Grace Kelly Childhood Cancer Trust

When pain does not go away

This publication is intended to supplement the advice given by your child's medical team. It was written by Dr Jennifer Kelly, GP, founder of the Grace Kelly Childhood Cancer Trust.

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About this booklet

If you are reading this, the likelihood is that your child, or a child close to you, has received treatment for cancer. This booklet is designed to be an information summary and to answer some of your questions. If you have any queries, please discuss them with your healthcare team.

This booklet will explain what pain is and how to recognise it in your child. It then focuses on when pain does not go away as we would expect. It looks at why pain may continue and ways of managing your child's pain. At the back is a glossary of terms for more information. Words that are included are in a bold font in the main text.

What is pain?

Pain is an unpleasant feeling that can occur as a result of an injury, illness or medical procedure. You do not need to see physical damage to experience pain. We know that infants and children of all ages experience pain, however young.

Pain is a common experience during treatment for cancer, but it usually resolves after treatment ends. Unfortunately, for some children, the pain does not improve in the way we expect. This can be called chronic pain.

When your child experiences pain

When your child experiences pain, your child's medical team will try to identify the cause. This will include checking for a physical cause such as tumour growth, scar tissue or a blocked shunt (if they have one). The team will also look for muscle spasms, a difference in the length of your child's limbs and a number of other possible causes.

Pain experience

No two children feel pain in the same way. For one child the pain may be manageable, for another child, the pain may be so severe it causes marked distress.

Factors that affect pain

The degree of pain your child experiences is affected by a number of physical and emotional factors. These factors then interact influencing how your child feels pain.

If your child's pain is starting to dominate their life, they may begin to feel as if they have lost control. Pain can affect their self-esteem, make them less active and less sociable. Children and teens with chronic pain often feel alone or misunderstood. Understandably, they may become low in mood and sometimes depressed.

Chronic pain

Chronic pain can be diagnosed when pain remains after the resolution of the illness, injury or treatment which originally caused it. It is thought to occur due to changes in the way that the body sends and receives signals resulting in an imbalance in the pain transmission system. This imbalance means that pain does not resolve in the way we would normally expect.

Who gets chronic pain?

Chronic pain can affect anyone, but tends to be more common in children who have experienced acute severe pain in the past. A large study of childhood cancer survivors shows that whilst most cancer survivors do not have chronic pain, there are certain individuals who seem to be more commonly affected. These include survivors from bone tumours, other solid tumours and Hodgkin's lymphoma. It is unclear why this is, but it is thought that chemotherapy and particularly high dose radiation have an effect on children's growing bodies.

Who will treat my child's pain?

Initially, your child's pain will be managed by their oncologist or general practitioner.

If the pain does not improve, a pain team will become involved. These teams offer a range of specialists who can help your child manage pain. These can include a consultant, physiotherapist, psychologist, pharmacist and pain nurse.

Confusingly, sometimes the pain team is also called the palliative care team. If this is the case in your child's hospital, please do not be alarmed. It is simply because the palliative care team can be the most specialised at helping control

the most troublesome pain and also look after people with chronic pain. In larger treatment centres, these two teams may often be separate.

> The first step of treatment for long-term pain is usually to treat the cause. Even if no cause is found, the pain remains very real. In these instances, pain is likely to be due to an imbalance in nerve signalling, or differences in how the brain perceives pain.

Most pain is treatable

Almost all pain can be treated, but not always with pain medication. Often a more holistic approach to pain management is needed. No one should live in chronic pain without help so it is important to ask for support. There are teams who work with people to help them manage and reduce their pain. Pain needs to be approached from a number of different angles to ensure that your child is as free from pain as possible.

If your child has been diagnosed with chronic or long-term pain, it may be treated with a combination of lifestyle change, medication and training in pain coping skills. These skills can help boost self-confidence and make them more able to manage their symptoms.

Boys and girls differ in their sensitivity to pain

Whilst it is important to think of boys and girls as equals, when it comes to pain, they are different. Girls are more likely to be sensitive to acute pain and are more likely than boys to develop chronic pain, especially around puberty.

Understanding why your child has chronic pain

Chronic pain can occur for a number of reasons. Often, we don't know exactly why it occurs, but there are certain conditions that make chronic pain more likely. Some will be more common in children who have had cancer because of the treatments they have required, such as surgery, radiation and some medications.

Radiation therapy and its links with chronic pain

Radiation treatment uses high-energy rays to kill cancer cells and shrink tumours. It affects normal cells as well as cancerous ones. Bones, soft tissue, muscle, and blood vessels are very sensitive to radiation, and especially during times of rapid growth.

In some children, this can result in unequal bone growth so that the treated side of the body does not grow in the same way as the untreated side. Bone pain, stiffness, or weaker bones (osteoporosis) can occur. This in turn may affect the way your child walks, contributing to chronic pain.

Other causes

Sometimes your child may experience chronic pain for another reason. Pain can come from an unhealed wound, a **fistula** or chronic infection to name but a few. For fistulas and wounds, a significant part of the treatment is wound care and the use of specialist dressings. However, your child may also need pain relief. Long term pain that has a specific cause in this way responds better to conventional pain relief than pain with no obvious cause.

Types of chronic pain

Neuropathic pain

Our nerves carry information to and from the brain. They tell us if something is sharp, hot, cold or painful. **Neuropathic pain** occurs when damage or irritation has occurred to the nerves, for example by pressure from a tumour. Cancer treatments including certain chemotherapy drugs, surgery, and radiation can cause neuropathic pain in some individuals.

If your child is experiencing neuropathic pain, they may well describe it as a burning, shooting, stabbing or tingling feeling. Younger children may struggle to describe the pain but will act as if they are in significant discomfort. The pain can be intermittent or constant, and is often worse at night. The pain caused by nerve damage can often be stubborn to treat but there are a number of treatments that can be tried. These include **amitriptyline, gabapentin** and **pregabalin** (see section on medication for chronic pain).

Peripheral neuropathy

Peripheral neuropathy develops when damage occurs to the nerves that carry messages to and from the brain and spinal cord to the rest of the body (the peripheral nerves).

Peripheral neuropathy is one of the more common causes of chronic pain in children following treatment for cancer. Certain types of chemotherapy can cause damage to the nerves in the hands and feet resulting in sensations of tingling, burning and pain.

Your child may say that their feet or hands feel numb, or weak. This can affect certain everyday tasks such as writing, tying shoelaces or even walking. Peripheral neuropathy most commonly develops during treatment and may well continue after treatment. It is rare for symptoms to start for the first time after treatment has ended.

Unfortunately, there is no specific treatment that can reverse nerve damage, but often symptoms will improve over time. Some children find heat packs or elastic stockings helpful, but often medication will be needed (see medications for nerve pain). Your child may also be offered input from a physiotherapist or occupational therapist to help maintain strength and to support them with everyday skills.

Avascular Necrosis

Avascular necrosis (AVN) is a condition that develops following the loss of blood supply to an area of bone. When a blood supply is interrupted (becomes avascular), the bone tissue can start to break down (necrosis). Eventually, the bone can weaken and even collapse. If this occurs near to a joint, for example the hip, it can affect the joint causing further pain. The symptoms can range from mild discomfort to marked pain. In the early stages, most children will have few symptoms, but as the condition progresses, most will experience joint pain with movement, or when they are resting.

AVN can occur in all children but is more common in those who have had treatment for cancer. It can occur in any bone, especially at the end of long bones for example near the hips and knees. It can sometimes affect several bones at the same time (multifocal AVN).

Certain medications such as prednisolone and dexamethasone (given during cancer treatment) can increase the risk of AVN occurring. The risk of AVN is also higher if your child was aged 10 years or over during treatment, or if they received high dose radiation especially to their legs.

Managing AVN in your child can be challenging, but the main aim is to reduce pain and stiffness to make it easier for them to use their joints. Your child will probably need regular pain relief, gentle exercise and occasionally the use of crutches, or a cast to help them heal. Very occasionally surgery is required.

Your child may be advised to avoid high impact exercises, such as running and jumping but if possible they should continue with low impact activity such as swimming and cycling. It is important to follow the advice of your child's care team.

Referred pain

Sometimes it can be hard to pinpoint the exact source of your child's pain. If this is the case, they may be experiencing **referred pain.** This is where pain can be felt in one area of the body, whilst originating from a different location. The reason for this is the way in which sensory nerves connect.

An example of referred pain would be where an infection at the base of the lung can actually result in a sharp pain in the shoulders.

When no physical cause for pain is found

This is a very common frustration for parents and children who are experiencing chronic pain. It may feel like no one is listening. You may worry that people are trying to label your child as depressed, rather than listening to the problem and trying to ease the pain.

Chronic pain is best treated by using a combination of different approaches that affect the mind and body. This is because the mind and body are connected in so many different ways. Our memories, thoughts and emotions are intertwined meaning a holistic approach can give the best chances of success.

Research has shown that certain treatments such as **Acceptance Commitment Therapy** (ACT) or **Cognitive Behavioural Therapy** (CBT) can benefit children experiencing chronic pain.

If your child has chronic pain for long enough, they may become low in mood. This can have an effect on their level of activity and their ability to cope with pain. Indications that your child may be feeling depressed include a poor appetite, broken sleep or feeling low in energy. They may be more withdrawn than normal, or feeling down or hopeless.

The best treatment approach for chronic pain

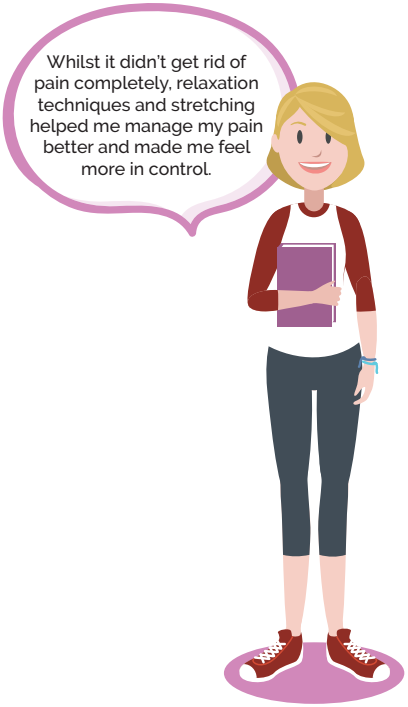
If your child's pain has become chronic, the care team may suggest a trial of different treatments. This might include pain relief medications and lifestyle changes, but what works best will depend on your child.

Lifestyle modifications

Certain changes in lifestyle can make a difference to how a child will manage their chronic pain. These changes can include:

- Increased exercise.
- Improved pacing of activities so that your child does not do too much on one day with a negative impact on the next.
- Improved sleep routine.
- Taking prescribed medications regularly to keep on top of pain.
- Trying to increase participation in social activities.
- Relaxation, meditation and distraction techniques.
- Support groups, massage, music, and counselling may also be useful.

Often management techniques do not take the pain away completely, but it may teach your child to manage it more effectively.



Medication for chronic pain

The aim of treatment is to control symptoms without causing troublesome side effects. Initially it may be suggested that your child tries regular pain relief such as paracetamol or ibuprofen. Your child's team will advise you on whether these are safe to use following treatment for cancer. The other medications used will depend on the severity and type of pain.

If your child does not experience improvement with regular **analgesia**, they could be offered other appropriate options such as specific treatments for muscle spasms or nerve pain. If these measures do not help, occasionally your child will be offered opioid analgesia such as oral morphine solution (Oramorph®), modified release **morphine** or **fentanyl** patches.

These medications can be helpful in some circumstances. However long term use can result in tolerance, meaning that ever increasing doses are required to achieve the same level of pain relief. As a result, opioid based analgesia is reserved for occasional flare ups (break-through pain) or if other treatments are not helping.

Medication for neuropathic pain

If your child is experiencing neuropathic pain, they may initially be started on a low dose of medication which is then gradually increased (titration). It will usually take a few days for neuropathic pain medications to reach their full effect. Sometimes this can make your child a little sleepy but often this will improve over time.

Amitriptyline is a medication which is used in low doses for treating neuropathic pain. When used in higher doses, it can be used as an antidepressant medication. When treating neuropathic pain, amitriptyline is usually started at a low dose at night and then gradually increased.

Gabapentin is used to treat nerve pain and as an anti-epileptic medication. It works by helping reduce the electrical activity in the brain to reduce pain. Usually it is started at night and then increased to two or three times a day.

Pregabalin (Lyrica) is used to treat neuropathic pain and as an anti-epileptic medication. It works in a similar way to gabapentin by reducing the electrical activity in the brain, reducing pain signals. Usually started at night, it can be increased to twice or very occasionally three times a day.

Other useful treatments

Depending on the cause of your child's pain, there may be other options available. For example, pain from a specific nerve can be treated with a **regional nerve block** and muscle spasm can be treated with **baclofen.**

Occasionally your child's pain team will suggest a trial of lidocaine patches. These are medicated plasters that contain lidocaine, a **local anaesthetic.** These can help by temporarily blocking pain messages. Lidocaine patches are not suitable for everyone but if suggested for your child, they can be helpful in the treatment of neuropathic pain.

Off-licence prescribing of medication

Sometimes, your child could be prescribed a particular medication even though they are outside the recommended age range advised by the manufacturer. This is often the case when treating nerve pain in children because there may not be enough trial data available for that drug's specific use in a child. Off-license prescribing is frequently used in the treatment of rare conditions. Your child's doctor will usually speak to you about this before commencing treatment.

Prevention can be key

If your child has chronic pain, it is important they understand the need to take their medication regularly. If taken in this way, it can help your child to get on top of pain and make it more manageable.

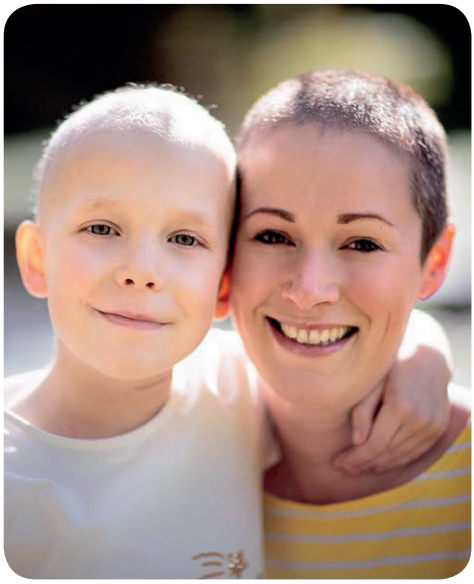
Waiting until pain is unbearable before taking medication means your child will be chasing the pain, making it very difficult to gain full control of their symptoms.

Mutual support

Some children and young adults who experience chronic pain will find it beneficial to talk to others in a similar situation. This can make them feel less alone and allow them to identify things that might help. Ask your pain team if there are any groups in your local area which might be suitable for your child.

About you

It can be hard caring for someone with chronic pain, especially when it is your own child. Looking after yourself often takes a low priority, but this is essential to enable you to care effectively for your child. Asking a friend or relative to sit with your child for an hour or so can help you come back with renewed energy.



Getting better

Getting better can take time and requires a lot of effort. There are no quick solutions and this can be frustrating. Chronic pain can have a major impact on the day to day life of the whole family so it is important it is managed in the best possible way. It can take time to get the treatment right, and the plan may need to change as your child's needs alter. If one treatment does not help as much as you had hoped, there are often other options available to try.

It is best to aim for treatment options that improve your child's ability to cope with their pain and give them a good quality of life by getting them back to school, carrying on with their hobbies, socialising and being a child again.

A Glossary of terms for parents

ACT
Acceptance Commitment Therapy. A talking therapy helping to change behaviour by altering the way you experience your thoughts, feelings and sensations. This helps to disconnect people from struggling with pain and other symptoms.

Amitriptyline
A medication used to treat nerve pain. It also has been used in the past (usually in much higher doses) as an anti-depressant. It works by disrupting the transmission of pain signals to the brain.

Analgesia
Medication that reduces pain, a painkiller.

Baclofen
A muscle relaxant that is used to help with muscle spasms in individuals with certain neurological conditions.

CBT
Cognitive behavioural therapy. A talking therapy that can help you manage your problems by changing the way you think and behave.

Fentanyl
A strong pain killer similar to morphine. It can be used in the form of a lozenge, tablet under the tongue, infusion or as a pain relieving patch to help with severe pain.

Fistula
An abnormal connection or passageway that connects two organs or vessels that do not usually connect. These may occur following surgery or as a result of chronic infection.

Gabapentin
A medication used to treat nerve pain. It is also an anti-epileptic medication (used to treat seizures).

Local anaesthetic
A drug that is used to block pain messages. It can be used as a cream before procedures, injected or used as a pain patch.

Morphine
This is a strong opioid painkiller that is good for treating moderate to severe pain.

Neuropathic pain
Pain caused by damage or injury to the nerves that transfer information between the brain and spinal cord from the skin, muscles and other parts of the body.

Pregabalin
A medication used to treat nerve pain. It is also an anti-epileptic medication (used to treat seizures).

Regional nerve block
A procedure in which local anaesthetic is injected directly near a nerve to block pain.

Shunt
A small tube (catheter) that can help transfer fluid from one area to another. These are sometimes used in the brain.

Grace Kelly Childhood Cancer Trust

The Grace Kelly Childhood Cancer Trust is a UK children's cancer charity that concentrates on funding research and providing support for children with rare childhood cancers. We also work to provide education on the signs and symptoms of childhood cancer and how it may present.

For more information please see our website.

Grace Kelly Childhood Cancer Trust

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