HOST

HOLISTIC ASSESMENT OF SLEEP AND DAILY TROUBLES IN PARENTS OF CHILDREN WITH SEVERE PSYCHOMOTOR IMPAIRMENTS

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Sleep Questionnaire for Children with Severe Psychomotor Impairments
Version 1.0

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Dear Parents,

This questionnaire should help us to get an extensive overview of your child's sleep condition in order to initiate comprehensive treatment. All information being gathered from this and further questionnaires as well as information gained in the talks will be treated as strictly confidential.

Please answer all questions, even those that appear unimportant to you. Sleep problems are very complex, so that even seemingly unimportant details are of importance to us. If you do not understand a question, please highlight this question with a question mark.

Your data and your child's data are subject to **medical confidentiality**.

Information gathered in this questionnaire will be stored and further analyzed anonymously, i.e. there is no link between information and the actual person.

We kindly ask you for your agreement to store the data on you and your child.

This agreement can be taken back at anytime without giving reasons. In case you do not want to agree to the use of your data, or if you decide to take back the agreement at any given point of time, there will of course be **no disadvantage** to your child's treatment.

Your Palliative Care Team

AGREEMENT

First and last name

I AGREE TO STORING AND ANONYMOUSLY USING MY AND MY CHILD'S DATA AS ASSESSED IN THE QUESTIONNAIRES.

- Yes
- No

Place / Time

Signature

GENERAL INFORMATION ON THE CHILD AND THE FAMILY

THE QUESTIONNAIRE IS FILLED OUT BY:

◯ mother ◯ father ◯ other: ....

GENERAL INFORMATION ON YOUR CHILD:

Sex: ◯ female ◯ male country of birth: ....

Age: .... years height: .... cm weight: .... kg

What diagnosis was made for your child?

....

....

....

What medication does your child take?

....

....

....

Caregiver's marital status?

◯ live together ◯ divorced since: ....

◯ widowed since .... ◯ never lived together

With whom does your child live predominantly?

◯ biological parents ◯ biological mother ◯ biological father

◯ biological mother and partner ◯ biological father and partner

◯ grandparents or other relatives ◯ adoptive parents

◯ foster parents ◯ children's home ◯ other (please specify) ....

How many children live in your household? .... children

How many persons (including children) live in your household? .... persons

GENERAL DATA ON CAREGIVER

PLEASE ANSWER THE FOLLOWING QUESTIONS **SEPARATE FOR MOTHER AND FATHER!**

	MOTHER	**FATHER**
How old are you?	.... years	.... years
In which country were you born?	....	....
What is your native language?	◯ English ◯ other	◯ English ◯ other
If English isn't your native language, describe your proficiency in English?	◯ very good ◯ good ◯ bad ◯ no abilities	◯ very good ◯ good ◯ bad ◯ no abilities
Which religion do you have?	◯ none ◯ Christian ◯ Jewish ◯ Islam ◯ Buddhism ◯ Hinduism ◯ other	◯ none ◯ Christian ◯ Jewish ◯ Islam ◯ Buddhism ◯ Hinduism ◯ other
What is your profession?	.... ◯ fulltime part time: .... % ◯ stay at home	.... ◯ fulltime part time: .... % ◯ stay at home

I SLEEPING HABITS

THE FOLLOWING QUESTIONS RELATE TO **YOUR** SLEEP HABITS DURING THE PAST **4 WEEKS.**
PLEASE CONSIDER THIS TIMEFRAME IN ALL QUESTIONS.

1. When have you usually gone to bed?	about .... o'clock
2. How long has it taken you to fall asleep?	about .... minutes
3. How many hours of sleep did you actually get at night? (This may be different than the number of hours you spend in bed)	about .... hours
4. When have you usually gotten up in the morning?	about .... o'clock

5. PLEASE CHOOSE THE ONE ANSWER, THAT FITS THE BEST:

	Never	Less than once a week	Once or twice a week	Three or four times a week
5a. Hoe often did you sleep in a room together with your child?	◯	◯	◯	◯
5b. How often did your partner help you with your child's caring during the night?	◯	◯	◯	◯
5c. How often did extrended care assist you with your child's care during the night?	◯	◯	◯	◯

6. WHO PRIMARILY TOOK CARE OF YOUR CHILD DURING THE NIGHT?

◯ mother ◯ father ◯ siblings

◯ relatives (e.g. grandparents) ◯ extended care

7. HOW LONG WERE YOU OCCUPIED WITH YOUR CHILD IN TOTAL DURING THE NIGHT?

about .... minutes

8. WHEN YOU WOKE UP AT NIGHT BECAUSE OF YOUR CHILD, HOW LONG DID IT USUALLY TAKE UNTIL YOU FELL ASLEEP AGAIN?

about .... minutes

9. HOW OFTEN DID YOU HAVE TROUBLE SLEEPING, BECAUSE YOU...

	Never	Less than once a week	Once or twice a week	Three or four times a week	Five or more times a week
9a. ... were woken up by your child?	◯	◯	◯	◯	◯
9b. ... got up to look after your child?	◯	◯	◯	◯	◯
9c. ... had to to care for your child at night (e.g. respositioning)?	◯	◯	◯	◯	◯
9d. ... were worried that something could happen to your child while sleeping (e.g. seizure, spasm)?	◯	◯	◯	◯	◯
9e. ... worried about your child's condition concerning the future?	◯	◯	◯	◯	◯
9f. ... Other reason(s)?	◯	◯	◯	◯	◯

10. HOW OFTEN HAVE YOUR SLEEP INTERRUPTIONS DUE TO YOUR CHILD'S CONDITION CAUSED...?

	Never	Less than once a week	Once or twice a week	Three or four times a week	Five or more times a week
10a. ... insufficient sleep?	◯	◯	◯	◯	◯
10b. ... increased bad temper or distess?	◯	◯	◯	◯	◯
10c. ... difficulties to keep up enough enthusiasm to get things performed?	◯	◯	◯	◯	◯
10d. ... trouble staying awake while driving, eating meals or engaging in social activities?	◯	◯	◯	◯	◯
10e. ... a negative mood change?	◯	◯	◯	◯	◯

11. OVER THE YEARS, DID A LACK OF SLEEP DUE TO YOUR CHILD'S CONDITION…

	Applies mostly	Applies often	Apllies sometimes	Applies rarely	Never applies
11a. … restrict your social activities (e.g. meeting friends)?	◯	◯	◯	◯	◯
11b. … have a negative impact on your relationship with your partner?	◯	◯	◯	◯	◯
11c. … have a negative impact on affection and sex life with your partner?	◯	◯	◯	◯	◯
11d. … other consequences?	◯	◯	◯	◯	◯

Please specify:

12. DURING THE LAST FEW YEARS, DID THE LACK OF SLEEP DUE TO YOUR CHILD'S CONDITION ASSOCIATED STRESS CAUSE…

	Applies mostly	Applies often	Apllies sometimes	Applies rarely	Never applies
12a. … a crisis in your partnership?	◯	◯	◯	◯	◯
12b. … illness?	◯	◯	◯	◯	◯
12c. … absence at your work?	◯	◯	◯	◯	◯
12d. … other consequences?	◯	◯	◯	◯	◯

Please specify:

13. WOULD YOU LIKE TO ADD SOMETHING THAT YOU CONSIDER IMPORTANT FOR YOUR CHILD'S SLEEPING BEHAVIOR OR ACTIVITY THAT WAS NOT ASSESSED WITH THIS QUESTIONNAIRE?

THANK YOU!

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