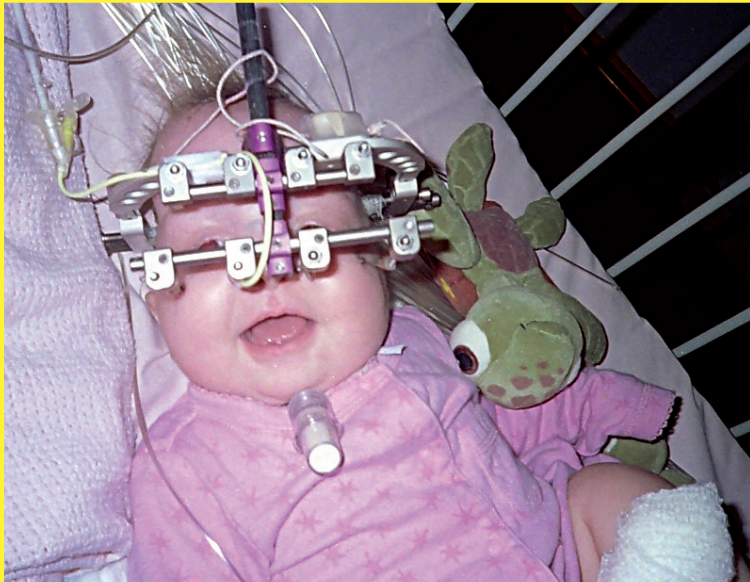


# Having a RED frame

**A patient  
and  
parent  
guide to  
the RED  
frame**



**Great Ormond Street Hospital  
for Children NHS Foundation Trust**

**The RED frame, which stands for 'Rigid External Distraction', has been used successfully for many years in children and adults to help correct many facial problems by advancing 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 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 (callus) forms when a bone is broken.

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

This process occurs in four stages:

1. The cut to divide the bone which is to be lengthened
2. A period of time in which the new bone (callus) is allowed to form
3. A phase of "active distraction" when the bones are lengthened (1-2mm a day for up to four weeks)
4. Consolidation phase when the new bones becomes hard (ranging from 6 to 12 weeks)

After the operation, your child will need about a week to recover before the turning (distraction) of the RED frame screws starts.

We use special screwdrivers to help with the turning. We aim to distract 1mm a day. Turning takes place twice a day with a ½ mm turn each time. The turning is usually started at the back of the frame using the black/brown headed screwdriver. Turning at the front of the frame may be undertaken later on when smaller final adjustments maybe needed to either just the forehead or jaw area. This is done using the purple headed screwdriver.

## **Why is this done?**

In some complex craniofacial conditions, the bones of the face do not grow adequately, which can cause functional problems with your child's eyes, breathing, feeding and chewing and affects the development of their teeth.

In older children and young people this type of operation may be offered for appearance change and therefore becomes a choice that they themselves can be involved in or make.

This procedure can therefore 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, which 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 the face. The RED Frame is fixed to the skull and face by screws, pins and fine wires passed through the skin into the bone. A short time after the operation, the screws are turned once or twice a day, this will slowly bring the face forward into its new 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 specialist nurse, surgeons, anaesthetist, psychologist, speech and language therapist, orthodontist, and ophthalmologist. Your child may require 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 ensure you are well supported throughout the decision making process.

We will liaise with your school and community teams about your child's operation. Sometimes we can visit the schools as well to help them understand what will happen to your child.

## Your child's admission to hospital

For many families, this may not be the first time your child has stayed in hospital. However every hospital stay is different with its own challenges for each family.

Each craniofacial unit has its own admission procedures and will give you information leaflets in advance of the admission date, but please contact your specialist nurse with any queries or concerns regarding your child's admission.

## Staying in hospital

Your child will have a pre-operative appointment prior to their admission; this will include some tests and assessments to make sure your child is well enough for their operation.

On the day of surgery your child will be in the operating theatre for most of the day and will be transferred to the high dependency unit afterwards 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 take an active role in your child's care as much as you feel able.

## Care after your 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 often are closed for a day or two with this swelling.

## Living with your frame

It is important that your child's frame is looked after well by:

### 1. Pin site care:

You will be shown how to do this using cotton buds and cool boiled water and how to ensure the pins at the side of the frame are prevented from loosening.

### 2. Hairwashing and wound care:

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

### 3. Mouth care:

There are wounds inside the mouth. Your child will need to use a soft tooth brush and mouthwash after each meal.

### 4. Diet and nutrition:

Your child may need supplementary feeding with a nasogastric tube initially. The ward dietitian will be involved. At the earliest opportunity your child will be encouraged to eat a high calorie, soft diet. Your child will not be able to chew hard foods until the frame is removed. Please see back of this booklet for suggestions regarding a soft diet.

- A nutritious diet will aid recovery and wound healing.

### 5. Sleeping:

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

### 6. Pain:

Your child will be given appropriate and adequate pain medication for as long as they require it.

### 7. 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 getting 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.

## How to turn (distract) the frame

The majority of children will be able to go home during the distraction phase, but for some this may not be possible. If you are going home, you will be given an individual written plan for this. You will be asked to keep a record. Please ensure you bring this 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, discharge around pin sites and wound
- Clean the frame as directed including daily shower / bath and hair wash
- Check position of frame
- Turn the device as instructed by your team

### When to contact your unit

- Loosening of device
- Redness, discharge of any fluid from wound, pins or nose
- Fever, headache or visual disturbance
- A fall or blow to the device
- An increase in swelling after the initial post-operative swelling has gone down.

## How is the frame removed?

This is done under a general anaesthetic usually as a day case procedure.

## Some suggestions for foods suitable for a soft diet for the first few weeks following surgery.

The suggestions listed are for all age groups – please note that some foods may not be appropriate for children under one year old.

### 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

### Cereals

- Porridge or Ready-Brek® made with milk
- Weetabix®, cornflakes or Rice Krispies® well soaked in milk
- Bread – cut off the crusts and do not toast

### Meat and poultry

- Well cooked and tender minced meat (Shepherd's pie or cottage pie)
- Corned beef hash or meat loaf
- Chilli con carne
- Skinless sausages
- Tender meat in stews, hotpots or casseroles – do not use large chunks of meat

## Fish

- Flaked fish in white, cheese or parsley sauce
- Fisherman's pie, fish cakes, fish and potato nests
- Fish mousse or light pate
- Tinned fish such as salmon or sardines
- Tuna mixed with mayonnaise

## Eggs and cheese

- Scrambled, poached, boiled or as an omelette
- Egg mayonnaise
- Egg dishes such as sweet or savoury egg custard or soufflés
- Quiche
- Cauliflower cheese
- Cottage cheese
- Grated cheese
- Dairylea® triangles, cheese spread or cream cheese

## Pulses and nuts

- Baked beans with grated cheese
- Mushy peas
- Lentils made into dahl
- Smooth peanut butter
- Avoid whole nuts due to the risk of choking

## Pasta and rice dishes

- Lasagne
- Moussaka
- Bolognaise sauce with pasta
- Macaroni cheese
- Ravioli
- Pasta with different sauces such as goats' cheese, mushroom, carbonara or creamy tomato
- Tinned spaghetti
- Noodles
- Rice

## Potatoes and vegetables

- Soft carrot, parsnip, turnip, swede, cauliflower, broccoli and courgettes are all easy to mash
- Avoid raw vegetables
- Try adding grated cheese, extra butter or margarine and serve with white sauce, cheese sauce or gravy
- Ratatouille
- Instant mashed potato as a quick alternative to fresh
- Mash the inside of a jacket potato with butter and add a suitable filling
- Dips such as hummus, guacamole or taramasalata

## Fruits

- Tinned or stewed fruit such as apples, pears and peaches
- Fresh fruit such as banana, melon, strawberries, soft plums

## Desserts and snacks

- Milk puddings such as rice pudding or semolina
- Full fat yoghurt, fromage frais or milk jelly
- Full fat ice cream or sorbet
- Jelly or trifle
- Mousses and whips
- Ready made chocolate desserts
- Egg custard
- Crème caramel
- Blancmange
- Home made, powdered, ready made cartons or tins of custard
- Fruit fools and purees
- Cheesecake
- Bread and butter pudding
- Sponge pudding with custard or cream
- Lemon meringue pudding
- Fruit crumble
- Savoury or sweet pancakes
- Biscuits dipped in a hot drink to soften
- Soft cake

## Drinks

- Milk shakes
- Hot milky drinks
- Fruit juices
- Build Up®

## Sample menu

### Breakfast

- Cereal or porridge with full fat milk
- Bread (crusts removed) with margarine/butter and jelly-type jam, egg, fish or cheese
- Full fat milk (with blended fruits or flavouring such as Nesquik®)
- Milk or tea/coffee with milk

### Lunch

- Meat/fish/eggs/cheese/baked beans
- Potato/rice/pasta/bread (crusts removed)
- Soft cooked vegetables
- Soft fruit or suitable pudding from suggestions above

### Evening meal

- Meat/fish/eggs/cheese
- Potato/rice/pasta/bread (crusts removed)
- Soft cooked vegetables
- Soft fruit or pudding from suggestions above

### Snack

- Soft dessert/snack as listed above - for example soft cake with custard, ice cream or yoghurt or soft cheese on bread.
- Full fat milk (with blended fruits or flavouring such as Nesquik®)

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**Out of hours or weekends:**

Koala ward 020 7829 8826 ask for the nurse in charge



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