

Fatigue and pancreatic cancer

How to deal with tiredness



Introduction

This booklet is for people with pancreatic cancer who have fatigue (extreme tiredness), and their family and friends.

Fatigue is a very common symptom of cancer and is often called cancer-related fatigue. Many people with pancreatic cancer will have tiredness and fatigue at some point during cancer and treatment.

If you have fatigue, speak to your doctor or other members of your medical team. You can also speak to our specialist nurses on our confidential Support Line. There are ways to manage fatigue. Your medical team can help, and there are also things you can try yourself.

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How to use this booklet

It can be hard to take in lots of information when you have fatigue. You don't have to read this booklet all at once. Look at the contents on page 2, read the sections that feel most helpful, and read other sections later if you need to. There is more information on our website and we provide a lot of support (see page 52).

Use the symbols to help you find more help.



Call our Support Line free on **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**



Read more on our website at:
pancreaticcancer.org.uk/information
Order or download our free booklets at:
pancreaticcancer.org.uk/publications



Questions to ask your doctor or nurse



Things you can do to help yourself

At the end of the booklet there is:

- A list of common medical words on page 49.
- Contact details of the organisations we mention on page 53.

What is fatigue?

Key facts

- Fatigue is extreme tiredness. It isn't the same as just feeling tired. You might feel both mentally drained and physically exhausted.
- Fatigue is common for people with pancreatic cancer.
- It affects people in different ways. It can be constant or it can come on suddenly, for no clear reason.
- It may affect you before, during and after any treatments. It may last for several months after treatment, or sometimes longer.
- It can have an effect on your daily life, making it harder to do things like work and household tasks.
- Fatigue isn't always linked to how much activity you have been doing.
- People often find fatigue hard to cope with as you may not be able to do things you have always done.

People sometimes think that fatigue is something they have to put up with if they have cancer. But there are ways to manage it and things that may help you deal with it. You can read more about these on pages 23-38. There's also information about what causes fatigue and ways to deal with these on pages 7-22.

How might fatigue affect me?

Some people may have fatigue which has a big impact on them. For other people, it may have less impact. You may also have good days when you feel less tired.

You may have no energy and feel weak, and find it difficult to do the things you used to enjoy. Even the smallest things may make you feel worn out. It can be difficult to tell in advance when you will feel tired. Even after sleeping, you may still feel tired.

Fatigue can limit everyday activities, like working or household tasks. Fatigue can also affect your relationships with friends and family. Some people may feel guilty if they can't play such a big part in family life. It can be hard to explain to other people how you feel and how fatigue affects you.

Some people have problems concentrating or remembering things. It can be very frustrating not being able to do things you have always done.

People often find fatigue upsetting. It can be difficult to cope with, and may make you feel down. Read more on page 32.

People sometimes worry that fatigue is a sign that the cancer is getting worse, but this isn't necessarily the case. Although people with advanced cancer that has spread may start to get more fatigue, people who had early cancer also often have fatigue.

It is important that you speak to your doctor or nurse if you have fatigue or are struggling, especially if you are feeling low or down.



“ I don't think people understand the difference between tiredness and fatigue. Tiredness is when you want to sleep but with fatigue you can't do anything.”

What causes fatigue?

Key facts

- Fatigue may be caused by the cancer itself.
- It may also be caused by the symptoms of the cancer, such as pain, problems with digestion, and problems sleeping.
- Fatigue can be a side effect of treatments for the cancer, such as surgery, chemotherapy and radiotherapy.
- It can sometimes be a side effect of other medicines.
- Sometimes it is difficult to tell what is making you tired. A fatigue diary may help with this. You can see an example of a fatigue diary on page 50.
- It is important that you tell your doctor or nurse if you have any fatigue. They should check for possible causes and work out the best ways to deal with it.
- There are ways to deal with fatigue. Read more about these on page 23.

The cancer

The cancer itself can cause fatigue, although we don't fully understand how or why this happens. People may have fatigue when they are diagnosed, even before they start treatment. Other symptoms caused by pancreatic cancer, such as problems digesting food, can also cause fatigue.

Problems with digestion and diet

The pancreas makes enzymes which help to break down your food. This is part of digestion. Your body then gets nutrients and energy from your food. Pancreatic cancer can affect digestion, which means that you don't get the energy you need from your food. This can cause fatigue.

Problems with digestion can also cause loss of appetite, tummy discomfort, diarrhoea and sickness. These can all mean that you may eat less, and so get less energy from your food. Fatigue may also mean that you feel less like eating.

Pancreatic enzyme replacement therapy (PERT) helps to manage these problems with digestion. It replaces the enzymes that your pancreas would normally make. Common brands include Creon, Nutrizym and Pancrex.



What can I do?

- If you haven't seen a dietitian (see page 25), ask to be referred to one. They can help you make sure you get enough nutrients and energy from your food.
- Ask your dietitian, nurse or doctor about whether you need PERT.
- Some people may need nutritional supplements to help get all the nutrients they need. Speak to your dietitian, nurse or doctor about whether these might help.



“The cancer affects your eating, making you weak. It affects your toilet habits, which makes you feel uncomfortable so you don’t want to eat anyway. It all has a knock-on effect – all these little things add to fatigue. It’s all connected.”



You can speak to our specialist nurses on our free Support Line about digestion and PERT.



Read more about diet and PERT in our booklet: **Diet and pancreatic cancer.**
Or at: pancreaticcancer.org.uk/diet

Pain

Pancreatic cancer can cause pain for some people. Pain may be linked to fatigue, although we need more research into this.

Having pain can be exhausting, and it may cause problems sleeping. Your fatigue may be worse when you have more pain and you may feel less tired when you have less pain.



What can I do?

- Tell your doctor, nurse or GP about any pain as soon as you can. The earlier you get treatment, the better the chance of getting the pain under control.
- Ask to be referred to the palliative care team. Palliative care provides specialist care which aims to prevent and manage complex symptoms, including pain. It's not just for people at the end of their life.



Read more about pain and how to manage it in our booklet: **Pain and pancreatic cancer**
Or at: **pancreaticcancer.org.uk/pain**

Problems with blood sugar levels (diabetes)

Sometimes, pancreatic cancer can cause diabetes. This is a condition where the amount of glucose (which is a type of sugar) in your blood is too high. Diabetes may make you feel tired, lethargic and confused.

If you are diagnosed with diabetes, you will need advice that is specific to you because of the cancer. There are different types of diabetes, and information on the internet may not be right for you because of the pancreatic cancer. It's important that you eat well to maintain your weight, and that your diabetes is managed around this. Don't try to reduce how much you eat to manage your diabetes.

If you have diabetes and haven't seen a dietitian or diabetes nurse to help you manage it, ask your doctor or nurse to refer you.



Read more about diabetes and pancreatic cancer at: **pancreaticcancer.org.uk/diabetes**

Being sick

Pancreatic cancer can make you feel and be sick (nausea and vomiting). This can be caused by the cancer or it can be a side effect of treatment.

Being sick can be exhausting. It may also mean that you don't absorb all the nutrients you need from your food, making you tired. But there are ways to manage sickness.



What can I do?

- Tell your doctor or nurse if you feel or are sick. Anti-sickness medicines may help.
- Some anti-sickness medicines can make you sleepy (see page 16), so let your doctor or nurse know if you also have fatigue.
- If you are being sick a lot (for half a day or more, or every few days) and it doesn't improve, contact your medical team or GP.



Read about sickness and ways to manage it at:
pancreaticcancer.org.uk/sickness

“ She couldn't do the everyday things she used to like getting out the house as much, the sickness made her constantly exhausted. Only rest and being able to eat what she could helped.”

Advanced pancreatic cancer

Advanced pancreatic cancer is cancer that has spread to other parts of the body, such as the liver and lungs. If you have advanced cancer, you may find that the fatigue gets worse over time, and that it has more of an effect on your daily life. This is normal, but it can be upsetting for you and your family.

Your medical team may be able to change the way they manage your symptoms to help with the fatigue.



What can I do?

- Speak to your doctor or nurse if your fatigue is getting worse, or having more of an impact.
- Be aware that you may find that you are less able to do some of the things to manage your fatigue, like physical activity. Other things may still help, such as planning your time to save energy or complementary therapies.
- Read about ways to manage fatigue on pages 23-38.

“ Seek medical advice, don’t just hope that it’ll pass. Confide in family members.”

“ The best advice she was given was to always listen to her body. And if she was overdoing it she should stop.”

Chemotherapy

Chemotherapy uses drugs to kill the cancer cells. It is one of the main treatments for pancreatic cancer. Fatigue is a common side effect of chemotherapy.

Some people find that the fatigue starts a few hours to a few days after having chemotherapy, and improves after a few days. It can take several months for the fatigue to fully improve.



What can I do?

- See how the chemotherapy affects you, and work out how much activity you can manage. For example, you may want to do very little on the days after chemotherapy when you are more likely to have fatigue.
- Speak to your doctor or nurse if you have fatigue. They may be able to change the dose of your chemotherapy to reduce the fatigue.

“ I was sleeping 17 hours a day. When I mentioned it to the oncology team, my chemotherapy dose was adjusted, resulting in improved wakefulness.”

“ My dad has chemo on Fridays. Come Tuesday and Wednesday, he can't get out of bed. After these two days though, he regains some energy and has 5 good days!”

Surgery

Surgery to remove pancreatic cancer, such as the Whipple's operation, is major surgery. If surgery to remove the cancer isn't possible, some people may have bypass surgery to treat a blocked duodenum or a blocked bile duct. This is also a big operation.

It is normal to feel tired and weak after surgery, and it can take several months to recover. Some people still get fatigue a year or more after surgery.



What can I do?

- Try to gradually get back to daily activities. You may find that physical activity helps (see page 28).
- Slowly build up how much you do, but don't overdo it. Rest when you need to.
- It may take time for your appetite to improve. Try starting with small amounts of food often, and then gradually eat more.
- Ask for help from friends and family after your operation. Read more about this on page 32.

“ It was hard to find the energy to do anything after surgery. I'm slowly improving but still regularly get times when I need to stop and sleep for an hour or so in the day.”

Radiotherapy

Some people with pancreatic cancer may have radiotherapy, which is sometimes combined with chemotherapy (chemoradiotherapy). Fatigue is a common side effect of radiotherapy. You may need to travel to hospital every day for treatment and this can make fatigue worse. Fatigue can last for several weeks or months after treatment finishes.



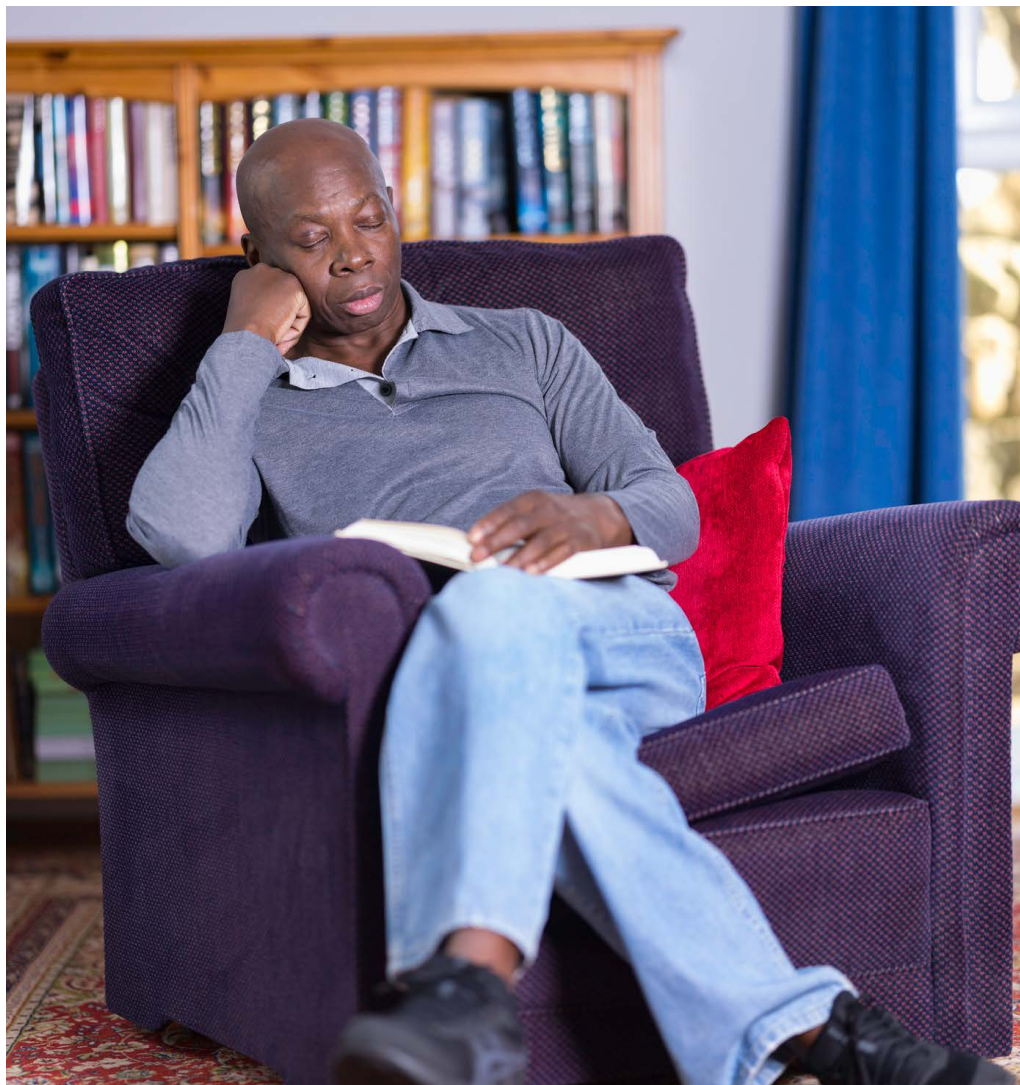
What can I do?

- If you have fatigue during or after radiotherapy, talk to your medical team about how to manage it.
- See how the radiotherapy affects you, and work out how much activity you can manage.
- Ask someone to drive you to hospital.

Medicines

Some medicines can make you feel sleepy, especially when you first start taking them or when the dose is changed. These include opioid painkillers, like morphine, and some anti-sickness medicines such as metoclopramide and lorazepam.

“ It took several weeks to realise that it was the metoclopramide that made me so fatigued after chemotherapy, not the chemotherapy itself.”



“You don’t realise how much the medication can make somebody really tired. Once he started taking the tablets he became very lethargic and sleepy, and couldn’t do as much.”



What can I do?

- Speak to your doctor or nurse if you think your medicine may be making you sleepy. They may be able to change the drug, change the dose, or suggest you take it at a different time.
- Don't stop taking your medicine without speaking to your doctor or nurse.
- Check whether your medicines will affect your ability to drive (see page 41).

Anaemia

Anaemia is a low level of red blood cells or haemoglobin. Haemoglobin is the part of the red blood cell that carries oxygen around the body. Anaemia can make you feel tired, dizzy, short of breath and have problems concentrating. It may have many causes, including chemotherapy. You will have regular blood tests to check your blood cell levels during chemotherapy. There are things your doctors can do to treat anaemia.

How you are feeling emotionally

When you have cancer it's natural to feel worried, anxious, down or stressed. But sometimes these feelings can become overwhelming. Anxiety and depression can be common in people with pancreatic cancer. And depression can be linked to fatigue in people with cancer.

Your medical team may be able to help with things that might be worrying you. For example, how to get advice about financial issues, or managing at home. Dealing with problems like these may reduce stress and anxiety.



What can I do?

- Family and friends can often provide a lot of emotional support.
- It can also help to speak to someone affected by pancreatic cancer. We have online support sessions and an online forum where you can connect with others.
- Our specialist nurses on the Support Line can also help with emotional support.
- Ask your doctor or nurse about whether there are psychological therapies available that might help. These include cognitive behavioural therapy (CBT) and counselling. These can help you talk through your feelings and find ways to deal with them.



Read more about dealing with the emotional impact of pancreatic cancer at:
pancreaticcancer.org.uk/coping

Problems sleeping

Problems sleeping can be common in people with cancer and can make fatigue worse.

- Your sleep may be disturbed by symptoms caused by the cancer or your treatment. These may include pain, discomfort, sickness, needing the toilet, itching or sweating.
- Feeling anxious or worried can also make sleeping difficult.
- For some people, going to bed at different times each evening can also make it harder to sleep at night.
- Sometimes people with pancreatic cancer may take steroids, for example for sickness or pain. Steroids can keep you awake, so it is better to take them before midday. Read more about steroids on page 36.

“ Sleep helped slightly but it was difficult to switch off and sleep.”

“ It helped to have quiet times during the day, sometimes in a different room to others.”

Having a nap (a short sleep)

You may find that napping during the day gives you a bit more energy. If having a short nap helps, then it is fine. Try to limit how long you nap to about 30 minutes, as sleeping too long can make it harder to sleep at night. You could set an alarm so that you don't keep sleeping. An occupational therapist (see page 24) can give you advice about napping.



What can I do if I have problems sleeping?

- Talk to your medical team. They can look at whether there is a particular problem, and how to manage it.
- Try going to bed at a regular time, as following a routine can improve your sleep.
- Make sure your bedroom is quiet, dark and comfortable. These things can all affect your sleep.
- If you are sweating a lot at night, use 100% cotton bedding and keep spare sets of sheets nearby so that you can change the bed easily.
- Doing some physical activity during the day may help. Read more on page 28.
- If you are worrying a lot at night, try to do something relaxing before you go to bed. For example, a warm bath might help.
- You might find that writing down your thoughts or worries helps you to stop thinking about them at night.
- Avoid caffeine (such as coffee and tea), alcohol or sugary foods or drinks before you go to bed, as they can affect your sleep.
- Limit how much time you spend on your phone, tablet or computer at bedtime, as this may affect your sleep.



- Cognitive behavioural therapy (page 30) may help to improve your sleep patterns.



Questions to ask your doctor or nurse

What is causing my fatigue?

Can my symptoms be treated, and will this help my fatigue?

Will treatment cause fatigue, or make it worse?

Would changing my treatment help the fatigue?

I'm not sleeping well – can you help?

Can I take any medicine to help me sleep?

What can help with fatigue?

Key facts

- Talk to your doctor, nurse or other health professionals about fatigue. They can help you manage it.
- Getting some support can help you deal with fatigue. Your medical team, our specialist nurses on the Support Line, and local cancer centres can all help.
- Planning your time so you do more when you have more energy, and rest when you need to, can help manage fatigue.
- Physical activity may help with fatigue and increase your energy levels.
- Family and friends can be a big support. They can also help with things like household tasks, childcare, or driving you to appointments.
- A type of talking therapy called cognitive behavioural therapy can help with fatigue and problems sleeping. It can also help you deal with negative thoughts, which may make the fatigue harder to cope with.
- Some people find that complementary therapies, like acupuncture, massage and meditation, help them cope with fatigue. There are lots of things you can try.

Who can help with fatigue?

It's important to talk to your medical team about any tiredness or fatigue. You should have a main contact in the medical team, who is normally a specialist nurse.

Your doctor or nurse may try to work out what is causing your fatigue and how bad it is. If they can find the cause they may be able to treat it. For example, treating symptoms or changing the treatment may help.

Palliative care or supportive care teams can also help manage complex symptoms, including fatigue. They also provide emotional and practical support, and aim to help people live as well as possible for as long as possible. These services aren't just for people at the end of their life. They are available at any point during your treatment or care.

“ Our palliative care nurse was super and was able to refer my partner to complementary therapies locally as well as offer other practical support.”

Other professionals who can help with fatigue

- **Occupational therapists (OT)** can provide advice on how to manage your fatigue so that you can carry on doing things you want and need to do. This can include how to change tasks, and equipment that can save you energy. They can also suggest ways to help you relax and sleep well. Your GP or nurse can refer you to an OT. You can also contact your council, as social services also provide occupational therapy.

- **Dietitians** provide advice about diet and nutrition, and help you manage digestion problems. This may also help you manage fatigue. If you haven't seen a dietitian, ask your hospital team or GP to refer you to one.
- **Physiotherapists** can give you exercises and advice to help you keep active. Read more about physical activity on page 28. Your doctor or nurse can refer you to a physiotherapist.
- **Psychologists** can help with the emotional effects of pancreatic cancer and fatigue. Read more about this on page 18. Your GP or nurse may be able to refer you to a psychologist.

Planning your time

Planning your time can help you deal with fatigue. This can help you do more of the things you want or need to do. But it is important to pace yourself. Don't try to do too much.

A fatigue diary can help you see when you have more energy and help you plan your time (you can find one on page 50). A diary can also help you describe your fatigue to your medical team and show how any treatment you are having affects it.

An occupational therapist (page 24) can help you plan your time to make the most of the energy you have.

Planning is useful, but things don't always go to plan. Don't give yourself a hard time if your plan doesn't work out.

**“ When you have a good day don't go mad.
Pace yourself so that you're not wiped out the
next two days.”**



What can I do?

- Plan to do activities when you have more energy and to rest when you need to.
- Spread activities that require more energy over a few days. Don't try to do everything on a good day, as it might make you more tired the next few days.
- Set yourself small, realistic goals. Break larger tasks or activities into smaller parts.
- Work out which activities are important, which you can get help with and which can wait. Focus on doing the important things, which should include things you enjoy. These can help you deal with stress and improve your mood. It's fine to put off something that's not important.
- If you use a fatigue diary, write down when you have fatigue, how bad it is, and anything that makes it better or worse. Try to include all activities, even things like having a shower or watching TV.
- If you feel too tired to keep a diary, you could ask a family member to do it for you. Family and friends can also help you prioritise activities.
- If you have a big event coming up, such as a birthday or wedding, plan your time so you have enough energy for it.



“I would plan for the fatigue if there was something coming up I needed to do, so I would ensure I was doing less on the day or two immediately before and after an event.”

Physical activity

There is good evidence that gentle physical activity can help with fatigue and increase energy levels. Physical activity is unlikely to make your fatigue worse. It can also help you feel better generally, improve your strength, and help you deal with stress.

Speak to your medical team about what type of activities are best for you, and any safety issues to be aware of.

A physiotherapist can give specialist advice about physical activity. An occupational therapist (OT) can help you include activity in your daily routine. Read more about them on page 24.

For physical activity to help, you need to do it regularly. But don't overdo it. For most people, doing ten minutes of gentle activity three times a day would be suitable. This could include:

- walking, such as going for a walk around the block or garden, or a longer walk, depending on what you can manage
- light housework or gardening
- sitting in a chair or lying on a bed or the floor, raising your leg, and holding it for a few seconds, before lowering it and repeating a few times
- lifting some small weights, tins of food or bottles of water, while sitting in a chair
- walking up and down a few steps.

It is important to do activity within your own limits. Take it easy and only do what you are able to. This will depend on how well you are. For example, you may not be able to do much if you are having chemotherapy.



What can I do?

- Ask your medical team what physical activity you could safely do.
- Speak to your doctor or nurse about being referred to a physiotherapist for support.
- Try to include gentle physical activity in your daily routine, and do activities you enjoy.
- A few short activity sessions may be easier than one long one.
- You might find that it's easier to be active with a friend or relative. But make sure that you are in control. Don't overdo it if the other person is able to do more than you.
- Some people find it helpful to join a group. Some cancer support services run exercise courses for people with cancer. Ask your GP about any services in your area.
- Macmillan Cancer Support has a lot of information about different ways of keeping active.

“ After chemotherapy ended, I was referred for physiotherapy. The sessions introduced gentle exercise to improve my core strength and stamina and were very helpful.”

“ Listen to your body. Rest when it tells you. Exercise, such as gentle walking or light gardening, if you can manage it.”

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy is a type of talking therapy. It can help you deal with problems by changing how you think and feel about them. There is some evidence that CBT can help people with cancer deal with fatigue and problems sleeping. It can also help with anxiety and depression (see page 18).

CBT is available on the NHS. You can access it yourself through the NHS psychological therapies service (IAPT) on the NHS website. Your GP can also refer you, or you can pay for it privately.

Dealing with negative thoughts

You might find that fatigue gets you down and you start to think quite negatively. For example, you might think that you should be able to do more or cope better. You might worry that other people think you are lazy or not trying hard enough. Or you might feel that things will never get better.

These kinds of negative thoughts are normal, but they can make it harder to deal with fatigue, and make the fatigue worse. If you have pancreatic cancer, it is normal to feel tired. Try not to feel guilty about not being able to do what you used to.



What can I do?

- Try to focus on positive things, such as what you can do, rather than what you can't.
- You might find it helpful to write down negative thoughts. This can help you deal with them. You could also write down positive things, as a reminder of what you can still do.
- Get some support to deal with negative feelings and low mood. Read more about support on page 32.
- Cognitive behavioural therapy (CBT) can help you find ways to deal with negative thoughts. Read more about CBT on page 30.

“ Accept that sometimes you can't do anything and don't beat yourself up about it. Celebrate what you have accomplished.”

“ Mentally – the negative self-talk about what I was not doing as opposed to what I have achieved did not help.”

Getting some support

Fatigue can be difficult to deal with and have a big impact on your life. Getting some support can help you cope.

Support from family and friends

Family and friends can be a big support. For example, they can help with practical things like household chores or driving you to hospital. This can help you save energy for more important things. You might find it easiest to ask people to do specific tasks. You may find that people like being able to help in this way.

Family and friends can also provide emotional support, which can help you cope.

“ Others want to help – just ask. There is no shame in asking, and it’s frustrating for your loved ones watching you struggle. Take all the help you can.”

Your medical team

Your medical team can provide support. You should have a main contact, who is often a specialist nurse if you are being cared for by the hospital, or a community or district nurse who cares for you at home. Tell them about the fatigue, as they can help you find ways to manage it.

How Pancreatic Cancer UK can help

We have a range of services that can help you deal with fatigue and other symptoms, and also provide emotional support.



You can speak to our specialist nurses on our free Support Line. They have time to listen and talk through your problems and concerns.

Our online support sessions are a chance to meet others with pancreatic cancer, share your experiences, support each other and feel understood. Our nurses often run sessions on managing symptoms, including fatigue. You can also share experiences and get support from others on our online forum. Read more about how we can support you on page 52.

Support from other organisations

Cancer centres provide information and support. Some run courses or provide services such as counselling or complementary therapies. Examples include Maggie's Centres and Macmillan information and support centres (see page 54).

Support groups

There are cancer support groups around the country where you can talk to other people going through similar experiences.



There are some groups specifically for pancreatic cancer. Find out more at: pancreaticcancer.org.uk/supportgroups

Social care

There may be times when you need extra support at home. Your local council's social services may provide support such as:

- help from care workers with everyday tasks, such as washing, dressing, preparing meals, or housework
- equipment or adaptations to the home
- respite or day centre care to give your family a break.

You may have to pay for some of the care. This will depend on what the service is and your financial circumstances. Speak to your GP, nurse or local Macmillan information and support centre for help organising care at home.



Read more about getting care at home on our website at: pancreaticcancer.org.uk/socialcare

Complementary therapies

Complementary therapies include things like acupuncture, massage and meditation. Some people find that complementary therapies help them cope with fatigue. There isn't a lot of evidence about them, and they don't work for everyone. But they may help you feel more relaxed, and might help with other symptoms. They can also be something to look forward to.

Don't stop any cancer treatments if you have complementary therapy. It's important to speak to your medical team before trying a complementary therapy, as some may affect your cancer treatment. And tell your complementary therapist about your cancer treatment. The Complementary & Natural Healthcare Council have a list of registered therapists.



Read more about complementary therapies at:
pancreaticcancer.org.uk/complementarytherapies

Distracting yourself

You may find that it helps to distract yourself from the fatigue. Try to focus on doing things that you enjoy. For example, you could see friends and family, do hobbies, or even just read or watch television. If you have a pet, you may also find that they help to distract you from fatigue.

“ Keeping my mind occupied as much as I could helped, with projects on my laptop, watching TV, & listening to the radio.”

Dealing with memory problems

Fatigue can make it hard to remember things and concentrate. This is normal, but it can be frustrating. An occupational therapist (see page 24) may be able to help with this. Speak to your nurse if you are having a lot of memory problems.



What can I do?

- Try using a diary, sticky notes, or your mobile phone to remind you of things.
- You could set an alarm if you need to remember something at a specific time.
- Pill boxes help you plan your medicine in advance, so that you don't forget to take it.
- Write a list of the medicines you take, the dose and when you need to take them. Tick them off each time you take them.
- Write a "to do" list of things you need to do. Cross things off as you do them.
- Make a shopping list and note things down as you think of them. Cross things off as you buy them. Some smartphones also have shopping list and reminder functions.

Steroids

Steroids are medicines that can be used to treat some symptoms and side effects, including pain and sickness. They may sometimes help with fatigue in the short term, particularly for people with advanced cancer. There is some evidence that they may make it easier to do physical activity (see page 28).

Steroids are not suitable for everyone, and they should only be used for a short time. If steroids are not taken properly, they can cause problems sleeping and stomach problems, so follow your doctor's advice. Steroids can cause your blood sugar level to rise. Your doctor or nurse will need to monitor this if you have diabetes.



Questions to ask your doctor or nurse

What can help manage my fatigue?

Would it help if I saw a dietitian, occupational therapist or physiotherapist? Can you refer me?

Would CBT or counselling help with worries and fatigue? How can I access these?

Would complementary therapies help?

I have a special event coming up. What would give me the energy to go to it?

What can I do to help me remember things?

Are there organisations or support groups that can help?

“ Rest when you need to. Try and exercise a bit and get fresh air. Try and recognise when your tired days are during treatment and expect to have much reduced energy levels.”



“ What helped? Care by family members – preparing fresh meals several times a day, taking mum out to a park where she could walk, escapist conversations and boosting her mental state.”

Dealing with the effects of fatigue on daily life

Key facts

- Fatigue can have a big impact on your daily life, and make it harder to do everything you used to do.
- If you are working, your employer must make reasonable adjustments (changes) to help you carry on working.
- Macmillan Cancer Support and Citizens Advice give expert information and advice on financial matters and benefits.
- It may not be safe for you to drive if you feel tired or sleepy. You may need to tell the DVLA, or the DVA in Northern Ireland, if your medicine or the cancer affect your driving (see page 41).
- Jobs like cooking, cleaning and shopping can use up a lot of energy. You could ask for help with these. Or find ways to save energy, like shopping online instead of at the supermarket. See page 42 for some more tips.
- Fatigue can affect your social life. This can be upsetting for both you and your friends and family. You could ask people to visit you at home instead of going out.
- Your family and friends may need support too. We also have information to help them look after themselves and support you with your fatigue (page 45).

Work and money

Having fatigue can make work difficult. For example, you may not be able to concentrate properly, or may struggle to travel into work. Talk to your employer about changes they can make so you can carry on working.

If fatigue is affecting your work, it can impact on your finances. It's important to try to deal with any money issues so that they don't become something you worry about.

There is lots of help available. Macmillan Cancer Support and Citizens Advice both give expert information and advice on financial matters and benefits.



Read more about work and money on our website at: pancreaticcancer.org.uk/money

- “ I'm fortunate that my colleagues understand and support me throughout the day, as I still have to have a rest in the work's first aid room every morning – without that I couldn't manage.”
- “ The fatigue made working full-time difficult so I had to work flexibly and schedule hours over 7 days to allow for rest periods.”

Driving

It may not be safe for you to drive if you feel tired or sleepy. Some medicines or treatments can make you tired and affect your driving. You must tell the Driver and Vehicle Licensing Agency (DVLA), or the Driver and Vehicle Agency (DVA) if you live in Northern Ireland, about your cancer if:

- your cancer affects your driving or
- the side effects of your medicine could affect your driving or
- your doctor says you may not be fit to drive.

Ask your doctor about driving. You can find out more at gov.uk, or at nidirect if you live in Northern Ireland. You may need to tell your insurance company as well.

Household tasks

Tasks like cooking, cleaning and shopping can use up a lot of energy. Try to spread these tasks out over the week, and work out which is most important and needs doing soonest. Don't use up all your energy on household tasks so that you have no energy left for things you enjoy.

“ Giving friends and family jobs to do helps them feel they can do something positive.”

“ I felt guilty that I couldn't do what I used to do such as housework and cooking. You have to learn to put yourself first during these times and rely on the support of others.” Jenny



What can I do?

- Ask family and friends to help with household tasks. You might find they like helping.
- An OT (see page 24) can help you find ways to do household tasks more easily.
- Try online shopping, or phone or mail order delivery services rather than going shopping.
- Use ready-made meals, or make large amounts when you do cook and freeze portions for future meals.
- Use things that can save energy when you are cooking. For example, use a food processor to chop vegetables, or buy prepared food such as chopped vegetables and grated cheese.
- Try energy saving things, like sitting down when you dress, shower or prepare food. OTs can provide stools for this.
- Drying yourself can use a lot of energy. Wrap up in a towelling dressing gown instead.
- Before you start any task, make sure you have everything you need ready, rather than having to go backwards and forwards to get things.
- If you can afford it, employ a cleaner or gardener.
- Macmillan Cancer Support or other local charities may have volunteers who can help with shopping, transport and other practical tasks.



“ My partner’s fatigue was caused by treatment. Knowing what days of his cycle he felt worst meant we could organise nice things, such as trips away or meals out, when we knew he wouldn’t feel so wiped out.”

Seeing friends and family

Seeing friends and family can be important. They may provide some normality and distraction from the cancer and fatigue. They can also be a big support. But fatigue can affect your social life. For example, you might get tired very quickly, or find it difficult to go out to see people.



What can I do?

- Plan your time (see page 25) so that you see people when you have more energy.
- Be honest with people (and yourself) about what you can manage. They will understand.
- People may worry about tiring you out, so tell them what would work for you.
- If you find going out tiring, ask friends and family to visit you at home.
- If you find it tiring to see people in person, you could have short phone conversations, send text messages, or use social media. You could set up an email or WhatsApp group to update several people at the same time.
- Plan activities that you can do with children while sitting down, such as crafts or reading.
- Talk to your medical team about any big events, such as weddings. They may be able to make temporary changes to your medicine to allow you to go to them more easily.

“ When my partner was on chemo we soon worked out what his better days would be and this helped us plan ahead. Friends were more than happy to fall in with this.”

“ I didn’t have the energy to see friends, or travel far. I found it best to acknowledge it and don’t fight it.”



Questions to ask your doctor or nurse

How can I get help at work or with my finances?

Can an occupational therapist help me with household tasks?

Is it safe for me to drive?

What support is available locally to help me cope with my cancer and fatigue?

Information for family and friends

It can be upsetting when someone you love has fatigue, with no energy to do much. But there are lots of ways you can support them. You may need support, too (see page 47).

It might be difficult for your family member to accept help, and they may worry about losing their independence. Let them know you want to help, and ask what would be useful.



What can I do?

- Understand how their fatigue is affecting them. Everyone experiences fatigue differently. It can go on for some time after treatment, and it can vary from day to day.
- You may be able to help them cope emotionally.
- You can help arrange a specific time each day when they will rest, so that everyone else knows not to disturb them.
- You can help with household tasks. Ask other family and friends to help, too.
- You could take on responsibility for organising daily life. For example, paying bills and organising medical appointments.
- You may take on some caring responsibilities. This might include helping with medicines, cooking, or helping them wash and dress.
- You may also need to organise professional care. Read more on page 34.
- If it isn't safe for them to drive, you could do the driving. If you are doing a lot of caring, you might also be very tired. So it may not be safe for you to drive either. Ask other family and friends to help.
- If they have children, you could help care for them.

Getting support for you

Supporting someone with cancer can be exhausting and upsetting. So it's important that you get support for yourself as well. You can speak to your family member's medical team. They will be able to provide you with emotional support, as well as answer your questions.

We support families as well as the person with pancreatic cancer. Read more about this on page 52.



If you need support, or have any questions about pancreatic cancer, fatigue, or how to care for your family member, speak to our specialist nurses on our free Support Line.



We have more information about looking after someone with pancreatic cancer in our booklet: **Caring for someone with pancreatic cancer: Information for families and friends.**

“ Not asking for help will not help you or your loved one. If you don't want to talk to friends or family, talk to the Pancreatic Cancer UK Support Line. They are amazing at just listening.” Nadia



“ My family found it tough to see me so fatigued as I used to be very active. Reassure them that their loved ones will get more tired during chemo and not to be too alarmed by this.”

More information and support

Useful medical words

We have explained some of the medical words you may hear.

Bile: fluid which helps digestion. It is produced by the liver and stored in the gall bladder.

Bile duct: a tube that carries bile from the liver to the duodenum.

Chemotherapy: a treatment that uses anti-cancer drugs to destroy cancer cells.

Duodenum: first part of the small intestine.

Enzymes: substances produced by different parts of the body, including the pancreas. Pancreatic enzymes help to break down food.

Jaundice: a symptom of pancreatic cancer. It develops when there is a build-up of a substance called bilirubin in the blood. It causes yellow skin and eyes, dark urine, pale poo, and itchy skin.

Radiotherapy: a treatment that uses high-energy x-rays (radiation) to destroy cancer cells.



You can find more medical words on our website at: pancreaticcancer.org.uk/medicalwords

Diary for managing fatigue

Use this diary to record your fatigue

	Monday			Tuesday			Wednesday		
	am	pm	eve	am	pm	eve	am	pm	
Rate your fatigue 0 to 10: 0 = no fatigue 10 = worst fatigue									
How did you feel today (for example, happy, worried)?									
What did you do today? (for example, showered, a short walk)									
What, if any, treatment did you have today? Include any changes to your care or medicines.									
Did anything make your fatigue better?									
Did anything make your fatigue worse?									
Note anything else relevant (for example, how you slept, problems with digestion)									

gue. You can also download it at pancreaticcancer.org.uk/managing-fatigue

Monday	Thursday			Friday			Saturday			Sunday		
eve	am	pm	eve	am	pm	eve	am	pm	eve	am	pm	eve

Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

Our specialist nurses are here to talk now

We can answer your questions, recommend practical steps, and provide emotional support when you need it most.

Call free on **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**

Expert information

Our free information can help you understand your care, ask questions, make decisions and live as well as you can.

Go to: **pancreaticcancer.org.uk/information**

Download or order our free publications at:
pancreaticcancer.org.uk/publications or call **0808 801 0707**

Our online forum

The forum is a supportive online space where everyone affected by pancreatic cancer can be there for each other.

Go to: **forum.pancreaticcancer.org.uk**

Our online support sessions

Our online support sessions are hosted by our specialist nurses and will give you the chance to connect with others.

Go to: **pancreaticcancer.org.uk/supportsessions**

Real life stories

Read other people's experiences of pancreatic cancer.

Go to: **pancreaticcancer.org.uk/stories**

Useful organisations

Citizens Advice

www.citizensadvice.org.uk

Information and advice on a range of issues including work, benefits, healthcare, patient rights and information for carers.

Complementary & Natural Healthcare Council

www.cnhc.org.uk

Information about complementary therapies and a register of therapists.

Disabled Living Foundation

www.livingmadeeasy.org.uk

Helpline: 0300 999 0004 (Mon-Thurs 10am-4pm)

Provide free and impartial information and advice about equipment to help with daily living.

Elizabeth Coteman Fund

www.ecfund.org

Tel: 01223 782171

Provide grants for people with pancreatic cancer who are struggling financially, for equipment and respite. Provide support and friendship to those affected by pancreatic cancer.

GOV.UK

www.gov.uk

Provides information about government services, including information about benefits, transport, money and guidelines for hospital parking.

NHS 111 Wales

111.wales.nhs.uk

Health information in Wales, including local services.

Macmillan Cancer Support

www.macmillan.org.uk

Support Line: 0808 808 00 00 (Every day, 8am-8pm)

Provides practical, medical and financial support for anyone affected by cancer, including family members.

Maggie's

www.maggies.org

Tel: 0300 123 1801

Centres around the UK and online offer free practical, emotional and social support for anyone affected by cancer.

NHS inform

www.nhsinform.scot

Provides information about different health conditions and living well, and local services in Scotland.

NHS website

www.nhs.uk

Provides information about health conditions, living well, care, and local services in England.

nidirect

www.nidirect.gov.uk

Information about local services in Northern Ireland, including health services and information and support for carers.

This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK.

We try to make sure that we provide accurate information about pancreatic cancer. We hope this will add to the medical advice and help you make decisions about treatment and care. This information should not replace advice from the medical team – please speak to the medical team about any questions.

Email us at **publications@pancreaticcancer.org.uk** for the sources used to write this booklet. If you have any feedback, email us or write to our Information Manager.

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Pancreatic Cancer UK

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