

PANUSTERS



YOUR GUIDE TO PAIN RELIEF IN ALDER HEY

ACKNOWLEDGEMENTS

This booklet could not have taken shape without the hard work and dedication of a focus group of young people, who provided the content and the characters and the overall design of the booklet. So a massive thankyou to...

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THIS BOOKLET AND HOW TO USE IT

The aim of this booklet is to give information about how we can help to reduce / stop pain in Alder Hey. With the exception of the first section about Pain Assessment:



The left- hand pages are in comic format for an 'easy read'.



The right-hand pages for older children and family members.

We recommend that you do not read both pages to avoid duplication.

WHO ARE THE PAIN TEAM?

The pain team is a group of people who work together to help patients who are experiencing pain.

The pain team includes doctors and nurses who, from Monday to Friday and Saturday morning (excluding bank holidays) visit the patients who need to be seen because of the pain killers they are having or the staff caring for you have asked us to help.

The pain team also work with Health Play Specialists to help children and young people having 'procedures' there is a section about this later in the booklet.

HOW DO YOU FEEL IN ALDER HEY?

If you are sore, in pain or hurting when you are a patient in Alder Hey – please tell the nurse or doctor who is looking after you.





WE CANNOT SEE
YOUR PAIN. YOU OR YOUR
FAMILY HAVE TO TELL THE
NURSE OR DOCTOR IF YOU
ARE SORE

PLEASE TELL US
ABOUT YOUR PAINTHE PAIN TEAM AND
ALL THE DOCTORS
AND NURSES ARE
HERE TO HELP.



1. PAIN ASSESSMENT

2. PAINKILLERS

3. PROCEDURES

4. GOING TO THEATRE

5. PCA / NCA

6. EPIDURAL

CONTEN

7. LOCAL ANAESTHETIC BLOCKS

8. GLOSSARY

TO HELP US TREAT PAIN WE NEED TO MEASURE IT. THIS IS CALLED 'PAIN ASSESSMENT'. WE USE SPECIAL TOOLS OR SCALES TO HELP US.

1. CRIES PAIN SCALE

for babies from 32 weeks gestational age

CRIES is a tool for babies and looks at the babies behaviours and needs. Because part of the tool looks at the babies breathing and oxygen needs — this is used by healthcare professionals only but it should be explained to you. The first column (shaded slightly darker) shows the signs of pain we look for.

No cry or cry which is not High pitched cry but High pitched cry and Crying high pitched consolable inconsolable Characteristic cry of pain is high pitched Requires 0, to Requiring 0, < 30% Requiring 0, > 30% No maintain SAO₂ >95 Consider other changes in oxygenation: pneumothorax, oversedation 10% - 20% increase in > 20% increase in heart Heart rate and blood Increased vital signs pressure +/- 10% baseline heart rate or blood pressure rate or blood pressure Take blood pressure last as this may wake the infant causing difficulty with other assessments Grimace / grunt Expression Neutral Grimace Grimace characterised by brow bulge, eyes shut, deepening naso-labial furrow, open mouth Wakes frequently Constantly awake Sleeplessness

Based on infant's state during the hour preceding assessment

Instructions: Each of the five categories (C) Crying; (R) Requires 02 to maintain SA02 >95; (I) INcreased vital signs; (E) Expression and (S) Sleeplessness is scored 0, 1 or 2 which results in a total score between 0 and 10

Krechel, S.W. & Bildner, J. CRIES: a new neonatal postoperative pain measurement score. Initial testing of validity and reliability. Paediatric Anaesthesia 5(1)53-61 1995



Used to measure pain in young babies



The tool measure 5 different ways that pain can be seen and measured in young babies



Each section is measured and scored either 0, 1 or 2 - the final score is between 0 and 10



If you are worried about your baby - please talk to the nurse looking after them



All pain should be treated.

2. FLACC PAIN SCALE for children aged 2 months to 7 years

FLACC is a tool for young children from 2 months to 7 years. The first column (shaded slightly darker) shows the signs of pain we look for. This tool is very easy to use and parents can become very skilled using this tool with assistance from nurses.

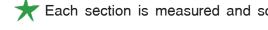
	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, clenched jaw, quivering chin
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back & forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging or 'talking to', distractable	Difficult to console or comfort

Instructions: Each of the five categories (F) Face; (L) Leg; (A) Activity; (C) Cry and (C) Consolability is scored 0, 1 or 2 which results in a total score between 0 and 10

Merkel, S.I. et al. Practica applications of research. The FLACC: a behavioral scale for scoring postoperative pain in young children. Pediatric Nursing 23(3)293-297 1997



This tool measures 5 different ways that pain can be seen in young children



TEach section is measured and scores either 0, 1 or 2 - final score is between 0 and 10



This tool is called an 'observational' tool because it looks at the child's behaviour and posture. It can be used by nursing staff or parents. If you want to be involved in this aspect of your child's care, the nurse will explain how this tool can be used.



All pain should be treated

PAEDIATRIC PAIN PROFILE OR PPP

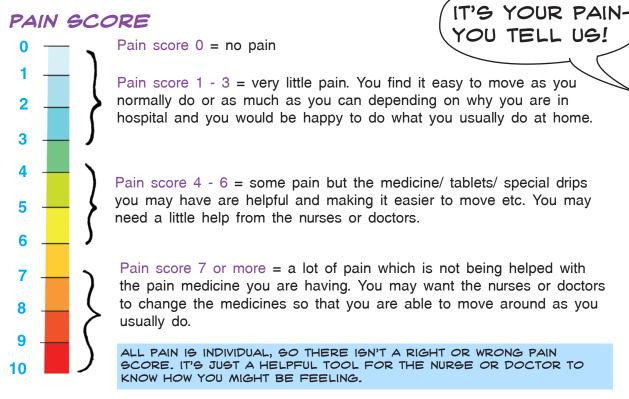
If your child is unable to communicate verbally and you use the "Paediatric Pain Profile" at home - please bring it with you when you come to hospital and inform your child's nurse.

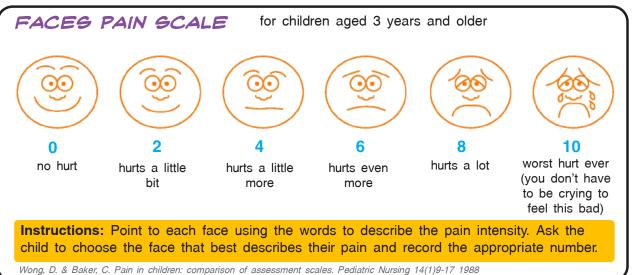


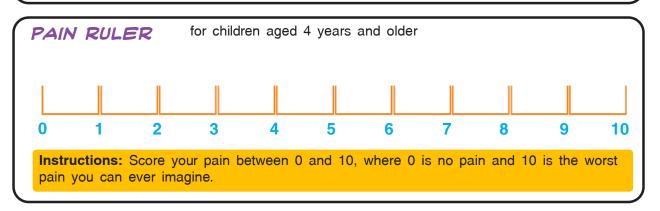
2 WAYS YOU CAN USE TO TELL US ABOUT HOW SORE YOU FEEL.

It is important for the nurses and doctors to know how much pain you have so we can give you the best painkiller.

The pain tools have numbers (we call this the "pain score") to help you.







These pain assessment tools have been tested by researchers to show that they score pain accurately therefore we are unable to change the way they look

PAIN IS DIFFERENT FOR EVERYONE. AS WELL AS THE PAIN OR SORENESS IT CAN MAKE YOU FEEL DIFFERENT THINGS BUT WE HAVE SOME IDEAS THAT YOU CAN USE THAT WILL HELP

Pain can make you feel...

TENSE OR STRESSED

Unable to relax, sleep, rest, makes you feel stiff

WORRIED

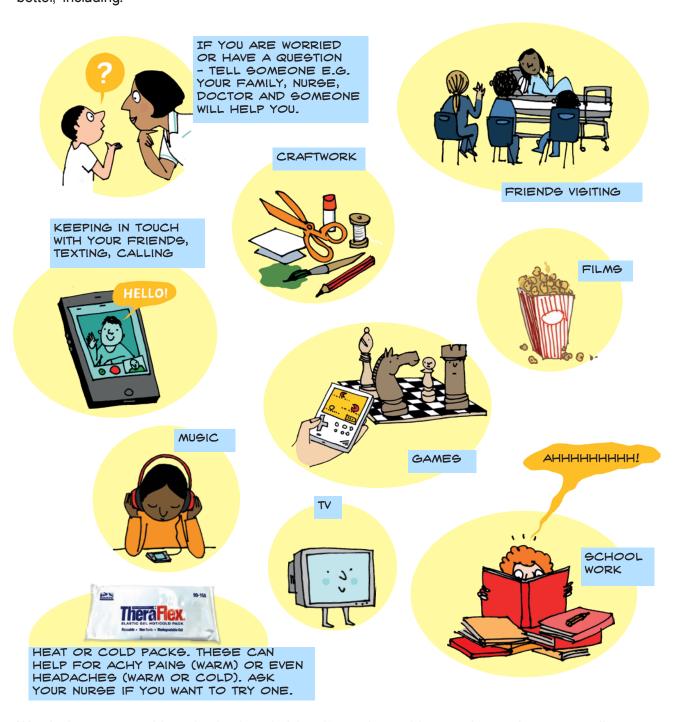
Am I okay? Is something wrong?

SAD

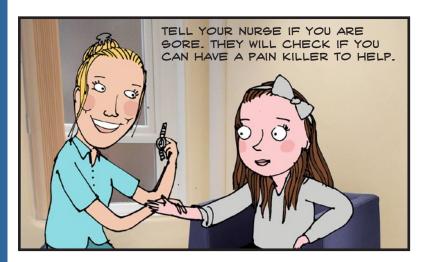
Not interested in anything, can't concentrate

... and all of these things can make your pain less easy to cope with.

There are a few ideas you and your family can use to reduce this and make you feel better, including:



We do have some things in the hospital but if you have things at home that can easily be used in hospital ask your family to bring them in — no bicycles please!



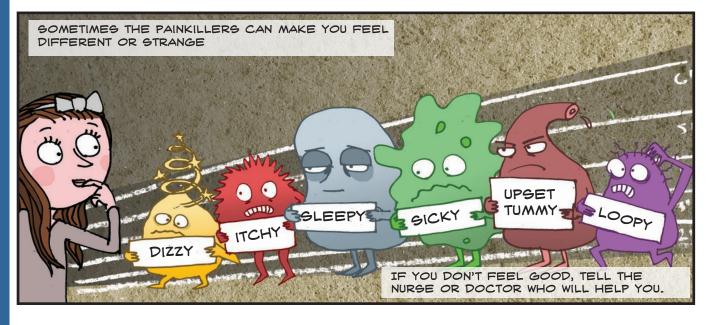












PAINKILLERS FOR MILD PAIN

PARACETAMOL
(CALPOL)® is used
widely in homes as well as
hospitals for pain. It can be
used alone or with other
painkillers.

IBUPROFEN (BRUFEN)® is used in homes and hospitals for pain. This painkiller belongs to a group of medicines called Non-Steroidal Anti-Inflammatory Drugs (NSAIDs). These

drugs work by reducing swelling and inflammation which reduces pain.

DICLOFENAC

(VOLTAROL)® is similar to, and works in the same way, as Ibuprofen. It should not be given to someone taking ibuprofen as this will not reduce pain but may cause side effects.

PARECOXIB is similar to ibuprofen and diclofenac BUT we can give this through a drip.

PAINKILLERS FOR MODERATE PAIN AND SEVERE PAIN, KNOWN AS "OPIOIDS"

TRAMADOL is given for moderate pain when other painkillers have not helped to reduce the pain. We do not give Tramadol to children under 4 years old.

MORPHINE is used for severe pain. We can give this by mouth, as a medicine or tablet, or via a drip using a special pump. This is called PCA or NCA – there is more about this later in this booklet.

FENTANYL is a man-made version of morphine and is used for the same reasons. We cannot give Fentanyl by mouth but we can use it in PCA or NCA or add it to epidural pain relief – there is more about PCA, NCA and epidural later in the booklet.

OXYCODONE is again man-made and works in the same way as morphine and fentanyl. We can give this by mouth or in PCA or NCA

OTHER PAINKILLERS

KETAMINE is used for severe pain. We can use this alone or with other painkillers including opioids.

CLONIDINE is another painkiller for severe pain we can use with other painkillers or on its own. Like Fentanyl it can be added to epidural pain relief.

DIAZEPAM (VALIUM) – is associated with treatment for anxiety but we use very small doses to reduce muscular spasms particularly after bony operations.

BUSCOPAN is a painkiller we use to help with abdominal or stomach cramps.

BACLOFEN is used to treat muscular spasm and is often used regularly by children at home as well as in hospital. If your child takes baclofen, please inform the doctor / nurse.

Generally, codeine is no longer used in children under 12 years old with 2 exceptions; 1) children under 13 weeks and 2) children who have been on codeine at home e.g. for chronic pain, without problems.

Some children cannot take some medicines for a number of reasons — if your child cannot take a particular medicine for any reason please ensure you tell the doctors and nurses.

There are several ways we can give painkillers to babies, children and young people, including:

BY MOUTH – as liquid medicine, tablet, caplet, capsule or dissolvable tablet.

INTRAVENOUSLY — given via a drip through a narrow tube into a vein.

BY SUPPOSITORY – a specially made 'tablet' that is placed into a child's bottom

where it dissolves quickly into the blood stream and reduces pain.

BY EPIDURAL OR LOCAL ANAESTHETIC BLOCK a different method of giving pain relief which is explained later in this booklet.

TOPICAL – a cream or gel

applied to skin to 'numb' the area from sharp pain e.g. needles.

INHALED - specifically refers to Entonox® or 'laughing gas' which is breathed in. Entonox is mainly used for procedures to reduce pain and/or anxiety, worries / fears of a child needing a procedure.

THINGS WE CAN DO TO HELP YOU WHEN YOU NEED A TEST OR PROCEDURE.









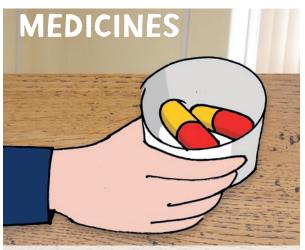
THE NURSE/
DOCTOR WILL
TELL YOU ABOUT
THE CHOICES WE
HAVE TO HELP
YOU AND PLAN
WHAT IS BEST
FOR YOU.



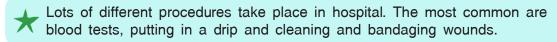
THE NURSE OR HEALTH PLAY SPECIALIST MIGHT GIVE YOU MEDICINE THAT YOU BREATHE IN. THIS MEDICINE HELPS TO MAKE THE PAIN BETTER AND MAKES YOU FEEL GIGGLY AND FLOATY.

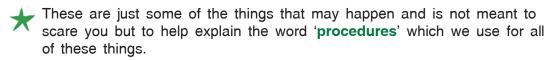






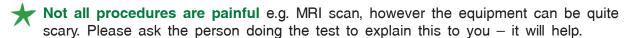
SOMETIMES WE USE MEDICINES TO HELP YOU FEEL COMFORTABLE AND RELAXED. WE WILL EXPLAIN WHAT THEY ARE IF YOU NEED SOME.

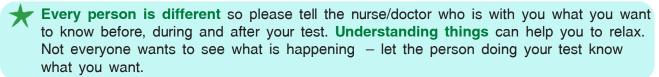


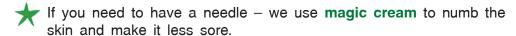




rocedures are all different and can hurt BUT there are lots of ways we can help.









We, or you, can use **distraction** e.g. bring your favourite computer game, music, toy etc. If you are brining something from home think about the procedure you are having e.g. an MRI scan means nothing metal.



Entonox or 'gas and air' is a medicine we use to reduce pain and any worries or fears you may have. It is easy to use — you just breathe it in using a mask or mouthpiece (a little like a flattened straw).

It works quickly – after about 10 breathes or even sooner! Some children (and adults) giggle when they use Entonox and the name 'laughing gas' is also used.

A nurse or health play specialist will stay with you whilst you are using Entonox and until it has worn off, about 5-10 minutes after you have stopped breathing it in. Because **Entonox works and wears off quickly** — we can use in outpatients without increasing the time you need to spend in hospital.



ENTONOX MOUTHPIECE

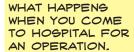


ENTONOX MASK

Some procedures need use to use stronger medicines either my mouth or in a drip.

These medicines work well but do not wear off so quickly – you will need to stay in the hospital until the medicines have worn off – usually a few hours.

Something personal – bring something with you that you can use during your visit before and during your procedure e.g. games, book, phone, music. It will help you to focus on something nice.





WHEN YOU COME TO THE HOSPITAL YOU WILL GO TO A WARD WHERE ALL THE CHILDREN GO BEFORE THEIR OPERATIONS.



BEFORE YOU GO TO THEATRE YOU WILL SEE A DOCTOR, NURSE AND ANAESTHETIST. THE ANAESTHETIST IS A DOCTOR WHO WILL HELP YOU GO TO SLEEP DURING YOUR OPERATION.

IF YOU ARE WORRIED OR SCARED PLEASE TELL A NURSE. IF POSSIBLE A HEALTH PLAY SPECIALIST WILL EXPLAIN WHAT



THE NURSE MIGHT PUT SOME MAGIC CREAM ON YOUR HAND OR FOOT TO NUMB THE SKIN AND MAKE NEEDLES LESS SORE.





YOUR WHEELCHAIR AND ONE MEMBER OF YOUR FAMILY CAN STAY WITH YOU UNTIL YOU ARE AGLEEP.











When you have an operation, a period of fasting or 'nil by mouth', is needed. This is for your safety and means your stomach will be empty during your operation. The fasting times are:

Children less than 12 months

Food 6 hours

Milk 4 hours

Breast milk 3 hours

Clear (still) drinks 1 hour

Children over 1 year old

Food 6 hours

Clear (still) drinks 1 hour

*

When you come to Alder Hey for an operation to will go to either:

SDU - Surgical Day Unit on the ground floor if you are going home the same day

or

SAL - Surgical Admissions Lounge on the 1st floor if you are staying at least one night.



The nurse on SDU / SAL will ask you some questions about you and any health-related issues.

The anaesthetist (the doctor who helps you to sleep during your operation) will visit before you go to theatre. They may wear their own clothes or theatre 'scrubs' that look a bit like pyjamas.

If you are worried or anxious about going to sleep or having an operation – please talk to the anaesthetist or the nurse.

A health play specialist can prepare young people of all ages for their operation and can, when possible, go to the theatre with you if this helps.

Before you go to theatre a nurse may put some magic cream on your hand or foot to numb the skin and make needles less sore.

You can walk, go on a trolley or in your own wheelchair to go to the anaesthetic room where you will go to sleep. One family member can stay with you until you are asleep.

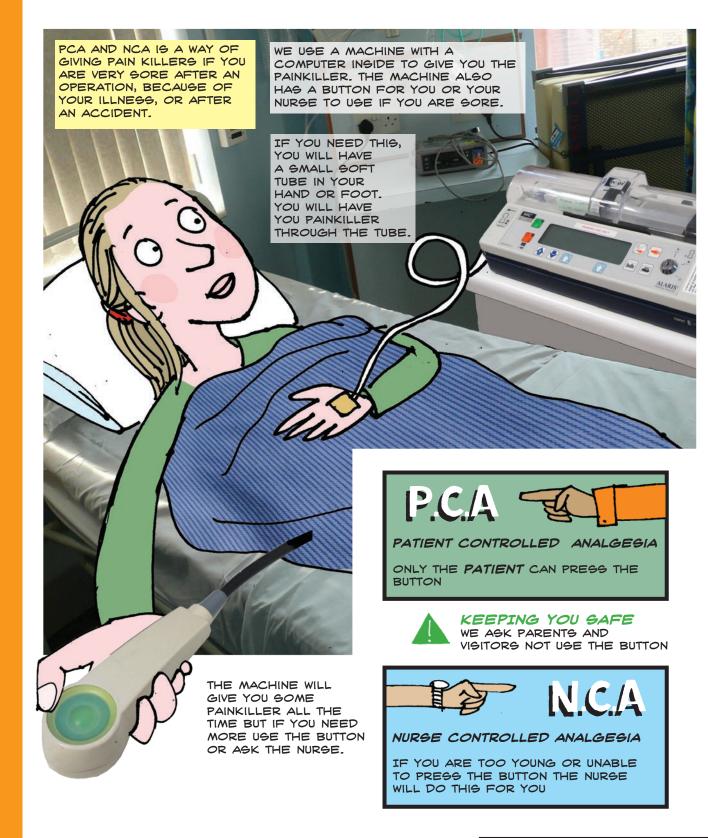
The anaesthetist will help you to go to sleep by either putting some medicine into a tube in your hand/foot or giving you a mask to breathe in some gas.

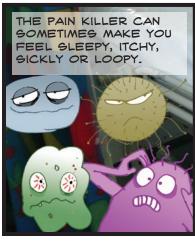
→ Whilst you are asleep – the anaesthetist will look after you.

After your operation you will wake up in a "recovery" area. A nurse will stay with you and look after you until you are fully awake and comfortable.

tlyou feel dizzy, sick or sore - please tell the nurse and they will help you.

When you are awake and are feeling okay - you will be taken back to either the SDU or to a ward.





DURING THE DAY AND IN THE NIGHT THE NURSE WILL ASK YOU IF YOU FEEL SORE, ITCHY OR SICK. TELL HER IF YOU ARE AND SHE WILL GET SOME MEDICINE TO MAKE THEM BETTER.



The difference between PCA and NCA

P.C.A

Patient Controlled Analgesia
ONLY the patient presses the button.

N.C.A

Nurse Controlled Analgesia

The nurse and sometimes the patient presses the button.

FOR SAFETY only the patient and hospital staff should press the button.

To give the pain killers using PCA or NCA we use a machine or 'pump' that delivers the medication through a small, soft tube in your hand, arm or foot.

The pump has a computer which we programme based on your weight to do 2 things:

- 1 give a small amount of pain killer all the time even when you are sleeping.
- 2 allows you or your nurse to press a button to get extra pain killer if you are sore.

Morphine, Fentanyl and Oxycodone are the pain killers we use. These are strong medicines to make pain a lot better and allow you to sleep, move, play, and speak with friends and family etc as you get better.

As you heal the pain reduces and you will need less pain killers. After 2-3 days (average) we will stop the pump and give you similar pain killers by mouth. At first, these are given regularly however after 1 to 2 days, and as you continue to heal and get better, you will only have them if your pain is bad. You will have other pain killers e.g. paracetamol which you will take for a few days maybe longer.

Sometimes the pain killers can cause problems. The most common ones we see are:

Nausea – feeling like you want to be sick

Sleepiness & unable to concentrate

Vomiting - being sick

Itching

We can give medicines to reduce or stop this, or change the medicine in the pump.



Rarely, these pain killers can cause more serious problems, including:

Sedation – very sleepy and not responding to verbal requests e.g. open your eyes

Breathing problems – breathing can be slow or less effective



These problems are observed for by nurses and are easily seen and recognised. They can be treated and sometimes we will change the medicine in the pump.

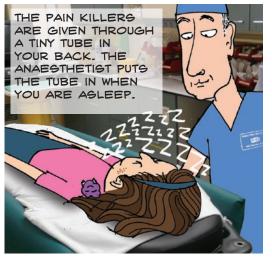


If you or your child has a PCA or NCA pump — they will be seen every day by a nurse or doctor from the pain team to check all is well. If the nurses or doctors on the ward have concerns they will also contact the pain team.

EPIDURAL IS A DIFFERENT WAY OF GIVING PAIN KILLERS AFTER A BIG OPERATION.

THIS IS THE PUMP WE USE TO GIVE YOU THE PAIN KILLERS. IT HAS A COMPUTER INSIDE SO WE GIVE YOU THE RIGHT



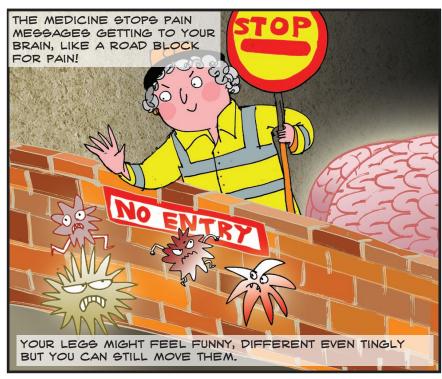






THE PUMP WILL GIVE YOU MEDICINE ALL THE TIME EVEN WHEN YOU ARE AGLEEP.









- **Epidural** is a way of giving pain killers through a very fine, soft tube that the anaesthetist puts into your back when you are asleep.
- To keep the tube clean the anaesthetist will cover it with a clear dressing and tape. The tape extends along your back and may finish on your shoulder which also keeps the tube from moving or falling out when you change position or move in bed.



THE SPECIAL DRESSING WHERE THE EPIDURAL GOES INTO YOUR BACK.

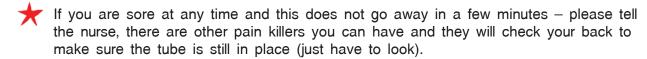
- The pain killer we use is called **levobupivacaine** it is a local anaesthetic and works by stopping pain messages travelling along the nerves to the brain. Sometimes we add either **fentanyl** which is an opioid or **clonidine** (see the medicines page). Both can make the epidural work better and clonidine can help to avoid spasm (like cramp) after leg surgery.
- The painkiller is given continuously via a pump even when you are sleeping. The pump is programmed with your weight so the correct dose of medicine is given.
- The nurse looking after you will check you regularly to see if you are sore or having any side effect from the pain killer. The nurse will check your temperature, breathing, heart rate and blood pressure to check you are okay.
- The pain killers we use do have side effects, the most common ones we see are:

Heavy legs that you cannot move

Tingling around lips and mouth, double vision

Feeling itchy or sick

Just tell your nurse if you feel any of these. We can help by adjusting the pump or giving other medicine.

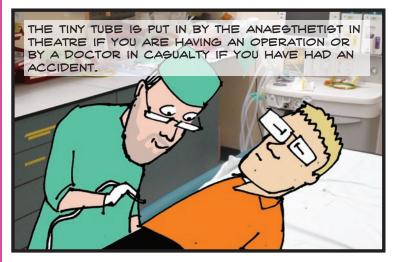


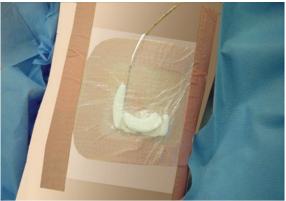
- Epidurals can stay in place for up to 1 week though it is usually less than this depending on the operation you have had.
- \star In small babies under 13 weeks the epidural is not given for longer than 48 hours.
- As you heal and get better you will need less pain killers. First we will stop the pump and give you other pain killers. The nurse will continue to look after you and make sure you are still comfortable with your new pain killers. After 6 hours, if all is well the tube will be removed.
- Don't worry if you are too sore when the epidural is stopped we will recommence it for another day while you continue to heal and get better. Although unusual there is nothing to worry about.

INFORMATION FOR OLDER CHILDREN & FAMILY MEMBERS

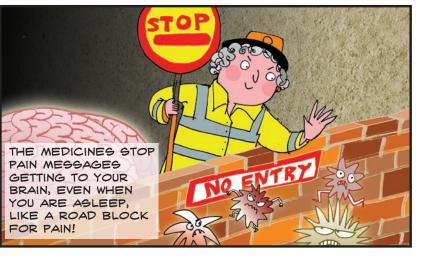






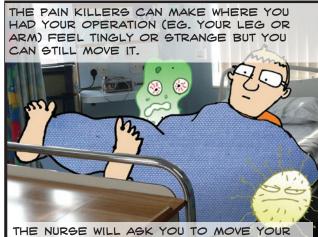


THE TUBE WILL HAVE A DRESSING OVER THE TOP TO STOP IT MOVING. YOU WON'T BE ABLE TO FEEL THE TUBE.



THE NURSE WILL CHECK YOU DURING THE DAY AND OVERNIGHT WHEN YOU ARE AWAKE. IF YOU ARE SORE PLEASE TELL THE NURSE - YOU MIGHT NEED TO HAVE OTHER PAINKILLERS AS WELL.





FINGERS OR TOES DEPENDING ON YOUR

OPERATION.

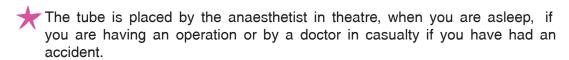
THE PUMP WILL GIVE YOU MEDICINE ALL THE TIME TO HELP YOU WITH YOUR PAIN, EVEN WHEN YOU ARE AGLEEP.



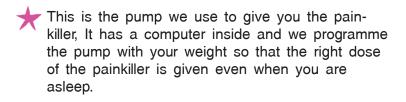




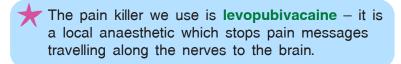
The pain killer is given via a very fine, soft tube which is inserted close to the site of the operation or injury.

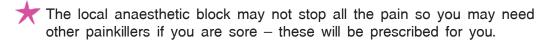


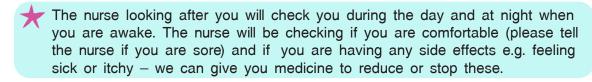
The tube is covered by a clear dressing to keep this area clean and dry and also to keep the tube in place. Because the dressing is clear nurses can see the site and ensure that it is okay.



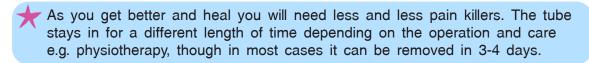








If you are sore the nurse will check to see the tube is still in the right place — if it is the pain team or anaesthetist can give you some extra pain-killer via the pump. If the pain killers are not working we can change the medicines you are on.



When the pump is stopped we will give you other painkillers. Initially, these are given regularly but as you continue to heal you will need less of these.

ANAESTHETIC = medicine given by a doctor to make sure that you sleep and do not have any pain during an operation.

ANAESTHETIST = a doctor who gives anaesthetic (see above).

ANALGESIA = another word for pain killer or pain medicine

SURGICAL DAY UNIT (SDU) = found on the ground floor. For children having an operation and going home on the same day.

GURGICAL ADMISSIONS LOUNGE (SAL) = found on the first floor. For children having an operation and staying in hospital for at least one night.

EPIDURAL = a way of giving very strong pain medicine through a very fine tube in your back.

LEVOBUPIVACAINE = a medicine that belongs to the group called local anaesthetics (see below)

LOCAL ANAESTHETICS = a group of medicines that stop pain messages travelling along special nerves to the brain – therefore stopping you feel pain or being sore.

LOCAL ANAESTHETIC BLOCK = a way of giving local anaesthetic through a fine tube to a part of the body affected by an operation to stop pain.

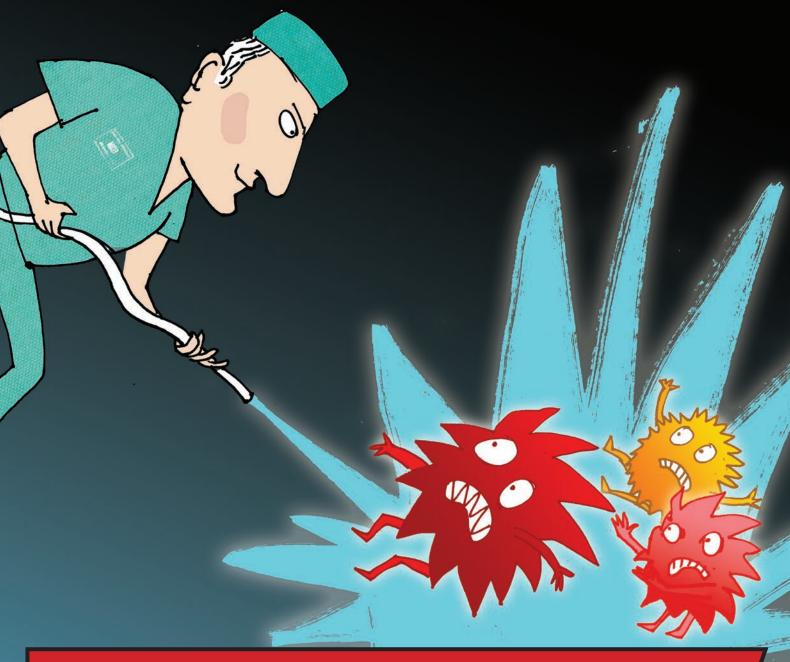
NCA = nurse controlled analgesia – see section on PCA and NCA in the booklet for explanation.

ORAL MEDICATION = swallowing medicine or tablets.

PCA = patient controlled analgesia – see section on PCA and NCA in the booklet for explanation.

PAIN TEAM = a group of anaesthetists and nurses who work together to help children who need pain medicine.

HEALTH PLAY SPECIALIST = a group of people who are trained to help a child to understand what you are having done including going to theatre, a special X-ray or having a needle. They use different methods to help you including using toys, games, books etc to explain things to you.



HELP US TO FIGHT YOUR PAIN!

If you have any comments about pain management while you're in hospital please speak to your nurse or doctor.

This leaflet provides general information – please discuss your individual pain management needs with the doctors and nurses caring for you.

This information can be made available in other languages and formats if requested.

Alder Hey Children's NHS Foundation Trust East Prescot Road

L14 5AB (for Sat Navs to find multi-storey parking area)

Hospital switchboard: 0151 228 4811

www.alderhey.nhs.uk