



WE'RE BRINGING  
THE GOOD FIGHT  
TO A BAD CANCER



Discover more about the  
Oesophageal Cancer Fund

Registered Charity Number: 20047726 CHY Number: 14542



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## OESOPHAGEAL CANCER FUND **STRATEGIC PLAN 2022 TO 2026**

[ocf.ie](https://ocf.ie)

## FOREWORD

### Where we have come from

2022 marks 21 years in operation for the Oesophageal Cancer Fund (OCF). The charity was founded on a challenge from Lucilla Hyland a young woman who lost her hard fought battle to Oesophageal Cancer in 2001. A group of her closest friends founded the charity in her honour to help others with this difficult cancer. They began with a dinner dance fundraiser, and soon turned their attention to the idea of Lollipop Day as a way of raising funds for Oesophageal Cancer research and awareness of the symptoms of Oesophageal Cancer.

The founding trustees and the CEO since inception, Noelle Ryan, have given an enormous amount to the organisation and the community of people with Oesophageal Cancer and survivors of Oesophageal Cancer. Noelle stepped aside in 2021 and handed over her role to Christine Littlefield. The charity owes a huge debt of gratitude to Noelle and the founding trustees for their commitment, leadership and expertise.

As the voice for Oesophageal Cancer in Ireland we have had a positive impact. After the initial period of activity, with a changing world, a cashless society, an evolving medical and cancer ecosystem for patient support, research and advocacy, the time is right to identify the why, what and when of our next 20 years.

### The road ahead

The Charity is in the process of transitioning from a fund to a company limited by guarantee. This new body will bring the charity forward into a rapidly changing landscape with the impacts of the global pandemic, Brexit and cost of living issues all factoring.

We will view these challenges through the prism of our 2022-2026 Strategic Plan which will also identify areas of development in the key pillars we have identified. Our plan has been developed in conjunction with our key stakeholders, industry partners and our planning consultant, Caroline McCamley of & Iampersand.

This Strategic Plan will ensure that the Oesophageal Cancer Fund transitions into our next critical phase with a structure that reflects best practice corporate governance with a skilled and driven Board and an empowered and accountable management team. We are well positioned to take on external challenges and take advantage of opportunities for sustainable development and growth.

I am honoured as Chair to lead our organisation into the future and support our team on the delivery of this plan and whilst our vision and direction has changed, we have not lost sight of our values, which were formed at inception, and are mirrored now, by the personal values of Lucilla Hyland.

**David Ryan**  
Chairperson

## OESOPHAGEAL CANCER FUND STRATEGIC PLAN 2022 TO 2026

The Oesophageal Cancer Fund (OCF) is the national charity for Oesophageal Cancer in Ireland. Bringing the good fight to a bad cancer. We are passionately committed to supporting everyone affected by Oesophageal Cancer and Barrett's Oesophagus so they get the earliest and best support and treatment possible and live full, long lives knowing we are by their side.

The Oesophageal Cancer Fund is made up of a small, dedicated core team, but we are also an army of thousands. The Oesophageal Cancer Fund is the people affected by Oesophageal Cancer, volunteers, donors, supporters, researchers, medical professionals and support and advocacy organisations. Who together give support, time, energy and money to help those affected by Oesophageal Cancer and Barrett's Oesophagus.

The Oesophageal Cancer Fund fosters a support community for people with Oesophageal Cancer, their families and carers to feel less alone and more connected. With our network of people who have shared the very specific experience of this disease, we know

from people with Oesophageal Cancer and survivors alike just how much it can mean to talk to someone who really knows, what they are going through.

The wider national community is also part of our strategy; we work to make sure the general population is aware of Barrett's Oesophagus and Oesophageal Cancer, and we work to motivate them to help us raise awareness and fight this difficult disease.

We are dedicated in our fight against the difficulties and challenges that Oesophageal Cancer presents. We are committed to fund vital research into this disease and we channel funding directly to carefully selected research projects and research organisations.



I have been a patron of the Oesophageal Cancer Fund since losing my father to the disease in 2006. The fantastic work the charity does in raising funds to support research into Oesophageal Cancer, supporting early detection of this disease and enhancing survivorship is vitally important. I am proud to continue to support the cause and continue to help raise awareness of the symptoms of Oesophageal Cancer.

**Padraig Harrington**  
Patron Oesophageal Cancer Fund

## OESOPHAGEAL CANCER FUND VISION, MISSION AND VALUES

The Oesophageal Cancer Fund (OCF) was founded on a challenge from Lucilla Hyland a young woman diagnosed with Oesophageal Cancer in 2001 who sadly lost her hard fought battle. Lucilla envisioned that everyone affected by Oesophageal Cancer receives the earliest and best support and treatment possible. Lucilla wanted there to be better awareness of Oesophageal Cancer - the risks and symptoms - to deliver early diagnosis and successful treatments. Lucilla Hyland laid down a challenge and we are unwavering in our determination to deliver on this.

**The VISION of the Oesophageal Cancer Fund** is that everyone affected by Oesophageal Cancer gets the earliest and best support and treatment possible. And that there is better awareness of Oesophageal Cancer to deliver early diagnosis and successful treatments.

**The MISSION of the Oesophageal Cancer Fund** is to work in partnership with people affected by Oesophageal Cancer, their families, clinicians, researchers, volunteers and other support and advocacy organisations. Together we want to improve the experiences and outcomes of people affected by Oesophageal Cancer through our dedicated support, advancing knowledge and awareness and engaging in research.

**The VALUES of the Oesophageal Cancer Fund** are inspired by Lucilla Hyland and who she was as a person. They are expressed in everything we do. Our Values are; Courage, Collaboration, Inspiring, Empowering and Tenacious.



## OESOPHAGEAL CANCER FUND KEY STRATEGIC PILLARS

The Oesophageal Cancer Fund has been in operation since 2001. Over these years we have supported patients, family members and carers to face the difficulty of an Oesophageal Cancer diagnosis and know they are not alone. We have funded many different research projects into Oesophageal Cancer and Oesophageal Cancer prevention by funding Barrett's Oesophagus research. We have also worked hard to raise awareness of Oesophageal Cancer and Barrett's Oesophagus.

Over the course of this strategic plan 2022 – 2026 we want to build on the work achieved so far. In developing this Strategic Plan we have widely consulted with a number of key stakeholders internally and externally to include our partners, people affected by Oesophageal Cancer and Barrett's Oesophagus, volunteers, family members, medical and research professionals and other peer support and advocacy organisations. Their advice and feedback guided our work in developing this plan and assessing current and future needs.

The Strategic Plan sets out four key ambitious strategic pillars we are committed to working in partnership with others to realise the goals of this plan.

The four strategic pillars of this plan are;

1. **People affected by Oesophageal Cancer, their Families and Carers**
2. **Awareness, Prevention and Early Intervention**
3. **Leading Edge Research**
4. **Organisation Structure, Governance and Financial Sustainability**

## THE OESOPHAGEAL CANCER FUND STRATEGIC DRIVERS

This plan is supported by four Strategic Drivers that will assist us in delivering this strategic plan.

These strategic Drivers are;

- **The experiences and needs of people affected by Oesophageal Cancer**
- **Working in partnership**
- **Empowering people affected by Oesophageal Cancer**
- **Innovation and improvement**



# OESOPHAGEAL CANCER FUND

## ORGANISATIONAL IMPACT

We want to ensure that we work in the best interests of those affected by Oesophageal Cancer and Barrett's Oesophagus and we are determined to make progress within our areas of strategic priority and deliver positive impact for people affected by Oesophageal Cancer, their families and carers.

The organisational impact we want to make working with our partners is to;

- Truly support and reflect the experiences of people affected by Barrett's Oesophagus and Oesophageal Cancer in Ireland
- Raise awareness of Oesophageal Cancer in the public mind
- Reduce the incidence of Oesophageal Cancer, focusing on Oesophageal Cancer prevention
- Enhance survivorship by increasing early diagnosis of Oesophageal Cancer
- Ensure holistic support for everyone affected Barrett's Oesophagus and Oesophageal Cancer
- Advance knowledge of Barrett's Oesophagus and Oesophageal Cancer that will deliver early diagnosis and tailored and successful treatments



# FOCUS 1 – People affected by Oesophageal Cancer

**OBJECTIVE** – Engage, involve, support, empower, act in the best interest of people affected by Oesophageal Cancer, their families and carers.

PRIORITIES	ACTION STEPS
1. Define the Oesophageal Cancer Fund's unique role with and for people affected by Oesophageal Cancer, their families and carers	a. Consult with people affected by Oesophageal Cancer, their families and carers to co-develop a set of actions which will make a significant difference in reflecting their personal experiences b. Consult with medical specialists and patient support services to identify gaps in patient support c. Develop a statement setting out the Oesophageal Cancer Fund's role and contribution to people affected by Oesophageal Cancer, their families and carers
2. Scope opportunities for partnership with patient support organisations to establish a comprehensive referral system. A streamlined and targeted pathway to the best information and support for people affected by Oesophageal Cancer, their families and carers	a. Map the service landscape b. Identify priority partners and explore the potential for joint action c. Pilot partnership initiatives and assess impact and value d. Develop long-term partnership relationships that meet the needs of Barrett's Oesophagus and Oesophageal Cancer patients
3. Identify the Oesophageal Cancer Fund's specific services and supports	a. Plan activities that the Oesophageal Cancer Fund is best placed to provide support to people affected by Oesophageal Cancer, their families and carers
4. Engage with peer organisations in Northern Ireland to establish island wide supports and services, and maximise collaboration opportunities	a. Develop a pilot programme to explore options, share information, participate in each other's events, pilot joint activities b. Develop a long-term plan to maximise collaboration and impact c. Promoting and supporting access to high quality and holistic treatment and care
5. Engage with the 6 Hospitals with centres treating patients with Oesophageal Cancer to ensure that we reach people who can benefit	a. Establish relationships with the key clinicians, specialist nurses and multi-disciplinary teams b. Establish a signposting mechanism to the Oesophageal Cancer Fund for patients and families, - on diagnosis, during and after treatment
6. Develop panels of people affected by Oesophageal Cancer, their families and carers. to contribute to and inform research and service development	a. Provide opportunities for people affected by Oesophageal Cancer, their families and carers where they can consider involvement b. Provide training and information that empowers research participants c. Link with clinicians, researchers and support services to harness the thinking and experience of the research panel members and participants
7. Keep the Oesophageal Cancer Fund rooted in the experience of people affected by Oesophageal Cancer	a. Establish mechanisms for effective involvement of people affected by Oesophageal Cancer across the Oesophageal Cancer Fund's activities, service development, research and advocacy

# **FOCUS 2 – Awareness, Prevention and Early Intervention**

**OBJECTIVE** – Raise general awareness of the risks and early symptoms of Barrett's Oesophagus and Oesophageal Cancer to promote prevention, increase early diagnosis, and intervention.

PRIORITIES	ACTION STEPS
1. Distinguish the Oesophageal Cancer Fund's role in raising general awareness of the risks and early symptoms	<ul style="list-style-type: none"> <li>a. Consult with people affected by Oesophageal Cancer, their families and carers, partners and medical specialists to identify gaps in awareness of the risks and symptoms</li> <li>b. Develop a statement setting out the Oesophageal Cancer Fund's role and contribution to raising general awareness of the risks and symptoms</li> <li>c. Develop partnerships with Primary Care and Pharmacies, and other key organisations, to develop a set of actions which will make a significant difference in raising general awareness</li> <li>d. Develop the Oesophageal Cancer Fund's specific communications and awareness messaging that can be developed annually</li> </ul>
2. Develop the Oesophageal Cancer Fund's specific information and education resources on the risks and symptoms of Barrett's Oesophagus and Oesophageal Cancer aimed at: <ul style="list-style-type: none"> <li>– The public</li> <li>– Health and related professionals</li> </ul>	<ul style="list-style-type: none"> <li>a. Research available public resources on Barrett's and Oesophageal Cancer in Ireland and other countries</li> <li>b. Consult with patients, carers, families, survivors and with partners, clinicians and medical teams</li> <li>c. Develop public information resources</li> <li>d. Research and consult on the information available to health professionals</li> <li>e. Develop the Oesophageal Cancer Fund's information and education resources for professionals in the field</li> </ul>
3. Scope opportunities for partnership in the delivery of education and awareness initiatives	<ul style="list-style-type: none"> <li>a. Identify priority partners and explore the potential for the development of education and awareness initiatives</li> </ul>
4. Develop the Oesophageal Cancer Fund's specific communications resources on the impact of Oesophageal Cancer and Barrett's Oesophagus and patient, carer and family experiences	<ul style="list-style-type: none"> <li>a. Develop the Oesophageal Cancer Fund's communications strategy and resources to communicate impact and the experiences of those affected by Oesophageal Cancer</li> </ul>
5. Develop an advocacy panel made up of people affected by Oesophageal Cancer to highlight the issues with clinicians, the media and the public	<ul style="list-style-type: none"> <li>a. Develop an advocacy strategy</li> <li>b. Identify potential panellists</li> <li>c. Provide training and support and structured opportunities for advocacy</li> </ul>

# **FOCUS 3 – Leading Edge Research**

**OBJECTIVE** – Support, influence and inform the development of research from the perspective of people affected by Oesophageal Cancer, their families and carers.

PRIORITIES	ACTION STEPS
1. Define the Oesophageal Cancer Fund's function in informing and developing research	<ul style="list-style-type: none"> <li>a. Assess the Oesophageal Cancer Fund's past research investment</li> <li>b. Define the current research landscape – focus, funding and leadership</li> <li>c. Develop a statement setting out the Oesophageal Cancer Fund's role and contribution to the next phase of leading edge research in the areas of; <ul style="list-style-type: none"> <li>• Oesophageal Cancer Prevention</li> <li>• Early diagnosis of Oesophageal Cancer</li> <li>• Enhanced Survivorship</li> </ul> </li> </ul>
2. Develop panels to contribute to and inform research represented by people affected by Oesophageal Cancer, their families and carers.	<ul style="list-style-type: none"> <li>a. Identify where the Oesophageal Cancer Fund is best placed to support patients, family members and survivors to contribute to and inform research practices</li> <li>b. Develop the Oesophageal Cancer Fund as a credible source of information on the experience of people affected by Oesophageal Cancer to inform research</li> <li>c. Develop Public Patient Involvement practices so that the Oesophageal Cancer Fund becomes a reliable credible source of effective PPI in research practice</li> </ul>
3. Scope opportunities for partnership in the delivery of effective research practice	<ul style="list-style-type: none"> <li>a. Map the research landscape in terms of <ul style="list-style-type: none"> <li>• Oesophageal Cancer Prevention</li> <li>• Early diagnosis of Oesophageal Cancer</li> <li>• Enhanced Survivorship</li> </ul> </li> <li>b. Identify priority partners and explore the potential for the Oesophageal Cancer Fund to contribute to research</li> </ul>
4. Engage with partner organisations in the dissemination of research outcomes	<ul style="list-style-type: none"> <li>a. Build strong relationships and partnerships and engage in research and dissemination consortia</li> <li>b. Use the learning and tools from research to disseminate, communicate and advocate</li> </ul>
5. Work together with partners on planning for the Barrett's Oesophagus Registry and Biobank	<ul style="list-style-type: none"> <li>a. Become more informed about the next generation research using the Barrett's Registry and Biobank</li> <li>b. Define the most effective role for the Oesophageal Cancer Fund in the next phase of the development and embedding of the Registry and Biobank</li> </ul>

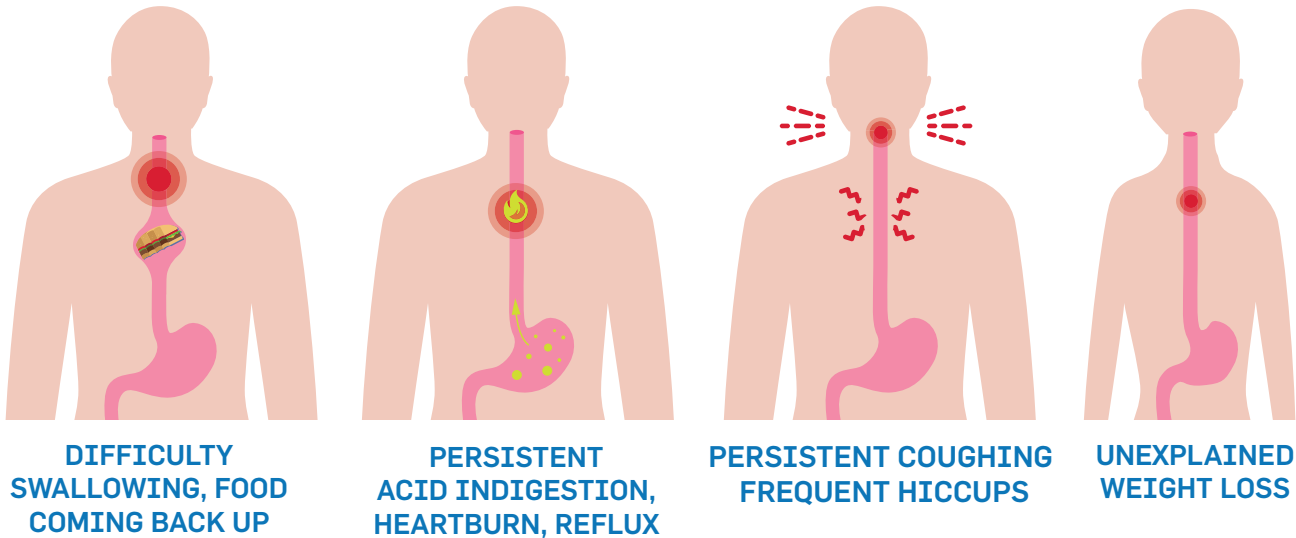
**FOCUS 4** – Organisational Structure, Governance and Financial Stability

**OBJECTIVE** – Implementing best practice governance, management & finance structures.

PRIORITIES	ACTION STEPS
1. Ensure effective governance practices are in place and adhere to national regulatory requirements and best practice guidance	a. Ensure the requisite skills and experience are in place for effective governance b. Implement effective systems at Board level that are carried through to all aspects of organisational operations to ensure compliance with relevant legislation, policy, standards, and regulatory frameworks c. Establish organisation wide policies and practices and the mechanisms to ensure oversight
2. Continually improve the effectiveness of the management and oversight of the Oesophageal Cancer Fund's Employee, Volunteer, operations, finance, and IT infrastructure	a. Monitor the management and oversight infrastructure to ensure the Oesophageal Cancer Fund operates in the most effective, stable and efficient manner b. Continually improve the organisations infrastructure, practices and systems to support development and improvement priorities c. Ensure effective management information systems allowing for accurate reporting on the work and outcomes for evidence-based decision-making and accountability
3. Invest in the development of the Oesophageal Cancer Fund's team	a. Develop and implement effective employment planning, policies and practices b. Deliver professional performance across the work of the Oesophageal Cancer Fund
4. Invest in the development of the Oesophageal Cancer Fund's volunteer team	a. Continually develop effective volunteer policies and practices b. Develop volunteer roles that are clearly defined c. Support volunteers and offer opportunities for development
5. Develop a sustainable funding model to deliver the Oesophageal Cancer Fund's objectives and work plans	a. Review financial and funding opportunities to develop a model that is sustainable, diverse, scalable, meets full compliance and reporting requirements and delivers excellent information for oversight and planning b. Define and implement the appropriate financial management and governance approaches to ensure the Oesophageal Cancer Fund fulfils all legal and regulatory duties c. Implement a financial risk assessment mechanism to protect organisational resources

# OESOPHAGEAL CANCER

## KNOW THE SYMPTOMS.



**Early diagnosis is Key**  
70% of people with symptoms of Oesophageal Cancer wait over 3 months before seeing their GP

Call your GP if you notice any of these symptoms persisting

