



WE'RE BRINGING  
THE GOOD FIGHT  
TO A BAD CANCER



Discover more about the  
Oesophageal Cancer Fund

Registered Charity Number: 20047726 CHY Number: 14542

# THEORY OF CHANGE OESOPHAGEAL CANCER FUND



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## THE CHALLENGE

- Oesophageal Cancer is one of the lesser-known cancers
- 500 people are diagnosed per year in Ireland with Oesophageal Cancer, often when the disease is already at an advanced stage
- Treatment for Oesophageal Cancer is invasive and recovery is often challenging
- Oesophageal Cancer is the sixth leading cause of death from cancer

## MAKING AN IMPACT

- The Oesophageal Cancer Fund was set up following the untimely death of Lucilla Hyland from Oesophageal Cancer in 2001
- Considerable progress has been made for patients with Oesophageal Cancer since that time
- More progress is both possible and badly needed
- The Oesophageal Cancer Fund needs funding and the commitment of key players to support its ongoing fight against Oesophageal Cancer

## CHANGE OVER TIME

- The Oesophageal Cancer Fund strives to make the journey for those affected by Oesophageal Cancer as smooth as possible:

# EARLY 2000s

## PRE-DIAGNOSIS

- Low public awareness of cancer generally and OC specifically
- Risk factors for OC (including Barrett's Oesophagus) not well understood
- OC symptoms ignored and/or masked by over-the-counter medication
- Limited Irish research on OC prevention

## DIAGNOSIS

- People with symptoms do not necessarily see their GP
- Many GPs do not recognise early symptoms of OC
- Delayed diagnosis
- Limited Irish research on early diagnosis of OC

## TREATMENT

- Delayed treatment
- Low survival rate 11%
- Limited Irish research on effective treatment

## POST-TREATMENT

- Insufficient emphasis on post-treatment care
- Struggle to manage the condition after treatment, both physically and mentally
- Potentially poor quality of life after treatment
- Limited Irish research on effective post-treatment care
- Very limited patient, survivor and caregiver support

# PRESENT

## PRE-DIAGNOSIS

- OCF work with media and increases public awareness
- Pharmaceutical industry continues to market over-the-counter medications that mask symptoms and no intervention to raise the possibility of OC
- National Barrett's Oesophagus Registry and Biobank has 9,000 patients on the registry

## DIAGNOSIS

- 2019 National Clinical Guidelines a welcome development
- 70% of people with symptoms wait three months before seeing GP
- Continued under-diagnosis, especially for those who struggle to advocate for themselves
- National Barrett's Oesophagus Registry and Biobank in use

## TREATMENT

- 2019 National Clinical Guidelines a welcome development
- OC treatment increasingly effective
- Delays in treatment due to late diagnosis
- Differences in access for patients in different parts of Ireland
- Improving survival rate 24%
- Research into effective treatments
- Limited liaison between hospitals treating OC patients

## POST-TREATMENT

- 2019 National Clinical Guidelines a welcome development
- Difficulty accessing HSE dietitians/clinical nutritionists, psychologists, physiotherapists and speech & language therapists
- Difficulty accessing complementary supports for managing condition (non-HSE)
- Lack of peer support groups
- Potentially poor quality of life after treatment
- Limited Irish research on effective post-treatment care

# FUTURE

## PRE-DIAGNOSIS

- The media continues to cover OC
- Other charities help to amplify OCF messaging
- The risk factors for symptoms of OC are as well-known as those for more common cancers
- Pharmaceutical industry makes users of over-the-counter medication aware of OC voluntarily or through regulation
- Pharmacists throughout country understand OC and make users of over-the-counter medication aware of OC
- National Barrett's Oesophagus Registry and Biobank contains all patients with Barrett's Oesophagus

## DIAGNOSIS

- People with symptoms do not delay seeing GP
- GPs across country are trained to recognise early symptoms of OC and make speedy referrals to specialists
- Healthcare providers in relevant hospitals automatically signpost OC patients to OCF
- People diagnosed with OC, and those who care for them, have access to practical information and emotional support to navigate the journey
- Significantly more research enabling early diagnosis

## TREATMENT

- Equitable access for those requiring treatment
- Considerably improved survival rate 50%
- People diagnosed with OC, and those who care for them, have access to practical information and emotional support to navigate the journey
- Significantly more treatment research translated into practice
- Ongoing liaison between hospitals treating OC patients

## POST-TREATMENT

- National Clinical Guidelines updated
- Equitable access for OC patients to HSE dietitians/clinical nutritionists, psychologists, physiotherapists and speech & language therapists
- Equitable access for people affected by OC to complementary supports for managing condition
- Equitable access for people affected by OC to peer support groups
- Enhanced wellbeing for anyone affected by OC