

Oxford Craniofacial Unit

Having a RED Frame

Information for patients, parents and carers



The **RED frame**, which stands for "**Rigid External Distraction**" has been used successfully for many years in children and adults, to advance the forehead and midface. The frame helps the craniofacial team to make adjustments to the shape of the face.

How does the RED frame work?

When your child has this operation, the surgeon will make cuts (osteotomies) to the bone in their face. The RED frame is then put on, to hold the bones and slowly pull (advance) them into their new position.

What is distraction?

Active distraction is the process by which new bone is generated in the gap between two bony edges. This is a similar process to when new bone forms when a bone is broken.

The bones to be distracted are separated by a cut and held in place by the RED frame.

This process occurs in stages:

- 1. Cuts are made to the bones which are to be advanced.
- 2. A phase of "active distraction", when the bones are advanced (1-2mm a day for up to 4 weeks).
- 3. Consolidation phase, to allow the advancement to stabilise (from 6-12 weeks).

The distraction usually starts immediately after the operation.

We use special screwdrivers to help with the turning. We aim to distract 1-2mm per day, turning at the front of the frame, using the special screwdriver.

Why is this done?

In some complex craniofacial conditions the bones of the face do not grow as they should. This can cause problems with your child's eyes, breathing, feeding and chewing, and affects the development of their facial bones.

In older children and young people this type of operation may be offered for a change of appearance.

This procedure can be used to treat babies, children and young people by gradually moving the facial bones into a new position.

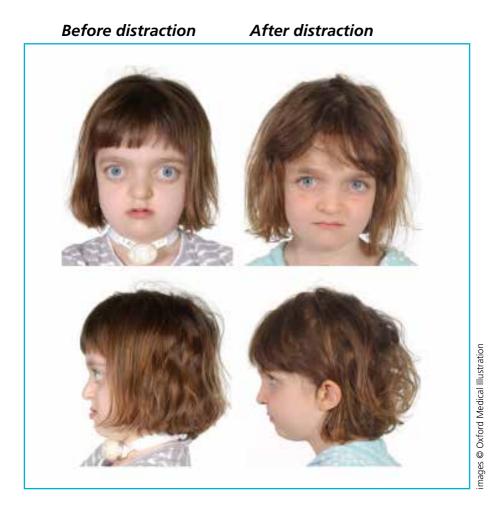
When will this happen?

Each child is unique and the timing of this procedure will depend on their individual needs. These will be assessed by your child's craniofacial team.

How will this happen?

When your child is in theatre under general anaesthetic, multiple cuts are made to the bones in their face. The RED frame is fixed to their skull with pins. Fine wires are passed through the skin and fixed to the bone of the face. These wires are attached to external screws on the RED frame.

A short time after the operation, the screws are turned once or twice a day. This will slowly bring the bones forward into position.



Deciding to have the RED frame

For some families there may be very little time to get used to the idea, due to their child's clinical condition, but for others the decision making process and the preparation may take longer.

For all children and families there will be input and support from the multidisciplinary craniofacial team. This will include your child's surgeons, anaesthetist, psychologist, speech and language therapist, orthodontist, ophthalmologist, dietitian and nurse specialist, if applicable.

Your child will need certain investigations as part of the preparation, such as sleep studies and CT scans.

The whole team works closely with you and your child, to make sure you are both well supported throughout the decision making process.

We will liaise with your child's school and community teams about their operation, if applicable.

Your child's admission to hospital

This may not be the first time your child has stayed in hospital. However, every hospital stay is different, with its own challenges.

Please don't hesitate to contact your nurse specialist with any queries or concerns about your child's admission.

Staying in hospital

Your child will have a pre-operative assessment before their operation, which will include some tests and assessments.

On the day of surgery your child will be in the operating theatre for most of the day. After the operation they will be transferred to either the paediatric intensive care unit or high dependency unit, for close monitoring for a few days.

We understand this will be a very anxious and stressful time for you and your family. The nursing staff will support and encourage you to actively take part in your child's care.

Care after you child's operation

Your child will feel a bit sore and bruised for a few days after the operation. Their eyes will be swollen and are likely to be closed for a day or two due to the swelling.

Living with a RED frame

It is important that your child and their frame are looked after well. This will involve:

Pin site care

You will be shown how to clean around the pins, using cotton buds with cooled boiled water.

Hair washing and wound care

Your child will be able to shower and bathe normally. Hairwashing is a vital part of keeping the wound and the pin sites clean.

Mouth care

There will be wounds inside your child's mouth. Your child will need to use a soft toothbrush and clean their mouth and teeth after each meal.

Diet and nutrition

To start with, your child may need supplementary feeding with a nasogastric tube. The ward dietitian will be involved in arranging this.

At the earliest opportunity your child will be encouraged to eat a high calorie, soft diet. They may not be able to chew hard foods until the frame is removed. A nutritious diet will aid recovery and wound healing.

Sleeping

Your child will find their own most comfortable position. This may involve support with several pillows. You may find travel pillows or V-shaped pillows useful.

Pain

Your child will be assessed and given appropriate and adequate pain medication for as long as they require it. The actual process of distraction is not painful.

Activities

As your child recovers from surgery and gets used to the frame, they will be encouraged to get back to doing their usual activities. This may include going back to school.

There are certain activities that your child will not be able to do whilst the frame is in place. These include swimming and certain sports. We will talk with you about this in more detail.

How to turn (distract) the frame

You will be shown how to do the turn the screws (distract) yourself. The majority of children will be able to go home during the distraction phase, but for some this may not be possible. If your child is going home you will be asked to keep a record of each turn. Please make sure you bring the record and your child's screwdrivers to each hospital visit.

Daily checklist of the frame in the morning

- Check pins, wires and screws to see if loose.
- Check for redness, swelling, or discharge around pin sites and wound.
- Clean the frame as directed, including a shower/bath and hair wash at least every other day.
- Check the position of the frame.
- Turn the device as instructed by your team.

When to contact your unit

- If the device becomes loose.
- If there is redness or discharge of any fluid from the wound, pins or nose.
- If your child complains of a headache, has problems seeing or has a fever.
- If your child falls or has a blow to the device.
- If there is an increase in swelling after the initial postoperative swelling has gone down.

How is the frame removed?

This is done under a general anaesthetic, usually with an overnight stay.

Soft diet advice

If you would like a list of food suggestions, please ask your nurse specialist.

General tips

- Feed your child small amounts more frequently this can be more manageable than larger meals three times a day.
- Try using sauces, gravy, butter, cream or custard to soften foods.
- Soften foods by chopping, mincing, mashing or using a blender.
- Avoid foods that are hard, sharp or require a lot of chewing.

How to contact us

Craniofacial Nurse Specialist

Tel: 01865 231 083 01865 231 003

Oxford Craniofacial Unit Office

Tel: 01865 231 085

Out of hours or at weekends:

Robin's Ward

Tel: 01865 231 254

Melanie's Ward

Tel: 01865 234 054

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 **PALSJR@ouh.nhs.uk**

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