

# Service Impact Summary Report 2019

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# 1. About this summary report

The Irish Cancer Society (the Society) is committed to monitoring the impact of our programmes and services.

We have created a collection of data banks to assess the impact of our services on service users at 4 key stages: prevention, support, survivorship and palliative care.

These data banks will help us to identify the positive changes our services bring to the people we aim to support. We also aim to develop a better understanding of how we can improve our programmes and services for the future.

This report will describe our programmes and services as well as give a summary of the impact monitoring project. It will also outline the main impact findings from the 2019 data banks.

## Cancer in Ireland

Cancer is a growing public health problem, with households across Ireland being affected in some way. By 2020, 1 in 2 people will receive a cancer diagnosis in their lifetime (1). Cancer was responsible for one-third of all deaths in 2013 (1). The percentage of deaths attributable to cancer has risen from 20% in the 1980s to over 30% today (1).

## Cancer cases are increasing

The number of cancer cases has been increasing by almost 3% a year since 1994 (1). Reasons for this include an increase in risk factors such as obesity, alcohol consumption and sun exposure. There is a higher incidence of cancer in more deprived populations.

**BY 2020  
1 IN 2  
OF US WILL  
DEVELOP CANCER  
IN OUR LIFETIME**



## Cancer is preventable

Four in 10 cases of cancer are preventable due to modifiable lifestyle and environmental factors (1). Of these, smoking is by far the most significant. Others include excess body weight, poor dietary choices, physical inactivity, alcohol consumption, specific infections, radiation (ultraviolet and ionising, including radon) and occupational hazards. However, a national survey found that the Irish population is largely unaware of cancer risk factors (2). This highlights a need to both raise awareness about the causes of cancer and to provide services that support people to live healthier lives.

### 10-YEAR SURVIVAL RATE FOR PROSTATE CANCER IS

**89%**

### 10-YEAR SURVIVAL RATE FOR LUNG CANCER IS

**15%**

## Cancer survivorship

People are surviving cancer for longer. Cancer survivorship begins at the time of diagnosis and continues until the end-of-life. There are more than 170,000 people living with and beyond cancer in Ireland today (1). Overall, the 5-year survival rate has increased from 44% for patients diagnosed between 1994 and 1998 to 61% for those diagnosed between 2009 and 2013 (1). At the Irish Cancer Society, we recognise the need to support cancer survivors by providing access to services, information and resources, which can maximise their quality of life.

## Palliative care

Palliative care is an approach that aims to improve the quality of life of patients and their families facing the challenges associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and treatment of pain and other problems, physical, psychosocial and spiritual (1). Palliative care services are organised into specialist and generalist services that operate in partnership, as part of an integrated network of providers such as the Irish Hospice Foundation and the Irish Cancer Society. Traditionally, many people think of palliative care as care provided at the last stage of life - around the time of death. However, in the last 20 years the scope of palliative care has broadened to providing care at an earlier stage in the disease trajectory. In this model of integrated palliative care provision, care is not dependent on prognosis. Palliative care may be provided to cancer patients in a variety of locations - at home, in a primary care setting, in hospital or in a hospice. It may be provided for varying periods of time.

### The Irish Cancer Society

At the Irish Cancer Society, we know that behind every statistic there is a person. We realise that being told "You have cancer" is life changing. We are determined to play our part, both in reducing the number of people who hear those words, and supporting people with a diagnosis in whatever way we can. One of the key ways we try to do this is by providing services that make a real difference to people's lives. This is at the heart of our work.

## 2. Our programmes and services

PREVENTION	SUPPORT	SURVIVORSHIP	PALLIATIVE
<ul style="list-style-type: none"> <li>▶ We Can Quit</li> <li>▶ Fit for Work and Life</li> <li>▶ X-HALE</li> <li>▶ Publications</li> <li>▶ Website information</li> <li>▶ Cancer Nurseline</li> <li>▶ Daffodil Centres</li> </ul>	<ul style="list-style-type: none"> <li>▶ Cancer Nurseline</li> <li>▶ Daffodil Centres</li> <li>▶ Volunteer Driver Service</li> <li>▶ Travel2Care</li> <li>▶ Financial Support Programme</li> <li>▶ Publications</li> <li>▶ Website information</li> </ul>	<ul style="list-style-type: none"> <li>▶ National Conference for Cancer Survivors</li> <li>▶ Counselling</li> <li>▶ Prostate Cancer Psycho-Educative Programme</li> <li>▶ Living Life</li> <li>▶ Strides for Life</li> <li>▶ Cancer Nurseline</li> <li>▶ Daffodil Centres</li> </ul>	<ul style="list-style-type: none"> <li>▶ Night Nursing</li> <li>▶ Cancer Nurseline</li> <li>▶ Daffodil Centres</li> </ul>

### CANCER INFORMATION SERVICES

Our Cancer Information Services comprise our Cancer Nurseline - a Freephone helpline staffed by cancer nurses - and our Daffodil Centres - hospital-based information and support centres staffed by cancer nurses and trained volunteers. They offer support and information at all stages of the cancer journey - Prevention, support, survivorship and palliative.

### CANCER PREVENTION PROGRAMMES AND SERVICES

- ▶ **Cancer prevention publications:** Leaflets, booklets, factsheets and posters informing people of how they can reduce their risk and spot cancer early.
- ▶ **Online information:** Cancer prevention information available on our website [www.cancer.ie](http://www.cancer.ie)
- ▶ **Fit For Work and Life:** A 12-week community health promotion and wellbeing programme aimed at young unemployed men and women.
- ▶ **X-HALE:** A cancer prevention programme that aims to prevent young people aged 10-24 from smoking, through education and empowerment.
- ▶ **We Can Quit:** A supportive, 12-week programme to help women who live in disadvantaged areas of Dublin and Cork to quit smoking and stay quit for good.

## CANCER SUPPORT PROGRAMMES AND SERVICES

- ▶ **Travel2Care:** A fund administered by the Society, for patients who are experiencing difficulty with transport while attending hospital appointments.
- ▶ **Cancer support publications:** Information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer and financial concerns.
- ▶ **Website information:** Cancer support information on our website [www.cancer.ie](http://www.cancer.ie)
- ▶ **Volunteer Driver Service:** Volunteer drivers bring patients to their chemotherapy appointments.
- ▶ **Financial Support Programme:** Helps cancer patients under the age of 18, and their families, who are unable to meet the specific financial burden that has come about as a direct result of their illness.

## CANCER SURVIVORSHIP PROGRAMMES AND SERVICES

- ▶ **Prostate Cancer Psycho-Educative Programme:** A 6-week programme that aims to enhance the physical and psychosocial wellbeing and quality of life for prostate cancer survivors.
- ▶ **Living Life:** An information and peer-support programme for people who have recently been diagnosed with secondary cancer.
- ▶ **Strides for Life:** A 15-week walking programme based on the Murphy Cardiovascular (METs) Programme which aims to bring cancer survivors through a structured exercise programme, gradually increasing fitness.
- ▶ **Counselling:** Free counselling sessions provided for cancer patients, their family members and significant others through the cancer support centres.
- ▶ **National Conference for Cancer Survivorship: Living Well with Cancer:** Two national conferences held for cancer survivors and their families which cover a wide range of survivorship issues.

## PALLIATIVE CARE SERVICES

- ▶ **Night Nursing:** End-of-life care provided by nurses for cancer patients in their own home. Up to 10 nights of care are provided.

### 3. Impact Monitoring

#### ONGOING

The Irish Cancer Society is committed to an ongoing, regular process of collection, analysis and distribution of information for monitoring the impact of our programmes and services on those who use them.

#### CHANGE

The project is measuring the change that our services bring to the people we aim to support and tracking changes across time, by comparing data year on year.

#### IMPACT

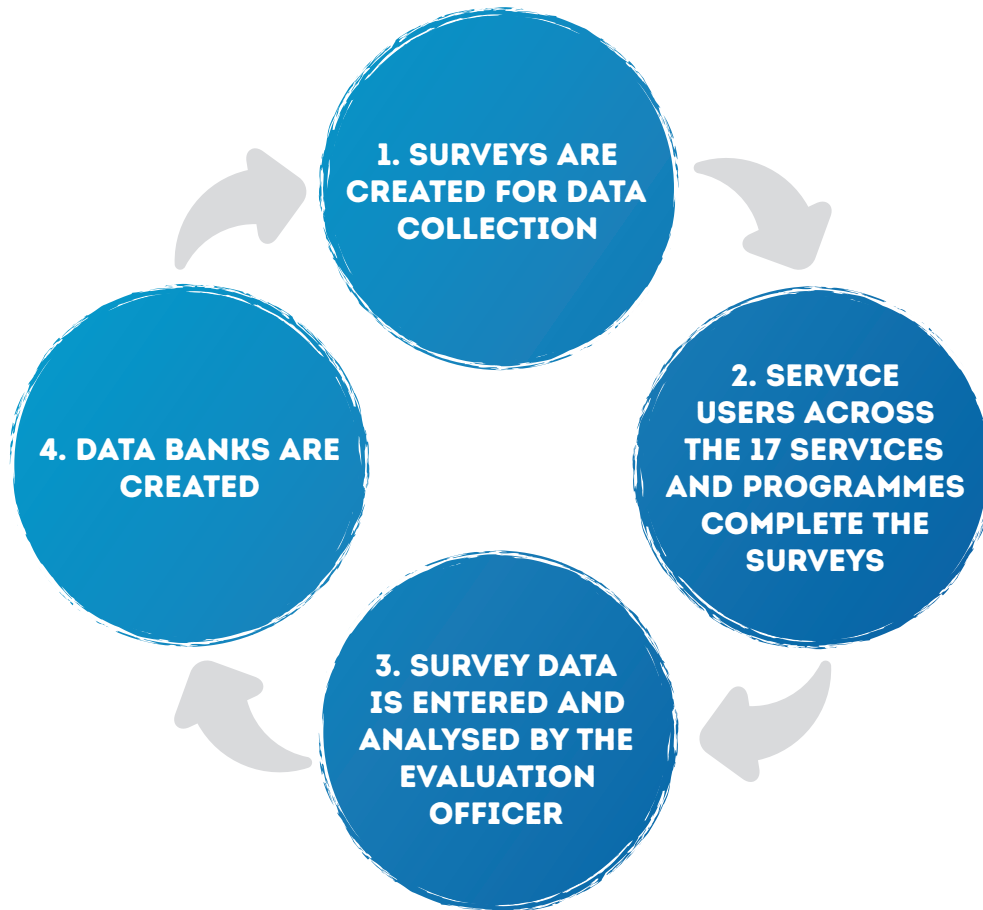
The Society offers 17 programmes and services to the public. It is essential that the services we provide make a positive difference in people's lives. It is only through monitoring the impact of our services that we can improve on their outcomes.

#### Impact monitoring allows us to:

1. Develop a greater knowledge of the people who use our services.
2. Identify factors that lead people to use our services.
3. Understand how our services and programmes benefit our service users and how they make people feel.
4. Identify how the services can be improved.
5. Evaluate the impact the service or programme has had on the service user.



## Impact monitoring methodology



1. Surveys are created to collect feedback from people who have used our services.  
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2. Service users from across 17 programmes and services complete the surveys.  
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3. The surveys are returned to the Society and entered by the Evaluation and Resource Officer.  
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4. The data is then analysed and data banks are produced.  
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## 4. Prevention

At the **preventive stage** we aim to educate and support people who are concerned about cancer and want to reduce their risk. We do this through programmes that support smoking cessation (**We Can Quit** and **X-HALE**), and promote wellbeing and health literacy (**Fit for Work and Life**), and through our free **cancer publications, website information, Cancer Nurseline and Daffodil Centres**.

**A PREVENTATIVE USER  
IS SOMEONE WORRIED  
ABOUT THEIR CANCER RISK  
OR WANTS TO ADOPT A  
HEALTHIER LIFESTYLE**



### **WE CAN QUIT**

The We Can Quit programme is a free, friendly and supportive 12-week smoking cessation programme to help women who live in disadvantaged areas of Dublin and Cork to quit smoking and stay quit for good. It is based on the successful American 'Sister to Sister' programme which demonstrated that a combination of peer support and anti-smoking medication helped women to quit (3). The We Can Quit programme was produced by the Society and tested as part of a development study, by the University of Stirling and Insights research. The programme is run in conjunction with the Health Service Executive (HSE) and local community organisations.

#### **How the service works**

Over 12 weeks, participants receive weekly group and one-to-one motivational support from trained community facilitators. They receive access to free nicotine replacement therapy (NRT), dispensed by a community pharmacy. There is a strong focus on the social, environmental and emotional connections between smoking, quitting and relapse. The We Can Quit model aims to provide women with the opportunity to develop skills, build confidence to quit and share experiences with each other.

## MAIN IMPACT FINDINGS

- ▶ 2 out of 3 women (66%) quit smoking by the end of the 12-week programme.
- ▶ All respondents reported feeling less lonely during their quitting journey.
- ▶ 7 out of 10 women felt more encouraged to go to the doctor if they were worried about their health.
- ▶ Being part of the programme meant that the women felt greater accountability to quit smoking. They felt the weekly meetings gave them the motivation to keep going on their quit journey.

### Why there is a need for the programme

Tobacco use is the leading cause of preventable death in Ireland, with 5,500 smokers dying each year from tobacco-related diseases (4). Ireland ranks second highest in Europe for smoking-related causes of death. A total of 21% of Irish females are current smokers. More women in Ireland are now dying from lung cancer than breast cancer. Women in lower socioeconomic groups have the highest rate of smoking in Ireland, with 56% of young women aged 18 to 29 years smoking (twice the rate found among women from more affluent groups). These women are less likely to quit smoking. Results from previous We Can Quit programmes have shown that half of women remained smoke free following a 6-month follow-up (5).

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*“Attending the programme has made me accountable, as I didn’t want to come to the group and to say I had relapsed.”*

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## FIT FOR WORK AND LIFE

Fit for Work and Life is a 12-week community health promotion and wellbeing programme. It is aimed at young unemployed men and women who are attending employability skills training programmes in low socio-economic areas. The aim of the programme is to help participants to navigate their way through the many confusing and often conflicting health messages and understand what it means to lead a healthy lifestyle. The programme is run in partnership with local community agencies and service providers.

### How the service works

The programme is a workshop-style, community-based education programme delivered by trained local people who live and work in their community. The facilitators are trained to an accredited standard and deliver the programme through existing community services such as Turas. The programme has been designed as a module, which can be integrated into a wide range of training programmes in the community. The programme covers the importance of health, wellbeing, cancer screening services and how to spot cancer early. It also educates participants on the health services and social supports available in their area.

## MAIN IMPACT FINDINGS

- ▶ 4 out of 10 people said they were determined to make healthy lifestyle changes.
- ▶ More than 7 out of 10 respondents said they would describe their health status as 'supported' and 'informed'.
- ▶ 7 out of 10 respondents said they would attend national screening appointments if they were called.
- ▶ Knowing the appropriate steps to take helped people to feel empowered to make the right choices for themselves.

### Why there is a need for the programme

Studies show that people from low socio-economic groups are more likely to have higher smoking rates, lower exercise levels and poorer dietary intake than those from higher socio-economic groups (6,7,8). These are all risk factors for developing cancer and other chronic diseases (9,10,11).

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*"It was good to learn how the little things can help the most."*

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Research has shown that community-based programmes aimed at addressing these issues are valuable in reducing people's risk of cancer and other diseases (12). Community partnerships are vital in the implementation of these programmes. Teaching people health messages from the Ottawa Charter (an agreement reached by countries promoting health for all) and the European Code Against Cancer equips them with the necessary lifelong skills to make better health decisions and empowers them to adopt better health behaviours (13,14).

### X-HALE

X-HALE (X'ing out harmful and lethal effects of smoking) is an initiative rolled out by the Society, which aims to prevent young people aged 10-24 from smoking, through educating and empowering young people, youth leaders and educators. Since 2011, the Society has supported over 270 youth organisations to take part in X-HALE. The programme aims to empower young people to learn the facts about smoking, develop skills and share important messages about smoking through film, art, dance, music and drama.

## How the service works

The programme is rolled out over a 6-month period in partnership with local youth and community organisations in low socio-economic areas around the country. Young people and youth workers are provided with smoking prevention training, resources, film workshops and project-planning sessions. These resources aid in the creation of a youth-led smoking prevention film with a smoke-free message for young people. The films are uploaded to YouTube and shared across social media platforms. They are then showcased at an award ceremony celebrating the achievements and accomplishments of the young people.

### MAIN IMPACT FINDINGS

- ▶ 83% of respondents said they are non-smokers.
- ▶ 7 out of 10 young people said they learned skills to raise awareness about tobacco issues online and in their local community.
- ▶ 96% said that smoking causes lung cancer.
- ▶ The X-HALE programme gave young people an opportunity to increase their knowledge around smoking and its negative effects on health.

## Why there is a need for the programme

Studies show that childhood behaviours such as smoking can track into adulthood (15). This youth programme is in line with the government's ambition to achieve a tobacco-free Ireland by 2025 (16). Teens aged 15-17 from lower socio-economic groups are more likely to smoke than those from a higher social group (17). In order to address these social differences, much of X-HALE's funding goes to youth groups in lower socio-economic areas. Research has also shown that efforts to engage young people in health messaging is more likely to be successful if digital media platforms are used (18). The number of children and young people who smoke in Ireland has decreased significantly in recent years, from 23% in 1998 to 8% in 2014. This is a 65.2% relative reduction. While this is a welcome trend, it still means that around 1 in 10 children and young people aged 10-17 years is a current smoker (19). Children and young people who smoke are over three times more likely to report poor or fair health compared to those who do not smoke (19).

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*"It meant a lot because I got to learn more about the dangers of smoking. I really enjoyed the learning experience."*

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## PREVENTION PUBLICATIONS

Our cancer prevention publications include a full range of booklets, leaflets and posters for those focused on reducing their risk of cancer. Our range includes 30 cancer prevention publications including *12 ways to reduce your cancer risk*, *Alcohol and Cancer*, *Be SunSmart*, *Healthy living and cancer – a woman's guide*, *Manual for men* (20).

### How the service works

All our information is available free of charge. We distribute our publications through our Cancer Nurseline, our 13 Daffodil Centres, through information stands at Relay for Life, hospitals, GP surgeries, cancer-screening programmes and community health clinics. Our publications are also available for download free of charge from our website. We also promote this information through our annual awareness campaigns, ensuring that the public have access to key facts about how they can reduce their risk of cancer and spot cancer early.

### MAIN IMPACT FINDINGS

- ▶ 3 in 4 respondents (75%) said they felt the amount of information was about right.
- ▶ 7 out of 10 people said they felt more knowledgeable about how to reduce their risk of cancer.
- ▶ 6 out of 10 people said they would take actions to reduce their risk of cancer after reading the publication.
- ▶ People felt more informed about the steps they needed to take in order to spot cancer early. The leaflets helped people to understand how to reduce their risk of recurrence of cancer.

### Why there is a need for this service

The Irish Cancer Society wants everyone to have the information they need on cancer prevention, treatment and care to help them make informed decisions and find the support they need.

4 in 10 cancers are preventable through lifestyle changes. What's more, diagnosing cancer at an early stage can often make a huge difference to how successful treatment is and can sometimes be life-saving. Our publications provide vital information on all aspects of risk-reduction, symptom awareness and screening.

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*"It's helped me to try to eliminate every possible risk to prevent a recurrence of my cancer."*

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Approximately 500,000 people order or download our publications every year – from student health co-ordinators, occupational health professionals, prison staff, community health workers, GPs and pharmacies to oncology departments, cancer support centres, patients and carers.

## WEBSITE INFORMATION

The Irish Cancer Society is the biggest provider of cancer information in Ireland. The availability of reliable and accessible cancer information is one of our key aims and integral to our cancer strategy. One way we provide cancer information is through our website (23). A total of 15% of the information on our website is cancer prevention information. Our website has been providing cancer information to the public since 1999.

### How the service works

We provide cancer information for people concerned about and affected by cancer on **www.cancer.ie**. Our cancer prevention section encourages people to reduce their risk of cancer through healthy lifestyle choices. We also educate people about the early warning signs of cancer and benefits of screening.

#### MAIN IMPACT FINDINGS

- ▶ Over 50% said they felt more supported to make positive changes to reduce their risk of cancer after reading the website.
- ▶ 8 out of 10 people said it was easy to find what they were looking for.
- ▶ People enjoyed the use of plain language to describe some of the topics.
- ▶ Learning about cigarettes and the negative health effects of smoking gave people the encouragement they needed to take the first steps.

### Why there is a need for the service

People want reliable health information from a trusted source. The internet has become one of the most important information sources for people seeking health information in recent years (22). The main advantages to accessing health information online include: greater access, anonymity, potential for interactivity and support. A study showed that 1 in 3 adults uses the internet to diagnose or learn about a health concern (23). Online information is also an effective tool to persuade people to adopt healthy behaviours (23).

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*"It has given me more incentive to quit smoking knowing there is more help if I need it."*

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## **CANCER INFORMATION SERVICES - PREVENTION**

The Cancer Nurseline and Daffodil Centres (Cancer Information Services) deliver an information service, which includes topics such as cancer screening, early detection and how to reduce your risk of cancer.

### **CANCER NURSELINE**

The Cancer Nurseline is a Freephone helpline staffed by cancer nurses. It provides support, advice and information to patients, carers, the general public as well as healthcare professionals. The Cancer Nurseline has undergone many evaluations to ensure a high standard of service that follows all policies and procedures. The service is accredited by the Helplines Partnership UK.

#### **How the service works**

The service is available Monday to Friday. During this period anyone needing support or information can call the Cancer Nurseline and speak to a cancer nurse. The nurse can advise them and send the caller our cancer prevention leaflets. All our nurses attend regular training to ensure that information provided is accurate and that they are aware of the latest advances in cancer prevention. The service also deals with email and social media queries and has a service for deaf people. The Cancer Nurseline is completely confidential.

### **DAFFODIL CENTRES**

Daffodil Centres are cancer information and support centres located in 13 hospitals nationwide. Cancer nurses and specially trained volunteers staff the centres. The centres provide face-to-face advice, help and support on cancer prevention. The centres are strategically located in central areas of hospitals with a high footfall.

#### **How the service works**

The centres are a walk-in service: no appointment or referral is necessary. Anyone can drop into the centre seeking advice or information on cancer prevention. The Daffodil Centres also provide leaflets on cancer prevention as well as having an information point where the public can browse through the Society's website.



## MAIN IMPACT FINDINGS

- ▶ More than 8 out of 10 people (84%) said they were worried about their risk of developing cancer.
- ▶ 9 out of 10 people said they were provided with information and practical support that wasn't available elsewhere.
- ▶ All respondents said they felt more knowledgeable about their risks of developing cancer.
- ▶ People who made enquiries were encouraged to take the next steps in implementing lifestyle changes by the nurse.

### Why there is a need for the service – Cancer Nurseline

The cancer nurses provide information on how to prevent cancer. Callers enquire about any issues or any specific questions they may have in relation to cancer. People can feel worried about their risk of developing cancer. Feeling distressed can act as a barrier to processing vital information. Helplines like the Cancer Nurseline have been shown to help patients understand their situation (24).

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*"I feel more confident about making changes for the better. I don't want to get cancer."*

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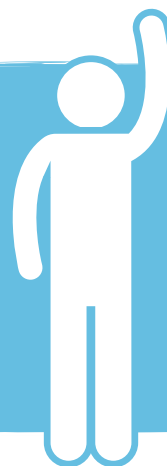
### Why there is a need for the service – Daffodil Centre

Studies show that people want reliable cancer prevention information from a trusted source (25). The Daffodil Centres offer information on local cancer prevention resources and services. The Daffodil Centres give patients, family members and hospital visitors greater access to cancer prevention information. The availability of a cancer nurse gives people the opportunity to talk about a cancer prevention concern in private. The Daffodil Centres provide a space where people can get information in their own time and at their own pace. People can visit the Daffodil Centres as many times as they like.

## 5. Support

At the **supportive stage** we provide practical and emotional support for people who have been given a cancer diagnosis and their friends and families. We do this by providing confidential advice through our **Cancer Nurseline** and **Daffodil Centres**, arranging transport for chemotherapy patients (**Volunteer Driver Service**), administering a travel fund (**Travel2Care**) as well as a financial support fund for children (**Financial Support Programme**) and through our free publications and our website information.

**A SUPPORTIVE SERVICE  
USER IS SOMEONE  
UNDERGOING TREATMENT  
AND THOSE WHO  
SUPPORT THEM**



### **VOLUNTEER DRIVER SERVICE**

The Volunteer Driver Service has been in operation since 2008. It provides free transport for cancer patients to and from their chemotherapy treatments and any chemo-related appointments. Patients must be attending one of the partnered hospitals of the service.

We also offer two limited services for patients undergoing radiotherapy. This applies to:

- ▶ Donegal patients who are staying for the full week (Monday to Friday) in Inis Aoibhinn (the Lodge) on the grounds of Galway University Hospital.
- ▶ Patients attending for radiotherapy treatment in St. Luke's Hospital, Dublin (any of the three hubs in Rathgar, Beaumont or St. James's) who can avail of transport on a Friday afternoon from St. Luke's to any of the Dublin transport stations to travel home.

#### **How the service works**

Patients are referred to the service by social workers or oncology nurses from any of the partnered hospitals. Once a referral is sent to our office, the team welcomes the patient to the service and usually books the patient's first drive with the service. The client also receives a welcome pack in the post, which informs the patient of all the details of the service. The service needs at least 3 working days' notice to arrange a driver to do the drive.

Our drivers are trained volunteers living across the country. The volunteers call the patients the day before their appointments to confirm all the details of the drive with the patient. The drive is a door-to-door service, with volunteers collecting the patient from their homes and picking them up following their hospital appointments when they are finished. The service is safe and confidential. All volunteers are Garda vetted, interviewed, trained and receive ongoing support.

#### MAIN IMPACT FINDINGS

- ▶ More than 9 out of 10 respondents (93%) said using the service reduced the financial burden related to travelling to hospital appointments.
- ▶ The majority of people travelled less than 100 km to and from their hospital appointments.
- ▶ Nearly all respondents felt less worried about getting to their appointments (98%) and that using the service helped to relieve pressure on family life (97%).
- ▶ The patient could attend hospital appointments without depending on family members to bring them. This allowed family members to continue to work or mind children at home.

#### Why there is a need for the service

Research has shown that arranging travel to their appointments has a negative effect on a patients' stress levels and their ability to cope with their diagnosis (26). Regular travel to cancer treatment appointments can be perceived as inconvenient and a practical hardship for many patients. This can be a barrier to treatment. An evaluation of the Volunteer Driver Service found that the service helped to reduce the stress associated with getting treatment (27). The study also revealed that the service helped to reduce 'no shows' at the hospital and patient cancellations. The service also reduced some of the financial, physical and psychological hardship faced by patients.

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*"It has meant everything and taken the pressure off me and my family and helped me to concentrate on my health."*

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#### FINANCIAL SUPPORT PROGRAMME

The Irish Cancer Society's financial support programme is to help cancer patients under the age of 18, and their families, who are unable to meet the specific financial burden that has come about as a direct result of their illness. This is a limited fund. It is awarded in cases where other non-charitable sources, such as social welfare, community welfare officers or community groups, are unable to help.

#### How the service works

A healthcare professional such as a medical social worker, cancer nurse, public health nurse or family doctor makes an application on behalf of the family.

## MAIN IMPACT FINDINGS

- ▶ Over a third of people (37%) said it would be 'difficult' to attend their children's hospital appointments without the Financial Support Programme.
- ▶ Nearly all the respondents (97%) said that receiving the financial support had reduced their financial pressure.
- ▶ 2 out of 3 people (66%) said they did not need to rely on family or friends for financial help.
- ▶ Families said they put the money towards travel costs such as fuel, parking and tolls. Attending hospital appointments regularly meant these costs added up, putting the families under financial pressure.

### Why there is a need for this service

Many families feel overburdened by the cost of childhood cancer, especially when facing the other challenges that cancer can bring (28). Our report, *The Real Cost of Cancer*, shows that families often struggle with expenses like household heating and electricity bills, mobile phone and broadband charges, household food and drink and childcare costs (29). The financial burden can be even greater on single-parent families, lower-income households and families living a greater distance from the hospital (30). Household budgets can be reduced greatly when a child has cancer, with parents more likely to stop working after their child is diagnosed (30). The financial support for children and their families fund is targeted towards relieving the financial burden of families experiencing childhood cancer.

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*"We had a round trip of 340 km every day for 30 days of radiotherapy. This was after spending 48 nights in hospital for different surgeries. Having received the money it took the pressure off the household and helped to cover the travelling costs."*

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## TRAVEL2CARE

Travel2Care is a limited transport support fund, made available by the National Cancer Control Programme (NCCP) and administered by the Society. The fund is available to cancer patients who are experiencing financial difficulty and travelling over 50km one way to designated cancer hospitals for tests and/or treatment appointments.

### How the service works:

There are two types of application form for Travel2Care:

- ▶ **Travel2Care Form A** is for a fund available to patients travelling for cancer tests. This form can be completed by the patient and is available to download from our website [www.cancer.ie](http://www.cancer.ie) or from our office.

- ▶ **Travel2Care Form B** is for a fund available to cancer patients travelling for ongoing treatment such as surgery, chemotherapy, radiotherapy or palliative care. The form is completed on behalf of the patient by a healthcare professional such as a cancer nurse or medical social worker. The healthcare professional assesses the patient to see if there is a genuine need for financial assistance. Once a form is received by the office it can take up to 10 days to be processed and then the money is paid by electronic transfer into the patient's bank account.

### MAIN IMPACT FINDINGS

- ▶ Nearly 3 in 10 (27%) said they were unlikely to attend their hospital appointments without Travel2Care.
- ▶ Nearly all the respondents (94%) said that receiving Travel2Care helped to reduce the financial burden of getting to hospital appointments.
- ▶ The majority of people travelled 50-100km to their hospital appointments.
- ▶ 8 out of 10 people felt more independent, as they didn't need transport from others.
- ▶ Patients were able to use their own transport to get to and from their hospital appointments. This helped to maintain the cancer patient's independence and safety, as they did not need to take public transport to attend appointments.

### Why there is a need for the service

There is a substantial cost associated with travelling to and from hospital appointments for cancer patients. Our *The Real Cost of Cancer* report examined the practical needs of cancer patients and highlighted the costs associated with patients travelling to and from treatment (29). The report highlights a wide range of expenses, with travel costs being one of the most prominent expenses for cancer patients. Expenses include the travel itself, parking, eating out while attending treatment and other associated costs such as child-minding. These expenses resulted in an average expenditure of €407 per month. Rural patients are especially vulnerable, as they tend to travel longer distances to attend a designated cancer centre.

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*"The main benefit was not standing at a bus stop getting wet, which is not suitable for cancer patients."*

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### WEBSITE SUPPORT INFORMATION

The Irish Cancer Society is the biggest provider of cancer information in Ireland. Making available reliable and accessible cancer information is one of our key aims, and integral to our cancer strategy. To achieve this, we provide cancer information through our website (6). A total of 12% of the information available on our website is cancer support information. Our website has been providing cancer information to the public since 1999.

## How the service works

We provide cancer information for people concerned about and affected by cancer on [www.cancer.ie](http://www.cancer.ie). Our cancer support web section encourages people to speak to a cancer nurse, find cancer support services in their local area, and apply for assistance with transportation and finances. There is also information on coping with a cancer diagnosis, cancer treatments and side-effects and end-of-life care, as well as information for carers and on life after treatment.

### MAIN IMPACT FINDINGS

- ▶ 3 out of 4 said the information was helpful.
- ▶ Nearly 8 out of 10 people (77%) said they felt more knowledgeable about cancer and its treatment after reading the website.
- ▶ Respondents enjoyed the use of simple plain language, which helped them to understand the information.
- ▶ Many said that they had questions around their health. Reading the information gave them explanations and insights into the information they needed. The website gave details of support services available to cancer patients. This gave them peace of mind.

## Why there is a need for the service

People want access to reliable cancer support information from a trusted source (31). The internet has become one of the most important sources for people seeking health information in recent years (32). The main advantages to accessing health information online include greater access, anonymity, potential for interactivity and support. One study shows that 1 in 3 adults uses the internet to diagnose or learn about a health concern (33), but finding reliable information online can be challenging. In a recent survey, trusted printed and online information were the most important services cancer patients / survivors wanted from the Society, and one of the most important for healthcare professionals (21). Patients tend to have better health outcomes when they are more informed about their disease, more involved with treatment choices and more invested in their healthcare.

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*"It gave me peace of mind to know questions most asked were the same ones I wanted to know answers to. The website gave me information and pointed us in the right direction to obtain other services when and if needed."*

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## Support publications

Our cancer support publications include a full range of booklets and factsheets on cancer types, treatments and side-effects and ways to cope with a cancer diagnosis. Our range of over 50 cancer support booklets includes *Coping with the Emotional Effects of Cancer*, *Talking to children about cancer*, *Coping with Fatigue*, as well booklets focusing on individual cancer types and treatments.

## How the service works

All our information is available free of charge. We distribute our publications through our Cancer Nurseline and our 13 Daffodil Centres. The booklets are used by consultants and cancer liaison nurses around the country to support conversations around diagnosis and treatment. They also act as a point of reference throughout the patient's cancer journey, signposting to Irish Cancer Society and other services and giving support with side-effects, emotional difficulties and practical issues. Our publications are also available to order or download free of charge from our website.

### MAIN IMPACT FINDINGS

- ▶ 1 in 4 who answered the survey were healthcare professionals.
- ▶ Nearly half of respondents (44%) said they read their booklet online.
- ▶ 7 out of 10 people said they found the amount of information about right.
- ▶ 6 out of 10 people said they understood their treatment and care options after reading their booklet.
- ▶ Some respondents noted that the booklets helped to inform them about cancer and the treatments available so that they could help others with a cancer diagnosis. With this knowledge, people were able to understand the information better and form questions that they could ask at hospital appointments.

## Why there is a need for this service

Cancer patients are keenly interested in receiving information about cancer (34). People who have access to reliable cancer support information have increased involvement in decision-making and greater satisfaction with treatment choices, as well as improved ability to cope and better communication with family members (35). The literature suggests that patient-tailored information can ensure that the appropriate type and amount of information is received (36). Not having access to information can lead to increased uncertainty, anxiety and distress (37).

While cancer information is available in many different formats, many patients prefer information in the form of reading material that they can take home (37). All our cancer information is designed to support people in conversations with their doctors, nurses, family and friends. Our booklets can also be a source of comfort and reassurance.

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*"I was given a copy of this booklet in 2009 when I was diagnosed with breast cancer and found it invaluable, dipping in and out as my treatment progressed. With my sister recently diagnosed, I wanted to refresh my mind on the stages and see what has changed in terms of treatment in the interim."*

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## **CANCER INFORMATION SERVICES - SUPPORT**

The Cancer Nurseline and Daffodil Centres deliver a cancer information support service to patients, families and healthcare professionals.

### **CANCER NURSELINE**

The Cancer Nurseline is a Freephone helpline staffed by cancer nurses. It provides support, advice and information to patients, those who support them, the general public, those with concerns about cancer as well as healthcare professionals. The Cancer Nurseline has undergone many evaluations to ensure a high standard of service that follows all policies and procedures.

#### **How the service works**

The service is available Monday to Friday. During this period anyone needing support or information can call the Cancer Nurseline and speak to a cancer nurse. The nurse can advise them, signpost them to relevant sources of information and send the caller our cancer support booklets. All our nurses attend regular training to ensure that information provided is accurate and that they are aware of the latest advances in cancer support. The service also deals with email and social media queries and has a service for deaf people. The Cancer Nurseline is completely confidential.

### **DAFFODIL CENTRES**

Daffodil Centres are cancer information and support centres located in 13 hospitals nationwide. Cancer nurses and specially trained volunteers staff the centres. The centres provide face-to-face advice, help and support. They are strategically located in areas of hospitals with a high footfall rate.

#### **How the service works**

The centres are a walk-in service: no appointment or referral is necessary. Anyone can drop into the centre seeking support, advice or information on cancer support. Daffodil Centres also provide cancer support booklets as well as having an information point where the public can browse through the Society's website.



## MAIN IMPACT FINDINGS

- ▶ 1 in 3 respondents described themselves as undergoing cancer treatment.
- ▶ More than 8 out of 10 (83%) felt less anxious about their situation after speaking to a cancer nurse.
- ▶ Half of the people felt more supported to adopt healthier lifestyle changes.
- ▶ The Daffodil Centre nurse helped people to feel supported during their cancer treatment. The open door provided a safe haven for people to come and talk about their concerns. Providing information and guidance to people helped to put their minds at ease.

### Why there is a need for the service – Cancer Nurseline

The majority of calls to the Cancer Nurseline are in relation to emotional support. The cancer nurses also provide information, which helps make sense of what's said during doctor's appointments, making patients feel more informed and in control of their treatment decisions. Callers also enquire about any issues or any specific questions they may have in relation to cancer. Studies have shown that 1 in 3 people diagnosed with cancer experiences significant distress (38). Feeling distressed can act as a barrier to processing vital information. The Cancer Nurseline can help to address this by using distress screening. This helps to ensure information is pitched at the right level and does not exacerbate distress levels. Helplines like the Cancer Nurseline have been shown to help patients understand their situation (39).

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"The main benefit of my visit was that feeling of support and that you are not alone at any time to talk about cancer. The open door policy promotes accessibility and encouragement to discuss your cancer diagnosis and concerns. Visiting the Daffodil Centre has given me first-hand experience of a wonderful supportive service. A much needed and appreciated service."

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### Why there is a need for the service – Daffodil Centre

Studies show that people need to source cancer support information (40). Daffodil Centres offer information on local cancer support resources and services. This gives patients, family members and hospital visitors greater access to cancer support information. The availability of a cancer nurse affords people the opportunity to talk through their concerns in a private and confidential manner. Daffodil Centres provide a space where people can get information in their own time and at their own pace. People can visit Daffodil Centres as many times as they like.

## 6. Survivorship

At the survivorship stage we hold an annual national conference (National Conference for Cancer Survivors). We connect people with a recent diagnosis to someone who has lived through that experience (Survivor Support). We also fund peer-to-peer educational and wellbeing programmes in affiliated cancer support centres (Living Life, Strides for Life, Prostate Cancer Psycho-Educative Programme), as well as funding counselling for survivors. The Daffodil Centres and Cancer Nurseline provide cancer information to cancer survivors and their families.

**A SURVIVORSHIP SERVICE  
USER IS SOMEONE WHO  
IS POST TREATMENT OR  
LIVING WITH CANCER AND  
THOSE WHO SUPPORT THEM**



### PROSTATE CANCER PSYCHO-EDUCATIVE PROGRAMME

This 6-week programme aims to enhance the physical and psychosocial wellbeing and quality of life for prostate cancer survivors. The programme achieves this by identifying and responding to supportive care needs, including coping strategies and managing lifestyle changes.

The programme provides opportunities for participants to share their experiences and concerns, increase their understanding of prostate cancer, explore their attitudes towards prostate cancer and develop their skills in coping with the disease.

The programme is facilitator-led, using an adult learning approach that builds on the knowledge, skills and experiences of the participants, as well as group discussions. It is only open to men who have had a diagnosis of prostate cancer.

#### How the service works

Over the 6 weeks, the programme provides advice and support. The sessions are run by trained facilitators with guest speakers, including healthcare professionals. The sessions cover topics such as the emotional and psychosocial effects of prostate cancer. The programme also provides participants with the opportunity to meet others in a similar situation. Sharing experiences helps to increase understanding of prostate cancer and develop coping skills.

## MAIN IMPACT FINDINGS

- ▶ Over three-quarters of the men (78%) said they understood more about prostate cancer and treatment choices.
- ▶ 9 out of 10 men said they were more knowledgeable about symptom management and side-effects.
- ▶ Three-quarters of the men said their quality of life improved after the programme.
- ▶ Nearly half the men (48%) rated their quality of life as 'good' following completion of the programme.

## Why there is a need for the service

In Ireland, prostate cancer is the second most common cancer in men (41). Each year over 3,400 men are diagnosed with prostate cancer in Ireland (41). Men with prostate cancer often have several treatment options, depending upon their stage of disease, age and presence of co-morbidity (42). Research explored the supportive care needs of men living with prostate cancer and highlighted that men struggle with psychological distress, sexually related issues and management of enduring lower urinary tract symptoms (43). Peer support groups had a positive effect and helped increase quality of life, as well as lower pain and increase the use of complementary therapies.

## LIVING LIFE

The Living Life programme is an information and peer-support programme for people who have recently been diagnosed with secondary cancer. The programme offers information, support and the opportunity to meet with other people who are living in a similar situation.

## How the service works

The programme is an 8-session closed group, run over 16 weeks for people who have been recently diagnosed with secondary cancer (within the previous 12 months). The sessions are delivered by healthcare professionals and cover a range of topics:

- ▶ Emotional and psychological effects of a secondary cancer diagnosis
- ▶ Practical advice including benefits and entitlements
- ▶ New treatments
- ▶ Talking to children and general communication

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*"My self esteem has improved and I appreciate how well I am. I was apprehensive about attending, being part of a group programme. Warm welcome, supportive throughout, now aware of the facilities and supports available. Gives added bonus of knowing another viable measure of support apart from medics, hospital personnel etc. is available on one's doorstep."*

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## MAIN IMPACT FINDINGS

- ▶ Half of the respondents felt more knowledgeable about symptom management and side-effects of secondary cancer.
- ▶ 2 out of 3 said they understood more about their secondary cancer.
- ▶ 6 out of 10 people rated their quality of life as 'good' after completing the programme.
- ▶ Hearing other people's cancer stories gave people reassurance to know they were not alone.

### Why there is a need for the service

Studies have shown that patients with secondary cancer have higher levels of unmet needs, especially around medical communication and information (44, 45). The Living Life programme helps to address this gap. Evidence shows that peer support has psychological benefits and helps people cope better with distressing situations (46). It also has a positive effect on relationships; as having someone else to relate to helps relieve the burden of care placed on those who support them (46). A systemic review showed that peer education delivered through trained facilitators has a positive effect on stress management, quality of life and healthy behaviours (47).

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*"I have found it benefited me to hear the worries and concerns of others. Meeting and talking to others with similar cancers has been very helpful to me."*

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## STRIDES FOR LIFE

Strides for Life is a 15-week walking programme for cancer survivors. It is based on the Murphy Cardiovascular (METs) Programme. Strides for Life brings a participant through a structured walking programme, gradually increasing fitness and training over its course. The programme aims to bring the individual to a level of fitness where they can reduce their risk of recurrence and improve their health and quality of life.

### How the service works

The Murphy METs Programme is individually designed to suit each participant's fitness level and weekly schedule. The workouts are measured and recorded in metabolic equivalents (METs). The participants meet a minimum of 9 METs/hour of walking on completion of the programme, which is the minimum weekly requirement shown for lowering a person's risk of disease. Each week sees the intensity of a person's tailored programme increase as their fitness improves.

## MAIN IMPACT FINDINGS

- ▶ 9 out of 10 respondents said the number of sessions were adequate (91%) and that they felt more proud of themselves (92%).
- ▶ More than 9 out of 10 respondents (94%) said they felt supported to continue improving their fitness after completing the programme.
- ▶ Almost half of respondents said their quality of life was 'very good' following the programme.

## Why there is a need for the service

The number of cancer survivors is growing rapidly. In 2016, the number of survivors stood at 173,000, which means that in 2019 that figure is over 200,000 people (48). Clinical research has established exercise as a safe and effective intervention to counteract the adverse physical and psychological effects of cancer and its treatment (49).

Studies have shown that exercising at a moderate intensity for 2-3 hours a week can help reduce the risk of bowel, breast and prostate cancer recurrence by as much as 50% (50). Research has also shown that many individuals living with and beyond cancer viewed exercise as a vehicle for recovery, and a means through which they could optimise their physical and psychosocial well-being (51). Cancer survivors who take part in community-based exercise programmes have less fatigue, better quality of life and an improved sense of wellbeing (52).

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*"It gave me confidence and will-power to exercise and feel good. I loved meeting new friends and enjoyed the chats about cancer experiences and non-cancer experiences. Being part of a group has been good especially when you're taken away from your workplace, friendship, and environment."*

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## NATIONAL CONFERENCE FOR CANCER SURVIVORSHIP: LIVING WELL WITH CANCER

The Irish Cancer Society runs an annual conference for cancer survivors, their family and friends, healthcare professionals and staff and volunteers from community-based cancer support centres.

The aim of the conference is to provide information and support to people to live well after a cancer diagnosis. In 2019, the Society held two conferences: one in Galway and one in Cork. It is where we hear from cancer patients and seek to understand and address the needs of the whole person, beyond their medical diagnosis. It is where we share, learn and support. Delegates hear from a range of speakers who share their experience, knowledge and expert opinions on the latest advances in treatments and other medical and lifestyle topics.

## How the service works

The conference is free to attend. People who are interested in attending the conference can register on our website or by post. The programme of events changes from year to year and covers a wide range of topics around living with, through and beyond a cancer diagnosis. There are practical sessions incorporating art, music, yoga, exercise and nutrition. There are also exhibitors from cancer services nationwide.

### MAIN IMPACT FINDINGS

- ▶ Nearly 6 out of 10 respondents (58%) were cancer survivors.
- ▶ 8 out of 10 felt more hopeful about the future after attending the programme.
- ▶ People enjoyed listening to cancer patients' survivor stories during the conferences. It gave them hope and positivity for the future.
- ▶ 9 out of 10 people liked the workshop options at the conference.
- ▶ It was clear that many attendees felt positive after the conference. Learning about the advances in cancer treatments as well as the survival rates gave people the hope they needed.

## Why there is a need for the service

A cancer diagnosis is a distressing event and affects all aspects of life for patients and their families. Cancer survivorship has also become more complex, with various needs. It is, therefore, crucial to identify and address the information and support needs of cancer patients in order to help them make decisions and cope with their diagnosis. A national conference provides a platform to fulfil cancer survivors' information and support needs as well as access to healthcare professionals. A review of the literature shows that people want to know more about their disease including treatment, test results, psychosocial and financial aspects of care (53).

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*"It was great to see a positive atmosphere and see people coping with their diagnosis/treatment."*

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## COUNSELLING

The Society funds counselling sessions through affiliated cancer support centres. Counselling is available for all patients who have had a cancer diagnosis, their family members and significant others such as a friend or a partner. Depending on the circumstances, this can take the form of one-to-one, couple or family counselling.

## How the service works

Many people find out about the counselling service when they go to one of our affiliated support centres. Usually, on their first visit, a person is met by a centre representative and told about all the available services. In some centres, this is a more formal process called an intake or an assessment meeting.

The Society asks that all counsellors subscribe to a short-term model for counselling that focuses on the issues related to cancer. The grant, given by the Society is intended to fund up to 8 sessions per person. However, sometimes a person might have a setback, either medical or emotional, that may require more sessions. The Society takes the counsellor's professional opinion in these circumstances.

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*"It has meant everything to me. Somewhere I am able to feel my feelings without having to bottle them up or worry about upsetting others. It allows me to feel and be me and be supported."*

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## MAIN IMPACT FINDINGS

- ▶ 9 out of 10 respondents said the number of sessions was adequate.
- ▶ Three-quarters reported relating better to family and friends and nearly 2 out of 3 feel more social after attending counselling sessions.
- ▶ More than 8 out of 10 people (83%) learned coping mechanisms to deal with their situation.
- ▶ More than half of the respondents rated their quality of life as 'good' after attending counselling sessions.
- ▶ People said the counselling sessions gave them the opportunity to express their feelings and emotions in a safe and private environment. Respondents said they would normally avoid talking with their families about difficult topics so as not to upset them. Many said the counsellor did not judge them, which helped to put them at ease.

## Why there is a need for this service

Psychological distress is a significant and ongoing problem for cancer patients throughout diagnosis, treatment and the years after treatment. An Irish study recently found that long-term psychological effects could be linked to physical symptoms (53). Depression and anxiety affect up to 20% and 10% of patients with cancer respectively (54). There is compelling evidence for the use of meaning-centred psychotherapy to improve meaning and quality of life and use of question prompt lists and communication skills training to improve communication with healthcare providers. (55).

## **CANCER INFORMATION SERVICES - SURVIVORSHIP**

The Cancer Nurseline and Daffodil Centres deliver a cancer survivor's information service to patients, families and healthcare professionals.

### **CANCER NURSELINE**

The Cancer Nurseline is a Freephone helpline staffed by cancer nurses. It provides support, advice and information to patients, those who support them, the general public as well as healthcare professionals. The Cancer Nurseline has undergone many evaluations to ensure a high standard of service that follows all policies and procedures. The service is accredited by the Helplines Partnership UK.

#### **How the service works**

The service is available Monday to Friday. During this period anyone needing support or information can call the Cancer Nurseline and speak to a cancer nurse. The nurse can advise and inform callers about our cancer survivorship services. All our nurses attend regular training to ensure that information provided is accurate and that they are aware of the latest advances in cancer survivorship. The service also deals with email and social media queries and has a service for deaf people. It is a confidential service.

### **DAFFODIL CENTRES**

Daffodil Centres are cancer information and support centres in 13 hospitals nationwide. Cancer nurses and specially trained volunteers staff these centres. They provide face-to-face advice, help and support and are strategically located in central areas of hospitals with a high footfall rate.

#### **How the service works**

The centres are a walk-in service, no appointment is necessary. Anyone can drop into the centre seeking advice or information on survivorship and other cancer-related areas. The Daffodil Centres also provide booklets and have an information point where visitors can browse through the Society's website.



## MAIN IMPACT FINDINGS

- ▶ 2 out of 3 respondents said they were finished cancer treatment.
- ▶ 8 out of 10 people said they felt more supported after speaking with a nurse.
- ▶ More than 9 out of 10 people (93%) said they felt motivated to try new things to improve their health.
- ▶ The nurse listened to people's concerns and answered their questions. It was important for people to get accurate information from a healthcare professional. The nurse advised people on appropriate booklets for their information needs.

### Why there is a need for the service – Cancer Information Services

With cancer numbers increasing year on year, the demand for expert information, support and advice is set to grow. Access to the most up-to-date, clear and reliable information helps to reduce anxiety and allows patients to make informed decisions with regards to their treatment and care. The Irish Cancer Society provides a Cancer Information Service where people can access information and support at home or face to face in hospitals. The service incorporates the Cancer Nurseline (Freephone 1800 200 700) and Daffodil Centres based in 13 hospitals across the country. In 2019 over 50,000 people affected by cancer availed of our Cancer Information Services.

The report *Evaluation of the Irish Cancer Society's Cancer Information Services* published in 2014 evaluated the impact of the service and identified how it can grow and adapt to meet the growing needs of those affected by cancer.

The report, which highlighted the benefit of the services, was the largest and most in-depth research project of any cancer information service here or internationally. It identified high levels of satisfaction among service users with all of the cancer information services provided by the Irish Cancer Society, including online services, Cancer Nurseline and Daffodil Centres. In addition, the information services were identified as having a positive impact on people affected by, or worried about cancer in terms of facilitating service users' understanding of cancer, cancer treatments and supports available to people affected by cancer.

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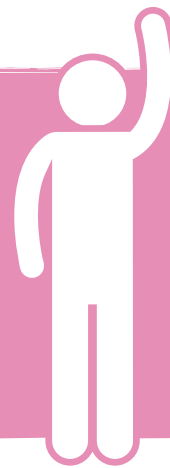
*"I hadn't slept and I was in meltdown and alone in the house. After the call, I was calmer, more logical and more empowered to ask key questions at my next visit. I appreciated the honesty and the directness of the responses from the nurse."*

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## 7. Palliative care

At the **palliative stage** we provide end-of-life support for patients and emotional and practical support for their friends and families. We do this through the provision of a home nursing service (**Night Nursing**). We also give palliative advice and guidance through our **Cancer Nurseline** and **Daffodil Centres**.

**A PALLIATIVE SERVICE  
USER IS SOMEONE WHO  
NEEDS END-OF-LIFE  
CARE AND THOSE WHO  
SUPPORT THEM**



### **NIGHT NURSING**

The Night Nursing service is a home nursing service established by the Society in 1986. The night nurses provide end-of-life care to cancer patients and their families in their own home. The service works to support and advise the patient's family as well as administer pain relief and provide other nursing care to the patient. The Society offers up to 10 nights of care per patient. The night nursing service responds to cancer patients who are dying with complex and demanding care needs and supports them to remain at home. There are currently 190 night nurses employed by the Society to provide the service. The service is almost entirely funded by voluntary donations. All nurses are An Bord Altranais registered, reference checked and Garda vetted.

#### **How the service works**

The local Community Specialist Palliative Care Team refers the patient to the service. The service then arranges a night nurse to visit the patient's home. The nurse monitors the patient throughout the night between 11pm and 7am, administering pain relief and taking care of all the patient's needs as well as supporting the family. It is free to use the service. Up to 10 nights of care are provided.

## MAIN IMPACT FINDINGS

- ▶ More than half of respondents were the spouse/partner of the patient.
- ▶ 4 nights of care was the average number of nights reported by families.
- ▶ 8 out of 10 (82%) said the patient did request to die at home.
- ▶ Nearly all the respondents said using the service allowed them to rest (96%) and that the Night Nurse treated the patient with respect and dignity (97%).
- ▶ 9 out of 10 (92%) said the service provided practical support to the families.
- ▶ It is clear from the data that the Night Nurse treated patients with dignity and respect. Families were very grateful for the level of care they provided. They kept the patient comfortable while letting the family get some much-needed rest. They were respectful of both the family's and patient's wishes at all times.

### Why there is a need for this service

The Irish Cancer Society Night Nursing Service is in existence since 1986. The Night Nursing Service is committed to enabling patients with cancer to die at home surrounded by their family and friends, and to promoting best practice in end-of-life patient care. Teno *et al.* examined the quality of end-of-life care in institutional settings as compared with deaths at home and found that family members of people who received care at home with hospice services were more likely to report a favourable dying experience (57).

This supports the findings of a night nursing evaluation conducted by the Irish Cancer Society Night Nursing Service (58). This demonstrated that 95% of family respondents were very satisfied with their interactions with the night nurse and the presence of a night nurse promoted comfort for the patient and supported the provision of total nursing care in the home setting. Teno *et al.* also found that many more people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and treatment perceived as respectful. Thus it can be concluded that palliative care in the home setting is often the most appropriate option for carers and patients.

The need for the night nursing service is likely to increase into the future, with the number of cancer cases expected to rise (NCRI). Clearly, the place of care and death is something service developers should pay heed to in their future development of cancer and palliative care services (59).

For those nearing end-of-life, it is vital that the night nursing staff have the confidence, competence and resources to ensure that the patient's palliative care needs are anticipated, assessed and responded to. The patient and their family must at all times remain central to the care plan, be fully informed and have opportunities to engage with and plan the care they will receive

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*"Nurse showed dignity and respect at all times. She answered all questions asked by the family in an appropriate manner."*

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with the night nurse. Underpinning this must be a service which is trustworthy, safe, reliable and meets the needs of the patient and family. Identifying the impact of the service on the patient and family will determine the future direction of the service and ensure the needs of this cohort of people are being met (60).

## **CANCER INFORMATION SERVICES – PALLIATIVE**

### **CANCER NURSELINE**

The Cancer Nurseline is a helpline staffed by cancer nurses. It provides support, advice and information to patients, those who support them and the general public, those with concerns about cancer, as well as healthcare professionals. The helpline service is free and is available during weekdays. There is also a service for deaf people through Sign Language Interpreting Service. Cancer Nurseline support is also available through email, social media and through our nurse-moderated online community on cancer.ie. The Cancer Nurseline has undergone many evaluations to ensure a high standard of service, following all policies and procedures. The service is accredited by the Helplines Partnership UK.

#### **How the service works**

The service is available Monday to Friday nationwide. During this time anyone concerned about palliative care or enquiring about palliative care services can contact the Cancer Nurseline to speak to a cancer nurse. The nurse can listen and provide tailored advice to the caller and send them out relevant end-of-life care information. The cancer nurses attend regular training to ensure that the information provided is accurate. The Cancer Nurseline is a completely confidential service.

### **DAFFODIL CENTRES**

Daffodil Centres are cancer information and support centres located in local hospitals across Ireland. Cancer nurses and specially trained volunteers staff the centres. They provide face-to-face advice, help, and support and are strategically located in central areas of hospitals with a high footfall rate.

#### **How the service works**

The centres are a walk-in service: no appointment or referral is necessary. Anyone can drop into the centre seeking advice or information on palliative care services. The Daffodil Centres also provide leaflets on palliative services, as well as having an information point where the public can browse through the Society's website.

## MAIN IMPACT FINDINGS

- ▶ Nearly 9 out of 10 (87%) said they felt more supported.
- ▶ The Daffodil Centre was there for people at every step of the way. It was important for people to feel welcomed by the nurse and that they could return to the Daffodil Centre whenever they wanted.

### Why there is a need for the service – Cancer Information Services

With cancer numbers increasing year on year, the demand for expert information, support and advice is set to grow. Access to the most up-to-date, clear and reliable information helps to reduce anxiety and allows patients to make informed decisions with regards to their treatment and care. The Irish Cancer Society provides a Cancer Information Service where people can access information and support at home or face to face in hospitals. The service incorporates the Cancer Nurseline (Freephone 1800 200 700) and Daffodil Centres based in 13 hospitals across the country. In 2019 over 50,000 people affected by cancer availed of our Cancer Information Services.

The report *Evaluation of the Irish Cancer Society's Cancer Information Services* published in 2014 evaluated the impact of the service and identified how it can grow and adapt to meet the growing needs of those affected by cancer.

The report, which highlighted the benefit of the services, was the largest and most in-depth research project of any cancer information service here or internationally. It identified high levels of satisfaction among service users with all of the cancer information services provided by the Irish Cancer Society, including online services, Cancer Nurseline and Daffodil Centres. In addition, the information services were identified as having a positive impact on people affected by, or worried about cancer in terms of facilitating service users' understanding of cancer, cancer treatments and supports available to people affected by cancer.

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*"The nurse gave me 100% support. I could not ask for more information, support, advice and honesty. Just knowing I could go back at any time means a great deal."*

*"I felt less alone in my situation and empowered by the information I received. Also I felt reassured that I could call again."*

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## 8. Discussion

### Cancer in Ireland

In 2019, it was estimated that more than 40,000 people in Ireland were diagnosed with cancer. 4 in 10 cancer cases are preventable. Many people in Ireland are still unaware of cancer risk factors. Hearing “You have cancer” can be devastating, but more and more people go on to live long lives after a diagnosis. There are now more than 170,000 cancer survivors in Ireland.

At the Irish Cancer Society, we know that behind every statistic there is a person. We are determined to play our part, both in reducing the number of people who receive a cancer diagnosis, and in supporting people with a diagnosis in whatever way we can. One of the key ways we try to do this is by providing services that make a real difference to people's lives.

### What are the issues?

**People who are concerned about their risk of cancer** need access to reliable information on prevention and early detection of cancer, a supportive environment to engage in a lifestyle change process, guidance and support on how to take the appropriate steps in reducing their risk of cancer and reassurance about their cancer concerns.

**Cancer patients and their families** need information, advice and support on dealing with a cancer diagnosis, cancer treatment and side-effects, talking about cancer, and coping with the emotional effects. They also need practical and financial support to attend multiple hospital appointments and support to deal with the significant financial hardship of a childhood cancer diagnosis and access to cancer information from a trusted source, in a variety of formats.

**People who have completed their treatment** need survivorship programmes and access to counselling services that help people come to terms with cancer and gain a sense of control in their lives. They also need the opportunity to talk to someone who has walked in their shoes or who ‘knows cancer - not just about cancer’ and the chance to share experiences.

**People at end-of-life** often prefer to be cared for and die at home. Their loved ones are often emotionally and physically exhausted and need support.

### What is the Irish Cancer Society doing about these issues?

The Society is committed to meeting the needs of people across all stages of cancer. Our impact monitoring data demonstrates that we are meeting many of these needs, but there are gaps and opportunity for development. The repetitive nature of the impact monitoring data is reassuring: recurring themes are common across services and programmes.

**Our cancer prevention programmes** provide a supportive environment for people to engage in a lifestyle change process. A continuous theme across all of our cancer prevention programmes was that the group support and guidance from community facilitators was key to achieving a lifestyle change. Our website and publications provide people with reliable information and reassurance. Our Cancer Information Services provide guidance and support on how to take appropriate steps in reducing cancer risk. It was clear that people valued this advice and guidance.

**People with a cancer diagnosis** value having open access to our nurses. Our website and publications help people learn more about their cancer as well as giving them accurate and reliable

information. Receiving financial grants helps to reduce the financial burden for patients and their families during a distressing time. People consistently value how the Volunteer Driver Service reduces the worry and pressure associated with arranging transport to and from their hospital appointments.

**Our survivorship programmes** facilitate people to meet others in a similar situation, which helps them to feel like they are not alone. The data shows that people come away from our survivorship conference with a better understanding of cancer and an increased sense of hope for the future. Counselling helps them to open up and express their feelings and emotions in a safe environment. The feedback shows that the Cancer Information Services offer practical advice and information to cancer patients during treatment.

**Our Night Nursing service** ensures that the patient dies at home with dignity. It is hugely important to families that they deliver on the patient's wish to die at home. Our Cancer Information Services provide people with peace of mind and reassurance to patients.

It is clear that our services and programmes consistently meet the majority of our service users' needs. The reports include negative feedback specific to each service and programme for our internal teams to examine. However, there are bigger challenges we need to consider. More and more people in Ireland will be affected by cancer in the years to come. Already the demand for our services is increasing substantially. We need to match the right level of resources to the ambition of these programmes and services.

All of our services and programmes must continue to meet the specific needs of our service users, particularly those who need them most. Social inequalities affect all stages of the cancer continuum, from prevention to end-of-life care; we need to ensure that we apply a health inequality lens to all our work so that our services and programmes are accessible to all.

The current National Cancer Strategy 2017-2026 calls for the development of programmes that address survivorship and psychosocial support needs in response to the growing numbers of cancer survivors in Ireland. This will likely have a knock-on effect on what we already provide (1). Similarly, the strategy notes that cancer prevention is a key area of interest; this too could affect the work we are currently doing in this area.

Finally, the National Strategy recognises the need for ongoing evaluation and the importance of the role of the patient. We hope that by running the impact monitoring project on an annual basis, we are ensuring that the patient voice is adequately represented in the planning and delivery of our services and programmes.

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