

# STEP BY STEP

## Common Side Effects Of Treatment



# Introduction

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Your cancer treatment can cause various side effects and sometimes the side effects of treatment can be more difficult to manage than the illness itself.

Some of these are very common and experienced by many. Some are much rarer and occur in very few patients. Sometimes the effects can be unexpected or more severe than you anticipated and the experiences of these side effects differ from person-to-person.

We know that many patients have lots of questions about the side effects of treatment and how to deal with them and we hope this booklet helps to answer some of them. This booklet is designed to provide you with information about the common side effects you may experience, what to expect and how they may be managed.

If you need specific advice or are concerned about a particular side effect, please contact your medical team or Clinical Nurse Specialist (CNS).

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2

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# In this booklet

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1. Fatigue .....	4
2. Hair loss .....	8
3. Increased chance of infection .....	12
4. Anaemia .....	14
5. Gastrointestinal side effects .....	16
6. Mouth changes .....	19
7. Cognitive effects or 'chemo brain' .....	21
8. Pain and tingling .....	25
9. Graft vs host disease (GVHD) .....	29
10. Useful contacts .....	38
11. About Leukaemia CARE .....	41

# Fatigue

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## Introduction

Fatigue is one of the most common symptoms reported by patients diagnosed with a blood or lymphatic cancer. Many patients may have already found that experiencing and managing fatigue is a large part of everyday life, and, unlike 'normal' tiredness, it is not relieved by rest so even the most simple of daily tasks can become challenging.

Research has shown that as many as three quarters of people with cancer feel fatigued at some time along their cancer journey. However, many people do not report any changes in their tiredness levels as it's assumed that it is a natural consequence of living with a blood cancer.

Fatigue is a very common condition for many people with a blood cancer and it is important that fatigue is addressed in the same way that other symptoms of your cancer and treatment are managed.

Remember, you can talk to your medical team about how you are feeling as there are many ways of managing your energy levels.

## What is fatigue?

Fatigue is often referred to as exhaustion, tiredness or lethargy. You may experience fatigue either physically or psychologically, so it can affect your ability to do everyday tasks, as well as your mental ability.

When experiencing fatigue, you may find that you experience other problems such as a lack of concentration, difficulty remembering things and even a loss in sex drive. These are all recognised as effects of fatigue.

## What causes fatigue?

There are a variety of reasons as to why you may be feeling fatigued:

- **Anaemia**

If you are anaemic, or have low levels of haemoglobin, this can affect your energy levels. The red blood cells that carry oxygen around your body are often reduced by leukaemia cells and chemotherapy. Blood tests will be able to establish whether you have anaemia and inform your medical team on the appropriate action to take.

- **Chemotherapy and radiotherapy**

If you have been through or are having chemotherapy treatment, fatigue may be a side effect of this process. Some of the medication you may have been prescribed can sometimes cause drowsiness, which may increase feelings of fatigue.

- **Depression and anxiety**

Anxiety and depression can contribute to fatigue. It is common for you to suffer with anxiety and depression after you've been diagnosed. These feelings do generally get better and easier to deal with. If you feel that your mood has been low for some time, you should speak to your medical team who will advise you on how to cope and manage your depression. Our Step-by-Step booklet on the emotional impact of a blood or lymphatic cancer will provide you with more information.

- **Diet**

A poor diet or loss of appetite can lead to spells of fatigue. It is important that your body obtains the nutrients it needs in order to be able to maintain healthy energy levels.

- **Other medication**

Some medication you may be given as part of your treatment such as painkillers and anti-sickness medicines can cause drowsiness.

## Managing your fatigue

There are a number of things that you can do to adapt to the changes in energy levels your body may go through. It's important that you speak to your doctor and nurses about your fatigue as they will be able to help work out a management plan for you.

- **Fatigue diary**

Some people find it useful to use a fatigue diary where they record their daily energy levels. This is a simple way to identify changes and any particular triggers as you can note the days and times when the fatigue is better or worse. Your physiotherapist, occupational therapist or Clinical Nurse Specialist (CNS) will be able to help you understand about conserving your energy levels to manage your fatigue.

- **Diet and nutrition**

Diet and nutrition is important to all people, but is even more important when you are experiencing fatigue. A well-balanced diet, high in protein with carbohydrates and lots of fresh fruit and vegetables can help sustain your body's energy. You should try and aim to drink between 6-8 glasses of water a day, to make sure you are well hydrated and keep any toxins flushed through your kidneys.

- **Exercise**

Research has shown that exercise is one of the best interventions for improving fatigue during and post-treatment. Exercise helps to build your stamina and increase your strength, which in turn increases your overall energy levels and sense of well-being. If you find yourself in and out of hospital, you can contact one of the physiotherapy team or ask your medical team about a structured exercise programme and advice about gentle, regular exercise.

- **Complementary therapies**

Some people find that complementary therapies such as yoga, meditation and aromatherapy can help with fatigue. These



kinds of therapies can help reduce your anxiety levels which in turn will reduce your fatigue. Other ways of energising yourself are through arts workshops and joining a choir, for example.

- **Sleep**

Getting the right amount of sleep is very important. Although it is possible to sleep too much! If you need to rest or sleep during the day, make sure that you take yourself off to bed rather than dozing on the sofa and try not to sleep for any longer than two hours at the very most. Relaxation techniques such as listening to a relaxation CD or breathing exercises have been found to promote a better nights sleep. You could also try to avoid drinking caffeine or alcohol before bed and opt for malted drinks or warm milk instead.

Managing fatigue is all about pacing yourself. Many patients find that close family and friends could help in doing everyday chores, and tasks, such as ironing or cleaning. Accepting help in this way and understanding that you may not be able to do as much as you once could, can help you feel less pressured and help reduce tiredness.

Most importantly, you should listen to your body, and appreciate that your lifestyle may have to change to accommodate fatigue. However, there are ways of managing it, and it should not debilitate you.

All of the tips described are ideas for you to try. Everybody will be different and it is important for you to find what works best for you.

# Hair loss

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## Introduction

Hair loss is one of the most common side effects that patients encounter following cancer treatment, but that doesn't mean it affects everybody.

Losing your hair can cause distress for both men and women, but there are many ways to cope with it.

## What is hair loss?

Hair loss is when you lose the hair on your body. You may lose all your hair, some of your hair, or maybe none at all. It is most commonly thought of as loss of hair on your head, but it can also affect your eyebrows, eyelashes and body hair. It can occur gradually, or fairly quickly in just a couple of days after treatment.

## What causes hair loss?

Hair loss can be caused by chemotherapy and radiotherapy. The anti-cancer drugs used in chemotherapy destroy cancer cells by disrupting their growth. This can also include the hair follicles because these cells are also always growing and dividing. However, normal cells do recover, so your hair will almost always grow back when your treatment is finished. Your medical team will discuss this with you before you start your chemotherapy.

It can take about two to three weeks for your hair to start falling out from when you start chemotherapy, but this can vary from person-to-person, and depending on the treatment you have had. You may notice that when you touch your hair, brush it or wash it, it starts to fall out.

8

Total body irradiation is another form of treatment that may cause hair loss. In a similar way to chemotherapy, it can cause hair loss all over your body.



## Coping with hair loss

Losing your hair can have profound effects on your emotions. Regardless of whether you are male or female, young or old, it can affect the way you feel about yourself and others.

Hair loss can make you feel less self-confident, sad or even depressed. The value of hair should not be underestimated by anybody, and feeling like this is perfectly normal. There are ways of helping yourself cope better with the loss of hair.

When it first begins to fall out, it can cause an uncomfortable sensation on the scalp, so some people shave it off or cut it very short rather than let it fall out on its own. This can give you a feeling of some control.

When you have lost your hair, always remember you have a variety of options available to you. You may decide to invest in a wig, headscarves or you may decide to do nothing at all.

## Wigs

It is common for patients to imagine wigs as looking very unnatural. However, this is no longer the case and wig-making techniques have become more developed so they look much more natural.

The NHS makes provision for the supply of wigs to people who need them in order to help cope with medical hair loss. Choosing a wig can be daunting, but it is good to consider whether you want to replicate the hair you already have or perhaps go with a different style or even colour. Take someone along with you when choosing your wig for advice and support, and don't be afraid to ask a professional for help. Also practice wearing your wig in your own home, so that you feel more comfortable and confident wearing it when you are out.

There are two main wig options to consider - synthetic fibre and human hair.

Synthetic fibre wigs are pre-styled and available in a range of colours. When they are washed correctly they revert back to their original style, and they are less prone to colour fade. They can last from 9-12 months, but this can depend on the length, as longer styles can be more prone to 'friction frizz' from clothing.

Human hair wigs can be heat styled to exactly how you like it. This means they require more attention and the colour can fade. They do not frizz like synthetic wigs, but can be more difficult to manage.

There are wig styles for men too which can be customised to suit. They are available at some wig suppliers. Please visit [www.lookgoodfeelbetterformen.org](http://www.lookgoodfeelbetterformen.org) for more information.

### **Alternative head wear**

Some people may decide to use a hat or headscarf instead of a wig. These can include regular hats and scarves, as well as more specialist headwear.

Not only is this option comfortable, it offers flexibility as you can change the head wear dependent on the temperature, your environment and even your clothing.

### **Going without a replacement**

You may decide that you would like to go au naturale, and instead of a wig, you may decide to define yourself with make-up and jewellery. Do remember that the skin on your scalp can be very sensitive, especially in the sunlight, so take precautions to protect yourself if you choose not to opt for a wig or alternative head wear.

Moisturising your scalp frequently stops it from becoming dry and itchy.

You could also try wearing a scarf or turban at night as we lose a lot of heat from our head so this often stops people waking up at night feeling cold.

**Tip:** Some patients find that turning their head upside down and massaging three to four times a day can help promote healthy hair follicles by increasing blood circulation to the head.

### **Other options**

If you lose your eyebrows and eyelashes, make-up can be a great way of enhancing your features. Why not visit a make-up counter at your local department store or beauty salon for advice?



# Increased chance of infection

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## Introduction

White blood cells help us to fight infections, so anything that lowers the count can make it easier for infections to be picked up.

Blood cancers and their treatment can affect the immune system in a number of ways. Some cancers, particularly lymphomas and leukaemias, may reduce the effectiveness of the body's natural immune defences. They do this by preventing the bone marrow from producing enough healthy white blood cells.

Several factors can affect the white blood count, including chemotherapy and radiotherapy so patients who are undergoing this type of treatment are often prone to picking up infections such as chest infections, coughs and colds.

## Chemotherapy

Chemotherapy can often have a major effect on the immune system and may reduce the body's defences against infection for quite some months, both during and after treatment. This is because chemotherapy reduces the number of white blood cells produced by the bone marrow. Patients undergoing chemotherapy are at risk of picking up infections 7-14 days after the chemotherapy, when the level of white blood cells are at their lowest. However, this is person and treatment dependent and can often happen before the seven days or after the 14 days.

## Radiotherapy

Radiotherapy often has a mild and temporary effect on the immune system, which is unlikely to cause any major problems except for people who have had radiotherapy to their whole body (total body irradiation). During total body irradiation, all the bone marrow in the body receives a dose of radiation that temporarily lowers the production of white blood cells, so the person will be at risk of infection for a while.

## Avoiding infection

You are the only person who understands what your body is telling you, so if you're feeling under the weather, avoid going out and about. You're more likely to pick up an infection or virus if you're feeling unwell. If you're feeling well, don't be afraid to go out. You just need to use your common sense and be a bit more cautious about who you are coming into contact with.

Try to avoid people with coughs and colds and busy places such as shopping centres and supermarkets, especially just after your treatment. This is called the nadir period – the period when your blood count is at its lowest.

Avoid having a takeaway and eating raw or uncooked foods. This is just a precautionary measure but will avoid any gastric upset.

The shingles infection is particularly common in people undergoing cancer treatment (such as chemotherapy) as it suppresses the immune system, making you more susceptible to infection. However, the shingles vaccine (as well as any other live vaccine) should not be given to anyone undergoing chemotherapy treatment because the immunity is lowered by the disease. If you do contract shingles, speak to your medical team straight away.

## Treatment of infections

Infections can usually be treated effectively with antibiotics. However, if left untreated, an infection can be difficult to get under control, and is often treated as an emergency.

Contact your doctor or the hospital straight away if:

- your temperature goes above 37.5 °C.
- you suddenly feel unwell, even with a normal temperature.

These are signs of a possible infection and you may need to have antibiotic treatment, either as tablets or by drip (intravenous injection).

The sooner you raise the alarm and let your specialist team know, the better.

# Anaemia

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## Introduction

Anaemia essentially means a lack of blood and in particular red blood cells. The red blood cells, or haemoglobin, are required to help carry oxygen around the body. It is fairly common in blood cancer patients and many will develop it at some point during their illness as a result of the illness itself or treatment.

Blood tests will be able to establish whether you have anaemia and inform your medical team on the appropriate action to take.

## What causes anaemia?

People can become anaemic for a number of different reasons. If you have leukaemia or a condition where the bone marrow isn't working properly, this can cause a drop in haemoglobin. Chemotherapy and other cancer drugs can affect your haemoglobin level, causing it to be low for the duration of the time you are on treatment, and often for a period of time afterwards as well. Often, the haemoglobin recovers after chemotherapy without people needing a transfusion.

## Symptoms of anaemia

Anaemia can often go undetected as the symptoms can vary and can be very vague, for example, tiredness, feeling weak and pale in colour. Many blood cancer patients often see these symptoms as a natural side effect of their illness.

If the number of red blood cells in your blood is low, you may feel like you have no energy. You may also become breathless.

These symptoms occur because the red blood cells contain haemoglobin, which carries oxygen around the body, are low, and therefore the oxygen level in the body is low.

## Treating anaemia

Initially, if you feel as though you have the symptoms of anaemia, you should contact your specialist nurse who may suggest that you visit your GP to have your bloods checked for levels of haemoglobin. Your doctors may recommend that you have a blood transfusion if your haemoglobin level is very low.

A blood transfusion will increase the number of red blood cells in your blood, which will enable more oxygen to be carried around the body, meaning you'll have more energy and you won't feel as breathless, tired or look as pale.



# Gastrointestinal side effects

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## Introduction

Cancer drugs can have various effects on your digestive system. Some can induce nausea and vomiting, others can cause constipation and diarrhoea. Different cancer drugs will affect people differently and while not all of them will affect your digestive system, gastrointestinal side effects are common.

## Nausea and vomiting

Chemotherapy induced nausea and vomiting (CINV) is a common side effect of many chemotherapeutic drugs. It is estimated that more than 70% of patients will experience some degree of CINV during their treatment.

### What causes CINV?

There are treatment and external factors that contribute to the risk of developing CINV. Some types of chemotherapy may not cause nausea and vomiting, while others may.

The chemotherapeutic drugs that are known to have a high risk of nausea and vomiting are referred to as **highly emetogenic chemotherapy** and the drugs that have a moderate risk are called **moderately emetogenic**.

External risk factors include:

- patients under 55-years-old
- history of low or zero alcohol consumption
- female patients
- history of morning sickness or motion sickness
- previous experience of CINV

## Types of CINV

There are several types of nausea and vomiting as a result of chemotherapy drugs:

1. Acute – occurs within 24-hours of receiving chemotherapy.
2. Delayed – occurs 1-5 days after chemotherapy treatment.
3. Breakthrough – occurs despite chemotherapy treatment.
4. Anticipatory – sickness triggered by taste, odour or anxiety related to chemotherapy.
5. Refractory – occurs during subsequent cycles when antiemetic drugs (a drug that is effective against vomiting and nausea) have failed in earlier chemotherapy cycles .

You may experience some, all or none of these types of CINV.

## Treatment of CINV

Treatment methods are available to help prevent and manage CINV. Anti-sickness drugs, called antiemetics, are often given before the dose of chemotherapy and given to treat breakthrough nausea and vomiting.

5-HT3 inhibitors are a very effective antiemetic. They work by blocking one or more of the nerve signals that cause nausea and vomiting. Some 5-HT3 inhibitors include: ondansetron, NK1 drugs such as Emend and dexamethasone.

Complementary therapies have also reportedly been effective in helping to reduce CINV. These include eating ginger, acupuncture, guided imagery therapy, music therapy and muscle relaxation.

## Changes in appetite

Cancer drugs can affect your appetite and you may lose your appetite for a variety of reasons. Feeling sick, changes in taste sensations and lethargy can all affect your appetite. Chemotherapy may put you off your food and some biological therapies such as interferon can cause taste changes, loss of

appetite as well and sickness and diarrhoea.

Some doctors and nurses advise you to avoid your favourite foods whilst undergoing cancer treatment as you may learn to associate the treatment with the food and go off it permanently.

If you're worried about losing weight due to a loss of appetite, your medical team will be able to recommend some high calorie drinks that you can sip.

## Diarrhoea

Diarrhoea is a common side effect of some chemotherapy drugs. It will usually occur in the first few days after treatment and can sometimes be quite severe.

If you do experience severe diarrhoea, you will become dehydrated quite quickly so it's important that you drink plenty of fluids. Make sure you tell your medical team if you are experiencing bad diarrhoea as there are treatments available that will be able to help you control it.

## Constipation

Some chemotherapy drugs and biological therapies, as well as some anti-sickness drugs given with chemotherapy, can result in constipation. This can be because the drugs affect the nerve supply to the bowel for a while.

Constipation is easily treated with laxatives and you should let your medical team know if you are experiencing constipation as they will be able to help you to relieve it.

Try to eat plenty of fresh fruit, vegetable and fibre which will help to encourage bowel movements. However, if your constipation doesn't ease, go back to your doctor or nurse.

# Mouth changes

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## Introduction

Sore mouth or oral mucositis, is the painful inflammation of the mucosal lining of the mouth. It is a common side effect of chemotherapy and usually begins four to ten days after chemotherapy and can last up to seven to ten days (or longer depending on treatment).

Not all patients receiving chemotherapy experience a sore mouth, although patients who receive high doses of chemotherapy or who undergo radiation to the head and neck have a higher risk of developing mucositis.

## Symptoms of sore mouth

Symptoms of oral mucositis include:

- mild to severe mouth pain
- erythema (redness)
- swelling
- difficulty in swallowing
- increases in, or decreased saliva

If you experience any of these symptoms after your chemotherapy, consult your doctor who will be able to advise you on how to manage sore mouth.

## Managing sore mouth

Good oral hygiene is the key to preventing or minimising oral mucositis. Good hygiene protects the mouth from infection, reduces irritation and the formation of plaque.

You can keep your mouth clean by:

- brushing teeth with a soft tooth brush regularly, especially after meals
- rinsing your mouth with a non-alcoholic mouth wash, salt water or baking soda
- keeping your lips moist to avoid dryness

Before you begin any course of chemotherapy, it is advisable to get a dental examination as this will help to correct any pre-existing dental problems.

You can also help to prevent mouth pain by:

- avoiding hot or spicy foods – keep them bland
- avoiding foods that are hard and could scrape the mouth lining
- drinking plenty of fluids to prevent dehydration which can occur due to difficulty in swallowing
- eating soft fruits
- avoiding chewing gum – there's a risk you might bite your tongue
- avoiding biting your lips
- avoiding or reducing alcohol and smoking
- you can also buy artificial saliva and oral solutions that can help with pain and discomfort. Ask your specialist for advice on what's available

### Treating sore mouth

For mild to moderate pain, your doctor may prescribe over the counter painkillers such as paracetamol. For more severe pain it may be necessary to prescribe stronger painkillers such as morphine.

Other medications such as sedatives may also be prescribed to aid rest when the mouth pain interferes with sleep.

Alternative therapies that have helped other patients include relaxation, massage therapy and counselling.

# Cognitive effects

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## Introduction

Many people who have received treatment for blood cancers report an invisible side effect which affects their cognitive – or thinking – processes. It is sometimes called chemo brain or chemo fog and refers to a range of thought processes.

Not everyone will be affected and the impact will vary from person-to-person.

## Causes of chemo brain

More research is needed about the causes of chemo brain and the symptoms are not yet completely understood. Studies of brain scans of patients treated with chemotherapy suggest that there may be changes to the structure of the brain and how it functions. This depends on the types of drugs given, the dose and the duration of the course.

Despite the name chemo brain, there are a number of other possible causes for these effects including hormonal changes such as early menopause, low oestrogen, anaemia and when radiotherapy is given in addition to chemotherapy. Other contributing factors include age, genetic factors and cancer itself.

Decreased concentration can also be caused by fatigue, depression, anxiety and stress. These are all common after treatment and so it is important to know that there are other factors involved.

Most people find that the effects only last for a short period of time. For others it takes a longer time for the brain to recover and the effects may last for some months or longer. In the meantime there are some strategies that you can use to help you cope and reduce the impact on your daily life.

## Symptoms

When suffering from chemo brain you may notice that you experience some or all of the following:

- memory difficulties
- struggling to find your words
- finding it hard to concentrate on a task
- planning, starting or completing tasks and multi-tasking is difficult
- taking longer to finish a task
- difficulty in making decisions and solving problems

These symptoms may be very subtle and difficult to describe. They can affect how you function in your daily life particularly when you are trying to resume life again after treatment. Please do seek help and support from your medical team if you are distressed.

## Coping with and managing chemo brain

When trying to cope with chemo brain, it is important not to put too much pressure on yourself. Keep your life as simple as possible and make sure you allow extra time to complete more complex activities. It may take some time for you to return back to your normal functioning. The following five tips may be useful to help you manage your symptoms and promote your recovery:

### 1. Understand what influences your memory or cognitive problems

When you first begin to experience cognitive problems, keep a log or a diary so you can record when you experience problems and what you were doing. It will help to note down how you were feeling at the time as what you felt might have influenced your cognitive functioning (e.g. hunger, noisy environment, fatigue etc.)

It might also help if you record when your brain was functioning well and what factors were involved. By doing this you can build up an accurate picture of what circumstances influence your functioning and you'll be better aware of when to do certain activities.

## 2. Activity scheduling and planning

Once you understand your memory and cognitive problems and what influences them, you'll be better able to plan your day. You can schedule more complex tasks at a time of day where your brain functions at its best. Similarly, you can leave simpler tasks to a time when you aren't functioning too well. To help plan your day, use a diary or calendar to monitor appointments, meetings and important dates so that you don't forget and miss them. At the end of the day, write a short summary of the day's events which will help you remember important things that you can refer back to if you need to.

## 3. Relieve stress

Memory problems can be stressful, but stress and anxiety can make things worse. Your brain can function much better when you are relaxed and calm. Relaxation isn't just about sleep - it's about making time to switch off your mind and body. Some people relax by exercising, others find watching TV or spending time with family is better for them. You're the one who's best placed to know what relaxes you and it is important to schedule relaxation into your day so you can rest your brain. Specific techniques such as 'relaxed breathing' or 'deep muscle relaxation' can help rest your mind. For more information on these techniques, take look at the NHS website or speak to a complementary therapist.

## 4. Learn coping strategies

To reduce your chances of forgetting things, you can employ some very simple coping strategies:

- Put objects such as your keys in the same place to minimise the chances of you losing them.
- Make lists of things you need to do, what you need to buy and where you have put things you might need.
- Write sticky notes and put them around your house in places where you're more likely to see them e.g. On the fridge and on the bathroom mirror.

- Repeating things back to people when you're having a conversation to commit things to your memory.
- Try to avoid busy and noisy environments when talking to people – it can make it harder to focus on what they're saying.

## 6. Brain training

When experiencing memory problems, it is tempting to stop doing mental activities to avoid being overwhelmed. However it's important to keep using your brain as it'll help you to recover. Activities such as crosswords, Sudoku and jigsaws can really help your brain 'tick over'.

Remember, everyone with chemo-related memory and cognitive problems will experience it differently. The severity and duration of the problems will vary considerably from person-to-person so it's important to not compare yourself to others and go at your own pace when coping with these problems.

If you're concerned about your memory and feel you need to talk to someone about it, you should visit your GP or talk to your medical team who can point you in the right direction and help you to manage your symptoms.



# Pain and tingling

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## Introduction

Peripheral neuropathy is a term used to describe damage to nerves that are outside the brain and spinal cord (peripheral nerves).

It is not caused by one specific disease and there are many different conditions and medications that can damage the peripheral nerves. The symptoms vary depending on which nerves are affected but peripheral neuropathy often affects the hands, feet and lower legs.

If you have any further questions, please speak to your doctor or nurse who will be able to advise you on managing and coping with peripheral neuropathy.

## Causes of peripheral neuropathy

One of the main causes of peripheral neuropathy is cancer and its treatment. There are several ways that the disease and anti-cancer drugs can cause peripheral neuropathy:

- Nerve damage – this is the most common cause of peripheral neuropathy in cancer patients.
- Radiotherapy – although rare, radiotherapy may damage nerves within the treated area. This may develop months or years after treatment.
- Paraneoplastic peripheral neuropathy – occasionally in some types of cancer, the body produces substances that damage peripheral nerves. This can occur in patients with myeloma and lymphoma.

You may be at higher risk of being affected by peripheral neuropathy if you:

- Are receiving more than one drug that can cause nerve damage.
- Have received previous anti-cancer drugs that can cause peripheral neuropathy.

- Have diabetes.
- Have low levels of vitamins and minerals in your body.

There are a large number of anti-cancer drugs that don't cause peripheral neuropathy. Your doctor will be able to discuss these with you and help you to consider your options.

## Symptoms of peripheral neuropathy

The symptoms of peripheral neuropathy vary depending on which peripheral nerves are damaged. Damaged nerves as a result of anti-cancer drugs usually affect the sensory nerves, but can also affect the motor and autonomic nerves.

Peripheral neuropathy usually affects the hands, feet and lower legs. The reason for this is because the nerves in these parts of the body are longer and the longer a nerve is, the more susceptible it is to damage.

Symptoms gradually improve once the drug is stopped, but can sometimes get worse for a few weeks after this, before they get better. This is known as coasting.

## Symptoms include:

- **Sensation changes**  
You may have a feeling of heaviness or a 'pins and needles' sensation in the affected area. You may also notice unusual sensations such as warmth or burning. You may also find that even the slightest touch in the affected area feels painful.
- **Pain**  
The pain can vary from person-to-person and can be mild or severe. The pain is often a sharp or stabbing feeling or a burning sensation. It can even feel like minor electric shocks. The good news is, there are treatments to relieve pain, which you can read about in this chapter.
- **Numbness**  
You may lose feeling in the affected area. Often the feet and finger tips are the first areas of the body to be affected.

- **Muscle weakness**

If a muscle isn't being stimulated by a nerve, it may lose strength. Depending on which muscles are affected, it may be difficult to walk or carry out tasks such as climbing the stairs.

- **Dexterity**

If the finger tips are affected, you might find it difficult to do fiddly tasks such as doing up buttons or tying your shoelaces.

## Coping and managing with peripheral neuropathy

If you're being given a drug that can cause peripheral neuropathy, your doctor will monitor you for signs of nerve damage before each treatment. The earlier damage is detected, the better, so it's important to tell your doctor if you notice any of the symptoms listed in this chapter, or they will get worse.

There isn't a treatment to prevent or reverse nerve damage caused by anti-cancer drugs. The most effective treatment is prevention of further nerve damage by either lowering the dose or stopping treatment altogether.

Most people find that their symptoms gradually improve as the nerves recover. For others, the damage will be permanent. People usually find ways to cope with this situation and find their symptoms become less troublesome over time.

Nerve pain can be managed in a number of ways:

1. **Drugs** – drugs can alter nerve impulses and relieve pain. Anticonvulsants, antidepressants and morphine can all be used to treat nerve pain.
2. **Acupuncture** – it's not clear how this type of complementary therapy works but it's suggested that it may block pain messages from being sent to the brain.
3. **Psychological support** – this may reduce anxiety and tension caused by the pain.
4. **Pain teams** – many hospitals have pain teams which are made up of specialist nurses and doctors who can advise on dealing with pain. Your GP or medical team can refer you if your pain is getting you down.

Peripheral neuropathy can affect different people in different ways. The level of support each person needs can vary from person-to-person. It's natural to feel isolated, lonely and frustrated if your symptoms start to affect your daily life. You may also feel anger, resentment and anxiety. It's important to remember that these feelings are all normal and your way of coping with the symptoms and side effects of your treatment.



# Graft vs host disease (GVHD)

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## Introduction

When a patient has a bone marrow or stem cell transplant, the body undergoes very high doses of chemotherapy. In some cases, the donated white blood cells can attack your own body's cells, which results in a condition called graft versus host disease (GVHD). After your transplant, your doctors and nurses will keep a very close watch for any symptoms of GVHD and will ask you to report any new symptoms. If your doctor suspects that you may have GVHD, you will have some tests and treatment for GVHD if you need it.

## What is GVHD?

GVHD is a complication of a bone marrow or stem cell transplant from another person. This is called a donor transplant or an allogeneic (aloe-gen-ay-ik) transplant. Bone marrow and stem cell transplants are treatments that use very high doses of chemotherapy, sometimes with radiotherapy. GVHD occurs when particular types of white blood cell (T cells) in the donated bone marrow or stem cells attack your own body cells. This happens because the donated cells (the graft) see your body cells (the host) as foreign and attack them.

T-cells are white cells that can identify "self" (cells that should be in our bodies) from "non-self" cells that should not be in our bodies for example bacteria and viruses. Once the donated bone marrow begins to grow in the patient's body, the donor's T-cells become very active and identify the patient's body tissue as "non-self".

## Graft versus tumour effect

Although GVHD is seen as a complication for some patients, GVHD may actually be useful if a bone marrow transplant is carried out due to having a haematological disease. As part of the process, donor T-cells may also recognise the host blood cells, including tumour cells, and seek to destroy them.

## Types of GVHD

GVHD is grouped according to when it starts after your transplant. It can be:

- Acute – starts within 100 days of your transplant.
- Chronic – starts at least 100 days after your transplant.
- Late onset acute GVHD and overlap syndrome.

### **Acute GVHD**

Acute GVHD can be mild or severe and it usually happens about two-three weeks after your transplant depending on the source of stem cells. Acute GVHD often starts with a rash on the palms of your hands and soles of your feet. Or you may have a rash on your face. The rash may be itchy. Acute GVHD may also affect your mouth, gut and liver, as well as your skin. This can cause diarrhoea, nausea, loss of appetite, and yellowing of the skin (jaundice).

### **Chronic GVHD**

Chronic GVHD can follow acute GVHD. It can appear several months after your transplant, even if you've not had the acute form. But you are more likely to get chronic GVHD if you have had acute GVHD. Like acute GVHD it may affect your skin, gut, liver or mouth. But it can also affect other parts of your body, such as your eyes, lungs, vagina and joints. Chronic GVHD may be mild or severe, and for some people can go on for several months or even years.

### **Late onset acute GVHD and overlap syndrome**

A National Institute of Health classification now includes late onset acute GVHD (starting after day 100) and an overlap syndrome with features of both acute and chronic GVHD. Late onset acute GVHD and the overlap syndrome occur more often after mini transplants (reduced intensity conditioning), which are being used more often now than in the past.

## Symptoms of GVHD

Symptoms in both acute and chronic GVHD range from mild to severe.

### **Acute GVHD symptoms include:**

- abdominal pain or cramps, nausea, vomiting, and diarrhea
- dry or irritated eyes
- jaundice (yellow coloring of the skin or eyes)
- skin rash, itching, redness on areas of the skin

### **Chronic GVHD symptoms may include:**

- dry eyes or vision changes
- chronic diarrhoea
- dry mouth, white patches inside the mouth, and sensitivity to spicy foods
- fatigue, muscle weakness, and chronic pain
- skin rash with raised, discolored areas, as well as skin tightening or thickening
- shortness of breath
- vaginal dryness/soreness/narrowing
- weight loss

## Diagnosis

Several laboratory and imaging tests can be done to diagnose and monitor problems caused by GVHD.

A biopsy of the skin, mucous membranes in the mouth or other parts of the body is the mainstay of diagnosis, although, occasionally diagnosis can rely on clinical symptoms and treatment might start before the results of the biopsy become available.

Patients with GVHD are unable to exhibit a full immune response and so you may not present the typical symptoms associated with infectious complications.

## Risk factors for GVHD

There are several risk factors for GVHD which can increase the likelihood that you develop GVHD after a stem cell or bone marrow transplant. These include:

**Age** - Older recipients have in general higher rates of GVHD.

**Graft source** - Peripheral blood stem cells have higher rates of GVHD than bone marrow stem cells.

**Donor type** - Unrelated donors carry a higher risk of developing GVHD.

**High number of white blood cells** - Donated stem cells or bone marrow that contains high numbers of T cells are more likely to cause GVHD. This is called a T cell replete transplant. Whilst this type of transplant may cause more GVHD, it may also lower the chance of relapse. T cell depleted transplants are the main conditioning regimen used in the UK and have a much lower risk of GVHD compared to T replete transplants.

**Conditioning** - Recipients of full intensity transplants are more likely to suffer from GVHD than reduced intensity conditioned transplants.

**Sex of the donor** - If your donor is a different sex to you, the risk of GVHD is slightly increased. This is particularly true if a male has a female donor who has had children or been pregnant in the past.

## Treatment of GVHD

Your treatment will depend on the grade of the GVHD. The grade depends on the number of organs affected (skin, bowel, or liver). GVHD can affect any or all of these three organs. The grade also depends on how bad it is.

**Grade 1** is mild GVHD – a quarter of your skin is affected.

**Grade 2** is moderate – up to half your skin is affected. There are mild changes in your liver or you may have some mild diarrhoea or nausea.

**Grade 3** is severe – more than half your skin is affected. You may look as though you have severe sunburn. Your liver is affected and you have stomach cramps and diarrhoea.

**Grade 4** is very severe – your skin has blistered and may have broken down in places. Your skin may be yellow (jaundiced) because your liver is not working properly. You may have severe diarrhoea. (Source: Cancer Research UK)

### Treating acute GVHD

If you develop acute GVHD at grade 2 or above, you'll usually have treatment involving medicines such as steroids to suppress the immune reaction. You may need to be admitted to hospital for monitoring and support with the symptoms.

### Treating acute GVHD of the skin

Mild to moderate GVHD means the rash may cover up to 50% of the skin surface. The skin can become itchy and treatment usually involves emollient creams (special moisturizing creams), medication to control the itch and/or steroid cream. It may be necessary to add in low doses of steroids by mouth.

Moderate to very severe GVHD means the rash covers more than 50% of the skin surface. Treatment will involve a combination of intravenous steroid infusions, steroid creams and emollient creams.

Some GVHD is difficult to treat and you may require additional medications or treatment. If you require additional treatment, this will be discussed with you by your medical team.

### Treating acute GVHD of the gut

Grade 1-2 will require low dose steroids (anti-inflammatory drugs) given by mouth or through a drip. Intravenous fluids may be required if the diarrhoea causes dehydration.

Painkillers for tummy cramps and anti-sickness drugs may also be given.

Grade 2-4 will include all the above treatments plus steroids, through a drip in a higher dose and/or other immunosuppressive drugs. Sometimes with GVHD the bowel will not tolerate food so you may not be able to eat, or even quite simply not feel like eating. In this case, feeding support may be given in one or two of the following ways:

- Naso-gastric (NG) feeding - where a tube is passed through the nose into the stomach, this is done while you are awake. Liquid food enters the stomach directly via the tube.
- Gastrostomy PEG - If you already have one of these this can be used instead of a naso-gastric tube. A gastrostomy PEG is put in place under a general anaesthetic by putting a special feeding tube through the abdominal wall into the stomach. This can be left in place for longer than an NG tube and would normally be planned before your transplant.
- If diarrhoea and vomiting are severe then you may need to be given nothing to eat or drink so that your (gut) stomach can rest. You would then require parenteral nutrition (PN). PN is when nutrition is given directly into the blood stream via your central line, allowing the gut to rest.

## Treating acute GVHD of the liver

- Low or high dose steroids or other immunosuppression drugs (as mentioned for gut GVHD) depending on the grade of acute GVHD of the liver.
- Medication to help stop itching, which can be given either by mouth, or by injection or drip.
- Painkillers if required.
- Blood product support, e.g. blood and platelets transfusions.
- Medication to improve blood clotting.

## Treating chronic GVHD

As with acute GVHD, your treatment will depend on the degree of your GVHD, and which part or parts of your body are involved. Treatment for chronic GVHD usually includes steroids.

## Treating chronic skin GVHD

The treatment for chronic GVHD of the skin includes keeping your skin clean using unperfumed soaps and moisturising creams.

If the skin problems are localised your doctor will prescribe steroid creams or you may be referred to a dermatologist. Because chronic GVHD can last for many months, sometimes years, you will need to carry on with the treatments for a long time. As with other chronic skin conditions this can take up a lot of time. You may need help from a partner or carer to manage your skin properly.

You can help yourself by wearing cotton clothes, washing in lukewarm water, patting your skin dry as opposed to rubbing and using lots of moisturising creams to relieve itchy, dry skin.

## Treating chronic gut GVHD

Chronic GVHD might affect your gut anywhere from your mouth to your bowel. Again it can last for a long time, so you may need to carry on with treatments long term.

You will need to clean your mouth regularly, especially if it is dry and sore.

If you have diarrhoea and find it difficult to drink enough fluids, you may need to have a drip. If you can't eat for whatever reason, your doctor may suggest feeding you through a tube. The tube will be either through your nose into your stomach, or directly into your bloodstream.

## Coping with chronic GVHD

The length of time chronic GVHD lasts varies. For many people it gradually improves over a few months, but for some it can last longer. The average length of time to have chronic GVHD is between one and three years.

Chronic GVHD can be very difficult to cope with, especially when you have been through such a lot of treatment and you may have been free of symptoms before your transplant. So dealing with long term, uncomfortable symptoms after your transplant can be hard to accept.

You may find it difficult to go back to work and get back to some sort of normal life again. This may lead to money worries or leave you feeling out of control which can leave you feeling low or depressed.

Some forms of GVHD can affect your appearance which may leave you lacking in confidence and may start to have an impact on your relationships.



It will help to share your feelings with other people, whether that's family, friends or your medical team. You can even speak to a support advisor on our CARE Line on 08088 010 444 who will be able to offer advice and support when you need it.



# About Leukaemia CARE

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Leukaemia CARE is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

## Our services

### CARE Line

Our 24-hour CARE Line is available any time of the day or night.

### Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience.

### Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

### Website

You can access up-to-date information on our website, [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk), as well as speak to one of our CARE advisers on our online support service, LiveChat (9am-5pm weekdays).

### Campaigning and Advocacy

Leukaemia CARE is involved in campaigning for patient well-being, NHS funding and drug and treatment availability.

### Journey magazine

Our quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals.

# Useful contacts

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There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- your haematologist and healthcare team
- your family and friends
- reliable online sources, such as Leukaemia CARE
- charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

## Cancer information and support

### Leukaemia CARE

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer. We provide emotional support through a range of support services including a 24 hour CARE Line, patient and carer conferences, support group, informative website, one-to-one buddy service and high quality patient information.

**Care Line: 08088 010 444 (Freephone 24 hours a day)**

**[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)**

**[care@leukaemiacare.org.uk](mailto:care@leukaemiacare.org.uk)**

### Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They also offer support to patients, their family and friends through patient services.

**020 7504 2200**

**[www.bloodwise.org.uk](http://www.bloodwise.org.uk)**

**[patientservices@bloodwise.org.uk](mailto:patientservices@bloodwise.org.uk)**



## Lymphoma Association

The Lymphoma Association provides information and support to people affected by lymphatic cancer.

**0808 808 5555**

**[www.lymphomas.org.uk](http://www.lymphomas.org.uk)**

## MDS UK

MDS UK provides information and support if you are affected by MDS.

**020 7733 7558**

**[www.mdspatientsupport.org.uk](http://www.mdspatientsupport.org.uk)**

## Myeloma UK

Macmillan provides free practical, medical and financial support for people facing cancer.

**0800 980 3332**

**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

## Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

**0808 800 4040**

**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

## Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

**0808 808 0000**

**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

## Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

**0300 123 1801**

**[www.maggiescentres.org](http://www.maggiescentres.org)**



## Counselling and emotional support

### British Association for Counselling and Psychotherapy (BACP)

The BACP aims to increase public understanding of the benefits of counselling and psychotherapy and raise awareness of therapy to increase its availability.

**01455 883300**

**[www.bacp.co.uk](http://www.bacp.co.uk)**

## Hair care and information

### My New Hair

A charity which provides unbiased information, support and advice concerning hair loss. They also provide access to a responsibly trained national network of salons which can cut and style wigs, as well as provide advice on when your hair begins to grow back.

**[www.mynewhair.org](http://www.mynewhair.org)**.

### Look Good Feel Better

Charity offering hair and beauty advice and workshops for women undergoing cancer treatment.

**[www.lookgoodfeelbetter.co.uk](http://www.lookgoodfeelbetter.co.uk)**



# Notes

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# Notes

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# Notes

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Leukaemia CARE is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

## Want to talk?



**CARE Line:** 08088 010 444  
(free from landlines and all major mobile networks)

**Office Line:** 01905 755977



[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)  
[care@leukaemiacare.org.uk](mailto:care@leukaemiacare.org.uk)

Leukaemia CARE, One Birch Court,  
Blackpole East, Worcester, WR3 8SG

Registered charity 259483 and SC039207

