The British Pain Society's

Managing cancer pain - information for patients

From the British Pain Society, supported by the Association of Palliative Medicine and the Royal College of General Practitioners

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What can be done for people with cancer pain?

There are medicines and expertise available that can help to control cancer pain. However, surveys show that cancer pain is still poorly controlled in many cases. As a result, patients must know what is available, what they have a right to and how to ask for it.

Cancer itself and the treatments for cancer, including both medicines and surgery, can cause pain. Treatments can be directed either at the cause of the pain (for example, the tumour itself) or at the pain itself.

Understanding cancer pain

Cancer pain can be complicated, involving pain arising from inflammation (swelling), nerve damage and tissue damage from many sites around the body. How the pain develops over time varies from person to person and depends on the type of cancer, its treatment and any other conditions that a person may have.

Neuropathic pain (nerve pain)

Nerve pain results from damage to nerves or nerve cells. In cancer, nerve damage may be caused by:

- the tumour itself;
- the growth of the tumour pressing on nerve tissue;
- the growth of the tumour blocking the blood supply to nerve tissue; or
- anticancer drug therapies and surgery.

Inflammatory pain

Pain is one of the main signs of inflammation. Damaged tissue releases chemicals and triggers a response by the white blood cells. The chemicals released increase activity in the tissue receptors that detect pain and cause the nerve fibres to become more sensitive.

Visceral pain

Visceral pain comes from the internal organs. The pain is hard to pinpoint in one area and often feels like a spasm or a heavy feeling. As the spinal nerves that pass pain from body sites in the case of visceral pain, the autonomic nerves may also be involved because these control many functions of the internal organs..

Visceral pain can be caused by:

- the cancer interrupting the blood flow to the internal organs;
- inflammation of the internal organs or their membranes caused by tissue damage;
- compression of internal organs by the tumour
- the tumour pressing on the internal organs; or
- the growth of the tumours stretching the internal organs.

Somatic pain (musculo-skeletal pain)

If cancer spreads to many bones around the body, this can cause somatic pain. Bones have a lot of nerve fibres. Inflammation and destruction of bone tissue by cancer cells can trigger the nerve fibres to carry pain signals. There are often many sites of the pain and the pain can sometimes move from one site to another.

Pain as a result of cancer therapy

Chemotherapy drugs such as taxols, platins, thalidomide and bortezomib can cause nerve pain. Pain can also be caused by surgery to remove tumours.

Knowing what to expect

Your mood can also influence the pain and make it worse. Fear and anxiety are natural feelings for people suffering from cancer and pain. Both cancer and pain are scary. Fear and anxiety do affect pain, especially when any new pain arises.

Because a lot of cancer pain is related to nerve damage, it can get worse over time, even when the cancer itself is under control. Worsening pain does not always mean that the cancer is getting worse or coming back, but the pain itself should be treated and so it is important to tell your doctor about it.

Your doctors understand the various ways that cancer causes pain and can use this knowledge to give you the most appropriate treatment for your pain. However, it is important to realise that cancer pain does not follow a predictable course and your doctor cannot tell you exactly what your pain will be like as you undergo treatment.

Options for controlling pain – most pain can be controlled

Drugs for pain explained

In 1986, the World Health Organization created a three-step ladder as a guideline for treating cancer pain. Mild pain might be successfully treated with medicines like aspirin (non-steroidal anti-inflammatory drugs or NSAIDs), but most forms of cancer pain need stronger painkillers. Although most cancer pain can be controlled with oral medication (which you swallow), other procedures for managing pain have an important role for some patients.

Opioid drugs such as morphine and codeine are the main drug treatment for cancer pain. They are often used along with other painkillers (called adjuvants) to improve the control of pain. Experience shows that switching between opioid drugs can improve their effectiveness.

The side-effects of opioid medicines include feeling sick (nausea), being sick (vomiting), constipation and feeling drowsy.

People can become tolerant to opioids. This means that the drugs have a reduced effect when you take them for a long time, and so a higher dose is needed to give the same effect. Tolerance can also mean that some side-effects are not as bad.

Fear of the pain returning is a natural response and may make you reluctant to start receiving opioids. However, starting opioid therapy as soon as the pain begins may make it easier for doctors to control your pain later on.

Tolerance is also important if you are having surgery. The dose of opioids that person who has developed a tolerance will need to control any pain after surgery may be higher than for patients who are not on opioids. Be sure to discuss this with your surgeon and tell your doctor or nurse if the pain relief after surgery is not working well enough.

Becoming dependent on opioids is quite common. Physical dependence means that your body adapts to the medicine so that, if you reduce the dose, you suffer from withdrawal symptoms. This is dependence, not addiction. Withdrawal symptoms include abdominal cramps, diarrhoea and sweating.

Addiction is characterised by legal or illegal drug-seeking behaviour. It is very rare in people taking opioids for pain relief. Prescribing suitable painkillers for people addicted to drugs is difficult and so, if this is your situation, make sure that you have access to specialist advice.

Although there are side-effects, opioids are a safe and effective way to control pain.

Other drugs such as antidepressants and anticonvulsants may also be used, especially for nerve pain.

You can take most medicines by swallowing them, but skin patches and injections are used. Sometimes a suppository placed up your bottom is the best way to deliver an effective dose, while at other times a small tube put in your spine might give the best relief.

In all cases, it is important to take your medicines at the times prescribed by your doctor or pharmacist.

What if medicines cannot control the pain?

Radiation therapy and chemotherapy for the tumour can reduce the pain caused by the tumour pressing on nerves or bones. Sometimes more invasive methods such as nerve blocks or surgery are needed. Most patients referred for cancer-related pain relief have at least two distinct pain sites, and many have more than four. Because of this, regional techniques such as nerve blocks do not control all of the pain.

Procedures to manage pain involve a multi-disciplinary specialist team, which includes psychological and social support. The aim of the procedures used to manage your pain is to allow you to take lower doses of the drugs to deal with the pain so that you suffer from fewer side-effects. As a result, this should lead to a better quality of life.

The healthcare team will usually try different procedures in a systematic way to relieve your pain.

They will often try local nerve blocks first, and then spinal infusions, which deliver drugs directly to the spinal fluid. If these procedures do not relieve your pain, they may try procedures that destroy the nerves that relay the pain to your brain. In individual cases, your healthcare team may not follow this path, especially if their experience shows that a procedure to destroy the nerves is likely to be the quickest and best route to relieving your pain.

Treatments which involve destroying nerves carry the risk of damage to the nervous system, which can itself cause new neuropathic pain. Your healthcare team will discuss this with you, along with other side- effects such as the loss of sensation.

Coping with cancer pain

Fear, anxiety, depression and lack of sleep increase pain and add to the suffering you can experience. You need to discuss all of these with your healthcare team. Hopefully your fear will be reduced if you fully understand your condition and can discuss with your doctor what the pain means to you and your family or carers.

Psychologists might be available to help you by giving you coping strategies or there may be a pain management programme that has access to expert psychological advice.

Tell your doctor how the pain affects your relationships with others, how it affects your mood, and how it affects your sleep.

If you are caring for elderly people with cancer, it is important to remember that old people are more likely to accept pain, less likely to report it and so are more likely not to control their pain enough. Other groups similarly at risk include people with mental disability, people with language problems, substance abusers, people overwhelmed by their condition or by the fact that they are at the end of their life.

Carers and doctors need to work together to make sure all these vulnerable groups have the best care available.

Describing pain – communicating with your doctors

People with cancer can experience pain arising from several pain sites, which may be caused by:

- the cancer itself;
- the treatment for the cancer; or
- other diseases.

After you have been diagnosed with cancer, as part of your initial assessment your doctor must ask you whether you have any pain. If no one asks you about pain, you should tell the doctor about it. Only you know how much pain you feel.

Understandably, most patients with cancer are frightened about their pain and might be reluctant to talk to their doctor about it. You should expect your healthcare team to assess and reassess your pain thoroughly.

You should be given and taught to use a pain diary to monitor the levels of your pain, the medication you need, how effective the pain relief is and the side-effects of the medication.

Your initial pain assessment should include a detailed discussion about your pain, including any persistent pain or breakthrough pain that you are experiencing and its effects on you. You should have a physical examination and should be asked about how you are feeling and coping with the pain. Your doctor will assess you for signs and symptoms associated with cancer pain conditions.

What is breakthrough pain?

This is a flare-up of moderate to severe pain in patients with otherwise stable persistent pain.

Things that your doctor will find helpful to know include:

- whether you get flare-ups;
- how often you get these flare-ups;
- how long the flare-ups last;
- how bad the pain is and how long it takes to get that bad;
- a description of the breakthrough pain;
- what triggers a flare-up; and
- what medicines and other treatments you are on and have tried in the past.

You may be asked to rate your pain on a scale from 0 to 10. There are formal questionnaires that your doctor can use to assess your pain. The details covered in this kind of questionnaire would include:

- where the pain is;
- a description of the pain;
- how severe or intense the pain is;

- how long the pain lasts;
- what makes the pain worse;
- what makes the pain better;
- what effect the pain has on your daily activities and daily life;
- what effect the pain has on your quality of life;
- what effect the pain has on your mood and state of mind;
- how the pain affects your relationships and social life;
- what medication you take and have taken in the past;
- whether you have had problems with any medicines such as opioids; and
- whether you have tried complementary therapies such as acupuncture or herbal remedies.

What if the pain changes?

If your pain changes, your doctors should carry out a new thorough assessment. It is important that they carefully reassess your physical condition to make sure that there are no new underlying causes of the pain that will mean that your treatment needs to be changed. People being treated for cancer may be at risk of developing pain as a direct result of the cancer treatment itself.

The key to controlling pain successfully is communication. Nobody knows how much pain you are in unless you tell them. Most pain can be treated. Your quality of life can be improved.

Talking to others with cancer pain

Ask about local self-help groups so that you can share your views with others who have the same condition as you.

Finding help to manage cancer pain

A lot can be done to manage pain. However, the journey through the services can be confusing and sometimes your treatment may not seem very well 'joined up'. It is true that there are still improvements to be made in how palliative care and pain services work together. If your pain is not being treated well enough, ask to be referred to a pain specialist.

Physiotherapists and occupational therapists can help you to manage your pain and prevent pain becoming worse because of poor posture, which can mean that you are unable to move around as easily. More and more, the rehabilitation of cancer patients is being seen as a major part of cancer therapy.

Therapies that might be offered by these services include help with posture, massage, transcutaneous electrical nerve stimulation (TENS), heat and cold treatments and general advice on your lifestyle.

References

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Methods

These recommendations have been produced by a group of relevant healthcare professionals and patients' representatives. The recommendations refer to the current evidence available relating to cancer pain.

Competing interests

This means that a doctor or expert may receive sponsorship or payment from a medical company, for example, for the work that they do.

Members of the group that has produced this leaflet have registered their competing interests as follows:

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