WE ARE MACMILLAN. CANCER SUPPORT

#### A practical guide to living with and after cancer

# **BONE** HEALTH



## About this booklet

This booklet is about bone health. It is for people who are having, or have had, cancer treatments that may affect their bones. This includes:

- high-dose steroids or steroids for three months or more
- hormone treatments for breast cancer or prostate cancer
- treatments that cause an early menopause in women
- treatments that affect testosterone levels in men.

This booklet explains which factors affect bone health and things you can do to help maintain healthy bones. It also tells you about drug treatments that can improve bone strength.

This booklet does not have information about cancer in the bone. We can send you information about cancer that starts in the bones (primary bone cancer) and cancer that has spread to the bones (secondary bone cancer).

We hope this booklet answers some of your questions. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history. We have included quotes from people affected by cancer. Some are from members of our Online Community (macmillan.org.uk/community). If you would like to share your story with us, visit macmillan.org.uk/shareyourstory Others are from people who have shared their stories on healthtalk.org

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk** 

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

#### How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list opposite to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

### Contents

What affects bone health? Looking after your bones Tests and treatments Further information





## WHAT AFFECTS BONE HEALTH?

The bones	6
Factors that affect bone health	10
Cancer treatments and bone health	15

### The bones

Bones have several functions. They:

- provide support and protection for your internal organs
- work with your muscles to allow your body to move
- store calcium and other minerals
- contain bone marrow, which is where your blood cells are made.

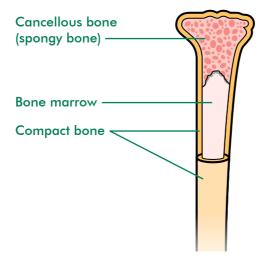
Bones have developed so that they are strong and rigid without being heavy. Bone is made from a protein called collagen, which is strengthened by calcium and other minerals.

#### Types of bone

There are two types of bone – compact bone and cancellous bone.

**Compact bone** is the hard, rigid shell on the outside of bones. Inside this shell is **cancellous bone**, which is arranged like a honeycomb or mesh with lots of spaces. It is sometimes called spongy bone, because the holes in it make it look a bit like a sponge.

#### The structure of a long bone



#### Bone growth and repair

Bone tissue is alive. It has a blood and nerve supply to stay healthy. Bones are constantly renewing themselves. This helps maintain their strength and shape.

Inside the bones, there are two types of bone cell:

- Osteoclasts, which break down and remove old bone.
- Osteoblasts, which build new bone.

Our bones stop growing in length by the time we are about 18 years old. But bones continue to increase in thickness (density) until our late twenties.

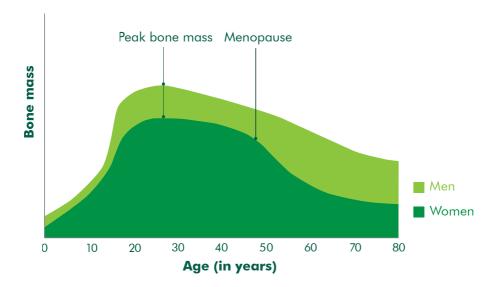
Bone density then stays about the same into our mid-thirties. After this, osteoclasts remove more bone than osteoblasts make. This causes bone density to slowly decrease.

#### **Bone thinning**

As we age, our bone density slowly decreases. This is called 'bone loss' or 'bone thinning'.

The hard, outer shell of the bones (cancellous bone) thins and the holes in cancellous (spongy) bone get larger. In time, bones become more fragile. This is why bone fractures are more common after the age of 65.

#### Bone mass at different ages



#### Osteoporosis

Some people develop osteoporosis as they get older. Osteoporosis means bone density is much lower than normal. The bones are weaker and more likely to break (fracture) – see page 12. The most common places to have fractures are the wrists, hips and spine.

Osteoporosis does not cause symptoms until a weakened bone breaks (fractures). But your doctor can do tests to assess your risk of osteoporosis and to check the health of your bones (see pages 36 to 39). The results of these tests help doctors decide if you need treatment to lower your risk of a fracture (see pages 40 to 47).



A healthy bone



A bone with osteoporosis

# Factors that affect bone health

Many factors can affect bone health and your risk of osteoporosis. There are some factors you cannot do anything about, such as your age or family history. But there are also factors you can control, such as your diet and levels of physical activity.

#### Age

Your bones are strongest when you are in your twenties. Bone loss begins in your thirties. The risk of a fracture due to bone loss increases steadily from the age of 50. Fractures are most common in women over the age of 65 and in men over the age of 75.

#### Gender

Both men and women can develop osteoporosis, but it is more common in women. This is because after the menopause, women lose bone density more quickly as their oestrogen levels fall. Oestrogen is a hormone that helps keep bones healthy.

#### **Physical activity**

Being physically active when you are a young adult helps make your bones stronger and denser. Regular exercise throughout life helps to maintain your bone strength. Weight-bearing exercises such as walking or climbing stairs are particularly helpful for bone strength.

#### Diet

Eating a balanced diet helps keep bones healthy. It is important to get enough protein, calcium and vitamin D (see pages 22 to 26). They help build bones and keep them strong.

#### Family history of osteoporosis

If one, or both, of your parents have had osteoporosis, you are more at risk of developing it too.

#### **Fractures**

If you break a bone after falling from a standing height or less, this is called a fragility fracture. After the age of 50, it can be a sign that you have weaker bones and are more at risk of having a fracture in the future.

#### Weight

People who have a low body weight are more at risk of fractures than people who weigh more.

Body mass index (BMI) is a measure of healthy weight. Your BMI is based on your height and weight. Guidelines recommend that for bone health and general health your BMI should be between 19 to 25kg/m<sup>2</sup>. Your GP or practice nurse can work out your BMI for you.

You can use the chart on the next page to check your BMI. Find the line that matches your weight and follow it until it crosses the line that matches your height. Speak to your GP or nurse if you are above or below the 'healthy' range.



#### **BMI chart**

Source: Department of Health

#### Smoking

Several studies have shown that smoking reduces bone density, weakens bones and increases the risk of osteoporosis. Our booklet **Giving up smoking** has tips to help you quit. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00** to order a free copy.

#### Alcohol

Drinking alcohol in moderation is not harmful to bone health. But if you often drink more than 21 units a week, your bone density may be reduced, increasing the risk of osteoporosis.

It is best to keep within the government guidelines of not drinking more than 14 units a week. If you regularly drink as much as 14 units per week, it is best to spread your drinking evenly over three or more days. You should also try to have several alcohol-free days a week. See page 27 for more information about alcohol guidelines.

Drinking alcohol also causes a higher risk of falls, which are a common cause of fractures.

#### Illness

Some illnesses have been linked to lower bone density. These include:

- diabetes (type 1 and type 2)
- asthma
- inflammatory rheumatic diseases, such as rheumatoid arthritis and lupus (SLE)
- inflammatory bowel diseases, such as Crohn's disease and ulcerative colitis
- long-term liver or kidney disease
- thyroid diseases, such as having an overactive thyroid gland
- eating disorders, such as anorexia.

If you have a disability that makes walking difficult or makes you less mobile, this can also mean you are likely to have a lower bone density.

#### **Medicines**

Some drugs may increase your risk of fractures and of developing osteoporosis. These include the following:

- **Steroids**, which are given to treat a number of illnesses, such as rheumatoid arthritis and asthma. They may also be used in some cancer treatments (see page 18).
- Some **anti-epileptic drugs**, such as phenytoin. Anti-epileptic drugs are mainly used to prevent fits (seizures) in people who have epilepsy.

# Cancer treatments and bone health

Cancer treatments that reduce the levels of the hormones oestrogen or testosterone can cause bone loss. This includes:

- hormonal treatments
- treatments that cause an early menopause in women.

If a treatment puts you at a high risk of changes in your bone health, your doctor may give you treatments to protect your bones (see pages 40 to 47).

#### Hormonal therapy for breast cancer

Some drugs that treat breast cancer work by reducing oestrogen levels. They include anastrozole (Arimidex<sup>®</sup>), exemestane (Aromasin<sup>®</sup>), letrozole (Femara<sup>®</sup>) and goserelin (Zoladex<sup>®</sup>). Taking these drugs for several months or more can cause bone loss and increase the risk of fractures.

'My cancer is hormone-positive so I've been on Zoladex and Arimidex, and this has resulted in my bone density being much lower than average for my age.'

Heather

Not all hormonal therapies for breast cancer cause bone loss. The drug tamoxifen reduces bone loss in women who take it after the menopause.

#### Hormonal therapy for prostate cancer

Some drugs for prostate cancer reduce the level of testosterone. These drugs include goserelin (Zoladex<sup>®</sup>), leuprorelin (Prostap<sup>®</sup>) and triptorelin (Decapeptyl<sup>®</sup>, Gonapeptyl Depot<sup>®</sup>). A side effect of these drugs is bone loss.

#### Chemotherapy drugs

Some chemotherapy drugs affect the ovaries or testicles. This can reduce the levels of oestrogen in women or testosterone in men. The effect can be temporary or permanent. Having lower than normal levels of these hormones before the age of 50 can lead to bone loss. Your cancer doctor or nurse can tell you if chemotherapy is likely to affect your hormone levels.

A few chemotherapy drugs, such as methotrexate and ifosfamide, may weaken bones. If your treatment includes these drugs, your doctor or nurse will talk to you about this.

#### Surgery

Hormone levels are reduced if:

- a man has an operation to remove both his testicles
- a woman has surgery to remove her ovaries before she has gone through the menopause.

The reduced hormone levels can lead to bone loss.

#### **Radiotherapy**

#### Radiotherapy to the ovaries

Radiotherapy to the ovaries before the menopause reduces oestrogen levels in women. This increases the risk of bone thinning (osteoporosis).

#### **Pelvic insufficiency fractures**

Radiotherapy can cause changes to the bone in the area being treated. It is most likely to happen when women are given radiotherapy to the pelvic area. This may be used to treat cancer of the anus, bladder, womb, cervix or rectum.

Radiotherapy can cause changes to the bone, meaning it cannot cope as well with the normal stresses put on it. This can lead to fractures. Doctors call these types of fractures pelvic insufficiency fractures (PIFs). PIFs are most likely to happen in the first two years after pelvic radiotherapy.

PIFs do not always cause noticeable symptoms. They may show up on a scan done for another reason. About 5 in 100 women (5%) develop symptoms due to a PIF. Symptoms can range from a mild ache to severe pain. There may be pain in the lower back or pelvis when moving. This can make walking difficult. Pain is not usually a problem at rest or during sleep. If you have a higher risk of osteoporosis (see page 9), you are more likely to have a PIF after pelvic radiotherapy. Looking after your bones may help to reduce your risk (see pages 22 to 33). You can reduce your risk by:

- not smoking
- eating well
- only drinking alcohol in moderation.

If you have pain in a bone, always tell your doctor. They can arrange for tests to check for the cause and give you treatment if needed.

#### **Steroid therapy**

Some people have steroids as part of their cancer treatment. Commonly used steroids include prednisolone and dexamethasone. High-dose steroid treatment or taking steroids for three months or more can cause bone loss and increase the risk of fractures.

#### **Targeted therapies**

Targeted therapies are drugs that target changes within cancer cells to stop them growing.

Some targeted therapy drugs may affect bone health. These drugs are:

- imatinib
- nilotinib
- dasatinib.

They may affect the level of calcium in the blood. If calcium levels are low for a long time, this can cause bone loss. It is important to get the recommended amount of calcium and vitamin D. Your cancer specialist will check your calcium levels with a blood test every 3 to 6 months. If your levels become lower than normal, they can give you treatment to correct this.

> 'I have had long-term side effects from my cancer treatment, like osteoporosis and stiffness. However, these side effects have encouraged me to make changes to my life: better diet and exercise and a more balanced way of life.'

Christine



## LOOKING AFTER YOUR BONES

What you can do

Exercise

22 29

## What you can do

There are changes you can make to improve your bone health and reduce your risk of osteoporosis. These changes are helpful for everyone, so your family and friends can benefit from them too.

#### Eat well

Eat a balanced diet. In particular, make sure you eat foods that contain calcium and vitamin D. This will help keep your bones strong and healthy.

A balanced diet includes:

- lots of fruit and vegetables
- some foods that are rich in protein, such as meat, fish, soya beans and lentils
- starchy foods (carbohydrates), such as rice, bread, pasta, potatoes and whole grains
- milk and dairy products, such as yoghurt and cheese
- only a small amount of foods that are high in fat, salt and sugar.

We have a booklet called **Healthy eating and cancer**, which we can send you. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00** to order a free copy.

#### Calcium

Public health bodies in the UK recommend most adults should have 700mg of calcium a day. If you have osteoporosis, your doctor may advise having 1,000mg a day.

Eat foods that are rich in calcium, such as:

- dairy products (these contain the highest amounts of calcium)
- tinned oily fish where you eat the bones (sardines are particularly high in calcium)
- leafy green vegetables, for example broccoli and curly kale
- nuts
- soya beans, tofu, kidney beans and baked beans
- dried fruit, for example figs, apricots and raisins.

If you have a dairy-free diet, make sure you eat non-dairy foods that contain calcium. You may also choose to have products with added calcium. These include some types of fortified non-dairy milks and orange juice. Always shake the carton well before use. This ensures the calcium mixes throughout the drink.

Some foods and drinks upset the calcium balance in the body. Avoid large amounts of them. They include:

- caffeine
- red meat
- salt
- fizzy drinks that contain phosphates, such as cola.

The National Osteoporosis Society has more information about the amount of calcium in specific foods (see page 57).



#### Get enough vitamin D

Vitamin D helps your body absorb calcium. It is important to get enough of it to maintain healthy bones and muscles.

Sunlight is the best natural source of vitamin D. In the UK, exposing your skin to sunlight daily between 11am and 3pm from May until September increases vitamin D levels. It is recommended that adults get ten minutes of sun on bare skin (without sunscreen) once or twice a day depending on their skin type. But take care not to burn, especially during strong sunshine. On cloudy days, it will take longer than ten minutes to get enough vitamin D.

We only get a small amount of vitamin D from the food we eat. But it is important to include vitamin D-rich foods in your diet, such as:

- oily fish
- red meat
- liver
- egg yolks.

Some breakfast cereals and fat spreads have vitamin D added to them. You can check the labels to find out.

During the winter months, when sunlight levels are low, it is difficult to get enough vitamin D from food alone. Because of this, government advice is for people to consider taking a daily supplement containing 10mcg (800 IU) of vitamin D.

The government advises that people who are more likely to have low levels of vitamin D consider taking a vitamin D supplement all year round. This includes people who:

- cover their skin when outside
- have dark skin, from African, African-Caribbean and South Asian backgrounds
- do not spend regular time outdoors every day, such as people who are housebound or in a care home.

You can buy vitamin D supplements from supermarkets, health food stores and pharmacies. If you are unsure what to buy, ask your GP or pharmacist for advice.

If you are having cancer treatment that increases the risk of osteoporosis, your GP or hospital doctor may prescribe vitamin D and calcium supplements for you (see page 40).

#### Don't smoke

If you smoke, giving up will be good for your bones and your general health. We can send you our booklet **Giving up smoking**, which has tips to help you quit. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00** to order a free copy.

#### Keep to alcohol guidelines

If you drink alcohol, stick to recommended guidelines. Current drinking guidelines recommend that men and women drink no more than two units of alcohol a day or 14 units a week.

One drink is not the same as one unit of alcohol. As a guide:

- a single measure (25ml) of spirits contains one unit
- half a pint of standard strength (3% to 4%) beer, lager or cider contains one unit
- half a pint of stronger (5%) beer, lager or cider contains one and a half units
- a standard glass of wine (175ml) contains two units
- a large glass of wine (250ml) contains three units.

Drinking large quantities of alcohol in one session (binge-drinking) is thought to be worse for your health than drinking a small amount each day. It is also recommended that you have a couple of alcohol-free days each week.

#### Get physically active

Most of us need to reduce the amount of time we spend sitting and get more active.

Physical activity and strength training makes bones stronger. It can also improve your co-ordination and balance, which makes you less likely to fall. Falls are a common cause of fractures, especially as people get older.

If you haven't exercised much before, you will need to start slowly. Talk to your doctor before starting any exercise programme. This is especially important if you have, or are at risk of, osteoporosis. Your GP can tell you if there are any exercises you should avoid. They can also tell you if there are any exercise schemes in your area. You can read more about exercise on pages 29 to 33.

> 'Even though I am very limited in what forms of exercise I can do, I still try and do little bits of movement. And especially weight-bearing exercise because that will keep the bones strengthened.'

Christine

### Exercise

There are lots of different ways to exercise. It is best to find something you enjoy. This will make it easier for you to keep doing it. You need to exercise regularly to get the most benefit.

It is best to do the following types of exercise:

- Activities that raises the heart rate for 30 minutes, five times a week. The 30 minutes could be made up of three 10-minute periods of activity. This type of aerobic activity strengthens the heart and lungs.
- Physical activity that improves muscle strength at least two days a week.
- Exercises to improve balance and co-ordination at least two days a week.

When exercising, do not push yourself too hard. At the end of an activity, you should feel warm and slightly out of breath, but not exhausted. With practice, you will soon find you are able to do more.

'After starting out with light exercise and just trying to increase my walking levels, I have now gone on to working out three times a week and love it!'

Clare

#### Weight-bearing exercise

Exercise that is weight-bearing is particularly good for your bone health. Weight-bearing exercises include walking, jogging, skipping, climbing stairs, dancing and hiking. Swimming and cycling are good for your heart and lungs but are not weight-bearing.

Weight-bearing exercises can be high-impact or low-impact. Check with your doctor if you are not sure if it is okay for you to do high-impact exercises. If you have a high risk of fractures or you have had a fracture in the past, you may be advised to only do low-impact exercises.

High-impact exercises include:

- jogging
- hiking
- skipping
- racket sports like tennis
- some types of dancing.

Low-impact exercises include:

- walking (either outside or on a treadmill machine)
- using an elliptical training machine or cross-training machine
- low-impact aerobics
- stair-step machines.



#### Strength-building exercises

These exercises make your muscles work harder than usual, against some form of resistance. They strengthen muscles, bones and joints. They may also improve your balance. You can do them with hand weights, machines or elastic bands.

#### Exercises to improve balance and flexibility

Having flexible joints helps you stay supple and prevent injuries and strains. Simple stretching exercises are a good way to start. It is best to do these stretches as a daily routine. They will only take you a few minutes.

Yoga, tai chi, pilates, body balance and qi gong are good for flexibility and balance. They can also help you relax and reduce stress. Balance exercises help increase strength as well as balance.

If you have osteoporosis or you have had a fracture in the past, avoid sudden movements or exercises where you bend forward and twist your waist. These movements can increase your risk of fractures in the spine.

#### Next steps

We can send you our booklet **Physical activity and cancer**. You can also get more information about physical activity and bone health from the National Osteoporosis Society (see page 57).

The infographic opposite shows the amount of physical activity recommended for adults. It also suggests different ways of doing it.

#### Physical activity guide for adults





## TESTS AND TREATMENTS

Tests to check bone health	36
Drug treatments	40
Specialist referral	48
Share your experience	49

# Tests to check bone health

If you think you are at risk of weakened bones (see pages 10 to 14), talk to your GP or hospital doctor. They can do tests to check your bone health.

### Fracture risk assessment tools

There are two online tools that doctors in the UK can use to see whether you are at risk of a fragility fracture (see page 12). These are called FRAX<sup>®</sup> and QFracture<sup>®</sup>. Your doctor may use one of these tests if you:

- are over the age of 40 and they are concerned about your bone health
- have risk factors for bone loss.

When your doctor uses the online tool, they will ask about your:

- height
- weight
- medical history
- possible risk factors for osteoporosis or fragility fractures.

The online tool then works out your risk of developing a fracture. The results will show whether you have a low, intermediate or high risk of a fracture.

# Dual energy x-ray absorptiometry scan (DXA scan)

This scan may also be called a bone mineral density scan (BMD scan). It checks the density of your bones. If your bone density is low, you have a higher risk of a bone fracture.

### Who has a DXA scan?

Your GP or hospital doctor may arrange for you to have a DXA scan if:

- a fracture risk assessment shows your risk of fracture is intermediate (between low risk and high risk)
- you are under the age of 40 and have a significant risk of fracture – for example, you have had more than one fragility fracture, or have recently taken high doses of steroids (see page 18)
- you have had an early menopause and you have not had hormone replacement therapy (HRT)
- you are a woman with early invasive breast cancer and you:
  - are going to start treatment with an aromatase inhibitor
  - have had an early menopause due to your treatment
  - are going to have treatment to stop your ovaries working
- you are a man with prostate cancer and you are going to start treatment with hormonal therapies that reduce testosterone levels – if you are on long-term hormonal therapy, you should have a DXA scan every year
- you are taking steroids.

#### How the scan is done

During the DXA scan, you lie on your back on a couch while a scanner moves above your body. The amount of radiation from a DXA scan is much less than from a normal x-ray.

The scan only takes a few minutes and is painless. It is important there are no metal fastenings such as zips in the area being scanned. You may be asked to put on a hospital gown for the scan.

#### **DXA** scan results

The results of the scan will show whether you have:

- normal bone density
- low bone density (osteopenia)
- osteoporosis (see page 9).

Your DXA scan results are reported as a number called a T-score. Your T-score is your bone density compared with the bone density of an average healthy young adult of your gender. Your T-score is the number of units that your bone density is above or below the average.

#### What your T-score means

T-score	
-1 and above	Your bone density is normal.
Between -1 and -2.5	Your bone density is below normal. Doctors call this osteopenia.
-2.5 and below	This score suggests you have osteoporosis. Your bone density is low and your bones are at higher risk of fracture.

### After bone health tests

If tests to check your bone health show you have low bone density or a high risk of fracture, your GP may advise you to:

- take calcium and vitamin D supplements (see page 40)
- take vitamin D supplements and increase the amount of calcium in your diet
- take a drug treatment, such as a bisphosphonate (see pages 41 to 43)
- eat a healthy, balanced diet (see pages 22 to 26)
- get enough sunshine (if this is possible)
- keep physically active (see pages 29 to 33).

# **Drug treatments**

There are different drug treatments that can help prevent or treat bone loss and reduce the risk of fractures.

### **Calcium and vitamin D supplements**

If you are having cancer treatments that are known to increase your risk of osteoporosis (see pages 15 to 19), your cancer doctor may advise you to take calcium and vitamin D supplements. They will usually organise a fracture risk assessment or a DXA scan (see pages 36 to 39) before deciding whether you need to take them.

You can buy vitamin D supplements without a prescription, but always ask your GP what dose to take. If you are thinking about buying calcium supplements, talk to your doctor. You may be able to get enough calcium from your diet.

# **Bisphosphonates**

These drugs are widely used. They can help to:

- reduce the risk of fractures in people with osteoporosis
- prevent bone loss caused by hormonal therapy and other cancer treatments (see pages 15 to 19)
- prevent cancer spreading to the bone
- treat cancer that has spread to the bone (secondary bone cancer or bone metastases).

Bisphosphonates reduce the activity of cells that break down bone (osteoclasts). This slows down bone loss. Bisphosphonates do not replace lost bone but they can stop further bone loss. This helps to make the bone stronger.

There are several bisphosphonates used to treat osteoporosis. These include:

- alendronic acid (Fosamax®)
- ibandronic acid (Bonviva®)
- risedronate sodium (Actonel<sup>®</sup>)
- zoledronic acid (Aclasta®).

Bisphosphonates used to treat bone loss and osteoporosis are usually taken as tablets or capsules. They may be taken daily, weekly or sometimes monthly. A few people may be given bisphosphonates by injection into a vein (intravenously) or as an infusion. You take the tablets first thing in the morning, on an empty stomach with a glass of water. You need to stay upright for 30 to 60 minutes after taking the tablet. This helps the drug move quickly into the stomach and reduces the risk of it staying in the throat or gullet where it can cause irritation. It also helps prevent the drug coming back up from the stomach into the gullet, which can happen when lying down or bending.

### Side effects of bisphosphonates

Possible side effects include:

- indigestion
- a sore throat or inflamed gullet
- pains in the muscles and joints
- flu-like symptoms, which usually settle after the first dose.

### **Rare side effects**

#### Thigh bone fractures (atypical fractures)

A few people taking bisphosphonates have developed fractures of their thigh bone without any obvious cause. Sometimes both thigh bones are affected.

If you have any thigh, hip or groin pain, tell your doctor and mention that you are taking bisphosphonates. They can arrange tests to check the thigh bones for any signs of weakness or fracture.

#### Osteonecrosis of the jaw (ONJ)

A rare side effect of bisphosphonate treatment is osteonecrosis of the jaw (ONJ). It happens when healthy bone tissue in the jaw becomes damaged and dies. This can cause loosening of the teeth and problems with the way the gums heal. The risk of ONJ is extremely low if you are taking bisphosphonates to treat osteoporosis. Fewer than one person will develop it for every 100,000 patient treatment years. To put it another way, if 10,000 people were treated with bisphosphonate tablets for ten years, one person would get ONJ.

ONJ is more likely to happen when bisphosphonates are given to treat cancers that have spread to the bones (secondary bone cancer). This is because higher doses of bisphosphonates are used to treat secondary bone cancer.

Before you start bisphosphonates, talk to your dentist. If you have not been to the dentist for six months or if you have dentures that do not fit well, ask for a check-up. This is because it is important to avoid having a treatment that could affect your jaw bone during bisphosphonate treatment. This includes having a tooth or root removed or dental implants put in. It is fine to have fillings, gum treatments or a scale and polish.

If you need to have a dental treatment that could affect the jaw while you are taking bisphosphonates, tell your doctor before you have the treatment.

#### Cancer of the gullet (oesophageal cancer)

Some studies have suggested that taking bisphosphonate as tablets or capsules for five years or more may slightly increase the risk of cancer of the gullet. But other studies have not shown this link. More research is needed before doctors know if there is a link. Because bisphosphonates can cause irritation of the gullet, people taking them are usually checked regularly for gullet problems. Tell your doctor if you have:

- pain or difficulty when swallowing
- chest pain
- new or worsening heartburn.



# Denosumab (Prolia®)

People who have to stop taking bisphosphonates because of problems such as indigestion, a sore throat or inflamed gullet may be given denosumab.

Denosumab is given once every six months as an injection just under the skin (a subcutaneous injection). If you have denosumab, your doctor may advise you to take calcium and vitamin D supplements.

Denosumab can cause some side effects. These include:

- skin, urine and chest infections
- constipation
- pain in the arms or legs
- a rash.

Rarely, denosumab can also cause osteonecrosis of the jaw (ONJ) or atypical thigh bone fractures. You can read more about these side effects on pages 42 to 43.

# Raloxifene (Evista®)

Raloxifene is used to treat osteoporosis in women who have been through the menopause. The drug shares some of the helpful effects of oestrogen, reducing the breakdown of bone and the risk of fractures.

It is only used for women who cannot take bisphosphonates. Women who are taking tamoxifen should not take raloxifene. This is because it may make tamoxifen work less well. Raloxifene is taken daily as a tablet.

### Hormone replacement therapy (HRT)

There are different types of hormone replacement therapy for both men and women. They can be given as tablets, injections, gels or patches applied to the skin.

#### **Oestrogen replacement**

Oestrogen helps protect women's bones. If your oestrogen levels are reduced as a side effect of your cancer treatment, your doctor may give you HRT to replace the oestrogen. This can help to protect bone health and reduce menopausal symptoms.

HRT may contain oestrogen and progesterone. This is called combined HRT. Or it may contain oestrogen only. It is most commonly given as tablets or as patches you apply to your skin (transdermal patches).

HRT can have benefits for bone health. But there are also potential side effects or risks from taking HRT. The risks and benefits of HRT are affected by:

- the type of HRT (combined or oestrogen only)
- whether HRT is taken as tablets or skin patches
- your age
- your general health
- your family history of blood clots
- your risk of cancer of the ovary and breast.

The type of cancer you have had can also be an important factor. If you have had breast cancer, HRT may not be suitable for you. Some doctors also think HRT is not suitable for women who have had ovarian cancer or womb cancer. If you have had one of these cancers, your cancer doctor can talk to you about this.

When you are deciding whether to have HRT, it is important to discuss the potential benefits and risks with your doctor. This will help you to decide if HRT is right for you.

#### **Testosterone replacement**

If a man has a low testosterone level because of cancer treatment, he can be given testosterone to get back to a normal level. This helps increase bone density.

If you have had prostate cancer, testosterone therapy may not be suitable for you. Your cancer doctor can talk to you about this.

### Treatment with parathyroid hormone (PTH)

The parathyroid glands make parathyroid hormone (PTH). These glands are attached to the thyroid gland in the front of the neck. PTH helps the body absorb calcium and stimulates the body to make bone.

A version of PTH called teriparatide (Forsteo<sup>®</sup>) is made as a treatment in the laboratory. You inject it just under the skin (a subcutaneous injection). A nurse can teach you how to do this. You have it every day for up to 24 months.

People who have broken bones because of severe osteoporosis may be given teriparatide. It cannot be given to people with cancer in the bone. It is also not suitable for people who have had radiotherapy to an area of bone.

# **Specialist referral**

If your GP or hospital doctor thinks you need specialist advice for osteoporosis, they may refer you to a hospital team that specialises in it. These teams may include doctors, nurses and physiotherapists who work closely with occupational therapists and pain specialists.



# Share your experience

If cancer treatments have affected your bone health, you may find it helps to talk about it with other people. Sharing your thoughts and feelings with others can help them too. Just hearing about how you have coped and what you have done to manage your bone health could be very helpful to someone in a similar situation.

There are also opportunities to influence future healthcare by sharing your experiences. Ways you can do this include:

- joining a patient group or forum
- volunteering with a cancer charity
- taking part in research or filling in a satisfaction questionnaire
- letting NHS staff know what you think about the care you received, or the care you would like to have received.

'I joined a patient forum. It's good to feel that I may help towards improving the lives of everyone affected by cancer.'

Donald



# FURTHER INFORMATION

About our information	52
Other ways we can help you	54
Other useful organisations	57

# **About our information**

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

#### Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

All of our information is also available online at **macmillan**. **org.uk/cancerinformation** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

### **Other formats**

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- ebooks
- large print
- translations.

Find out more at **macmillan.** org.uk/otherformats If you'd like us to produce information in a different format for you, email us at cancerinformationteam@ macmillan.org.uk or call us on 0808 808 00 00.

# Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets. If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan. org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

#### Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

#### **Macmillan Support Line**

Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous** 

#### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence. Find your nearest centre at macmillan.org.uk/ informationcentres or call us on 0808 808 00 00.

#### Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

#### Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/** selfhelpandsupport

#### **Online community**

Thousands of people use our online community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/ community

#### The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the online community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

#### Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

#### **Financial guidance**

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

#### Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

#### **Macmillan Grants**

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/ financialsupport** to find out more about how we can help you with your finances.

#### Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work** 

> Macmillan's My Organiser app This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

There are lots of other organisations that can give you information or support.

#### National

#### Osteoporosis Society Helpline 0808 800 0035

(Mon, Wed, Thu, Fri, 9am to 5pm, Tue, 9am to 7pm) **Email** nurses@nos.org.uk www.nos.org.uk

Offers support to people with or at risk of osteoporosis. Aims to increase understanding and awareness of osteoporosis, inform health professionals and fund research into the condition. The helpline is staffed by specialist nurses, and information resources are also available.

# General cancer support organisations

#### **Breast Cancer Care**

Helpline 0808 800 6000 (Mon to Fri, 9am to 5pm, Wed, 9am to 7pm, Sat, 9am to 1pm)

#### www.breastcancercare. org.uk

Provides information, practical assistance and emotional support for anyone affected by breast cancer. Specialist breast care nurses run the helpline. Also offers a peer-support service where anyone affected by breast cancer can be put in touch with a trained supporter who has had personal experience of breast cancer.

#### Cancer Black Care Tel 020 8961 4151 Email

info@cancerblackcare.org.uk www.cancerblackcare.org.uk Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

# Cancer Focus Northern Ireland

Helpline 0800 783 3339 (Mon to Fri, 9am to 1pm) Email

nurseline@cancerfocusni.org www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups. Cancer Research UK Helpline 0808 800 4040 (Mon to Fri, 9am to 5pm) www.cancerresearchuk.org A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

#### **Cancer Support Scotland**

**Tel** 0800 652 4531 (Mon to Fri, 9am to 5pm) **Email** 

info@cancersupportscotland.org www.cancersupport scotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

#### Maggie's Centres Tel 0300 123 1801 Email

enquiries@maggiescentres.org www.maggiescentres.org Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

#### **Penny Brohn UK**

Helpline 0303 3000 118 (Mon to Fri, 9.30am to 5pm) Email

helpline@pennybrohn.org.uk www.pennybrohn.org.uk Offers a combination of

physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques. The Prostate Cancer Charity Helpline 0800 074 8383 (Mon to Fri, 9am to 6pm, Wed, 10am to 8pm) Textphone 18001 0800 074 8383 www.prostatecanceruk.org Provides information and support for prostate cancer patients and their families, and funds scientific research into prostate cancer. Has a telephone helpline with experienced nurses for anyone concerned about prostate cancer. Can also arrange contact with other men with prostate cancer and their families who are willing to talk to people about their experiences. The website has a range of literature available to download or to order free.

#### **Tenovus**

#### Helpline 0808 808 1010 (Daily, 8am to 8pm) Email info@tenovuscancercare.org.uk

### www.tenovuscancercare. org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

# Equipment and advice on living with a disability

#### The Blue Badge Scheme (Department for Transport)

Allows drivers of passengers with severe mobility problems to park close to where they need to go. Local authorities deal with applications and issue badges.

#### England and Wales www.gov.uk/blue-badgescheme-information-council

#### Scotland www.mygov.scot/applyblue-badge/

#### Northern Ireland www.nidirect.gov.uk/ blue-badge-scheme

#### **British Red Cross**

Tel 0344 871 11 11 Textphone 020 7562 2050 Email

#### information@redcross.org.uk www.redcross.org.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

### **Disability Rights UK**

**Tel** 0207 250 8181 (Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm) **Email** 

enquiries@disabilityrightsuk.org www.disabilityrightsuk.org Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

# Disabled Living Foundation (DLF)

Helpline 0300 999 0004 (Tue to Thu, 10am to 4pm) Email helpline@dlf.org.uk www.dlf.org.uk

Provides free, impartial advice about all types of disability equipment and mobility products.

#### Scope

Helpline 0808 800 3333 (Mon to Fri, 9am to 5pm) Email helpline@scope.org.uk www.scope.org.uk

Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

### Support for older people

Age UK Helpline (England) 0800 169 2081 Helpline (Scotland) 0800 124 4222 Helpline (Wales) 08000 223 444 Helpline (Northern Ireland) 0808 808 7575 www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.

### Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

#### **Thanks**

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Claire Higham, Consultant Endocrinologist; Dr Helen Neville-Webbe, Consultant in Medical Oncology; and Professor Robert Thomas, Consultant Oncologist. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

#### Sources

We've listed a sample of the sources used in the publication below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk** 

Faithfull, Higham. Bone health and pelvic radiotherapy. Clinical oncology. 2015. 27. 668 to 678.

National Institute for Health and Care Excellence (NICE). Osteoporosis: assessing the risk of fragility fracture. Clinical guideline 146. 2012. Updated February 2017. National Institute for Health and Care Excellence (NICE). Technology appraisal guidance TA204. Denosumab for the prevention of osteoporotic fractures in postmenopausal women. October 2010.

National Osteoporosis Guideline Group (NOGG). Guideline for the diagnosis and management of osteoporosis in post-menopausal women and men from the age of 50 years in the UK. 2014.

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



#### Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

#### **Campaign for change**

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

#### Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

#### **Raise money**

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

#### **Give money**

Big or small, every penny helps. To make a one-off donation see over.

# Call us to find out more 0300 1000 200 macmillan.org.uk/getinvolved

# Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

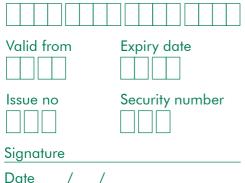
Email

Please accept my gift of  $\pounds$ 

(Please delete as appropriate) I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number



# Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. □

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



#### If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ This booklet is about bone health. It is for people who are having, or have had, cancer treatments that may affect their bones.

This booklet explains which factors affect bone health and things you can do to help maintain healthy bones. It also tells you about drug treatments that can improve bone strength.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk** 

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call our support line.

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