of time including months and years. As a consequence of having cancer and enduring treatment many side-effects can develop in the short and longer term that cancer patients have to live with. This can often be very debilitating and require ongoing care, medical management and support from other disciplines allied to medicine.

While more than half of all cancers are cured, the remainder progresses to secondary conditions requiring further treatment and care. This has a major impact on family and work life.

In order to illustrate the cancer journey for some patients we have given some examples below of the treatment consequences for some of the common and complex cancers.

These examples are only scratching the surface and serve only to demonstrate how the complexity of cancer care can become an extraordinary burden on the individual and their family. In the short timeframe given for submissions to the Expert Panel it is impossible to capture a comprehensive picture.

Cancer of the Mouth, Head and Neck:

These cancers require multiple specialists to be involved in their care and generate complex needs including:

- Patients require a tracheotomy that can be either temporary for several months or permanent. In order to be discharged home safely they require specialised equipment. If they don't have a medical card they have to buy it themselves. They will also need suction catheters and a nebuliser (costs €150- €250).
- There are other expenses associated with a tracheostomy (dressings, cleaning solutions, special tapes, and cleaning brushes) which will be required for as long as the patient has a tracheostomy.
- Patients may need a suction machine at home (cost €645 - €1466).
- Patients require a PEG feeding tube into the stomach to allow for nutrition as they are unable to eat or drink.
- Patients need dental extractions from one or two teeth to entire upper or lower set of all teeth and require ongoing dental care and oral hygiene management.
- Patients need dental shields so they can undergo radiotherapy.
- Patients require speech therapy to assess their swallow reflex and to re-educate their ability to speak.
- Patients require multiple visits to hospital or GP for unblocking of tubes, dealing with infections as a consequence of not being able to afford good care of tubes (they require specific hygiene practices and replacement by medical staff at intervals) in the longer term.

- Patients require access to expert dietician for specific dietary support when making a recovery post treatment and when tubes are removed several months later. This group often need to purchase blenders, juicers etc.
- Patients require ongoing public health nurse support during early phase of disease and sometimes later phase.
- In this example if a patient did have a medical card they would be covered for speech therapy, visits from the public health nurse, free GP visits, possibly dental treatment, dental shields, and medical equipment they need - suction machine, nebuliser. (Access to PHN and all community based support is guaranteed with a medical card whereas it is discretionary otherwise.)

Oesophageal cancer

These patients require additional support around the consequences of treatment and co-morbidities.

- Patients require a peg tube into the stomach to allow for nutrition.
- Patients require many over the counter products to support their well-being and digestive function.
- Patients require multiple visits to hospital or GP for unblocking of tubes, dealing with infections as a consequence of not being able to afford good care of tubes (they require specific hygiene practices and replacement at intervals) in the longer term.
- Patients require ongoing public health nurse support during early phase of disease and sometimes later phase.
- Patients will require support of dietician to help with malnutrition, weight loss and weight gain.
- Patients will need smoking cessation support.
- In this example if a patient did have a medical card they would be covered for NRT therapy as part of smoking cessation, visits from the public health nurse, and free GP visits.

Lung cancer

Lung Cancer is the biggest cancer killer in Ireland and worldwide. The majority of these patients are diagnosed at an advanced stage of disease and care often requires palliative interventions from the start. Patients with early stage disease generally have extensive surgery which equally requires considerable recovery.

- Patients require smoking cessation interventions.
- Both early and late stage patients commonly require portable oxygen for the home.
- Advanced stage patients require wheelchairs due to breathlessness.

- These patients also require significant adaption of their home (bathrooms and bedrooms relocated downstairs) because of the severity of their breathlessness.
- An important consideration is that Lung cancer has high mortality rates and low survival rates, so patients tend to be diagnosed with advanced disease and are extremely unwell. This has a knock on effect on family life and carers are forced to adapt resulting in travel costs, childcare costs and loss of earnings. This is reflected in the financial aid applications to the Irish Cancer Society.
- Lung cancer patients are the most distressed group of cancer patients due to symptom severity, poor prognosis, stigma and blame. Patients and family members often resort to private counselling services to help them cope.
- Patients who have lung surgery require supportive care from physiotherapists, public health nurse, occupational therapy and their local GP and require many over the counter products to support their general wellbeing and respiratory function.
- Palliative care services and nursing care in the home are considerable costs for lung cancer patients and their families. Lung Cancer patients avail of the Irish Cancer Society's Night Nursing Service more than any other patient group each year.
- In this example if a patient did have a medical card they would be covered for NRT therapy as part of smoking cessation, visits from the public health nurse, occupational therapy, free GP visits, possibly some counselling, medical equipment such as oxygen, wheelchairs, adaptations to the home, home help and physiotherapy.

Blood (Haematological Cancers) Leukaemia, Lymphoma and Multiple Myeloma

- Patients with blood cancers commonly have intravenous devices in place such as a PICC / Hickman lines which require specialist medical management. Patients are not always in a position to travel to the hospital and the PHN nurse may not be available / suitable to provide this care. Patients attend their GP frequently and have the associated cost of visit each time.
- Patients often require hospitalisation for extensive periods of time. This has a knock on effect on families, child care, transport costs etc.
- These patients experience significant levels of pain.
- Patients who have low grade diseases may be on treatment that is not covered on high tech prescriptions.
- In this example patients with a medical card would have access to free GP visits.

Female Breast

Patients with breast cancer may be treated surgically with either lumpectomy or mastectomy.

- Surgical procedures can result in a defect in the contour of the breast requiring breast prosthesis which needs to be fitted and replaced at least every 2 years.

- Patients require special bras with a minimum requirement of 2 bras per year. This is a lifetime requirement or until the patient has breast reconstructive surgery.
- The financial burden of Lymphoedema treatment is considerable and well recognised. Access to a medical card allows free physiotherapy for this condition.
- Cost of Lymphoedema garments for arms during and post treatment. Most patients require made to measure garments. The Irish Cancer Society gives some financial aid towards Lymphoedema treatment.
- Current cost of some hormone therapies i.e. anastrozole is over €100 for a month's supply, under the DPS scheme. This is normally long term medication (5 yrs.)
- In this example a patient would be entitled to specialist bras, breast prosthesis, physiotherapy, and garments for treatment of lymphoedema. They would also have the cost of their hormone therapy covered.

Prostate

3000 men are diagnosed each year. The majority of these men have either surgery or radiotherapy (with or without hormone therapy). The majority of the remainder will have hormone therapy alone and a small number of men will have no active treatment.

- Incontinence after surgery: Men can expect to need up to 4/6 pads a day, typically for 3-4 months following surgery. A small number of men have lifelong need for pads.
- Care of urinary catheter and wound post-discharge (public health nurse).
- Access to physiotherapy for those with urinary incontinence.
- Erectile dysfunction is common after both surgery and radiotherapy. Oral treatment for ED is restricted to 4 tablets a month for those with a medical card. Our Helpline has received requests for information to buy from overseas due to prohibitive costs for those without a medical card.
- Penile rehabilitation. Many doctors advocate taking oral medication twice weekly after surgery to help recover erectile function or to use a vacuum pump. Vacuum pumps are not currently covered on medical card (costs €199-€300).
- Hormone Therapy - can be from 6 months-3 years and lifelong in the case of advanced disease. Through tablet form and GP visit for administration of the injection.
- In this example the patient would be entitled to up to 4 incontinence pads a day; access to a public health nurse; physiotherapy; erectile dysfunction tablets; hormone therapy and visit to GP for hormone injection.

As highlighted in the examples above, for many cancer patients, if they do not have a medical card, there are significant medical costs arising from your cancer treatment.

Listed below are the highlights of the extra costs a cancer patient will incur if they do not have a medical card.

Extra costs for a cancer patient without a medical card

- **GP visits**
Many cancer patients will have frequent visits to their GP. We at the Irish Cancer Society believe that being able to access a GP free of charge during treatment and recovery from cancer would greatly benefit the over-burdening of the hospital system and direct patients into good quality primary care.
- **Medications**
Patients availing of the drug payment scheme are required to pay €144 euro a month for approved prescribed drugs, medicines and certain appliances. Cancer treatments e.g. Chemotherapy commonly requires supportive medications that are expensive and are not always covered by the DPS. Some medications are particularly expensive and are not covered by high tech scripts or the drug payment scheme. We have heard of patients who stopped treatment without telling their medical team because they couldn't afford to get their prescription filled.⁸
- **Medical equipment**
During treatment: Surgical Dressings / stoma care / nephrostomy care / incontinence care / prostheses / wigs/ pumps / suction machines / wheelchairs. At palliative care stage: Beds / Mattresses / commodes / safety measures - e.g. railings / house modifications etc. A significant number of Financial Aid applications are made to the Society for the above equipment.
- **Access to allied Health Care Professionals**
Following surgical management, patients often require support of allied health care professionals e.g. Speech therapists, occupational therapists, physiotherapists, dieticians, dentists and nurses in the community setting. Many patients without a medical card are forced to pay for private services for years following treatment.
- **Dental care**
Patients often require dental services before surgery and drug therapies are commenced. In these instances a dental card should be considered. We have received a small number of financial aid applications towards dental care.
- **Surgical Dressings**
Patients who are sent home with wounds that needs to be dressed every day, have to pay for dressings. In some areas if patients do not have a medical card, they do not have access to PHN to attend to the dressings. This results in extra GP visits and associated costs.

⁸ Oncology nurse

- **Wigs**
All patients on chemotherapy and radiotherapy incur extensive costs for hairpieces / scarves in the absence of a medical card. Wigs vary in price from approximately €350 to €1000 and patients usually require two for the duration of their hair loss which can extend over a 12 month period or sometimes longer.
Wigs also require maintenance for palliative patients who experience hair loss over long periods of time while on maintenance treatments.
- **Hospital charges**
Patients who do not have a medical card have to pay for out-patient charges (€100), A&E charges (€100) if they are not referred by their GP (to attend their GP in the first place to get the referral would cost €50-€80).
Public in-patient charges are €75 per night, up to a maximum of €750 in one year.
Cancer patients attending chemotherapy would generally have to pay day-ward costs of €75 per visit.

Even if a patient has a medical card they can incur additional expenses:

A prescription charge on each item dispensed of €2.50 per item up to €25 maximum per month. A medical card does not cover over the counter medication, mouthwashes, pain relief medication, manual lymph drainage, complementary or alternative treatments, some procedure costs such as ultrasound or PET scans, all incontinence pads or constipation treatment. Patients on many of the new target therapies need to use SPF creams and specific moisturising creams, which can be extremely costly.

“Patients are avoiding attending GPs or ED in between their hospital appointments because of cost.” - An oncology nurse

This chapter highlights that a cancer diagnosis has a very significant medical impact for patients involving complex treatment and medical complications which they will take home. The patients who do not have a medical card face significant costs to care for themselves at home. What is particularly stark is that without a medical card they do not have guaranteed access to a public health nurse or allied community based health professionals. In addition to this they do not have free GP care. This creates a cost barrier for some of them and they simply put off going to their GP.

Without the support of a public health nurse or being able to afford GP visits some cancer patients cannot attend to their wound dressings / stoma care / PEG tube and end up back in an acute setting. We have heard of one instance of a post-rectal surgery patient who

had to be readmitted to hospital to treat his VAC therapy dressing as he couldn't be treated in the community setting for this as he did not have a medical card. He occupied a surgical bed for 8 days. This incident is not unique.

Another major cost for cancer patients without a medical card is the €144 contribution to the DPS scheme.

For these reasons the Irish Cancer Society strongly believes that cancer patients should be entitled to a medical card during treatment based on their medical need.

A cancer patient's journey – aged 59, anonymous*

In September 2003 I was diagnosed with breast cancer after finding a small lump in my breast. I was married with 3 children aged 10 to 16 and working as a primary school teacher.

I began a year of treatment - 3 surgeries, six months of aggressive chemotherapy, and six weeks of radiotherapy. At the time I did not consider applying for a medical card. But, there were huge costs involved - medications, a wig, breast prosthesis, surgical bras, travel to and from hospital, parking fees, extra heating etc. - which caused severe financial strain.

I finished treatment in August 2004. I applied for six months unpaid leave to recover. I had now run out of sick leave.

Unfortunately, within a few weeks (September 2004) I was diagnosed with secondary breast cancer, with multiple metastases in my spine. My condition was now deemed incurable and prognosis was very poor. Treatment would be palliative with the aim of containing the cancer for as long as possible.

I attended St. James hospital weekly for I.V. treatment with Herceptin and 4 weekly Zometa - a bone strengthener. I also took a high tech oral chemotherapy - Zeloda- twice daily. I needed several other medications to deal with side effects – anti-nausea tablets, proton pump inhibitors, painkillers, eye-drops and sleeping tablets.

I had severe side effects - nausea, fatigue, dry eyes, infections, severe hand/ foot syndrome (which caused difficulties using my hands and walking more than a short distance). I required creams, ointments, special socks and shoes. I remained on this treatment for 4 years until the side effects became intolerable.

I developed lymphoedema and needed to attend a physiotherapist for manual lymph drainage and compression treatment. Firstly the treatment was daily, then weekly and monthly as it stabilised. Again it is a lifelong incurable condition. I require compression sleeves and gloves.

As a side effect of the treatment, and due to the risk of osteonecrosis of the jaw because of the Zometa treatment, I needed complex treatments in the Dental Hospital on a regular basis. I attended the psycho-oncologist to deal with the devastation caused by my terminal diagnosis. Due to lowered immunity I attended my G.P. or hospital at the first signs of illness. I had regular scans CT , MRI and heart scans every 3 months.

I had no option but to retire from my teaching job on the grounds of ill –health. We were under severe financial strain. In the early years my husband job shared to assist in my care. He later took early retirement.

I applied for a medical card. When I did apply it took several stressful months and the intervention of the hospital liaison nurse before I was finally awarded a medical card - valid for 1 year.

Nine months later I got a renewal form and the whole stressful process started again. This time my card had expired for 6 months - causing huge problems - before it was renewed, on the intervention of the public health nurse. And so it continued each year causing huge stress at a time when I needed all my resources to deal with my illness.

In 2010 my medical card was withdrawn and I was given a GP visit card. Again it had to be renewed yearly with the same stressful bureaucracy. In 2013 due to the stress involved and the negative press I decided it was not worth the effort and lost my card.

While thankfully I responded exceptionally well to treatment, have long outlived my prognosis and my cancer remains stable, I remain on treatment and attend the hospital 3 times weekly for I.V. Herceptin and Zometa, have regular CT, MRI and heart scans.

I attend the physiotherapist for lymphoedema treatment; need medications; compression sleeves; breast prostheses; surgical bras; and attend the Dental Hospital for any dental problems. I do not have the security of a medical card.

Through my own experience, my contact with other patients, and my voluntary work as a peer to peer supporter with the Irish Cancer Society I know how vital a medical card is to patients and how much stress and upset the present system causes. They absolutely need to be awarded a medical card on medical grounds so they can concentrate on dealing with their illness, and have the security of knowing that their medical needs will be met.

** This is a truthful account from a cancer patient*

Non-Medical Impact

Many cancer patients face medical costs as a consequence of their diagnosis as outlined above, particularly if they do not have a medical card. However, all patients regardless of whether they have a medical card or not, also feel a significant financial impact that is non-medical as a consequence of their cancer diagnosis. For instance a decrease in earnings, transport costs, childcare costs, and increased household bills.

For a long time the Irish Cancer Society has been aware that, for many people, a cancer diagnosis has not only been a health and psychological burden, but also a considerable

financial burden. For this reason the Irish Cancer Society provides financial support to cancer patients. In recent years we have been increasingly hearing from distressed cancer patients about the significant financial stress they are suffering.

An Irish study showed that 49 per cent of cancer patients reported increased financial stress and 32 per cent increased financial strain due to a cancer diagnosis.⁹

Another study found that patients' costs for those diagnosed with colorectal cancer amounted to an average of €12,782 for the first three months, a figure that was mirrored for caregivers.¹⁰ A Macmillan study from 2013 showed that 83 per cent of people diagnosed with cancer are £570 (€710) a month worse off as a result of the diagnosis.¹¹

“I suppose when you get sick first and mortality is kind of staring you in the face, you don't think about money. And then as you go along I suppose things are going ok. You know, you feel things are getting better (pause) you start thinking about money then, that's what I'm saying, you know. It hits like, you know.”

- Cancer patient¹²

The significant implications of cancer treatment on an individual and their families during Ireland's recession is borne out by the corresponding rise in applications to the Irish Cancer Society's Financial Aid Scheme.

Between 2000-2010 the Society has seen a doubling in demand for financial assistance paying out €3.5 million in grants between 2005-2010¹³. In the first quarter of this year there was 12 per cent increase in financial aid applications compared to last year. Overall there was a 5 per cent increase in applications from 2012 to 2013. Additionally, 18 per cent (1,332) of all enquiries to our Daffodil Centres related to financial issues in 2013.

If cancer patients are unable to afford these very basic provisions we offer assistance for,¹⁴ we think they are also unable to pay for regular GP visits.

The Society provides over €1 million a year to cancer patients who need financial help. Revealingly a majority of our applicants have medical cards. This highlights the significant

⁹ 'Associations between cancer-related financial stress and strain and psychological well-being among individuals living with cancer.' Linda Sharp, Aileen Timmons et al.

¹⁰ NCRI 2013 Linda Sharpe et al.

¹¹ 'Cancer's Hidden Price Tag' MacMillan 2013

¹² 'The Financial Impact of a Cancer Diagnosis' NCRI 2010

¹³ 'The Financial Impact of a Cancer Diagnosis' NCRI 2010

¹⁴ Grants are available for up to €1,000 from the Irish Cancer Society. Typically grants are awarded for one or more specified purposes, such as costs of travel to treatment appointments, fuel costs, cost of a wig, costs of home modifications, etc.

burden faced to those who additionally do not have a medical card. (From feedback, the Society believes our applicants tend to be medical card holders - not because non-medical card holders do not need the financial aid but because medical card holders will hear about our schemes from their medical social worker.)

In 2010, the National Cancer Registry of Ireland (NCRI) published a report funded by the Irish Cancer Society called 'The Financial Impact of a Cancer Diagnosis'¹⁵. It found the following:

- 45% of cancer patients paid fees for a hospital consultation (average amount €465).
- 36% had incurred costs for seeing a GP (on average €250).
- 29% incurred costs for prescription medications (on average €300) and 39% for over-the-counter medicines (€100 on average).
- 13% had paid for dietary supplements.
- 40% of breast cancer patients had incurred costs for wigs or hairpieces, spending on average €400.
- 79% of patients had transport costs. On average travel costs were €360 and parking were €75.
- Of those who were working at the time of diagnosis, 83% took some time off.
- Of those who took time off, half received some sick pay.
- 30% had a decrease in household income.
- 47% said household spending had increased.
- 55% had to use some or all of their savings.

In this survey 75 per cent of the participants had a medical card, which shows that even with a medical card cancer patients face a significant financial impact from a cancer diagnosis.

¹⁵ 'The Financial Impact of a Cancer Diagnosis' NCRI 2010

These findings are echoed in a Macmillan report which found that finances were negatively affected in 91 per cent of cancer patients' households.¹⁶

Employment

Most cancer patients are not able to continue to work during their illness and need to take some sick leave. In the initial stages after diagnosis, some patients will continue to work, but they usually have to stop when treatment starts, particularly chemotherapy. Occasionally patients will be well enough to work for a few hours, or at home, or between treatment sessions but whether this is possible depends on the flexibility of their employer. The discretionary nature of sick leave means that patient experiences vary.

Even if they do continue working part-time or receive sick pay almost all experience a decrease in income during treatment. Research by Macmillan said there is an average fall in income among working households of 50 per cent after diagnosis.¹⁷

A second breadwinner in the family may also be forced to take time off or reduce hours to care for a cancer patient during their illness and treatment. This adds further to the financial distress being experienced.

40 per cent of cancer survivors are of working age.¹⁸ An Irish study into employment and cancer diagnosis showed that 25 per cent were working at the time of diagnosis and 18 per cent continued working post diagnosis and 18 per cent left the workforce.¹⁹ Among those that resumed working the median absence was 30.1 weeks. This was the first study conducted into employment outcomes in cancer survivors in Ireland and it showed a high level of workforce departure and contributing factors to this were sick pay and medical card status.

As well as substantial loss of earnings for patients and family members, this results in lost productivity, the cost of which is borne by employers and society as a whole. Considering that there are 34,000 new cases of cancer diagnosed each year in Ireland²⁰, this suggests that the burden of cancer on employers and society is substantial.

According to leading UK cancer charity, Macmillan, one in three cancer patients will experience a loss of income on average of €1072 per month. A further third stopped working temporally or permanently.²¹

Some groups of cancer patients seem particularly vulnerable, those with young children and high mortgages, and those who are working at the time of diagnosis.

¹⁶ 'The hidden price of getting treatment' MacMillan 2006

¹⁷ 'The hidden price of getting treatment' MacMillan 2006

¹⁸ 'Social Welfare and legal constraints associated with work among breast and prostate cancer survivors: experiences from Ireland.' Linda Sharp, Aileen Timmons.

¹⁹ 'Social Welfare and legal constraints associated with work among breast and prostate cancer survivors: experiences from Ireland' Linda Sharp Aileen Timmons.

²⁰ NCRI

²¹ 'Cancer's Hidden Price Tag' MacMillan 2013

Self-employed patients are particularly vulnerable financially, since they may not have sufficient social insurance contributions for entitlement to illness benefit and may not be eligible for means-tested payments.

Other extra costs

As well as suffering a drop in household income at the same time cancer patients face an increase in costs. A major cost for cancer patients is transport costs to medical appointments and parking costs at hospital (70 per cent of cancer patients face this extra cost)²². This is particularly acute whilst patients are undergoing treatment and attending hospital for chemotherapy. Additionally, this cohort of patients will often not be well enough to travel on public transport or for those patients that live a distance from hospital they may need overnight accommodation. Other associated costs for a cancer patient are meals whilst at appointments; increased household bills due to more time spent at home or extra heating as of being unwell; new clothing due to weight change; house modifications (e.g. move bathrooms or bedrooms downstairs, or install a stair lift); help with housework; increased telephone bills; childcare costs; dietary supplements; dressings; counselling for patient or their family.

Conclusion

We are highlighting these non-medical costs in order to emphasise that for almost every cancer patient during treatment there is a decrease in household income whilst at the same time there is an increase in household and general costs. For patients without a medical card they are faced with these increased non-medical costs, whilst at the same time having to pay for many of their medical costs as well. This is placing cancer patients without a medical card in a financially vulnerable position. Over the last few years with an economic recession occurring and the restructuring of the medical card system the Society is hearing more and more from financially distressed cancer patients.

In our opinion the current medical card system is failing many cancer patients. There has been an overemphasis in the past to a person's financial means, without due regard to their medical need and the costs associated with that as well.

This submission gives an indication of the many costs that are associated with cancer. For many the financial burden of surviving it can be almost as stressful as the disease itself.

The Society asks that all those with a diagnosis of cancer should have access to a medical card for the duration of their treatment, including cancer patients whose cancer has returned and for those who have progressed to needing palliative care.

If their cancer is in remission and they are free of medical issues then they no longer need their card as there is not a 'medical need'. However, there may be cases where they are free of cancer but they are suffering from medical consequences arising out of their

²² 'The Hidden Price of getting treatment' Macmillan 2006.

cancer treatment i.e lymphoedema, incontinence, erectile dysfunction, the need for hormone therapy or physiotherapy, dental care, stoma care, etc.

In these instances it would seem logical and fair that they would retain their medical card whilst they are still in 'medical need'.

The Irish Cancer Society strongly believes that cancer deserves to be prioritised on the list of medical conditions that would entitle you to a medical card. Many cancer patients would benefit enormously from medical card eligibility.

ENDS.

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