

## Appendix 1

# INFORMATION FOR PARENTS / GUARDIANS SLEEP APNOEA and SLEEP STUDIES at ST MARY'S

Thank you for consulting us in the department of ENT (Ear, Nose & Throat) surgery at St Mary's Hospital. You have been given this information sheet because, based on what you have told us, we think that your child may possibly be suffering from sleep apnoea. This sheet explains what that is, and what will happen next.

### SNORING AND SLEEP APNOEA

Snoring is something that, sadly, many people are familiar with. The characteristic noise is caused by part of the throat vibrating during normal breathing. The genetically-determined shape of the throat can predispose to this, but there is usually another factor as well. In adults, this is most often excess weight around the neck, and in children, large tonsils and/or adenoid. In both adults and children, this vibration is most likely to happen when the muscles of the throat and neck are most relaxed – usually during deep sleep. Snoring may be annoying, but it is not usually dangerous to the health of the snorer.

“Apnoea” is the medical term for cessation of breathing, and “sleep apnoea” is when this happens during sleep (usually during snoring). In rare cases it can be caused by failure of control in the breathing centres of the brain (so-called “central” or “neurological” sleep apnoea), but in the great majority of children, it is caused by physical obstruction of the airway by large tonsils and/or adenoid; and is termed “obstructive sleep apnoea” or OSA.

Sleep apnoea is certainly very alarming, but please be reassured: we have never heard of a case where a child with OSA stopped breathing and died. The urge to breathe is simply too strong for that to happen. Instead, a child with OSA will go through a stress response, partly wake up, restore muscle tone, breathe normally, and fall asleep again. Sleep apnoea is considered serious not because of an immediate risk to life, but because of great stress on the heart and lungs, and the poor-quality sleep which results from recurrently waking.

### SLEEP STUDIES

Sleep apnoea is difficult to diagnose, because the episodes happen intermittently, and usually overnight. We also need to know how severe a particular child's problem is, in order to plan the correct treatment. This sort of diagnosis and risk-stratification usually requires a sleep study, where your child is monitored during sleep, and parameters such as heart rate and blood oxygen level are continually measured. This most often requires an overnight stay in hospital.

There are four possible outcomes of the sleep study: simple snoring with no OSA, mild, moderate and severe OSA. We base this judgement principally on the average number of episodes per hour, and also on how low the blood oxygen levels dip.

### OUR NEW PATHWAY

The NHS is required to treat all patients within certain time limits. Many children have this problem, and the pathway from your GP to our clinic, to a sleep study, to follow-up in our clinic, to the operating theatre is quite long. In order to shorten it (and therefore shorten your waiting time), we act directly on the results of your child's sleep study without waiting to see you again in the outpatient clinic.

This means that after the sleep study is completed, you will receive one of four letters, outlined below.

### Simple snoring with no OSA

There is no cause for alarm. During the study, your child did not stop breathing (or did so only very rarely), and as far as we can tell is getting good-quality sleep despite the snoring. We will not make arrangements to see you again, but if you would like to discuss things further, we would be happy to.

Mild OSA

Your child should probably have their tonsils and/or adenoid removed to improve their sleep and prevent things getting any worse, but there is no great urgency. We will book your child in for routine surgery (unless you contact us and tell us not to), and you should normally be able to leave hospital the evening after surgery.

Moderate OSA

Your child needs to have their tonsils and/or adenoid removed as poor sleep is affecting their health. We will arrange surgery (unless you contact us and tell us not to), and we will give your child a higher priority than one with mild OSA. Your child will need to stay in hospital overnight after surgery.

Severe OSA

Your child needs to have their tonsils and adenoid removed as poor sleep is seriously affecting their health and development. We will arrange surgery (unless you contact us and tell us not to) on a more urgent basis than other cases. Your child will need to stay in hospital overnight after surgery, and will be closely monitored. If your child has any other serious medical problems, we may need to arrange an intensive-care bed for the night, so please let us know if there's anything in their medical background that you think we need to know.

Usually, after your child has recovered from surgery, we make a further appointment in the clinic. This is so that we can check with you that the problem has resolved, since there are a few rare cases in which taking out the tonsils and adenoid does not cure the problem. Clearly, with these children, we would need to pick this up and start looking for another cause.

Throughout the whole process, we will make every effort to be as clear and open with you as we possibly can be. If anything is not clear, or you feel that there are things you need to discuss, please get in touch with the team at St Mary's. Please also bear in mind, though, that we work across different sites and treat many patients, so we cannot always respond immediately.

Many thanks for reading this.

*[signature]*

Matthew Rollin, FRCS

*[signature]*

Ali Taghi, FRCS

Many thanks for reading this.

**Appendix 2**

**INFORMATION FOR PARENTS / GUARDIANS  
RESULTS OF YOUR CHILD'S SLEEP STUDY**

Dear parent/guardian,

Your child recently underwent a sleep study under the care of St Mary's Hospital, to investigate the possibility of obstructive sleep apnoea (OSA). This letter is to inform you of the results, and explain what they mean.

RESULTS OF THE SLEEP STUDY

**MILD OBSTRUCTIVE SLEEP APNOEA**

Your child is suffering from OSA, but thankfully in a fairly mild form. Your child should probably have their tonsils and/or adenoid removed in order to improve their sleep and prevent things getting any worse, but there is no great urgency.

WHAT HAPPENS NEXT?

We will book your child in for routine surgery, unless you contact us and tell us not to. The next you hear from us will be an offer of a date for surgery. If it's not suitable, please get in touch and ask for it to be changed (although please bear in mind that since we normally offer the next available date, it's not usually possible to bring a surgical date forward).

Your child will typically go through a process of pre-operative assessment, to check their overall general health and fitness for surgery.

As you are aware, the intention of surgery is to improve your child's sleep. By law we are required to inform you of the potential risks of this surgery, which include bleeding from the mouth or throat in the few days following surgery, throat infection, pain and chipping or knocking a tooth during the procedure. There are also some potential risks relating to the anaesthetic, and we recommend that you discuss these with the anaesthetic team on the day of surgery.

On the day of surgery, we (or members of our team) will see you, take you through what will happen in the operation and recovery, and ask you to sign a form allowing the surgery to go ahead. You should normally be able to leave hospital the same day, in the evening.

Many thanks for reading this. Please feel free to discuss things further with the team on the day.

Yours sincerely,

*[signature]*

Matthew Rollin, FRCS

*[signature]*

Ali Taghi, FRCS

**Appendix 3**

## INFORMATION FOR PARENTS / GUARDIANS RESULTS OF YOUR CHILD'S SLEEP STUDY

Dear parent/guardian,

Your child recently underwent a sleep study under the care of St Mary's Hospital, to investigate the possibility of obstructive sleep apnoea (OSA). This letter is to inform you of the results, and explain what they mean.

### RESULTS OF THE SLEEP STUDY

#### MODERATE OBSTRUCTIVE SLEEP APNOEA

Your child needs to have their tonsils and/or adenoid removed as poor sleep is affecting their health.

### WHAT HAPPENS NEXT?

We will book your child in for surgery as soon as reasonably possible, unless you contact us and tell us not to. The next you hear from us will be an offer of a date for surgery. If it's not suitable, please get in touch and ask for it to be changed (although please bear in mind that since we normally offer the next available date, it's not usually possible to bring a surgical date forward).

Your child will typically go through a process of pre-operative assessment, to check their overall general health and fitness for surgery.

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On the day of surgery, we (or members of our team) will see you, take you through what will happen in the operation and recovery, and ask you to sign a form allowing the surgery to go ahead. Your child will need to stay in hospital overnight after surgery, and you should normally be able to leave hospital the next morning.

Many thanks for reading this. Please feel free to discuss things further with the team on the day.

Yours sincerely,

*[signature]*

Matthew Rollin, FRCS

*[signature]*

Ali Taghi, FRCS

Appendix 4

## INFORMATION FOR PARENTS / GUARDIANS RESULTS OF YOUR CHILD'S SLEEP STUDY

Dear parent/guardian,

Your child recently underwent a sleep study under the care of St Mary's Hospital, to investigate the possibility of obstructive sleep apnoea (OSA). This letter is to inform you of the results, and explain what they mean.

### RESULTS OF THE SLEEP STUDY

#### SEVERE OBSTRUCTIVE SLEEP APNOEA

Your child needs to have their tonsils and/or adenoid removed as poor sleep is seriously affecting their health.

### WHAT HAPPENS NEXT?

We will arrange surgery (unless you contact us and tell us not to) as soon as reasonably possible. The next you hear from us will be an offer of a date for surgery. If it's not suitable, please get in touch and ask for it to be changed (although please bear in mind that since we will normally be offering a date on an urgent basis, it's not usually possible to bring this date forward).

Your child will typically go through a process of pre-operative assessment, to check their overall general health and fitness for surgery. Your child will need to stay in hospital overnight after surgery, and will be closely monitored. If your child has any other serious medical problems, we may need to arrange an intensive-care bed for the night, so please let us know if there's anything in their medical background that you think we need to know.

As you know, the intention of surgery is to improve your child's sleep. By law we are required to inform you of the potential risks of this surgery, which include bleeding from the mouth or throat in the few days following surgery, throat infection, pain and chipping or knocking a tooth during the procedure. There are also some potential risks relating to the anaesthetic and the recovery, and we recommend that you discuss these with the anaesthetic team on the day of surgery.

On the day of surgery, we (or members of our team) will see you, take you through what will happen in the operation and recovery, and ask you to sign a form allowing the surgery to go ahead.

Many thanks for reading this. Please feel free to discuss things further with the team on the day.

Yours sincerely,

*[signature]*

Matthew Rollin, FRCS

*[signature]*

Ali Taghi, FRCS

Appendix 5

## INFORMATION FOR PARENTS / GUARDIANS RESULTS OF YOUR CHILD'S SLEEP STUDY

Dear parent/guardian,

Your child recently underwent a sleep study under the care of St Mary's Hospital, to investigate the possibility of obstructive sleep apnoea (OSA). This letter is to inform you of the results, and explain what they mean.

### RESULTS OF THE SLEEP STUDY

#### SIMPLE SNORING WITH NO OSA

There is no cause for alarm. During the study, your child did not stop breathing (or did so only very rarely), and as far as we can tell, he/she is getting good-quality sleep despite snoring.

In this situation, there is no need for us to see you in the clinic again, so we will not automatically make another appointment.

On the other hand, if there are things that you would like to discuss further, we would be happy to see you again in the clinic, so please contact us and make another appointment.

Yours sincerely,

*[signature]*

*[signature]*

Matthew Rollin, FRCS

Ali Taghi, FRCS