

Helping Children Cope with Pain



Helping sick children and young people meet their healthcare needs

Action for Sick Children Scotland (ASCS) is the only Scottish charity which promotes the needs of all sick children and young people within our healthcare system. We work for improved standards and quality of care for children and young people when they are ill in hospital, at home or in the community. We aim to represent their needs and those of their families and ensure that their voices influence health policy, planning and practice. We do this in partnership with parents, carers, professionals and children and young people themselves.

We work with children, young people and their families by giving healthcare information and support. We recognise the importance of quality, appropriate and timely information in helping sick children, young people and families to cope better with worrying or unknown situations.

Children do experience medical treatment, illness and sometimes accidents which will result in pain. We hope this guide will support parents and carers to help their children with their pain at such times. It may answer some of the questions families have and can be used with any other information you receive from your GP, Nurse or hospital.

ASCS is a member of the European Association for Children in Hospital (EACH) which has produced the EACH Charter. This sets out ten standards for children and young people's health care at time of illness. Hospitals are working towards meeting these standards.

ASCS is grateful to its Family Participation Group and healthcare professionals for input to this booklet.

Helping Children Cope with Pain

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In this guide ‘my child’ and ‘your child’ refers to children looked after by birth parents and other carers for example foster and kinship carers.

Pain Explained

What is pain?

Pain is usually the body's useful warning signal that something is wrong. All children feel pain, just as adults do. Sometimes the reason for the pain is obvious, like a broken bone or appendicitis, but sometimes we don't find anything to explain it or there seems to be more pain than we would expect. This is because pain has a lot to do with the way that nerves work.

How do you know if a child is in pain?

By watching the child: Your child may seem quieter than usual, noisier or agitated, more sleepy, tense, flushed or pale. As a parent/carer you are often the best judge of this, as you will usually notice when your baby or child seems different.

By listening to your child: Let them know that it is alright to say that 'it hurts'. Tell them that they can be helped if they feel sore. Even very small children can use pain charts (see page 12 of this guide).

By checking that the main problem is pain: Adults talk about being hurt when they mean either their body or their feelings – physical or emotional pain. So a child may use the same words when tired, sad, upset, uncomfortable or reacting to other circumstances.

Why is it important to manage pain properly?

Doctors and nurses aim to control pain within safe limits. Treating pain properly can help children to get better more quickly. It can help them to relax, sleep and play.

A child shouldn't have to wait in pain, because the fear of being in pain makes it much worse. Helping a child to know that their pain matters and that it can be controlled will help to reduce their fear and give painkillers a better chance to work. If the first dose is not enough a higher dose of painkiller may be needed. One doctor says:

'The aim is to prevent pain from developing, by regular, continuous treatment. We make a best guess which may or may not be correct. If you or your child is not happy with the level of pain control, please tell someone so that it can be changed.'

Can I do anything?

Yes, parents and carers have a key part in helping the child avoid or cope with pain. You know your child best.



Pain Control without Drugs

How to help your child cope

The following suggestions work best for mild pain, or around a short event like an injection, and usually involve parents, carers, nurses and play specialists. Using the same routines can help the child to deal better with feelings of fear, anger and confusion.

Comfort and support them – pain is much worse when children are scared, tense and tired. Stroking and cuddling may make them feel a bit better – sometimes they want to squeeze someone’s hand while the pain lasts. Just being there helps, especially during tests and treatments that may be painful. If possible, stay with your child if they want you there and you can cope.

Distraction can help many children during treatments and tests. You and your child will know best what can hold their attention and help ‘block out’ everything else. Ideas for distraction are included on page 5.

Handy tips for dealing with Pain

- ▶ Talk to the nurse or doctor beforehand. If you can find out about what is going to be done, you and your child may be able to plan how you will do this together. Tell staff how you plan to help your child so that they can support you to do this.
- ▶ Let your child know it is ok to make noise or say that ‘it hurts’.
- ▶ Let your child have the choice of watching the needle go in or not.
- ▶ It may help your child to give injections to a teddy.
- ▶ Make sure that you are calm, positive and confident. Don’t show that you are upset or tell your child about a difficult experience that you have had.
- ▶ Staff may suggest that your child uses a TENS machine which blocks transmission of pain signals or hot or cold packs.



Explain as much as possible

Fear increases pain. The worst pain is fear of the unknown, so children need to know what to expect, to be given choices and some control. They feel less upset if they are told honestly:

- ▶ Why they have to have the procedure
- ▶ That it is meant to help them, not upset them
- ▶ When it will hurt.

If other procedures are planned which will not cause pain, make sure to tell your child so they don't worry about what comes next.

Do not tell them that it is not going to hurt, if it will.

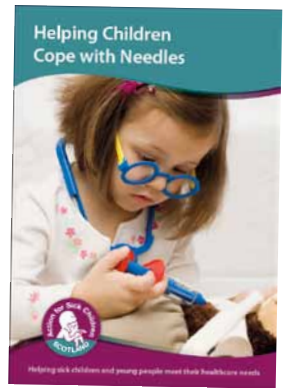
Quite often you can find out what your child needs to know if you get them to talk about their pain, and to show you how they feel by drawing or painting. Puppets, toys and hospital play sets are useful 'tools'.

Distractions

Stories, DVDs, CDs, music and games, puppets or pop-up books or telling jokes may help children to feel less pain. The more you get the child to tell a story or work the puppets, the better. If your child has to have a needle, you could rub the other arm. Deep breathing, slowly counting 4 breaths in and 4 breaths out, or blowing bubbles can soothe children. It can also help to calm you, which can have a positive effect on the child.

You can find more useful information in Action for Sick Children Scotland's 'Helping Children Cope with Needles' guide.

www.ascscotland.org.uk/default.asp?page=20



Use your child's imagination

Many hospital staff teach children and parents 'mind-over-body' methods which help children deal with pain. These are used either on their own or along with drugs. Children are more able to live in their imaginations than adults, so it is worth encouraging them to use this method. There may be someone in your hospital who can help you start to use these with your child. Here are some examples:

- ▶ Before a blood test encourage your child to imagine putting on a special long glove that blocks the pain.
- ▶ A child who is feeling sick could imagine having a cool drink which soothes their mouth down to their stomach.
- ▶ A child with eczema could imagine rolling in special snow.
- ▶ A child with long-term pain could think of slowly reducing the volume control on the TV or computer to a level that makes the pain bearable.
- ▶ To help your child relax, ask them to shut their eyes and imagine walking slowly down ten steps to a door which opens into a place where they feel safe and happy, somewhere they really enjoy, like a fun fair, swimming pool or their bedroom at home. Then lead them back through the door and slowly back up the stairs. By this time the pain may not have gone away, but it may not feel so bad.

Keep in close contact and comfort your child as much as possible during the procedure.

Pain Control with Drugs

Is there any such thing as perfect pain control?

No, any drug can have side effects. In general drugs with a stronger pain killing effect have more side effects. Some drugs make children feel sick or itchy. They may become constipated or have strange dreams, yet when pain is the main problem, it should be relieved. Side-effects can be reduced by using extra drugs, such as anti-emetics to stop sickness, or by changing the pain control method. Using the non drug approaches described early can also help. Using the same routines can help the child to deal better with their feelings and this can help medicines that treat more serious pain to have more effect.

Do some children need more pain relief than others?

Yes, there is no such thing as the 'right standard dose'. The amount is right if it suits that child and is within safe limits. The medical team will work out what dose is best for your child.



Pain jargon explained

Analgesia: pain relief. Analgesic drugs like Paracetamol taken by mouth can control mild pain. Severe pain may need a combination of drugs given by mouth or suppository, intravenous infusion or as an injection.

Sucrose: works as an analgesic to give pain relief to babies and young infants.

Anaesthetist: a medical doctor who specialises in pain relief.

Anaesthetic: pain relief given when a child undergoes an operation or procedure.

Local anaesthetic: pain relief given to provide loss of feeling and to limit pain in part of the body. This can be given by a special spray, cream or gel rubbed into the skin which dulls or blots out pain from needles – or by an injection or epidural/spinal, a tiny tube fitted near the spine, through which pain relief is fed slowly.

General anaesthetic: pain relief given when the child is unconscious to keep the child asleep and free from pain.

Anti-emetics: drugs which stop the child feeling and being sick.

Acute: short-term, sudden onset.

Chronic: long-term – usually doctors will say the pain is chronic if it goes on for more than three months, or if there's still pain after you would have expected an injury to have healed.





What are the different options?

Sometimes a drug can have different names (for instance ibuprofen / nurofen / brufen are all the same medicine) or similar types of drug can have the same effect (for example ibuprofen, diclofenac and naproxen), so it is important to take care that only one of each type is given to a child at any one time. You can ask the pharmacist for advice about any medicines you need for your child.

Examples of pain relief drugs

For mild pain: before giving any drug it is good to take time to try to check if your child has physical pain or is feeling sore for other reasons. Often a cuddle, comfort and distraction can avoid or lessen the need for medicine. It is wise to avoid children thinking that any feeling of hurt needs drug treatment to cure it.

Paracetamol; paracetamol suspensions such as Calpol and Disprol are available to buy without prescription in a pharmacy. Ask the pharmacist's advice about how much you should give your child.

Neurofen/Ibuprofen for babies and children is also available over the counter; check with your doctor or nurse about using this with your child. These should be avoided if the child could be dehydrated.

Even for mild pain relief always follow the directions on any medication you give to your child.

The following medicines should only be given on medical advice and need to be prescribed by a doctor:

For moderate pain: Diclofenac, Indomethacin, Naproxen. Codeine may be considered for children over 12 years old.

For severe pain: Morphine, Diamorphine.

A child who continues being in pain may need to have a higher dose, or to take the drug more often, or to go on to a stronger one, within safe limits. Sedating drugs like Midazolam or Diazepam (Valium) are rarely used with other drugs; they reduce anxiety and recall of the pain but do not reduce pain and some children do not like them. The anxiety that often affects a child in pain can be helped by a clinical psychologist or play therapist. Severe pain needs powerful drugs, and used in the right way, your child will not become dependent on them.

There are specialist paediatric pain services available in Scotland. Ask your doctor for a referral if you feel your child needs this service. See this website for more details www.knowledge.scot.nhs.uk/pain/patient's-page/pain-in-children-and-young-people.aspx

How are these drugs given?

Pills, tablets or liquid medicine can be given by mouth – this is the easiest way if your child accepts them and can wait for them to take effect. Your child needs to be able and willing to drink. If the child is old enough they may be given the choice as to how they would like to take their pain relief.

IV (intravenous) drip – if your child cannot have medicine by mouth, they will probably have a drip fixed into a vein and drugs may be fed in painlessly through the drip. The dose is adjusted to the needs of the child either by nurses on the instruction of the anaesthetist or ward doctors. Following surgery pain relief may be given by a pump or PCA (Patient Controlled Analgesia) where the child can receive a dose of analgesia when they need it up to a safe upper limit.

If the child is having long-term treatment for a chronic problem, it is possible, although unusual, for the child to get a central line (for example a Hickman or Portacath line). This will be explained to you and your child by the specialist team in charge of treatment.

Spinal or Epidural – after some major operations, anaesthetists may set up an epidural near the spine. They may also give a 'nerve block' injection before the child wakes up which dulls the pain for hours.

Other options – some pain is relieved by creams, skin patches, suppositories and nose-sprays.



What about pain-killing injections?

Injections can sometimes be used, for example for dental treatment, although relieving pain by injection tends not to be used for children. IM (into a muscle) injections are rarely used as some children find them distressing and they take half an hour or more before they start to work.

Sometimes, although it is unusual, an analgesic is given through a fine needle or plastic tube placed just under the skin, for longer term relief of severe chronic pain at home.

What about severe pain?

For severe pain, PCA (Patient Controlled Analgesia) is very useful. This pain relief drip is timed to give a set dose, very slowly. There is a small button or pump for patients to press when they want or need it – either after surgery, or because their pain is coming on again, or before physiotherapy, or when a wound is dressed. The patient can press the button as often as they need to and because the infusion is monitored, it is not possible to get too much medicine. Children do well with this kind of pain relief and often use less than the maximum dose allowed.

When immediate relief of severe pain is needed such as after serious injury, a strong analgesic may be given as a gentle spray into the child's nose. This can only be done by a nurse or doctor trained to do this and able to deal with any side effects. Another way to give quick pain relief is to use

an inhaled gas called Entonox which is more often used in the maternity unit. It is often used for putting on a plaster cast or for another short procedure. It is a strong pain reliever and wears off very quickly.

How is long-term pain dealt with?

This guide is mainly about pain during a *short illness* or *after surgery*. If there is *long-term* pain, doctors, nurses and often the clinical child psychologist will probably be working with you and the child to help to manage it. If not, perhaps both you and your child could talk to the doctor, using some of the points raised here as a guide. In the meantime, keeping a pain diary can help you to see how much relief is needed, the best times to take it, the 'triggers' which seem to start off the pain, and how to avoid them. To find out how strong the pain is you can use a pain chart like the one on page 12.

What about repeated, sudden attacks of pain?

If your child is in pain they should rest, keep warm, have plenty to drink and take Paracetamol and any other medications advised by their medical team. If attacks of pain happen repeatedly your GP may refer the child to a paediatrician who will try to find out the cause and advise on how to avoid the pain if possible or how to treat the pain. If the attack is severe, hospital may be the best place for help. Your child should be given urgent treatment as soon as they arrive in hospital. Ask for a card or letter from your doctor to show to hospital staff explaining what must be done.



Answers to Questions

Young Patients may ask

It may help to talk about the following with your child. Let them know that they can ask their doctor or nurse about these or any other questions.

Q. 'Will they keep me in hospital if I say that it hurts?'

A. If you have pain, it is better to say so, because if the pain is treated properly you may get better more quickly and get home sooner.

Q. 'Should I wait until the pain gets very bad before I ask for help?'

A. The drug may take an hour or more to work. It is worth asking for something before the pain gets bad and you get very tense.

Q. 'Will I need an injection?'

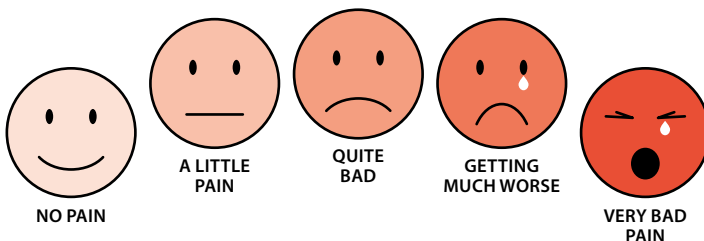
A. Pain relief is usually given another way. If you do need an injection, you can ask a nurse or a doctor for a special cream which dulls the pain from some injections. Depending on the type of cream, it needs to be on your skin for 30 minutes or one hour before the injection. Sometimes a spray, which feels very cold, can be used and which works immediately.

Q. 'I have had pain medicine but I'm still sore. What can be done?'

A. The doctor and nurse know how much medicine you can safely have. Be sure to tell them that you are still in pain. In the meantime it could help to try ways to take your mind off the pain – reading a story, listening to music, imagining being in a safe, happy place.

Q. 'Will the nurses think I'm a wimp if I say that it hurts?'

A. The nurses may not know you are in pain, and you need to tell them. You are the expert who knows how much it hurts. Perhaps this chart will help you to show which face fits how you feel now.



Helpful organisations/information

Action for Sick Children Scotland www.ascscotland.org.uk Tel: 0131 553 6553

Helping Children Cope with Needles Guide
www.ascscotland.org.uk/default.asp?page=20

Hospital Playbox to Help Prepare Children
www.ascscotland.org.uk/default.asp?page=82

Arthritis Care www.arthritiscare.org.uk/LivingwithArthritis/Youngpeople
Information for young people. Helpline Tel: 0808 800 4050

Contact-a-Family www.cafamily.org.uk Information on medical conditions and family support groups. Helpline Tel: 0808 808 3555

Great Ormond Street Hospital for Children NHS Trust Tel: 020 7405 9200

Distraction Therapy www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/distraction-therapy/

Topical anaesthetics www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/topical-anaesthetics/

Fear of Needles www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/fear-of-needles/

My Hospital Passport Booklet designed in the Royal Hospital for Sick Children, Glasgow to help children attending for treatment or procedures. Contains Bright Ideas cards including distraction and relaxation cards. Scottish hospitals with paediatric services have this booklet which can be requested from the child's medical team, the Play Service or Paediatric Psychology Service
[www.knowledge.scot.nhs.uk/child-services/communities-of-practice/psychology-\(paediatric\).aspx](http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/psychology-(paediatric).aspx)

Information for parents/carers of children aged 2 to 6 years
www.mychildispain.org.uk

National Association of Health Play Specialists www.nahps.org.uk

NHS Education Scotland (Knowledge Network) Information on Pain in Children and Young People www.knowledge.scot.nhs.uk/pain/patient's-page/pain-in-children-and-young-people.aspx –

NHS Health Scotland Tel: 0131 536 5500
Guide to Childhood Immunisation Up to 5 Years
www.immunisationscotland.org.uk/uploads/documents/20395-AGuideToChildhoodImmunisationsUpToFiveYearsOfAge.pdf

My Pain Toolkit for Young People and Teenagers Living with Pain
www.pain toolkit.org/assets/downloads/ptk-for-teenagers2012.pdf

Action for Sick Children Scotland is the only charity in Scotland dedicated to informing, promoting and campaigning on behalf of the needs of ALL sick children and young people within our healthcare system.

For information in your language phone 0131 553 6553.

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欲想索取閣下所操之語文資料，請致電 0131 553 6553。

Aby uzyskać informacje w Waszym języku, prosimy o kontakt pod numerem telefonu 01315536553.

For a full list of publications please go to the Action for Sick Children Scotland website at www.ascscotland.org.uk

For all other information please contact:



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