



CP Respiratory Checklist

A Respiratory Checklist for Children and Young People with Cerebral Palsy

Version for young people aged 12 - < 18 years

This is an interactive risk checklist for children and young people with cerebral palsy. It will help you understand risk factors for respiratory disease.

The questions are based on research conducted in Western Australia between 2011 and 2017. They address significant risk factors for respiratory hospital admissions for children and young people with cerebral palsy.

This checklist takes less than 5 minutes to complete. At the end, it lists the factors that may put you or your child at risk of respiratory disease in the future, and gives general advice designed to empower you to work with health professionals to achieve positive outcomes.

If there are many risk factors, it simply indicates a greater risk of respiratory disease, but this does not mean that it will necessarily develop. Be alert but not alarmed, and remember, knowledge is power.

The checklist is accessible online at www.telethonkids.org.au/cpchecklist

Disclaimer

This risk calculator (**Risk Calculator**) is not a clinical assessment and does not constitute medical or therapeutic advice. It does not replace medical examinations or the advice of a doctor or health professional.

The Risk Calculator cannot predict whether or not an individual will develop a respiratory disease. It identifies an individual's risk factors, based on the information the person completing the Risk Calculator (**User**) provides and on evidence from Western Australian research on people with cerebral palsy aged 1 to 26 years. However, many other factors will also affect an individual's health.

The Risk Calculator is intended to be used only as an informative tool and guide. It does not contain all risk factors for respiratory disease in children and young people with cerebral palsy. The information on this website and in the Risk Calculator should not replace any professional medical advice or lead the User to ignore any professional medical advice.

Ability Centre, Princess Margaret Hospital for Children, and Telethon Kids Institute recommend that the User discuss any medical issues, including the results of the Risk Calculator with their trusted health professional, who can provide individualized advice about prevention and treatment options to consider and clinical assessments that likely will be advisable.

Ability Centre, Princess Margaret Hospital for Children, and Telethon Kids Institute accept no responsibility or liability for any perceived or actual harm or damage to the User, or any other person affected in any way by the completion of the Risk Calculator by the User. The User is solely responsible for their own and their child's health and wellbeing.

The User acknowledges that they are responsible for the disclosure or non-disclosure of the results. Only the User is authorized to disclose the results of the Risk Calculator to any third party. The User understands that the Risk Calculator does not constitute or replace any medical advice, and that they must seek the advice, treatment and support of qualified medical professionals for any medical conditions and symptoms, evident in the past, present or future.

Terms of Use

The Risk Calculator has been developed to help you understand some of the risks to respiratory health that young people with cerebral palsy (CP) sometimes experience. These risks may or may not lead to respiratory disease in the long term.

The risk factors for respiratory disease in CP are very complex and not well understood. Individual outcomes will vary depending on various biological and environmental factors, other medical conditions, and lifestyle choices (e.g., smoking), many of which are beyond the scope of the Risk Calculator. Any person may develop respiratory complications or disease, even those who are low risk. Symptoms experienced are often treatable and can be well-managed, especially when the young person with CP and their family are empowered with information and have the opportunity to work with a multidisciplinary team of health professionals.

Some people with CP are at high risk of experiencing respiratory disease, but never develop it. Other people with CP have few or no identifiable risk factors, but nevertheless develop respiratory illness at some point in their lives. It is therefore important to be alert but not alarmed, and use the results from the Risk Calculator as a point of reference for further investigation by health professionals, where needed.

The Risk Calculator aims to help you to understand more about the risk factors that people with CP may experience through their lives, but it is important to remember that the data inputted is self-reported and not based on a medical examination. Therefore, it should not be used to replace the medical advice, support and treatment provided by a qualified medical professional. If you have any concerns about the risk of developing respiratory disease, please see a qualified medical professional.

We advise that Users who are under 18 either complete the Risk Calculator with their parent or a trusted adult, or discuss the results with their parent or a trusted adult to ensure appropriate action is taken based on the results.

CP Respiratory Checklist

Version for young people aged 12 - < 18 years

1. Name: _____ 2. Date: _____

2. Date of birth: _____ 4. Sex: _____

Medical History

No Yes

5. In the **past 12 months**:

Has your child been admitted to a hospital ward as an inpatient for chest/breathing/respiratory-related issues, or developed these during their hospital stay?

<input type="checkbox"/>	<input type="checkbox"/>
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6. In the **past 12 months**:

Has your child had 2 or more courses of antibiotics for chest/breathing/respiratory-related issues?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Swallowing

No Yes

7. Does your child ever take formula or liquids through a nasogastric or gastrostomy tube?

<input type="checkbox"/>	<input type="checkbox"/>
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8. Does your child require food with modified texture (e.g., soft or puréed)?

<input type="checkbox"/>	<input type="checkbox"/>
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9. Does your child require thickened drinks (or naturally thick drinks)?

<input type="checkbox"/>	<input type="checkbox"/>
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10. Does your child ever cough or choke on their saliva?

<input type="checkbox"/>	<input type="checkbox"/>
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Mealtimes

No Yes

11. Think about your child during the past 3 months. When they are well:
Does your child ever have a gurgly voice during or after eating, drinking or tube feeds?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

12. Think about your child during the past 3 months. When they are well:
Does your child ever wheeze, cough or sneeze during or after eating, drinking or tube feeds?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

13. Think about your child during the **past 3 months**. When they are **well**:
Does your child ever choke during or after eating, drinking or tube feeds?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

Seizures

No Yes

14. Think about your child during the **past 3 months**. When they were **well**:
Did your child have any seizures?

<input type="checkbox"/>	<input type="checkbox"/>
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Please continue to next page.

Gastro-oesophageal reflux disease (GORD)

- | | No | Yes |
|---|--------------------------|--------------------------|
| 15. Has your child ever been diagnosed with gastric reflux? | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Has your child ever had any medications for reflux (e.g., Losec, Somac)? | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Has your child ever had any anti-reflux surgery (e.g., Nissen Fundoplication)? | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Think about your child during the past 3 months . When they are well :
Does your child ever vomit or regurgitate during or after eating, drinking or tube feeds? | <input type="checkbox"/> | <input type="checkbox"/> |

Respiratory symptoms

- | | No | Yes |
|--|--------------------------|--------------------------|
| 19. Think about your child during the past 3 months . When they are well :
Does your child cough every day ? | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. Think about your child during the past 3 months . When they are well :
Does your child sound chesty or phlegmy when breathing every week ? | <input type="checkbox"/> | <input type="checkbox"/> |
| 21. Think about your child during the past 3 months . When they are well :
Does your child sound wheezy when breathing every week ? | <input type="checkbox"/> | <input type="checkbox"/> |

Snoring

- | | No | Yes or not sure |
|--|--------------------------|--------------------------|
| 22. Does your child snore every night ? | <input type="checkbox"/> | <input type="checkbox"/> |

Mobility

23. Please complete the Gross Motor Function Classification System (GMFCS) on the next page.

GMFCS-E&R Family Report Questionnaire:
for Young People Aged 12 - 18 Years

Please read the following and mark **only one box** beside the description that best represents your child's movement abilities.

My child...

Has difficulty sitting on their own and controlling their head and body posture in most positions

and has difficulty achieving any voluntary control of movement

and needs a specially adapted chair to sit comfortably and be transported anywhere

and has to be lifted or hoisted by another person or special equipment to move

Can sit with some pelvic and trunk support but does not stand or walk without significant support

and therefore always relies on wheelchair when outdoors

and can achieve self-mobility using a powered wheelchair

and can crawl or roll to a limited extent to move around indoors

Can stand on their own and only walks using a walking aid (such as a walker, rollator, crutches, canes, etc.)

and finds it difficult to climb stairs, or walk on uneven surfaces without support

and uses a variety of means to move around depending on the circumstances

and prefers to use a wheelchair to travel quickly or over longer distances

Can walk on their own without using walking aids, but needs to hold the handrail when going up or down stairs

and therefore walks in most settings

and often finds it difficult to walk on uneven surfaces, slopes or in crowds

and may occasionally prefer to use a walking aid (such as a cane or crutch) or a wheelchair to travel quickly or over longer distances

Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail

and walks wherever they want to go (including uneven surfaces, slopes or in crowds)

and can run and jump although their speed, balance, and coordination may be limited

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