



# About your baby's nasopharyngeal airway (NPA)

This leaflet explains about your baby's nasopharyngeal airway. If you have any further questions or concerns, please speak to a doctor or nurse caring for you.

#### What is Pierre Robin sequence?

Your baby has been diagnosed with Pierre Robin sequence. This is the medical name used when a baby is born with a small set back chin (micrognathia) a large tongue that falls back into the airway (glossoptosis) causing airway obstruction and a cleft palate. These features can make it more difficult for a baby to maintain a safe airway.

#### What is an NPA?

An NPA is a flexible, plastic tube (referred to as an endotracheal or ET tube) which is adapted for your baby to help them breathe. The tube is passed through the nostril into the back of the throat (nasopharynx) to make sure the tongue does not fall back and obstruct the airway. An NPA is one of the safest ways to support your baby's breathing and is generally required for the first 14 weeks of life.

#### Why does my baby need an NPA?

Some babies benefit from having an NPA to support their breathing and to make sure the tongue is kept in a safe position. This airway makes their breathing more comfortable and means a baby can be cuddled and handled more easily for things such as nappy changing and travelling in a car seat. The NPA may also make it easier for a baby to feed by bottle and gain weight, though this may take some time to establish at first.

#### Does having an NPA mean my baby will need to stay in hospital for longer?

In order for your baby to be discharged home from hospital two main care givers will need to be trained to change the NPA once at home. Our guidelines advise that each care giver observes at least one NPA change and carries out at least two changes under supervision within the hospital environment. This is a minimum requirement to prepare for discharge. In addition you will need to be trained to use a suction machine and, if your baby has a nasogastric feeding tube, trained to use this safely also. Support from a cleft nurse, neonatal staff and community nursing team will be provided during this period. Equipment and all supplies you need will be provided to you by the community nurse team in your area. The team caring for you and your baby will work closely together to support a smooth and timely discharge home.

#### How long will my baby need an NPA for?

As your baby's jaw grows the tongue position changes and it will become easier for your baby to maintain a safe airway. From around 14 weeks of age your cleft nurse will consider weaning



the NPA. This involves assessment of your baby's breathing and increasing periods of time without the NPA while your baby is monitored. Your cleft CNS will support you during this time.

# How will my baby feed?

All babies with a cleft of the palate require help with feeding and may need to use a specialist feeding bottle. Those with Pierre Robin sequence and an NPA may need extra time to develop sucking skills and may need a nasogastric feeding tube (NGT). Your cleft nurse will assess your baby and offer feeding support. A speech and language therapist (SALT) may also be involved.

### Can I bath my baby?

It is quite safe to bathe a child with an NPA. However be careful to make sure water does not get into the NPA as this could cause your baby to cough. If water does get into the tube you can suction the NPA to clear it.

# Can I take my baby out?

When a baby has a NPA, day to day activities may be slightly different. When you go out, you'll need to prepare to make sure NPA equipment and suction is always available (however short the distance). An emergency kit should be with the baby in case of blockages and so you can change it quickly at all times. It's normal to feel overwhelmed at the beginning while you are adjusting to your baby needing an airway and this may have an impact on you feeling able to take your baby out to begin with. This will improve with time and you will gain confidence in managing the NPA.

# How often should I suction the NPA?

The NPA needs to be kept clean and unblocked so that your child can breathe easily. We advise suctioning before feeds. Your baby may need additional suctioning when they have a cold. However, every baby varies in the amount of suctioning needed. In our experience, parents learn to recognise when their baby needs to be suctioned. Always make sure your hands are clean and dry before you suction. We recommend passing a suction catheter to 0.25cm beyond the longest part of the NPA. Do not apply suction on entry into the NPA. Apply suction with a rolling movement of the catheter on removal for 5-10 seconds. If the secretions are thick you can put 0.5ml of saline into the NPA before you leave hospital. If you need any further support, you can contact the team using the details at the end of this leaflet.

# How often should I change the NPA?

We recommend changing the NPA at least once a week OR if it you are concerned it is blocked. Your cleft CNS/community nursing team will offer weekly support for the first few weeks while you carry out the changes.

# When should my baby be on an oxygen saturation monitor?

Make sure the oxygen saturation monitor is used at night and when your baby is asleep or unsupervised for any period of time. If you plan to use a sling to carry your baby we recommend checking your baby's saturations the first time you try this position.

# Which nostril should be used for the NPA?

We generally alternate the nostril on a weekly basis. However, it can be sometimes be difficult to pass an NPA via one of the nostrils. This may mean that we use the same nostril for the NPA each week. This is not known to cause any problems in the long term but you may notice your baby's nostrils look slightly different in size. This will resolve with time after the NPA is no longer being used.

#### Are there any risks?

As with any airway there is always a risk the NPA may become blocked. To reduce this risk we recommend suctioning the tube regularly (see above - **How do I care for the NPA**). You will soon be able to recognise when your baby needs you to clear the NPA. Signs to look out for include noisier breathing, faster breathing, decreasing oxygen saturations or your baby becoming agitated or unsettled. Look out for their muscles sucking in near the throat, chest, ribs or a change in colour (looking pale or dusky).

#### What do I do if I think the NPA is blocked?

If you are worried the NPA is blocked we advise suctioning with a catheter along its full length. If this does not improve your baby's breathing reposition your baby laying on their side or stomach while you prepare to remove the NPA. The next step is to remove the NPA and pass a new NPA. If you are unable to pass another NPA, position your baby on their stomach, stay with your baby and call 999.

#### Will the NPA make my baby's nose sore?

We advise looking for any change in colour (rim of nostril appearing red or white) or soreness around the nostril. If signs appear, please contact your cleft nurse.

#### What position should my baby sleep in?

In accordance with sudden infant death syndrome (SIDS) guidelines we recommend putting your baby to sleep on their back in the same room as you for the first six months. The recommended room temperature is 16-20°C. Please see SIDS guidelines from The Lullaby Trust for further information: www.lullabytrust.org.uk/safer-sleep-advice/

# **Contact us**

If you have any questions or concerns, please contact a member of our team:

Rebecca Bailey – Kent	07768 474876
Helen Daniel – Surrey	07717 571931
Joanna Leigh – Kent	07810 483923
Jackie Matthews – Sussex	07970 261781
Ruth Mirza – Surrey	07717 864003
Sally Moran – London	07768 474667
Beverley Willshire – London	07976 292232

Contact any of the above numbers to talk to the team. Please note there is a nursing service provided 7 days a week. Phones are diverted to the nurse on-call at weekends and bank holidays. Text messages are not diverted, so please call if you need advice.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w**: www.evelinalondon.nhs.uk/leaflets

#### **Evelina London Medicines Helpline**

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003, Monday to Friday, 10am-5pm e: letstalkmedicines@gstt.nhs.uk

#### Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) e: pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) e: complaints2@gstt.nhs.uk

#### Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 e: languagesupport@gstt.nhs.uk

#### NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111 w: 111.nhs.uk

#### **NHS** website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

#### Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch. t: 0800 731 0319 e: members@gstt.nhs.uk w: www.guysandstthomas.nhs.uk/membership

#### Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, w: www.guysandstthomas.nhs.uk/leaflets, or e: patientinformationteam@gstt.nhs.uk

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