Discharge advice for babies with uncorrected tetralogy of Fallot (TOF)

Information for patients, parents and guardians

What to do if your baby has blue skin and lips (a cyanotic spell)
Babies with TOF may suddenly become blue, or pale and floppy. This is called a ‘cyanotic spell’ and is due to cyanosis, a low level of oxygenated blood running around the body.

This page provides information about what to do if your baby has a cyanotic spell.
If you have any questions, please speak to a member of your child’s healthcare team.

What is cyanosis?
Cyanosis is caused by a low level of oxygenated blood flowing around the body.
It may cause your baby to appear blue around the lips, mouth or finger beds.
The level of the cyanosis depends on the size of their pulmonary valve narrowing.

Sometimes, cyanotic spells can be triggered by the following:
- pain
- crying
- feeding
- passing stools/wind
- dehydration
- fever

Not all cyanotic spells can be prevented, but there are some steps you can take to reduce the risk of your baby having one:
- Treat any causes of pain appropriately using comfort measures, and/or medication if necessary.
- Treat a high temperature by removing excess clothing and seeking medical advice.
- Ensure your baby has adequate fluid intake and monitor for any signs of dehydration such as:
  - sunken fontanelle (soft spot on top of head)
  - dry skin and mouth
  - few or no tears when they cry
  - fewer wet nappies than usual (most children have six to eight wet nappies per day).

If your child is blue and becomes pale or floppy, dial 999 immediately and ask for an ambulance.
If your baby is blue but not pale or floppy and remains alert:

- keep calm and reassure them
- bring their knees up to their chest (this increases the blood pressure going around the body and forces blood flow to the lungs)
- call 999 if the cyanotic spell continues (even if your baby remains alert)

It’s important to call us if your baby has a cyanotic spell, even if it stops quickly, as they may need medical review and medication. Call the E1 Ocean Ward team on 023 8120 6470 and ask for the ‘on call’ registrar.

If you need a translation of this document, an interpreter or a version in large print, Braille or on audiotape, please telephone 023 8120 4688 for help.

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