



Caring for Someone with Lung Cancer

A guide for carers



This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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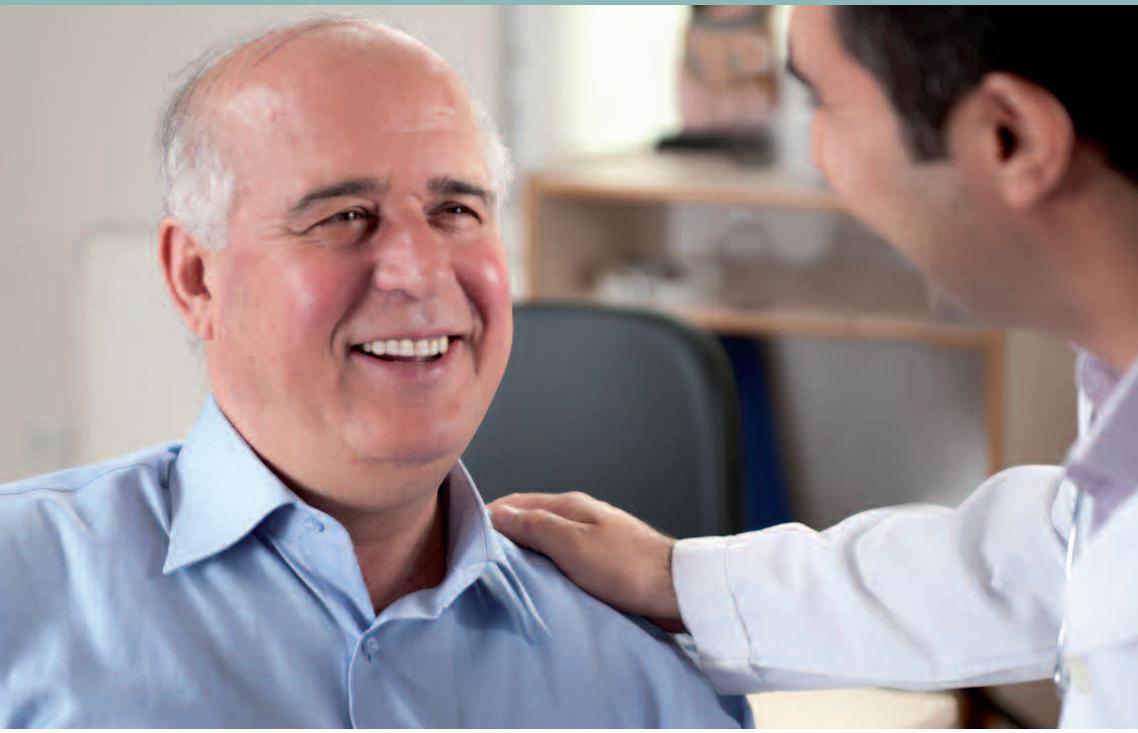
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Introduction

Lung cancer is the fourth most common type of cancer in Irish men and women. Sadly, more Irish people die from lung cancer every year than all together from breast, prostate and bowel cancers.

Being diagnosed with lung cancer can be a very frightening experience for both the patient and their loved ones. If you are a carer for someone diagnosed with lung cancer, this booklet is for you.

If you have concerns or questions about lung cancer, how you might support and care for a family member or loved one, you can speak to a specialist cancer nurse on the National Cancer Helpline 1800 200 700. The freefone helpline is open Monday–Thursday, 9am–7pm and Friday 9am–5pm.



What does a carer do?

When someone is diagnosed with lung cancer, life changes for them, their family and their friends. Life also changes for you, the carer.

A carer is an unpaid person who helps the patient with lung cancer. A carer could be a family member, partner, friend or neighbour.

Nowadays patients spend less and less time in hospitals and more time at home. So carers are important members of the medical or healthcare team. Often, the carer knows most about the patient. For example, the time they wake, how long they sleep, when they start to feel uncomfortable, how much they eat or drink, when they are most likely to be tired, and so much more.

Your role as a carer will constantly change, depending on your loved one's needs. Caring includes:

- Medical care
- Practical care
- Emotional care



How does it feel to be a carer?

Some people get a lot of satisfaction in helping their loved one when they are sick. Becoming a carer often draws people together. You may even find that you become closer to your loved one during their illness.

But becoming a carer can also be very overwhelming. It is common to wonder 'why me' and feel trapped if you are suddenly in a caring role. You may also feel unprepared and unable to give the care that is needed. Do not worry about this, as there are people to help you. This booklet will give you useful tips on being a carer and let you know who to ask for help, if needed.

Every relationship is different and sometimes there are strains. When a loved one becomes sick, do try and put past differences aside and focus on the present problem. Working together might even help to heal old wounds.



Working together as a team

Often patients have several people who can act as carers. Some carers are live-in carers, others are part-time or even long distance carers. It is a good idea to meet as a group and discuss who can give care from the start. Remember your loved one will know what care they need and want, so do not forget to include them in the meeting.

As a carer, it is important to realise your limits from the start. Speak with your loved one and other family members and friends and try to share out the caring responsibilities fairly. Some carers may have less time to offer. For example, if they have a full-time job or young children.

Be kind to each other and try to remain flexible and help each other out. Remember it is normal for everyone to give care in their own way. The important thing is that you are all there because you care about your loved one.



Giving medical care

Many carers are involved in the medical care of a family member or loved one. Medical care can include:

- Giving nursing care
- Managing and giving medications
- Managing side-effects
- Accompanying your family member or loved one to their appointments
- Reporting problems to the medical team

Here are some tips on giving medical care.

Educate yourself

It is a good idea to learn about lung cancer and become familiar with the medical terms that the doctors and nurses use. Our *Understanding Cancer of the Lung* booklet is full of information about lung cancer. It is written especially for lung cancer patients and their loved ones. For a free copy, call the National Cancer Helpline on 1800 200 700. You can also read the lung cancer information on our website www.cancer.ie

Write out questions

Once you have read the *Understanding Cancer of the Lung* booklet, write out any questions you might have. Discuss these questions with your loved one and other carers. If you would like to speak to a specialist cancer nurse in confidence, call the National Cancer Helpline 1800 200 700. It is best to sit down with your loved one and write out what questions they have before each appointment.

Attend appointments

Appointments can be an anxious time and often involve results of tests and treatment decisions. For this reason, do attend appointments with your family member or loved one. Bring a notebook so that you can ask your questions and take note of the answers. This will be useful when telling the rest of the family or friends later.



Ask for advice

Ask the hospital doctors and nurses for advice on how to care for your loved one. If they need wound dressings, injections or other medical care, the nurses can advise you on what to do or where to go. If you feel comfortable, the nurses will teach you how to give medical care. If not, they will advise you about what services are available in the community. For example, the GP or public health nurse.

Find out who's who

Do keep a record of important names and phone numbers. Ask the nurses to give you telephone numbers to call if you need to ask a question in between appointments. Remember to take note of who to call if your loved one becomes unwell at home.

Managing symptoms and side-effects

If your loved one is having a symptom or side-effect of their treatment, speak to the nurses and doctors in the hospital. You can also speak to a specialist cancer nurse on the National Cancer Helpline 1800 200 700. We have several booklets written about cancer symptoms, treatments and side-effects, which you might find useful.

For a free copy of any of the following booklets and factsheets, ring the helpline. You can also read this information on www.cancer.ie

- *Breathlessness and Cancer*
- *Cancer Pain*
- *Coping with Fatigue*
- *Diet and Cancer*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*



Nursing care

As a carer, you may have to give some nursing care to your loved one. For example, if they are very breathless, they might need help washing and dressing. It is important to ask your family member or loved one when they need help, as they know best.

You can also hire a nurse or carer to give care in your loved one's home. For more information on nursing agencies, contact the National Cancer Helpline on 1800 200 700.

Palliative care

The palliative care team are specialists in managing symptoms and helping patients to have a good quality of life. Many people are frightened when they hear the word 'palliative'. This is natural. But remember these doctors and nurses are experts in helping patients and their loved ones cope with the emotional and physical effects of lung cancer.

Palliative care is care given to patients when a cure is no longer possible. Sadly, many lung cancer patients cannot be cured. The aim of their treatment then is to slow down their disease and control their symptoms.

Palliative care does not mean that your loved one will not receive treatment. If you are concerned about the symptoms your loved one is experiencing, ask your doctors and nurses to refer them to palliative care.

Home care

Palliative care is also available in the community. In this case, it is given by the homecare team. This is a team of nurses and doctors who can call to a patient at home and check their symptoms. For example, the homecare team can control your loved one's pain and make changes to their pain medicine if needed.

The homecare team works closely with the GP and can be a useful support for your loved one and his or her carers. The palliative care team in the hospital can also refer your loved one to the homecare team.



Giving practical care

Carers often give practical care to patients. Practical care can include doing household chores, preparing meals and providing transport. Sometimes these roles can be overwhelming when you have other responsibilities. For example, housework in your own home, looking after your children or going to work. Speak with the other carers and try to share out the practical jobs fairly.

Try to keep your life as normal as possible by prioritising what needs to be done. Here are some tips on giving practical care, such as household chores, preparing meals, and helping with transport and finances.

Household chores

Try to prioritise what needs to be done and share it out fairly among the carers. Ask your family member or loved one what they would like done. Remember it is their home. Your loved one may be entitled to the home help service, so do speak to the medical social worker in the hospital or your local Health Service Executive (HSE) office.

Preparing meals

If your loved one is not feeling well, or having side-effects after their treatment, they may not have any appetite. It can then be hard to know what meals to prepare. Speak to the hospital dietitian or call the helpline on 1800 200 700 for a free copy of our *Diet and Cancer* booklet. This booklet gives helpful tips for carers about meals for someone with cancer.

The HSE also runs a Meals on Wheels service. Your family member or loved one may be entitled to this service. Again, speak to your local HSE office or medical social worker about this service.

Transport

Carers can also help their loved ones with travel to hospital for appointments and other outings.

There is also help available if carers cannot help with travel. Travel2Care is a fund to help patients travelling to any of the eight designated cancer care centres and other approved centres. The fund was made available by the National Cancer Control Programme (NCCP) and is run by the Irish Cancer Society.

If your loved one is travelling to a rapid access diagnostic clinic for lung cancer in St James's Hospital, St Vincent's University Hospital or Beaumont Hospital, all in Dublin, or Waterford Regional Hospital, they can also apply for this scheme.

The NCCP plans to roll out this service to all eight centres in the future. To apply for this scheme, contact a healthcare professional in the hospital you are attending.

For more information on this travel scheme, contact:

Travel2Care, Irish Cancer Society

Tel: 01 231 6619 or email travel2care@irishcancer.ie

Website: www.cancer.ie/travel2care.php

Finances

It is a good idea to talk to your loved one about their finances from the start. If you are in contact with a medical social worker, they can advise you on how to apply for suitable payments or supports for your loved one. The Irish Cancer Society has also produced a guide to social welfare benefits that you may find helpful. It is called *Social Welfare Support: A Guide for Cancer Patients*.

For more information, go to www.cancer.ie or call the National Cancer Helpline on freefone 1800 200 700 for a free copy.

You can also call into your local Dept of Social Protection office, speak with an information officer in a Citizens Information Service in your area, or meet with the community welfare officer.

Financial aid

In certain cases, families find it hard to cope financially because of a diagnosis of cancer. Your loved one may have special needs because of their illness or due to treatment. A special fund is run by the Irish Cancer Society to help you if your family finances cannot cope with the extra expenses. The fund only applies if you are experiencing specific hardships.

If you feel this fund applies to you, talk to your oncology social worker, palliative care social worker or oncology liaison nurse in the hospital.

Information on managing your finances is also available. Contact the Money Advice and Budgeting Service (MABS) for advice on 1890 283 438 or visit the website www.mabs.ie

Carer's entitlements

The Carer's Leave Act 2001 allows employees in Ireland to leave their job temporarily to care for someone who needs full-time care and attention. The shortest period of leave allowed is 13 weeks and the longest is 104 weeks. Carer's leave is unpaid but the law makes sure that your job is kept open for you while on leave.

You may be eligible for Carer's Benefit if you have enough PRSI contributions. If you do not qualify for Carer's Benefit, you may qualify for Carer's Allowance, which is means tested. You can take Carer's Leave even if you do not qualify for either of these payments.

For more information on carer's entitlements, contact the National Cancer Helpline for a free copy of our booklet, *Social Welfare Support: A Guide for Cancer Patients*.

You can also contact:

Carer's Allowance/Benefit Section

Tel: 043 40000 or 01 704 3000

For general enquiries about State benefits and services, contact:

Citizens Information Board

Tel: 01 605 9000

LoCall: 1890 777 121

Website: www.citizensinformationboard.ie

Medical equipment

If your loved one needs medical equipment, such as portable oxygen or a wheelchair, speak to the nurses and doctors in the hospital. They will advise you. The following organisations may also be useful.

Medical products and equipment

Assist Ireland

Tel: 1890 277 478

Website: www.assistireland.ie

Breathing equipment

Air Products Ireland

Tel: 1850 240 202

Website: www.airproducts.ie

Wheelchairs

Irish Wheelchair Association

Tel: 01 818 6400

Website: www.iwa.ie



Giving emotional care

Giving emotional care is probably the most difficult part of being a carer. You may find it hard to know how your loved one is feeling and what you can say to help. For this reason, the Irish Cancer Society produced a booklet called *Lost for Words: How to Talk to Someone with Cancer*. It gives advice and tips to help you support your family member or loved one. For a free copy or to talk to a specialist cancer nurse in confidence, call 1800 200 700.

Here are some tips below on how to give emotional care for the patient.

- Listen to your loved one.
- Everyone deals with cancer in a different way.
- Your loved one will have different feelings at different time.
- Find out about support.
- You know your loved one best.

Listen to your loved one

When talking with your loved one about their illness, it can be very tempting to try and solve their problems. Remember you cannot change the fact that they are sick, but you can help them to come to terms with it by listening. Listening is a simple but very good way to communicate.

Everyone deals with cancer in a different way

You may be surprised at how your loved one reacts to their cancer diagnosis. But it is normal for people to cope with a lung cancer diagnosis in lots of different ways. Sadness, anger, anxiety and denial are all very different but very common reactions. Your job as carer is not to change how your family member or loved one feels but to support them. Listening to them and accepting how they feel are simple ways to show your support.

Different feelings at different times

It is also normal for your loved one to experience different feelings at different times during their illness. This can be hard for you as a carer because you do not know what to expect. There may be certain times when your loved one experiences strong feelings or changes the way they feel. These times include:

- After diagnosis
- While waiting for results
- When treatment is finished
- If the cancer returns after treatment
- If the treatment has not worked

Find out about support

Support is available for lung cancer patients. This includes cancer support centres, counsellors, booklets and online forums. You can be of help to your loved one by gathering information on what is available in your area. For more information, contact the National Cancer Helpline 1800 200 700 and speak to a specialist cancer nurse in confidence.

If you are concerned that your loved one is not coping well with their illness, speak to their doctors, nurses or medical social worker. Some hospitals have a psycho-oncology service. This is a team of nurses and doctors who specialise in helping cancer patients who find themselves unable to cope with their illness, despite all their efforts.

You know your loved one best

Think about a difficult time in the past and how you and your loved one coped. Remember you know your loved one best so do not be afraid to talk to them. It is a good support for both of you if you can talk about your feelings together.

Keep life normal

Lung cancer is likely to bring many changes to your loved one's life and that of their carers. But it should not take over. Try to admit these changes but do keep living as normal a life as possible. Do not forget to include your loved one in normal activities like birthday celebrations or other events. Everyone needs something to look forward to, and they too need a break from lung cancer.

Useful resources

The following booklets are available from the helpline free of charge:

- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can ever Understand? Talking about Your Cancer*
- *Understanding the Emotional Effects of Cancer*
- *Talking to Children about Cancer: A Guide for Parents*

A DVD called *Living with Lung Cancer* is also available from the helpline. It includes interviews with lung cancer patients and their family and friends. It has topics such as 'getting the news', emotional support and positive actions. The DVD is an excellent tool for both patients and their carers. You can also find it on our website www.cancer.ie



Taking care of yourself

Sometimes caring for someone who is sick can be exhausting. You might have other concerns such as a job, taking care of children and day-to-day tasks like housework and preparing meals. It is not unusual for carers to become tired and stressed, so do take care of yourself from the start.

You may not even realise that you are stressed. If you are feeling tired, tearful or angry and finding it hard to cope, it is important to admit it.

Here are some tips below on how to look after yourself:

- Get organised.
- Know your limits.
- Look after yourself.
- Stay healthy.
- Take time out.
- Go easy on yourself.
- Get help if you feel overwhelmed.
- Deal with your emotion.
- Find support.

Get organised

Life can suddenly become very busy when a loved one becomes sick. Use a notebook and make lists of what needs to be done. This will help you prioritise what care is needed. The Irish Cancer Society has also produced a useful notebook called the *Journey Journal* to keep track of tests, appointments, treatments, etc. Call the National Cancer Helpline 1800 200 700 for a free copy.

Family meetings are a good idea from the start to make sure everyone is working together. Do not forget to include your loved one and ask them what help they would like.



Know your limits

Remember you cannot do everything on your own and it is okay to ask for help. If you are finding it hard being a carer, tell your other family members, friends and your loved one. Make sure the work of caring is shared out fairly.

Look after yourself

It is important that you get plenty of rest, eat well and take exercise. Do not feel guilty about looking after yourself. By taking care of yourself, you will be better able to care for your loved one. Simple things like going for a 30-minute walk every day will keep you fit and alert. It will also give you a break from your role as carer.

If you feel you are not coping, losing your appetite, not sleeping or not feeling well, talk to your GP.

Stay healthy

It is normal to worry that you too might get cancer. There are some steps that you can take to reduce your risk of cancer.

- If you smoke, plan to quit.
- If you drink alcohol, cut down on the amount you drink.
- Eat a healthy diet.
- Stay at a healthy weight.
- Protect your skin from the sun and avoid sunburn.
- Tell your GP if you notice any changes in your body.

If you would like to speak to someone about quitting smoking, call the National Smokers' Quitline on callsave 1850 201 203 for advice, support and information.

If you are worried about your risk of cancer, talk to your GP or call the National Cancer Helpline on 1800 200 700. You can speak to one of our specialist nurses in confidence.

Take time out

Some people find it useful to keep a diary and write down how they are feeling. If you are not comfortable doing this, try to talk to someone. It is important that you have support, such as friends and family members that you can turn to when you are tired and stressed. Try to plan outings and meetings that do not involve discussing your loved one's illness. It is okay to need a break.

Go easy on yourself

This is a very difficult time so remind yourself you are doing the best you can. Being a carer is not easy. Recognise signs of stress and ask for help if you need it. Remember giving care to a loved one when they are sick is making a difference to them in one of the most difficult times of their life. As a carer, there are many different feelings you might experience. These are all normal.

Feeling overwhelmed

Becoming a carer can be a sudden and dramatic change to your life. So it is normal to feel overwhelmed at times. Let other carers, family and friends know your feelings and try to share out the role of caring fairly.

Deal with your emotions

You may experience guilt, anger, sadness and anxiety as a carer.

Guilt: Witnessing a loved one become sick is not easy. You may feel that you are not doing enough. You may even feel guilty that they got sick and not you. Many carers feel like this. Try to talk to someone about how you are feeling and know that you are doing your best. Rather than focusing on these feelings, try to think about positive actions that you can do to help.

Anger: Anger is a very common feeling for both patients and carers. You can be angry for many different reasons, including at the cancer or at the changes in your life. Anger can affect your ability to think clearly. It helps to talk to someone and find out why you are feeling angry. If you are finding it hard to talk to your family and friends, discuss your feelings of anger with your GP.

Sadness: As well as dealing with new responsibilities, you have to deal with the sad news that someone you love and care for is sick. This is not easy and it is very normal to feel sad. Try to share your feelings with a friend or family member. It is also okay to share these feelings with your loved one, as they will probably be feeling this way too.

Anxiety: Carers can feel anxious for different reasons. You may feel overwhelmed at your new responsibilities or find yourself taking on your loved one's worries. Talk to them and other carers about your concerns.

Find support

Support is available for carers. Your GP, local cancer support centres, counsellors, online forums and the National Cancer Helpline are all there to help.

For more information, contact the National Cancer Helpline 1800 200 700 and talk to a specialist cancer nurse in confidence.

Useful websites

There are many websites that have online forums for patients and carers to chat to each other. An online forum is a type of message board or discussion site on a website. It is a good way to talk to people who are going through the same experience as you and who share your feelings.

Irish Cancer Society Lung Cancer Forum

www.forum.cancer.ie

Patient and Family Online Support

www.lungcancer.org

Lung Cancer Patient Stories

www.roycastle.org

Macmillan's Online Community

<http://community.macmillan.org.uk/whatsnew/default.aspx>

Cancer Buddies Network

www.cancerbuddiesnetwork.org

Health Talk Online

www.healthtalkonline.org

American Cancer Society

www.cancer.org





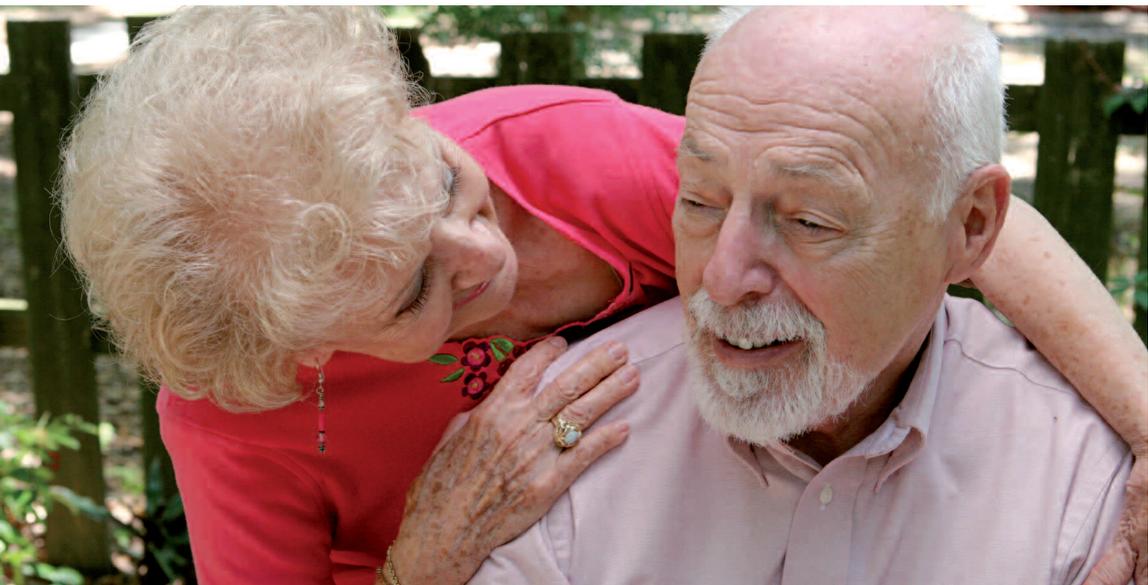
Caring for someone seriously ill at home

If your loved one is seriously ill and wishes to remain at home, you will need a lot of support. It is best if you and all the carers meet with the palliative care team in the hospital as a group. That way you can share out the care to be given. The Irish Cancer Society has produced a booklet called *A Time to Care: Caring for Someone Seriously Ill at Home*, especially for this difficult time. For a free copy, contact the helpline on 1800 200 700.

Night nursing service

The Irish Cancer Society offers 80 hours of nursing care to patients with cancer who wish to remain at home and be cared for by their families and friends. These hours are usually at night but can also be during the day. This service is free of charge. It aims to give extra support for the person who is ill and for his or her carers during what can be a difficult and anxious time.

To get in touch with the service, contact your specialist palliative care nurse, public health nurse or your GP, who can then contact the Irish Cancer Society.



Useful organisations

Carers Alliance Ireland

Tel: 01 874 7776 Website: www.carealliance.ie

The Carers Association

Tel: 057 932 2920 Website: www.carersireland.com

Caring for Carers

Tel: 065 686 6515 Website: www.caringforcarers.ie

Citizens Information Board

Tel: 01 605 9000 LoCall: 1890 777 121

Website: www.citizensinformationboard.ie

Department of Social Protection

Website: www.welfare.ie

Department of Health and Children

Tel: 01 635 4000 Website: www.dohc.ie

Health Service Executive

CallSave 1850 241 850 Website: www.hse.ie

Revenue Commissioners

Website: www.revenue.ie

For more information, call the National Cancer Helpline

Freefone **1800 200 700**

(Monday–Thursday, 9am–7pm; Friday 9am–5pm)

or email helpline@irishcancer.ie

for confidential advice from our cancer nurse specialists.

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

Tel: (01) 231 0500 Fax: (01) 231 0555 Website: www.cancer.ie

The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life, with three programme areas to achieve them: advocacy, cancer services and research.

