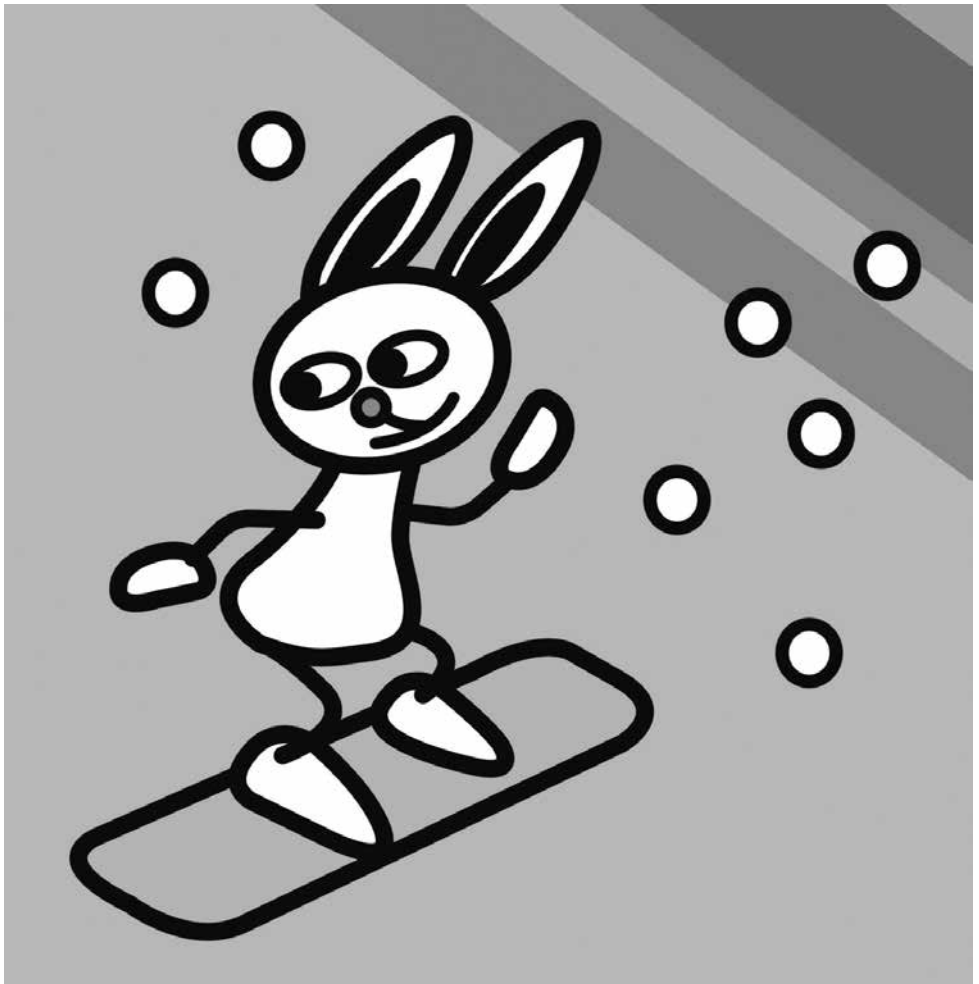


Spires Cleft Service

Helping your child cope with an operation

Information for parents / carers



Introduction

Babies who are born with a cleft lip or palate will inevitably experience a number of medical procedures during their childhood. Some children may begin to think of medical treatment as a positive challenge, while for others they may begin to fear hospitals or dentists and become extremely worried about visits.

Children can become fearful of procedures for a range of reasons. For example, they may have had a previous bad experience (e.g. a staff member taking a number of attempts to find a vein), they may have picked up on worries from family members or friends, or they may have read something confusing and hold an unhelpful belief based on this (e.g. some children are frightened about having blood taken as they fear they may 'run out of it').

This leaflet has some ideas of what you can do to support your child with hospital visits and medical procedures.



Strategies to help your child cope

When helping a child who is afraid it can be useful to think about their **past experiences**. Understanding this can give us a clue as to what might help them next time around; try to think about any problems they may have had, whether the procedure was explained to them, whether local anaesthetic cream or spray was used (if applicable) and what particularly was frightening for them.

Talking to your child about what's involved in the procedure can also be helpful. Sometimes young children enjoy trying it out on a doll or teddy. Using pretend syringes and doctors' play equipment can also help. There are also a number of story books available that can help a child make sense of their treatment and hospital visits. If you aren't sure what's involved in a particular test or procedure, a play specialist can support you and your child in preparing and practising for the procedure. You will meet a play specialist at your child's pre-operative visit. They also have a reading list and contact numbers for further support.

Please see under 'Quick links' at www.ouh.nhs.uk/children

Where possible it can help to **involve your child in choices** about their treatment, for example, whether to sit on a lap or on a chair may be something they can decide – or they can think about what music they would like to listen to or computer game they would enjoy. This can help children feel they have some control over their experience, and with that can come a greater sense of familiarity and confidence.

We naturally want to protect our children from upsetting or difficult information, but it's also important to **be honest** and tell the truth. For example, saying something won't hurt may not always be the case and can lead to a loss of trust in the adults around them if children were not expecting something to be painful. It is important children know how long a procedure might last and that they don't need to 'be brave'. It's all right to cry, cuddle or make a noise. Even if children are having 'magic cream' or spray before an injection via a little 'straw' or cannula is put in place, it can help to let them know that they will still

feel a bit of pressure. If you are not sure what's involved in a procedure, please ask the clinical nurse specialists or a member of the Play Team.

Distraction is a key part of supporting a nervous child through a procedure. It involves any activity that can take a child's mind off what's happening. Thinking with a child beforehand can help with this and ideas include watching a DVD, listening to music, reading a book, thinking of as many words as possible that begin with a particular letter, counting in sevens and so on. Usually it's helpful for one adult to take the lead in this so that the child can focus their attention fully on them.

Conversely, some of the children like to watch everything that is happening and this helps them to feel in control. There is no right or wrong way, different children have different preferences. You will probably know what your child prefers, but it's always OK to ask "would you like to see what's going on or shall we think about something else?"

Many children also find **relaxation exercises**, such as relaxed breathing, help them to feel calmer before and during their procedure. Helping a child imagine they are breathing to slowly blow up a balloon in their belly, and then slowly let it go down, is one technique many children find easy to imagine. It's worth practising this with your child beforehand.

Your role as carer is also important during a procedure and for some children having a cuddle during an injection helps them to feel safe. It's worth reflecting on your own experiences with medical procedures as children are very skilled in picking up how their grown-ups are feeling. If you would like some help with this you can talk with the cleft team.

Once the procedure is over, noting which aspects of support your child found helpful and which were less useful can be beneficial for planning any future care.

If you would like any further support in helping your child to prepare for their cleft treatment please contact the Spires Cleft Service.

Tel: **01865 226 965**

Coming into hospital with your child

As the parent / carer of a child with a cleft, you may feel familiar with hospital visits and have memories of your child's early treatment. However, it is unlikely that your child will have any memory of their early operation(s).

For some children, coming into hospital can be an exciting adventure, while others may feel worried about what might happen. We want your child to feel confident about their time in hospital and preparation is an important part of this.

This section is aimed at helping you to prepare your child for their hospital visits. If you think your child would benefit from further support please let one of the cleft team know.

Below are a few ideas that may help get them ready for their visit:

Preparing to come to hospital

- Your child may be invited for a **pre-operative appointment** where our play specialists will show them a picture book about each stage of their treatment. This can also help answer any questions that they might have.
- For most operations we offer a **ward visit** beforehand. This will help your child picture where they will be and meet some of the people that will be caring for them when they stay.
- Lots of children like to be **involved in packing** their hospital bag. Favourite toys can be included and it can be a good chance to talk about any other questions your child might have.
- When in hospital, the **play specialists** are available to help children with any procedures they may be worried about. Play specialists have expertise in supporting children during treatment.

Talking to your child about the operation

- Talk to your child about their operation using **simple language**. It can take children a while to absorb new information so you may need to repeat yourself a number of times. It's important that they know where they are going, that they are going to have an operation and basic details about what to expect, e.g. how long they think they will be staying.

- Continue to **encourage** your child to **ask questions**; if you are unsure about the answer, it's OK to say so – you can find out together by asking hospital staff. Older children may find it helpful to make a list of questions to bring to an appointment or to their admission.
- Discuss with your child **why** they are having the procedure/operation, and how soon they will feel the benefits afterwards. It may also help to include siblings in this discussion, if age-appropriate.

Before you go home

- It's natural to focus on your child's operation and hospital stay; however it's also important to think with them about **preparing to come home** afterwards. For example, it can help a child to know that starting to eat and drink or walk around will be key to being discharged home. As a parent you can always discuss with staff what the specific discharge criteria are.

Going home

Make sure you have appropriate food at home. If your child is on a special diet after surgery, it can be helpful to plan ahead together and involve them in choosing what food they will eat. It may be helpful to include your child in a conversation about what activities they can do when recovering at home.

How to reassure your child

- It's usually OK to hold your child's hand during a procedure or to give them a hug before it begins. These can be important ways to **soothe your child** and you will know what they find helpful.
- You can let your child know it is **normal to feel nervous** and they can let you or one of the staff know if they are worried or in pain.
- If children cry or shout out that's OK too. They **don't need to feel under pressure to be brave**.

Ideas for talking to your child about having an anaesthetic

Having an anaesthetic is often a key concern for parents and children alike. It can be a difficult thing to explain. Here are some ways to talk to your child about what's involved.

"Having an anaesthetic helps you have a very deep sleep where you can't hear, see or feel anything while the doctors are doing your operation."

"Your anaesthetist will give you anaesthetic medicine all the way through your operation and will look after you by checking your heart rate and your breathing, and making sure you are comfortable all the way through the operation."

"When the operation is finished they will give you a different medicine to wake you up."

How does it work?

"There are two ways to go to sleep, breathing sleepy air from a mask or having a little straw in the back of your hand. There is a thin piece of metal inside the straw to help it go in; this is thrown away afterwards."

"If you have a straw, you can usually have magic cream which stops it from hurting."

"Sometimes it's possible to choose whether to have a mask or a straw and sometimes the anaesthetist will decide which is best for you."

"Your grown up (for example Mum or Dad) can be with you when you go to sleep and will be there again when you wake up."

"Your doctor will give you medicine to stop you feeling sore when you wake up. You can ask for more if you need it."

"If you have any questions before your operation, you can ask your doctors or tell your grown-up."

How to contact us

If you would like any further support in helping your child to prepare for their cleft treatment please contact the Spires Cleft Service.

Tel: **01865 226 965**

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALS@ouh.nhs.uk**

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