

# CPQOL

## Cerebral Palsy Quality of Life

Version 2 July 2013

Quality of Life Questionnaire  
for Adolescent (CP QOL-Teen)

Primary Caregiver Questionnaire





# Quality of Life Questionnaire for Adolescents (CP QOL-Teen)

## Primary Caregiver Questionnaire

We would like to ask you some questions about how you think your teenager FEELS about aspects of their life such as family, friends, health and school.

Each question begins with 'How do you think your teenager FEELS about.....?'

For each question we want you to choose the best number that shows how you think your teenager FEELS.

You can choose any number from 1 (Very unhappy) to 9 (Very happy).

This questionnaire has been designed for adolescents with all different types of cerebral palsy and some questions might be hard to answer. Please just do your best to give an answer for each question. The questionnaire is measuring how your teenager feels, not what they can do.

Here is an example:

**Q.** How do you think your teenager feels about...

*the way they get along with people generally?*

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
1	2	3	4	5	6	7	8	9

**Q.** How do you think your teenager feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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*their life in general?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their life as a whole?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their quality of life?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*how happy they are?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

## Family & Friends

**Q.** How do you think your teenager feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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*the way they get along with people generally?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they get along with you?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the support they get from their family?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they get along with their brothers & sisters?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

OR  they do not have any brothers or sisters

*the way they get along with other teenagers outside of school (not school friends)?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they get along with adults?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*hanging out on their own?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*hanging out with friends?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*going on trips with the family?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*how they are accepted by their family?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

## Family & Friends

**Q.** How do you think your teenager feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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*how they are accepted by other teenagers outside of school (not school friends)?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*how they are accepted by adults?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*how they are accepted by people in general?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*being able to do things they want to do (i.e their ability to do things, not whether they're allowed to)?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they 'have a go' and try new things?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*themselves?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their positive attitude?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their future?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their opportunities in life?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

## School

**Q.** How do you think your teenager feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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*the way they get along with other teenagers at school? (If they attend more than one school, please think about the school where they spend the most time).*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they are included by other students at their school?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they get along with their teachers?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they get along with their carers?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

OR  they do not have a carer.

*how they are accepted by other students at school? (If they attend more than one school, please think about the school where they spend the most time).*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*how they are accepted by the staff and teachers at their school?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*being treated the same as everyone else at their school?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

## School

**Q.** How do you think your teenager feels about...

*their ability to keep up academically with their peers  
(i.e. their school work)?*

Very unhappy	Unhappy		Neither happy nor unhappy		Happy		Very Happy	
1	2	3	4	5	6	7	8	9

*their ability to keep up physically with their peers?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their ability to participate at school? (If they attend  
more than one school, please think about the school  
where they spend the most time).*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

## Participation

*their ability to participate in leisure and recreational  
activities?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their ability to participate in sporting activities? (This  
question is asking how they feel about their ability to  
participate in sport, not whether they do).*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their ability to participate in social events outside of  
school?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their ability to participate in your community?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---



# Communication

**Q.** How do you think your teenager feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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*the way they communicate with people they know well (using any means of communication)?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they communicate with people they don't know well (using any means of communication)?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way other people communicate with them?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they communicate with people using technology? (e.g. text message, the internet)?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

## Health

**Q.** How do you think your teenager feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
--------------	---------	---------------------------	-------	------------

*their overall health?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their physical health?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they get around? (i.e. their mobility)?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*how they sleep?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way they look?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the changes happening to their body to do with puberty?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*being able to do things by themselves without relying on others?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*what may happen to them later in life?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*what they have achieved in their life?*

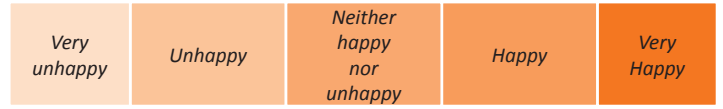
1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*succeeding in the things they want to be good at?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

## Health

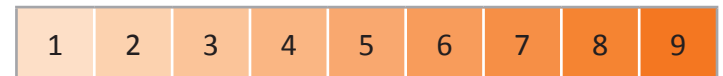
**Q.** How do you think your teenager feels about...



*their ability to get around your neighbourhood?*



*their ability to get from place to place (i.e transport)?*

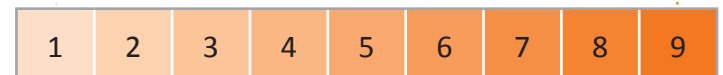


*their plans for the future?*



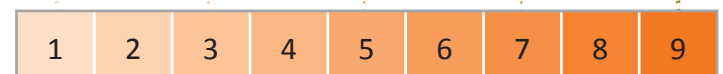
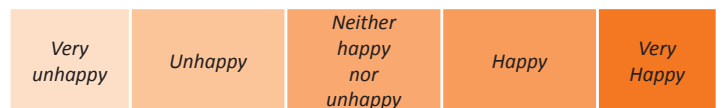
The next question has a different response scale ranging from “Not concerned at all” to “Very concerned”

*Is your teenager concerned about having cerebral palsy?*

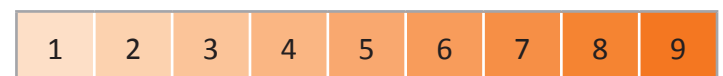


The next 2 questions are asking how your teenager feel about using parts of their body, not whether they can use parts of their body.

*the way they use their arms and hands?*



*the way they use their legs?*



# Health

**Q.** How do you think your teenager feels about...

The next 3 questions are asking how your teenager feels about your ability to complete daily activities, not whether they can complete the activities.

*their ability to dress him/herself?*

*their ability to eat or drink independently?*

*their ability to use the toilet by him/herself?*

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

# Special Equipment

**Q.** How do you think your teenager feels about...

*the special equipment they have at home? (e.g special seating, standing frames, wheelchairs, walkers, AFOs, visual aids, hearing aids, communication aids).*

OR  they do not need any special equipment at home.

*the special equipment they have at school? (e.g notetakers, special seating, standing frames, wheelchairs, walkers, laptops, visual aids, hearing aids, communication aids).*

OR  they do not need any special equipment at school.

*the special equipment that is available in the community (ramps, escalators, wheelchair access)?*

OR  they do not need any special equipment in the community.

*their access to special services available in the community (e.g. for employment, moving out of home)?*

OR  they do not need any special services in the community.

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
1	2	3	4	5	6	7	8	9

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

# Pain and bother

**Q.** How do you feel about...

The next question relates to any pain that your experiences

*how much pain does your teenager have?*

No pain at all					A lot of pain			
1	2	3	4	5	6	7	8	9

If your answer is (1) "No pain at all" please skip to page 16.

If you answered (2) or above, please proceed to the questions below

*the level of pain they experience?*

Not upset at all					Very upset			
1	2	3	4	5	6	7	8	9

*the level of discomfort they feel?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their ability to cope with pain?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*their ability to control their pain?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way that pains gets in the way of their life?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*the way pain stops them from being themselves?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*how pain takes away from their everyday fun?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

## Access to Services

The next set of questions are about YOU and how you feel about your access to services

**Q.** How do you feel about...

The next few questions are about access to services not use of services

*your teenager's access to treatment?*

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
1	2	3	4	5	6	7	8	9

*your teenagers's access to physiotherapy?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*your teenager's access to speech therapy?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*your teenager's access to occupational therapy?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*you teenager's access to specialised medical or surgical care?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*your ability to get advice from a paediatrician?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

*your access to specialists services available in the community? (e.g. for employment, moving out of home)?*

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

OR  I have never tried to access these services

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

# Access to Services

The next set of questions are about **YOU** and how you feel about your access to services

**Q.** How do you feel about...

your access to respite care?

OR  I have never tried to access respite care  
(please skip the next two questions)

the amount of respite care you receive?

how easy it is to get respite care?

your teenager's access to community services  
and facilities (e.g after-school programs, holiday  
programs, community based groups such as  
Adventures, Scouts and Guides)?

your teenager's access to extra help with learning at  
school?

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
1	2	3	4	5	6	7	8	9

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---



## Now some questions about you...

The next set of questions are about YOU and how you feel about your access to services

**Q.** How happy are you?

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
1	2	3	4	5	6	7	8	9

**Q.** How do you feel about...

your physical health?

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy				
1	2	3	4	5	6	7	8	9

your work situation (paid or unpaid)?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

your family's financial situation?

1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---

The next question has a different response scale ranging from "Not at all confident" to "very confident"

**Q.** How confident are you that you can report how your teenager feels?

Not at all confident								Very confident
1	2	3	4	5	6	7	8	9

Thank you for helping us with our questions

