



Pain

A guide for patients and carers

Always there to care

About pain

Not everyone who has a life-limiting illness will experience pain.

For those who do, the experience is varied for each individual, dependant on their condition and their personal circumstances. Pain does not always get worse as a condition progresses. There are also different causes for pain.

When a clinician assesses pain they will consider the likely cause, the impact on your life and the other treatments you are receiving to tailor a management plan that is most suitable for you. This plan may need to be reviewed and adjusted as pain can change over time.

It is important to understand that some pains may not always be removed altogether, but in many cases can be reduced. Often it is easier to address pain earlier, so it is important to report pain even if you consider it to be mild.

Causes of pain

For those with cancer, pain can be due to the cancer itself, or as result of treatment (surgery, chemotherapy, radiotherapy).

Pain from cancer can arise due to pressure the cancer places on other structures of the body, such as nerves, bones or organs. Sometimes this can be rapid in onset and require urgent attention.

A common cause of pain in those with life-limiting illness is due to 'wear and tear'. As people lose muscle mass (due to reduced mobility or ageing process), underlying arthritis can become painful as the joints and bones have less support.

There are many other causes of pain. Not all pain is related to your current health condition. If you are concerned about new pain then seek appropriate help. Trying to elicit the cause can be done by your clinical team asking questions about the pain, physical examination and sometimes imaging (X-Rays/scans) or further tests may be required.

Talking about pain

Asking questions about the pain is helpful for your clinician to both understand the cause of the pain, but also help in creating a management plan. It can be helpful if you keep a diary of the pain so that you can answer questions more accurately. The kind of questions your clinician may ask will include:

Where do you get the pain? Is it just one pain? Or multiple pains (keep a diary for each pain)?

When do you get the pain? Is it at a certain time of day or doing something in particular? How often do you get it? Is it there all the time?

How would you describe the pain? Is it dull (like toothache) or sharp (like a knife)? Does it burn or feel like an electric shock? Does it come in waves or gripe?

How severe is the pain? If you could score pain on a scale of 0 (no pain) – 10 (worst pain imaginable) what score would you give it?

What do you do when you get the pain? Does anything make it better? Or worse? – record how often you take the painkillers and how effective they are and any side effects (drowsiness, hallucinations, nausea)

Do you experience other symptoms with the pain? Such as nausea/vomiting, weakness or numbness of an arm/leg, altered sensation, altered vision, breathlessness?



Who can help with pain?

All healthcare professionals can have a role to play in pain management, so reporting to who is already involved in your care may be the first port of call (such as GP, district nurse, care assistant). If your pain is new, severe or of concern then accessing emergency advice and assessment might be appropriate.

How may the various professionals help?

Doctor or GP Your doctor may decide to prescribe some pain killers for the pain and/or refer to another health professional. They may request further tests to elicit the cause of the pain.

Nurses (incl District Nurse) They may advise and support you with an existing treatment plan or assess whether they feel something new is going on that requires further input. If your pain is related to wounds or pressure areas, they may be the main health professional responsible for these issues. Specialist Nurses – (eg Cancer specialist nurses, macmillan nurses, respiratory nurses, heart failure nurses, complex care matrons) may also have specialist knowledge in assessing and managing your symptoms.

Physiotherapist/Occupational therapist If moving is difficult or aggravating your pain, then getting support with this may be very helpful. Adapting to do things differently may be all that is required to make you more comfortable. They may advise on walking aids, other equipment or exercises to help you maintain independence or regain muscle strength. Some therapists may also advise on TENS (transcutaneous electrical nerve stimulation).

Counsellor, psychologist or faith leader We know that the experience of any physical symptom (including pain) can be exacerbated by emotional or spiritual distress. Dealing with additional anxiety or depression can be very effective in managing pain.

Complementary therapist When we engage with relaxation modalities, endorphins (natural pain killers) are released. Massage can also help to relax painful, tense muscles. Gentle heat can also be helpful for many individuals (being careful not to cause burns). Finding activities you enjoy can also release endorphins – such as art

Lymphoedema therapist Lymphoedema is a specific condition resulting in swollen, heavy and sometimes painful areas of the body (usually but not exclusively a limb). The additional weight can put extra pressure on the body resulting for example in back ache. Effective treatment of the lymphoedema can alleviate the need for additional pain killers.

Pharmacist Your pharmacist can help advise on your existing treatment regimen and effective use and safe disposal of medicines. They can also give advice on over the counter remedies that may be of use or signpost to other health professionals.

Care Assistant Often carers can advise/signpost or speak directly, to other health professionals involved in your care. Sometimes carers can be those who experience the pain with you when they are assisting with any washing/dressing. They can help prompt you to complete your pain diary.

Hospice Team Within the hospice, you may have any or all the above professionals involved in your care. We work together holistically and our input complements one another.



Pain killers and treatments

Often, but not always, pain may require medical input.

Pain killers can be divided into different types:

- Simple – e.g. paracetamol
- Anti-inflammatories – e.g. ibuprofen, naproxen, steroids
- Neuropathic – some antidepressants and antiepileptic drugs eg amitriptyline, pregabalin
- Opioids – weak (eg codeine, tramadol) and strong (eg morphine, oxycodone, fentanyl)
- Others – bisphosphonates

Some cancer treatments, such as chemotherapy and radiotherapy, can be effective in treating pain

Injections – certain pain types are suitable for nerve blocks or other injections. These are given by specialist anaesthetists within the chronic pain team who have additional training in these procedures.

You may experience side effects from the medication you have been given. If this happens, talk to the professional who prescribed it for you. It may be they can give you additional advice or make some adjustments to your medication to reduce or alleviate the side effects. If the treatment does not work, the dose may require adjusting or an alternative treatment may be tried.



What can I do for my pain?

Keep a diary and report pain to someone involved in your care.

Take your pain killers as prescribed and as you have been advised to. If you have concerns about them then speak to a healthcare professional.

Be kind to yourself – pace yourself. As health changes we often need to review the way we do things. Perhaps you may need some additional help with domestic chores, or spread them out over the week rather than doing in one go. If you are offered equipment to help, use it.

Be honest with health professionals about your pain, they cannot give you the most appropriate help unless they know the truth of your experience. Be honest about what worries you most about the pain.

Try activities that lift your mood (to release endorphins) or distract you from the pain – nothing exacerbates pain more than sitting and focussing on it. Relaxation, using gentle music and soft lighting helps to combat stress hormones that exacerbate pain. Relaxation may be particularly important if pain is affecting your sleep or impacting on other aspects of your life, such as work, finances and care for other dependants (such as family or children).

Living with long-term pain can be a challenging journey through denial, anger, resentment and sadness, in addition to any feelings you may be experiencing about your overall health. Talking about the impact the pain is having on you with those closest to you, may help the journey to feel easier, and may help them in understanding how best they can support you.

If you have any further questions or would like additional information on pain and pain management, then do speak to a health professional involved in your care.

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