The Chailey
Sleep Questionnaire

Child's name

Age

Assessment centre

We acknowledge SCOPE's funding for the initial development of the Questionnaire.

Introduction

This Sleep Questionnaire evaluates sleep problems in children with severe cerebral palsy. It can be completed in the child's home or in the clinic.

Why do we need sleep?

Lack of good quality sleep can have a negative effect on learning, mood, behaviour and physical development.

Why do we need to evaluate sleep?

We know that sleep problems occur frequently in children with cerebral palsy. Despite this, sleep is not systematically assessed and clinicians do not have a specific tool to routinely gather information about sleep disturbance. Children with complex physical disability have treatment and equipment prescribed for night time usage which may impact on sleep. This questionnaire can be used by any member of the child's multidisciplinary team and can be used as a guide to clinical management or to highlight areas of concern prior to prescription.

What are likely sleep problems in children with cerebral palsy?

There are many reasons why children with cerebral palsy have disturbed sleep. There can be a problem with sleep initiation (falling asleep), sleep maintenance (staying asleep) or a combination of both. Sleep is a learned behaviour and requires experience at an early stage to establish good patterns. This is often not the case in children with severe disability where prematurity, trauma to brain sleep centres, frequent hospitalisations and ill-health can all combine to produce disruptive nights leading to difficulty in establishing good sleep habits.

The complications of cerebral palsy can also lead to disturbed nights. Some children sleep in postural equipment or cannot independently change sleeping position. Epilepsy, as well as the anticonvulsants used to treat it, can disturb sleep. Breathing problems can occur at night and some children can experience musculoskeletal pain that leads to disturbed sleep.

What are the likely consequences of chronic sleep problems?

Chronic sleep problems lead to daytime sleepiness and reduced ability to cope with daytime activities. Sleep disruption in children has negative consequences for parents/carers and other family members who may be woken and have to get up several times in the night.

How to use the Sleep Questionnaire

This Questionnaire should be used in consultation with a parent or carer and for a child with cerebral palsy at Gross Motor Function Classification System (GMFCS) Levels III-V (Palisano et al. 1997). The Questionnaire should take about 30 minutes to complete. It is recommended that a **One Week Sleep Diary** be completed in conjunction with the questionnaire to provide further details (Appendix 1).

The **Clinical Profile** Section should highlight areas impacting on sleep and should be brought to the attention of the child's paediatrician.

The **Sleep Profile** Section should highlight problem areas which can then be addressed. Standard references on management of sleep problems are listed below. There is a **glossary** of clinical and sleep related terms on page 23.

If an **action** is required, in relation to any of the answers given, the **action box** next to the appropriate question should be ticked. On the summary page at the end of each profile section an action plan can be written for each of the problem areas as highlighted by the ticked action boxes. Further to this a review date should be included on the summary page to verify if the actions required have been carried out.

Where this symbol is shown, and if this problem usually occurs, it should be brought to the attention of the child's paediatrician **urgently**.

This Questionnaire is being piloted and it is a requirement that an anonymised copy of the completed Questionnaire and the Feedback Form (Appendix 2) is posted back to the research department at Chailey Heritage Clinical Services.

References

Durand, V.M. (1998) *Sleep Better! A Guide to Improving Sleep for Children with Special Needs.* Paul H. Brookes Publishing Co.

Ferber, R. (2002) *Solve your Child's Sleep Problems: A Practical and Comprehensive Guide for Parents*. London: Dorling Kindersley Publishers Ltd.

Khan, Y. and Underhill, J. (2006) Identification of Sleep Problems by Questionnaire in Children with Severe Cerebral Palsy. *Developmental Medicine and Child Neurology Suppl. 48* (European Academy of Childhood Disability): 23.

Newman, C.J., O'Regan, M. and Hensey, O. (2006) Sleep disorders in children with cerebral palsy. *Developmental Medicine and Child Neurology*, 48: 564–568.

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E. and Galuppi, B. (1997) Development and Reliability of a System to Classify Gross Motor Function in Children with Cerebral Palsy. *Developmental Medicine and Child Neurology*, 39: 214–223.

Quine, L. (1997) *Solving Children's Sleep Problems: A Step-by-step Guide for Parents*. Huntington: Beckett Karlson Ltd.

SCOPE webpage on sleep: www.scope.org.uk/help-and-information/families-and-parenting

Stores, G. (2001) *A Clinical Guide to Sleep Disorders in Children and Adolescents*. Cambridge: Cambridge University Press.

Stores, G. and Wiggs, L. (2001) *Sleep Disturbance in Children and Adolescents with Disorders of Development: Its Significance and Management*. London: MacKeith Press.

Background information

Child's name:

Date of birth:

Gender ☐ Male ☐ Female

Home address:

Home telephone number:

Name of school and class teacher:

Is the school:

☐ Mainstream
☐ Special
☐ Dual placement

Name and address of GP:

Name and address of paediatrician:

Questionnaire completed by:

Name of interviewer:

Name of parent or carer:

Why is this Questionnaire being completed?

☐ Clarify sleep disturbance and aid management
☐ Identify medical problems impacting on sleep
☐ Risk assessment tool before prescribing sleep system
☐ Repeat questionnaire to monitor progress
☐ Research purpose
☐ Other (please state):

Clinical Profile

CHILD'S NAME DATE: /

GENERAL

ACTION ✓

1 **Primary Diagnosis** ☐

2 **GMFCS Level** ☐

3 **Details of recent surgery (last six months)** ☐

4 **Details of recent hospitalisation (last six months)** ☐

5 **Current medication and doses** ☐

6 **Details of recent medication changes (last six months)** ☐

7 **Communication difficulties and use of alternative or augmentative communication systems** ☐

CHILD'S NAME DATE: /

NIGHT-TIME CARE

ACTION ✓

8 Does your child need medication during the night? ☐ yes ☐ no ☐

8a If yes, please give details: ☐

8b How is the medication administered? ☐

☐ orally ☐ rectally ☐ gastrostomy ☐ other route

8c How often, per week, is the medication given during the night? ☐

9 Does your child need a feed during the night? ☐ yes ☐ no ☐

If yes,

9a How is the feed given? ☐ nasogastric ☐ gastrostomy ☐ other ☐

9b Does this wake your child? ☐ yes ☐ no ☐ sometimes ☐

10 Does your child require any other night time care? ☐ yes ☐ no ☐

10a If yes, please give details: ☐

SENSORY IMPAIRMENTS

ACTION ✓

11 Does your child have problems with his/her vision? ☐ yes ☐ no ☐

11a If yes, please give details: ☐

12 Does your child have a hearing problem? ☐ yes ☐ no ☐

12a If yes, please give details: ☐

CHILD'S NAME DATE: /

ORTHOPAEDIC PROBLEMS ACTION ✓

13 Does your child have orthopaedic problems? ☐ yes ☐ no ☐

13a If yes, please give details: ☐

13b Do these problems cause pain during the night? ☐
☐ yes ☐ no ☐ sometimes

13c If yes, please give details: ☐

SPINAL CURVATURE (SCOLIOSIS OR KYPHOSIS) ACTION ✓

14 Does your child have Scoliosis or Kyphosis? ☐ yes ☐ no ☐

If yes,

14a Please grade the degree of Scoliosis or Kyphosis ☐
☐ mild ☐ moderate ☐ severe

14b Is the Scoliosis or Kyphosis getting worse? ☐ yes ☐ no ☐

14c Is spinal surgery planned or has it happened? ☐ yes ☐ no ☐

14d If yes, when:

14e Does your child wear a spinal jacket? ☐ yes ☐ no ☐

14f Does your child sleep in a spinal jacket? ☐ yes ☐ no ☐

BREATHING PROBLEMS ACTION ✓

15 Has your child had a chest infection in the last 6 months? ☐ yes ☐ no ☐

If yes,

15a How many chest infections has your child had in the last 6 months? ☐
☐ 1 ☐ 2–5 ☐ 6+

15b How many of these required antibiotics? ☐ none ☐ some ☐ all ☐

15c How many required hospitalisation? ☐ none ☐ some ☐ all ☐

CHILD'S NAME DATE: /

16 **Is your child's breathing disturbed during sleep?** ☐

☐ yes ☐ no ☐ sometimes

17 **Does your child snore?** ☐

☐ yes ☐ no ☐ sometimes

18 **Does your child's breathing stop and start during sleep?** ☐

☐ yes ☐ no ☐ sometimes

19 **Does your child have shallow breathing during sleep?** ☐

☐ yes ☐ no ☐ sometimes

20 **Does your child struggle for breaths during the night?** ☐

☐ yes ☐ no ☐ sometimes

21 **Is your child's breathing at night interrupted with snorts and gasps?** ☐

☐ yes ☐ no ☐ sometimes

22 **Does your child gag or choke during the night?** ☐

☐ yes ☐ no ☐ sometimes

23 **Is your child's breathing poorer in certain sleep positions?** ☐

☐ yes ☐ no ☐ sometimes

23a If yes, what positions? ☐

24 **Does your child have recurrent ear or throat infections?** ☐ yes ☐ no ☐

25 **Have your child's tonsils or adenoids been removed?** ☐ yes ☐ no ☐

25a If yes, please give details: ☐

26 **Does your child find it difficult to recover from a cold?** ☐ yes ☐ no ☐

27 **Does your child find it difficult to cough?** ☐ yes ☐ no ☐

CHILD'S NAME DATE: /

TISSUE VIABILITY ACTION ✓

28 Does your child have problems with their skin or pressure sores? ☐ yes ☐ no ☐

28a If yes, please give details: ☐

28b Do these problems cause pain or discomfort at night?: ☐ yes ☐ no ☐

28c If yes, please give details: ☐

NUTRITION & FEEDING RELATED PROBLEMS ACTION ✓

29 Does your child have difficulties chewing or swallowing? ☐ yes ☐ no ☐

29a If yes, please give details:

30 Does your child have problems with feeding? ☐ yes ☐ no ☐

If yes,

30a Is your child fed by nasogastric /gastrostomy feeds alone? ☐ yes ☐ no ☐

30b Is your child fed by combination of tube and oral? ☐ yes ☐ no ☐

30c If yes, please give details: ☐

31 Does your child experience vomiting/regurgitation during: ☐
daytime ☐ yes ☐ no **night time** ☐ yes ☐ no

32 Is there a risk of aspiration? ☐ yes ☐ no ☐

32a If yes, does your child require any drugs to control this? ☐ yes ☐ no ☐

32b If yes, please give details: ☐

Continued

CHILD'S NAME DATE: /

33 Does your child experience periods of constipation? ☐ yes ☐ no ☐

33a If yes, please give details: ☐

33b Does this cause discomfort at night? ☐ yes ☐ no ☐

SEIZURES, FITS AND NEUROLOGICAL ACTION ✓

34 Has your child ever had a seizure or fit? ☐ yes ☐ no ☐

34a How many seizures or fits has your child had in the last 6 months? ☐
☐ none ☐ 1–5 ☐ 6–10 ☐ 11–20 ☐ daily

34b What time of the day or night do the fits usually happen? ☐
☐ early morning ☐ afternoon ☐ evening ☐ night time

34c Please please give details: ☐

34d How long do the fits last? ☐
☐ seconds ☐ less than 15 minutes ☐ more than 15 minutes

34e How many different medications are needed to control the fits? ☐
☐ none ☐ one ☐ two ☐ three ☐ more than three

34f What are the names of the medications? ☐

35 Does your child indicate that they suffer from headaches? ☐ yes ☐ no ☐

36 Does your child seem to have a headache in the mornings? ☐ yes ☐ no ☐

37 Does your child have a cerebral shunt? ☐ yes ☐ no ☐

If yes,

37a Has the cerabral shunt caused any problems in the last six months? ☐
☐ yes ☐ no

37b If yes, please please give details: ☐

Clinical Profile: Summary

CHILD'S NAME

Problem area	*Ref/Q.*	*Action plan*	*Initials*
General			
Night time care			
Sensory impairment			
Orthopaedic and spinal curvature			
Breathing			
Tissue viability			
Nutrition and feeding			
Seizures and neurological			

Flagged questions

Review date

Name of clinician

Signature of clinician

Sleep Profile

CHILD'S NAME DATE: /

GENERAL ACTION ✓

1 What time does your child usually go to bed on ☐

schooldays ☐ weekends or school holidays ☐

2 What time in the morning does your child usually wake up on ☐

schooldays ☐ weekends or school holidays ☐

3 What time does your child usually get up, or is aided to get up on ☐

schooldays ☐ weekends or school holidays ☐

4 Does your child have a set bedtime routine? ☐ yes ☐ no ☐

4a If yes, please give details: ☐

5 What is your child's favourite sleeping position? ☐

6 Does your child take daytime naps? ☐ yes ☐ no ☐

If yes,

6a How many naps a day does your child take? ☐

6b How long (approximately) does your child nap for? ☐

CHILD'S NAME DATE: /

GENERAL CONTINUED ACTION ✓

7 Does your child regularly spend nights away from home? ☐ yes ☐ no ☐

7a If yes, please give details about where and when:

7b If yes,
Does your child sleep better when ☐ at home ☐ when away ☐ the same ☐

8 Does your child use postural management equipment? ☐ yes ☐ no ☐

8a If yes, please give details:

9 Does your child use a sleep system or lying support? ☐ yes ☐ no ☐

If yes,

9a What brand does your child use:

9b How many nights per week does your child sleep in the sleep system or lying support? ☐

9c For how long each night does your child sleep in the sleep system/lying support? ☐

9d Does your child sleep better or worse in the sleep system/lying support? ☐

9e If the sleep system/lying support is no longer used by your child what were the reasons for discontinuing its use? ☐

CHILD'S NAME DATE: /

BEDTIME ROUTINE ACTION ✓

Usually 5–7 nights per week
Sometimes 2–4 nights per week
Rarely 1 night per week
Never 0 nights per week

10 Does your child go to bed at the same time each night? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

11 Once in bed does your child fall asleep within 20 minutes? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

11a If not, how long is it before your child falls asleep? ☐
☐ 20–30mins ☐ 30–45mins ☐ 45mins+

12 Does your child fall asleep alone in his/her own bed? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

13 Does your child fall asleep alone in his/her parent's bed? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

14 Does your child fall asleep alone at night in other places, e.g. sofa, wheelchair? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

15 How many children sleep in the same bedroom as your child? ☐
☐ 0 ☐ 1 ☐ 2 ☐ 3+

16 Does your child need a parent with them in order to fall asleep ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

17 Does your child need medication to help them fall asleep or stay asleep? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

17a If yes, please give details about type and dose: ☐

18 Is your child reluctant to go to bed at bedtime, eg, refuses to stay in bed, or cries? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

CHILD'S NAME DATE: /

NIGHT-TIME BEHAVIOUR ACTION ✓

Usually 5–7 nights per week
Sometimes 2–4 nights per week
Rarely 1 night per week
Never 0 nights per week

19 Does your child wake during the night? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

If yes,

19a How many times a night does your child wake? ☐ 1–3 ☐ 4–6 ☐ 7+ ☐

19b How long, on average, are the waking periods? ☐
☐ 0–10 mins ☐ 11–30 mins ☐ 30+ mins

19c Do you attend to your child when they wake during the night? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

20 Does your child cry when they wake during the night? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

21 Does your child wake during the night sweating, screaming and distressed? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

22 Does your child move, or are they moved, to someone else's bed when they wake up during the night? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

22a If yes, please give details about whose bed: ☐

23 Is your child restless and moves a lot during the night? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

24 Does your child talk or vocalise whilst asleep? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

25 Does your child grind his/her teeth whilst asleep? ☐
☐ usually ☐ sometimes ☐ rarely ☐ never

26 Does your child bang his/her head or rock back and forth whilst falling asleep or when asleep? ☐ ☐ usually ☐ sometimes ☐ rarely ☐ never

CHILD'S NAME DATE: /

NIGHT-TIME BEHAVIOUR CONTINUED

ACTION ✓

27 Does your child wet the bed during the night? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

28 Or, if your child wears nappies or pads are they wet and/or soiled in the morning? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

29 Does your child wake during the night in pain? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

29a If yes, please give details: ☐

30 Can your child change his or her position at night? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

31 Do you or someone else need to change your child's position during the night? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

32 Do you think your child sleeps too little? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

33 Do you think your child sleeps too much? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

34 Is your child drowsy and takes a lot of time to become alert in the morning? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

35 Does your child seem tired to you in the morning? ☐

☐ usually ☐ sometimes ☐ rarely ☐ never

Sleep Profile: Summary

CHILD'S NAME

Problem area	*Ref/Q.*	*Action plan*	*Initials*
General			
Bedtime routine			
Night-time behaviour			

Review date:

Name of clinician:

Signature of clinician:

Glossary

of clinical and sleep related terms

Aspiration – the inhalation of food particles and/or fluid into the lungs.

Cerebral palsy – a persistent disorder of posture/movement due to trauma to the developing brain.

Cerebral shunt – an artificial shunt used to drain excess fluid from the brain.

Epilepsy, fits, convulsions, seizures – a disorder of brain activity,

Gastero-oesophageal reflux – the passage of stomach contents and secretions into the food pipe.

Gastrostomy – feeding through a tube in the stomach.

GMFCS – Gross Motor Function Classification System: a five-level system to classify the motor involvement of children with cerebral palsy on the basis of their self-initiated movement with particular emphasis on sitting, walking and wheeled mobility.

Kyphosis – excessive outer curvature of the back causing hunching of the back.

Nasogastric – feeding via a tube put down through the nose and mouth into the stomach.

Obstructive sleep apnoea – the complete or partial cessation of breathing during sleep due to an obstruction in the upper airways.

Orthopaedic problems – problems involving bones and muscles.

Postural management equipment – equipment to support children when lying, sitting or standing.

Scoliosis – excessive sideways curvature of the back.

Sensory impairment – disorder of the senses, most commonly vision or hearing.

Sleep behaviour – behaviour around sleep times.

Sleep systems/lying supports – equipment to support children in the lying position during the day or night.

Spinal jacket – polypropylene jacket used to maintain position of the spine.

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