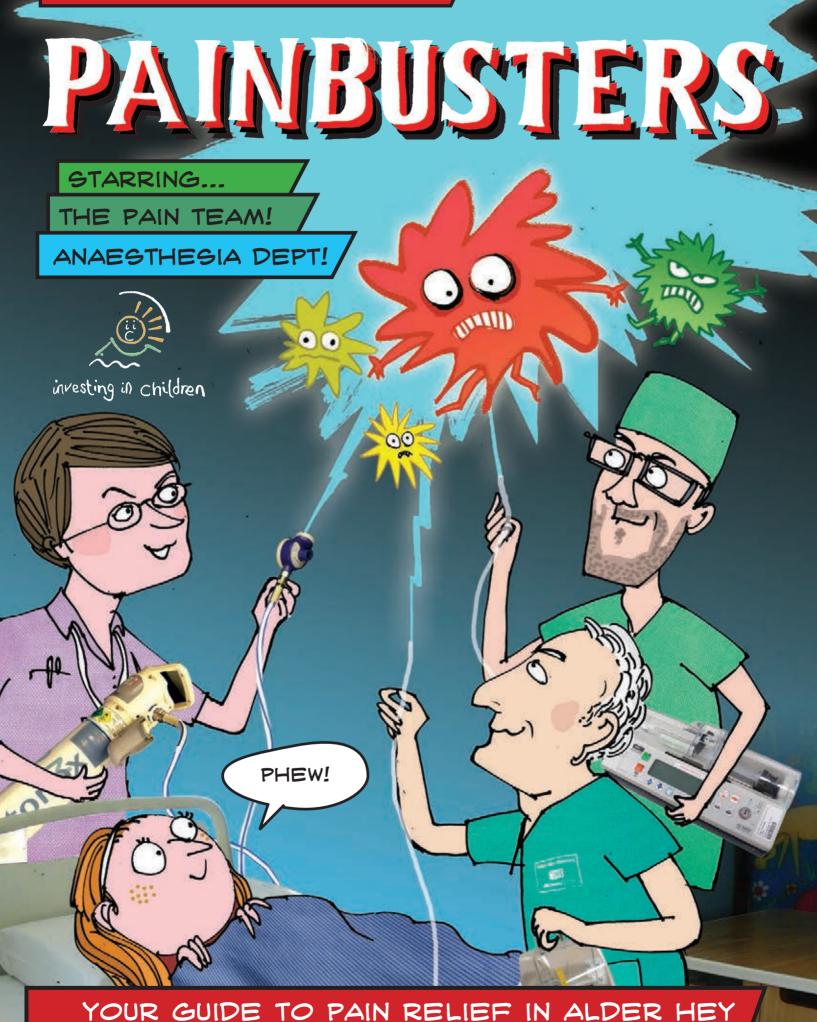
WHO YOU GONNA CALL?

Alder Hey Children's **NHS** NHS Foundation Trust





# 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...

#### 🛧 Emily Delahunty

- ★ Clare Sellers
- 🗡 Ellie Larkins
- 🗡 Ewan Hutton
- 🗡 Naomi Mills
- 🗡 Rebecca Sellers

Not forgetting the parents and staff...

- Ros Larkins Annette Delahunty Fran Dooley Liz McArthur Cheryl Williams
- Liz Bland Kim Bennett Mary Cunliffe Steve Roberts Rishi Diwan

# WHAT IS THIS BOOKLET ABOUT?

The aim of this booklet is to provide information about the different ways we relieve pain in Alder Hey.

# WHO ARE THE PAIN TEAM?

The pain service at Alder Hey is a group of people who work together to help, support and advise children and young people who are experiencing pain. We also help, support and advise families and our colleagues.

The pain team includes doctors and nurses who, from Monday to Friday (excluding bank holidays) visit the wards to see children and young people who need strong pain medicines OR children and /or families who ask to see us.

The pain team also work with the play specialists to help children having procedures – you will read more about these later in the booklet.

#### HOW DID YOU FEEL IN ALDER HEY?

Were you sore, hurting or in pain? Did your nurse and/or doctor help you? Did we do well or not? We can learn a lot of things from doing things right or wrong so please tell us. Our contact details are below.

You can also tell us what you think about this information booklet, again, whatever you say, we can learn from it.

# YP OF OF

# CONTACT US

You can write to us at;

The Pain Team Department of Anaesthesia Alder Hey Children's NHS Foundation Trust Eaton Road West Derby L12 2AP



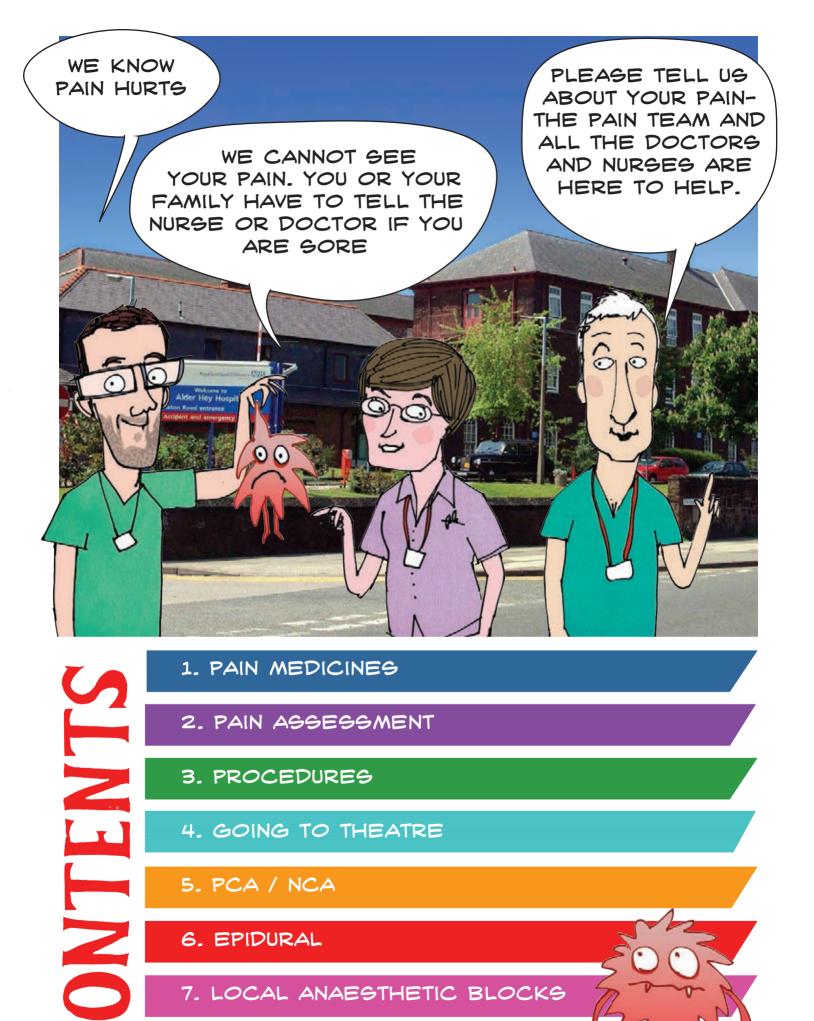
You can ring us on; 0151 252 5223

- direct line to our secretary.



You can email us at;

pain.service@alderhey.nhs.uk



3. PROCEDURES

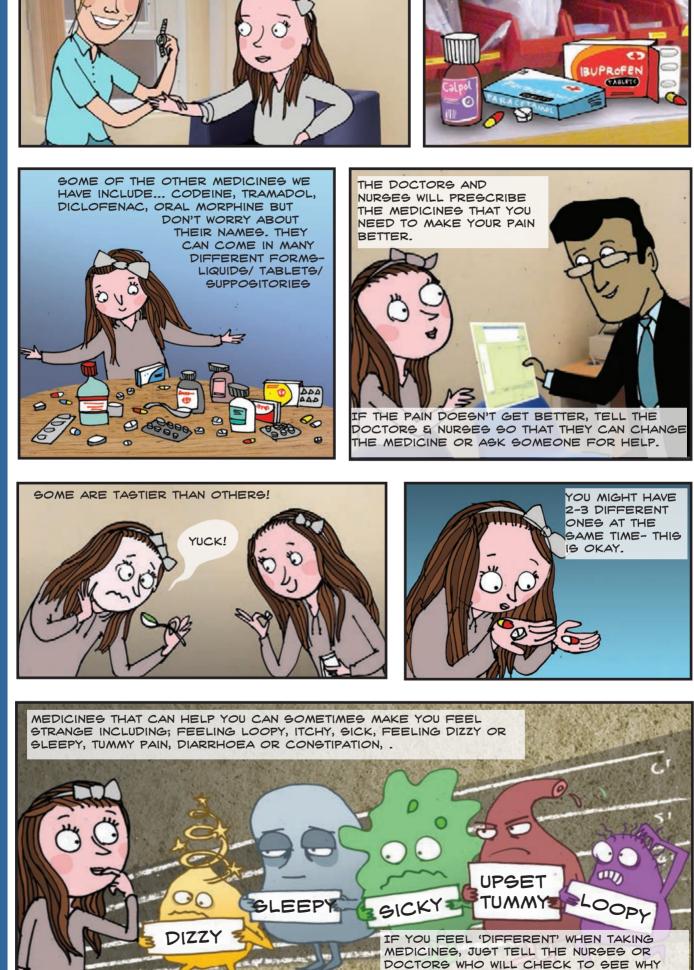
4. GOING TO THEATRE

5. PCA / NCA

6. EPIDURAL

7. LOCAL ANAESTHETIC BLOCKS

8. GLOSSARY



YOU DON'T FEEL VERY GOOD.

EVERY TIME THE NURGE TAKES YOUR TEMPERATURE AND PULSE THEY WILL ASK IF YOU ARE SORE. WE HAVE LOTS OF DIFFERENT MEDICINES TO HELP STOP OR MAKE

PAIN BETTER. SOME YOU MAY HAVE SEEN AT HOME E.G. PARACETAMOL

(CALPOL) AND IBUPROFEN.

Below is information about the medicines we use to treat pain. All medicines have side effects, too many to write here, however the nurse, doctor or pharmacist can tell you about these.

#### PARACETAMOL (CALPOL®)

 is probably the most widely used and best known pain killer. It can be used alone or with other pain killers.

**IBUPROFEN** – sometimes called Brufen<sup>®</sup> This medicine belongs to a group called Non-Steroidal Anti-Inflammatory Drugs or NSAIDs. It works by reducing swelling and inflammation which reduces pain.

#### DICLOFENAC (VOLTAROL®)

is similar to, and works
in the same as, ibuprofen.
It should not be given to
someone taking ibuprofen –
this will not reduce the pain
but can increase side effects.

**CODEINE** – may be used for more intense pain. Research has shown that codeine works better when given at the same time as paracetamol. Codeine can cause constipation quite quickly therefore we encourage children to walk (if they can), drinks lots of fluids (if allowed), and eat fruit and vegetables (if allowed). We can give laxatives if this happens.

**TRAMADOL** – works in a similar way to codeine but is less likely to cause constipation. We do not give tramadol to children under 5 years old.

**MORPHINE** – is a strong pain killer used after major operations or serious accidents e.g. burns and for children with very painful illnesses. In most cases we use special pumps to give morphine in a very controlled way aiming to treat pain continuously. (See 'PCA / NCA' for more information).

**FENTANYL** – is a 'manmade' version of morphine and is used for the same reasons. Fentanyl can also be added to epidural pain relief (See 'Epidural' for more information). **KETAMINE** – a strong pain killer we can use alone or with other medicines including morphine and fentanyl.

**CLONIDINE** – another strong pain killer we use with other pain medicines to reduce pain after operations or illness. Clonidine can also be added to epidural pain relief.

DIAZEPAM (VALIUM®)

- you may recognise this medicine being associated with anxiety but we use it in very small doses to relieve muscular spasms particularly after bone operations.

**BUSCOPAN** – is used to reduce 'tummy 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.

Some pain killers can make you feel sick, itchy or drowsy (sleepy) – the nurse looking after you will check you and if necessary we give you other medicines to control these and will explain these if you need them.

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

There are several ways we can give medicines to babies, children and young people, including;

**BY MOUTH** – as liquid medicine, tablet, caplet (an oval tablet), capsule (soft caplet) or dissolvable tablet.

**INTRAVENOUGLY** – these are given in a drip through a tube into a vein.

**BY SUPPOSITORY** – a specially made 'tablet' that is

placed into a child's bottom where it dissolves into the blood stream and reduces pain.

BY EPIDURAL CATHETER - this is explained later in this booklet.

**TOPICAL** – a cream or gel applied to the skin. We use

Ametop®, EMLA® and LAT gel. They all work in a similar way to reduce sharp pain e.g. needles.

**INHALED** – medicine called Entonox® or 'laughing gas' which you breathe in. Mostly used during procedures to reduce pain and or worry/ anxiety/fear.

If your child needs intensive care similar medicines will be used but in different doses  $\sim$  this will be explained further by the staff.

# MEAGURING PAIN IN BABIES & YOUNG CHILDREN

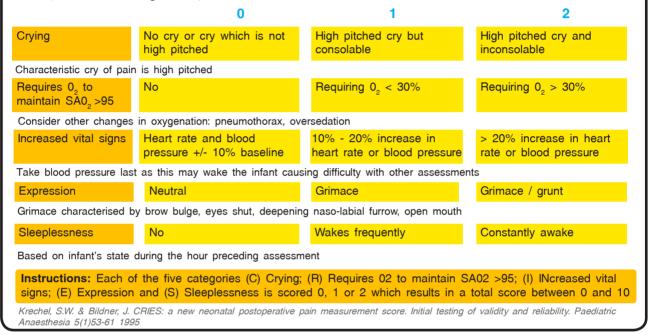
can be used by parents or nurses.

To help us to see the level of pain, hurt or soreness a child is experiencing we use special measures called "pain assessment tools"

The tools on this page are (1) for babies and (2) for young children between 2 months & 7 years. Although mostly used by nurses, all healthcare professionals can use both these tools.

#### 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.



#### 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

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

## MORE INFORMATION FOR FAMILY MEMBERS

# CRIES PAIN ASSESSMENT

- Tor small babies and infants from 32 weeks gestation.
- ★ This tool is made up of 5 different sections relating to the behaviours observed in babies who were experiencing pain in research studies.
- $\star$  Each of the 5 sections can be scored 0, 1 or 2 making the minimum score "0" and the maximum "10".

🗡 All pain should be treated.

Severe pain is usually associated with high pain scores e.g. "7" or more and will probably need strong pain killers e.g. morphine

- When pain scores are lower babies × will be given other pain killers e.g. paracetamol, codeine and then they will be observed to ensure that the pain killers given are helping.
- This tool is very useful to help us to know whether baby is crying because they are hungry, missing family, upset or sore.
- $\star$  If you are with your baby and you are worried about their pain - please speak with the nurse caring for your child.

# FLACC PAIN ASSESSMENT

\star For children aged 2 months to 7 years

- ★ This tool is made up of 5 sections. Each of these shows a different aspect of pain seen in young children during research studies. It is used in many hospitals and is seen as a very reliable tool for measuring pain.
- ★ Each of the 5 sections can be scored 0, 1 or 2 making the minimum score "0" and the maximum "10".

main should be treated.

★ Severe pain is usually associated with high pain scores e.g. "7" or more and will probably need strong pain killers e.g. morphine.

✤ When pain scores are lower children will be given other pain killers e.g. paracetamol and/or codeine and then they will be observed to ensure that the pain killers given are helping.

This tool can be used by all members of staff and family members. As you can see - the different sections of the tool look at simple aspects of a child's behaviour - many parents and other members of the family like to be involved in their child's care. If you wish to help by using this tool - please ask the nurse caring for your child or ask to speak to the pain service (please see inside front cover for details of when we are available).

## PAEDIATRIC PAIN PROFILE OR PPP

- $\star$  A special pain tool for children with complex and additional needs who are unable to communicate their pain.
- This tool is based on behaviours observed when children are experiencing pain. Children, young people, parents, carers and families were involved in the research to develop this tool.
- $\star$  Normally this is parent held but may be introduced to you when you and your child visit Alder Hey. If you think that PPP may help you and your family - please ask to speak with the pain service.
- For children who are unable to communicate their pain the Paediatric Pain Profile is available. Please ask your nurse to contact the Pain Team.

# SELF ASSESSMENT for children from 3 years old.

The pain assessment tools on this page are **Self Assessment**. This means that they are for you to use to tell us how much pain, soreness or hurt you have. It is important for the nurses and doctors to know how much pain you have.

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

#### PAIN SCORE

Pain score 0 = no pain

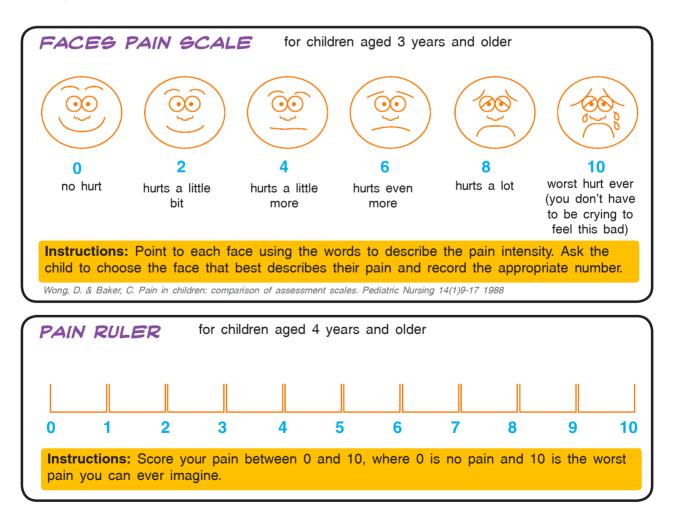
Pain score 1 - 3 = very little pain. You find it easy to move as you normally do or as much as you can depending on why you are in hospital and you would be happy to do what you usually do at home.

IT'S YOUR PAIN-

YOU TELL US!

Pain score 4 - 6 = some pain but the medicine/ tablets/ special drips you may have are helpful and making it easier to move etc. You may need a little help from the nurses or doctors.

Pain score 7 or more = a lot of pain which is not being helped with the pain medicine you are having. You may want the nurses or doctors to change the medicines so that you are able to move around as you usually do.



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



# HOW IS YOUR PAIN MAKING YOU FEEL?

DO YOU THINK YOU ARE MORE UNCOMFORTABLE RATHER THAN GORE?

IS THERE A DIFFERENCE FOR YOU?

CAN YOU BE BOTHERED TO UGE YOUR TOYS, READ YOUR BOOKS OR WATCH TV, OR ARE YOU TOO SORE? CAN YOU MOVE EAGILY OR ARE YOU TOO GORE?

> IF YOU CAN, AND ARE ALLOWED, TO WALK, DOES YOUR PAIN MAKE IT WORSE OR TOO HARD TO WALK?

CAN YOU PLAY GAMES ON YOUR BED OR DOES THE PAIN STOP YOU ENJOYING YOURSELF?

DOES THE PAIN STOP YOU SLEEPING, OR WAKE YOU UP? DOEG YOUR PAIN AFFECT HOW YOU SPEAK TO OTHER PEOPLE, FOR EXAMPLE YOUR FAMILY OR FRIENDG?

These questions apply to all age groups though in younger children it may be family members who recognise these 'quality' issues i.e. not talking, not moving, not playing etc..

IF YOU ARE GORE, AND IF YOU'RE FEELING ANY OF THESE, AGK YOUR NURSE TO CONTACT THE PAIN TEAM. THEY MIGHT BE ABLE TO HELP!



PROCEDURES



Lots of different procedures take place in hospital. The most common are blood tests, putting in a drip and cleaning and bandaging wounds.

These are just some of the things that may happen and is not meant to scare you but to help explain the word '**procedures**' which we use for all of these things.

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

In some cases the procedure **does not hurt at all** but the equipment can be scary and worry you. We can also help with this.

Explaining what is happening is really important. If you have a question – please ask your nurse or the doctor. This can help you to understand and feel less worried or scared. Also, if you don't want to look – tell the nurse or doctor.

If you need to have a needle we use a special cream called Ametop® which will numb your skin. We also use distraction – a game, a puzzle, a story, etc to help you relax and concentrate on something nicer.



**Entonox** – or 'gas and air' is another medicine we can use to help you during a procedure. It is easy to use – you just breathe it in using a mask or mouthpiece. It works quickly after just 5-10 breaths and helps to reduce pain and any fears or worry you may have. Some children (and adults) giggle when they use Entonox – and the name 'laughing gas' is also used. A nurse or play specialist will stay with you during the procedure and until the Entonox has worn off – usually 5-10 minutes after the procedure is finished.



ENTONOX MOUTHPIECE

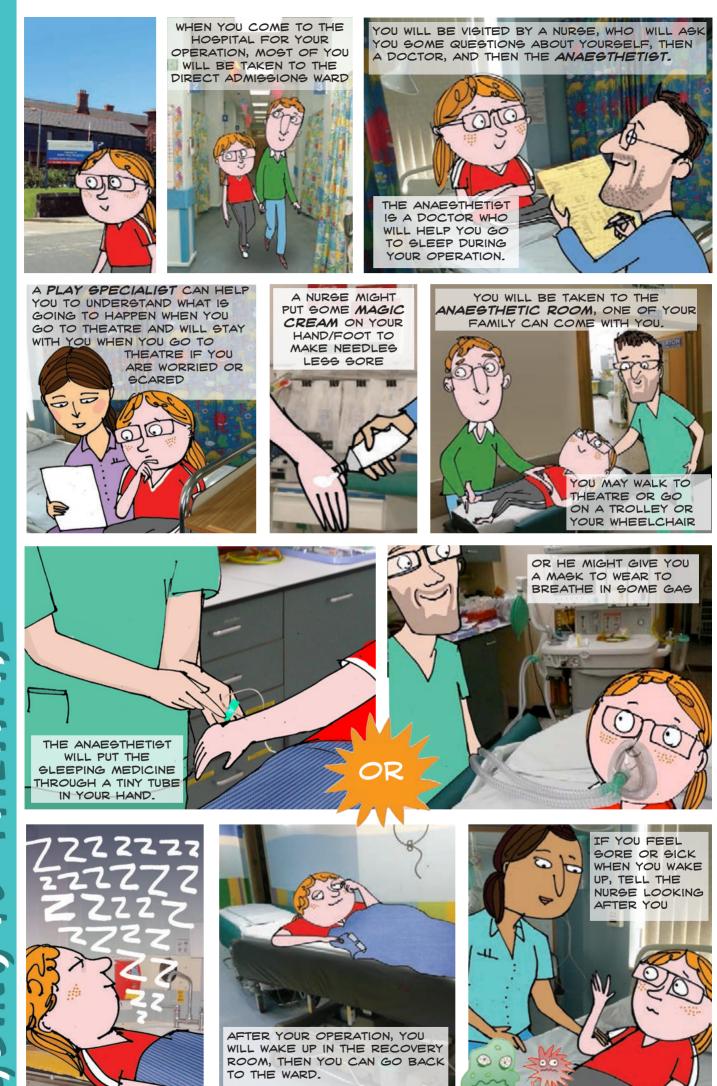


ENTONOX MAGK

Because it wears off so quickly we use Entonox for children coming into hospital for an outpatient appointment and they don't have to stay in hospital for any longer than usual.

For some procedures we need to use stronger medicines either by mouth or through a drip e.g. morphine or midazolam. These medicines work very well but don't wear off so quickly so, you would have to stay in hospital a little longer than usual to wait until the medicine wears off

Something personal – you may have a favourite game, book or something you can really focus on, why not bring it along or ask your family to bring it in if this helps you.





★ \ f

When the operation is planned ~ a period of fasting or "nil by mouth" is needed. This is for your safety and means your stomach will be empty when you have your operation. There are different time periods for fasting which change between young children (under 12 months) and older children. The fasting periods are as follows:

Under 12 months old				
Food	6 hours	6 hours	From 1 year of ag	е
1000			Food	6 hours
Milk	4 hours		Clear (still) drinks	0 hours
Breast milk	3 hours		Clear (still) drinks 2 h	2 hours
Clear (still) drinks	2 hours			

 $\star$  On arrival to the hospital you will be taken to the Direct Admissions Unit (DAU)

All hospital staff wear identity badges.

The nurse on the DAU will ask some questions about you and any health-related issues.

The **anaesthetist** (the doctor who will help you go to sleep during your operation) will also visit before you go to theatre. The anaesthetist may be wearing "theatre scrubs" – sometimes called pyjamas – or their own clothes.

Some children, young people and parents can be worried or anxious about the operation, going to sleep or other issues. This is not uncommon – please talk to the anaesthetist or nurse if this is a problem.

A play specialist can prepare children and young people for what may happen when they arrive in theatre especially if you are worried or frightened. The play specialist can also go with you to theatre if this will help.

Before going to theatre a nurse will put cream on your hand or foot so that needles are less painful. The cream is called Ametop® or 'magic cream'.

When you go to theatre you could walk or go on a trolley or your wheelchair. You are taken to a special room where the anaesthetist will help you to go to sleep before you have your operation. One of your family can come to theatre with you and stay until you are asleep.

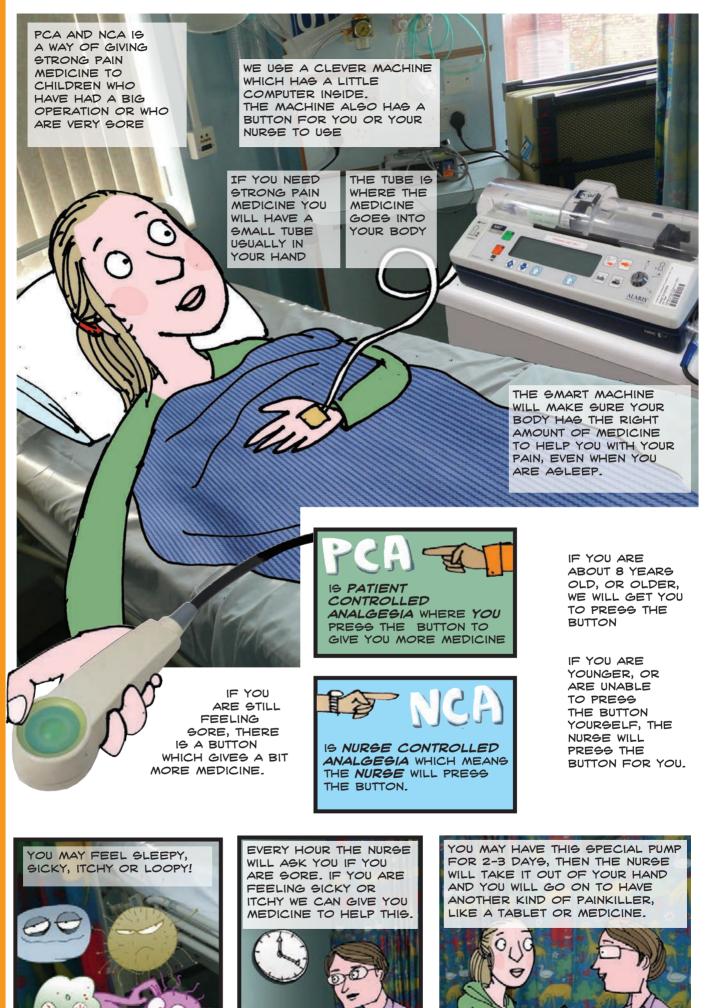
The anaesthetist will help you to go to sleep by either putting medicine through a small plastic tube in your hand or foot **OR** by giving you a mask to put over your mouth and nose and breathe in sleeping gas.

Twhilst you are asleep you will have your operation and the anaesthetist will look after you.

After the operation you will be taken into the **recovery room** where you will wake up. A nurse will be looking after you until you are fully awake and comfortable.

When you wake up you may feel a little **dizzy or sore** – tell the nurse looking after you and they will help.

+ When you are feeling okay – you will be taken back to the ward and allowed to sleep.



PCA/NCA

all)

#### The difference between PCA and NCA.



patient controlled analgesia.

nurse controlled analgesia

Morphine and fentanyl are strong pain killers (medicine) used when children have operations or are in severe pain due to their condition or an injury.

Patient controlled analgesia or PCA is a method used to give medicine via a small tube into a vein.

PCA uses a special pump to give the medicine using a computer programme inside the pump.

BUT if you are still sore - you will have a small button to press which gives you more medicine. The pump has a small computer inside that is programmed to allow a safe amount of the medicine to be given in any one hour - so you can press the button whenever you need more medicine.

 $\star$  The medicine can make the pain a lot less sore and help to make your stay in hospital as comfortable as possible.

If you are a young person or unable to use the button for any reason we use Nurse controlled analgesia or NCA. This ensures that all children and young people, whatever their age, medical condition or stage of development can be given strong medicine to reduce their pain or soreness.

 $\star$  Sometimes, the medicine can cause some problems as well as reducing your pain. The most common ones are:

Nausea – feeling sick	Sleepiness
Vomiting – being sick	Itching

We can give you other medicines, in your drip, to stop these or even change your pain medicine if we need to.

The medicine can also cause more serious problems including;

Sedation	very sleepy and not responding to verbal commands
Breathing problems	breathing can slow down or be less effective

These serious problems are rare and are easily observed and treated. If necessary we can also change your medicine.

# EPIDURAL



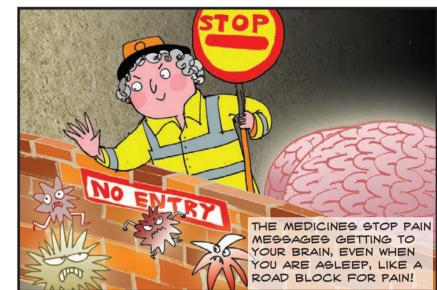
YOUR LEGS MAY FEEL DIFFERENT, EVEN TINGLY BUT YOU SHOULD BE



WHEN YOU ARE GETTING BETTER YOUR NURSE WILL REMOVE THE TUBE FROM YOUR BACK. WHEN THEY TAKE THE TAPE OFF IT MAY STING A BIT,

LIKE TAKING A PLASTER OFF.



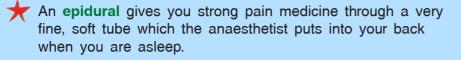








YOU WILL WAKE UP WITH TAPE OVER YOUR SHOULDER- THIS WILL KEEP THE TUBE IN PLACE.



To make sure the tube stays in place the anaesthetist will use a special clear dressing. The tube is also taped along your back to stop it falling out.



THE SPECIAL DRESSING WHERE THE EPIDURAL GOES INTO YOUR BACK.

The medicine in the tube is called 'levobupivacaine' which is a local anaesthetic and works by stopping pain messages getting to the brain.

The medicine is given continuously via a special pump. The anaesthetist programmes this for your age and weight to give you the correct dose.

- The pump works **24 hours a day**, even when you are sleeping, so you will continue to have pain medicine.
- The nurse looking after you will check you regularly to make sure you are not having any side effects. They will explain this to you.
- ★ If you are sore we can give you more medicine using the pump. We may need to have a look at your back to check that the tube is still working. Sometimes we might need to change your medicine to something different. Whatever happens – the pain team or the anaesthetist will explain this to you.
- Epidural can sometimes make you feel sick or itchy please tell your nurse if you do as we can give you different medicines to stop this.
- Your nurse might ask you to take other pain killers when you still have the epidural – this is to make sure that you do not have pain when your epidural is stopped.

F Epidurals stay in for up to 1 week but it depends on your operation.

When it is stopped we leave the tube in place for about 6 hours to make sure your pain is controlled with other pain killers.

 $\star$  If you get sore we may put the epidural back on until the next day.

A LOCAL ANAESTHETIC BLOCK IS A SMALL TUBE WHICH IS PLACED NEAR TO WHERE YOU ARE HAVING YOUR OPERATION. THIS IS USED TO GIVE STRONG MEDICINE AFTER OPERATIONS TO CERTAIN PARTS OF THE BODY, FOR EXAMPLE A LEG OR A FOOT TO STOP IT HURTING.





THIS IS THE SPECIAL PUMP WE USE TO GIVE YOU THE MEDICINE.

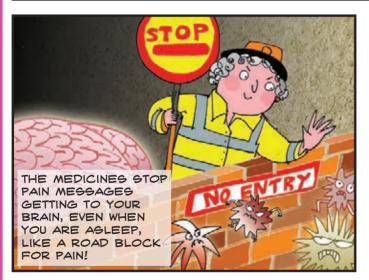
IS HAS A SPECIAL COMPUTER THAT HELPS US TO MAKE SURE YOU GET THE RIGHT AMOUNT OF MEDICINE.

THE TUBE WILL BE PUT IN, WHEN YOU ARE AGLEEP, BY THE ANAESTHETIST IF YOU ARE HAVING AN OPERATION OR BY THE DOCTOR IN CASUALTY IF YOU HAVE AN ACCIDENT.





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





THE MEDICINE MAY MAKE YOUR LEG OR ARM FEEL FUNNY OR TINGLY BUT YOU SHOULD STILL BE ABLE TO MOVE IT. SOMETIMES THE MEDICINE CAN MAKE YOU FEEL SICK OR ITCHY BUT WE CAN STOP THIS.

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





HOW LONG WILL IT BE IN FOR? UGUALLY 2-3 DAYG.



These are similar to epidurals (see previous section) but instead of the tube (which is very narrow and soft) being placed into your back it is placed close to the site of your operation e.g. for an operation on your leg the tube will be placed in your groin close to the nerve that would normally send pain messages to the brain.
 The tube is placed by the anaesthetist whilst you are asleep in theatre or the doctor in casualty if you have had an accident e.g. broken your leg.
 The tube is covered by a clear dressing so the nurses can check the area to make sure all is well and also to stop the tube falling out.
 The medicine in the tube is called levobupivacaine which is a local anaesthetic that stops pain messages travelling along nerves to the brain.

The medicine is given continuously via a special pump which is programmed to give you a safe amount all the time – even when you are sleeping.

The nurse looking after you will check you regularly to make sure you are not having any side effects. They will explain this to you.

If you are sore we can give you more medicine using the pump. We may need to have a look at your back to check that the tube is still working. Sometimes we might need to change your medicine to something different. Whatever happens – the pain team or the anaesthetist will explain this to you.

Your nurse might ask you to take other pain killers when you still have the tube in place and the local anaesthetic is being given- this is to make sure that you do not have pain when this medicine is stopped.

Local anaesthetic blocks stay in for different amounts of time depending on your operation or your accident.

When it is stopped we will give you other pain killers to keep you comfortable.

**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).

**ANALGEGIA** = another word for pain killer or pain medicine

**DIRECT ADMISSIONS UNIT** = a ward where children coming into the hospital go to be seen by doctors and nurses.

**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.

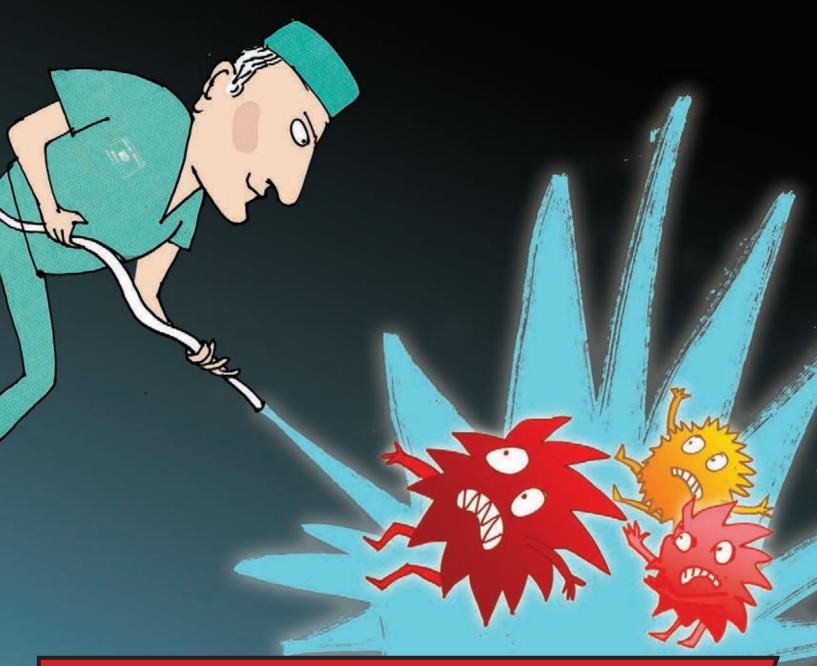
**ORAL MEDICATION** = swallowing medicine or tablets.

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.

**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.

Can you think of any other words that need explaining? if so, talk to one of the Pain Team!



# HELP US TO FIGHT YOUR PAIN!

If you have any comments about pain management while you're in hospital...

Please speak to the Pain Team, or email pain.service@alderhey.nhs.uk

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 Eaton Road Liverpool L12 2AP Tel: 0151 2284811 www.alderhey.nhs.uk