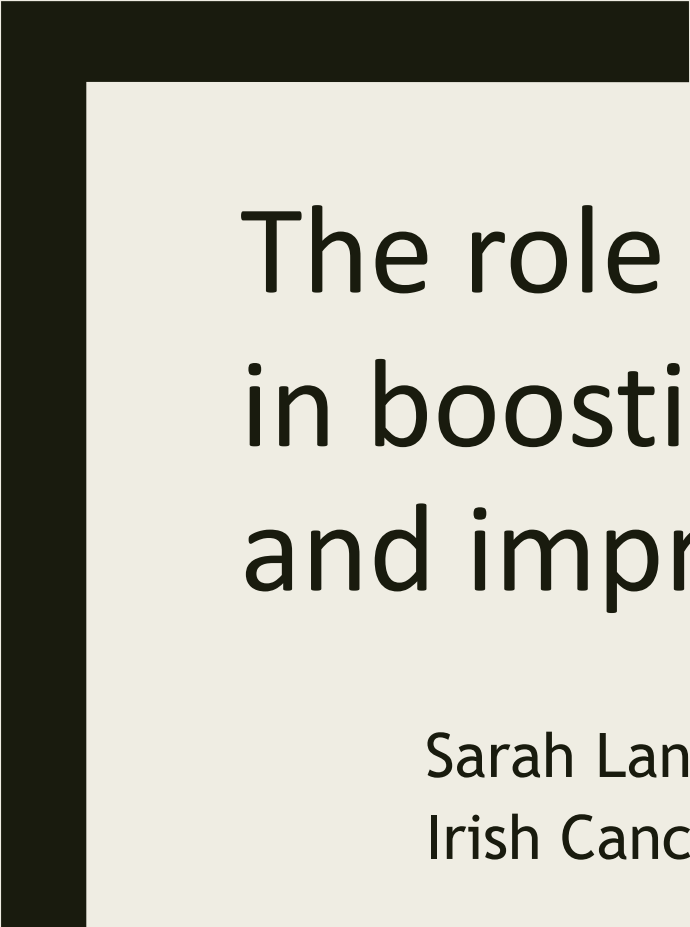
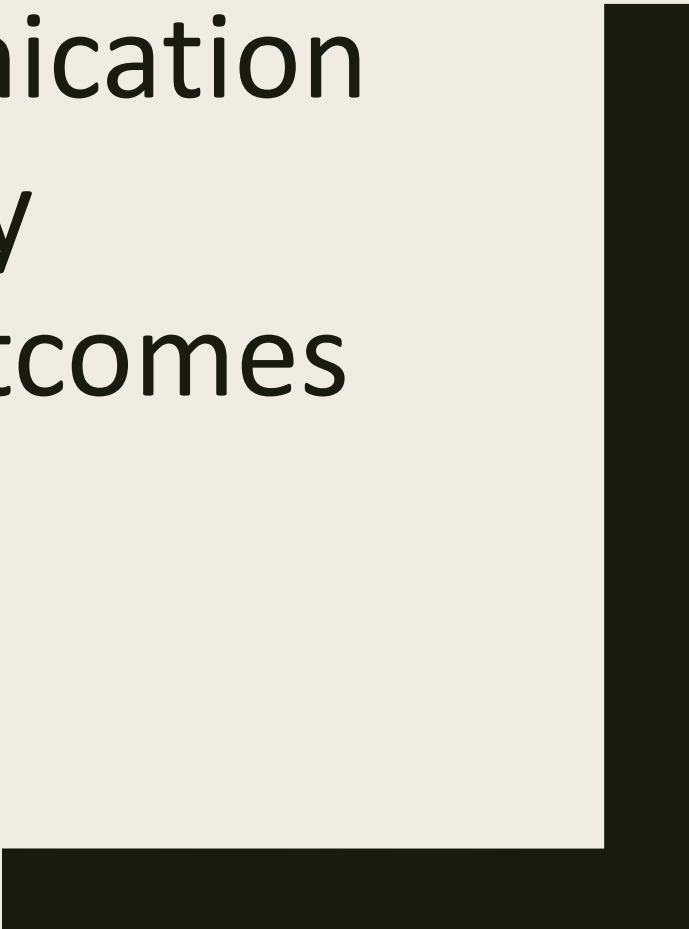




The role of clear communication in boosting health literacy and improving cancer outcomes

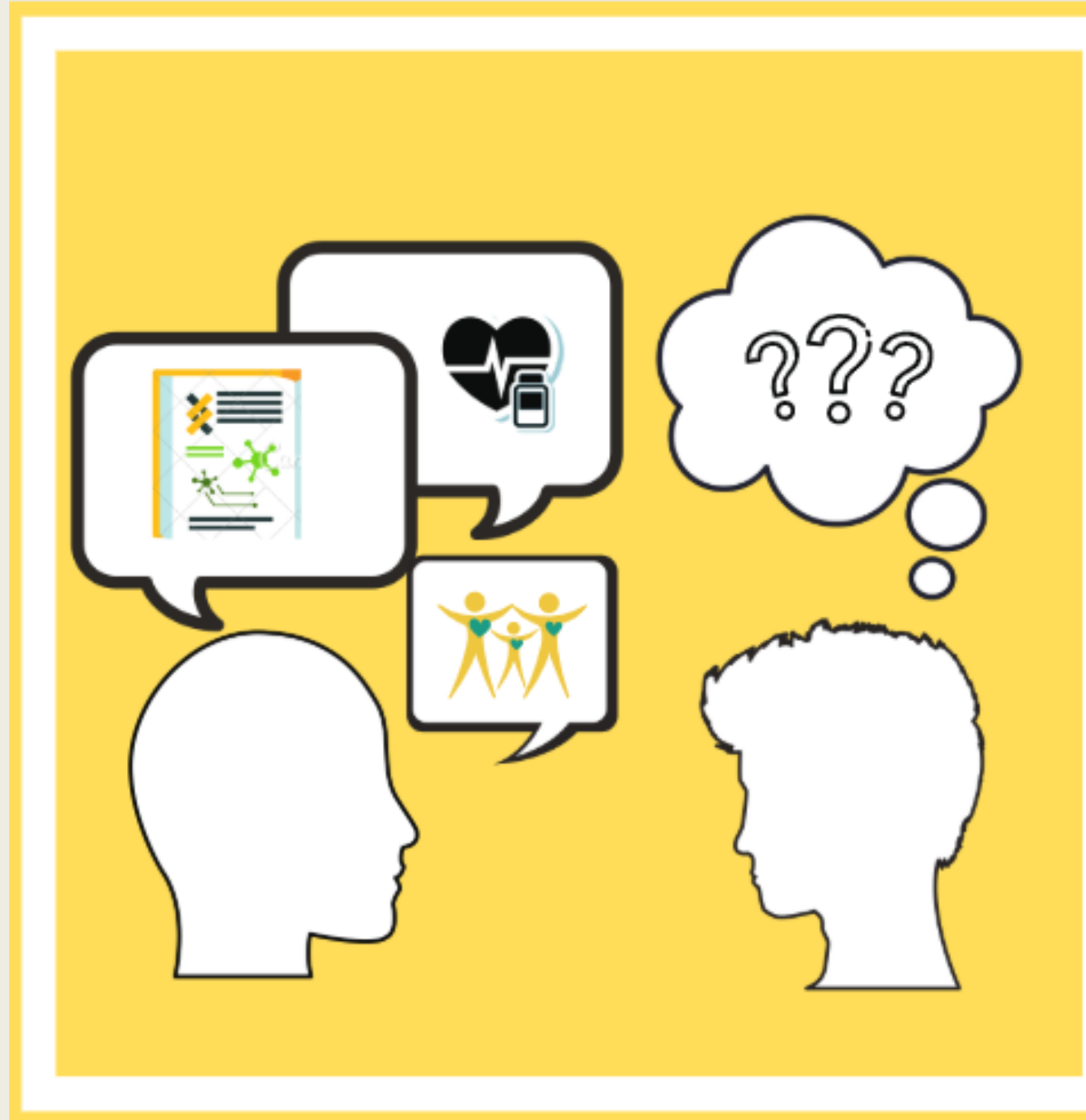
Sarah Lane
Irish Cancer Society



Health literacy

- Get
- Understand
- Use

Health information





Why health literacy matters



Low health literacy is bad for your health

Preventing health problems

Managing health problems

Reducing risk



Symptoms and diagnosis



Understanding treatment

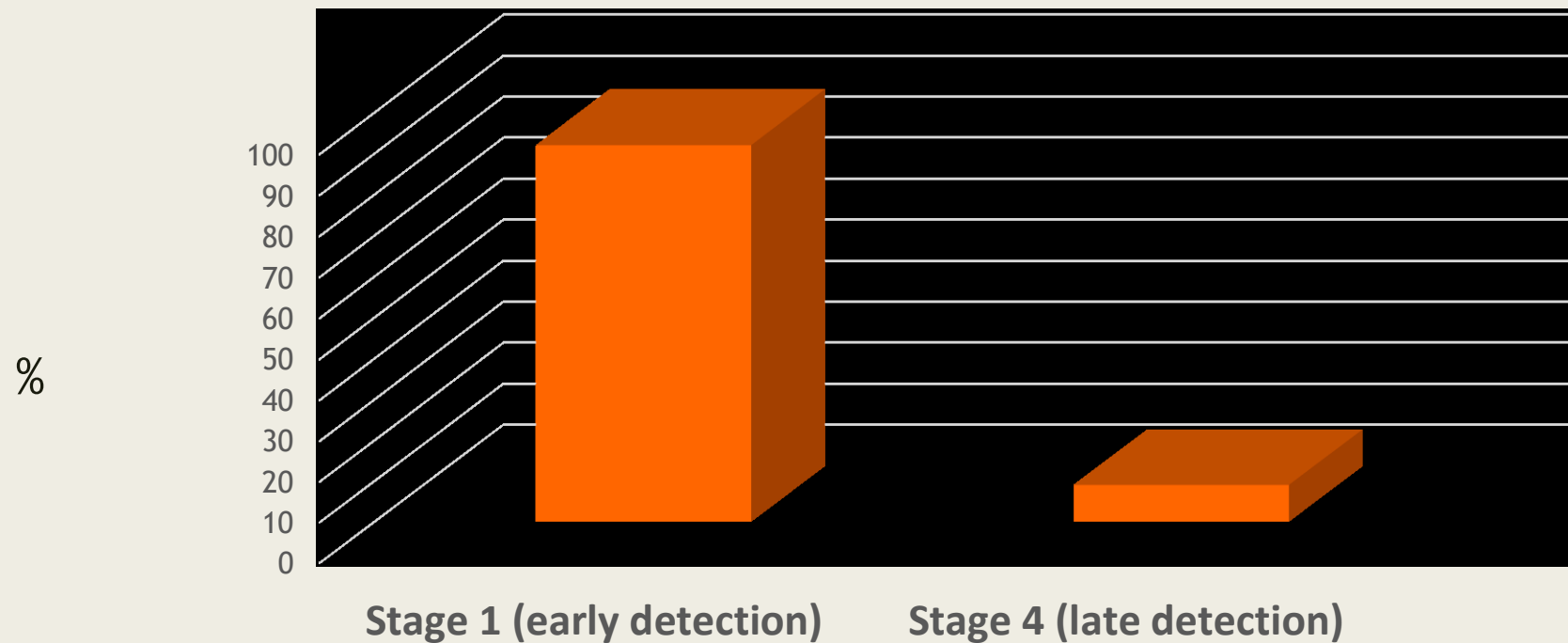


Coping with side-effects



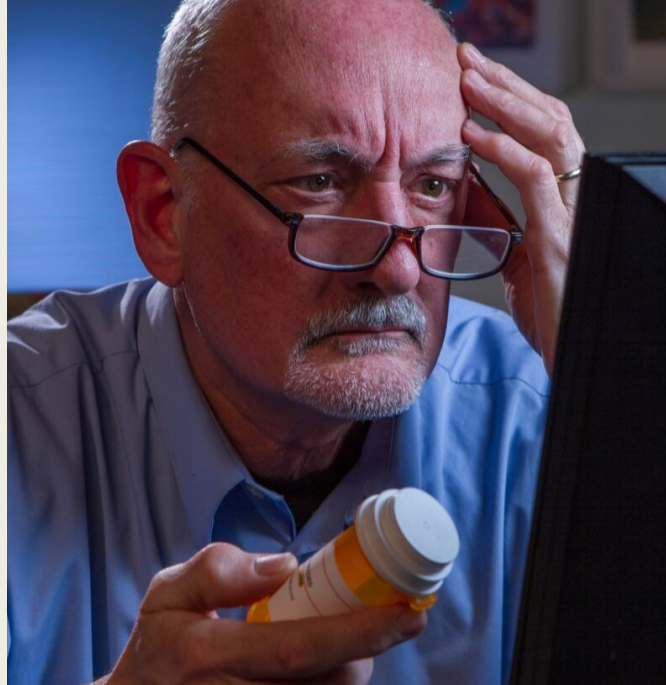
Delayed diagnosis is deadly

Bowel cancer: 10 year survival



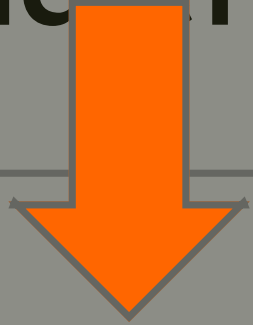
Clear communication

Improves
patients' physical
and mental
health



Better communication for better health

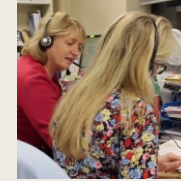
Understanding your audience



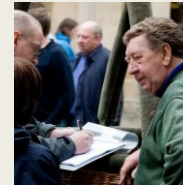
Communication that connects



Focus groups



Enquiries



Survey



User testing



Research



Staff engagement / training

Health literacy barriers

- Literacy difficulties
- Information format
- Emotions/beliefs
- Structural issues

■ Literacy difficulties

Easy to read

- Plain language principles
- Visual communication

Easy to navigate

- Summaries / key facts
- Informative headings
- Clear sections
- Layered web information

Health
information
is often
hard to
understand

Visual communication

Before

due to cancer or infection. A sample of the lymph glands can also be taken and examined under a microscope.

Liver ultrasound: This scan is done in the X-ray department of the hospital. A picture is built up of the tissues inside your liver and upper abdomen using sound waves. While lying on your back, a gel will be spread over the area to be scanned. A small device like a microphone is used to take the scan. This makes sound waves, which are then changed into a picture by a computer. The test does not hurt and only takes about 10 minutes.

MRI scan: This scan uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but can be very noisy. You will be given earplugs to wear during the scan. You may have an injection before the scan to show up certain areas of your body. During the scan you cannot wear any metal jewellery or hair clips. If you have certain medical devices implanted, like a pacemaker or metal pin, you are not suitable for the test. Your doctor will advise you about this. Most people don't need to stay in hospital after the scan.

PET scan: This test is done in the nuclear medicine department of specialist hospitals. You will have to fast for 4 hours beforehand. If you are a diabetic, tell your doctor before the test so you can be given special advice.

As part of the test, a blood sample is taken to measure your blood sugar. Then a very small amount of a mildly radioactive sugar is injected into a vein in your arm. After the injection, you must wait for about 60 minutes before the scan can be taken. You might want to bring a book, magazine or music with you or a friend to keep you company.

A scan is then taken of your body. Cancer cells absorb more of the radioactive sugar than normal areas, so these areas will show up on the scan. The level of radioactivity used in these scans is very low and is not harmful. It disappears from your body within a few hours. Drinking clear fluids will help to flush it from your body more quickly.



PET scan

Laparoscopy: This test allows your doctors to look inside your tummy using keyhole surgery. It will help them to decide if you are suitable for major surgery or not. It is done under general anaesthetic and you will need to stay overnight in hospital. Just before the test you may be given sedation to relax you before going to theatre.

While you are asleep, your doctor will make a small cut in your tummy and put in a mini telescope called a laparoscope. By looking through the telescope, your doctor can see the organs close to your oesophagus and check the lining of your tummy for cancer. A small sample of tissue (biopsy) may be taken and examined under a microscope.

During the test, carbon dioxide gas is passed into your abdominal cavity. This can give you uncomfortable wind and/or shoulder pains for 3 or 4 days. Walking about or taking sips of peppermint water often eases the pain. After a laparoscopy you will have one or two stitches at the wound site. Usually they dissolve as your wound heals.

Waiting for results

It may take about 1-2 weeks for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with a specialist nurse or relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to one of our cancer nurses.

How is oesophageal cancer staged?

The stage of a cancer describes its size and if it has spread to other parts of your body. Knowing the stage of the cancer helps your doctors to decide the best treatment for you.

The staging system normally used in cancer of the oesophagus is called TNM. This stands for tumour, node, metastasis. It refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis). Your doctor uses this information to give your cancer a stage - from 0 to 4. In general, the lower the number, the less the cancer has spread.

After

Telling people about your diagnosis



Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also to worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet *Who Can Ever Understand?* It can help you find ways to talk about your cancer and to ask for the help and support you need.

What tests will I have?



- Tests you may have after being diagnosed with cancer include CT scan, endoscopic ultrasound, PET scan, MRI scan and occasionally a laparoscopy.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

CT scan

This is a special type of X-ray that builds up a detailed picture of the tissues inside your chest. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You might be asked to fast (not eat) for a few hours before the test.

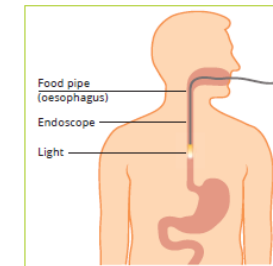
You may also be given an injection or a special drink to help show up parts of your body on the scan.

Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary. The doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.



Endoscopic ultrasound (EUS)

An ultrasound probe is passed through a tube into your body through your mouth. This probe makes sound waves that allow your doctor to see the tissues inside your oesophagus and nearby areas. This can help your doctor assess the size and depth of the tumour.



Visual communication

Before

After

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Patients and their families sometimes find it difficult to come to terms with the illness. Many people also feel that they cannot talk to a close friend or relative. In this case, counselling can provide emotional support in a safe and confidential environment. Call the helpline 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly at night) to patients seriously ill at home and give support for their families. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse. Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. ICS night nurses provide care to the patient and support to families in their own home.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Financial aid

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid. If you would like to request this kind of help, contact your oncology or medical social worker at the hospital where you have been treated. He/she should fill in an application form and return it to the Irish Cancer Society. If there is no social worker available, another health professional involved in your care may apply on your behalf.

Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.

>>> If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.



Useful organisations

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline:
1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Cancer Research Ireland
Website: www.cancer.ie/research/why.php

The Carers Association
Market Square
Tullamore
Co Offaly
Tel: 057 932 2933
Email: info@carersireland.com Website:
www.carersireland.com

Citizens Information Board (formerly
Comhairle)
Ground Floor
George's Quay House
43 Townsend Street
Dublin 2
Citizen Information Service:
1800 777 121
Tel: 01 605 9000
Email: info@ciboard.ie
Website: www.citizensinformation.ie

**Dept of Social Protection - Information
Service**
Oisín House
212-213 Pearse Street
Dublin 2
Tel: 1850 662 244
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted
Reproduction Ireland)
Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion HSE
Website: www.healthpromotion.ie

Irish Clinical Oncology Research Group
Website: www.icorg.ie

Irish Nutrition & Dietetic Institute
Ashgrove House
Kil Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@ind.ie
Website: www.ind.ie

Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

Publications and website information

We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for free copies of our publications.



If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Visual communication - no words needed

How can I check myself?

- 1 Examine your body front and back in the mirror, then right and left sides with arms raised
- 2 Bend elbows and look carefully at forearms and upper underarms and palms
- 3 Look at the backs of legs and feet and the spaces between toes and soles
- 4 Examine back of neck and scalp with a hand mirror. Part hair for a closer look
- 5 Finally, check back and buttocks with hand mirror



12 ways to reduce your cancer risk



Do not smoke



Avoid second-hand smoke



Be a healthy weight



Be physically active in everyday life



Have a healthy diet



Avoid alcohol



Avoid too much sun



Avoid pollutants



Get screened for cancer



Breastfeed your baby / Limit HRT



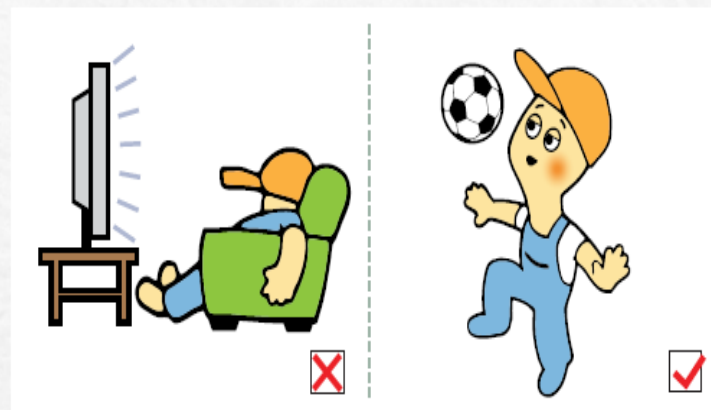
Get vaccinations - Hepatitis B for babies / HPV for girls



Find out if you are exposed to radon gas in your area

Based on the European Code Against Cancer

Physical activity: Quick guide



Clearer navigation, colour-coded sections

Before

After

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- 5 What does that word mean?

About oesophageal cancer

- 7 What is cancer?
- 8 What is the oesophagus?
- 9 What is oesophageal cancer?
- 10 What causes oesophageal cancer?
- 12 What are the symptoms of oesophageal cancer?
- 12 How is oesophageal cancer diagnosed?
- 17 How is oesophageal cancer staged?
- 18 What are the types of oesophageal cancer?

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- 41 Chemotherapy
- 46 How is advanced oesophageal cancer treated?
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- 54 Cancer and complementary therapies

Coping and emotions

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- 62 How can my family and friends help?
- 63 How can I talk to my children?

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- 83 Questions to ask your doctor
- 83 Your own questions

Introduction

This booklet has been written to help you understand more about cancer of the oesophagus (gullet). It is also known as oesophageal cancer. By reading the booklet you can learn more about its diagnosis, treatment and side-effects, and also any feelings you might have at this time.

We hope it answers some questions you may have. But we cannot advise you about which treatment to choose. You can only make this decision along with your doctors, when all your test results are ready.

At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time. You can also call the freephone National Cancer Helpline 1800 200 700 to discuss any queries or concerns you have.



Reading this booklet

It is easy to be overwhelmed by all the information you have to take in. But you do not need to know everything about oesophageal cancer straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline 1800 200 700, if you wish.

If reading this booklet helps you, do pass it on to your family and friends who might find it helpful too.



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Support resources

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Summary information

Before

Introduction

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After

Fast facts

Can my cancer be treated?

Page xx

Kidney cancer can be successfully treated for the vast majority of patients. If the cancer is found at an early stage it can often be cured. Your doctor will advise you about your treatment.

Will I be OK?

Page xx

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things – for example, if the cancer has been found early and your general health. Everyone's prognosis is different. Your doctor will advise you on what is likely to happen in your situation.

What kind of treatment might I have?

Page xx

Surgery: An operation to remove your whole kidney or the part that contains cancer

Thermal ablation: Using a needle-type instrument, which delivers heat to the tumour to destroy it

Arterial embolisation: Injecting a substance into the main blood vessel to your kidney, to block the cancer's blood supply and slow its growth

Targeted therapies: Tablets to stop the cancer growing

Immunotherapy: Tablets or injections to help your body's immune system to fight cancer

Will I get side-effects?

Page xx

Some treatments can cause side-effects, but they usually go away after you finish treatment. You can read about the different treatments to learn more about any possible side-effects.

There are treatments to help with most side-effects, so tell your doctor if you have any. Don't suffer in silence!

We're here for you

Page xx

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Cancer Nurseline on 1800 200 700
- Drop in to a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

See page 84 for more about our services.



MEMBER

Cancer Nurseline Freephone 1800 200 700

■ Format barriers

Written materials don't work for

Fewer than 1 in 5
men with low health
literacy said they
would get health
information from
brochures or leaflets

82%



Alternative ways of giving information



People with low health literacy often prefer to get information face to face

Work with information gatekeepers



Build a relationship with the people talking to your information audience

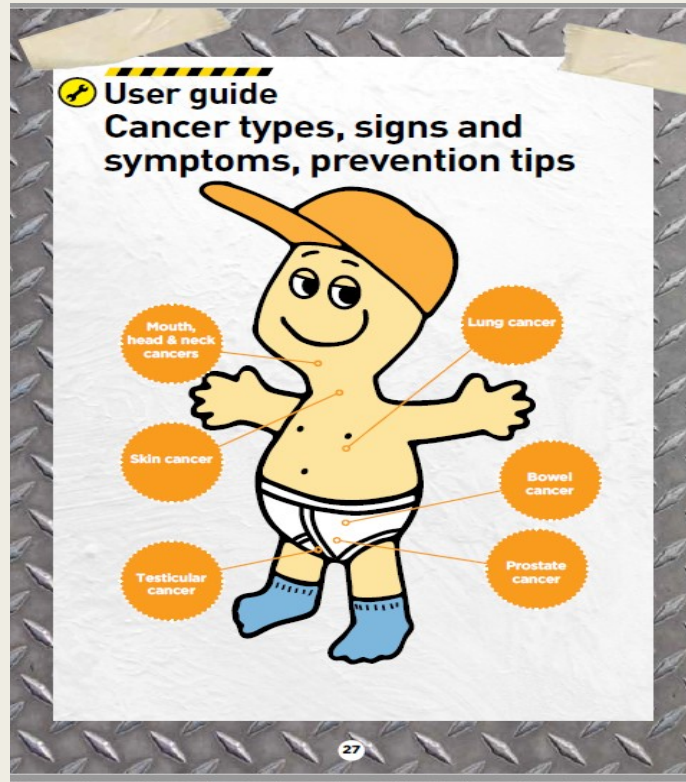
■ Emotional barriers



Negative emotions can damage health literacy

- Fear
- Fatalism
- Misinformation / false beliefs
- Denial
- Negative expectations
- Personal beliefs, values
- Anxiety, distress

Humour vs fear



“Play with your balls - doctor's orders!”

Men liked humour, as it diffused their fears and anxiety about cancer

Finding the fearful - Engagement strategies

- Community and youth groups
- Patient groups, GPs and hospitals
- Conferences
- Information stands
- Media advertising
- Social media
- Workplace initiatives

Get
proactive
with hard-
to-reach
audiences



Fear can make people avoid health information.

■ Structural barriers



- Financial issues
- Transport problems
- Availability of services
- Standard of care
- Computer access / skills

Building health literacy

- Saves lives
- Improves lives

