# Quality of Life in Childhood Epilepsy Questionnaire: QOLCE-55 Version 1.0 (English)

Goodwin SW, Lambrinos AI, Ferro MA, Sabaz M, Speechley KN. Development and assessment of a shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). Epilepsia 2015;56(6):864-72.

### **USER INFORMATION**

#### Citation:

Individuals using the QOLCE-55 should cite the following reference in their work:

Goodwin SW, Lambrinos AI, Ferro MA, Sabaz M, Speechley KN. Development and assessment of a shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). Epilepsia 2015;56(6):864-72.

Ferro MA, Goodwin SW, Sabaz M, Speechley KN. Measurement Equivalence of the newly developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). Epilepsia 2016;57(3):427-35.

#### **QOLCE-55 Item Allocation:**

- 1. Cognitive functioning (22 items): section 1.1 a-v.
- 2. Emotional functioning (17 items): section 2.1 a-k and section 2.2 a-f.
- 3. Social functioning (7 items): section 3.1 a-g.
- 4. Physical functioning (9 items): section 4.1 a-i.

#### Scoring Instructions:

- 1. Recode all items such that higher scores indicate higher well-being.
- 2. Convert the pre-coded numeric values of items to a 0-100 point scale, with higher converted scores always reflecting better quality of life. Responses should now be coded as 0, 25, 50, 75, 100.
- 3. Calculate the mean value of the items in each subscale. Adjust the denominator to include only items answered.
- 4. To calculate the total score, take the unweighted mean of the four subscales.

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#### INSTRUCTIONS

The following questions ask about your child's health and well-being. Answer the questions by ticking the appropriate box. Certain questions may look alike but each one is different. Some questions may ask about problems your child does not have. Please try to answer each question as it is important for us to know when your child does not have these problems. There are no right or wrong answers. If you are unsure how to answer a question, please give the best answer you can.

#### SECTION 1: YOUR CHILD'S COGNITIVE FUNCTIONING

The following questions ask about some problems children have with concentrating, remembering, and speaking.

1.1 Compared to other children of his/her own age, how often during the past 4 weeks has your child:

		Very Often	Fairly Often	Some- times	Almost Never	Never	Not Applicable
a.	had difficulty attending to an activity?						
b.	had difficulty reasoning or solving problems?						
c.	had difficulty making plans or decisions?						
d.	had difficulty keeping track of conversations?						
e.	had trouble concentrating on a task?						
f.	had difficulty concentrating on reading?						
g.	had difficulty doing one thing at a time?						
h.	reacted slowly to things being said and done?						
i.	found it hard remembering things?						
j.	had trouble remembering names of people?						
k.	had trouble remembering where s/he put things?						
I.	had trouble remembering things people told him/her?						
m.	had trouble remembering things s/he read hours or days before?						
n.	planned to do something then forgot?						

		Very Often	Fairly Often	Some- times	Almost Never	Never	Not Applicable
0.	had trouble finding the correct words?						
p.	had trouble understanding or following what others were saying?						
q.	had trouble understanding directions?						
r.	had difficulty following simple instructions?						
s.	had difficulty following complex instructions?						
t.	had trouble understanding what s/he read?						
u.	had trouble writing?						
v.	had trouble talking?						

## SECTION 2: YOUR CHILD'S EMOTIONAL FUNCTIONING

Below is a list that describes how your child might feel in general.

2.1 <u>During the past 4 weeks</u>, how much of the time do you think your child:

		All of the time	Most of the time	Some of the time	A little of the time	None of the time	Not Applicable
a.	felt down or depressed?						
b.	felt happy?						
c.	wished s/he was dead?						
d.	felt frustrated?						
e.	worried a lot?						
f.	felt confident?						
g.	felt excited or interested in something?						
h.	felt pleased about achieving something?						
i.	felt nobody understood him/her?						
j.	felt valued?						
k.	felt no one cared?						

Below are statements that describe some children's behaviour. Please try to answer all questions as well as you can, even if some do not seem to apply to your child.

2.2 <u>Compared to other children his/her own age</u>, how often during the <u>past 4 weeks</u> do each of the following statements describe your child?

		Very Often	Fairly Often	Some- times	Almost Never	Never	Not Applicable
a.	was socially inappropriate (said or did something out of place in a social situation)						
b.	angered easily						
c.	hit or attacked people						
d.	swore in public						
e.	was obedient						
f.	demanded a lot of attention						

### SECTION 3: YOUR CHILD'S SOCIAL FUNCTIONING

Below are statements that describe some children's social interactions and activities. Please try to answer all questions as well as you can, even if some do not seem to apply to your child.

3.1 During the past 4 weeks, how often has your child's epilepsy:

		Very Often	Fairly Often	Some- times	Almost Never	Never	Not Applicable
a.	limited his/her social activities (visiting friends, close relatives, or neighbours)?						
b.	affected his/her social interactions at school or work?						
c.	limited his/her leisure activities (hobbies or interests)?						
d.	isolated him/her from others?						
e.	made it difficult for him/her to keep friends?						
f.	frightened other people?						
g.	During the past 4 weeks, how limited are your child's social activities compared with others his/her age because of his/her epilepsy or epilepsy-related problems?	Yes, limited a lot	Yes, limited some	Yes, limited a little	Yes, but rarely	D No, not limited	

## SECTION 4: YOUR CHILD'S PHYSICAL FUNCTIONING

The following questions ask about physical activities your child might do.

4.1. In his/her daily activities during the past 4 weeks, how often has your child:

		Very Often	Fairly Often	Some- times	Almost Never	Never	Not Applicable
a.	needed more supervision than other children his/her age?						
b.	played freely in the house like other children his/her age?						
C.	played freely outside the house like other children his/her age?						
d.	gone swimming (i.e., swam independently)?						
e.	participated in sports activities (other than swimming)?						
f.	stayed out overnight (with friends or family)?						
g.	played with friends away from you or your home?						
h.	gone to parties without you or without supervision?						
i.	been able to do the physical activities other children his/her age do?						