

## THE CEREBRAL PALSY TOOLKIT From Diagnosis to Understanding

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© CP NOW 2015 cover photo https://www.flickr.com/photos/slgc Dear Parents and Family,

The period after you hear about your child or family member's diagnosis feels overwhelming and often scary. This resource has been created with you in mind, by parents of children with CP who have been where you are now, and who want to tell you that **you are not alone**.

You may not know where to begin in the CP Tool Kit or where to find the strength to open the pages before you. **Take your time and know that you do not have to read everything in a day or even a week or even a few months**. Some days you will feel stronger and more prepared to learn than others. The Tool Kit may be used like an encyclopedia, referencing sections as needed, or some of you may find relief by reading it in order from cover to cover. However you decide to approach the Tool Kit, be gentle with yourself and use the information to empower you and your family.

Our cover includes a large picture of a dandelion. Dandelions symbolize positivity, hope and survival, often finding unthinkable ways to emerge through cracks in the sidewalk. I have been fascinated by how the qualities of the dandelion have captured our experience with our daughter whose persistence and resilience have repeatedly surprised us. As we move further from the day when my daughter was diagnosed with cerebral palsy, the playfulness of the dandelion has also been a gentle reminder to simply enjoy each other as mother and daughter, outside of doctor and therapy visits and her diagnosis of cerebral palsy.

I have wanted to pursue this CP Tool Kit project since the day my daughter was diagnosed with cerebral palsy and our family struggled to find the information and support we needed. Our team of passionate and dedicated parents and professionals have worked together to bring you a comprehensive resource about early brain injury/disturbances leading to cerebral palsy. It is our goal to empower you with the knowledge you need to ask important questions, advocate of your child, and strengthen your family.

Sincerely,

. I. L. Shintin

Michele Shusterman Founder and Executive Director of CP NOW



IF YOU ARE READING THIS, someone you love or care for has been diagnosed with cerebral palsy. Cerebral palsy, or "CP" for short, describes a group of movement disorders caused by an injury or disturbance in the early developing brain, and specifically the areas involved with creating movement.

When parents and families get a diagnosis of CP, they often feel confused about what the diagnosis means for their child's future. They wonder what to do to best help their child. Emotional reactions can be strong and decisions can be difficult. **Although the diagnosis of cerebral palsy may feel overwhelming, it does not define or dictate what your loved one's future will look like.** Discoveries in <u>neuroplasticity</u>, and research into the brain's ability to change and recover from injuries like those that cause CP, are offering new insight and hope for the CP community.

The Cerebral Palsy Tool Kit was created to help you sort through some of these emotions and answer your questions and concerns related to CP. It will guide you through the initial diagnosis period, direct you to other helpful resources and provide information to you about the different approaches to treating and managing CP.

The CP Tool Kit Parent Leadership Committee Jennifer Lyman Anna Meenan Lori Poliski Michele Shusterman Christina Youngblood

**DISCLAIMER** Please note that the CP Tool Kit is for educational purposes only. CP NOW does not provide medical or legal advice or services. Rather, CP NOW provides general information about cerebral palsy as a service to the community. The information provided in this Tool Kit is not a recommendation, referral or endorsement of any resource, therapeutic method, or service provider and does not replace the advice of medical, legal or educational professionals. The purpose of the CP Tool Kit is to help you initiate discussions and evaluate evidence with your own professional team. Consult with your medical team about potential risks and benefits for medications, treatments, interventions, and/or programs you wish to consider using for your unique situation. CP NOW has not validated and is not responsible for any information or services provided by third parties. You are urged to use independent judgment and request the most current references and information when considering any resource associated with the provision of services related to cerebral palsy.

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