



The Right to be Forgotten beyond cancer: **Access to financial products and services**

February 2022

Research conducted by Core Research, 2021

1. Introduction

Today, approximately 200,000 people in Ireland are living beyond a cancer diagnosis.ⁱ

Thanks to advancements in treatment and screening, far more people live beyond cancer now than in the 1990s, when over 2 in 5 survived.ⁱⁱ Now, over 3 in 5 people diagnosed with cancer are alive 5 years after their diagnosis.ⁱⁱⁱ The number is even higher for children diagnosed with cancer, with 4 in 5 children living 5 years after their diagnosis.^{iv}

We know there is a large financial burden for people as they go through treatment, with significant new costs and a loss in income associated with time off work. However, after cancer treatment, people also face other challenges, be it difficulties in returning to work, or in accessing financial products or services, such as insurance and loans.^v People can experience such financial penalties long after their cancer treatment.^{vi}

The Irish Cancer Society's Real Cost of Cancer surveys highlighted some of the financial challenges experienced by people diagnosed with cancer and their families during treatment. The Real Cost of Cancer research from 2015 and 2019 revealed that some people affected by cancer struggled to get any type of cover as a result of their cancer diagnosis; others explained how monthly premiums increased or the quote provided was unaffordable. People previously diagnosed with childhood and adolescent cancer also spoke of similar challenges, including difficulty in accessing life assurance, personal loans and/or facing higher premiums on their insurance.^{vii}

Since 2016, five European Union (EU) member states have implemented policies to protect people living beyond cancer. Through "Right to be Forgotten" laws, after a specified timeframe post-recovery, people living beyond cancer who are seeking access to financial products or services no longer have to declare their diagnosis or face penalties.^{viii} The European Parliament recently adopted a resolution^{ix} calling for EU member states to ensure that by 2025 there is a Right to be Forgotten a maximum of 10 years after cancer treatment ends for adults and 5 years after the end of treatment for people diagnosed before age 18.

The Irish Cancer Society wants to ensure that everyone lives well with and beyond cancer. The Irish Cancer Society asked Core Research to research the experiences of people affected by cancer when seeking to access financial products or services in Ireland. The findings are stark and lay bare the many barriers faced by people affected by cancer:

- People affected by cancer were more likely than the general population to feel they experienced difficulty

when dealing with banks and insurance providers and when purchasing financial products.

- Refusal and unfair treatment were the greatest reported difficulties experienced by those affected by cancer, at a higher rate than the general population.
- Only 1 in 4 people affected by cancer feel they have been treated fairly when buying financial products in Ireland, compared to half the general population.
- Seven in 10 people in the general population and 9 in 10 affected by cancer believe that a cancer diagnosis should not mean having an additional premium on insurance costs or be a barrier to getting credit.
- Nine in 10 people believe that the Right to be Forgotten should apply to people affected by cancer.

Many people, particularly people diagnosed with cancer as children or adolescents, face unjust financial penalties years or decades after their treatment has ended. The inability to access loans or insurance impact people affected by cancer in practical ways, hindering their dream to purchase their own home, to travel and get on with their life after cancer.

This report conveys the experiences of people affected by cancer when they try to access financial products or services, and gives voice to their challenges, concerns and frustrations. In this report, we set out actions designed to support people affected by cancer for the Government, financial providers and the Irish Cancer Society to address these issues and ensure that people are not financially punished years after a cancer diagnosis.

Acknowledgements

Thank you to all the people who responded to the surveys and who participated in the interviews. Your engagement made this work possible, and we hope it will act as an instigator for change.

We would like to acknowledge the work of Core Research in conducting the research and compiling the findings.

We would also like to thank all organisations and individuals who shared information about the survey online.

The Research

The Access to Financial Products and Services research sought insights from the general population and people affected by cancer. The research took place in three parts:

Description		No. of respondents/ participants
National survey	A nationally representative survey of the general population.	1,000
Targeted survey	Responses collected in an online survey, promoted through Irish Cancer Society communications channels. The survey was open to people affected by cancer	97
Interviews	Telephone/video calls with people affected by cancer	10

In the surveys and interviews, respondents were asked about their experiences of dealing with financial institutions and purchasing a selection of financial products or services (e.g. life assurance, owner-occupier mortgage, health insurance, etc.) in the Republic of Ireland.

For the purposes of this project, financial products and services relate to different types of insurance and loans. For the purposes of this research, a person is considered to be “affected by cancer” if they had a personal diagnosis at any point in their life, or if their partner/ spouse had a diagnosis at any point in their life.

Of those who responded to the targeted survey for people affected by cancer, over 8 in 10 were female and more than 7 in 10 (75%) were aged 45 or older. Almost half (49%) reported having had cancer in the past, while roughly 4 in 10 (38%) reported that they were currently a cancer patient. Almost 3 in 5 (59%) respondents affected by cancer reported that they had health insurance. While the majority did not report having other listed products, a significant proportion (2 in 5; 41%) had life insurance/assurance, more than 1 in 4 had travel insurance (28%), 1 in 5 had mortgage protection insurance/mortgage repayment protection (21%), and 1 in 3 had an owner-occupier mortgage (35%) and/or a personal loan (33%). A limitation of the targeted survey is the low base sample size and representativeness of those who opted-in.



2. Experiences of people affected by cancer when seeking access to financial products or services

The initial part of our research involved surveying the general public and people affected by cancer. The research shows that more people who are affected by cancer feel that banks and insurance providers are difficult to deal with, compared to the general population. People affected by cancer reported refusal and unfair treatment as the most common difficulties they experienced, at a higher rate than the general population. We discuss these findings more in this section.

Accessing financial products or services can be a difficult experience

Survey respondents were asked about their experiences dealing with financial institutions, such as banks, insurance providers and credit unions. The findings clearly demonstrated how people affected by cancer were significantly more likely to feel banks and insurance providers were difficult to deal with (see Table 1). Almost 2 in 5 people affected by cancer found banks difficult to deal with compared to 1 in 5 of the general population. Meanwhile, almost 1 in 4 of the general population had difficulty dealing with insurance providers. The proportion of people affected by cancer who reported difficulty with insurance providers was twice that of the general population (47%). Very few respondents reported any difficulty when dealing with credit unions.

Table 1: Overall, how would you rate the ease of dealing with the following financial institutions in the Republic of Ireland?

Difficulty dealing with financial institutions	Affected by cancer (n=97)	General population (n=822)
Banks	38%	21%
Insurance providers	47%	23%
Credit Unions	7%	6%

Access to financial products or services

The majority of people affected by cancer (3 in 5; 59%) who responded to the survey reported that they had difficulty when trying to access financial products. This compares to 2 in 5 (42%) in the general population.

People affected by cancer reported difficulty at a significantly higher rate than the general population, including for income protection, travel insurance and mortgage insurance (see Table 2). Overall, the difficulties may suggest significant challenges in becoming a home-owner. To illustrate, one-quarter of those affected by cancer had difficulties obtaining an owner-occupier mortgage, compared to 11% in the general population. Over 1 in 3 affected by cancer had difficulty getting life insurance, compared with 10% in the general population.

Table 2: Have you ever had difficulty purchasing any of the below financial products in the Republic of Ireland?

Financial product/service (% who had difficulty purchasing)	Affected by cancer (n=97)	General population (n=879)
Life insurance/assurance	34%	10%
Owner occupier mortgage	24%	11%
Personal loan	23%	17%
Serious/specified illness cover	22%	---
Income protection insurance	20%	8%
Mortgage protection insurance/mortgage repayment protection	20%	9%
Travel insurance	20%	9%
Health insurance	16%	13%

Refusal and unfair treatment are common reported difficulties

Of the respondents affected by cancer, 7 in 10 people believed that their experience with cancer played a role in the difficulty they faced.

Survey respondents were asked to explain the type of difficulty they had in purchasing financial products or services (see Table 3).¹ Of those who reported the difficulty they experienced, almost half of the respondents affected by cancer stated that they were refused by one or more providers, compared to 3 in 10 in the general population. One-quarter of the general population believed they were treated unfairly by the financial institution due to personal circumstances; however, 2 in 5 people affected by cancer reported this difficulty. The general population reported other difficulties at a higher rate compared to people affected by cancer, e.g. process took too long, poor customer service, lack of clarity or transparency. To illustrate, of those who reported the difficulty they experienced, over 2 in 5 people (45%) in the general population stated that the quote was unaffordable, compared to 1 in 3 affected by cancer. One explanation for this may be that people affected by cancer are refused early in the application process and therefore the other difficulties experienced by the general population when purchasing financial products and services do not apply.

Table 3: What was the difficulty you experienced in purchasing...?

Difficulty experienced	Affected by cancer (n=57)	General population (n=417)
Refused by one or more providers	49%	30%
Treated unfairly by the financial institution due to personal circumstances	40%	25%
Too much documentation required	37%	39%
Unaffordable quote	33%	45%
Difficulty obtaining quotes	30%	33%
Process took too long	23%	42%
Poor customer service	23%	33%
Lack of clarity and transparency	21%	33%
Poor communication	19%	31%

Few people affected by cancer believe they have been treated fairly

When asked if they agreed that insurance was granted fairly in Ireland, only 2 in 10 people affected by cancer agreed, compared with almost 3 in 10 from the general population (see Table 4). Half of the general population felt they were treated fairly when applying for credit or insurance products. However, fewer people affected by cancer reported they were treated fairly when buying insurance products (3 in 10) or when applying for credit from financial institutions (4 in 10). These findings demonstrate that people affected by cancer feel they experience unjust treatment when seeking out financial products and services, in particular when seeking out insurance, at a higher rate than the general population.

Table 4: Respondents' level of agreement with perception of fairness when seeking access to financial products or services

Perception of fairness (% Agree)	Affected by cancer (n=97)	General population (n=879)
I believe that insurance is granted fairly in the Republic of Ireland	19%	28%
I feel I have been treated fairly when buying insurance products	27%	51%
I feel I have been treated fairly when applying for credit from financial institutions	39%	49%



¹ The answers are based on a respondent's experience in trying to access one or more of the following products or services: life insurance/assurance; owner-occupier mortgage; personal loan; serious/specified illness cover; income protection insurance; mortgage protection insurance/mortgage repayment protection; travel insurance. Anyone who experienced difficulty was asked to share a reason.

People affected by cancer should not be penalised when seeking access to financial products or services

No person should be punished for having had cancer. The overwhelming majority of the general population (7 in 10) do not believe that a person affected by cancer should be penalised or face barriers when trying to get insurance or credit (Table 5). Amongst people affected by cancer, 9 in 10 believe that cancer should not be a barrier to getting credit or mean additional premiums on insurance. The findings demonstrate clear support for action to change how people affected by cancer are treated when seeking financial products and services. Support for the Right to be Forgotten as an action to change the treatment of people affected by cancer is explained in the following subsection.

Table 5: Respondents' level of agreement with treatment of people affected by cancer

Treatment of people affected by cancer (% Agree)	Affected by cancer (n=97)	General population (n=879)
A cancer diagnosis should not mean an additional premium on insurance costs in the Republic of Ireland	90%	72%
A cancer diagnosis should not be a barrier to availing of credit from financial institutions in the Republic of Ireland	90%	70%

The Right to be Forgotten should be implemented to support people living beyond cancer

The Right to be Forgotten for people living beyond cancer would mean their past diagnosis cannot be taken into account when accessing financial products or services. The overwhelming majority of respondents (9 in 10) from the general population agreed that the Right to be Forgotten should apply to people living beyond cancer when given the following description:

"[...] the Right to be Forgotten means that, after a specified period of time, people who have survived cancer either do not have to declare their diagnosis, and/or can no longer be treated differently to people who have not had a cancer diagnosis when applying for some types of insurance and/or loans."^x

As such, there is clear and strong support for a policy to end the unfair treatment of people living with cancer.

Difficulties and burdens associated with accessing financial products or services

Some people affected by cancer shared their experiences in seeking access to financial products or services in more detail through interviews, once the surveys had been completed. People explained how they did not have prior information on the process for seeking financial services or related challenges. They also felt that they lacked clarity on policies specific to people affected by cancer as well as on their rights. Many expressed their frustrations and disappointment with the process. Nonetheless, people were able to articulate their needs and potential solutions to the issues they faced. These needs include more information on what to expect when applying for financial products or services, financial institutions which are more understanding and empathetic, and a change to how premiums are calculated. This section outlines some of the challenges and solutions in more detail.

Lengthy and burdensome application process

For some, gathering documents related to their diagnosis was a lengthy process. In addition, there was an administrative burden on an individual to gather the requested documentation for their application. Some people also felt that they were placing a burden on their medical team, and there was a degree of reluctance to reach out to them.

"[...]it's not a very enjoyable experience. A lot of the frustration was when I had to do stuff online. It was really hard to find things and getting the paperwork together. I'm glad I had the broker to do the running around"

"Having to contact the outpatient department and gathering all of the medical information, you feel like you're wasting their time."

"I had trouble applying for mortgage protection because of a previous cancer diagnosis. The amount of paper work required and the invasive personal questions were excessive."

Some feel a lack of nuanced consideration in the application process

Another issue is the potential disadvantage when decisions are made with no detailed or personalised consideration on diagnosis and prognosis.

"It's like computer says no... you miss the days of the local branch manager where they could tailor the policy after hearing your case"

Review by consultants unfamiliar with applicants' history and progress

Once interviewees had managed to submit documentation and relevant information, their information was reviewed by third party medical consultants, rather than their own medical team, who would be more familiar with their situation. Such a measure led to frustration, with applicants questioning the criteria upon which decisions were made (e.g. rates of survival, latest treatments, prognoses, etc.).

Penalties for a past cancer diagnosis

Many of the people interviewed explained they faced a lack of options when attempting to access loans and/or insurance, which meant that they struggled to find a provider who would listen to them or approve their request. Many interviewees mentioned that once they were able to access financial products or services that they were met with penalties such as higher premiums and interest rates (meaning higher payments). This often means their journeys towards accessing financial products and services ends before it even begins.

"Once you mention you've had cancer, the shutters come down."

"I didn't get to speak to someone properly, it was just a 'no sorry.'"

"I didn't even bother asking for a loan."

"I still don't have life cover, even though my scan was clear last time."

"It was just the cost of it for my premium. It's not fair. Anyone with a heart condition traveling on an airplane is a bigger risk than someone with cancer."

People are left feeling demoralised

The process and experience of applying for financial products or services took an emotional toll on interviewees, and was described as stressful.

"Feel low. Demoralised...like I caused my illness..20 questions and hoops to jump through left me deflated."

"Very long process, very stressful, require too much information on cancer diagnosis, diagnosis creates a lot of barriers, even though am in remission."

People need more information

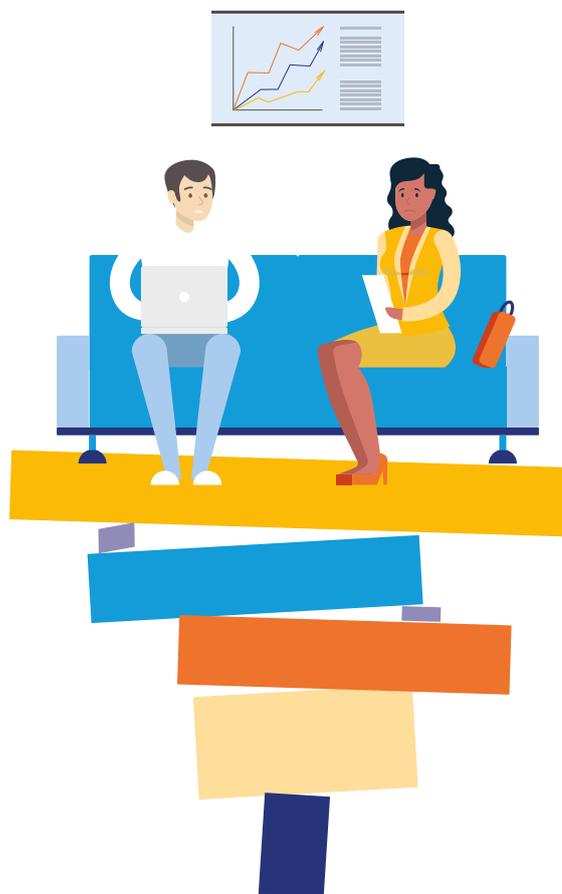
People can be unaware of their options before engaging with providers. Not all people were aware that they could approach a broker to assess their options, although this is an additional burden and can mean incurring more costs.

People also felt that existing policies and regulations are not clear to them. In general, providers should communicate (in plain language) their guidelines/policies for people with a history of cancer, how their current medical condition or medical history (where recovered) might affect their ability to purchase or renew financial products or services, and options for progressing with an application. Such information should also include information on a person's rights when applying for finance and how they might seek support if they are treated unfairly.

People affected by cancer need better structural support

Interviewees also explained that they wished to have a voice in conversations with providers, and that financial providers could show more patience and greater understanding for people affected by cancer. For instance, interviewees wanted financial institutions to have a better understanding on how to interact with people affected by cancer. Some explained that this could be achieved through training, by having a dedicated expert to liaise with this group, and by basing decisions on up to date medical evidence.

Interviewees expressed support for the Right to be Forgotten, describing it as a positive step towards ensuring a fair hearing when seeking financial products or services.



3. Discussion

Cancer can cast a financial shadow long after diagnosis and recovery.^{xi} People living beyond cancer continue to pay a price for their diagnosis, in some cases, for years after their treatment has ended.^{xii}

Internationally, the burdens placed on people living beyond cancer have been recognised.^{xiii} For instance, an All.Can report, based on an international survey, showed that people with a past cancer diagnosis faced issues, including lost income, and an ability to access insurance and loans.^{xiv} People with a past diagnosis of childhood cancer can face myriad financial burdens later in life, including challenges in getting life insurance.^{xv}

Barriers to financial stability were reported in the Irish Cancer Society's reports on the Real Cost of Cancer, particularly for people with a past diagnosis of childhood and adolescent cancer.^{xvi} Getting cancer so early in life means long-term expenses pile up. Buying medications and prostheses is expensive, and some report fewer opportunities for accessing education and employment. A French survey of people with a past diagnosis of childhood cancer recognised a negative relationship between access to insurance and home loans, and a disclosure of a cancer diagnosis. Of the respondents who tried to access financial products or services, 30% reported difficulty in getting a home loan and 10% in getting a personal loan.^{xvii} Those who did not disclose their cancer diagnosis were less likely to report difficulty with home loans (13.9%) or personal loans (6.8%).^{xviii} Since then, France has changed the law to combat unfair treatment of people with a past cancer diagnosis.

In recognition of the disparate treatment and unfair penalties levied on people affected by cancer, 5 European countries² introduced a solution to this problem: the Right to be Forgotten. In these countries, when a person has been cured of cancer for a specified timeframe, "the Right to be Forgotten" means by law that they no longer have to declare their past diagnosis, nor can they be penalised for a past diagnosis when applying for financial products or services.^{xix} Different timeframes for being "forgotten" exist for different cancer types with a maximum limit of 10 years for an adult diagnosis, or 5 years for a childhood, adolescent or young adult (CAYA) diagnosis.^{xx} The Right to be Forgotten is supported in Europe's Beating Cancer Plan. The European Parliament adopted a resolution on Strengthening Europe in the Fight Against Cancer on 16 February 2022, in which it calls for member states to implement the Right to be Forgotten, by 2025, for people who have finished cancer treatment after a specified period of time. The European Parliament also calls for other measures such as introducing the Right



² Belgium, France, Luxembourg, the Netherlands, Portugal.

to be Forgotten into EU legislation, where relevant, as well as to into the Treaty on the Functioning of the European Union to establish common standards around consumer protection policy.”^{xxi}

4. Actions to support people affected by cancer

People affected by cancer should have fair access to financial products or services. The Irish Cancer Society outlines its recommendations in this section, chief among them is for the Government of Ireland to implement the Right to be Forgotten for people living beyond cancer when seeking to access financial products or services in Ireland.

Recommendations for the Irish Government

- Amend the Central Bank Act 1942 and other relevant legislation to incorporate the Right to be Forgotten for people living beyond cancer.
- ◊ The legislation should include timeframes post-recovery after which a person no longer has to declare their cancer diagnosis. These timeframes should reflect the latest evidence and be tailored by cancer type. The maximum timeframe should be no longer than 5 years for people diagnosed with cancer at any age. In addition, legislation should also outline the responsibilities of banks/financial/insurance institutions. Such legislation would remove barriers for people living beyond cancer, particularly those who finished treatment years or decades ago, including people diagnosed as children and adolescents who face many financial burdens associated with their past diagnosis.
- Ensure additional capacity, resources and funding for the National Cancer Registry of Ireland to keep the evidence base current. This would involve multi-year funding to continuously update the latest available epidemiological data to inform survivorship and quality of life beyond cancer. These data should inform the timeframes after which a person no longer has to declare their diagnosis.
- The Competition and Consumer Protection Commission (CCPC) should undertake a market study on access to financial products or services, particularly insurance, for people living with and beyond a serious illness, including cancer, to further establish a current baseline and to provide further recommendations to improve customer protections.
- Liaise with European counterparts who have implemented the Right to be Forgotten for people living beyond cancer to learn about best practice.

Recommendations for the Oireachtas Cross-Party Group on Cancer

The Oireachtas Cross-Party Group on Cancer was established in 2021 to serve as a platform to discuss policy and practical matters of concern to people affected by cancer. The Cross-Party Group includes Teachtaí Dála and Senators from across the political spectrum, and is supported by the Irish Cancer Society.

- The Oireachtas Cross-Party Group on Cancer will introduce a cross-Party Private Members’ Bill, seeking to enshrine the Right to be Forgotten into law in 2022, should Government not act to do so.

Recommendations for financial institutions and regulators in Ireland

Financial service providers

- Update criteria to ensure that people who are living beyond cancer can avail of products or services with no penalty after a specified timeframe following the end of active treatment.
- Develop expertise and build capacity to ensure a trained individual is assigned to applications from people with serious illness, including cancer.
- Provide transparency as to how rates, premiums and risk classes are calculated for people going through cancer treatment and people who have finished cancer treatment, publish details of waiting periods post-cancer treatment, which insurers put in place before people can access a policy.
- Develop more and easier to find information for people who wish to buy or renew financial products following a cancer diagnosis so they can best assess their options. Such information should outline policies and guidelines for people affected by cancer when they seek to access any financial product or service, and what they might expect from their experience.
- Engage with the Irish Cancer Society, and other relevant representative organisations, to learn more about the experiences of people living with and beyond cancer and how to engage with this group.
- Engage in sensitivity training for staff who are interacting with people living with and beyond a serious illness, including cancer.

Regulator

- Financial service providers are regulated by the Central Bank of Ireland. The Central Bank of Ireland should establish a monitoring and compliance framework and guidelines in line with any new legislation on the Right to be Forgotten.

Actions for the Irish Cancer Society

Advocate for change on behalf of people living with and beyond cancer

- The Irish Cancer Society will advocate for legislation to support the Right to be Forgotten.

Meet some of the informational and support needs

- The Irish Cancer Society will introduce support to help people affected by cancer understand banking, insurance and other financial products or services.
- We will engage with financial institutions to discuss the experiences of people affected by cancer and their needs.

5. Conclusion

In Ireland, 1 in 25 people is living after a cancer diagnosis.^{xxii}

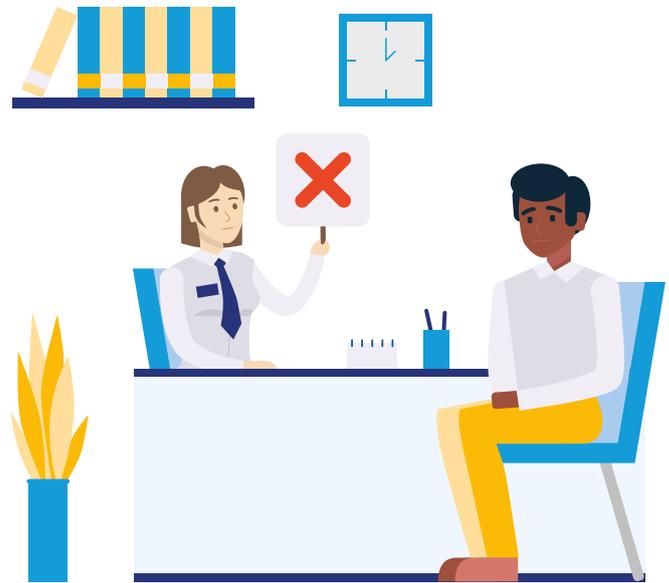
People who have finished their cancer treatment want to get on with their lives, but oftentimes access to financial products and services can be out of grasp. People feel that they are treated unfairly and are penalised for their past diagnosis. The experience can be frustrating, confusing and stressful, with information gaps on rules, policies, regulations and individual rights. People affected by cancer deserve the same fair treatment as everyone else when applying for insurance or credit, making it easier to travel, buy a home, and live a full life.

Now is the time to take action so all people thrive beyond cancer. The Government, financial providers and the Irish Cancer Society each have a role to play.

The Irish Cancer Society will continue to bring the experiences of people affected by cancer to the attention of the Government and the general public. We will also continue to provide a listening ear, as well as practical support to people who need it.

The Government must pass legislation to enshrine the Right to be Forgotten so people previously diagnosed with cancer can get on with their lives. For the legislation to be properly implemented, accurate data and meaningful oversight are needed. Financial providers also have a role to play. We encourage them to engage with the Irish Cancer Society to learn more about the needs of people living beyond cancer, to provide a sympathetic service and to offer plain-language and transparent information to people affected by cancer seeking to purchase their products or services.

The Irish Cancer Society looks forward to working with all stakeholders to create real change for people affected by cancer.



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