

Pain and advanced prostate cancer

This fact sheet is for men with advanced prostate cancer who are having problems with pain. Partners and family members may also find this information helpful. It describes the types and causes of pain that you might have and possible ways of treating and controlling your pain. It also provides information about sources of support. Each hospital and specialist team will do things slightly differently so use this information as a general guide and ask your specialist team for more details about the care you will receive.

This fact sheet focuses on pain caused by prostate cancer spreading to the bones. For information on other causes of pain speak to your specialist team or call our confidential Helpline on 0800 074 8383.

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What is advanced prostate cancer?

Advanced prostate cancer is cancer that has spread outside the prostate to other parts of the body. It is also called 'metastatic' prostate cancer. The cancer is not curable but treatment can keep it under control for many months and sometimes years. Prostate cancer can spread to any part of the body but it most commonly spreads to the bones and lymph nodes. You can read more about how advanced prostate cancer is diagnosed

and treated in our Tool Kit fact sheet, **Advanced prostate cancer.**

Do all men with advanced prostate cancer have pain?

No, not all men will have pain. Some men will have no pain at all and others will have varying amounts of pain. More than a quarter (25 per cent) of men with prostate cancer that has spread to the bones will not have any pain. Men whose cancer has spread to several places will often only have pain in a few of these places. With the right treatment, pain can usually be relieved or significantly reduced.

What causes pain in men with advanced prostate cancer?

There may be more than one cause of pain. Possible causes include:

- The cancer may have spread to the bones.
- The cancer can sometimes spread to the lymph nodes, making them swollen and uncomfortable.
- Your pain may be due to something else and not your cancer.

If the cancer spreads to the lymph nodes it may lead to a condition called lymphoedema, which is caused by a blockage in the lymphatic system. The lymphatic system is part of the body's immune system and carries fluid called lymph around the body. If the lymphatic system is blocked, the fluid may build up in the body's tissues and cause swelling (lymphoedema), usually in the legs. The blockage may be caused by the cancer itself or by some treatments, such as surgery or radiotherapy. Lymphoedema is not common in prostate cancer. You may be at greater risk if you have had surgery and/or radiotherapy to lymph nodes. Lymphoedema may cause discomfort or pain but there are treatments to manage it.

Your specialist team should investigate the cause of your pain and then offer you the most appropriate treatments.

What happens if prostate cancer spreads to the bones?

The most common place for prostate cancer to spread to is the bones. Up to eight out of ten men (80 per cent) with advanced prostate cancer will have cancer that has spread to the bones. This does not mean that you have bone cancer. It means that some of the prostate cancer cells have spread to some areas of bone. This is called secondary prostate cancer. The cancer that has spread to the bone is called 'bone secondaries' or 'bone metastases'. In this fact sheet we use the term 'metastases' to describe prostate cancer that has spread to the bones.

The growth of the cancer in the bone causes the bone tissue to break down. This weakens the bone and may cause pain. The first areas of bone to be affected are likely to be those closest to your prostate including your pelvic bone, hips, lower spine and upper thighs. Pain in these areas can affect how you walk and move around. The pain may only be in one area but over time it can spread to several parts of your body. Men who have bone pain often describe it as a dull aching or stabbing that can get worse with movement. There are several effective ways of treating pain caused by bone metastases. You can read more about these on page 4.

Metastatic spinal cord compression

Prostate cancer cells can also spread to the bones of the spine (vertebrae). This can lead to a complication called metastatic spinal cord compression (MSCC) where the cancer cells press on the spinal cord. MSCC is rare. We do not know how many men with advanced prostate cancer develop MSCC, but we do know it happens in around five to ten out of every 100 people (five to ten per cent) with some form of advanced cancer. If it does happen you need to get treatment as soon as possible. Speak to your specialist team for more information about your risk.

MSCC may cause any of the following symptoms:

- Pain in your lower, middle or upper back or neck that is severe or different from usual pain. The pain may get worse when you cough, sneeze, lift, strain or go to the toilet, and it may wake you at night or stop you from sleeping.
- A narrow 'band' of pain around your stomach area or chest.
- Pain that moves down your arms or legs.
- Weakness in your arms or legs, difficulty standing or walking, or falling.
- Numbness or pins and needles in your legs, arms, buttocks, stomach area or chest, that does not go away.
- Problems emptying your bladder and/or bowel. You may be unable to empty your bladder and/or bowel, or you may have no control over emptying them.

These symptoms may also be caused by other conditions, but it is still important to get medical advice in case you do have MSCC.

MSCC is a serious condition. If you have any of the symptoms listed above, contact your specialist team straight away. Do not wait to see if it gets better and do not worry if it is an inconvenient time, such as the weekend. You should have been given information about who to contact if you have any symptoms. If you do not have any contact details, go to accident and emergency (A&E) at your local hospital and tell them that you have prostate cancer and the symptoms of MSCC.

Some men are worried about becoming addicted to stronger pain-relieving drugs like morphine. If you are taking morphine to relieve pain then addiction is unlikely. Remember that you might not start with the strongest type of pain-relieving drugs, and the dose will be carefully controlled by your specialist team.

Hormone therapy

Men with advanced prostate cancer may be offered hormone therapy to shrink or slow down the growth and spread of the cancer. This may prevent and relieve your pain. Hormone therapy is often the first treatment used to manage pain. You can read our Tool Kit fact sheet, **Hormone therapy**, for more information.

If your hormone therapy is no longer controlling your cancer as effectively, other treatments are available to help delay or manage symptoms such as pain. For more information please read our Tool Kit fact sheet, **Treating prostate cancer after hormone therapy**.

Steroids

If other treatments such as hormone therapy are no longer working, you may be offered a low dose of steroids to treat your prostate cancer. Higher doses may be used to reduce pain. If your prostate cancer has spread to the bones or the spine, it may cause swelling and press on the nerves, causing pain. Steroids can help to reduce swelling around the cancer. You may be able to take steroids in combination with pain-relieving drugs and other types of treatment.

Like most medicines, steroids can cause side effects. These include:

- An increased appetite.
- Increased energy. Some people find that they feel irritable, as steroids can make your mind more active.
- You may put on weight and notice that your hands and feet are swollen. This is because the steroids cause water retention; it is the increased fluid that causes the weight gain.
- You may have a slightly higher risk of getting infections.

- Steroids can cause indigestion and may irritate the lining of the stomach, sometimes causing bleeding. You will need to take them after a meal or snack. Your specialist team may prescribe additional tablets to help to protect your stomach.
- Bone thinning (osteoporosis).
- Raised sugar levels in your blood and urine.

Your specialist team should discuss and monitor possible side effects with you. Do not stop taking steroids suddenly as this can make you very ill.

Your specialist team should give you a steroid treatment card which explains that you are taking steroids. You should carry this with you at all times. It should be shown to anyone treating you (doctor, nurse, dentist), whatever the reason, as it is important that they know that you are taking steroids.

Chemotherapy

Chemotherapy involves using anti-cancer (cytotoxic) drugs to kill cancer cells. The aim of this treatment is to shrink the cancer cells and slow the growth of cancer. It does not cure prostate cancer but it can help with symptoms such as pain and improve your quality of life. Chemotherapy can cause side effects, including a sore mouth, and other medicines can help manage these. Read our Tool Kit fact sheet on **Chemotherapy** for more information.

Palliative radiotherapy

Palliative radiotherapy can slow down the growth of cancer and help control symptoms in men with advanced prostate cancer. This is different from having radiotherapy to treat cancer that has not spread outside the prostate gland (localised prostate cancer). Palliative radiotherapy can shrink the cancer cells in the bones and stop them pressing on nerves and causing pain. You can read more about palliative radiotherapy, including side effects, in our Tool Kit fact sheet, **Palliative radiotherapy for advanced prostate cancer**.

Bisphosphonates

Bisphosphonates are drugs that treat pain caused by cancer that has spread to the

bones. They do not treat the cancer, but they can help reduce pain. Bisphosphonates bind to areas of the bone that have been damaged by the cancer and slow down the breakdown of bone tissue. This helps to strengthen the bone and relieve pain. Like other drugs, bisphosphonates can sometimes cause side effects. For more information about treatment with bisphosphonates read our Tool Kit fact sheet **Bisphosphonates** or speak to your specialist team.

Reporting unusual side effects: The Yellow Card Scheme

If you think you are experiencing a side effect from your medication that is not mentioned in the information leaflet that comes with it, then you can report it using the Yellow Card Scheme. This is run by the Medicines and Healthcare products Regulatory Agency (MHRA). They will investigate and if they find a problem with a medication then the MHRA will take action to protect the public. There are three ways you can report a side effect:

- Use the online Yellow Card form at www.yellowcard.gov.uk
- Ask your pharmacist for a Yellow Card form
- Call the Yellow Card freephone on 0808 100 3352

Surgery to strengthen the bone

If there is an area of bone that has been badly damaged by cancer, surgery may be an option, although it is not often used. A metal pin or plate is inserted into the bone under general anaesthetic to strengthen and stabilise the area of affected bone. You may have radiotherapy following the operation to help prevent the cancer growing in that area.

Transcutaneous electrical nerve stimulation (TENS)

Some NHS pain clinics and specialist teams may offer TENS to help manage pain. This involves sending small electrical currents to nerves in your body using a small machine.

Doctors think that these currents may block the pain signals caused by the cancer. A very small study recently found that TENS could help some people with bone pain, but more research is needed into this.

Complementary therapy

There are many different complementary therapies available including acupuncture, aromatherapy, massage, reflexology and hypnotherapy. Many people find that complementary therapies are helpful in coping with cancer pain. They can also help you to feel more in control of your treatment and that you are actively doing something to improve your health. However, there is little evidence to show that complementary therapies help relieve cancer pain, and we need more research into this.

A personal experience

"I have acupuncture and reflexology every week and they are the most effective pain relievers for me. Not only do they maintain suppleness but if I have a specific pain site they remove the pain within a short time."

Tell your specialist team about any complementary therapy you are having or are thinking about having to help with your cancer. Some complementary therapies have side effects and some may interfere with your cancer treatment. You should also tell your complementary therapist about any cancer treatments you are having.

When choosing a complementary therapy, make sure that the therapist is properly qualified and belongs to a professional body. Complementary therapy organisations such as the Complementary and Natural Healthcare Council will be able to give you more advice about finding a therapist. Some hospitals and cancer clinics also offer complementary therapies. Macmillan Cancer Support and Cancer Research UK provide more information about different types of therapies available and important safety issues to consider. You can find contact details of all these organisations on page 11.

What other things can I do to help control my pain?

In addition to the treatments already mentioned, you may find some of the following ideas helpful:

- Generally looking after yourself, for example by maintaining a good diet or taking regular gentle exercise, may help you to feel better. Read our Tool Kit fact sheet **Diet, exercise and prostate cancer** for more information about healthy eating and exercise.
- Change your position frequently to stay as comfortable as possible and prevent stiffness.
- Hot or cold packs may help to relieve some types of pain. Wrap them in a towel so that they do not hurt your skin.
- Try listening to music, reading, watching television or chatting with a friend or family member to try and take your mind off your pain.
- Try relaxation techniques such as deep breathing, relaxation tapes or a relaxing bath.

These suggestions may help you to feel more comfortable and more in control of your pain.

Where can I get support?

As well as getting medical help to treat your pain, most men find it helps to get some emotional support. Feeling more in control of your emotions can help you feel better.

Close friends and relatives often say that it can be difficult to watch a loved one in pain. They can feel helpless and have trouble coping so they may also need emotional and practical support.

If you are feeling low or anxious, it may be useful to talk to a counsellor. Counselling may help you cope if you are experiencing pain. You may be able to get a referral to a counsellor through your specialist team or GP.

You may find it helpful to speak to someone with personal experience of pain caused by prostate cancer. Our support volunteers are all personally affected by prostate cancer and are trained to listen and offer support over the telephone. Call our confidential Helpline on

0800 074 8383 and ask to be put in touch with a support volunteer. There are also prostate cancer support groups throughout the country where you and your family can meet other people affected by prostate cancer. You can find details of your nearest group on our website at www.prostate-cancer.org.uk or ask your specialist team.

If you have access to the internet, you can join our online community on our website. This is for men with prostate cancer and their families to share experiences, information and support.

You may also find that it helps to talk to your specialist team or a specialist cancer nurse such as a Macmillan or Marie Curie nurse. Many specialist nurses have counselling training and can help you work through some of your concerns. They also know a lot about cancer pain and how to manage it. Specialist nurses can also offer emotional support for you and your family. They work very closely with the district nurses and your GP. You can ask your GP or specialist team to refer you to these nursing services.

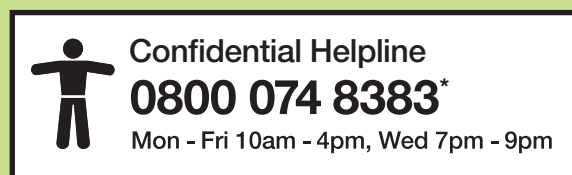
The Prostate Cancer Charity makes every effort to make sure that its services provide up-to-date, unbiased and accurate facts about prostate cancer. We hope that these will add to the medical advice you have had and will help you to make any decisions you may face. Please contact your doctor if you are worried about any medical issues.

The Prostate Cancer Charity funds research into the causes of, and treatments for, prostate cancer. We also provide support and information to anyone concerned about prostate cancer. We rely on charitable donations to continue this work. If you would like to make a donation, please call us on 020 8222 7666.

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Reviewed February 2011
To be reviewed February 2013



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We hope you have found this information useful. If you have any comments or suggestions about any of our publications, you can email literature@prostate-cancer.org.uk or write to The Information Team at The Prostate Cancer Charity, 100 Cambridge Grove, London W6 0LE

References to sources of information used in the production of this fact sheet are available on our website.

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