

**We are a community
determined to help
anyone affected
by cancer in Ireland.**

**OUR STRATEGIC PLAN
2020-2025**

IMPACT OF COVID-19



Irish Cancer
Society Night Nurse
Aveen Murray

Since we developed this strategic plan in late 2019, Ireland has been hit by COVID-19 and this has had a major impact on people affected by cancer.

Cancer screening has been paused and treatment plans have been interrupted. Fear of getting the virus has stopped many people from going to the GP with potential cancer symptoms, increasing the likelihood of delayed diagnoses. Social distancing requirements have forced patients to stay physically apart from family and friends at a time when they badly need emotional support. Families of terminally ill patients have been unable to be with their loved ones in their final hours.

Since the start of this crisis, the Irish Cancer Society has done everything we could to help people with cancer cope with the impact of COVID-19.

We have:

- ★ Increased the opening hours of our freephone Support Line 1800 200 700 and expanded the service to include non-medical information such as advice on welfare entitlements.
- ★ Recruited additional volunteer drivers nationwide to ensure we can continue to provide free transport to chemotherapy for cancer patients despite the challenges posed by COVID-19.

- ★ Introduced a remote counselling service to help people who can't attend in-person counselling due to the pandemic.
- ★ Developed tailored information about coronavirus and cancer which is available on our website for those affected by cancer.
- ★ Pivoted to digital and virtual fundraisers to help us ensure we can continue to provide these crucial services and introduce new ones.

We have also been the voice of the cancer community to politicians, officials and the media during the coronavirus pandemic, highlighting the negative effects of the crisis on people with cancer and pushing for these to be addressed.

For as long as Ireland is affected by COVID-19, we will continue to do everything we can to reduce its impact on people affected by cancer. We will remain flexible and respond to new needs as they emerge. We will also put pressure on Government to urgently address the backlog in cancer services caused by COVID-19.

However, we also remain focused on the future.

Although our new strategic plan was drafted without knowing the impact this virus would have on cancer patients and services, its ambition, vision and goals are more relevant than ever before and we are committed to doing everything we can to achieve them.

The coronavirus outbreak has revealed what is really important to each of us, above all else - our health. The solidarity, selflessness, kindness and compassion displayed by our nation, and particularly our frontline workers, has been a huge source of national pride. Post COVID-19, the Irish Cancer Society will work to ensure this is not lost and that we get back on track to delivering the world class services and outcomes that people affected by cancer in Ireland deserve.

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CEO & CHAIR MESSAGE



**Averil Power, CEO,
and Dermot Breen,
Chairman, of the Irish
Cancer Society**

Every three minutes, someone in Ireland hears the words 'You've got cancer'. At the Irish Cancer Society, we know all too well the impact cancer has. The fear and uncertainty it brings. The physical, emotional and financial burden it imposes. The enormous grief when it takes the life of a loved one too soon. The effect on the lives of those who are fortunate to survive it but struggle to cope with lasting effects like depression, infertility, incontinence and fatigue.

The Irish Cancer Society is a community of patients, survivors, volunteers, supporters, health and social care professionals and researchers. We have all been affected by cancer and we are all determined to do everything we can to ensure less people get the disease, more patients survive it and everyone has access to world-class treatment, care and support.

Our vision is that, by 2025, three out of every four cancer patients in Ireland will survive their diagnosis and, in future, no one in Ireland will die from the disease.

When we first started Daffodil Day in 1986, just three out of ten Irish people survived their cancer diagnosis. Today, six in ten do. Some cancers, like childhood blood cancers, that were previously almost always fatal are now largely curable. Nine out of ten people also now survive prostate, breast and testicular cancer. As a result, there are now over 200,000 cancer survivors in Ireland.

The pace of medical and scientific progress is so remarkable that, with sufficient investment, a future where no one dies from cancer is now potentially within our grasp. Advances like the HPV vaccine mean it will be possible to eliminate some cancers. Others will become chronic, manageable illnesses, just as HIV is now.

Ending cancer deaths is an ambitious goal but with sufficient investment and international collaboration it is an achievable one. Under this strategic plan, the Irish Cancer Society is committed to doing everything we can to help bring that day forward. We will invest in world-class research and work with our international counterparts to advance the global fight against cancer. Our services and advocacy work will ensure Irish patients benefit from global advances and enjoy the best treatment and care.

At the same time, we will push for world-class cancer prevention so as many people as possible don't have to face cancer at all. We will work to ensure everyone affected by the disease has the medical, emotional and practical support they need to have a good quality of life. And we will help to make high quality palliative care available to all.

As always, success will only be possible with the continued generosity of our volunteers and supporters. The Irish Cancer Society receives just 3% of our income from the State. We are therefore reliant on the generosity of our individual, community and corporate donors to fund all of our work – our vital support services and our lifesaving research.

Over 500,000 Irish people are expected to get cancer in the next decade. With your support, we are determined to be there for everyone who needs us, providing advice, care and hope.

At the Irish Cancer Society, we know all too well the impact cancer has.

Achieving our vision will also require us to maintain and enhance our partnerships with individuals and groups who share our commitment to improving the lives of people affected by cancer. Collaboration has always been at the heart of our work. By working in partnership with medical professionals, researchers, policy makers, charities and others, we have achieved far more than we could have done alone. Through enhanced local, national and international partnerships, we will deliver even more in the coming years.

Together, we will save lives and significantly improve the lives of people affected by cancer in Ireland.

Averil Power
Chief Executive

Dermot Breen,
Chairman



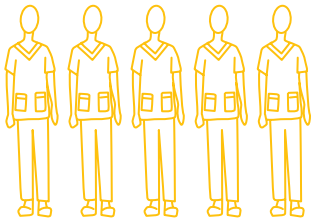
FUNDRAISING

Without our supporters and volunteers, we're powerless. We depend on this generous community to ensure we can help everyone who needs us.

Alison Farrelly from Dublin is pictured remembering those friends and family who have passed away from Cancer at the Garden of Hope in the Iveagh Gardens Dublin during the Irish Cancer Society's Daffodil Day 2018

Everything we do to save lives relies on money from this community. They are the lifeblood of the Irish Cancer Society.

To meet the increasing demand for our services. We need to continue to grow our support and volunteering, so that we can fund even more research to save lives and invest in services and support that will help everyone affected by cancer.



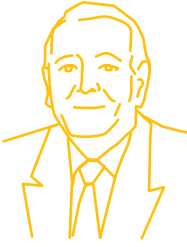
Since our last strategy in 2013, we have delivered 60,000 Nights of Care to 15,000 cancer patients in their own homes through our Night Nursing Service.

WHO WE ARE

We are a community of patients, survivors, volunteers, supporters, health and social care professionals and researchers. Together we are transforming the experiences and outcomes of people affected by cancer through our advocacy, support services and research.



We provide information, advice and support in hospitals, by phone and online, as well as services and support networks for people affected by cancer.



We were founded on October 10, 1963 by Irish GP, Austin Darragh. Since then, we have been dedicated to preventing cancer, detecting it early and caring for and supporting people with cancer and their loved ones.



Over the last decade we have invested more than €30 million of your donations into world-class cancer research taking place right here in Ireland. This included the establishment of BREAST-PREDICT.



We rely on the generosity of the public for 97% of our income.



Our Nurseline and Daffodil Centres have supported over 150,000 people affected by cancer since 2013.



Our Volunteer Drivers brought almost 6,000 patients to 78,000 hospital chemotherapy appointments over the lifetime of our last strategy from 2013-2019.

WHAT WE
HAVE ACHIEVED

When we first started Daffodil Day, roughly 3 out of 10 Irish people survived cancer. Today, 6 out of 10¹ do. This is thanks, in no small part, to improvements in public services that have come about as a result of our collaborative advocacy work, as well as advances in cancer research.

THESE INCLUDE:

Three

Additional investment in cancer services under Ireland's three National Cancer Strategies in 1996, 2006 and 2017

The centralisation of cancer surgeries into centres of excellence, so patients are treated by healthcare professionals with more experience and expertise in their particular type of cancer

€1m

The establishment of bowel cancer screening with a €1 million investment from the Irish Cancer Society (2014)⁴

2015

Phased extension of breast cancer screening to 65-69-year-olds from 2015²

15,000

Our investment in Cancer Trials Ireland has given 15,000 patients access to new treatments they wouldn't have received otherwise³

WE HAVE WORKED IN PARTNERSHIP TO HELP THOUSANDS OF PEOPLE AVOID GETTING CANCER THROUGH MEASURES SUCH AS:

The workplace smoking ban (2004), warning images on cigarette packs (2011) and plain packaging legislation for cigarettes (2015)

Legislation requiring cancer advisory labelling on alcohol (2019)

Cross-party support for Public Health (Sunbeds) Act (2014)

Reversing the decline in the uptake of the HPV vaccination for girls through the establishment of the HPV Alliance (2017) and extension of the scheme to boys (2019)

WHAT WE
WILL ACHIEVE

Our Big
Commitments

- | | | | |
|----|---|-----|--|
| 1. | We will address the unmet needs of anyone impacted by a cancer diagnosis or at risk of an inherited or genetic cancer. | 6. | We will take actions that accelerate the elimination of HPV cancers in Ireland. |
| 2. | We will offer much greater support for cancer survivors. | 7. | We will increase our investment in world-class cancer research. |
| 3. | We will drive innovation in public cancer services by piloting new, world-class initiatives that improve experiences and outcomes. | 8. | We will double the number of patients on clinical trials through our research and advocacy work. |
| 4. | We will develop new services that help people cope with the non-medical side of cancer, such as a Financial Entitlements & Advice service and a Returning to Work online hub for employers and employees. | 9. | We will drive nationwide change that makes it easier for people to reduce their risk of cancer. |
| 5. | We will provide more services for children and adolescents with cancer, and their families. | 10. | We will enable more people with cancer to die at home. |

MISSION

The Irish Cancer Society is a community of patients, survivors, volunteers, supporters, health and social care professionals and researchers.

Together, we are working to save lives and improve the lives of people affected by cancer in Ireland.

VISION

By 2025, 3 out of 4 Irish cancer patients will survive their diagnosis and everyone affected by the disease will have access to world-class treatment, care and support.

In future, no one in Ireland will die from cancer.

OUR VALUES

We are compassionate and caring

Everyone's cancer journey is individual and we reflect that in everything we do. From the time you are diagnosed, right through treatment and beyond, we provide personal support that is right for you.

We are inclusive

It doesn't matter who you are or where you come from, we are here for you. We are working hard to ensure everyone in Ireland has the same access to care and support during their cancer journey.

We demand excellence from ourselves and others

We are constantly demanding more of ourselves and others on your behalf. We always believe there is room for improvement and we strive for excellence in all we do. Our services and decisions are informed by best quality knowledge, data and expertise.

We value collaboration

Collaborating and working in partnership with world-class medical professionals, researchers, organisations and supporters helps us deliver more. We want to be inspired and to improve by challenging ourselves and by benchmarking ourselves against world-class results. We build alliances and work with local communities and global partners to deliver the best results.

We are accountable and transparent

We work to the highest standards of governance and financial management. This means we are honest, ethical and efficient in our work. We hold ourselves accountable for the delivery of our goals and objectives. Our latest annual report can be viewed at www.cancer.ie/annualreport

We support sustainability

We care about our communities and environment. We strive to be a sustainable organisation and minimise our impact on the world around us.



**MAKING THIS VISION
A REALITY**

30 years ago, only 3 out of 10 Irish people survived cancer. Today, thanks to improvements in cancer detection, treatment and care, more than 6 out of 10¹ do.

Some cancers, like childhood blood cancers that were previously almost always fatal, are now largely curable. 9 out of 10 people⁵ also now survive prostate, breast and testicular cancer.

In fact, the pace of medical and scientific progress is so remarkable that, with sufficient investment, a future where no one dies from cancer is now potentially within our grasp. Advances like the HPV vaccine mean it will be possible to eliminate some cancers. Others will become chronic, manageable illnesses, just as HIV is now.

Detecting all cancers early

Detecting all cancers as early as possible is central to realising this vision. All cancers are much easier to treat and have a greater chance of cure if caught early. For example, 19 out of 20 bowel cancers are cured if caught in stage 1, but less than 1 in 10 patients will be alive 5 years after a stage 4 cancer diagnosis.

Yet, currently, 6 out of 10 eligible people don't avail of bowel screening, 1 in 4 don't take part in breast screening and 1 in 5 don't undertake cervical screening.⁶ Boosting participation in these programmes could save hundreds of

lives every year. Advances in technology mean that screening for lung and prostate cancer, two of Ireland's most common cancers, may also be possible in the near future.

Bowel Screen was set up with a €1 million investment from the Irish Cancer Society. We have worked hard to improve public understanding of the other screening programmes and promote participation. Over the next 5 years, we will redouble our efforts to improve Ireland's screening programmes and to maximise participation. We will also improve public awareness of cancer symptoms and lobby Government to improve access to GPs, diagnostic tests and scans so potential cancers are investigated earlier.

Improving treatments

Improving treatments in cancer care also have the potential to save thousands of lives in the years ahead. In recent decades, chemotherapy and radiation treatments have become more targeted, while new drugs have radically improved outcomes for some cancers. Centralisation of cancer surgery into centres of excellence also means more people are being treated by healthcare professionals with greater experience and expertise in their particular type of cancer. Immunotherapy, empowering the patient's own immune system to find and kill cancer cells, also offers greater hope for the future.

Thanks to the generosity of our donors, the Irish Cancer Society has invested €30 million in cancer research over the last ten years. Our funding for Cancer Trials Ireland has also enabled 15,000 people³ to access new treatments they would not have benefited from otherwise.

We have pioneered improvements in public hospital care for Irish cancer patients, funding initiatives such as support nurses for men with prostate cancer, rehabilitation programmes for cancer patients, and establishing pilot clinics to help women overcome the side effects of cancer treatment.

**Ireland deserves
world-class care**

Over the next 5 years, we will increase our investment in the best Irish cancer research, and work with our counterparts in other countries to ensure Irish cancer patients benefit from global research advances. We will lobby Government to deliver on the National Cancer Strategy in full, so Ireland can have truly world-class cancer services. And we will continue to fund doctors and other healthcare professionals to pilot innovative new ways of improving patient care.

These, and the other initiatives set out in this strategy, have the potential to save thousands of lives in the years ahead.

**World-class prevention
and support**

At the same time, we will push for world-class cancer prevention so as many people as possible don't have to face cancer at all.

We will work to ensure everyone affected by the disease gets the medical, emotional and practical support they need to have a good quality of life. And we will help to make high-quality palliative care available to all.

Through our research, advocacy and support services, we will transform experiences and improve lives.



OUR PRIORITIES

Shannen Joyce, the face of Daffodil Day 2020, pictured with her daughter Róisín

We will reduce the fear of cancer through our support services

Healthy Living

Fewer preventable cancers

We will influence Government policy and laws so that everyone has the best chance of living a life free from cancer. We will invest in research that uncovers new ways to prevent cancer. We will provide advice to those who need it.

Catching Cancer Early

More cancers caught early

We will give people the best chance of surviving cancer. We will lead advocacy campaigns, innovate services, fund research, and work in partnerships that will eliminate the survival gap between Ireland and other European countries.

Treating Cancer

World-class cancer treatment for everyone

We will lobby Government so that all cancer patients are given timely access to treatments that will work best for them. We will reduce the fear of cancer through our support services and invest in research that has the potential to transform lives.

Living Well

Living well after treatment

We will make sure the emotional, physical, financial and practical needs of those who have undergone cancer treatment are met. We will provide services that will directly support people, so they are better able to cope with the impact of cancer. We will undertake research that will help us improve cancer patients' quality of life.

End-of-Life Care

Holistic support for people dying from cancer

We will ensure people dying from cancer have access to the full range of supports needed by them and their families. We will drive changes from Government that will mean more people can die at home. We will prioritise research that guides the development of our own supports and informs our advocacy to improve public services for people dying from cancer.

OUR PRIORITIES

Healthy Living

Our Priorities Healthy Living

We are all born with a risk of cancer. For some of us, that risk is greater due to our genes.

As a nation, we are faced with the incredible opportunity of saving more lives from cancer by investing in ways that actually prevent it. Experts now believe that by empowering people with the right support, information and services, 4 in 10 cancers could be prevented.⁷

Yet, in Ireland, lives are still being lost unnecessarily.

As many as 19,000 avoidable cancers⁸ are found every year. This number is growing.

Giving people the best chance of reducing their risk of cancer, by not smoking or drinking alcohol excessively, being a healthy weight and getting vaccinated, are some of the ways lives can be saved.

People who suffer from inequalities in health are particularly at risk of preventable cancers and need specific support. The good news is that if those supports are put in place, the potential for saving lives is enormous.

There is also hugely promising new research into the role of genetics and genomics in determining our risk of cancer. Developments in this area are taking place all the time. Our cancer system needs to be ready to take action on ground-breaking research findings.

Already, there are tests that can detect some gene changes linked to cancer. People who undergo this type of testing are empowered to take action that can reduce their chances of ever getting cancer. Yet, investment in this area has been majorly lacking. It needs to be prioritised to give people the best chance of avoiding cancer.

The solutions will involve everyone, because we cannot do it alone.

Our advocacy is central to the systemic change needed to stop the predictions from becoming a reality. We need Government to stand up and take responsibility for the huge shift in policy and multiannual investment that is required to make the healthy choice the easy choice.

We have done it before. The Irish Cancer Society has been behind many of the country's most effective health campaigns. We partnered with other groups to progress public health initiatives such as the introduction of the workplace smoking ban; we provided funding to roll out bowel cancer screening; we addressed the decline of the uptake of the HPV vaccine by establishing the HPV Alliance; and we secured cross-party support for sunbed legislation.

We can do it again.

Greater Government support needs to be given so people don't smoke, or are helped to quit if they do. Reducing our smoking rate will not only cut the cancer rate, but also reduce health inequalities between some of Ireland's richest and poorest communities.

The State also needs to meet the objectives set out in national policies like 'Healthy Ireland': Sláintecare and the National Cancer Strategy, which contain measures to address our alcohol and obesity crisis.

We also need Government action to tackle the rising problem of physical inactivity by investing in national infrastructure that prioritises walking and cycling.

THE NUMBERS:

4/10

4 in 10 cases of cancer are potentially preventable every year⁵

3/10

Smoking is responsible for almost 3 in 10 cancer deaths every year⁹

400

Almost 400 cases of cancer are caused by HPV infection each year¹⁰

1/10

Up to 1 in 10 cancers diagnosed are linked to an inherited faulty gene¹¹

No woman should go through what I have experienced and am still going through.



Kim

I am a proud survivor of cervical cancer. I am sharing my story as an example of exactly why women should get screened and vaccinated.

Sheer embarrassment about the smear test meant I only got mine done a year late at 26, after experiencing pain and bleeding. Really, I had nothing to worry about - the test itself is only slightly uncomfortable and takes 10 seconds.

The results detected abnormal cells in my cervix, and after further tests I received my cancer diagnosis on July 19, 2012. I'll always remember the doctor's words: 'I am sorry to tell you this Kim but you have cancer.'

The next few weeks were a whirlwind of scans, tests and hospital appointments.

I had surgery for a radical hysterectomy on September 3, 2012. I said my goodbyes to my family before going into the theatre, and all I remember afterwards was the burning pain - I was in more bits than a box of Lego!

I got the all-clear on September 24, but that wasn't the end of it. I still had to deal with the after-effects - bowel issues, fibromyalgia, early menopause and further surgeries, along with the reality that I can't have any more children.

There have been positives to my story. Despite all of these difficulties I graduated with my BSc, and set up a support network for cervical cancer in Ireland - my pride and joy!

The whole point of telling you this is to show how avoidable it all is. I was too late to receive my vaccine, a vaccine that has been proven safe time and again. As long as I'm here, I will continue to advocate for it.

No woman should go through what I have experienced and am still going through. So please, please get the HPV vaccine and attend your smears.

Kim Hanly
34, Tallaght

Our Priorities 2020-2025

ADVOCACY



Stack the odds in everyone's favour

We believe informed health choices should be really easy for people regardless of their background, education, location, race or income. This is why a Government-led national approach to smoking, obesity, physical activity and alcohol is needed.

We will campaign for Government to step up and meet its own smoking, obesity, physical activity and alcohol targets, contained in national strategies.

To do this, they will need to provide the infrastructure, the resources, the legislation and the support to offer everyone the best chance of living a life free from cancer.

We also need to ensure that particular effort and investment is made by Government to help those who are most at risk of preventable cancers. There is a clear relationship between preventable cancers and social and economic disadvantage. This must be recognised and action taken at a national level.

For instance, if people from disadvantaged areas were properly supported to stop smoking, reduce their alcohol consumption, while increasing the uptake of the HPV vaccine, diseases like head, mouth, neck and cervical cancers, and their hugely invasive treatments, could be eliminated.

Lastly, the needs of people with a genetic risk of cancer are not even close to being met. We will lobby Government for the services, workforce and ongoing care that is needed to bring genetic services to an international standard.

Prevention offers the most cost-effective long term strategy for the control of cancer. World Health Organisation⁷

RESEARCH



Gather strong data to help drive change

Cutting edge research has greatly added to our understanding of the risk factors and the biology of preventable cancers. We will continue to make investments that add to this knowledge, hoping that new ways to prevent cancer will be discovered.

We already know of the huge potential of research into cancer genomics and genetics, and how this could genuinely transform the future of cancer. The Irish Cancer Society will make investments in high-impact national and international research initiatives that accelerate progress in this area.

Our greatest challenge is how to apply what we know about preventing cancer to achieve the scale of change needed. This will require us to identify, research and evaluate new approaches empowering people to reduce their risk of cancer.

The findings of our research will be critical in moving from a health service focused on diseases to a nation that prioritises wellness.

A further research priority will be to uncover the needs and experiences of people who use genetic services, the barriers they face and possible solutions.

We are just inadequately resourced to deal with where genetics was 20 years ago, not to mention where it is now. We don't even have a genetics laboratory in the country. So we have to send all our tests abroad at considerable expense to get genetic testing done. So even something as basic as that, we just don't have.

Prof. David Gallagher, Consultant Medical Oncologist and Consultant Medical Geneticist¹²

SERVICES



Inform people about how to reduce cancer risk

We will empower people to reduce their risk by making it easier for people to make decisions that are in line with the European Code Against Cancer.

We are working toward the elimination of HPV-caused cancers in Ireland and will continue to encourage more people to get vaccinated, so that the potential of the HPV vaccine is realised. We will continue to challenge misinformation about the vaccine and provide evidence-based information and resources for parents.

We will significantly increase our focus on the huge challenges faced by people with a genetic or hereditary risk of cancer and will design supports and information that meet the needs of this group.

The most strenuous efforts must be made to target more deprived populations in cancer prevention and early diagnosis interventions. There is incontrovertible evidence of the enormous impact of socioeconomic status and deprivation on death rates from some cancers in Ireland.

Prof. John Kennedy, National Cancer Strategy 2017-2026¹³

- By 2025, our advocacy will have inspired transformative change across the health and social care systems; our services will have supported and informed thousands of people; research we fund will have guided us toward a better future for everyone.
- ★ We will build a strong, cross-sectoral advocacy coalition that will campaign for Government to deliver the change needed to meet national targets in the National Cancer Strategy: Sláintecare, Healthier Ireland and other national strategies on tobacco, alcohol, obesity and physical activity.
 - ★ We will ensure the cancer system is set up so that patients in Ireland benefit quickly from research discoveries that could enable them to prevent cancer.
 - ★ We will campaign for Government policy to focus on practical ways to empower people to reduce their risk of preventable cancers.
 - ★ Working in partnership, we will drive national advocacy demanding the full implementation of the National Skin Cancer Prevention Plan.
 - ★ In partnership, we will drive the delivery of countrywide, systemic changes prioritising health, such as active travel, balanced diet for school-going children and increasing girls' participation in physical activity.
 - ★ We will lead policy action so that waiting time targets for evaluation, counselling and genetic tests are met, with waiting times for preventative surgery or other risk-reduction procedures within the recommended limits.
 - ★ We will provide a pre and post treatment workshop to everyone who makes the decision to get risk-reduction surgery because of a positive genetic test.
 - ★ We will provide counselling to anyone who needs it before and after having risk-reduction surgery.
 - ★ We will lead a campaign to eliminate all HPV-caused cancers in Ireland.
 - ★ We will campaign for extended regulations on tobacco and alcohol so anyone seeking to quit smoking can access comprehensive supports, and those drinking alcohol to excess can reduce their intake to recommended levels.
 - ★ In partnership with other organisations, our advocacy will deliver regulations that prevent the marketing of e-cigarettes to children, with e-cigarettes comprehensively regulated.
 - ★ The Government and local authorities will make investments in active living and travel that empower the public to exercise more.
 - ★ We will partner with other organisations to ensure the Alcohol Act is implemented in full.

Catching Cancer Early

Our Priorities
Catching Cancer Early

Finding cancer at the earliest opportunity is the best chance someone has of successful treatment and having a good quality of life.

Despite this, there are still some people who face a late-stage cancer diagnosis.

While the survival rates for cancer have risen, fewer people are surviving cancer in Ireland than in many other European countries.¹⁴

The reasons for this are complex but increasing the number of cancers diagnosed at the earliest opportunity is a critical first step to narrowing this gap.

Urgent change is needed to move from laggard to leader.

The National Cancer Strategy recognises that stage at diagnosis is probably the most important determinant of survival and contains a number of targets to achieve earlier diagnosis.¹⁵

This will mean giving GPs rapid and direct access to cancer tests, supporting more people to use the national cancer screening services, raising public awareness of the signs and symptoms of cancer and the benefits of early detection, driving Government investment in proven ways to catch cancer early.

The Irish Cancer Society will lead advocacy campaigns, innovate services, fund research and work in partnerships that will eliminate the survival gap between Ireland and other European countries. Working within an international network of cancer organisations, we will bring knowledge, best practice and leadership to Ireland, driving changes that will ultimately save lives.

THE NUMBERS

7/10 7 in 10 lung cancers are diagnosed at late stage (stage 3 and stage 4)¹⁵

6/10 Almost 6 in 10 do not accept their invitation for bowel screening¹⁶

8/10 More than 8 out of 10 ovarian cancer patients alive at 5 years if caught at stage 1¹⁵

2/10 Fewer than 2 in 10 ovarian cancer patients alive at 5 years if caught at stage 4¹⁵



I feel I was one of the lucky ones. I didn't have any symptoms of pancreatic cancer. I went to the doctor with headaches. And she insisted I get checked and make a day free to go for tests.

Redmond

I feel I was one of the lucky ones. I didn't have any symptoms of pancreatic cancer. I went to the doctor with headaches. And she insisted I get checked and make a day free to go for tests.

An X-ray showed up something in my stomach, so I was referred for a CT scan and on to a pancreatic specialist for a biopsy. This showed pre-cancer cells on the head of my pancreas. By the time I went for surgery in September 2017, it was cancer.

I kept working on and off throughout my treatment and this helped me a lot. Being able to get out and about made a difference.

People often asked how I was so positive, but what else could I do? Sitting at the fire crying wasn't me. I dealt with it by getting out on the days when I could, and working on the phone or by email when I was able.

I have three children, Cian (17), Molly (16) and Enya (15), and I suppose I would have shielded them from it as much as possible.

I found the Irish Cancer Society's Volunteer Driver Service helped ease the burden of organising transport to treatment.

6 months is a long time to be expecting family and friends to provide lifts.

With the service, I didn't have to worry about how to get to treatment, so it took a lot of pressure off me. The drivers understood the scenario. If you wanted to talk they let you, if you didn't they understood.

Redmond McGuire,
56, from Cork

Our Priorities 2020-2025

ADVOCACY



Close the survival gap

Faced with the stark reality that there is a survival gap, we are making the early detection of cancer a strategic advocacy priority.

Over the next 5 years, we will campaign for change so that we have a health service that is designed to diagnose cancer quickly. This is a critical aspect of world-class cancer services for people to live longer with a good quality of life.

The National Cancer Strategy contains a target to increase the number of colorectal, breast and lung cancers diagnosed at stages I and II by 10%.¹⁷ While the link between stage of diagnosis and cancer survival is complex, it is clear that treatment at an early stage offers the greatest potential for improved 5-year survival.

Unfortunately, it is people who are already disadvantaged in other areas of their lives, who are more likely to be diagnosed with cancer at a late stage.¹⁸ More needs to be done to reduce this inequity.

We also need to ensure that the survival gap between cancers is closed, with particular attention being given to those with a rare, difficult-to-treat or metastatic cancer.

Despite improvements, a survival gap continues to exist between Ireland and the best performing European countries. **National Cancer Strategy for Ireland¹⁹**

SERVICES



Encourage early diagnosis through information and support

The Irish Cancer Society is uniquely placed to advise people who have symptoms of cancer to seek medical help. Through cancer.ie, our Daffodil Centres and Cancer Nurseline, we can offer advice and support to people who have concerns.

Our support services staff will reduce the fear of waiting for a cancer test or test result.

We will run national awareness campaigns that will increase awareness of the signs and symptoms of cancer. We will make sure that all members of the public are empowered to take action as a result, including people from minority groups and those who are socially and economically disadvantaged.

Our services will provide clear information to ensure more people are aware of cancer signs and symptoms, and are empowered to take action where they have a concern.

People living in deprived areas are 40% more likely to die from their cancer within 5 years of diagnosis, with survival rates worse for stomach, colorectal, lung, breast and prostate cancers, as well as lymphoma and leukaemia.

National Cancer Registry of Ireland¹⁸

RESEARCH



Innovate and inform through exceptional research

We know the importance of being diagnosed with cancer early, but we still have a lot to learn. To bring international insights, transformational ideas and innovation to Irish decision-makers, we will leverage our global network of leading cancer organisations and understand what they are doing well, and how we can apply it in Ireland.

Over the next 5 years, we will also make investments in promising new ways of testing for cancer earlier.

We will work with the National Screening Service to understand why people don't take up cancer screening when invited to do so. This research will inform how we communicate with people about cancer screening.

Early detection, screening and diagnosis have been proven to significantly improve patient survival rates and quality of life, as well as to significantly reduce the cost and complexity of cancer treatment.

American Society of Clinical Oncology (ASCO)²⁰

By 2025, our advocacy will have inspired transformative change across the health and social care systems; our services will have supported and informed thousands of people; research we fund will have provided insights that will guide us toward a better future for everyone.

- ✦ We will influence Government so that waiting times for cancer tests are in line with clinical targets, and targets in the National Cancer Strategy are met. We will also advocate for the full funding and implementation of Sláintecare, so that its vision for quicker and equal access to tests and treatment can be realised.
- ✦ We will support the National Screening Service in innovating and trialling new ways to encourage more people to accept their invitation for cancer screening every year, particularly focusing on groups that have low uptake rates.
- ✦ We will use our global network to learn more about catching cancer early and bring best practice to Irish patients.
- ✦ We will undertake research to understand the financial, social and cultural barriers to people attending their GP, hospital or screening appointment. We will take action on the findings, supporting the ambition in the National Cancer Strategy that the number of colorectal, breast and lung cancers diagnosed at stages I and II will increase by 10%.
- ✦ Our support services will reduce the fear of anyone waiting for a cancer test.
- ✦ We will bring cutting-edge innovation in cancer screening programmes to Ireland. We will champion new opportunities to catch cancer early as international evidence on screening programmes for diseases like lung and prostate cancer becomes available. We will also ensure the most possible people benefit from existing screening programmes, in line with national health policy.
- ✦ We will support the work of the health services so that the signs and symptoms of cancer are better understood by the public, with particular focus on disadvantaged groups.
- ✦ We will apply pressure, where necessary, to ensure that the Scally Report's recommendations are implemented in full.

OUR PRIORITIES

Treating Cancer

Our Priorities
Treating Cancer

For anyone diagnosed with cancer, their first thoughts are whether they will survive. Thankfully, with advances in surgery, chemotherapy, immunotherapy, radiotherapy and other treatments, doctors can reassure many patients that there is a future after cancer.

However, the pace of progress hasn't been the same for everyone. To avoid a widening survival gap, innovation is urgent for rare cancers, metastatic cancers, cancers affecting children and young adults, as well as hard-to-treat cancers like lung, pancreatic and oesophageal cancers and brain tumours.

Through international partnerships, and working with global research leaders, we will be part of a movement that is focused on the needs of those who have been left behind.

For instance, only 3 in 10 women with ovarian cancer live for 5 years or more after diagnosis, compared to almost 9 in 10 women with breast cancer. Fewer than 1 in 10 men with pancreatic cancer lives for 5 years after being diagnosed, compared to over 9 in 10 prostate cancer survivors.¹⁵

It is critical that we focus on those most underserved by existing treatments and create a national culture of research, innovation and learning.

While there is so much still to learn about treating cancer and making those treatments less invasive, other countries are prioritising investment in research.

But Ireland falls far short.

Only 30 of the 3,500 people diagnosed with cancer every month are added to clinical trials.⁸ Attracting and fostering the best and brightest talent in research is a critical aspect of cutting-edge cancer care. It is also the only way many people with cancer will get access to the newest treatments and drugs that may extend, improve or save their life or the lives of future generations.

Advances are also being made that enable people with incurable cancers to live long, high-quality lives. Healthcare professionals are looking after patients in challenging circumstances.

It is critical that the progress and hope brought about by innovation and science is not undone because basic elements of cancer services are not being delivered upon.

THE NUMBERS

11,000
cancer patients have surgery every year²¹

7,000
cancer patients have radiotherapy every year²¹

7,000
cancer patients have chemotherapy every year²¹

30
Fewer than 30 cancer patients are being added to a clinical trial every month⁸

7/10
7 in 10 patients received surgery within the recommended timeframe¹⁶

0
0 comprehensive cancer centres in Ireland

TREATING CANCER



Hearing the words ‘You have cancer’ at the age of 17 is utterly surreal. I had just started my first semester in college.

Alan

Hearing the words ‘You have cancer’ at the age of 17 is utterly surreal. I had just started my first semester in college. I was putting down the vague symptoms I was experiencing, such as having very little appetite, to adapting to student life.

I started to develop pains in my feet and it felt like I was walking across a stony beach. After a visit the Vhi SwiftCare clinic I was referred immediately to Beaumont Hospital. It was there I was diagnosed with Hodgkin Lymphoma.

Over the course of 5 years I had many types of cancer treatment. Chemotherapy, radiotherapy, a stem cell transplant and, after I relapsed, chemo again. Thankfully, I’m 8 years cancer-free now.

I had great family support while I was going through my cancer. My parents and brother were always there for me. It was very difficult though, especially at such a crucial stage in life when you are branching out on your own for the first time. It was hard on friendships too. People didn’t know what to say to me or how to act, so they just avoided me. But others really showed their true colours and were there for me.

Alan Gorman
29 years old from Swords, Co. Dublin

Our Priorities 2020-2025

ADVOCACY



Give everybody the same chance to have world-class cancer treatment

All patients should be able to receive the evidence-based treatment that will work best for them, and be given it within the recommended timeframe. We believe that is a right of anyone diagnosed with cancer in Ireland and will fight for it to become a reality.

Achieving this will require us to push for investment in cancer hospitals so that the staff, equipment, beds and medicine are all available to meet the current and future needs of people with cancer. All cancer surgeries should take place in Designated Cancer Centres and there needs to be sufficient capacity to meet the demand for radiation oncology. We also need to make sure that proven cancer treatments are being made available to patients quickly and that there are no disadvantages to being treated in Ireland compared to other countries.

Clinical trials are one of the best ways for patients to access the world's newest treatments. We are underperforming in this area and will focus our advocacy work on turning this around.

We will ensure the Government delivers its promise of a Comprehensive Cancer Centre, as this will truly move the country toward world-class cancer research and care.

SERVICES



Reduce the fear and worry of cancer treatment

Being diagnosed with cancer is life-changing. Many of the feelings and emotions are negative and understanding the medical path ahead can be confusing. The Irish Cancer Society will use its services to reduce the fear and worry for anyone with questions or concerns about cancer treatment and its side effects.

Our support services will link patients with others who have had a similar diagnosis to help them better understand the challenge ahead. Our nurses will help cancer patients understand and access the range of practical and psychological supportive services which can ease the burden often associated with treatment.

Our volunteer drivers will ensure that more patients than ever will not have to worry about getting to and from their chemotherapy appointments.

We know that patients facing a rare, metastatic, genetic, childhood and adolescent cancer have additional needs that are not currently being met. We will prioritise these groups by focusing on and designing services and information around them.

"By increasing investment in cancer trials infrastructure, we could be offering Irish cancer patients more options and potentially better outcomes. Cancer trials can extend lives and give people a better quality of life."

Prof. Bryan Hennessy, Clinical Lead, Cancer Trials Ireland²²

RESEARCH



Invest in research that has impact

Major improvements and investments are needed to encourage more cancer research to take place in Ireland. As Ireland's largest voluntary funder of cancer research, we are uniquely positioned to drive this change.

We will work with other major funders of cancer research to improve the treatment options of every person with cancer, particularly those with rare, childhood, genetic, metastatic or hard-to-treat cancers. This will help close the survival gap between cancers.

Patients should be given every opportunity to survive and live well. Greater access to innovative care that blends the best treatment, support and quality of life is badly needed. We will fund investments that will increase the number of patients who are able to access this kind of care.

We will work with a broad group of healthcare professionals to foster their research expertise and drive evidence-based improvements in patient care.

There is a need to develop a uniform service specification that ensures all children with cancer have equitable access to an appropriate range of clinical and laboratory services for diagnosis, treatment planning and follow-up.

National Cancer Strategy 2017-2026²³

By 2025, our advocacy will have inspired transformative change across the health and social care systems; our services will have supported and informed thousands of people; research we fund will have provided insights that will guide us toward a better future for everyone.

- Working in partnership with the medical, political, industrial, scientific and academic communities, the Irish Cancer Society will drive fundamental change across the health research landscape. As well as creating an environment where pioneering research can take place, our collaborative advocacy will create the conditions to deliver double the number of cancer patients on clinical trials.
- Holding Government to account on its own targets, we will make sure that all child, adolescent and adult patients receive treatment within the recommended timeframes.
- Engaging with the Designated Cancer Centres, patients, families and medical staff, we will identify gaps that lead to poor experiences for patients, and advocate for the resourcing of the cancer system so that the buildings, facilities, equipment and workforce required to meet the needs of patients are provided.
- The Government promise of a Comprehensive Cancer Centre will be delivered on, as a result of our campaigning.
- The fear and anxiety experienced by people receiving cancer treatment will have reduced amongst the people who use our services.
- Research, advocacy and supports provided by the Irish Cancer Society, that are focused on the needs of rare, childhood, genetic, metastatic or hard-to-treat cancers will have increased.
- We will partner with other cancer charities and share experiences, insights and resources to improve the outcomes and experiences of people with unmet need.
- We will maintain pressure on Government so that all planned cancer surgeries will take place in Designated Cancer Centres, leading to better chances of survival.
- Working with parents of children with cancer, we will ensure the National Children's Hospital delivers the world-class cancer treatment facility for children and young adults that has been promised.
- We will build up evidence-based resources that empower patients and tackle misinformation regarding cancer treatments and cancer prevention.

OUR PRIORITIES

Living Well

Our Priorities
Living Well

While more lives are being saved from cancer, not enough attention has been given to the quality of those lives.

Every person with cancer needs access to help that focuses on more than just their cancer treatment, especially support that addresses financial, practical and emotional concerns. However, State support and services are patchy and inconsistent.

The scale of unmet need amongst cancer survivors and those living with cancer is enormous.

Physical issues include incontinence, bowel problems, sexual dysfunction, lymphoedema, weight changes, sleep disturbance and fatigue.

Emotional and psychological effects include shock, distress and fear of recurrence, low self-esteem, depression and difficulties returning to work.

Social and intimacy issues include lack of support, fear of burdening family and friends, loss of identity and altered relationships.

Financial issues include increased stress due to lack of or reduced household income and an increase in costs to help manage side effects of treatment.

On top of the lack of services, many people find out that they don't seem to fit anywhere within the cancer system. People with metastatic cancers don't feel like survivors as they may be receiving lifelong treatment. Teenagers with cancer fall between the child and adult services. People who have had risk-reduction surgery may never get cancer but still face significant challenges. Those living with a rare cancer may face misunderstanding and poor treatment options. And people with cancers that require treatments that physically alter their appearance, like treatment for head and neck, mouth and throat cancers, can suffer from lifelong psycho-social issues.

With 200,000 people facing these challenges, the scale of the unmet need is phenomenal.²⁵

The Irish Cancer Society is committed to bringing about system-wide change, which will meet the needs of those who have been left wanting for too long. As the national cancer charity, we have a critical

role in delivering the transformative change needed in this area. We will innovate services, track progress through patients' experiences and help build a future where everyone's quality of life is improved.

THE NUMBERS

200,000
cancer survivors every year²⁵

1/25
More than 1 in 25 people in Ireland are now cancer survivors²⁵

6/10
30 years ago, 3 in 10 patients survived cancer; in 2019, 6 in 10 survive²⁵

€756
Average cost associated with a cancer diagnosis is €756 per month²⁴

7/10
7 in 10 face an income drop, averaging over €18,000 a year²⁴

2/3
2 in 3 cancer patients find medical card application complicated²⁴

1/4
1 in 4 was provided information on social welfare benefits by the hospital²⁴



Cathy

I am strong and determined to make the most of my situation and live in the now.

I was diagnosed with breast cancer in 2005. I was working with my husband John on setting up a new business and life was busy with our three boys, Sean, Conor and Liam, who were 11, 8 and 6 at the time.

I had surgery, chemotherapy and radiotherapy at St. James's Hospital in Dublin. We worked very hard to try and keep life as normal as possible during this time and were lucky to have the support of family and a close circle of friends.

In April 2016, after 11 years of regular scans and appointments, I noticed an unusual pain in my side. My very diligent GP referred me for a scan and the news came that my cancer had come back. I had developed secondary breast cancer in my liver and bones.

This was a devastating blow for John and me and the boys.

But my life is so much more than my cancer diagnosis. Sometimes, the reality of it all hits home and I panic, temporarily! I try not to dwell on the future too much. I attend my local Cancer Support Centre, and recently, a course of reflexology has really benefited me.

I am strong and determined to make the most of my situation and live in the now.

Cathy Lynch
56 years old from Co. Offaly

Our Priorities 2020-2025

SERVICES



Directly support anyone who needs it

Having cancer is hard. It's harder than hard. Sometimes life seems impossible. The reality is that no one lives their life waiting for cancer, so when it hits, the shockwaves crash across every part of life.

Our services are designed to support people during this immensely difficult time. Our army of volunteers drive cancer patients to chemotherapy appointments so they can focus on the day ahead. Our team of expert cancer nurses offer free support and advice on our National Cancer Nurseline and in Daffodil Centres, so the public gets information from a trusted source at a time that suits them. Our Children's Fund provides financial support to the families of children with cancer, so they can concentrate on the needs of those they love. By working in partnership with cancer support centres around the country, we enable patients to access support and care at a location that works for them.

We run chemotherapy education programmes so patients know what lies ahead. We employ dedicated specialist support nurses who work with prostate cancer survivors. And our peer support volunteers provide patient-to-patient support across the country. Over the next 5 years we will expand and improve these existing services. We will also do much more. We will develop new supports to help people cope with the emotional, physical, practical and financial impact of cancer.

We will help people manage their treatment side effects by trialling services and innovating care in the community, such as a survivorship clinic to help women deal with consequences of cancer treatment. Through a new support service, we will help people understand what financial help the State can provide and we will work to ensure they are not penalised by banks and insurers because they had cancer. We will also help people get back to work when they are ready, advising them of their rights and educating employers about how to support them.

We will be doing so much more in this area too, like working with experts in mental health and social care who can make an immeasurable difference to someone's quality of life. We will be there for everyone who has received a cancer diagnosis for as long as they need us and ensure they live the best life possible.

ADVOCACY



Improve the quality of life of people with cancer

We believe that the quality of life of people who have been diagnosed with cancer can be significantly improved. While there is a lot the Irish Cancer Society can and will do, it is leadership at Government-level that can produce system-wide change and transform the experiences of everyone.

Our goal is that people are supported long after their initial cancer diagnosis. We want a cancer system that is focused on quality of life for child and adult patients and survivors, and that everyone has access to the tailored range of supports they need. We believe that many of these supports can be delivered locally. This would make such a difference to people who currently have to travel to hospitals for care that should be delivered in the community.

We will reduce the financial burden of cancer by continuing our campaigns for lower Government charges, better access to entitlements, and more support for those who aren't able to return to work.

We will be part of transforming experiences by funding services like fertility preservation, improving men and women's sexual health, and leading change through piloting the world's best support services, like our women's health initiative.

More comprehensive State support could have hugely positive impact on the lives of cancer patients. We will engage with Government so that psychological and emotional care is offered to every cancer patient, that bras, prosthesis and wigs are offered to all, and consistent, quality care for people with lymphoedema is offered, no matter where the patient lives.

RESEARCH



Uncover unmet need through research

We have an opportunity to trail-blaze research in the area of cancer survivorship. While we have already led important research in this area, we know that there is so much more we need to uncover.

We need to learn more about what care and support is important to people after a cancer diagnosis, particularly amongst those with less common cancers, those with a metastatic cancer, childhood cancers and those who have had risk-reducing treatment. We have a responsibility to prioritise research amongst those groups we know least about. Otherwise, there is a risk of widening inequality between those who have a good quality of life and those who don't. Indeed, it is the survivors of cancers that have received comparatively little research focus to date, that arguably have the greatest need for support.

Understanding where support services could help address the many issues faced by people with cancer is a first step in transforming the lives of hundreds of thousands of families across the country.

It is therefore clear that the needs of people living with and beyond cancer in Ireland are not currently being met. **National Cancer Registry of Ireland⁵**

The increasing numbers of cancer survivors living well beyond their initial diagnosis have increased awareness of cancer survivorship, but much remains to be learned about the issues survivors face. **American Cancer Society²⁶**

By 2025, our advocacy will have inspired transformative change across the health and social care systems; our services will have supported and informed thousands of people; research we fund will have provided insights that will guide us toward a better future for everyone.

- ✦ We will help people access State benefits and exercise their rights in areas such as employment, mortgages and insurance. Our engagement with banks and insurance companies will be reflected in policies more supportive of people living with cancer.
- ✦ We will run National Cancer Patient Experience Surveys so that we can uncover gaps and poor experiences and take action through advocacy.
- ✦ Everyone affected by cancer will have access to trusted information, advice and support from the Irish Cancer Society on medical and non-medical issues.
- ✦ We will offer pre and post treatment workshops for every person being treated for cancer in Ireland, so they are better able to cope with what is ahead.
- ✦ Our campaigning will have pressed the Government to deliver its promise of rolling out a National Psycho-Oncology Service that is available to all cancer patients.
- ✦ We will trial a fertility preservation programme for survivors of childhood and adolescent cancers and advocate for it to be the State standard of care.
- ✦ Through sustained pressure on Government, the quality of life of people living with cancer will have improved through the provision of tailored State supports and the reduction of statutory charges.
- ✦ Ensuring the lifelong needs of children and adolescents with cancer and their families are met will be a priority for our advocacy, services and research departments.
- ✦ By making decision-makers aware of the financial impact of cancer, more people with cancer will have a medical card and access to other entitlements.
- ✦ Our research will outline the financial needs of adult survivors of childhood cancers requiring ongoing care. We will campaign for medical cards to be provided to meet lifelong healthcare costs.
- ✦ Innovative cancer supports and services will be piloted and mainstreamed into national cancer services.
- ✦ By building strong partnerships with doctors, nurses and other professionals who support people living with cancer will understand how the Irish Cancer Society can help.

End-of-Life Care

Our Priorities
End-of-Life Care

Although the number of people surviving cancer is increasing, it is still Ireland's biggest killer.²⁷

Every family knows someone who has died too soon. Despite this, survival and treatment options dominate discussions about cancer. But until there is successful treatment for everyone, greater focus is needed on the care and support requirements of the 1 in 4 of the Irish population who will die from cancer.

When someone is told they are going to die from cancer, there are so many things to consider. Some are immediate, like how to tell close family and friends, some more distant, like financial planning. Some people will require long-term access to palliative care services, others will need to consider end-of-life supports.

For parents and families of children facing a terminal cancer diagnosis, there are complex and specific needs that require individualised solutions.

We need to do more to ensure that national and standardised approaches addressing the physical, emotional, social and spiritual elements of care are available to all people dying from cancer.

Early provision of palliative supports can extend life by up to 3 months.³⁰ We will break down the barriers and fears of palliative treatment through our services and advocacy. It's vital that the growing number of people who are reaching the end of their lives have regular conversations and get support that's right for them and their families, so they can find their best way through whatever the future holds.

THE NUMBERS

7/10 7 in 10 people want to be cared for at home at end-of-life²⁸

3/10 3 in 10 people are cared for at home²⁸

5/10 5 in 10 people fear that their desired place of care will not be available when they need it²⁸

12 12 counties have no inpatient hospice

7,400 nights of care provided by Irish Cancer Society night nurses in 2018²⁹

Mel

I was often assigned to look after patients who were being withdrawn from treatment and I feel like this is where I began to develop a passion for palliative care.

I will never forget the grandmother's hug.

I started my training later in life, aged 36. My first job as a qualified nurse was working in the NHS ICU, which was an extremely challenging environment.

I was often assigned to look after patients who were being withdrawn from treatment and I feel like this is where I began to develop a passion for palliative care. I began working for the Irish Cancer Society in May 2018.

One of the most rewarding experiences I had was when I cared for a paediatric patient. The grandmother thanked me and gave me the tightest hug for taking the assignment, as this allowed for her grandchild to come home. Although by far my toughest assignment to date, I feel it was the most rewarding. I had the incredible privilege of being part of a team who supported this family. As a parent myself, I just couldn't imagine the pain and heartbreak of losing a child. The degree of love they displayed not only for the sick child but toward their other children and each other was humbling to say the least. I will never forget this family, I will never forget the grandmother's hug.

I believe everyone facing end-of-life should, where possible, be supported in their decision to die where they feel is right for them.

And most people would prefer to die in their homes.

I'm constantly humbled by a patient's family and friends who, with little to no healthcare knowledge, take on the task of facilitating their loved ones' wishes and full-time care.

When caring for someone so unwell, it is a 24/7 job. It's a relay race. And our work enables the family to pass the baton of care onto us and get some much needed rest.

Mel

Irish Cancer Society
Night Nurse

Our Priorities 2020-2025

SERVICES



Enable people to die at home

Most people would like to die at home. The Irish Cancer Society’s Night Nursing service enables almost 2,000 patients²⁹ a year to do so. We offer nursing care, practical support and reassurance. We also aim to keep patients comfortable and free of pain while in our care.

However, we know that we are not meeting the needs of everyone and that there are families who do not know the free service exists. Over the next 5 years, we will increase the number of patients who use this service. To do this, we will work with cancer hospitals and palliative care teams to raise awareness amongst healthcare professionals of how we can support them and patients in providing end-of-life care at home.

The support the Irish Cancer Society showed my mam and our family in the final weeks of her illness was so appreciated. It allowed us to have one last wonderful Christmas with my mam at home. She was so happy in her last couple of weeks, in her own home, that it was almost hard to believe her illness was so serious. A very tough illness incredibly had a beautiful ending. Our family often talks of your nurses and how special they really are.

Irish Cancer Society Night Nursing Client

ADVOCACY



Deliver holistic end-of-life care for everyone

Palliative and end-of-life care is not of the same standard across the country. Where you live matters when it comes to accessing services for people dying from cancer.³¹ This might mean the difference between dying at home or in hospital, or between getting emotional support or not.

We know that when people’s needs are met, there is a lot less anxiety and worry for them and their family. Therefore, patchy State care isn’t acceptable. We are turning our attention to delivering change that will improve the standard of support for everyone. Our advocacy will uncover sub-optimal care, highlight inconsistencies and bring about better experiences.

As well as providing nursing support in the last days of life, the Irish Cancer Society will help people prepare for death by ensuring a full range of holistic supports are in place within the health system, and that access to them is automatically triggered upon the diagnosis of a terminal cancer, such as practical advice and emotional care.

We will also help to support people who are coping with the diagnosis of a loved one, particularly the parents and siblings of a child with a life-shortening cancer.

Where there are gaps between what the State provides and what people with cancer need, we will apply pressure on the Government and HSE to do more.

RESEARCH



Apply best practice

There is still so much we don’t know about the needs of people with terminal and untreatable cancers. We will prioritise research that is aimed at reducing the anxiety and improving the quality of life of people in this group. We will work with patients, family members and medical professionals to understand what services are in place now, and to identify ways to improve them and provide a good quality of life.

By applying the learnings from international best practice and using insights from Irish research, it is possible to build a support and care system for people dying from cancer that patients, family members, medical professionals and the health service can all be proud of.

Communication about end-of-life care and decision-making during the final months of a person’s life is very important. Research has shown that if a person who has advanced cancer discusses his or her options for care with a doctor early on, that person’s level of stress decreases and their ability to cope with illness increases.

National Cancer Institute, United States³²

By 2025, our advocacy will have inspired transformative change across the health and social care systems; our services will have supported and informed thousands of people; research we fund will have provided insights that will guide us toward a better future for everyone.

- ✦ Because of the nursing care we provide and our advocacy action, all people with cancer medically able to die at home will be enabled to do so.
- ✦ We will use our influence with Government to deliver a full range of holistic State supports for patients with terminal or untreatable cancer.
- ✦ Working in partnership with other service providers, we will push for change so that end-of-life care and supports are provided close to or in a person’s home.
- ✦ We will work alongside other organisations and patient groups to ensure that palliative care is available out of hours and at weekends, regardless of where someone lives.
- ✦ In consultation with families and medical teams, we will seek the delivery of age-appropriate palliative and end-of-life services for children and young adults with untreatable cancers in their local community.
- ✦ We will make sure that the State provides emotional and bereavement support for anyone impacted by cancer, especially parents and siblings of a child with cancer and children who have a parent with a cancer diagnosis.
- ✦ We will make the medical community aware of how the Irish Cancer Society can support them in providing end-of-life care.
- ✦ Through new research we fund, we will better understand the needs and preferences of people dying from cancer and design services and advocacy campaigns around the findings.
- ✦ Our research will have uncovered ways to reduce the anxiety and worry of someone told they have a terminal or incurable cancer and we will have applied these insights in a practical way.
- ✦ We will campaign for the Government to deliver on its commitment that palliative and end-of-life care will be consistent with international best practice, regardless of where someone lives.



The start line at the Irish Cancer Society's Colour Dash in the Phoenix Park, 2019

**This journey is
one we can only
make together.**

**STRUCTURED
FOR SUCCESS**

To support the achievement of what we have outlined in our ambitious new strategy, we must ensure that the Society is structured for success. With this in mind we will ensure that:

We are an agile, patient-focused and transparent organisation with a culture of innovation, ethical practices and environmental responsibility.

We have the right people, structures and supports in place and encourage the continued training and development of our staff and volunteers.

We deliver an ambitious and inspirational fundraising programme to support our new strategy. We will strive to increase our income so we can reach more people living with cancer as well as diversifying our fundraising base.

Our strategy will be a living document that guides our activity until 2025. We will revisit and benchmark regularly, providing an annual update on our progress.

REFERENCES

1. National Cancer Registry Ireland. Cancer in Ireland 1994-2017 with estimates for 2017-2019: Annual report of the National Cancer Registry; P18. Cork (Ireland): National Cancer Registry Ireland; 2019.
2. BreastCheck. BreastCheck Publishes Screening Statistics for 2015-2016 [internet]. Dublin: BreastCheck; 2017 August 8 [cited 2020 March 6]. Available from: <https://www.breastcheck.ie/content/breastcheck-publishes-screening-statistics-2015-2016>
3. Cancer Trials Ireland. Our history. Dublin; Cancer Trials Ireland; 2020 [cited 2020 March 6]. Available from: <https://www.cancertrials.ie/about-us/our-history/>
4. Culliton G. Cancer Society provides €1 million for bowel cancer screening. Irish Medical Times [Internet]. 2009 July 20 [cited 2020 March 6]. Home: News. Available from: <https://www.imt.ie/news/cancer-society-provides-e1-million-for-bowel-cancer-screening-20-07-2009/>
5. National Cancer Registry Ireland. Cancer in Ireland 1994-2017 with estimates for 2017-2019: Annual report of the National Cancer Registry; P8. Cork (Ireland): National Cancer Registry Ireland; 2019.
6. Health Service Executive. Performance Profile July - September 2019 Quarterly Report. Dublin (Ireland): Health Service Executive; 2019.
7. World Health Organisation. Cancer Prevention. Geneva (Switzerland). World Health Organisation; 2020 [cited 2020 March 6]. Available from: <https://www.who.int/cancer/prevention/en/>
8. National Cancer Registry Ireland. Cancer in Ireland 1994-2017 with estimates for 2017-2019: Annual report of the National Cancer Registry. Cork (Ireland): National Cancer Registry Ireland; 2019.
9. PART 1 CHAPTER 2 IMPACTS OF TOBACCO USE 4 Howell F R Shelley E (2011). Mortality attributable to tobacco use in Ireland. The Faculty of Public Health Medicine RCPI Winter meeting; Dublin.
10. National Cancer Registry Ireland. HPV-associated cancers in Ireland: report from the National Cancer Registry; P1. Cork (Ireland): National Cancer Registry Ireland; 2017.
11. Cancer Research UK. Family history and inherited cancer genes. London (UK). Cancer Research UK; 2020 [cited 2020 March 6]. Available from: <https://www.cancerresearchuk.org/about-cancer/causes-of-cancer/inherited-cancer-genes-and-increased-cancer-risk/family-history-and-inherited-cancer-genes>
12. Lynch D. Serious deficiency in Irish genetics resourcing — expert. Irish Medical Independent [Internet]. 2019 October 21 [cited 2020 March 6]. Available from: <https://www.medicalindependent.ie/serious-deficiency-in-irish-genetics-resourcing-expert/>
13. Kennedy J. National Cancer Strategy 2017-2026; P3. Dublin (Ireland): Department of Health; 2017.
14. Organisation for Economic Co-operation and Development. Deaths from cancer (indicator). Paris (France). Organisation for Economic Co-operation and Development; 2020 [cited 2020 March 6]. Available from: <https://data.oecd.org/healthstat/deaths-from-cancer.htm>
15. Department of Health. National Cancer Strategy 2017-2026; P20. Dublin (Ireland): Department of Health; 2017.
16. Department of Health. National Cancer Strategy 2017-2026 Key Performance Indicators: December 2018. Dublin (Ireland): Department of Health; 2018.
17. Department of Health. National Cancer Strategy 2017-2026; P131. Dublin (Ireland): Department of Health; 2017.
18. National Cancer Registry Ireland. Cancer inequalities in Ireland by deprivation, urban/rural status and age: a National Cancer Registry report; P1. Cork (Ireland): National Cancer Registry Ireland; 2016.
19. Department of Health. National Cancer Strategy 2017-2026; P55. Dublin (Ireland): Department of Health; 2017.
20. The Asco Post. World Cancer Day 2019: Emphasis on Early Detection. The Asco Post [Internet]. 2019 April 2 [updated 2019 April 2; cited 2020 March 6]. Available from: <https://www.ascopost.com/News/59711>
21. National Cancer Registry Ireland. Cancer incidence projections for Ireland 2020-2045; P86. Cork (Ireland): National Cancer Registry Ireland; 2019.
22. Cancer Trials Ireland. Prof Bryan Hennessy at Joint Oireachtas Committee; 2020 March 27 [cited 2020 March 6]. Available from: <https://www.cancertrials.ie/2019/03/prof-bryan-hennessy-at-joint-oireachtas-committee/>
23. Department of Health. National Cancer Strategy 2017-2026; P89. Dublin (Ireland): Department of Health; 2017.
24. Irish Cancer Society. The Real Cost of Cancer; P4. Dublin (Ireland): Irish Cancer Society; 2019.
25. Irish Cancer Society and National Cancer Registry Ireland. The Unmet Needs of Cancer Survivors in Ireland: A Scoping Review 2019; P1. Dublin, Cork (Ireland): Irish Cancer Society and National Cancer Registry Ireland; 2019.
26. American Cancer Society. Survivorship and Quality of Life Research. American Cancer Society [Internet]. 2020 [cited 2020 March 6]. Available from: <https://www.cancer.org/research/we-conduct-cancer-research/behavioral-research-center/cancer-survivorship-grants.html>
27. Central Statistics Office. Vital statistics yearly summary 2018; P6. Cork (Ireland): Central Statistics Office; 2019.
28. Weafer J A. Irish Attitudes to Death, Dying and Bereavement 2004-2014; P6. Dublin (Ireland): The Irish Hospice Foundation; 2014.
29. Irish Cancer Society. Irish Cancer Society Annual Report 2018: Preventing, Supporting, Caring; P22. Dublin (Ireland): Irish Cancer Society; 2019.

30. Temel JS et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. 2010 August 19 [cited March 6 2020]; 363 (8): P733. Available from: <https://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678?articleTools=true>
31. Health Service Executive. Palliative Care Services Three Year Development Framework (2017 – 2019); P34. Dublin (Ireland): Health Service Executive; 2017.
32. NIH National Cancer Institute. End-of-Life Care for People Who Have Cancer. NIH National Cancer Institute [Internet]. 2012 May 10 [cited 2020 March 6]. Available from: <https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/care-fact-sheet>



Nina Kelly from Limerick pictured on the Molly Malone Statue Dublin during the Irish Cancer Society's Daffodil Day 2014

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