

Cystic Fibrosis Unit Infant Physiotherapy Information

Information for families

Great Ormond Street Hospital for Children
NHS Foundation Trust

Physiotherapy for infants with Cystic Fibrosis

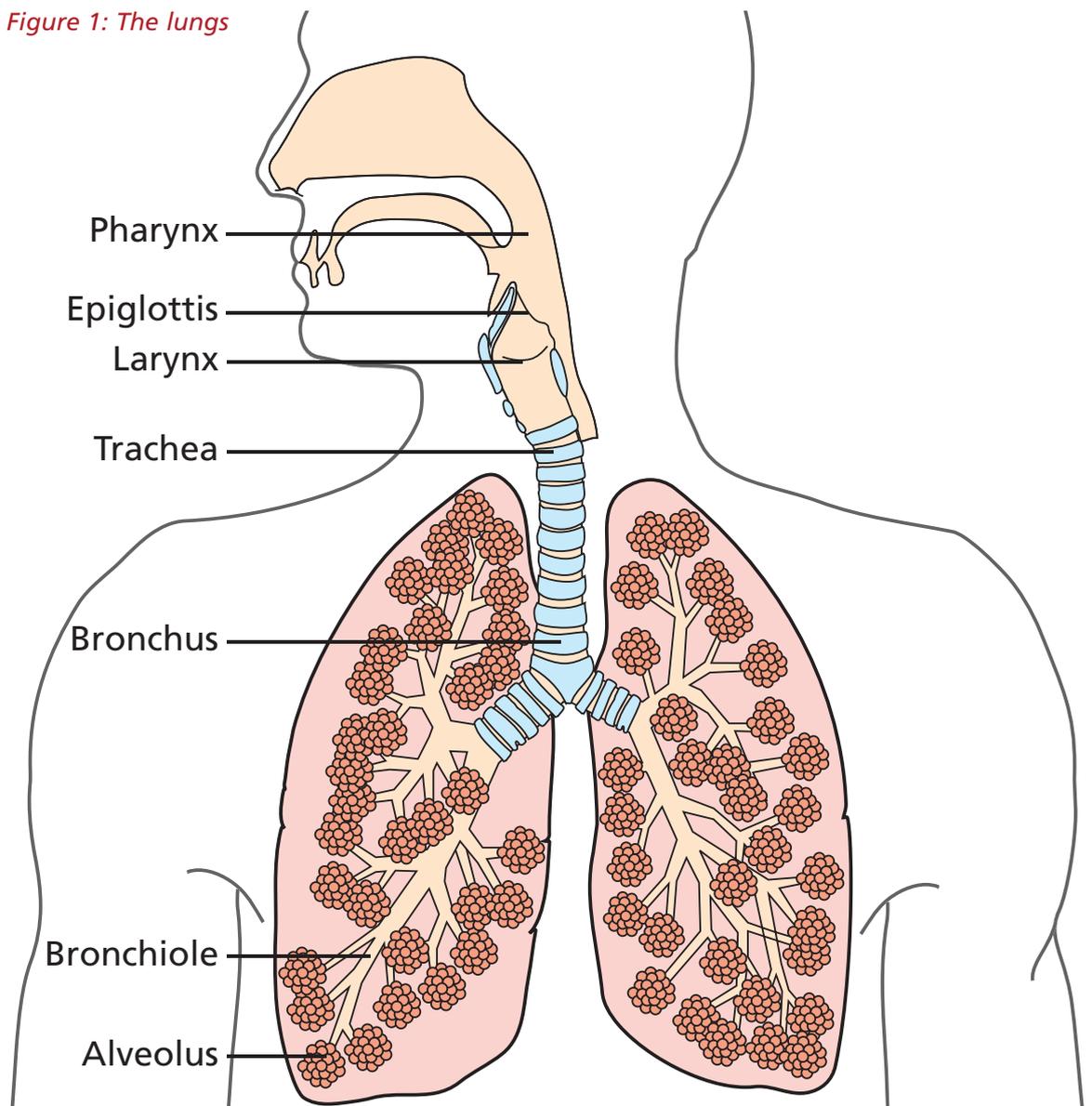
Physiotherapy is an essential part of the treatment for cystic fibrosis (CF) and should start as soon as the diagnosis of CF is confirmed.

This information booklet explains the type of physiotherapy treatment used for infants with CF at Great Ormond Street Hospital (GOSH). Further information is available online from the CF Trust website (www.cftrust.org.uk).

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Figure 1: The lungs



THE BASICS

How the lungs work

Each person has two lungs (left and right). The lungs are divided into different lobes. The purpose of the lungs is to transfer oxygen from the air we breathe into our blood. Our blood then transports the oxygen to the tissues and organs of our bodies, which need oxygen to function. The respiratory system starts at the back of the throat with the windpipe (trachea), which then branches off into two smaller airways (bronchus) one going into each lung. In each lung the airways branch in a tree-like manner. Eventually they form small air filled sacs called alveoli at the edge of the chest.

Oxygen from the air we breathe in is transferred from the air sacs into the blood. The lining of the airways continually produces mucus to keep the airways moist and to trap dust and debris that may enter the lungs. The airways are lined with microscopic cilia (hairs) which help to move any mucus (phlegm) up to the throat, allowing it to be cleared through coughing.

How CF affects the lungs

In CF the mucus produced by the lungs is stickier than normal which can make CF lungs more prone to infection. Infection in the lungs can also lead to inflammation (swelling) of the airways. Not all children are affected in the same way or to exactly the same degree.

In order to keep your baby's lungs healthy, it is important that we try to keep them free from infection.

We do this by;

- carrying out physiotherapy treatments
- reviewing them frequently
- taking cough swabs
- giving antibiotics and other medications

Do all babies with CF need physiotherapy treatment?

There have been many advances in the care of CF. Until relatively recently most babies who were diagnosed with CF had significant problems with their chest and with their weight. Due to improvements in medical care and earlier diagnosis (in particular screening all newborns for CF), many babies diagnosed with CF nowadays are well and do not have obvious signs of chest infections or problems gaining weight. It is very important that all babies with CF are monitored very closely and treatment is given early. All babies must also be seen regularly by their CF team, including the physiotherapist.

Physiotherapy treatment is still a very important part of the treatment for CF. All babies should do an exercise session every day and parents and carers should also be very familiar with the airway clearance treatment that they have been taught for their baby and be able to know when and how to carry out this airway clearance treatment.

EXERCISE

Exercise is an essential component of the physiotherapy management of children with CF. Exercise activities are a very good way of exercising the lungs and keeping them healthy. It helps to ensure that air gets to all the different parts of the lungs and helps to keep them clear. It is also good for the baby's muscles, bones and joints and for their general development.

How to exercise your baby

Even a very small baby can 'exercise'. The following are examples of how.

- a. Gym ball bouncing: bouncing on a gym ball with your baby on your lap (figure 2).



Figure 2: Sitting on a gym ball with your baby

When sitting on the ball with your baby you should make sure you are in a good position and your baby's head is supported (especially when they are still quite young)

At least one structured session of exercise should be done every day for at least 15 minutes.

This exercise session can often be carried out in conjunction with some breathing exercises when children are very young.

- b. Moving your baby around in different positions, doing arm and leg stretches stretching their arms (figures 3i, ii, iii)

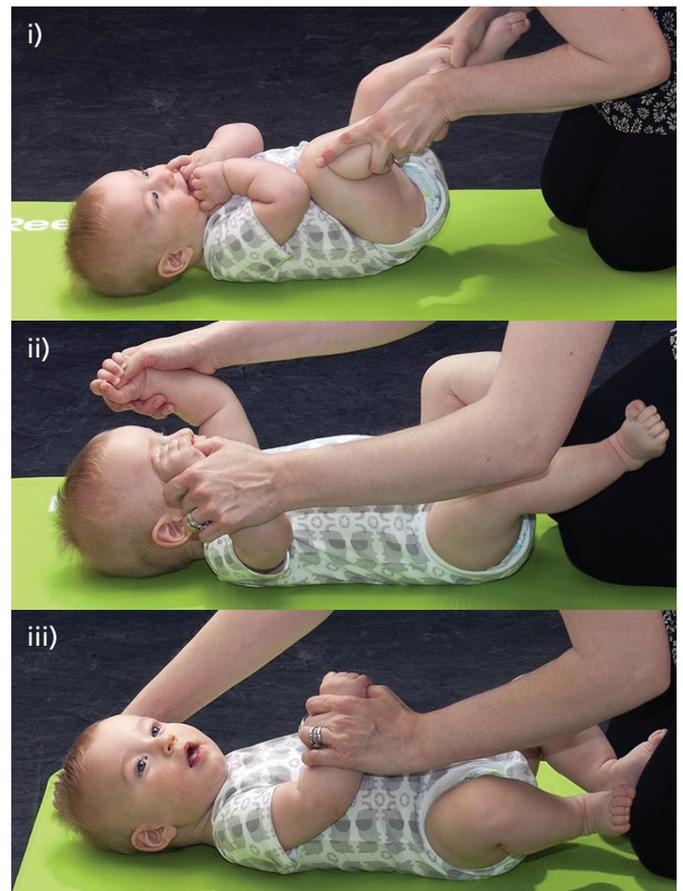


Figure 3: Leg and arm exercises for your baby- knees to chest (i), 'cycling' legs, (ii & iii) arm exercises.

- c. Once your baby has received all of their routine immunisations, they can also take part in water based activities such as 'parent and baby' swim sessions



Figure 4: Infant swimming

- d. Once your baby is over the age of about three months you can start including 'rough and tumble' play and more advanced gym ball activities.

Examples of these activities include:

- throwing your baby up and down in the air,
- lying your baby on their tummy on the gym ball – roll the ball forwards and side to side. You can place toys on the floor to encourage them to reach out with their arms (figure 5)
- holding your baby in a sitting position on the gym ball move your baby from side to side and forwards and backwards.

- e. Once your baby is able to crawl you can add in more activities including:

- **Chest mobility exercises** – crawl over various surfaces, reach overhead with both arms for toys, reach to either side with both hands to encourage twisting round and rolling activities
- **Tummy (core muscles) strengthening exercises** – rolling, sitting independently, pushing or pulling toys
- **Leg strengthening exercises** – crawl over various surfaces, climb up and down on the couch/bed, squat while holding onto the couch or independently to get toys, play in a squat position with a toy or puzzle, walk up and down stairs with hand held
- **Endurance exercises** – crawl up and down the stairs, ride toys such as a tricycle, walk with child's hand held

REMEMBER

At least one structured session of exercise should be done EVERY DAY for at least 15 minutes.



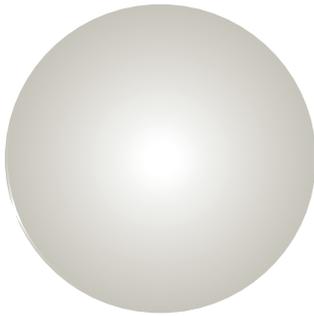
Figure 5: Gym ball activities

IMPORTANT ADVICE WHEN USING A GYM BALL

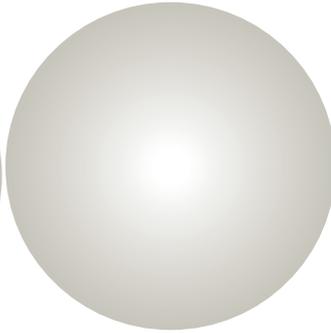
It is essential that you use a ball that is suitable for your height as it is very important that you do not cause injury to yourself.

1. What size ball should you use?

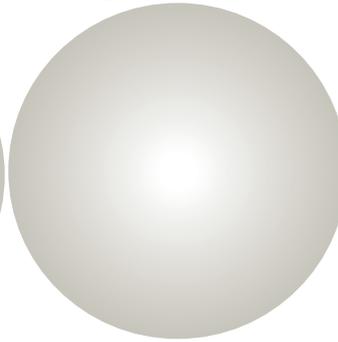
The size of the ball you use is determined by your height.



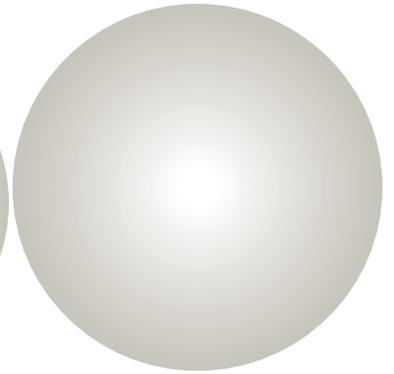
45cm Gym ball
– suitable for height
5'0" (152cm) or shorter



55cm Gym ball
– suitable for height
5'1"-5'6" (155-167cm)



65cm Gym ball
– suitable for height
5'7"-6'1" (170-185cm)



75cm Gym ball
– suitable for height
6'2" (188cm) or taller

2. How to look after your posture on a gym ball

It is very important that you look after your own posture when you are sitting on the ball with your baby.



When sitting on the ball

1. Your feet should be flat on the floor and hip distance apart.
2. Your hips, knees and ankles should be at a right angle (90 degrees).
3. Your thighs should be parallel to the floor (not angled downwards)
4. Your spine should be in the 'neutral' position meaning that your lower back should not be arched too far forwards or backwards.

Figure 6: Correct sitting posture on a gym ball

AIRWAY CLEARANCE

If your baby is very well and has very little in the way of chest problems it may not be necessary to carry out airway clearance treatments as well as their exercise session every day. However, it is very important that you and your baby are familiar with an airway clearance technique. It is also very important that you are taught how to assess your baby's chest and familiarise yourself with the recommended airway clearance technique so that you can use the technique whenever it is necessary.

There are several different airway clearance techniques, but only some of them can be used in babies. This is because babies cannot cough or do breathing exercises to command, and so treatment has to be given to them. The most common chest physiotherapy treatments used for babies are:

1. Infant PEP – most commonly used at GOSH
2. Modified Postural drainage and percussion
3. Assisted autogenic drainage

Important note: Airway clearance should always be carried out either **before** a feed or **at least one hour after** a feed to prevent reflux (regurgitation) of their food and to prevent your baby being sick.

Infant PEP

PEP stands for positive expiratory pressure. When using this technique with infants, a soft face mask is placed on the baby's face. As the baby breathes out a small amount of back pressure is applied to the lungs. This helps to open up the airways, change the distribution of the air in the lungs and will help to clear any mucus if there is any there.



Figure 7: Astra PEP system – mask, t-piece and different coloured resistors

How to use the infant PEP

1. Sit on an appropriately sized gym ball in the correct position
2. Hold your baby (depending on their age) either in the crook of your arm or in sitting on your lap in front of you.
3. Start bouncing on the gym ball holding your baby in a safe position.
4. Once you and your baby are comfortable bouncing you can then introduce the infant PEP.
5. Place the mask gently over your baby's nose and mouth and continue to bounce (it is usually best to tuck the mask under your baby's chin first and then over their nose) (figure 8)
6. Your baby can breathe through the mask but may wriggle a bit the first few times you use it as they are not used to it yet.
7. Try and hold the mask over your baby's nose and mouth for 30 seconds up to one minute then remove the mask for 10 to 15 seconds to allow your baby to rest (continue bouncing during this time if you are on a gym ball).
8. Repeat this on/off cycle for 10 to 15 minutes as tolerated.
9. When you first start using the mask your baby may wriggle a bit. You should try and be as calm as you can and persevere so that your baby can get used to it and understands that it is a part of their treatment.
10. Your physiotherapist will decide which colour of resistor is most appropriate for your baby.



Figure 8: Using the Infant PEP

Important points to remember

- If your baby coughs while the mask is on, remove the mask to allow your baby to cough properly.
- Your baby may not like the mask at first but it is important to build up their tolerance to the mask over time.

Cleaning the infant PEP

It is essential that the equipment is kept clean to prevent infection. To clean the PEP mask system, take it apart (ie separate the t-piece from the mask and remove the resistor from the grey port) after each use and wash in warm soapy water - your usual washing up liquid is fine. Shake to remove any excess water and leave to air dry on a dry clean and absorbent surface or dry kitchen towel.

Sterilise in either a steam steriliser or using boiling water once a week at least.

Do not use a microwave steriliser as the equipment will melt.

For storage in between use, wrap the infant PEP in a clean lint free cloth (such as a tea-towel) or place it in the bag provided or a clean plastic box with a lid and keep it in a dry dust-free environment. Avoid keeping the equipment on a window sill.

Other airway clearance techniques occasionally used at GOSH

1. Modified postural drainage and percussion

Modified postural drainage (mPD) uses different body positions to help the drainage of mucus from particular areas of the lungs. It also may help to increase the airflow to different parts of the lungs. In babies, treatment usually consists of about five minutes in each postural drainage position with a total treatment time of about 15 minutes. This can be combined with a manual technique called percussion. Your physiotherapist will teach you these skills if appropriate.

2. Assisted autogenic drainage

This is an airway clearance technique that uses different levels of breathing to help clear mucus from the lungs. Your physiotherapist will teach you exactly how to apply this technique if it is felt that it will help your baby.

Important note: If at any time your baby has a cough or an increase in cough you should use the breathing assessment checklist to guide your treatment plan as you may need to increase the number of treatment sessions or you may need to change the treatment technique. If you have any questions you should always discuss with your CF team and CF physiotherapist.

BREATHING ASSESSMENT FLOWCHART

The aim of physiotherapy treatment is to keep your baby fit, to clear any mucus from the lungs and to change the way the air moves in the lungs. Many babies with CF do not show any signs of a chest problem, so it is important that you are familiar with the way your baby normally breathes so that you can recognise changes.

There are things that you can see, feel and hear if your baby has secretions in the chest or is unwell with a chest infection. Babies are obviously unable to tell us whether they are unwell, so it is important that you learn to recognise the signs. This is not difficult to do and you can very quickly learn to become familiar with recognising chest symptoms and knowing when to increase treatment.

The first step is to take the time to look at your baby with their clothes off and familiarise yourself with the following:

- The way their nostrils and head move as they breathe
- Whether they breathe through their nose or mouth, and whether you can hear any sounds other than the air moving in and out.
- The colour of your baby's skin and lips

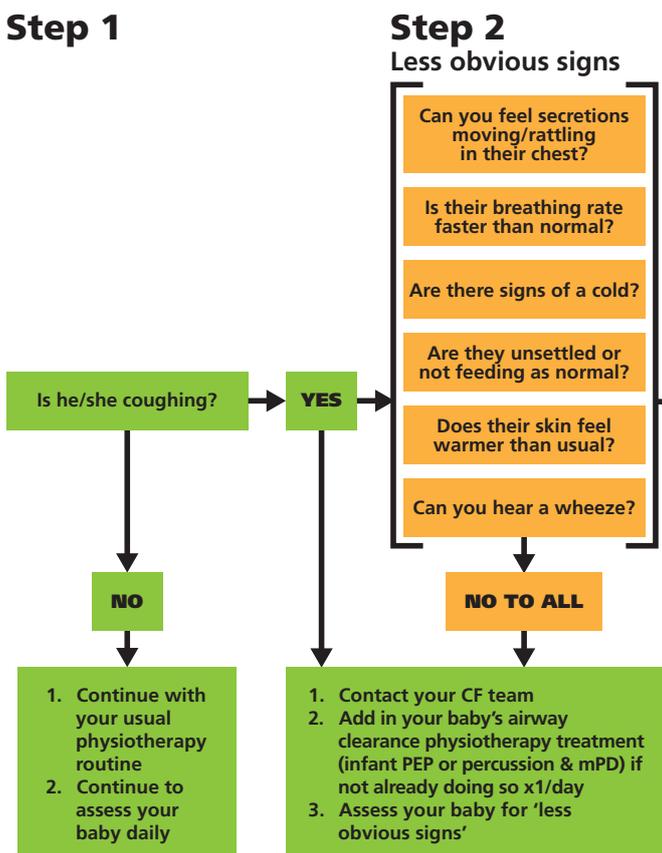
- The movement of their chest as they breathe.
- How fast or slow they are breathing (normal for a baby under a year is 30 to 50 breaths per minute and for a baby 1 to 2 years of age 20 to 40 breaths per minute).
- The feel of their chest as they breathe
- The way your baby breathes when asleep and when awake
- If your baby coughs and whether the cough is wet or dry.

Your physiotherapist will teach you to recognise what is normal. You will learn to recognise changes, when to be concerned and when you should increase physiotherapy treatment.

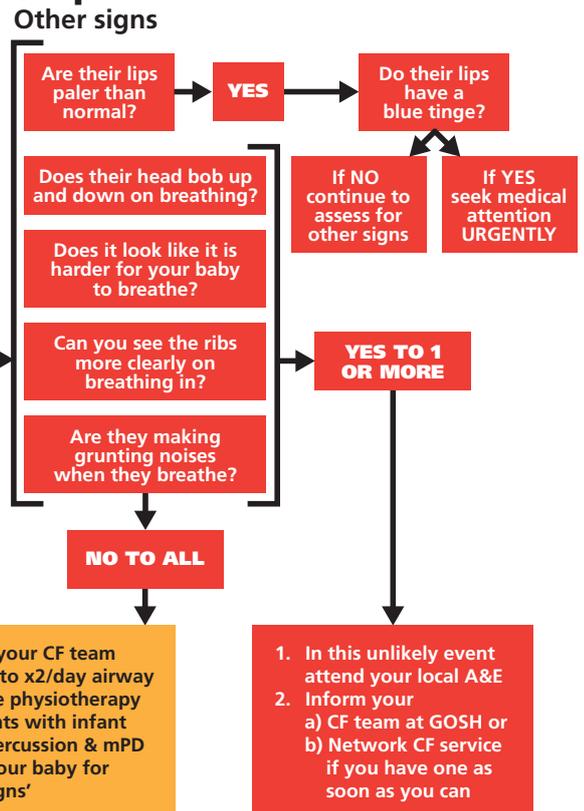
Use the following assessment checklist to help you to assess for any changes. It is important that you 'practise' using this form when you are with your physiotherapist until you are confident and understand what you are looking for.

Note: This flowchart has been adapted from the UK ACPCF breathing assessment check list

Step 1



Step 3



PHYSICAL ACTIVITY

Daily physical activity is **essential** for health for ALL children and adults. Physical activity is also very important for a baby's normal growth and development.

Your baby should do some physical activity every day.

Physical activity

The time your baby spends being sedentary (that is, being restrained or sitting) should be minimised during the day. Daily infant physical activities include:

1. **"Tummy time"** is very important for all infants and should be done everyday for at least 10 minutes (this does not have to be in one session you can break it up into smaller sessions throughout the day) when your baby is awake to help their development and to change the airflow through your baby's lungs.

Note: Your baby should always be supervised when you are doing tummy time.

- Lie on your back and hold your baby on your chest facing you
- When your baby is very small you can place a small rolled up towel under your baby's chest to help your baby lift their chest up when they are lying on their tummy.

2. Floor-play

- Place your baby on a mat or in a baby gym with toys on both sides to encourage your baby to roll and to turn their head and reach with both hands

3. **Reaching for and grasping objects** (activity gym), play in sitting, pulling, pushing (such as trolleys when they are starting to walk) and playing with other people



Figure 9: 'Tummy time' positions



Figure 10: Floor play positions



Figure 11: Play in sitting- encouraging your baby to turn their body around and to reach for objects.

YOUR CHILD'S PHYSIOTHERAPY PROGRAMME

Your physiotherapist will complete this for you so that you have a written record of your home physiotherapy programme.

PHYSIOTHERAPY TREATMENT	TYPE	FREQUENCY
EXERCISE (choose one x15 mins/day)	Structured session with parent	
	Gym ball activities	
	Swimming	
BREATHING ASSESSMENT TOOL		Daily
AIRWAY CLEARANCE (±exercise)	Infant PEP + gym ball bouncing	
	Modified postural drainage and percussion	
	Assisted autogenic drainage	
PHYSICAL ACTIVITY	Tummy time 10 mins	Daily
	Floor play activities	Daily
	Activities in sitting	Daily

Physiotherapist's Signature: _____

Date: _____

EXAMPLE PLAY AND EXERCISE EQUIPMENT

(The following are examples only and other brands may be available.
Inclusion in this list does not constitute endorsement by GOSH).

Bumbo® seats



Trolleys



Baby gym

www.lovekidszone.co.uk



Happy Hopperz®

www.happyhopperz.co.uk



Play tunnels

www.bestpricetoy.com



Scoters

www.micro-scooters.co.uk



Junior trampoline

www.amazon.co.uk



Balance bikes & Tricycles

www.balancebikes.org.uk

www.kettlerusa.com



PLAY EQUIPMENT NOT RECOMMENDED

These pieces of equipment are NOT recommended by paediatric physiotherapists in the UK.

Baby walkers



Door hanging bouncers



Notes

Notes

A photograph of a baby underwater, surrounded by many bubbles. The baby's face is partially visible, looking towards the right. The water is clear and blue. A semi-transparent white box is overlaid on the top half of the image, containing contact information and an important note.

Cystic Fibrosis Unit Contact Details

GOSH switchboard 020 7405 9200

CF Office 020 7762 6714

Badger Ward 020 7829 8813

E-Mail cysticfibrosisunit.query@gosh.nhs.uk

**IMPORTANT NOTE: REMEMBER IF YOU ARE WORRIED
ABOUT YOUR BABY AT ANY TIME YOU SHOULD
ALWAYS CONTACT THE CF OFFICE FIRST**

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Compiled by the CF Physiotherapy Team in collaboration with the Child and Family Information Group

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www.gosh.nhs.uk