

Coping with Fatigue

Caring for people with cancer

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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.

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.



Specialist nurse	Tel:
Family doctor (GP)	Tel:
Medical oncologist	Tel:
Radiation oncologist	Tel:
Surgeon	Tel:
Medical social worker	Tel:
Emergency	Tel:
Treatments	Review dates

If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services in 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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First published by the Irish Cancer Society in 2002.

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

Next revision: 2015

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ISBN 0-95323-690-1

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Introduction

This booklet has been written to help you find ways to cope with fatigue. This is sometimes caused by cancer and its treatment. It can affect children as well as teenagers and adults. The word fatigue is used to describe feelings of tiredness that may be present all or most of the time. The tiredness is not relieved by rest and may stop you from doing the things you normally do. It 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.

At the end of this booklet there is a list of books and CDs you might find useful. There is also a list of websites and special groups to help and support you at this time.



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 a section and 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 on 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm. Or if you wish, you can visit a Daffodil Centre if one is located in your hospital. See page 40 for more about Daffodil Centres.



Causes and effects of fatigue

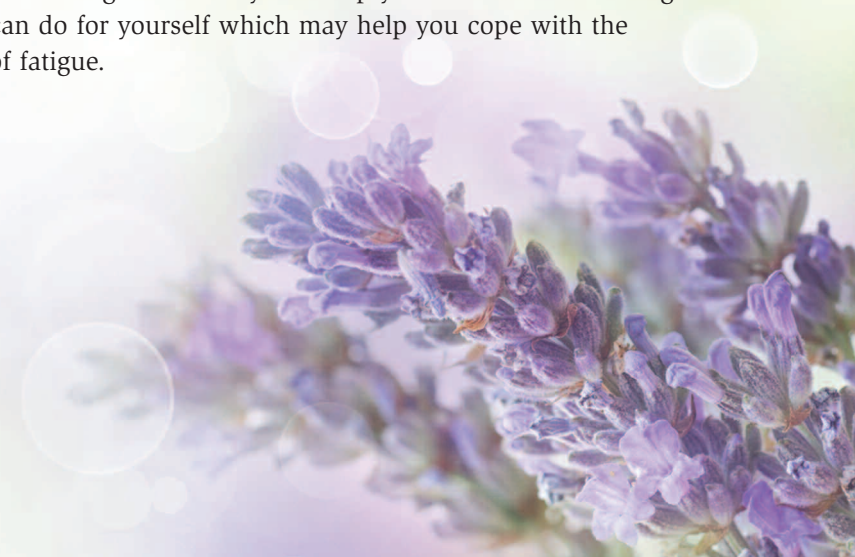
Fatigue

Fatigue is very common during cancer and its treatment. In fact, 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 at least 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 has shown that people with cancer find that it is the symptom, or side-effect, which is most disruptive to their daily life. Do let your doctor or nurse know how you are feeling so that they can help you. 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, if surgery to your stomach leads to problems with absorbing food.
- **Chemotherapy and radiotherapy:** You may feel very tired during and after chemotherapy and radiotherapy. It may be due to the treatment itself or travelling to and from the hospital. Your energy levels should start to improve 6 months to a year after the 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. He or she 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 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

Radiotherapy for cancer can reduce the number of red blood cells made by your bone marrow for a time. This only happens if the treatment is being given to an area of your body which includes the bone marrow. Such areas include the breast bone (sternum), the hip bones, or the long bones of your arms and legs.

Chemotherapy can also reduce the number of red blood cells made. This may lead to anaemia. Your doctor will keep a check on 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. He or she 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. 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.

Erythropoietin 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.

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 the National Cancer Helpline 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 you can call the National Cancer Helpline on 1800 200 700 for a copy of our factsheet on pain and cancer.

>>> 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 the drugs used 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 identify ways that will help you to maintain your energy.

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 the National Cancer Helpline 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. 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 even avoid socialising because it is too much effort.

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, bathing. 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 have 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 a fever (high temperature) or 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. 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 are 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 34 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 the National Cancer Helpline on 1800 200 700 or 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. He or she 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. See pages 44–48 for a list of cancer support centres.

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 during the day.
- Cycle your bike.
- Do some gardening.

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



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 are having chemotherapy, it is best to avoid the swimming pool. Consider using the gym during the off-peak times when quieter.
- If you are 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 are anaemic or have low platelets, ask your doctor for advice before starting. (Anaemia is a low number of red blood cells, whereas platelets are cells that help your blood to clot.)
- If you get chest pain, dizziness, nausea, difficulty breathing or a racing heart, do stop the exercise and tell your doctor.
- Do not exercise if you feel unwell, are breathless, in pain, or have any symptom that worries you. Discuss it with your doctor.
- Continue to wear compression garments during exercises if you have lymphoedema.
- Avoid high-impact exercises or contact activities if you have bone secondaries or osteoporosis.

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 wind down 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. Get up if you wake at night worrying or your thoughts are racing. Write down all your thoughts in the 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
- Reliving 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.
- Take 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 is involved.

- Body awareness – concentrating on different parts of your body
- 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. Relaxation CDs can also be bought in most bookshops or music shops.

There is also a list of organisations at the back of this booklet that provide support for people with cancer, their families and friends through complementary therapies, counselling and information.





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.

WEEKLY DIARY

TIPS ON USING THIS 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.

WEEKLY DIARY

For more fatigue diary pages, call the National Cancer Helpline 1800 200 700 or download from our website: www.cancer.ie

WEEKLY DIARY

WEEK COMMENCING

CIRCLE HOW YOU ARE FEELING EACH DAY

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

WEEK COMMENCING

CIRCLE HOW YOU ARE FEELING EACH DAY

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

WEEKLY DIARY

WEEK COMMENCING

CIRCLE HOW YOU ARE FEELING EACH DAY

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

WEEKLY DIARY

WEEK COMMENCING

CIRCLE HOW YOU ARE FEELING EACH DAY

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

WEEKLY DIARY

WEEK COMMENCING

CIRCLE HOW YOU ARE FEELING EACH DAY

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

WEEKLY DIARY

WEEK COMMENCING

CIRCLE HOW YOU ARE FEELING EACH DAY

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

WEEK COMMENCING

CIRCLE HOW YOU ARE FEELING EACH DAY

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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

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Many people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country in which you live. In Ireland, cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

Conventional therapies

Conventional therapies are treatments that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, hormone therapy and biological therapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy

Many people find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. The diet therapy in particular can often be restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition.

Most doctors do not believe that such treatments can cure or control cancer.



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



Before you decide to change your treatment or add any methods of your own, do talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, do talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. Ensure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Patients with Cancer*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700. Or if you wish, you can visit a Daffodil Centre or download a copy from 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 the National Cancer Helpline 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

Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- Medical social worker
- Cancer nurse specialists
- Psycho-oncology services
- Family doctor (GP)
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society helpline nurses



Medical social worker: The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on practical and financial supports and services available when you go home.

Cancer nurse specialists: Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. The nurses along with other members of your medical team work together to meet your needs.

Psycho-oncology services: In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

Family doctor (GP): You may feel comfortable talking to your family doctor (GP) about your cancer too. He or she can discuss any of your queries and offer advice and support.

Community health services: When you go home, there are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home),

welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

Support groups: Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. There are also cancer support centres in most counties in Ireland and they can offer a wide range of services. Some are listed at the back of this booklet. Useful websites, including patient forums, are also listed. You can also download the Irish Cancer Society's *Directory of Cancer Support Services* from www.cancer.ie

Irish Cancer Society: The staff of the Cancer Information Service will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about your financial matters. For example, getting life insurance. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for information about any of the services outlined above or for support services in your area.

>>> Remember that there are many people ready to help you.

Health cover

Health cover falls into two groups – cover for medical card holders and cover for all other groups. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances

At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You may have to pay a prescription charge of €1.50 per item up to a limit of €19.50 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €600 or less, you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office.

If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card. But it will depend on your financial circumstances and how long your treatment is expected to last. In this case, your spouse and children will not be covered if your means are over the limit. If you wish to apply for a medical card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical

appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at your hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care or inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

If you have private insurance, your tests might not get done as quickly as you would like. Your health insurer has to approve some tests in advance. For example, MRI and PET scans. Sometimes it might take 24–48 hours to get approval from your health insurer.

Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Carer's Leave
- Appliances
- Travel to hospital



For a free copy of *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download a copy at www.cancer.ie

Application forms for the benefits below are available from social welfare offices or Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Department of Social Protection, PO Box 1650, Dublin 1. Tel: (01) 704 3300 or Locall 1890 928 400. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 65. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. This means if you

have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months because of a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your medical social worker or the Department of Social Protection.

Carer's Benefit

If you are employed but wish to care for a sick relative full time, you might qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged between 16 and 66 years, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home.

Carer's Leave

By law you may be entitled to unpaid temporary leave from your employer. Carer's leave allows you to leave your employment for up to 104 weeks to care for someone in need of full-time care and attention. The leave will be unpaid, but you will have your job kept open for you while you are on leave. You do not need to be eligible for carer's

allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection.

Appliances

If you have a medical card most appliances are free of charge or subsidised. For example, if you have hair loss due to chemotherapy, you are entitled to 1-2 free or subsidised new hairpieces every year. The subsidy will depend on the HSE area.

Travel to hospital

You can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres, usually for patients with medical cards.

See page 42 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

For social welfare queries, contact:

Dept of Social Protection – Information Service

Oisín House
212–213 Pearse Street
Dublin 2

Tel: 1850 662 244
Leaflet line: 1890 202 325
Email: info@welfare.ie
Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area.

HSE infoline: 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

Information is also available from your local Citizens Information Centre. A list of these centres is available from:

Citizens Information

Citizen Information Phone Service: 0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie



If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 42 for more details. You can also call the National Cancer Helpline on 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 43 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 49 for more information.

Irish Cancer Society services

The Irish Cancer Society funds a range of support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support groups
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website **www.cancer.ie** provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- **Message Board** is a discussion space on our website to share your stories and experiences with others.
- The **CancerChat** service is a live chatroom with a link to a CIS nurse.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** (@IrishCancerSoc).

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See pages 44–47 for more details.

Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. It can provide you and your relatives with information, advice and emotional support from time of diagnosis and for as long as is needed. All the volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. They are carefully selected after recovery and are trained to provide information and reassurance on the phone. The service is provided on a one-to-one basis and is confidential. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the National Cancer Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Oncology liaison nurses

The Society funds some oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer information booklets and factsheets

These booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. These booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from www.cancer.ie or picked up at a Daffodil Centre.



Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society may be able to provide limited financial help to patients in great need. You may be suitable for schemes such as Travel2Care or Financial Aid.

Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

Travel2Care: If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their chemotherapy using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700. You can also visit the website www.cancer.ie or a Daffodil Centre.

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

The Carers Association

Market Square
Tullamore
Co Offaly
Tel: 057 932 2920
Freefone: 1800 240 724
Email: info@carersireland.com

Citizens Information

Citizen Information Phone Service:
0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Samaritans

[Confidential support service if feeling distressed or suicidal. Offices nationwide]
112 Marlborough Street
Dublin 1
Tel: 01 872 7700
Freefone: 1850 60 90 90 90
Email: jo@samaritans.org
Website: www.samaritans.org

Health insurers

AVIVA Health

(formerly VIVAS Health)
PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare (formerly Quinn)

Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
Local: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups

ARC Cancer Support Centres
Dublin and Cork (see pages 45 and 46).

Brain Tumour Support Ireland
Medical Social Work Department
St Luke's Hospital
Highfield Road
Rathgar
Dublin 6
Tel: 01 406 5163

CanTeen Ireland
Young Peoples' Cancer Support Group
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Freefone: 1800 200 700
Email: info@canteen.ie
Website: www.canteen.net

Lakelands Area Retreat & Cancer Centre
Multyfarnham
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Thyroid Cancer Support Ireland
Cooksgrove
Killynan Cooke
Cloghan
Mullingar
Co Westmeath
Tel: 087 909 0836
Email: info@thyroidcancersupport.ie
Website: www.thyroidcancersupport.ie

Connaught support groups & centres

Athenry Cancer Care
Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080

Ballinasloe Cancer Support Centre
Society Street
Ballinasloe
Co Galway
Tel: 090 964 5574 / 087 945 2300
Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre
2 Church Street
Belmullet
Co Mayo
Tel: 097 20590
Email: caraiorrais@gmail.com

East Galway Cancer Support Centre
The Family Centre
John Dunne Avenue
Ballinasloe
Co Galway
Tel: 087 984 5574 / 087 945 2300
Website: www.eastgalwaycancersupport.com

Gort Cancer Support Group
The Hawthorn
Ennis Road
Gort
Co Galway
Tel: 086 312 4220
Email: gcsupport@eircom.net
Website: www.gortcs.ie

Mayo Cancer Support Association
Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Group
Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: vitahouse@eircom.net

Sligo Cancer Support Centre
44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website: www.sligocancersupportcentre.ie

Tuam Cancer Care Centre
Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Leinster support groups & centres

ARC Cancer Support Centre
ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre
ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Arklow Cancer Support Group
25 Kingshill
Arklow
Co Wicklow
Tel: 085 110 0066
Email: arklowcancersupport@gmail.com

Balbriggan Cancer Support Group
Unit 23, Balbriggan Business Park
Balbriggan
Co Dublin
Tel: 087 353 2872

The Bella Rose Foundation
[Women with cancer]
Merry Maid House
West Park Campus
Garter Lane
Citywest
Dublin 24
Tel: 086 879 3242
Email: thebellarosefoundation@gmail.com

Bray Cancer Support & Information Centre
36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@braycancersupport.ie
Website: www.braycancersupport.ie

Cuisle Centre
Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: info@cuislecentre.com
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support
Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Éist Cancer Support Centre Carlow
The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Support Centre
George's Street
Drogheda
Co Louth
Tel: 041 980 5100 / 086 817 2473
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport.com
Website:
www.greystonescancersupport.com

Haven Cancer Support and Therapy Group

Haven House
68 Hazelwood
Gorey
Co Wexford
Tel: 053 942 0707 / 086 250 1452
Email: info@thehavengroup.ie
Website: www.thehavengroup.ie

HOPE Cancer Support Centre

22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

Kilkenny Cancer Support Services

Walkin Street
Kilkenny City
Tel: 085 721 9280
Email: info@kilkennycancersupport.com
Website: www.kilkennycancersupport.com

Lakelands Area Retreat & Cancer Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Newbridge Cancer Support Group

144 Allenvue Heights
Newbridge
Co Kildare
Tel: 083 360 9898
Email:
newbridgecancerhealinghelp@gmail.com

Rathdrum Cancer Support Centre

34 Main Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

Tallaght Cancer Support Group

Millbrook Lawns
Tallaght
Dublin 24
Tel: 087 217 6486
Email: ctallaght@yahoo.ie

Wicklow Cancer Support Centre

1 Morton's Lane
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support groups & centres**Cancer Information & Support Centre**

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: cancersupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

Kerry Cancer Support Group

124 Tralee Town House Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupport@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven

5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.org

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630 / 087 691 2396
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

South Eastern Cancer Foundation

Solas Centre
7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Email: infosecf@eircom.net
Website: www.secf.ie

Suimhneas Cancer Support Centre

2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email:
suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Youghal Cancer Support Group

161 North Main Street
Youghal
Co Cork
Tel: 024 92353 / 087 273 1121

Ulster support groups & centres**Cancer Support and Social Club**

Tiernaleague
Carndonagh
Co Donegal
Tel: 086 602 8993 / 087 763 4596

Coiste Scaoil Saor ó Ailse

Knockastoller
Bunbeg
Letterkenny
Co Donegal
Tel: 087 121 7857
Email: scaoilsaor@hotmail.com

Crocus: Monaghan Cancer Support Centre

The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965

Cuan Cancer Social Support and Wellness Group

Cootehill Credit Union
22-24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

The Forge Cancer Support Group

The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924

Living Beyond Cancer

Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) /
074 910 4477

Support group & centres unaffiliated to Irish Cancer Society

Cancer Care West

Inis Aoihbhinn
University Hospital Galway
Costello Road
Galway
Tel: 091 545 000
Email: info@cancercareswest.ie
Website: www.cancercareswest.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group

Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

Good and New Cancer Drop In Centre

Unit 1, Portlink Business Park
Port Road
Letterkenny
Co Donegal
Tel: 074 911 3437

Killybegs Cancer Support Group

Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Solace: Donegal Cancer Support Centre

St Joseph's Avenue
Donegal Town
Tel: 074 974 0837
Email: solacedonegal@eircom.net

For other support groups or centres in your area, call 1800 200 700.

Useful contacts outside Republic of Ireland

Action Cancer

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society

Website: www.cancer.org

Cancer Focus Northern Ireland

40-44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerhelp.org.uk

Macmillan Cancer Support (UK)

Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
77-81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net

National Cancer Institute (US)

Website: www.nci.nih.gov

Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Cancer and Complementary Therapies*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Diet and Cancer*
- *Understanding the Emotional Effects of Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Managing the Financial Impact of Cancer: A Guide for Patients and their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*



Cancer at Your Fingertips

Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 1859590365

Challenging Cancer: Fighting Back, Taking Control, Finding Options

Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1859590683

Feeling Tired All the Time

Dr Joe Fitzgibbon
Gill and Macmillan, 2002
ISBN 0717132854

Understanding and Managing Persistent Cancer-Related Fatigue

Dr Sonya Collier and Dr Anne-Marie O'Dwyer
St James's Hospital, Dublin, 2011
[DVD also available. Call 1800 200 700 for information]

What You Really Need to Know about Cancer

Dr Robert Buckman
Macmillan, 1997
ISBN 0330336282

101+ Square Meals

[Budget and nutrition]
Norah Bourke et al
MABS/HSE West/Paul Partnership/Limerick VEC/Safefood, 1998
ISBN 187407514X
[For more details, see www.mabs.ie]

Useful CDs

Coping with Sleep Problems (CD)

Talking Life Series
Royal College of Psychiatrists, 2008
ISBN 978-1901910162

Healthy Sleep (CD)

Andrew Weil & Rubin Naiman
Sounds True Inc, 2007
ISBN 978-1591795834

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

Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions:

Eileen O'Donovan, Cancer Information Service Nurse

Prof Peter Daly, Consultant Medical Oncologist

Pauline Kehoe, Oncology Liaison Nurse

Mary Quinn, Clinical Nurse Specialist

Susan Rowan, Patient Education Editor

Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

Would you like to be a patient reviewer?

If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.



If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email **fundraising@irishcancer.ie**

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

