

Coping with Fatigue

Caring for people with cancer

Coping with fatigue

This booklet has been written to help you cope with fatigue due to cancer and its treatment. It has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. The information in this booklet is an agreed view on managing fatigue and the key aspects of living with it.

If you are a patient, your doctor or nurse could go through the booklet with you and mark sections that are important for you. You can also list below the contact names and information that you may need.

>>>	Name	Telephone 
Specialist nurse		
Family doctor (GP)		
Medical oncologist		
Radiation oncologist		
Surgeon		
Medical social worker		
Emergency		

**WE ARE
MACMILLAN.
CANCER SUPPORT**

The Irish Cancer Society thanks Macmillan Cancer Support for permission to adapt the text of their booklet *Coping with Fatigue* and acknowledges the contribution of the original authors of the booklet.

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. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

FATIGUE ADVISERS

Dr Miriam O'Connor, Consultant Medical Oncologist
Ada Kinneally, Clinical Nurse Specialist (Oncology)

EDITOR

Tara Droog

First published by the Irish Cancer Society in 2002.

© Irish Cancer Society 2002, reprinted 2004, revised 2006, 2007, 2010, 2011, 2013, 2017

Next revision: 2020

Product or brand names that appear in this booklet are for example only. The Irish Cancer Society does not endorse any specific product or brand.

All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from the Irish Cancer Society.

ISBN 0953236901

Contents

4 Introduction

Causes and effects of fatigue

5 Fatigue

6 What causes fatigue?

11 Effects of fatigue

12 How to talk about fatigue

Ways of treating fatigue

13 Coping with fatigue

18 Eating and drinking

18 Taking exercise

22 Sleeping well

24 Relaxation

27 Cancer and complementary therapies

28 Looking after someone who has fatigue

Support resources

31 Coping with the financial impact of cancer

33 Irish Cancer Society services

35 Local cancer support services

36 Helpful books

37 Questions to ask your doctor

38 Your own questions

Introduction

This booklet has been written to help you find ways to cope with fatigue. Fatigue is when you feel very tired most, or all, of the time. It can be caused by cancer itself or the side-effects of treatment. You may get tired quickly, and not feel better after resting and sleeping. This may also affect how you cope with your illness and make you feel sad and upset. People who have fatigue usually have no energy. You may find it hard to do simple, everyday things that people usually take for granted.



Reading this booklet

Read the sections of this booklet that are of interest to you. You may find there is a lot of information to take in and that it can be hard to concentrate, especially if you are feeling anxious or worried. Remember you do not need to know everything about fatigue straight away.



Read the parts that you're interested in, and read more when you want more information.

If you don't understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie

Or if you wish, you can visit a Daffodil Centre if one is located in your hospital. See page 33 for more about Daffodil Centres. Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.



Cancer Nurseline Freephone 1800 200 700

Causes and effects of fatigue

Fatigue

Fatigue is very common during cancer and its treatment. About 3 out of 4 patients will feel fatigued at some stage of their cancer journey. You may feel overwhelmed by the effect fatigue has on you. It can often reduce your enjoyment of life. Feeling tired all the time is especially difficult when you are already coping with cancer.

Fatigue may be due to the cancer itself or as a result of symptoms caused by the cancer. It can also be a side-effect of treatment. Health professionals caring for people with cancer now consider fatigue to be as distressing and disabling as other side-effects of cancer treatment. Fatigue is recognised as a major problem for many people with cancer.

»»» Treating the causes of fatigue can help to reduce it.

There are ways in which your doctor can treat your fatigue. Treating the causes of fatigue can help to reduce it. Research shows that people with cancer find that it is the symptom, or side-effect, which is most disruptive to their daily life. It's important to tell your doctors and nurses about your fatigue and how it makes you feel, without playing it down. They will be able to help you and give you advice. There are also things that you can do for yourself which may help you cope with the problem of fatigue.



What causes fatigue?

There are many causes of fatigue and knowing about them may help you to cope with it. The possible causes of fatigue include:

Treatment

- **Surgery:** It can take quite a while to recover from surgery. You may feel tired and need to take things easy for a while. This effect is usually temporary. But some types of surgery may cause ongoing problems with fatigue. For example, surgery to your stomach may lead to problems with absorbing food. If you are unable to absorb nutrients from food this can affect your energy levels.
- **Chemotherapy and radiotherapy:** You may feel very tired during and after chemotherapy and radiotherapy. This can be due to the treatment itself as well as travelling to and from the hospital. Your energy levels should start to improve 6 months to a year after treatment. But some people still feel tired 2 years after their cancer treatment has ended.
- **Hormone therapy:** Hormone therapies are treatments that can stop or slow the growth of cancer cells. They do this by blocking hormones that can encourage some cancers to grow. This may make you feel tired. Hormone therapies can also cause hot flushes, night sweats and insomnia (trouble getting to sleep), leading to broken sleep and fatigue. Hormone therapies can be given for several years, so it is important to talk to your doctor or nurse if you are concerned.
- **Biological therapies:** These are a form of treatment that makes your body's immune system attack cancer cells. There are a number of different biological therapies available to treat various types of cancer. Some but not all therapies can cause a flu-like reaction or tiredness after treatment. These side-effects usually go away when treatment stops or soon afterwards. Talk to your doctor or nurse. They will explain your treatment to you and show you how to reduce the side-effects.

Anaemia

Anaemia is a common cause of fatigue in people with cancer. It is caused by a shortage of haemoglobin (Hb) and oxygen in your bloodstream. The red blood cells, which contain haemoglobin, carry oxygen to all the cells of your body to provide energy. If the number of red blood cells is low, the amount of oxygen reaching your cells is reduced.

If you have anaemia, you might:

- Feel breathless some or all of the time. You may also feel dizzy and lightheaded
- Lose interest in sex (men and women)
- Find that you cannot get or maintain an erection (men)
- Have trouble getting to sleep
- Have aching muscles and joints
- Have chest pain due to heart problems (angina)

Causes of anaemia

Chemotherapy can reduce the number of blood cells made. This is a common cause of anaemia.

Radiotherapy can also cause anaemia if it's given to an area of the body that contains bone marrow. Red blood cells are made in the bone marrow. Radiotherapy given to the breastbone (sternum), the hip bones, or the long bones of the arms and legs is most likely to reduce the production of red blood cells.

You will have regular blood tests to check your haemoglobin if you have cancer or are having cancer treatment.

You can use the pull-out fatigue diary in the centre of this booklet to record your haemoglobin levels. Over time you will see how this affects your everyday life and level of fatigue. You may find that you feel much more tired when your haemoglobin is low. If you feel very tired tell your doctor or nurse. They may be able to give treatment for the anaemia. This can reduce the fatigue and help you to feel better.

>>> If you feel very tired, tell your doctor or nurse.

Treatment of anaemia

The treatment for anaemia will depend on the cause.

If you have mild anaemia, you might just need a course of iron tablets. You may also be asked to try to eat more foods rich in iron and vitamin C. Your doctor or nurse will give you advice on your diet.

With more severe anaemia, your doctor may decide to give you a blood transfusion or erythropoietin therapy.

A blood transfusion gives red blood cells directly into your bloodstream (through a drip). This will quickly increase the number of red blood cells travelling around your body.

Erythropoetin is a natural hormone which helps make red blood cells. Manmade versions of erythropoietin are available. They can be given if you are having chemotherapy to raise your level of red blood cells and reduce feelings of fatigue.

Electrolyte imbalance

Electrolytes are salts and minerals, such as sodium, potassium, chloride and bicarbonate, which are found in the blood. Symptoms of an electrolyte imbalance can include fatigue. An electrolyte test can help find out if there's an electrolyte imbalance in the body. Treatment for an electrolyte imbalance will depend on which electrolyte is out of balance and by how much.

Eating problems

If you are feeling sick (nausea), you are likely to eat less. This means you will not be getting enough energy from food. If you are actually vomiting, you are not absorbing the food. You may feel weak and tired as a result. If you have nausea or vomiting, your doctor can prescribe anti-sickness drugs (anti-emetics) that can help. These should be taken regularly. Poor appetite due to treatment can mean that you have less energy. Chemotherapy in particular can cause changes in appetite and taste. If you find that some foods no longer appeal to you, try new and different ones. Talk to the hospital dietitian who will advise you on the best foods to eat.

>>> You may find it helpful to get someone else to prepare food for you.

Ways to cope with eating problems

It is best to eat small meals more often. You may find it helpful to get someone else to prepare food for you. If you do not feel like eating, try using ready-made, high-calorie drinks. You could try unflavoured high-energy powders that add calories to food without adding bulk. Most of these drinks and powders can be bought in any pharmacy. Some are available on prescription, and your doctor can arrange for you to get them.

The Irish Cancer Society has a booklet, *Diet and Cancer*, that might help you. The booklet has helpful tips on coping with eating problems caused by cancer or its treatment. For a free copy, call Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre or download one from www.cancer.ie

Pain

Many people with cancer do not have any pain. But for people who do get pain it can be a common cause of fatigue. If you are in pain, tell your doctor or nurse about it straight away. Be honest about the level of pain you are in. There is no need to suffer in silence or play down the amount of pain that you have. Surgery, radiotherapy and chemotherapy can all help to ease your pain. There are also a lot of good painkillers available today. If the medication does not kill the pain, tell your doctor or nurse. You may need to try out different painkillers before you find one that suits you best.

There are other ways to treat pain such as nerve blocks and epidural injections. If you need more information do ask your doctor or nurse or call our Cancer Nurseline on 1800 200 700.

>>> If you are in pain, tell your doctor or nurse about it straight away.

Medication

Your doctor may prescribe medication to control pain or reduce the side-effects of treatment. Some of these drugs may cause fatigue or make you feel drowsy. Ask your doctor before you start any new medication what side-effects you can expect. The fatigue and drowsiness usually wear off after a few days. But if the fatigue persists tell your doctor or nurse, as your medication can be changed.

Insomnia

Insomnia means you have trouble getting to sleep or staying asleep for 3 or more nights in the week over a long period of time. This can make it hard to concentrate and stay awake during the day and to do normal daily activities. Insomnia may be linked to your cancer treatment if it started when your treatment began. But there are many reasons why people with cancer can have difficulty sleeping. Looking for causes may help you and your doctor or nurse find ways to help you get regular, good-quality sleep.

Other symptoms

Cancer may cause other symptoms such as breathlessness or fluid retention. These symptoms are common causes of fatigue. If you have an infection or fever, your body needs more energy and this may lead to fatigue. Treating the different symptoms that are causing or contributing to fatigue can often help to relieve it. It is important to let your doctor or nurse know about any symptoms that you have.

Other medical conditions

It is possible that you may have a medical problem unrelated to your cancer. For example, diabetes, a cardiac (heart) problem or an underactive thyroid can cause fatigue or make your fatigue worse.

Psychological effects of cancer

Anxiety, depression, stress and tension can all contribute to fatigue. You may find that you have trouble getting to sleep. You may feel anxious or depressed when you are first diagnosed with cancer. These feelings generally become easier to manage as you adjust to your illness.

You may find it useful to share how you feel with your partner, family or a close friend. If your mood continues to be low most of the time, you may need help to overcome depression. You can discuss this with your doctor. He or she can refer you to a counsellor or prescribe medication if you think that would be helpful.

The Irish Cancer Society has a booklet, *Understanding the Emotional Effects of Cancer*, which can help you recognise if you are depressed. It also suggests ways of overcoming and dealing with depression. For a free copy, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre or download one from www.cancer.ie

Effects of fatigue

Fatigue can affect you in different ways. Some people find that their fatigue is very mild and does not interfere much with their daily life. But for others it is very disruptive. It is very important not to compare yourself to other people with cancer. Cancer and its treatment affects people in very different ways.

Fatigue can often affect the way you think and feel. You may find it impossible to concentrate on anything. This may affect your work but it can also happen with things that you usually enjoy doing. Even reading or watching TV can be difficult.

Fatigue can affect your relationships with family and friends too. It can make you impatient with them and other people around you. You might have no energy for socialising. The different levels of fatigue are described in the fatigue diary at the centre of this booklet.

Common effects of fatigue

Some of the more common effects are described below:

- You cannot complete the smallest chore. Brushing your hair, showering or cooking can seem impossible.
- You feel as if you have no energy and could spend whole days in bed.
- You have trouble thinking, speaking or making decisions. You may find it difficult to remember things.

- You might feel breathless after only light activity. You may feel dizzy or lightheaded.
- You have trouble getting to sleep (insomnia).
- You lose your sex drive.
- You may feel sad and upset.

How to talk about fatigue

You might find it helpful to write down the questions you want to ask your doctor or nurse about fatigue. Ask them to repeat and explain anything that you do not understand. Write down the answers if you like. Your doctor or nurse can only help if you tell them about your symptoms. It can be hard for anyone to understand how much fatigue can affect your life unless they have experienced it themselves. You may need to emphasise to your doctors and nurses the difficulties that it is causing you.

>>> Do tell your doctor or nurse how you are feeling.

Discuss everyday actions that you find difficult, such as climbing stairs, cooking, showering. If you have kept a fatigue diary you can bring it along to share with the medical team looking after you.

At times you may find it hard to discuss your emotions, especially when you are ill. You might worry that you will upset yourself and others. Do tell your doctor or nurse how you are feeling. It might help if you bring someone to the appointment with you. You may find it hard to remember what the doctor or nurse has said and your relative or friend can help to fill in the gaps. There is also a list of the most commonly asked questions at the back of this booklet.

Ways of treating fatigue

Coping with fatigue

Planning

Planning ahead is important. Ask your doctor before you start treatment what side-effects you can expect. Do the things that are most important to you when you feel least tired. Use the fatigue diary to write down the times when you feel at your best and when you feel most tired. This will help you to plan your activities depending on your energy levels.

Energy levels: Keep a note of your energy levels during the day. Do this by taking time to check yourself and listen to your body. This will help you to identify the days on which you are best able to work. You may have to accept the fact that you won't be able to do everything you used to do. It may be helpful early on to decide which activities you are prepared to give up. Remember not to use up all of your energy on doing tasks. Try to find time each day to do something you enjoy.

Rest and sleep: Pace yourself and plan enough rest and sleep periods. It makes sense to plan a period of rest after a period of activity. You may find that you need to rest after meals too. Short naps and rest periods are useful as long as they don't stop you from sleeping at night.

Treatment: It is also important to plan your days around your treatment. Try to avoid anything energetic or stressful for 24 hours before and after your treatments or if you have low blood counts.

In the home

Plan your day so that you have time to rest and do the things you want to do most. The fatigue diary at the centre of this booklet will help you to see how treatment affects your energy levels. It will allow you to plan activities for times when you have more energy. Doing things for yourself is very important but try not to feel guilty if you have to ask for help from other people. Think about some of the following suggestions.

Managing day-to-day

Ask your family, friends and neighbours to help you around the house, with travelling to hospital, with your children or with the shopping. Talk to your medical social worker also and find out what support services are available. Use the extra free time to rest or do something you especially enjoy.

>>> Hints & Tips – everyday tasks

- Spread tasks out over the week.
- Do a little bit each day rather than a lot in one go.
- Ask others to do heavy work where possible.
- Employ a cleaner. If you cannot afford one, talk to your medical social worker or public health nurse. You may be entitled to a home help.
- Use a wheeled shopping bag to carry supplies and groceries.
- Sit down to do whatever chores you can.
- Use long-handled dusters/mops/dustpans where possible.



Shopping

Ask others to do the shopping for you. If possible, do your shopping on the internet and have it delivered. If you cannot, or would rather do the shopping yourself, these suggestions may help:

>>> Hints & Tips – shopping

- Make a list before you start.
- Write the shopping list following the layout of the store.
- Ask someone to go shopping with you. Get a lift to and from the shops.
- Use the shopping trolley for support. Avoid lifting heavy weights.
- Stock up on household items you use regularly. Do this when you feel less tired or have someone to help you with the extra shopping.
- Ask for help in the supermarket with packing your bags and carrying groceries to the car, or ask for home delivery.
- Shop at less busy times.



Laundry

If you live with other people ask them to do their own washing and ironing. If this is not possible, do a small amount of washing and ironing each day.

>>> Hints & Tips – laundry

- Use a trolley where possible to transport your washing to and from the washing machine.
- Get help to hang out the washing.
- Use a lightweight iron.
- Iron essential items only.
- Sit down to iron.
- Slide the iron onto a heatproof pad to avoid lifting.

Meal preparation

Try cooking simpler meals. There is a large range of ready-made meals available in most supermarkets. Stock up on these and use them when you are especially tired. Ask members of your family to have their main meal during the day, if possible, when they are at work or at school.

>>> Hints & Tips – cooking & food preparation

- Prepare meals when you're feeling less tired.
- Make up double portions so that you can freeze half for later.
- Sit down while preparing meals. Avoid bending and stretching when preparing meals.
- Don't lift heavy pans or dishes out of the stove or oven. Ask others to move heavy items to the table.
- Line grill pans with foil to cut down on cleaning. Use oven dishes you can serve from, to save washing up. Let dishes soak rather than scrubbing them and leave dishes to dry. Use a dishwasher if you have one and ask others to load and unload it.
- Use placemats instead of tablecloths. They are easier to clean.
- Ask someone to take out your rubbish bags.



Childcare

One of the worst aspects of fatigue is feeling that you are letting your family down. This can be even more upsetting when you have young children. There are many things that may help.

- First of all, explain to your children that you are feeling tired and cannot do as much with them as before. You may be surprised at how well they respond.
- Plan activities with your children that can be done sitting down. Reading a book, drawing or colouring, doing a puzzle, or simply watching a favourite television programme together is an ideal way to spend time with your children.
- Go to places where you can sit down while your children enjoy themselves.
- Do not lift smaller children. Use a pram or buggy if you have to transport them.
- Ask your children to help you with light jobs around the house.
- Accept offers from others to take your children to and from school or help with childcare. Get babysitters in from time to time so you can do some of the things you enjoy doing.

In the workplace

During or after cancer treatment you may need to reduce your hours or stop working altogether. It can help to talk to your employer, human resource manager or occupational health department. Let them know that you may need some time off due to the cancer or its treatment. Don't feel that you have to work if you are too tired.

Some people find that their tiredness is mild and does not interfere much with their work. Others find that it has a greater impact. For example, you may find it hard to concentrate or make decisions. This can affect the quality of your work. Fatigue can also change the way you think and feel, and this can affect your relationships with your colleagues.

If you do want to carry on working, you may be able to find ways of making your work less tiring.



Hints & Tips – managing fatigue in the workplace



- Talk to your employer about how you can plan and prioritise your work for when you feel less tired.
- Identify aspects of your work that may be too draining and ask your employer if these can be put on hold or given to another colleague. If necessary, ask about a short-term change of duties.
- Where possible, extend deadlines and ask colleagues to help you with some of your work.
- Keep a diary of your energy levels throughout the day. You may notice that there are times when you are more productive without too much effort.
- Discuss the possibility of flexible working hours, reduced working hours or working from home.
- Let colleagues know how you will manage your work, how to contact you and when you will check in with them.
- Plan short breaks every now and then to rest.
- Talk to your occupational health adviser if you have one. They have a duty to support you doing your job and help you with any health problems that may affect your work.

If you cannot continue working or are self-employed, it may be useful to talk to the Department of Social Protection. You may be entitled to claim certain benefits. See page 32 for more information.

Eating and drinking

If you have problems eating you may begin to lose weight. This may be due to the cancer or your treatment. Sometimes when you are weak or tired you can also lose interest in your food. It is best to try and eat as well as you can. Here are some suggestions that might help.



Hints & Tips – eating and drinking

- Keep a diary of what and when you eat every day. If you have taste changes, try new foods, or eat the foods that taste best.
- Ask for help in preparing your meals.
- Try eating little and often. Eat small meals and snacks throughout the day.
- Eat when you feel hungry.
- Drink lots of clear fluids such as water and fruit juice.
- If you do not feel like eating, try replacing some meals with high-calorie drinks.
- Ask to see a dietitian if you are losing weight. He or she will keep an eye on your weight and give you advice on the best foods to eat.



There is a useful booklet called *Diet and Cancer* available from the Irish Cancer Society. For a free copy, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or download one from www.cancer.ie

Taking exercise

Try to remain active and exercise a little both during and after cancer treatment, even if you do not feel like it. Remember to get a good balance between being active and taking time to rest. This allows your muscles time to recover after activity. If exercise is impossible, try to remain active in your daily routine.

The benefits of exercise

Research has shown that there are many benefits to exercise:

- It helps to reduce the symptoms of fatigue, the side-effects of cancer treatments, and improves your overall quality of life.
- It keeps and improves your physical abilities and prevents your muscles wasting due to inactivity.
- Regular exercise builds up your physical fitness level, improves your energy, strength, balance, stamina and co-ordination.
- Regular exercise along with a healthy diet can help reduce the risk of breast cancer and bowel cancer coming back. It can also help you keep a healthy weight and heart.
- Light exercise encourages your body to release endorphins. These are often called ‘feel good hormones’. When released, they can lift your mood and sense of well-being.

Remember a little exercise is better than none. So even a short walk is a good place to start. It is never too late to look for advice.

Who can advise me?

Your doctor, specialist nurse or physiotherapist can all give you advice. You might also be referred to a physical activity programme.

Doctor or specialist nurse: Do ask your doctor or nurse for advice before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you, while considering any other medical conditions you might have. The amount you do will depend on your type of cancer, your treatments, and your general fitness level. Be careful not to overdo it at the beginning, but build on it gradually.

Physiotherapist: The physiotherapist at the hospital can advise you about which exercises would suit you best. They can offer advice on how to get started with exercising and ways to improve your balance. Advice on exercises to strengthen your hands, arms or legs can also be given. The physiotherapist can offer tips on how to manage fatigue and teach you other exercises to meet your needs.

Physical activity programmes: You might be able to take part in a supervised group exercise programme. Or you can be referred there by a health professional. Experienced fitness trainers run these groups over a number of weeks. The programmes can be a good source of peer support as well as being sociable. They can also motivate you to get and remain active safely. In fact, you might find it easier to keep exercising if you do it with other people. Before you start, your trainer will explain the benefits and risks of increasing your physical activity. After that, you may be asked to give your written consent. The fitness trainer will match the types of exercises to your individual needs, bearing in mind your current fitness level. They will then support you throughout the programme.

Your nearest cancer support centre may run a physical activity programme or have information about one in your area. Call our Cancer Nurseline on 1800 200 700 to find your nearest cancer support centre or see our online directory at www.cancer.ie

How to get started

Start gradually if you have not been taking regular exercise before your cancer diagnosis. Regular exercise usually means 30 minutes of moderate activity at least 3–5 times a week. At this level, your heart rate will increase but you can still talk. You can build up to this gradually and also break up the 30 minutes into three 10-minute sessions.

A simple and free activity like walking is excellent. You could also increase it a little further every day or every week. Set yourself some achievable goals, while pacing yourself and listening to how your body feels. Your muscles will tell you when you need to ease back or rest.

Even doing an activity like tai chi or yoga for a few minutes every day can help. Recording your achievements in a diary every day can also help you to check your progress. Overall, make sure the exercises are safe, work well and are enjoyable.






Simple ways to keep active:

- Go for a walk or a cycle.
- Do some gardening.
- Park your car in the farthest parking space at work and walk to the building.
- Take the stairs instead of the lift.
- Get off the bus a few stops before your destination and walk the rest of the way.

Tips on using this pull-out diary

You may notice that you feel more fatigued on certain days of your treatment cycle than others. Plan your activities for the days of your cycle that you feel best.

Describe your fatigue this way

- | | | |
|----------|---|---|
| 1 |  | = Can do most normal activities |
| 2 |  | = Can do less than normal activities |
| 3 |  | = Can do some normal activities |
| 4 |  | = Can hardly do any activities |
| 5 |  | = Can not do any activities |

On the diary pages, fill in the dates for each week of treatment. Circle how fatigued you feel every day so you can describe how you felt to your doctor.

There is also space each week for you and your doctor to record the treatment you have received and your blood counts.

PULL-OUT WEEKLY DIARY




































PULL-OUT WEEKLY DIARY




































Week commencing _____

Week commencing _____

Circle how you are feeling today

Circle how you are feeling today

MONDAY	1 	2 	3 	4 	5 
TUESDAY	1 	2 	3 	4 	5 
WEDNESDAY	1 	2 	3 	4 	5 
THURSDAY	1 	2 	3 	4 	5 
FRIDAY	1 	2 	3 	4 	5 
SATURDAY	1 	2 	3 	4 	5 
SUNDAY	1 	2 	3 	4 	5 

MONDAY	1 	2 	3 	4 	5 
TUESDAY	1 	2 	3 	4 	5 
WEDNESDAY	1 	2 	3 	4 	5 
THURSDAY	1 	2 	3 	4 	5 
FRIDAY	1 	2 	3 	4 	5 
SATURDAY	1 	2 	3 	4 	5 
SUNDAY	1 	2 	3 	4 	5 

Make a note of how your fatigue affects your ability to do daily activities

Make a note of how your fatigue affects your ability to do daily activities

Treatment received

Treatment received

Blood counts

Blood counts




































HAEMOGLOBIN g/dl	WHITE BLOOD CELLS	PLATELETS	BLOOD TRANSFUSION

HAEMOGLOBIN g/dl	WHITE BLOOD CELLS	PLATELETS	BLOOD TRANSFUSION

PULL-OUT WEEKLY DIARY

Week commencing _____

Circle how you are feeling today

MONDAY	1 	2 	3 	4 	5 
TUESDAY	1 	2 	3 	4 	5 
WEDNESDAY	1 	2 	3 	4 	5 
THURSDAY	1 	2 	3 	4 	5 
FRIDAY	1 	2 	3 	4 	5 
SATURDAY	1 	2 	3 	4 	5 
SUNDAY	1 	2 	3 	4 	5 

Make a note of how your fatigue affects your ability to do daily activities

Treatment received




































Blood counts

HAEMOGLOBIN g/dl	WHITE BLOOD CELLS	PLATELETS	BLOOD TRANSFUSION

PULL-OUT WEEKLY DIARY

Week commencing _____

Circle how you are feeling today

MONDAY	1 	2 	3 	4 	5 
TUESDAY	1 	2 	3 	4 	5 
WEDNESDAY	1 	2 	3 	4 	5 
THURSDAY	1 	2 	3 	4 	5 
FRIDAY	1 	2 	3 	4 	5 
SATURDAY	1 	2 	3 	4 	5 
SUNDAY	1 	2 	3 	4 	5 

Make a note of how your fatigue affects your ability to do daily activities

Treatment received




































Blood counts

HAEMOGLOBIN g/dl	WHITE BLOOD CELLS	PLATELETS	BLOOD TRANSFUSION

PULL-OUT WEEKLY DIARY

Week commencing _____

Circle how you are feeling today

MONDAY	1 	2 	3 	4 	5 
TUESDAY	1 	2 	3 	4 	5 
WEDNESDAY	1 	2 	3 	4 	5 
THURSDAY	1 	2 	3 	4 	5 
FRIDAY	1 	2 	3 	4 	5 
SATURDAY	1 	2 	3 	4 	5 
SUNDAY	1 	2 	3 	4 	5 

Make a note of how your fatigue affects your ability to do daily activities

Treatment received




































Blood counts

HAEMOGLOBIN g/dl	WHITE BLOOD CELLS	PLATELETS	BLOOD TRANSFUSION

PULL-OUT WEEKLY DIARY

Week commencing _____

Circle how you are feeling today

MONDAY	1 	2 	3 	4 	5 
TUESDAY	1 	2 	3 	4 	5 
WEDNESDAY	1 	2 	3 	4 	5 
THURSDAY	1 	2 	3 	4 	5 
FRIDAY	1 	2 	3 	4 	5 
SATURDAY	1 	2 	3 	4 	5 
SUNDAY	1 	2 	3 	4 	5 

Make a note of how your fatigue affects your ability to do daily activities

Treatment received

Blood counts

HAEMOGLOBIN g/dl	WHITE BLOOD CELLS	PLATELETS	BLOOD TRANSFUSION

PULL-OUT WEEKLY DIARY

Week commencing _____

Circle how you are feeling today

MONDAY	1	2	3	4	5
TUESDAY	1	2	3	4	5
WEDNESDAY	1	2	3	4	5
THURSDAY	1	2	3	4	5
FRIDAY	1	2	3	4	5
SATURDAY	1	2	3	4	5
SUNDAY	1	2	3	4	5

Make a note of how your fatigue affects your ability to do daily activities

Treatment received

Blood counts

HAEMOGLOBIN g/dl	WHITE BLOOD CELLS	PLATELETS	BLOOD TRANSFUSION



Hints & Tips – exercise safely



- Exercise on a flat surface and avoid exercises that might increase your risk of falling or injuring yourself.
- Make sure you drink enough water during and after exercise to prevent dehydration.
- Wear well-fitting supportive shoes like laced flat shoes or trainers.
- If you're having chemotherapy, it is best to avoid the swimming pool. Consider using the gym during the off-peak times when quieter.
- If you're having radiotherapy and have a skin reaction, avoid the swimming pool until after your skin has healed. The chemicals in the water may cause an irritation.
- If you're anaemic or have low platelets, ask your doctor for advice before starting. (Anaemia is a low number of red blood cells and platelets are cells that help your blood to clot.)
- If you get chest pain, dizziness, nausea, difficulty breathing or a racing heart, stop the exercise and tell your doctor.
- Don't exercise if you feel unwell, are breathless, in pain, or have any symptom that worries you. Discuss it with your doctor.
- If you have lymphoedema, continue to wear compression garments during exercises.
- Avoid high-impact exercises or contact activities if you have bone secondaries or osteoporosis.

Email cancernurseline@irishcancer.ie

Sleeping well

It is vital to keep a normal sleeping routine when you are unwell. Sometimes your fatigue may make you feel like sleeping all the time. Sleeping well is very important and may help to reduce fatigue. It may also reduce your need to sleep during the day. There are many ways to overcome fatigue. Your nurse or doctor will be happy to discuss these with you. In the meantime it may help if you:

Relax before going to bed. Give yourself at least half an hour to relax before going to bed. During this time avoid being overstimulated. Set aside any work and slow down the pace. Read a book, listen to relaxing music or watch some light television. Go to bed when you feel sleepy.

Sleep just long enough. Limiting time in bed seems to produce better quality sleep. Sleep as long as you need to feel refreshed and healthy during the following day.

Wake up at the same time every day. A regular wake-up time in the morning may strengthen your sleep routine. It may eventually lead to a regular time of getting to sleep.

Exercise regularly if you can. A steady daily amount of exercise may help to deepen sleep over the long term. This is best done during the day rather than in the hours close to bedtime.

Eliminate noise. Occasional loud noises, such as aircraft flying overhead, disturb sleep. If your bedroom is noisy, you could mask some of the noise using a small electric fan, or you could use earplugs.

Keep a steady temperature in your bedroom. Temperature extremes can disturb sleep. The room temperature should be comfortably warm.

Keep your bedroom for sleep. It may help to remove the television set from your bedroom. This helps to create a calm relaxing space and keeps noise and stimulation to a low level. Turn off your mobile phone and other electronic devices, and avoid working or eating in bed.

»»» Sleeping well is very important and may help to reduce fatigue.

Be comfortable. Make sure your bedding and nightwear are comfortable. It often helps to use 100 per cent cotton fabric for both bedding and nightwear, especially if you are having hot flushes or night sweats.

Have a bedtime snack. Hunger can often disturb sleep. A light bedtime snack, warm milk or a hot drink might help you to sleep better. But try to avoid eating a heavy meal or spicy food in the hours close to bedtime.

Avoid stimulants. Many poor sleepers are very sensitive to stimulants. It is best to avoid cola drinks, coffee, strong tea and chocolate during the evening.

Know how naps affect you. Some people find that daytime naps help them sleep better at night, while others sleep less well after them. Find out what suits you best. If you do nap, set your alarm clock. Ideally you should not sleep for longer than half an hour. If possible, take your nap in the earlier part of the day.

Limit your intake of alcohol. If you are feeling tense, alcohol can help you to fall asleep more quickly, but the sleep tends to be broken. So avoid large amounts of alcohol near bedtime.

Keep a notebook and pen beside your bed. If you wake at night worrying or your thoughts are racing, write down your thoughts in a notebook and give yourself permission to let them go until the morning. Then if you wish, you can work through them the next day with the support and advice of others.

Know when to say enough. Rather than lying in bed tossing and turning you could also get up and watch television or read a book. Wait until you feel tired again and then go back to bed. Audiobooks with stories may help you to sleep. These are available online and in most public libraries or bookshops. Mental exercises can also help you to sleep. These usually take about 10 minutes and include:

- Trying to remember the lines of a poem or Christmas carol

- Making alphabetical lists of girls' or boys' names, countries, trees or flowers
- Recalling a favourite experience in every detail
- Writing mental letters
- Relaxation exercises

Your body will still benefit from lying quietly in bed, resting, even if you are not actually asleep. It can help to turn the clock face away from you or put it in a drawer. 'Clock watching' can often make things worse. Although you might feel as if you have been awake all night, you may well have managed to have several hours of good-quality sleep.

Relaxation

It is very important that you make time for activities that relax you. Stress uses up energy and might make you tired. It is natural to feel more stressed than usual when you start your cancer treatment. The following suggestions may help you to relax:

- Talk to others about anything that is worrying you. You may find it difficult to talk to your family and friends. Ask your doctor to refer you to a counsellor if you think it would be helpful.
- Try to take your mind off your worries by reading, seeing friends and listening to music.
- Do some light exercise such as walking.
- If you can, try to avoid situations that make you anxious.

Many people find it difficult to unwind, especially if the stresses and strains of the day are difficult to forget. But specific relaxation techniques can help to relieve tension.

Types of relaxation exercises

There are two types of relaxation exercise:

- Physical exercises that help to relieve tension in your body
- Mental exercises that help to relax your mind

You will get the most benefit from these techniques if you practise them for 5 to 15 minutes each day. Just experiment until you find the best one for you.

It is not possible to describe each technique in detail in this booklet, but the following list will give you an idea of what's involved.

- Body awareness – concentrating on different parts of your body
- Progressive muscle relaxation – tensing and relaxing each part of your body in turn (see page 26)
- Breathing exercises
- Imagery exercises
- Relaxation CDs or online downloads: music or natural sounds such as birdsong and rippling streams

You may need help in finding a relaxation method that suits you. Ask if there is a nurse or other health therapist available to help you. They might also be able to put you in touch with people or organisations that are specially trained in teaching relaxation techniques.

Using guided relaxation CDs or MP3 files can be a good way to learn different exercises. The exercises often need to be guided for the first eight to ten times so that you can learn the skill of relaxing and letting go. There are many resources available on the internet that are free to download.

Local cancer support services also provide support for people with cancer, their families and friends through complementary therapies, counselling and information. Call our Cancer Nurseline on 1800 200 700 to find your nearest cancer support centre or see our online directory at www.cancer.ie





Relaxation technique – progressive muscle relaxation



Before you begin this technique, create a peaceful space. Find a quiet comfortable room, turn off your phone and make sure that you will not be disturbed for 10 or 15 minutes. Turn on some relaxing music, light a candle and burn your favourite scented oil if you wish. You might also want to dim the lights.

When you are ready:

- Sit or lie on a comfortable well-supported chair, couch or bed.
- Close your eyes if you wish.
- Take deep breaths – in through your nose and out through your mouth.
- Place your hands over your tummy.
- When you breathe in, your tummy should rise, pushing your hands up. This is called abdominal breathing.
- Practise breathing like this a few times.
- Starting with the muscles in your feet and working upwards, tense (squeeze) each muscle group for 10 seconds. Then let it go so that it feels relaxed and heavy.
- Work your way up through your body including your back, shoulders, neck and forehead. Finish with your arms and hands.
- If a part of your body is injured, leave it out.
- When your whole body feels relaxed, continue to focus on your breathing.
- Lie for a few minutes in relaxation and stillness.
- When you are ready to finish, slowly open your eyes, wriggle your toes and stretch a little.
- Allow yourself to become aware of your surroundings again.

Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

Alternative therapies: Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

If you decide to have complementary or alternative treatments...



Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. Others can interfere with standard treatment or cause serious side-effects.

More information

To find out more about the different complementary and alternative therapies read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website www.cancer.ie

Looking after someone who has fatigue

Looking after someone who has fatigue may not be easy. You may feel tired with all the worry and the extra work. It can be very straining as you adapt to a new way of life. Do find out as much as you can about the illness and its treatment. It can also help to plan as much as you can ahead of the discharge date. Ask to speak to a medical social worker about the community services that are available. Also ask for a contact name and telephone number at the hospital so that you can talk to someone if you have a problem.

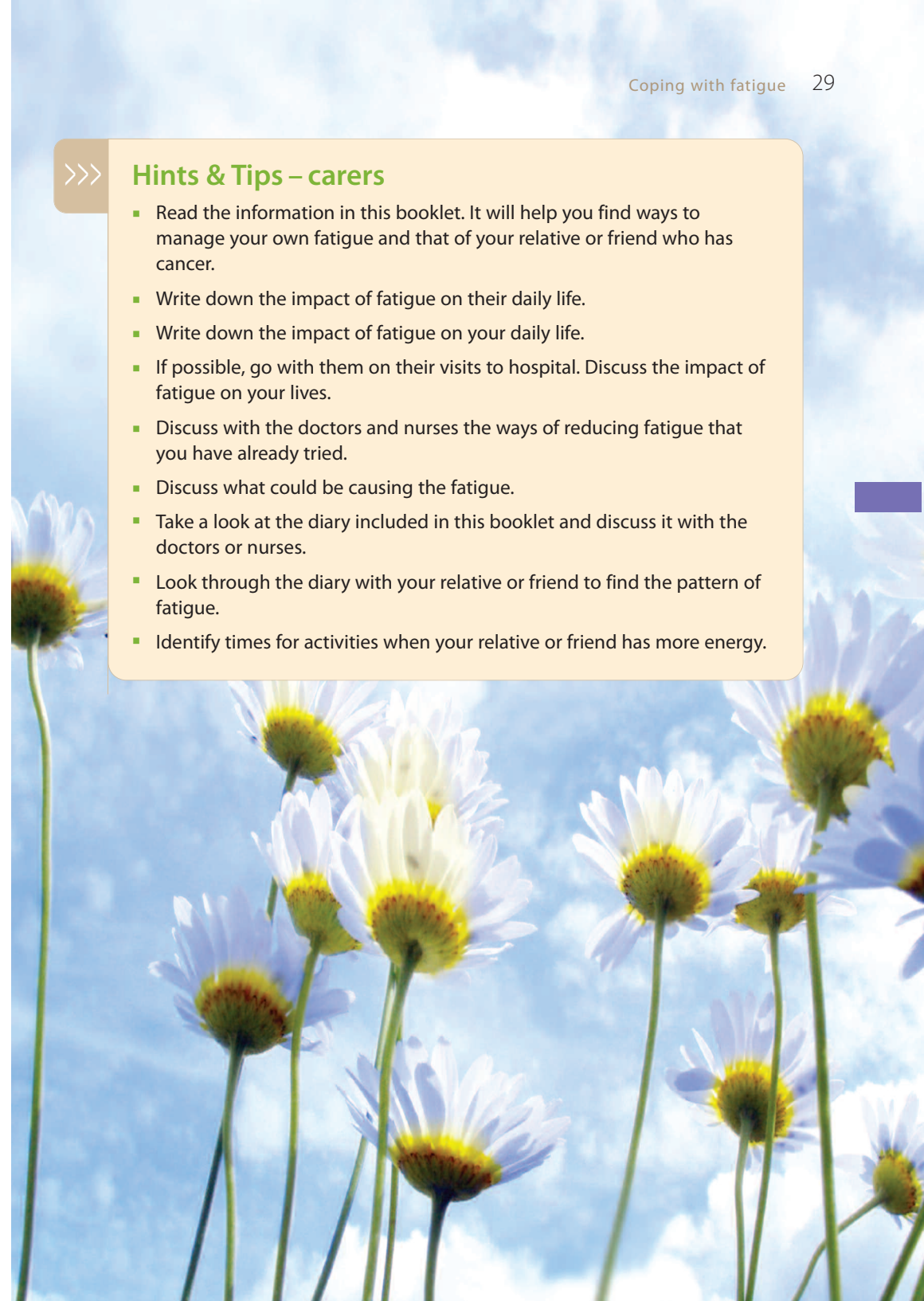
Looking after yourself

Caring for someone can be tiring. But it is important that you look after yourself so you can continue to support your relative or friend. Set aside some time for yourself each week and do something you really enjoy. This can be hard when you have a lot to do and do not want to let your relative or friend down. It might help to involve other people and organisations with the caring so that you both do not become too tired. If you are worried or upset, it might help to call our Cancer Nurseline on 1800 200 700 and speak in confidence with a cancer nurse specialist. You will also find useful information for carers by visiting www.cancer.ie/how-we-can-help



Hints & Tips – carers

- Read the information in this booklet. It will help you find ways to manage your own fatigue and that of your relative or friend who has cancer.
- Write down the impact of fatigue on their daily life.
- Write down the impact of fatigue on your daily life.
- If possible, go with them on their visits to hospital. Discuss the impact of fatigue on your lives.
- Discuss with the doctors and nurses the ways of reducing fatigue that you have already tried.
- Discuss what could be causing the fatigue.
- Take a look at the diary included in this booklet and discuss it with the doctors or nurses.
- Look through the diary with your relative or friend to find the pattern of fatigue.
- Identify times for activities when your relative or friend has more energy.



Support resources

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Medicines
- Visits to hospital
- Appliances, like wigs
- Overnight stays in hospital

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Partial Capacity Benefit, Carer's Allowance, Carer's Benefit and Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 34 for more details of our Volunteer Driving Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for



- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

For a free copy of the booklet, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The booklet is also available on our website: www.cancer.ie

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 35 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
 - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
 - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional.

- **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.
- **Our 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 a free copy 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.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's Strides for Life walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: www.cancer.ie.

You may find the following helpful:

Who Can Ever Understand: Talking About Your Cancer

Understanding the Emotional Effects of Cancer

Understanding Cancer and Complementary Therapies

Lost for Words: How to Talk to Someone with Cancer

Talking to Children about Cancer: A Guide for Parents

A Time to Care: Caring for Someone Seriously Ill at Home

Managing the Financial Impact of Cancer. A Guide for Patients and their Families.



Questions to ask your doctor

Here is a list of questions you may wish to ask. Never be shy about asking questions. It is always better to ask than to worry.

- Will the cancer treatment that I am getting cause fatigue?

- Are there ways to control my fatigue or make it better?

- How can I cope with my fatigue?

- What are the things I can do to help with my fatigue?

- How can I best support my relative or friend who has fatigue?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer



Notes



Join the Irish Cancer Society team



If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments and suggestions.
Please email reviewers@irishcancer.ie

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

Cancer Nurseline Freephone 1800 200 700

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Email: cancernurseline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

