

# Views on Cerebral Palsy Diagnosis

This is a voluntary research survey. The survey should take 10-15 minutes to complete. Your responses will be collected anonymously. By responding to this survey, you agree to participate. You are under no obligation to participate and can choose to not respond.

**Some people with cerebral palsy have symptoms because of a brain injury that happened around birth or early in life. Others with those same symptoms may get them from a genetic change.**

**We would like to know your views about what it means to carry a cerebral palsy diagnosis and what it means to carry a genetic diagnosis for cerebral palsy symptoms.**

**It is important for us to understand your views on your diagnoses. Our goal is to summarize and share the information gathered from this survey with medical providers to help them better understand your perspectives and optimize how they diagnose cerebral palsy and related disorders.**

**At many points in the survey, text boxes are available for you to share additional thoughts you might have about your responses. We appreciate any information you would be willing to provide. However, the bulk of these text box responses are OPTIONAL.**

**After you complete this survey, you will be able to see a summary of all participants' responses so far. As a reminder, all responses are anonymous.**

Who in your life carries a cerebral palsy diagnosis?

(PLEASE NOTE: this survey is designed for those with a cerebral palsy diagnosis or those who have personal experience caring for someone with a cerebral palsy diagnosis)

- ☐ I do
- ☐ My loved one for whom I am a caregiver or family member
- ☐ Neither of the above

In what year was the person in your life with cerebral palsy born?

- ☐ 2019
- ☐ 2018
- ☐ 2017
- ☐ 2016
- ☐ 2015
- ☐ 2014
- ☐ 2013
- ☐ 2012
- ☐ 2011
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- ☐ 1967
- ☐ 1966
- ☐ 1965
- ☐ 1964
- ☐ 1963
- ☐ 1962
- ☐ 1961
- ☐ 1960
- ☐ Before 1960

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Where does the person in your life with cerebral palsy live?

- ☐ United States
  - ☐ Canada
  - ☐ Other
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In which state or territory?

- ☐ Alabama
- ☐ Alaska
- ☐ Arizona
- ☐ Arkansas
- ☐ California
- ☐ Colorado
- ☐ Connecticut
- ☐ Delaware
- ☐ Florida
- ☐ Georgia
- ☐ Hawaii
- ☐ Idaho
- ☐ Illinois
- ☐ Indiana
- ☐ Iowa
- ☐ Kansas
- ☐ Kentucky
- ☐ Louisiana
- ☐ Maine
- ☐ Maryland
- ☐ Massachusetts
- ☐ Michigan
- ☐ Minnesota
- ☐ Mississippi
- ☐ Missouri
- ☐ Montana
- ☐ Nebraska
- ☐ Nevada
- ☐ New Hampshire
- ☐ New Jersey
- ☐ New Mexico
- ☐ New York
- ☐ North Carolina
- ☐ North Dakota
- ☐ Ohio
- ☐ Oklahoma
- ☐ Oregon
- ☐ Pennsylvania
- ☐ Puerto Rico
- ☐ Rhode Island
- ☐ South Carolina
- ☐ South Dakota
- ☐ Tennessee
- ☐ Texas
- ☐ Utah
- ☐ Vermont
- ☐ Virginia
- ☐ Washington
- ☐ West Virginia
- ☐ Wisconsin
- ☐ Wyoming
- ☐ Other

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In which province or territory?

- ☐ Alberta
- ☐ British Columbia
- ☐ Manitoba
- ☐ New Brunswick
- ☐ Newfoundland and Labrador
- ☐ Northwest Territories
- ☐ Nova Scotia
- ☐ Nunavut
- ☐ Ontario
- ☐ Prince Edward Island
- ☐ Quebec
- ☐ Saskatchewan
- ☐ Yukon

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In which country?

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At what age was the cerebral palsy diagnosis made?

- ☐ < 2 years old
- ☐ 2-5 years old
- ☐ 6-10 years old
- ☐ 11-18 years old
- ☐ >18 years old
- ☐ I don't know

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Who made the cerebral palsy diagnosis?

- ☐ General pediatrician
- ☐ Child neurologist
- ☐ Orthopedist
- ☐ Physical medicine and rehabilitation specialist
- ☐ Developmental pediatrician
- ☐ Adult neurologist
- ☐ Family practice physician
- ☐ Adult medicine physician
- ☐ Physical or occupational therapist
- ☐ I don't know
- ☐ Other

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If you responded "Other", please describe

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In addition to cerebral palsy, what other diagnoses have you or your loved one been given?

- ☐ Periventricular leukomalacia (PVL): brain tissue injury that happens most commonly with premature birth
- ☐ Intraventricular hemorrhage (IVH): brain bleeds that happen most commonly with premature birth
- ☐ Hydrocephalus: build-up of fluid around the brain that can happen after brain bleeds and can require surgical placement of a shunt for fluid drainage
- ☐ Stroke: loss of blood flow to a specific part of the brain
- ☐ Hypoxic-ischemic encephalopathy (HIE): loss of blood flow or oxygen to the whole brain
- ☐ Genetic diagnosis (examples include Down syndrome, Prader-Willi syndrome, single gene changes, and chromosomal deletions and duplications)
- ☐ Brain infection (including meningitis or encephalitis)
- ☐ Autism
- ☐ Attention deficit hyperactivity disorder (ADHD)
- ☐ Epilepsy
- ☐ No other diagnoses
- ☐ I don't know
- ☐ Other

If you responded "I don't know" or "Other", please explain

What is the genetic diagnosis that you or loved one carries?

Has a medical professional told you that any of the diagnoses listed above caused cerebral palsy in you or your loved one?

- ☐ Yes
- ☐ No
- ☐ I don't know

Which diagnosis/diagnoses were described to you as the cause?

Has a medical professional described any OTHER causes of cerebral palsy in you or your loved one?

- ☐ Yes
- ☐ No
- ☐ I don't know

Please describe the other cause(s) explained to you

What, if anything, have medical professionals told you about the cause of cerebral palsy in you or your loved one (select all that apply)?

- ☐ The cause has not been discussed with me
- ☐ The cause is medically unknown
- ☐ I don't know
- ☐ Other

If you responded "I don't know" or "Other", please explain

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Did you find it valuable or would you find it valuable to know the cause of your or your loved one's cerebral palsy?

- ☐ Yes  
☐ No  
☐ I don't know

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Please explain

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If a genetic cause was identified or could be identified for your or your loved one's cerebral palsy symptoms, which diagnosis option do you feel would be best:

- ☐ Being given a genetic diagnosis and NOT a cerebral palsy diagnosis.  
☐ Being given a cerebral palsy diagnosis and NOT a genetic diagnosis  
☐ Being given BOTH a cerebral palsy diagnosis and a genetic diagnosis  
☐ I would be equally comfortable with any of the above diagnosis options  
☐ I don't know  
☐ Other

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Please explain why you chose this response regarding diagnosis options

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Has a medical practitioner ever told you that having a genetic diagnosis means you CANNOT also have cerebral palsy?

- ☐ Yes  
☐ No  
☐ I don't know

What do you feel a cerebral palsy diagnosis, genetic diagnosis, or other diagnosis could provide for you or your loved one (select all items that apply).

If you feel a particular item is provided by all three diagnosis options, please feel free to check only the box labeled "Provided by ALL DIAGNOSES" for that item.

	Cerebral palsy diagnosis	Genetic diagnosis	Other diagnosis	Provided by ALL DIAGNOSES
A way to understand how my or my loved one's symptoms might change over time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A way to explain symptoms to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A way to justify access to therapy services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Access to a community of people with similar experiences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clarity regarding what caused my or my loved one's symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please explain your choice of "I don't know" or "Other"

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**Sometimes, a person's ability to function in the world has an effect on their views about the world. For example, a person's functional abilities might affect their need for therapy services which may in turn affect how they view the need for diagnostic labels.**

**In this FINAL SECTION, we are interested in knowing how the person with cerebral palsy in your life (be it you or your loved one) functions during tasks associated with movement, communication, eating, drinking, and vision.**

**Of note, these questions are designed to help describe the functional abilities of individuals with cerebral palsy who are at least 3 years old.**

Are you comfortable answering questions about the functional abilities of the person in your life with cerebral palsy?

- ☐ Yes  
☐ No

For the questions about function below, please choose the BEST POSSIBLE response, knowing that you may have some uncertainty about choosing between two options.

How does the person in your life with cerebral palsy (either you or your loved one):

Get around?

- ☐ By walking without needing a wall or railing for support  
☐ By walking, sometimes using a wall or railing for support but without needing a hand-held device like a cane or walker  
☐ By walking using a hand-held device like a cane or walker  
☐ By using a powered wheelchair without the help of another person  
☐ By using a wheelchair driven by another person

Use hand-held objects?

- ☐ Holds objects easily and uses them well  
☐ Holds objects but uses them slowly or with some difficulty (like needing to use a table to help hold up the object while using it)  
☐ Holds objects but requires the help of others to use objects  
☐ Holds some objects and uses them sometimes with the help of others  
☐ Does not hold or use objects

Communicate with others (including both giving messages to AND understanding messages from others)?

- ☐ Communicates well with familiar and unfamiliar people  
☐ Communicates slowly with familiar and unfamiliar people  
☐ Communicates with familiar people, but not unfamiliar people  
☐ Sometimes, but not always, communicates with familiar people  
☐ Does not or only rarely communicates with familiar people



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Eat and drink?

- ☐ Eats and drinks all textures and thicknesses safely and well
- ☐ Eats and drinks all textures and thicknesses safely but slowly
- ☐ Safely eats only mashed or pureed foods plus some soft foods that require chewing
- ☐ Safely eats only well-mashed or pureed foods and does not safely eat foods requiring chewing
- ☐ Does not eat or drink safely but may be able to do small tastes of food or drink.

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Use vision?

- ☐ Uses vision well to identify objects
- ☐ Uses vision to identify objects but uses other movements to help with vision (like head turning or eye blinking to make up for problems with eye movements). Does not need objects to be made easier to see in order to identify them.
- ☐ Uses vision to identify objects but needs the object to be made easier to see (like by using bright lights or by putting objects on opposite color backgrounds)
- ☐ Uses vision but needs to also use other senses to identify objects (like feeling the object). Often does not identify objects well.
- ☐ Does not use vision

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Do you have any final thoughts about the contents of this survey or feedback you would like to share?

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