

THE ADULT CP TOOLKIT

# Navigating Life with Cerebral Palsy



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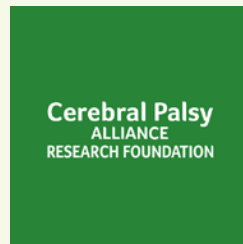
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*The Adult CP Toolkit* is made possible by

Ipsen Pharmaceuticals and Cerebral Palsy Alliance Research Foundation



as well as The Weinberg Family Cerebral Palsy Center at Columbia University



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To my fellow adults with CP:

**I've never known life without cerebral palsy, and neither have you. That's why you're here—and why the Cerebral Palsy Research Network worked hard to put this toolkit together.**

There's lots of information about children with cerebral palsy (CP) out there already, and there's a huge focus on our first years. That's important, and I understand why. But children with CP become adults with CP, and if you're like me, you probably felt frustrated and left behind once you realized there weren't nearly enough resources focused on the many CP-related changes we experience in the decades following our teen years.

**That's what this toolkit is for.**

**It's long for a reason: We're bridging a big gap and there's a lot to cover!** Within these pages, you'll see contributions from CP experts, essays from adults with cerebral palsy, a joint piece from a parent and her adult son, and quotes throughout from adults with CP.

This is meant to be a starting point—a reference guide to send you in the right direction and on your way, a companion to consult when you have a question, and a resource you can turn to when you don't know where else to begin.

This toolkit is here so you know you're not alone—and so you know that there is a caring community of people who want to help you make informed decisions about your life while taking your CP into account. It's a community that's dedicated to finding more answers for adults—one that's focused on education, preventing or delaying CP-related changes, and encouraging wellbeing for everyone with CP.

**It's a community that includes you. Welcome! I'm so glad you're here.**

*Jocelyn Cohen*

Jocelyn Cohen  
Vice President of Programs and Operations  
Cerebral Palsy Alliance Research Foundation



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Welcome.

I am so glad you are here with us.

*The Adult CP Toolkit* is a resource that has been long overdue for adults with cerebral palsy. As the parent of an adult with CP who just turned 18, I am deeply invested in addressing the unmet needs of our community, including access to important health-related information like this resource provides.

**The CP Research Network approaches every project, including this toolkit, with the active participation, insight, and guidance of our community members.** This toolkit is a passionate collaboration of over 50 people, including adults with CP, their family members, clinical and professional experts, and CP health researchers, who came together to provide meaningful and reliable health information and practical insight about living life as an adult with CP. **Our intention is to empower and support you so that your path is easier to navigate and feels a little less lonely.**

As you read through *The Adult CP Toolkit*, we invite you use it in whatever way best supports you. You might choose to access individual topics as needed or read it from cover to cover. Some of you may feel that the health information confirms your experiences of aging with CP. Others may need to take things more slowly, particularly if this information is new to you. Whatever the case may be, know that the more we learn together, the better equipped we will be as a community to address these various concerns and conditions.

Take this information and share it with your healthcare providers or perhaps the one physician in town who listens to you. Connect that physician with our clinician-focused resources to help them stay informed about the state of science and evidence-based treatments for people with CP. Together we will improve the care and treatment of people with CP.

With deep respect and humility,



Michele Shusterman  
Director of Education & Community Engagement  
Parent and Cofounder of the Cerebral Palsy Research Network

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We are grateful to the following individuals who made donations to the CP Research Network to support its development and distribution.

**CHAMPIONS**

Arthur Baines

Daniel Dietrich in memory of Margaret 'Peg' Moul, founder of Margaret E Moul Home

Dr. and Mrs. Edward Hurvitz in honor of the CP Research Network

Robert Luby

Deirdre Mcdowell

Duncan Wyeth in honor of Michele Shusterman

**PATRONS**

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Kimberly Crocker

Lynda McNamara

Harlan Zimmerman in honor of Eric

**FRIENDS**

Libby Calloway

April Charest-Gillis in honor of Anna Taylor

Daniel Dietrich in honor of the residents at Margaret E Moul Home

Susan Hailman

Britt Hernandez in honor of Samuel Hernandez

Dr. Linda Krach

Jacoba Langford

Brittany Lopez in honor of Ethan Lopez

Connor Phillips

Paul Stonchus

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## A Note on the Language Used Throughout the Toolkit

We recognize that people have a wide range of preferences when it comes to language surrounding disability, sexuality, and gender identity, reflecting how they see themselves and wish to be referred to. Throughout this toolkit, we have tried to use language that will feel acceptable even if it isn't your preference. We hope you will feel connected to this groundbreaking body of work and labor of love that we have taken great care to present to you with respect and honor.

—The CP Research Network *The Adult CP Toolkit*  
Leadership Team

## Who Is The Cerebral Palsy Research Network?

The CP Research Network was founded by two parents of adult children with CP. Adults with CP face unique healthcare challenges and changes as they age, and research on adults with CP, in particular related to providing the best medical care, has been lacking for decades. When the organization was established in 2015, one of its main goals was to ensure that research into the care and treatment of adults with CP would be prioritized. As we approach our 10-year anniversary and prepare to launch this resource, we continue to advance research and support wellness programming for adults with cerebral palsy. From developing adult pain surveys together with adults with CP, to collecting information in our registries about your experiences and the care you receive, we remain committed to improving adult care by advancing research that our community members say that they value most.

## Note About Accessibility

Please contact us at [info@cprn.org](mailto:info@cprn.org) to request an alternative format of this resource or, if you have another accessibility need.



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**DISCLAIMER:** Please note that *The Adult CP Toolkit* is for educational purposes only. The Cerebral Palsy Research Network does not provide medical or legal advice or services. Rather, the Cerebral Palsy Research Network and its contributors provide general information about cerebral palsy as a service to the community. The information provided in this toolkit is not a personal 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 Adult CP Toolkit* is to help you initiate discussions and evaluate evidence and expert opinions with your own professional team. Consult with your medical team about potential risks and benefits for medications, treatments, interventions, and/or programs you are considering for your unique situation. The Cerebral Palsy Research Network has not validated and is not responsible for any information or services provided by third parties. You must 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.

In the event that you interact with organizations and/or individuals based on information in this toolkit, including payment and delivery of goods or services, and any other terms, conditions, warranties, or representations associated with such dealings, are solely between you and those organizations and/or individuals. You should investigate these organizations or people as you feel necessary or appropriate before proceeding with any online or offline transaction with them.

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Introduction:

# A Collective Message from Our Community



Image by Krystina Rogers.

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As I sat in my favorite local coffee shop and began to knit together the pieces of our *Adult CP Toolkit*, I noticed something. Although I'd looked at its various sections many times, I realized that our adult contributors had a very strong central message. **They want you to know that one of the best strategies for making your way through life as an adult with CP is to self-advocate. It isn't about how much you know but rather how well you know yourself and are willing to communicate about your needs.**

Let that sink in for a moment, because it's quite a powerful message.

Finding this message felt a bit like discovering buried treasure right under my nose. As a parent of a young woman on the brink of adulthood, I couldn't imagine a greater gift than this very authentic insight. Section after section defined self-advocacy, our adult contributors and clinicians alike emphasizing how it is vital to the topic they discussed.

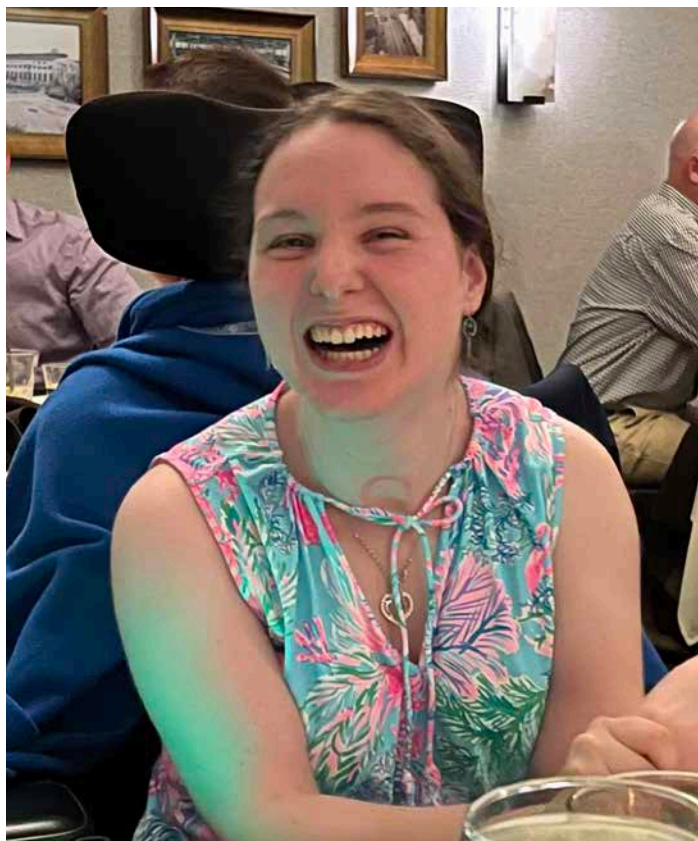


Michele, Co-Founder of the CP Research Network and her daughter Lilly Shusterman.

As my daughter faces adulthood, there are so many things on my mind and on hers, and the prospect of guiding her toward adulthood feels so daunting. But as we both have been processing the next phase of her life, I feel like even if we don't and can't know everything ahead of us, we can prepare her by continuing to lay the foundation for her to understand herself—what she needs and desires, as well as how and where to ask for guidance to navigate life, particularly in its unpredictable moments.

It is our greatest wish that the insight in this *Adult CP Toolkit* from our adults with CP and caregivers, drawn from their lived experience, helps smooth this next phase for you as you navigate adulthood. Our resource captures the voices, wisdom, and sometimes even the pain of our community members, alongside current practical strategies and evidence, and future hopes and directions for a more empowered and brighter future for our adults with CP.

—Michele Shusterman  
Parent and Cofounder, Cerebral Palsy  
Research Network



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## A Note to Families Reading This Resource and the Clinicians Who Support Them

To families caring for a child or other loved one with CP, we see you. *The Adult CP Toolkit* is the first of its kind—the first comprehensive resource for adults with CP, but it’s only a starting point. The Cerebral Palsy Research Network also hopes to create more resources related to adulthood and the period of time leading up to it.

We acknowledge there will likely be parents and teens curious about this resource because information about life with CP as an adult is scarce. If you are reading this from the perspective of a parent, caregiver, or guardian, we hope that this toolkit will help answer some of

your questions related to living life as an adult with CP. **Please keep in mind that as an adult resource it includes some mature content, and there may be aspects of the content that may be processed more easily in sections over time.** We encourage you to consider and determine what feels appropriate for your family by reviewing the resource first for yourself.

We’re building this community together—conversation by conversation, resource by resource. This toolkit is a foundation for discussing adulthood that will grow over time to incorporate more perspectives and experiences of adulthood and the transition period.



Photo by Lana Svet.

Now we turn to the story of one family in our community and what transition looked like for their triplets, two of whom have CP and all of whom transitioned to college in different ways. There are many other stories and experiences related to entering adulthood, including young adults who transition to employment, volunteer experiences, day programs, or different types of community living.

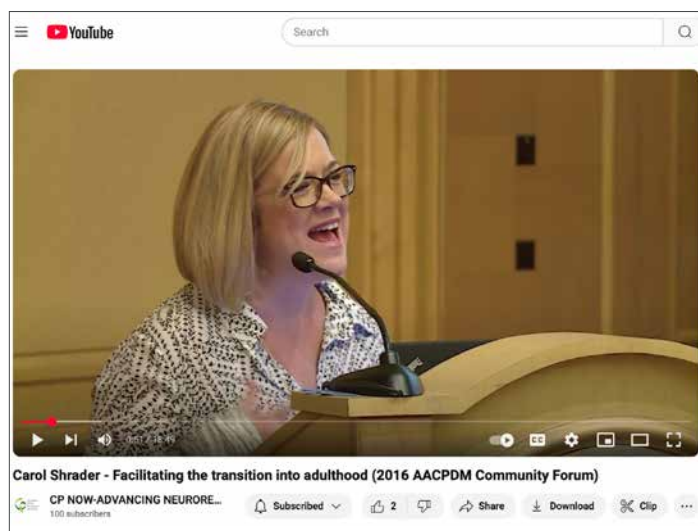
You can participate in discussions with other members of the community in our MyCP community forum: [cprn.org/mycp/forum](https://cprn.org/mycp/forum)

### Meet the Shrader Family: A Family Perspective on Transitioning to Adulthood

The Shrader family triplets, two of whom have CP, transitioned to college at the same time. Their mom, Carol, shares their hiccups, hurdles, and successes as they navigated the transition to adulthood and the changes they experienced along the way in these two pieces:

“Facilitating the Transition into Adulthood,” a talk presented at the 2016 American Academy of Cerebral Palsy & Developmental Medicine Community Forum: [youtu.be/5RXLo8z0fG0](https://youtu.be/5RXLo8z0fG0)

“Preparing for College,” a three-part blog post written for the CP Research Network: [cprn.org/preparing-for-college-a-three-part-series](https://cprn.org/preparing-for-college-a-three-part-series)



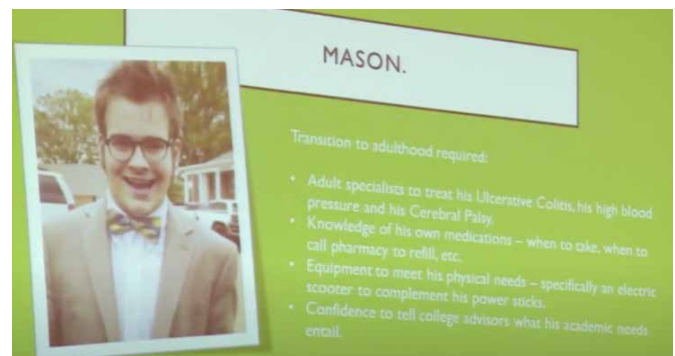
“I am going to tell you that I think the world with my three children in it as adults, and the world with your children [in it] as adults, is a world I want to live in.”

—Carol Shrader, mom of four adults, including two triplets who have CP.

To hear more from Benjamin and Carol, see the section “Hiring and Training Your Personal Caregivers” on page 36.

For more information and insight about transitioning to adult healthcare, check out our section Bridging the Healthcare Transition Gap which begins on page 66.

On the next page we share outlines for Mason and Benjamin Shrader’s transition planning. Creating a list of areas to target can help you organize your thinking and begin to strategize ways of meeting adult related needs.



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# Mason and Benjamin: Two Brothers, Two Different Transition Plans

## MASON

Transition to adulthood required:

- Adult specialists to treat his ulcerative colitis, his high blood pressure, and his cerebral palsy
- Knowledge of his own medications—when to take, when to call pharmacy to refill, etc.
- Equipment to meet his physical needs—specifically an electric scooter to complement his “power sticks”
- Confidence to tell college advisors what his academic needs entailed

## BENJAMIN

Transition to adulthood required:

- Doctors to manage his medical issues and cerebral palsy
- Physical therapists trained in neuromuscular issues willing to see adult
- Personal care attendant to meet his daily living needs
- Equipment to help him navigate his world – power wheelchair, iPad and holder for communicating with friends/family, laptop with voice-recognition software, and chargers for all
- Schedule that he can manage

## Additional Resources

*Transition Support for Families*

Here are a variety of resources to help you prepare for the transition to adulthood.

A video for parents about letting go from Cerebral Palsy Foundation, “Letting Go (At Least a Little Bit)”: [yourcpf.org/expert-videos/letting-go-least-little-bit](http://yourcpf.org/expert-videos/letting-go-least-little-bit)

Got Transition is a comprehensive resource hub about making the transition from pediatrics to adult healthcare: [gottransition.org](http://gottransition.org)

*A Family Toolkit: Pediatric-to-Adult Health Care Transition* from Got Transition can support your family in making the transition to adulthood: [gottransition.org/resource/?hct-family-toolkit](http://gottransition.org/resource/?hct-family-toolkit)

PEAK Parent Center offers low- or no-cost webinars and workshops around transition on a regular basis: [peakparent.org](http://peakparent.org)

The Arc offers transition and future-planning support for people with disabilities: [futureplanning.thearc.org/pages/learn/future-planning-101](http://futureplanning.thearc.org/pages/learn/future-planning-101)

1.

# Transitioning to Adulthood

Discovering Yourself and  
Your Self-Advocacy Voice



Image by Meritt Thomas.

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## How Does Our Community Feel About the Transition to Adulthood?

To anyone on the cusp of adulthood, whether they have CP or not, the word “adult” can feel scary. That’s okay. Transitioning to adulthood is a significant life change, particularly for individuals with cerebral palsy (CP) and their families. It’s okay to feel like this process is a bit daunting or overwhelming. This period presents unique challenges and opportunities that are related to daily living and social and emotional growth. Setting yourself or your loved one up for success means approaching these changes with the right tools, support systems, and resources to establish an identity as an adult and maintain your health and wellbeing.



“The road to adulthood in our household has been bumpy and filled with many emotions. Despite my daughter’s fierce defense of her independence, she told us just two weeks before her 18th birthday that she doesn’t feel ready to be an adult. Over the last two years, she has felt a lot of pressure to keep pace with her peers. I have tried to assure her that despite the fixed timelines she perceives in our society, she can create her own path and timeline for moving through life as an adult. It’s no different from how we approached her childhood, except that now we will gently hand over the reins.”

—Michele, parent and care partner

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## A Teen's Perspective

“I often think about what my life will look like when I am an adult. In some ways I understand that my disability does affect the choices of my life like where I can live and what I need to be successful. I want to be as independent as possible. I don't want to live with my parents—I want to find my own community of people.



Alena Skinner, community member offering sharing her lived experience during the CP Research Network Annual Meeting in 2025.

I would love to live on my own or with a friend. There are times when I worry about being a burden, but I am realizing that I have the ability to take up space in the world and that most people are willing to help me with not a second thought. It is comforting to know that I am not the first person with a disability to function in a world that is not built for people with disabilities! When I created the podcast *I Can Totally Do That*, I was just trying to learn about different careers that people with disabilities have, but I learned so much about how people with disabilities can live and accomplish their goals.

A big skill that I have learned in preparation for the future is advocating for myself and my needs! I feel like I am also pretty creative in just making things work when things are not accessible to me, like holding a door open with my feet so I can go through the door when there isn't an automatic door opener. Because of my ability to advocate for myself I feel like I can feed my adventurous spirit when choosing activities.”

—Alena Skinner, 17-year-old podcast host

In the next essay, Jocelyn Cohen shares her perspective as an adult with CP, offering both personal reflections and practical tips for embarking on the journey to adulthood. We hope the stories presented in this guide provide you with support and guidance as you navigate this challenging—yet exciting—time.

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# Change as a Constant: Tips for Transitioning to Adulthood with Cerebral Palsy

By Jocelyn Cohen



When I was little, I remember feeling like my beloved orthopedic surgeon—my go-to expert for everything cerebral palsy—had all the answers. With warmth and lots of experience, he guided my parents’ decisions about whether I needed more or less physical therapy or occupational therapy; if I should keep, swap, or ditch my leg braces; and if I needed yet another surgery. He always involved me in conversations in ways that made me feel valued and understood, even when I was in kindergarten. I assumed he—or someone—would always be around to answer my CP-related questions.

It was a huge assumption to rest on my then-tiny shoulders, and for more than 30 years, it held true. But when he died, it broke my heart, and I had to process his loss and a change in my lifelong CP care all at the same time. It was overwhelming, and I was also experiencing new pain. But I was too drained to do anything about it.

I needed a break from dealing with my CP, but I realized that was impossible.

I can never stop dealing with CP. It’s a part of me that demands attention, and it always will.

As personal as this is, I’m sharing my experience because I know that having a disability can feel isolating. While our experiences may not be identical, they probably overlap in lots of different ways. I created this list of tips and hope you’ll use the ones that work for you. I also hope you know that there’s a whole community here to help if you need us.



Image by Micheile Henderson.

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As a kid, I thought adults would have all the answers about my cerebral palsy, and that if the ones in my life didn't have them, someone else definitely would. But now that I'm well past my high school years, I know that it takes time, energy, and perseverance to navigate the changes that can happen with CP in adulthood—and that we still have to face unanswered questions about our disability and how it will continue to affect us. That's why I'm sharing some tips and insights with you.

If you are on the cusp of adulthood, just turned 18, or have been an adult for a few years, this advice is for you. If you're a parent or care partner of an adult with cerebral palsy, you should read this for insight on the transition to adulthood for your loved one.

**1 You're the leader now.** This means your life is up to you, whether you make decisions independently or build a team that helps guide your choices. You—and your team, if you have one—make medical decisions and decide what you do for fun, when and where you travel, if you pursue more education, and more.

Medical decisions can be complex, and it's understandable if they intimidate you. You may find it useful to write down questions or concerns before any appointment and to bring a friend or family member with you. As you make these choices, don't be afraid to ask for second opinions and to consult people you trust.

**Throughout this process, remember that you're the only one who knows what it feels like to live in your body.**

When it comes to other decisions, you know what you're capable of, how far you want to push yourself, what you want to learn, how you'd like to explore the world, and what you want to achieve. The path to those accomplishments might zigzag around some bumps and take longer to navigate, but there are many different ways to get there. Share your wants and aspirations with your support network and ask for their assistance if you need it.

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**2 Your relationship with your CP might change.** If you grew up viewing your cerebral palsy one way, be prepared for that to shift. As you get to know yourself more deeply, including the ways your body and mind work together, you may find that you feel differently about your disability. **You may gain a greater understanding of the amount of rest or care you need and be able to more freely share what your boundaries are—and know when you need to adjust them.**

Your feelings about CP may also change from day to day or over periods of time depending on many factors. Accessibility issues at home and in your community, whether you have some friends with CP, the way your parents and care partners have framed your disability throughout your childhood, and the experiences you have throughout the decades of your life can all influence your perspective. Getting to know yourself and understanding the different ways your disability impacts you can help you move through life.

**3 How your CP affects you physically will likely change.** You're used to your CP. Whatever therapies, surgeries, or other interventions you've undergone have gotten you to this point. You know how your CP affects your everyday life—your pain levels, mobility levels, hand function, and more. As you age, though, your body will change—and it will probably happen sooner than you expect. Certain parts of the aging process affect us earlier than people without CP, and while we're not exactly sure why yet, it helps to be prepared for a shift so you can plan for it with your support network and your care team.

The mobility you're used to may decrease. Your stamina for sitting or standing in certain positions may lessen. You might experience more joint, muscle, or nerve pain than when you were a teen or younger adult. You might get tired more quickly.

It's important to remember that everyone experiences cerebral palsy differently, so it's also possible that *only some* or *none* of this will happen to you earlier than your peers without CP. While it may feel daunting, understanding what could happen may also inform the timing of some larger life decisions, including travel and other activities that require more energy.

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**4** **The doctor(s) you see for your CP might change—and that’s hard.** I was fortunate to see the same doctor for my CP until my early 30s. I’d built an enduring relationship with a nurturing person who’d shaped my life, watched me grow, and was one of my biggest supporters.

My original doctor—technically a pediatric orthopedic surgeon—was also comfortable treating adults with cerebral palsy. Not every pediatric doctor is, though, and your doctor(s) may not have the same level of comfort or expertise. You may need to seek out new physicians once you turn 18 or 21, depending on your insurance. If this is the case, hopefully your doctor began speaking with you about this a while ago. If you need more guidance in this area, check out, “Bridging the Healthcare Transition Gap” on page 66.

If you need to find a new doctor, check out the CP Research Network’s online list of their member hospitals and health systems that treat adults with CP at [cprn.org/cerebral-palsy-finding-a-doctor](https://cprn.org/cerebral-palsy-finding-a-doctor).

No matter how much notice you have, this can be a difficult and emotional change to make. Be gentle with yourself and know you’re allowed to feel anything and everything you’re feeling.

If you need to search for a new doctor to treat your CP, remember that it’s a two-way relationship. You have a say in your care, in who treats you, and in how they do so.

**5** **You’re the expert on yourself.** Whether or not the doctor who treats your CP changes when you enter adulthood, you’ll need medical care for other reasons, as everyone does. As you go to appointments with primary care physicians or specialists, remember that you’re the expert on how cerebral palsy affects your daily life, how your body feels, changes you’ve experienced, accommodations you need, and more.

It’s often helpful to call a new doctor’s office before your first visit to explain your access needs and understand how well they can accommodate you. If you need help communicating your needs at any point, you can reach out to a trusted care partner, family member, or friend for assistance. They can ask about the best way to submit questions to the appropriate people, whether that’s an office manager, potential medical provider, or other staff member.

Even though it can be tiring and sometimes frustrating, you’ll likely need to educate people about how your disability affects you and your access needs in nonmedical settings, too.



Scan to  
access  
MyCP

For more on self-advocacy, see “Self-Advocacy in Adulthood” on page 27 and “Self-Advocacy in Healthcare” on page 70.

If it’s challenging or uncomfortable for you to communicate verbally, find a method that works for you to advocate for yourself. This could look like using assistive devices to amplify your voice; working with someone in your support network to create a list, card, or handout that you show others; calling ahead and/or messaging through a patient portal; or another way that works for you.

**6 Find your community.** Whether you meet and socialize with people online, offline, or a combination of both, there’s a place for everyone. MyCP from the CP Research Network ([cprn.org/mycp](https://cprn.org/mycp)) is a valuable community space, especially if you’re looking to connect with people to talk about cerebral palsy. But CP isn’t the only thing about you—far from it!

What interests you? What makes you happy and gives you energy? There’s a group somewhere for each of your interests and passions, so head online and see what you can find locally or virtually.

The most important thing is that you find people you enjoy being around who understand you in some way. It’s one of the best parts of adulthood. Welcome to it!

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# Developing a Disability Identity and Self-Advocacy Voice

## What Is a Disability Identity and How Does It Impact Your Life?

Your disability identity is how you internalize and relate to your disability. Developing a disability identity might include accepting your medical condition, acknowledging your challenges, and understanding your experience of life with CP. There's no one right way to develop a disability identity. It's certainly not a linear process! Your disability identity is only one part of you—you are more than just your CP—but it is real and a significant aspect of who you are. **Developing a sense of self that includes your disability and what it means to you has meaningful benefits for your wellbeing.** As you navigate life as an adult with CP, your disability identity needs to be integrated into your view of yourself.

“I am happy with who I am. I don't need to walk in order to feel good about myself. Being in a wheelchair is all I have known.”

—Lilly, self-advocate

Your identity may change over time. Your early life with CP might focus on medical interventions and learning coping strategies. Adulthood brings new responsibilities and challenges and new opportunities for self-definition. Recognizing and valuing your unique perspective as a person with CP, while also developing a strong sense of your strengths and distinct insights, is essential to seeing yourself beyond societal stereotypes and discrimination, including ableism. Building a broad sense of self is important to navigating the world.

**ABLEISM:** Valuing people with disabilities less than nondisabled people

“Internalized ableism is so hard to overcome partially because those beliefs are so often reinforced in society. It's not just in our heads. It's in our daily lives and experiences . . . and then it gets in our heads.”

—Alice Wong, *Disability Visibility: First-Person Stories from the Twenty-First Century*

“Anyone can become disabled at any time. We are people just like everyone else.”

—Alice Wong, *Disability Visibility: First-Person Stories from the Twenty-First Century*



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It is natural to feel overwhelmed about moving into adulthood, particularly as a disabled adult trying to establish yourself in a society where you face additional barriers to achieving your goals. While there are many resources on how to handle medical aspects of CP, there are far fewer sources of information about how to develop a balanced sense of self that includes your disability identity. Psychotherapy can be helpful in sorting through and understanding these different aspects of who you are and who you are becoming in the context of being an adult. In the talk “How Can We Redefine Disability?,” Tom Shakespeare offers many perspectives on disability and ways people think about it: [youtu.be/tzN\\_tMk4Q8w](https://youtu.be/tzN_tMk4Q8w).

### Developing Your Self-Advocacy Voice

Embracing your disability identity is not just about acknowledging a part of yourself; it's about recognizing the value and perspective your disability brings to your life and to the wider world. Your experiences are powerful.

Advocating for yourself requires understanding what issues matter to you and how you want to take action. Many people, as they unpack their experiences of living with CP, see that prejudice and lack of accessibility are their biggest barriers and begin to focus their advocacy efforts on those areas. **By understanding your needs and rights, you can become a powerful voice for yourself and others.** Everyone has their own style of advocacy—not all of us use a megaphone and that's okay! Developing your own voice and style takes time. It's important to explore what works for you and take risks.

As an adult with cerebral palsy, you will have to fight for your rights as a human, as an adult, and as a person with a disability. Transitioning to adulthood is hard for everyone, whether or not they're disabled. **But having cerebral palsy means you may need to have extra conversations and remind people more often of your capabilities, expertise, and needs.** Sometimes

these conversations can feel uncomfortable or draining. Know that you don't fight your battles alone. Your voice matters, and you have a lot of support from people around you, even if it doesn't always feel that way. Find your allies and reach out to other people even if they don't face the same challenges that you do.

“Advocacy is not just a task for charismatic individuals or high-profile community organizers. Advocacy is for all of us; advocacy is a way of life. It is a natural response to the injustices and inequality in the world.”

—Ki'tay Davidson, social justice advocate

### Types of Self-Advocacy

**“You will have to remind others, regardless of the relationship they have with you, that you have gifts to contribute to the world and you will not accept being dismissed or disrespected.”**

—K Pleasant, Founder and Executive Director, Cerebral Palsy Positive ([cerebralpalsypositive.org](https://cerebralpalsypositive.org))

Speaking or acting on your own behalf to achieve a goal regarding your personal needs is called self-advocacy. Advocacy can take many forms—from personal conversations to political activism. It is a vital part of identity development. At times, self-advocacy is going to be difficult, but it's an important reality of living with a disability to recognize and work on accepting.

Many people will have inaccurate preconceived ideas about your abilities. Do not allow anyone else to tell you what you cannot do. You will have to advocate for yourself or call upon mentors or other resources to help you access what you need to thrive in different environments

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and life experiences. A mentor such as another disabled adult who has already successfully navigated similar issues or a professional counselor may serve a valuable guide.

**TIP:** If you experience lots of stress, movement and exercise are great stress relievers. See “Physical Activity and Exercise” on page 96.

“I once heard the phrase ‘Disability is a full-time job I don’t get paid for,’ and I feel like this captures this experience to the letter.”

—Benjamin Shrader, self-advocate and activist

Here are a few kinds of self-advocacy:

**Professional advocacy** may be required in the workplace or in environments where your professional skill sets are being applied. Professional advocacy is important when people assume without asking that that you are not capable of certain tasks in a business or work capacity. This can be stressful to deal with on a daily basis. Remember that there are also people who will look beyond CP and *know* that you only need an opportunity to shine.

**Personal advocacy** is when you may have to assert what you are capable of to family members, your partner, and acquaintances. Family members may believe that they are “protecting” you without your permission. When you advocate for yourself in different settings and with different people, remind them that you are your own person, and although you appreciate their care and support, you will let them know if you need their assistance.

Acquaintances and others who want the honor of being in your space and businesses that want to earn your patronage will listen to you, respect your wishes, and act accordingly. If you feel that they are not doing so, let them know. Then make a choice to either give them another chance or part ways.



Image by Joe Chen.



**Person-centered advocacy** is when we speak and act in partnership with another person to help them achieve a goal regarding their personal needs. Example: Helping someone arrange reliable transportation to a recurring appointment or event.

**System advocacy** is speaking and acting with multiple individuals to achieve a goal that will benefit many people. Example: Working to have accessible play equipment installed in a neighborhood park or an accessible wheelchair spot created at a local sports or concert venue.

**Legal advocacy** is when we work to ensure that we are given our full rights and protections under federal, state, or local statutes, most often with a state protection and advocacy agency or a disability law center. Example: Pursuing enforcement of designated parking or access to a public facility.

## Additional Resources

The ADA National Network provides information, guidance, and training on how to implement the Americans with Disabilities Act (ADA). Find your regional center at [adata.org/find-your-region](https://adata.org/find-your-region).

*Developing a Disability Identity and Self-Advocacy Voice*

[Disability.gov](https://www.disability.gov) has served as the federal government's website for comprehensive information on disability programs and services nationwide. At the time of publication this site was not operating. We leave it here with the hope that it will return.

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# Self-Advocacy in Adulthood: A Personal Perspective

By Greg Moomjy



Everyone, regardless of whether they have a disability, needs different accommodations and assistance to navigate their daily lives. No two people are affected by CP in the same way, so your self-advocacy will depend on your needs.

I, for instance, use a power chair and need help transferring to the toilet, shower, and bed. Yet I have other friends who also use power chairs who do not. Still other people I know with CP are ambulatory and can even drive.

Yet I can confidently say that as adults with CP, we all share the desire to be as independent as possible, and to make our own choices about our daily life, work, and social lives.

Self-advocacy looks different for everyone, and your strategies or approach may change based on the circumstance and the people involved.

Sometimes self-advocacy is writing a letter to a local newspaper, attending a local government meeting about improving accessibility in your city, or talking to a boss or professor in private. There are so many ways to advocate for yourself and different strategies work for different people.



Image by Chris Kofoed.



It is helpful to have friends and connections in the wider CP community who truly understand our unique situations as individuals with CP and have advocated for themselves as well. It is rare for a person with CP to have someone else in their family with CP, which can feel isolating. So, building a support network of friends and allies that you can count on will provide you with a range of perspectives, experiences, and emotional support as you weather different periods of your life.

### **Creating Connections and Coping with Tough Emotions**

You can learn how to advocate for yourself by looking for examples of self-advocacy from your own community. In my case, a local CP support group has been an invaluable tool to help me learn how to start advocating for myself—whether that be at home with my family or in my medical care.

This group has helped me form long-lasting relationships and great friendships. It includes people I rely on to help me strategize about how to attain my needs, particularly when my family does not understand what I am experiencing. For instance, just recently, I was talking to a friend about strategies for coping with grief—in particular, the problem of being unable to safely express my frustration in a healthy way. **His suggestion to let out my frustration led to me buy a screaming goat button online. And now when I get frustrated, I simply ask one of my aides to bring me the button.** Hearing the screaming goat never fails to make me laugh. I've also taken up boxing. Throwing punches at my aides while they hold the gloves is really therapeutic.

While you likely won't be able to fix everything right away, precisely because your needs and wants will change over time, talking to people and making connections in the community will help you clarify what is most important to tackle at this point in your life, as well as how best to go about it.

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# Additional Resources

## *Self-Advocacy in Adulthood*

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Finally, we are very fortunate to have a wealth of self-advocacy resources in the form of remarkable literature, documentaries, TV, movies, podcasts, and blogs. It has never been easier to keep up with the wider disabled community and to learn from the experiences of others, which you can borrow insight from to hone your own style of self-advocacy. Some of my favorite podcasts are *Disability After Dark* with Andrew Gurza ([andrewgurza.com/podcast](http://andrewgurza.com/podcast)) and *Disability Deep Dive*, which is put out by Disability Rights Florida ([disabilityrightsflorida.org/podcast](http://disabilityrightsflorida.org/podcast)).

Some other helpful resources can be found on the websites of the University of Cincinnati's Center for Excellence in Developmental Disabilities ([ucucedd.org](http://ucucedd.org)) and The Arc ([thearc.org](http://thearc.org)).

Although Can Child ([canchild.ca](http://canchild.ca)) is a pediatric and caregiver-focused resource, their concepts and tools can be used throughout the lifespan because they are important lifelong skills. Their framework of the six "F-words"—Function, Family, Fitness, Friends, Fun, and Future—is an excellent tool to help create balance in your life. Creating more balance in your daily activities and goals will help you in turn create more balance for yourself and your family. Find it at [canchild.ca/en/research-in-practice/f-words-in-childhood-disability](http://canchild.ca/en/research-in-practice/f-words-in-childhood-disability).

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# Finding Your Place in Society and Practical Matters



Image by Richard Loader.

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# Becoming Part of Your Community

Community engagement is a very broad concept that includes all the activities that we participate in with other individuals outside of our home. This interaction with other people can happen when we physically leave our home, or it can occur virtually from home when we connect with others through social media, webinars, and other interactive platforms. Our community engagement can simply involve a leisure activity like shopping, a stroll in the park, dining at a restaurant, going to a movie, or attending a concert, sporting event, art fair, or book signing.

## A Parent's Perspective on Her Daughter's Daily Life

“My daughter Erica is 23 years old. Her high school team helped us a lot with her transition to adulthood. We tried to find her some employment options through our state vocational habilitation agency, but that didn't pan out. She is on a wait list for an adult day program that offers supported employment.

Meanwhile, Erica's life is full and she enjoys her days and her relationships. She goes to a social club three days a week, where members do fun activities on-site and also go out into the community in groups of three or four to places of their choosing. She is in a recreation group that offers activities around Central Ohio. She attends fellowship groups at two different churches in our community. She goes to respite weekends at a camp about an hour from our

home. Her best friend is someone she met at this camp, and they keep in touch on their iPads, follow each other on social media, and share links for music and other mutual interests. Erica also has a boyfriend, and they talk and video chat several times a day.”

—Lynne Fogel, Blacklick, Ohio  
(shared with Erica's permission)



The Fogel family, clockwise from left: Natalie, Jeff, Lynne, and Erica seated in front.

## An Example of Community Engagement

By reading *The Adult CP Toolkit*, you are already engaged with our CP community. We invite and encourage you to expand and deepen your engagement with this community by signing up for the MyCP community portal and participating in future MyCP/CP Research Network activities such as watching our webinars, completing our surveys, and/or expressing your feelings and ideas on our community forum. Visit our website for more information about community activities that may interest you: [cprn.org](http://cprn.org).

## Community and Connection

Finding a community that shares similar experiences can be transformative. Connecting with others who have CP provides not just practical advice but also emotional support and a sense of belonging. It can be fascinating to learn the many ways people with the same diagnosis of CP view and experience the world similarly or differently. This community can be a source of empowerment, helping you to see your identity as a person with CP as an integral and positive aspect of who you are.

“Disability is pain, struggle, brilliance, abundance, and joy. Disability is sociopolitical, cultural, and biological. Being visible and claiming a disabled identity brings risks as much as it brings pride.”

—Alice Wong, *Disability Visibility: First-Person Stories from the Twenty-First Century*

If you’re looking for a welcoming space where you can interact with other disabled adults to form friendships and further understand your own experience, you may find them locally. Some options include Centers for Independent Living, adaptive programs through your community’s parks and recreation organizations, developmental disability councils, formal and informal self-advocacy and disability action support groups, art groups, and disability pride groups.

The broader disability community has created several notable films, including the Academy Award-winning documentary *King Gimp* and the Academy Award-nominated *Crip Camp*, which show people with cerebral palsy and other disabilities exploring and growing their identities, and developing a sense of disability pride.

Our visibility in a public setting helps change public perceptions and attitudes about us and the disability experience.



Source: @PacingPixie on Instagram. Reproduced with permission.

## Community Living

According to Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) presented by the United Nations, people with cerebral palsy and other disabilities have the human right to live in their community. At this time the resources might not exist yet for you to live in your community. Resources vary widely by state and area. Talk to your local Center for Independent Living about what is possible for you.

### Living in the community means living:

- where you choose
- with people you choose
- with the freedom to do what you want when you want to

You can live in the community even if you have an intellectual or learning disability. You can live in the community even if you cannot communicate through speech. You can live in the community even if you need a lot of help or support to do things. You can have **informal** support from family or friends or **formal** support from paid caregivers.

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## Examples of ways you may live in your community:

- Cara lives in the community. She lives in an apartment with a roommate. Her roommate helps her carry heavy things. Cara helps her roommate open packages. They support each other. This is informal support.
- Michael lives in the community. He lives in a house. He has paid caregivers who push him in his manual wheelchair, help him shower, and are there if he needs help at night. This is formal support.
- Kathy lives in the community. She lives with her family. Her parents help transfer her to and from her wheelchair and help her get dressed. But she also has paid caregivers that drive her van, help put her into bed at night, and help her onto the toilet during the day. This is a mix of formal and informal support.

With the right equipment, living space, care partners, and other support, people with significant medical and physical disabilities can live in their communities rather than a care facility. However, whether you can live in your community when you have a disability will depend on the kind of support you need and the availability of resources to support you. Every person has the right to communicate where and how they want to live. Ideally, our local communities will continue to improve the quality and availability of resources to make the wishes of its community members with disabilities possible.

**Centers for Independent Living (CILs)** can help you live in the community. Despite their name, no one actually lives at a CIL. CILs are nonprofit organizations. They are run by and for people with disabilities.

**Here are some examples of ways CILs may be able to help you or your loved one:**

- They can help you apply for Medicaid and other benefits.
- If you're living in an institution and want to get out, they can help you sort out how to move into the community and what resources and support you may need.
- They can also help you stay in the community if you're already living there. They can teach you skills to support you in living in the community.
- Some CILs offer classes to support your daily living skills such as cooking classes.
- Some CILs may provide you with technology to help you do things on your own.
- Your CIL may have equipment loan closets where you can try out wheelchairs and other equipment.
- CILs also engage in advocacy to pass laws and policies that help people live in the community.

One thing that CILs are not able to do is help with legal cases. For instance, if you want to sue someone for discrimination, a CIL can't help with that. However, a CIL can guide you to a place that can help you. This is called "information and referral."

There are CILs all across the United States. To find one near you, go to the National Council on Independent Living's website ([ncil.org](https://www.ncil.org)) and click on "About" and then "Find Your Center for Independent Living."

## Residential Living Options

There are different residential/living options in each state and area, and each state has their own Director of Disabled Services. Head to the National Association of State Directors of Developmental Disabilities Services

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([nasddd.org/state-agencies](https://nasddd.org/state-agencies)) to learn more.

**To help you figure out what's right for you, here are some examples of living situations:**

**Independent Living Services (ILS)** are for adults with developmental disabilities. They offer functional skills training to help you live independently in the community. These homes are not licensed, but they are funded and monitored by regional centers. You'd typically live alone or with a roommate in your own home or apartment. You can work with an agency to help you employ and supervise aides to assist you with your personal needs. Aides may work as little as three times per week for an hour or two, or they could work three to six hours every day. This will depend on your needs.

**Supported Living Services (SLS)** typically require working with an agency to help you find a living space to rent in the community. You can choose a roommate or two, and if you need overnight care, a paid roommate will stay the night. They will provide care and supervision if you're unable to live alone.

People who use SLS typically require a full-time aide to assist with personal care, cooking, cleaning, and other household needs. SLS agencies will work with you to find affordable housing options and financial support, such as Supplemental Security Income (SSI) to help pay for your aide.

**Adult Foster Care (AFC)** may work for you if you have an intellectual disability in addition to your cerebral palsy. With AFC, families host you in their own home and provide a wide variety of care based on your needs. AFC families usually foster one person, and they receive a monthly stipend to help with this care.

**Adult Residential Facilities (ARF)** are group homes licensed by the state to provide services to all people with developmental disabilities.

Depending on their license, homes can serve anywhere from one to more than 15 people. These are typically staff-operated homes, with caregivers who work shifts, and there is 24-hour coverage seven days a week. The homes are required to follow licensing and regional centers' laws and regulations.

**Intermediate Care Facilities, which may be labeled Developmentally Disabled (ICF/DD), Developmentally Disabled–Nursing (ICF/DD-N), and Developmentally Disabled–Habilitative (ICF/DD-H)** typically house six or more residents, and they can be in a home setting or a hospital setting. ICF/DD or ICF/DD-H may be right for you if you need assistance with activities of daily living and self-care, and require 24-hour supervision. ICF/DD-N may be right for you if you have nursing needs, such as G-tubes, injections, and uncontrolled seizure disorders. ICF/DD-Ns have a nurse on staff at least eight hours per day.

**Here are some additional tips for deciding which residential or program options are best for you or your loved one with CP:**

- Explore all of your options with as much lead time as possible because your first-choice home may have a waiting list of a year or more.
- Tour at least three options before deciding on one.
- Ask your friends or acquaintances if they are happy where they live.
- Make sure you ask about transportation, including whether or not a home or facility has a wheelchair-accessible vehicle to transport residents.
- Inquire about how frequently residents go out into the community.
- Ask if the homes you're considering offer an option to try them out for a weekend before making a decision.

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# Hiring and Training Your Personal Caregivers

By Benjamin Shrader and Carol Shrader



Many people with disabilities and their families say that their number one goal is independence. But too often we define independence as simple self-sufficiency rather than what it truly should be—having the autonomy to make your own decisions no matter how many people it takes to make that happen. In our case, the key to autonomy has been finding a good personal care attendant.

There are several ways to cover the cost of personal care assistance, including personal funds, long-term care insurance, Medicaid (which varies by state), Medicare, and state programs for community-based services (e.g., New Jersey’s Jersey Assistance for Community Caregiving).

We recognize that employing a good personal care attendant is easier said than done and offer the following tips and encouragement for casting the widest net to hire your own personal care attendant:

## → Advertise

In college, advertising the position with a flyer, which I posted not just on my campus but nearby colleges, gave me a robust mix of applicants, including friends, young people interested in medical professions, and current professional students looking for experience. Universities with graduate programs may also have nursing schools. Once word got out that the first of my care attendants had been accepted to medical school, I had a waiting list for applicants!

## → Use Social Media

Share your flyer near and far and ask friends to do the same.

My first attendant in college came through a friend who lived 150 miles away but knew someone she thought would be perfect—she was!



### → Explore Local Agencies.

Moving to a new city after college meant I didn't have the previous connections I had enjoyed on campus. My attendants have been provided through a local home healthcare agency. The key to making this work is recognizing that each assignment might not be a good match. I have had to learn to communicate not only with my attendant but with the case supervisor about my likes and dislikes. I have had to learn that my instincts and my comfort level matter. It is OK to not accept everyone the agency sends.

- Some Centers for Independent Living and State Agencies also have funds for hiring and finding personal care assistants.
- Look at websites designed for matching caregivers and care recipients.

Once you have a personal care attendant in place, it is important to focus on training. Even attendants provided through an agency will require training on your personal needs, your personal equipment, and your personal routine.





Through Benjamin's own trials and errors—and a few successes—he offers these tips:

- Be mindful of monotony. This is your daily routine. It is going to feel repetitive to you saying it out loud. Remember, though, this is the first time your attendant has heard it. There is no such thing as overexplaining.
- Be thorough. The seat belt on your wheelchair may seem self-explanatory, but I have learned to make no assumptions when describing my medical equipment.
- Feel free to use your sense of humor to lighten the situation but also recognize that it is not your job to make the attendant comfortable with the role. Do not burden yourself with this if it does not feel natural.
- Involve a parent or prior caregiver who can assist in explaining your daily routine. They will notice things you take for granted and ensure nothing is left to chance.
- Record your care routine. By making a video of the process (a mock process, fully clothed), you can have your attendants watch (and rewatch if necessary) in order to further familiarize themselves with your routine.

Hopefully these tips set you on the path to successfully hiring a team of personal care attendants. It is our fervent wish that the relationships you forge will unlock new levels of true independence and autonomy.

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# Emergency Preparedness

Emergencies come in many forms, including fires, hurricanes, earthquakes, and other natural disasters. Getting seriously sick or injured can also be an emergency. People with disabilities face higher risks in these situations, so getting early warnings and evacuating in time can be lifesaving.

**Emergencies can be scary, but being prepared can help you stay safe.** It's important that you develop emergency action plans for different kinds of emergencies such as natural disasters, but also for health-related events that may require emergency procedures. Designate people to help you and make sure they know where they can reference these documents when needed.

You can find templates and information for gathering and organizing emergency-related information on websites such as [ready.gov](https://www.ready.gov). This public service offers a wide range of emergency planning through both its website and mobile app. Many organizations and nonprofits also provide tools for creating emergency action plans tailored to specific health conditions. For example, the Epilepsy Foundation has a Seizure Action Plan. We include this example because epilepsy impacts approximately 40% of people with CP: [epilepsy.com/preparedness-safety/action-plans](https://www.epilepsy.com/preparedness-safety/action-plans).

“Practice how you’re going to get out of your home. If you’re going to need help, it’s OK. This is about the family getting out safely and alive. It was hard to be carried [out of my home when I am used

to walking independently] but desperate times call for desperate measures. When you practice ahead of time, you can figure out ways to do it yourself. Which is what I was able to do with my parents. Don’t panic. It only makes it worse. Deep breaths and one step at a time.”

—Devin, community member

## Tips for Staying Safe in Emergency Situations

- **Add your information to first responder databases and registries.** Make sure firefighters and other emergency responders such as local police know that there is a disabled person living in your house. You can call your local fire department when you move in to find out what kind of database is in use in your area to track the needs of people with disabilities during an emergency or disaster.
- **The National Public Safety Alliance for Individuals with Disabilities** NPS-AID ([nps-aid.org](https://www.nps-aid.org)) is a national initiative where community members can provide critical information about their or their loved ones’ disabilities. It allows law enforcement and first responders to quickly locate information about those individuals in the event of an emergency or interaction with public officials.

Keep in mind that these are voluntary registries and it's up to you to determine you or your family member's comfort level in self-reporting information.



- Place stickers in your house that tell emergency responders that there is someone disabled living there and where they are likely to be. However, you should weigh this consideration alongside the possibility of signaling your disability to potential intruders.
- Ask if your school or workplace has an evacuation wheelchair or emergency sling. This is a special wheelchair that can go down steps. In an emergency, such as a fire, you will typically need to take the stairs for safety reasons (even if the elevators may be working). If you can't go down stairs or if you move slowly, an evacuation wheelchair or sling could help you get out of the building quickly. Ask your school or workplace who is trained to use this device and how often they are trained. If they don't have an evacuation transport system, ask them to get one for your safety.
- Ask your administrators to clearly mark relevant evacuation routes, specific stairwells to use, and rescue points, and make sure you have the opportunity to safely practice emergency evacuation.
- Buddy systems are also important in these scenarios for supporting people who may lose their access to the equipment or devices that help them negotiate daily living and communication. Make sure you designate a

main buddy and backup buddy for mobility assistance in an emergency. This will also be important if cerebral palsy affects your communication abilities.

- If you have a service animal, ensure that they also understand exit routes and that your school, workplace, roommates, and neighbors know that you have a service animal.
- Always have a list of your medications on hand. You could also have an easily identifiable bag that's prepacked with a few days' worth of medications (be sure to keep medications in date) and any required clothing or equipment, like battery chargers for your assistive technology, a flashlight, phone, or headlamp, and perhaps a small generator, as well as any other personal supplies.
- Consider a medical alert bracelet and create a water-resistant fact sheet that explains your disability needs and includes emergency and medical contacts. You can also use a health app on your phone. Include your medical history and important information such as whether you have a baclofen pump or other metal implants inside your body.
- Make sure doctors and other medical providers (like emergency medical technicians or paramedics) know about all the surgeries you've had. Tell them if you have other conditions in addition to CP, like epilepsy or asthma. This information could change how they treat your illness or injury.
- If you have to take an ambulance to a hospital, it might not be able to take your wheelchair. Ask a family member, friend, or caregiver to keep your wheelchair safe if you have to be separated from it.
- In other emergency situations that require evacuation to a shelter, it's important that any supports—crutches, a walker, a wheelchair, a support animal—should accompany you. Be sure to let anyone helping you know about medications that might require refrigeration. This can be

recorded on a water-resistant fact sheet or a health app on your phone, as mentioned above. Emergency shelters are required to have backup power for medical devices, including power wheelchairs.

→ Keep extra supplies for your service/support animal if you have one in case you have to leave for a shelter.

Stock up on supplies like bottled water, a hygiene kit, or water tablets for emergencies, as well as flashlights, GPS trackers for tracing the location of important items if they get lost, cell phone chargers, and cash. If you use a communication device, program emergency numbers into the device. If you use a power chair, purchase an additional power pack.

Having backup power such as a small generator will help you keep critical items that you rely on frequently charged. If you purchase a generator, make sure you know how to properly operate it ahead of time and that it has enough power to charge the items you need to have on hand.

In some cases, and within a specific period of time during a disaster, a generator and fuel may be reimbursed partially or fully by the Federal Emergency Management Agency (FEMA).

### **A Personal Perspective on Emergency Preparedness**

The following advice was shared by a parent who has been through several fire evacuations with her son who has cerebral palsy. One of her evacuations took place after her son had a surgery and was not able to walk to the car with her. During another evacuation, the terrain from their house to their vehicle was too difficult for him to navigate quickly. Ultimately, she and her family decided to move to a different location in order to decrease the challenges associated with evacuating.

### **These were issues we encountered during evacuations:**

1. The availability of personnel and resources to assist with our evacuation.
2. The urgency of the need to evacuate ASAP and the time it would take for help to reach us were both significant.
3. Not everyone is in a position to carry their adult-size child, significant other, or loved one in a time of emergency. You may want to consider purchasing an emergency sling or evacuation chair to transport yourself or your loved one.

“Be aware that not all adults may be there during an evacuation. Practice evacuation solo runs so there’s a plan in place and an awareness of any issues that may arise. This will allow you time to troubleshoot issues, find alternative ways for evacuating, and determine what goes and what stays.”

—Christina, parent and caregiver



## Evacuation Chairs (Evac Chairs) or Stair Stretchers

If you or your loved one are nonambulatory, consider an evacuation chair or sling depending on your resources. You will also need to take into account the person's ability to position themselves in a stable and upright position. Some state Medicaid waivers will pay for these as part of the plan of care. For people in a designated FEMA recovery area, these may also be reimbursable as medical equipment.

Evacuation chairs are available in both manual and motorized designs. If you or your loved one can't get out of your home without assistance due to steps or terrain, then evacuation chairs, stretchers, and slings can save lives. You can purchase one online or through a large retailer.

There are many different types of evacuation chairs and slings available depending on your or your loved one's needs. Some designs allow for one person to transfer the chair user (depending on everyone's abilities and positioning needs), and there are also two-person transfer devices. Some are foldable and portable and may come with a storage bag for travel. If you aren't sure what to buy, you can ask a therapy professional for more insight. Also, keep in mind the needs of the person or people who may be required to help with emergency transfers.



Example of an evacuation chair.

Photo permission and credit: line2ems.com. We are not affiliated with this retailer, and by sharing photos of their products we are not stating or implying that we recommend them specifically. Please conduct your own research to determine which products best suit your needs. Online user reviews can be a good resource for further information on evacuation chairs.

The top priority is to evacuate safely while minimizing injuries. Equipment can be replaced. People can't.

## Additional Resources

[Ready.gov](https://www.ready.gov) is a government website for emergency preparedness

The US Centers for Disease Control and Prevention provides information on emergency preparedness and disability inclusion: [cdc.gov/disability-emergency-preparedness/about](https://www.cdc.gov/disability-emergency-preparedness/about)

### *Emergency Preparedness*

The World Institute on Disability gives details on emergency and disaster planning, as well as disability inclusiveness and disaster resilience: [wid.org/disaster-services](https://www.wid.org/disaster-services)

The Partnership for Inclusive Disaster Strategies is a hub for disability and disaster-related needs: [disasterstrategies.org](https://www.disasterstrategies.org)

# Preparing for Employment

Securing employment can be a meaningful accomplishment in the life of any adult. Having a job can help you build self-esteem and offer you independence in ways you haven't experienced before, including new financial independence. Before we continue, let's acknowledge that finding the right job can be *hard*. However, persistence often pays off and there are many people and resources available to support you along the way. Sharing your skills and expertise as a volunteer or learning new ones through internships can also be fulfilling and give you opportunities to explore different environments and professions. Over time, building skills as a volunteer or intern may open up new opportunities for you, perhaps paid ones. It may also provide you with structure and routine that support your health and wellbeing.

The following information is provided as a resource and for educational purposes only. We strive for accuracy, but laws change, websites may be removed, and individual needs and circumstances vary.



“One big misconception is that I am not able to follow directions, learn, or be employable. I want to work so I can be independent and get my own apartment”.

—Marcus Stewart, “27 Eye-Opening Quotes from People with Disabilities,” *Good Housekeeping*

There are several factors to think about as you prepare for employment. Getting a job (paid or unpaid), while challenging for everyone, presents additional obstacles for disabled people. Work with your local agencies (like CILs), vocational rehabilitation centers, and mentors to address issues related to securing reliable and accessible transportation, identifying and establishing accommodations for yourself, and to stay motivated and encouraged.

**ACCOMMODATIONS:** Removing obstacles that impede access so a person with disabilities can function and participate in an activity or place.

As we strive for fewer barriers to employment, better hiring practices, and a more inclusive working world, there is also much we can do to set ourselves, or our loved ones, up for success.

Return on Disability is a Canadian company founded by Rich Donovan, an adult who has CP. The organization works to help companies around the globe understand the value and benefits of designing work environments for people with disabilities: [rod-group.com](http://rod-group.com)

## Know Your Rights

Five important federal laws protect individuals with disabilities from discrimination in employment and during the job application process.

- 1. Americans with Disabilities Act (ADA):** A civil rights law that prohibits discrimination against people with disabilities in employment, transportation, and other public services.
- 2. Rehabilitation Act:** A law that, among other things, prohibits employment discrimination against people with disabilities by any business that works with the federal government.
- 3. Workforce Innovation and Opportunity Act:** A law designed to help workers who face challenges in employment, including people with disabilities, with training and protections.
- 4. Vietnam Era Veterans' Readjustment Assistance Act:** A law that requires employers with federal contracts to provide equal opportunities to veterans with disabilities.
- 5. Civil Service Reform Act:** A law that protects people with disabilities in federal employment.

Although many employers and individuals have a basic understanding of the Americans with Disabilities Act, they may be less familiar with other laws. A brief summary of each law, as well as additional information and compliance resources for employers, can be found at the Office of Disability Employment Policy's website: [dol.gov/agencies/odep/publications/fact-sheets/employment-laws-disability-and-discrimination](https://dol.gov/agencies/odep/publications/fact-sheets/employment-laws-disability-and-discrimination).

Given the recent changes in federal Diversity, Equity, Inclusion, and Accessibility (DEIA) participation, you may wish to determine if a potential employer has DEIA plans and services in place.



## Helpful Questions to Ask Yourself Before Your Job Search

### Why do you want a job?

Seeking a job can offer you a sense of fulfillment and independence. Of course, finding and actually securing the right position can be difficult and perhaps a little scary. Still, it is possible. Think about the things that you value most and how you can uniquely contribute to a particular business. You can discuss your ideas with the people closest to you or a vocational rehabilitation counselor. There are often local job readiness resources that you can find by searching the internet for job readiness in your area.

### Related questions about why you may want a job:

- Will the income be important to you or your family?
- Could it affect your disability benefits?
- Are you seeking a place to meet people and socialize?

### What interests you?

Change to O\*NET Resource Center's Interest Profiler ([onetcenter.org/IP.html](https://onetcenter.org/IP.html)) can help you better understand the kinds of activities and occupations you may find interesting.

My Next Move ([mynextmove.org](https://mynextmove.org)) allows you to browse potential careers.

**What kind of accommodations will you need?** How will you be able to perform your job responsibilities? You can access potential resources to support your employment through entities like vocational rehabilitation offices or your state Department of Disability Services (DDS; the name may vary slightly by state).



Vocational rehabilitation may offer the following services:

- Disability benefits counseling—how your employment may affect your benefits
- Resume development
- Job skills training and placement
- Employment accommodations such as assistive technology
- Consultations for improving accessibility in the workplace

Contact your local vocational rehabilitation office to apply at [askearn.org/page/state-vocational-rehabilitation-agencies](https://askearn.org/page/state-vocational-rehabilitation-agencies).

## Writing a Winning Resume and Cover Letter

It's important to recognize and acknowledge that your strengths and experience impact the

workforce positively—use that to your advantage! Your resume presents information about your skills, related experience, and education. It also may list your strengths and accomplishments. Sites like [AskAManager.org](https://www.askamanager.org), as well as local agencies like a vocational rehabilitation office, can help you prepare your resume. Your cover letter should serve as a concise introduction to who you are, your interest in a particular job and company, and why you make a good candidate for addressing the employer's needs.

The “Resume and Employment Guide for People With Disabilities” from Resume Builder—co-written by Jeff Arseneaux, an adult with cerebral palsy—offers information related to building a resume, finding a job, and workplace rights. Access it at [resumebuilder.com/career-center/comprehensive-resume-and-career-guide-for-people-with-disabilities](https://resumebuilder.com/career-center/comprehensive-resume-and-career-guide-for-people-with-disabilities)

## How to Look for a Job

Your approach to job hunting will depend on your preferences, resources, and objectives. It may include looking online (on websites like [LinkedIn.com](https://www.linkedin.com), [Idealist.org](https://www.idealists.org), or others), talking to friends, or working with your local employment office.

1. **Employment databases** allow you to explore employment opportunities and search by location. For example, [Indeed.com](https://www.indeed.com) allows you to search by job title and/or city. They also have resources on resumes, interviewing, pay and salary, and career planning.
2. Your **friends and family** can help you refine your list of personal interests, skills, and knowledge.
3. **Local job fairs and transition events** can introduce you to agencies and organizations that can help you make the transition to adulthood. Contact your local Department of Disability Services (the name may vary slightly in each state), vocational rehabilitation agencies, or local school district to learn about events like this.

DiversityFIRST Jobs ([diversityfirstjobs.com](http://diversityfirstjobs.com)) is an online resource for people seeking jobs and employers interested in a diverse workforce. Employers and recruiters post open positions to find quality employees. Job seekers can post resumes and sign up for email alerts about new job postings for free.

CareerCircle ([careercircle.com](http://careercircle.com)) allows people with disabilities to search for a job that's right for them.



## Interviewing

Before an interview, think about these practical considerations:

**Transportation:** Sort out how you will get to and from work.

**Personal daily needs:** Make a list of your personal care needs and the resources you have to help you address your needs during your workday. You may find it helpful to ask peers with similar needs, consult a job coach through your local vocational rehabilitation agency or Center for Independent Living, or read discussion forums for people with disabilities to help you organize your thinking and identify possible solutions.

**Consider ahead of time what kind of accommodations you know offhand that you may need to be employed.** Know your rights! It is important to communicate with your potential employer during the hiring process about both your qualifications and your need for support. Ask peer mentors or job coaches with experience in this type of conversation to help you determine when it's appropriate for you to have these discussions. Some people choose to wait until after they have been offered a job to discuss their needs for job accommodations.

**You are not legally required to disclose your disability to a potential employer, but you may need to if you require reasonable accommodations for your interview.** Your disability may also be apparent during the interview process, and you may choose to proactively discuss some aspects of your disability. Ultimately, as employees with cerebral palsy prepare to work in places that are predominantly set up for nondisabled people, they must advocate for their needs.

Businesses will have different obligations under the law to provide support for disabled employees. Know that it may take more than one conversation to sort out these issues together. Some work-related accommodations may include installing ramps or improving building and workspace access, modifying work schedules or providing items like a tilted keyboard stand, wheelchair-accessible desk, or perhaps setting up a chair-level filing system.

Title I of the Americans with Disabilities Act requires that employers provide reasonable accommodations to people with disabilities. For more information about this subject, you can visit the US Department of Labor website. There are lots of reliable resources for employers and employees to better understand the obligations and boundaries of

accommodations: [dol.gov/agencies/odep/program-areas/employers/accommodations](https://dol.gov/agencies/odep/program-areas/employers/accommodations).

In addition to the practical considerations we've touched on here, there are many other aspects to preparing for a job interview. A number of resources are available to support you. INCLUDEnyc has valuable tips to help you get started: [includenyc.org/help-center/resources/interview-tips](https://includenyc.org/help-center/resources/interview-tips).

## Addressing Your Work-Related Support Needs

When it comes to identifying and addressing support needs for people to take part in employment, there are many moving parts and a diversity of potential resources to address them. Establishing open communication with your employer and their HR department can help foster a cooperative approach to identifying and implementing accommodations to support you in your work environment. Your Center for Independent Living may assist with workplace assessments and transition planning. These centers can help identify needs and potential solutions throughout the workday. When employers and employees work together with shared goals, innovative solutions often emerge that benefit everyone.

Below are some examples of how accommodations in the workplace can support employees with disabilities:

### Understanding and Addressing Physical Access Issues

A knowledgeable professional—such as a physical therapist, occupational therapist, or vocational rehabilitation consultant—can assess your workplace and make recommendations to help you function more successfully. This includes evaluating your access to the building entrance, your workstation, shared areas like restrooms



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and break rooms, and the exit. Depending on your situation, you may work with a rehabilitation engineer. The Rehabilitation Engineering and Assistive Technology Society of America (RESNA) maintains a database of certified professionals to help you get started: [resna.org](https://resna.org).

Physical access accommodations might include ramps instead of steps, automatic door openers, sufficiently wide doorways, and accessible bathrooms and break rooms. Some accommodations may be relatively simple—like adjusting the height of a desk or enabling accessibility settings on internal software systems.

Keep in mind that some architectural changes—like making restrooms accessible or widening doorways—can be costly for your employer, and they may require self-advocacy. Understanding your rights under the Americans with Disabilities Act (ADA) and consulting mentors, legal professionals, or local agencies like Centers for Independent Living can guide you through these conversations.

### Exploring Assistive Technology in the Workplace

Assistive technology can also be a powerful tool to support your work. Examples include voice

recognition software, screen readers, magnification tools, headphones, and adaptive keyboards. For more details, see “Opening Up Opportunities with Assistive Technology” on page 54.

### Supporting Your Health and Wellbeing at Work

Caring for yourself allows you to do your work more efficiently and feel better while doing it. Be proactive about monitoring changes in your health and function. People with CP may experience early onset arthritis, fatigue, or chronic pain, which can affect job performance. Talk with your healthcare team about symptom management, treatment options, positioning strategies, and assistive technology that can support your best work.

Just like anyone working several hours a day, you should take regular screen breaks, avoid being sedentary when possible, and schedule time for self-care outside of work in whatever way best serves your health.

Establishing work-related accommodations can support your health over time. These may include flexible hours, additional breaks, remote work options, or even a leave of absence when needed.

## Additional Resources

### *Preparing for Employment*

The ADA National Network provides information, guidance, and training on the Americans with Disabilities Act: [adata.org](https://adata.org)

ADA National Network Employment Resource Hub: [adata.org/employment-resource-hub](https://adata.org/employment-resource-hub)

The ADA Guide to Disability Rights Laws: [ada.gov/resources/disability-rights-guide](https://ada.gov/resources/disability-rights-guide)

“Guideposts for Success” from the Office of Disability Employment Policy provides information on what youth need to successfully transition to adult life: [dol.gov/agencies/odep/program-areas/individuals/youth/guide](https://dol.gov/agencies/odep/program-areas/individuals/youth/guide)

Project SEARCH is a one-year school-to-work program to explore employment with support: [projectsearch.us](https://projectsearch.us)

# Volunteering in Your Community

“One of the biggest things that’s so toxic about ableism and capitalism is this idea that our worth is based on our productivity. We are interdependent. We know there’s more to our worth than just whether we’re taxpayers or whether we can work forty or more hours a week.”

—Alice Wong, *Year of the Tiger: An Activist’s Life*

Volunteering is a great way to get to know your community, make friends, and interact with people who have a different perspective. It’s also a great way to work with people who are passionate about the same things you are! There are many different ways to volunteer in your community, and sometimes these opportunities may open up possibilities for paid employment as well.

If you don’t see any volunteer opportunities related to what you love doing, start one! Whether you live somewhere urban, suburban, or rural, you often have contact with agencies, organizations, and informal groups that work to improve the environment; support vulnerable populations such as unhoused people, domestic violence survivors, or people with drug addictions; develop and maintain cultural, recreational, and spiritual programs; and seek to ensure that all people feel they are valued. Most of these entities are nonprofits with few financial resources, and they depend on volunteers like us to achieve their goals.



Keep in mind that volunteers may not receive the same accommodations as regular employees. The Job Accommodation Network offers some insight into the subject of the ADA and volunteers: [askjan.org/publications/consultants-corner/vol04iss02.cfm](https://askjan.org/publications/consultants-corner/vol04iss02.cfm).

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Some volunteer activities can only be done in person, but you can often help virtually or by phone. Many volunteer opportunities exist with programs that have a disability focus, such as:

1. Centers for Independent Living (learn more at [acli.org/programs/aging-and-disability-networks/centers-independent-living](https://acli.org/programs/aging-and-disability-networks/centers-independent-living))
2. Adaptive recreation programs (for example, Move United: [moveunitedsport.org](https://moveunitedsport.org))
3. Local events to raise public disability awareness
4. Your local United Cerebral Palsy affiliate (get connected at [ucp.org](https://ucp.org))
5. The CP Research Network often needs volunteers to support our Community Action Committee or to advance CP research. Some of these opportunities may be paid. Let us know what you may enjoy doing to advance our mission by emailing our leadership team at [info@cprn.org](mailto:info@cprn.org).

## Navigating Your Finances

Many aspects of adulthood with CP require additional spending to accommodate our personal abilities and skills, and to ensure that we live our lives the way we want to. The balance between qualifying for programs and services you need and earning your own money can be tough to manage. With this in mind, it's important for you to identify the personal, local, and national resources you may need to help you navigate finance-related issues.

In many areas, credit unions, school systems, libraries, and disability advocacy organizations, such as Centers for Independent Living ([acli.org/programs/centers-independent-living/list-cils-and-spils](https://acli.org/programs/centers-independent-living/list-cils-and-spils)) offer free or low-cost financial literacy classes that focus on financial planning and management. If it's feasible for you, consider consulting with a financial expert who understands these issues.





## Basic Costs to Consider

Here are some costs to consider as part of your financial planning. You may be eligible for benefits or programs that will help you cover some of these expenses in full or in part.

→ **Transportation:** If you are unable to drive and do not live near accessible public transportation, you may need to rely on rideshare services to be mobile and independent. However, depending upon a variety of factors—distance, traffic, and time of day—the prices vary with each trip. At the local level, public transportation authorities may provide free or discounted fares for paratransit services (also called demand-responsive transport), which provide transportation for people who cannot use fixed-route transportation systems such as a city bus or train.

- **Housing:** Although it is often very expensive, regardless of where you live, you need to ensure that your home is accessible. For instance, if you live in an apartment, look for buildings with multiple elevators so that a mechanical failure will not leave you stranded on your floor or in your lobby. Many volunteer and social service programs work to create housing access for people with disabilities. These include Kiwanis clubs, Boy Scouts or Girl Scouts, 4-H, faith-based groups, and building trades associations like woodworkers' guilds and engineer societies.
- **Healthcare:** You'll likely see more than one specialist or therapist, and you may also undergo outpatient procedures and major surgeries. You may have private insurance through your employer. Or, due to a variety of factors, you may need to rely on Medicaid ([Medicaid.gov](https://www.Medicaid.gov)). Medicaid is subject to a cap, which means that if you earn or receive more than a certain amount, you may lose your benefits. Healthcare access may also mean increased transportation costs.
- **Unexpected expenses:** It's especially important to plan for unexpected medical expenses, as well as other unforeseen expenses that may come up. Mobility aids, for example, can break and require costly maintenance.

## Financial Support Programs

The following benefit and savings programs provide support for people with disabilities. Keep in mind that each program has its own criteria that must be met both to apply and to continue receiving benefits. **Medicaid** or **Medicare** may apply to you for healthcare coverage.

## Medicaid/State Waiver Programs

The home and community-based services (HCBS) waiver program—also called Medicaid waivers—helps people with disabilities stay in their communities instead of moving into long-term care facilities. Each state has its own programs and eligibility criteria. States must get



federal approval to waive certain Medicaid eligibility rules so that more people with disabilities qualify for coverage and services that support independent living. Through these state waiver programs, qualifying individuals may access specialized healthcare coverage and additional benefits such as adult daycare, transportation, and employment services.

Contact your local Department of Disability Services (DDS; note its name may be slightly different in your state) for the most up-to-date information on waiver programs. These programs will vary by state and may have long waiting periods. Your DDS can answer questions about program eligibility and coordinating benefits.

**An ABLÉ account** ([ablenrc.org](http://ablenrc.org)) allows you to save money for disability-related expenses without counting against Medicaid limits. Availability and criteria are different in each state.

**Supplemental Security Income (SSI)** is an important federal financial support program. It offers basic financial assistance for older adults or individuals of any age with a disability who have limited income and resources. Learn more at [ssa.gov/ssi](http://ssa.gov/ssi).

**Social Security Disability Insurance (SSDI)** is federal financial support for a person with a disability (who must meet the Social Security Administration's strict definition of disability) who is unable to work, or whose ability to work is limited. Spouses, ex-spouses, children, and some grandchildren may be eligible for family benefits under SSDI. Work history is typically part of determining the amount someone is eligible to receive, but someone who meets the Social Security Administration's criteria for disability before the age of 22 may be considered for benefits based on a parent's work history. Visit [ssa.gov/disability](http://ssa.gov/disability) for more details.

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The Social Security Administration also has a helpful guide to disability benefits: [ssa.gov/pubs/EN-05-10029.pdf](https://www.ssa.gov/pubs/EN-05-10029.pdf)

The Ticket to Work program ([yourtickettowork.ssa.gov](https://www.yourtickettowork.ssa.gov)) helps people who receive Social Security due to a disability find work and keep their health coverage.

**Special needs trusts**, which are established by your parents, caregivers, or family members, enable you to receive money for disability-related expenses without triggering or affecting income qualifications for state and national programs. These trusts also have amount guidelines, and it's best to consult an attorney to learn more or get started.

**If you're employed**, some of the assistance programs above may still work for you because not all of them have income-related qualifications. Below are some potential sources of financial planning and support through your employer.

- Investigate your employer-sponsored healthcare benefits to understand what plan offers the best coverage for your needs, including prescriptions and physical therapy.
- Take advantage of company-sponsored retirement plans, employee matching, and other offerings like stock options.
- Treat any bonus you receive as an opportunity to save or invest.
- If your employer offers any courses on managing personal finances, use the opportunity to help you plan for your financial needs.

## Additional Resources

*Navigating Your Finances*

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The National Disability Institute is a non-profit dedicated to financial literacy and empowerment for people with disabilities: [nationaldisabilityinstitute.org](https://www.nationaldisabilityinstitute.org)

The Arc offers free financial planning resources: [thearc.org/financial-planning-resources](https://www.thearc.org/financial-planning-resources)

3.

# Opening Up Opportunities with Assistive Technology



Image by Melissa Askew.

# Unleashing Possibilities: A Guide to Adaptive Equipment for Adults with Cerebral Palsy

## What is Assistive Technology?

Assistive technology (AT) refers to an object, piece of equipment, software, or other technology that helps people with disabilities access the world and manage their daily activities and personal needs. Not all assistive technology looks like R2-D2. This technology or adaptive equipment often provides more independence and opportunities for education, employment, recreation, and daily living activities. Using AT may also contribute to a positive sense of health and wellbeing.

It's common for people with CP to use more than one piece of assistive technology, which can include mobility equipment, daily living equipment, and positioning equipment.



“I think the line between technology and assistive technology is really blurry, right? Everybody who has an iPhone can use Siri, and Siri is a form of assistive technology for a lot of people with disabilities. . . . When more people think of [AT] as a standard feature, it could only help everyone.”

—Alice Wong, *Disability Visibility: First-Person Stories from the Twenty-First Century*

## A Few Types of AT and Examples

- **Mobility equipment:** walkers, gait trainers, wheelchairs
- **Daily living equipment:** bidets, toilet/shower chairs, adaptive eating utensils
- **Positioning equipment:** support pillows, seat and back cushions, standers
- **Communication technology:** speech-to-text software, augmentative and alternative communication (AAC)

Assistive devices can be categorized as high-tech (e.g., power chairs) or low-tech (magnifiers or large-print books), as well as software (screen readers) or hardware (canes, crutches, wheelchairs).

## A Note on Financing AT

The Assistive Technology Act (AT Act) of 2004 is a federal law designed to maximize people with disabilities' ability to select, access, and use assistive technology. **It requires each state to provide programming and resources that connect people with disabilities to the technology they need to thrive in their communities.** The law also ensures that individuals with disabilities and their advocates are included in the design of AT programs and services in their communities through advisory councils.

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The National Assistive Technology Act Technical Assistance and Training (AT3) Center has a state-by-state directory of AT Act programs and their personnel: [at3center.net/state-at-programs](https://at3center.net/state-at-programs).

People with disabilities may apply for funding for AT purchases through the **Assistive Technology (AT) Alternative Financing Program (AFP)**. Through this program, some (but not all) states may offer low-interest revolving loans for people with disabilities to purchase adaptive technology.

Find out how to contact your state loan program through the Center for Assistive Technology Act Data Assistance at [catada.info/state](https://catada.info/state).



### Where Can You Get Assistive Technology?

While some adaptive equipment is basic and inexpensive, other items come with a hefty price tag. They may also require long waiting periods for costly repairs and may wear down over time. Test out any device before committing to a major investment. You can ask about trying out a device from product dealers, local agencies, and perhaps state AT reuse programs.

As a child, you and/or your family may have worked with therapists to get equipment from a variety of sources. As an adult, you may work directly with wheelchair vendors, and getting insurance companies or agencies to pay for necessary equipment can be more challenging because coverage tends to be more limited. For instance, in many states, securing funding for gait trainers or standing frames for adults can be particularly difficult.

- Depending on availability, you can purchase items that are not covered and other assistive technology from **medical equipment websites**. These may require a referral from a physician and/or a seating evaluation.
- If you're a college student, **your school's disability services** team may be able to help you access certain assistive devices.
- **Medicare or state health insurance** can cover select assistive technology.
- **State programs** established through the AT Act of 2004 (see the last section) may help you access AT.
- **Centers for Independent Living (CILs)** may also help you access the technology you need. Your local **Department of Rehabilitation Services** or **vocational rehabilitation center** may also be able to help.
- **Adaptive equipment recycling centers** buy, refurbish, and sell equipment (see the next section for more on used equipment).

### How Can You Pay for Equipment as an Adult?

After you turn 18, you'll likely have fewer options for equipment coverage, and by 21, even if you are covered under someone else's plan until 26, your choices will be even more limited. This is why it's crucial to apply for services through **adult service agencies**.

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Adult service agencies may have waiting lists that will delay your access. Therapists often recommend ordering and starting the approval process for major pieces of equipment, like wheelchairs and communication devices, around your 20th birthday to ensure they will be approved and delivered before you lose access to funding.

Most insurance providers will cover one piece of mobility equipment for adults every five years. They will typically pay for the most inexpensive equipment that you can safely use to get around your home and engage in your daily activities. If you need additional mobility equipment, you may have to find other sources to cover the cost, such as support from a nonprofit organization or personal funds.

If you're in school, working, or want to work but are limited by an inaccessible work environment, you may qualify for vocational rehabilitation services to cover the cost of the adaptive equipment you need for school or work. For example, if you use a walker to complete your daily activities at home, your insurance company will cover its cost. If you need a wheelchair to do your job, a vocational rehabilitation program may fully or partially cover its cost. **If inaccessible work environments keep you from pursuing employment, vocational rehab may help determine what adaptive equipment and physical adaptations you need to be successful in a potential work environment.**

If you work and receive financial support from a developmental disabilities (DD) Medicaid waiver, ask about working with a job coach, therapist,



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or someone on your team who can evaluate the environment and make recommendations for equipment or changes to allow you to work safely. For more on workplace assessments, see page 47.

### **Purchasing Used Equipment**

Because new adaptive equipment can take so much time, energy, and money to get, people often purchase used equipment. If you see an item that you are interested in purchasing, discuss its appropriateness with a therapy professional who understands your support needs. It's also important to know whether the equipment has been evaluated by a reliable professional who can assess the fit and function of used equipment and any safety issues that may need to be addressed prior to use.

You'll likely be responsible for repairs to any used equipment you purchase. Some states have open or application-based equipment reutilization or exchange programs that sanitize and refurbish donated items, work with vendors to repair equipment when necessary, and reassign the equipment to someone who needs it.

There are also device exchange programs to connect people who have equipment they no longer use with those who need similar equipment. Equipment on these exchanges is available either for free or at a lower cost.

Adaptive technology can enhance your mobility and communication abilities, enable you to perform many tasks and engage in social interactions, and ultimately help you reach your personal goals.

## **Additional Resources**

### *Assistive Technology*

The National Assistive Technology Act Technical Assistance and Training (AT3) Center lists AT Act program offices by state and US territory. It also offers educational events, publications, and other resources about acquiring and maintaining AT: [at3center.net/state-at-programs](https://at3center.net/state-at-programs)

The ADA National Network provides information regarding funding assistance for the purchase of assistive devices, ramps, and other equipment and home improvements for people with disabilities: [adata.org/faq/what-funding-assistance-available-in-dividuals-disabilities-purchase-assistive-devices-ramps-etc](https://adata.org/faq/what-funding-assistance-available-in-dividuals-disabilities-purchase-assistive-devices-ramps-etc)

Assistive Technology Blog talks about various technologies, devices, and software, as well as issues related to disability: [assistivetechologyblog.com](https://assistivetechologyblog.com)

AT Today is a British news site about assistive technology: [attoday.co.uk](https://attoday.co.uk)

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# How Using Assistive Technology Impacts My Life: A Personal Perspective

By Fayza Jaleel



As a fourth-year college student, I want to share my perspective on and experience with assistive technology. The obvious devices that I use daily are my crutches and scooter. I have used crutches since I was eight years old, and I use a scooter to get around areas I would have trouble getting to independently with my crutches, or places that are clearly too far for me to walk. I also bring my scooter to lab classes and the dining halls at college so that I can carry things and free up my hands without the added assistance of a stool.

I find the scooter to be beneficial for me. Being less reliant on campus transportation is nice, and going long distances with friends and being able to go to things that take place at night is great, too. However, there's a trade-off, because I am more reliant on functioning elevators and doors being accessible on public transportation—and sometimes they aren't. When there is an elevator malfunction, I either have to reroute or rely on some very good able-bodied friends for help. Sometimes I need help and people assume I don't, and sometimes I don't need help and people assume I do. I don't like when people don't ask if I need help before helping me.

Prior to using my scooter, I'd use a stool and my crutches in lab classes, and that process would be more difficult. It was not easy to get a stool that fit lab specifications and that I could sit on for a three-hour lab period.



Image by Michael Yantis.

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I also use braces, although fitting my braces in my shoes takes more time than going without, and I'm not particularly efficient at it. It's easier to put my braces on over my pant legs, but it is also more visible, and I don't like how they look. I choose to wear them when I'm not rushing off to class and have the time, which has flipped from when I used to wear them when I was younger. I think I've found them most helpful for conserving energy when I'm walking long distances or during midterm and final exams when I am a bit more stressed.

There are certain brands of shoes that make wearing braces easier, and I think my shoes are generally a size up and wider than they'd be without braces, which helps with getting them on. I also use a shower chair to shower, and I use dictation software when I am typing up multiple long papers—even though I prefer typing—because it takes me too much time to type a long paper out by hand. I also use Zoom with captioning to take notes.

Because of how broad assistive technology is, there are even more pieces of technology that I use, but these are the main ones that I use on a daily basis.

*Update from FJ:* I now use a wheelchair that elevates when I'm in a clinical setting because it allows me to maneuver around more easily.

# Assistive Tech on the Horizon

## A Note From Remarkable

The Remarkable US Accelerator program, part of Cerebral Palsy Alliance Research Foundation (CPARF), aims to support entrepreneurs who are building life-changing *and* affordable assistive technology that makes the lives of people with disabilities better. Given the varied nature of CP, it's hard to share every potentially helpful option for AT here, so we invite you to connect with us through our website, [remarkable.org](https://remarkable.org), where we highlight the startups that have worked with us.



If you'd like to help us with our Remarkable program, please reach out to CPARF at [remarkable.org/contact](https://remarkable.org/contact).

Working with earlier-stage companies allows people with CP and other disabilities to be a part of the design process, and we love to bring people with disabilities in to meet with our startups, or newly emerging companies, at all stages to help them understand and serve your needs and desires. Given that many innovations in the CP space are focused on pediatrics, getting the input of adults with CP early on can really widen access for everyone.

Looking up the vendors at different conferences is generally a good way to learn about new innovations. Below is information about a trade show dedicated to showcasing disability products, as well as conferences with vendor halls whose conference programs are usually available online.

The Abilities Expo ([abilities.com](https://abilities.com)) is an accessibility trade show where you can check out various assistive tech options. They host events in seven locations every year, so there may be one near you. If traveling or attending somewhere in person is challenging, they also have an online marketplace, and you can see the vendors for each location on their website.

## AT CONFERENCES

Assistive Technology Industry Association: [atia.org](https://atia.org)

CSUN Assistive Technology Conference: [csun.edu/cod/conference](https://csun.edu/cod/conference)



An adult with lived experience discusses cerebral palsy study with Mary Gannotti, PT, PhD and adult CP clinician researcher.



Image by Georg Krause.

## Additional Resources

*Assistive Tech on the Horizon*

M-Enabling: [m-enabling.com](http://m-enabling.com)

The AARP has a startup directory as part of their AgeTech Collaborative, and you can search their database of companies based on filters such as mobility and health: [home.agetechcollaborative.org/startup/directory](http://home.agetechcollaborative.org/startup/directory)

*USA Today* has a column called Reviewed, which reviews accessibility products: [reviewed.com/accessibility](http://reviewed.com/accessibility)

Finally, All Access Life ([allaccesslife.org](http://allaccesslife.org)) is a nonprofit begun by an adult with CP and his aide. They created a website that showcases the latest trends and movements in adaptive products and assistive technologies.

4.

# Health Topics for Adults with Cerebral Palsy



Image by Yoksel Zok.

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# Bridging the Healthcare Transition Gap

While many children, teens, and young adults with CP are seen by pediatric healthcare providers, entering or transitioning to adult-based healthcare as a young adult is important. This is because adults with CP have different needs than children with CP, and adult healthcare providers receive different training than pediatric providers. While transitioning to adult-based care and leaving long-standing relationships with pediatric providers can be overwhelming and even scary, there are steps you can take to help make this transition process smooth and thoughtful.

## Getting Ready for Transition

Ideally, discussions around the transition to adult healthcare will start very early—at around 12 to 14 years old! It's OK if you started later—most people do. Don't hesitate to start the discussion about transition with your medical providers if they haven't yet brought it up with you.

Your healthcare transition begins with a discussion with your pediatric provider(s) about their clinic's transition policy, if they have one. Ask about the age at which they stop caring for patients and how they handle the transition of information to the next set of providers. It's important to talk about timing and how your pediatric provider can support this transition. For example, can they provide specific recommendations for adult clinicians in their specialty?

As you're getting ready to transition to adult healthcare, it's helpful to create a medical summary with your pediatric care team. This is a document that you and your pediatric providers create. It contains important information that an adult provider should know. Consider asking your pediatrician for a specific visit focused on completing this together.

It includes things like:

- Your medications and allergies, including medications you've tried in the past that were ineffective or had bad side effects.
- Your medical and surgical history.
- Your functional and neurological baseline. This means what you're able to do when you're at your healthiest. It includes things like how you move (walk with or without assistance, use a wheelchair, etc.), how you communicate, and how easily you're able to use your hands.
- Any baseline X-rays or other scans.
- Who your pediatric team members are.
- Common emergency issues with suggested tests and treatment considerations. For example, when your spasticity worsens, are urinary tract infections a common culprit?

The Got Transition Medical Summary and Emergency Care Plan can help you prepare an updated medical summary for emergency planning: [gottransition.org/6ce/?leaving-medical-summary-emergency-plan](https://gottransition.org/6ce/?leaving-medical-summary-emergency-plan)

For more information about preparing for emergencies, see page 39.



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## Addressing Adult Concerns: Unique Aspects of Adult Care

In the pediatric healthcare setting, parents or caregivers make decisions for their child. But in the adult setting, the decision-making often starts with *you*. You'll have to make choices about what doctors you'll see and how often you visit them. A **primary care physician (PCP)** can help you manage your overall health and determine which specialists you may need to see.

**SPECIALIST:** A healthcare provider who focuses on a specific area of medicine

**There are not enough PCPs or specialists who are knowledgeable about providing care to adults with CP.** Many think responses such as “It’s hard to say” or “You have CP, and that’s just the way it is” are acceptable answers when you’re seeking support in addressing a health issue. Sometimes you may feel that you know more about CP than some of your clinicians (and sometimes you’d be right)! You may need to find providers who are more knowledgeable about CP or willing to learn about caring for adults with CP.

“I wish [my PCP] realized that every issue can’t be blamed on CP and to trust that I recognize when something is different with my body.”

—K Pleasant, Founder and Executive Director, Cerebral Palsy Positive ([cerebralpalsypositive.org](http://cerebralpalsypositive.org))

In some unique cases, one of your specialists (e.g., a physiatrist, physical therapist, or orthopedic surgeon) may offer to coordinate and manage your care in the way a primary care physician typically does. It’s important to still have a PCP for more routine things like blood pressure checks and flu shots.



The conditions that cause cerebral palsy often impact more than just the parts of the brain responsible for movement. As a person with CP, you will have your own set of health conditions and symptoms that may be very different from those of another person with CP. These need to be taken into consideration when discussing treatments and potential impacts as you age.

**It is important to take your time with treatment decisions.** As you hear about treatments for cerebral palsy, make sure you consider the specific symptoms you wish to address as well as your goals, and discuss what treatments are most promising to target these issues with your medical care team.

The amount of information and evidence about whether a treatment is associated with achieving certain goals for people with cerebral palsy—like improving functional movement, increasing walking speed, or reducing pain—can vary. It’s important to understand what is or is not known when making treatment decisions as well as the quality of the evidence.

Make sure that you and your providers are clear on how you hope a treatment will help you. This ensures that everyone understands what concerns you are targeting and that the treatments can be chosen to best match your particular needs.

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# The Treatment Decision Checklist

This list is designed to help get you started with your treatment decision-making process. Ultimately, you have to determine your comfort level in pursuing any treatment, whether it is established and widely researched or a new, experimental, or “off-label” treatment. These are highly personal decisions, but hopefully the following considerations will empower and encourage you to have more in-depth discussions with your professional care team and family.



Image by Jakub Žerdzicki.

- 1 Has the treatment been studied in people with CP?** The best evidence is based on studies of people of the same age range and diagnosis, with similar motor function or abilities, and derived from sound scientific research that is published in peer-reviewed journals (where peer experts review the articles included in a journal and determine their quality and the scientific merit before they are published).
- 2 Has the treatment been evaluated on people or just animals?** A treatment that works on animals may or may not work on humans.
- 3 Is the evidence based on a treatment that is clearly defined?** What does the treatment claim to do, and will this accomplish the goals you have in mind? What evidence is there to show that the treatment makes a difference for those specific goals?
- 4 Has the treatment been tried on a reasonable number of people?** Things that work on one, two, or a handful of people could have happened by chance or for unrecognized reasons that won't apply to others.
- 5 In studies, was the treatment group of CP patients compared to a similar group of CP patients who did not get the treatment (control group)?**
- 6 Could the evidence about a treatment really just be a “placebo effect”?** This is when people think they are better just because they expect to be better and not because of any real effect of the treatment. The placebo effect is not necessarily a bad thing, and it's quite powerful. However, it is important to consider whether positive outcomes from a treatment are stronger than a placebo effect.
- 7 What costs are associated with the treatment and is it affordable?** Give this serious consideration, as new treatments, especially those sold on the internet, may be expensive and have hidden costs. Are there other, cheaper, or more conventional treatment options that are just as effective? Insurance companies are understandably wary of paying for treatments whose benefits are not scientifically substantiated.

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**8 What is the cost in terms of time?** Consider the amount of time required to participate in the treatment and decide whether your time may be better spent in other ways. Some programs may be impractical when you consider the impact on your work, study, travel, relationships, and other valued aspects of your life.

**9 What are the treatment's expected benefits for a person with CP?** Are the goals realistic? How will you evaluate these goals? Will you compare the effects before and after the treatment? And what is the time frame that you will use to evaluate these goals to determine if the treatment is helpful and still worth your time and money? Keep in mind that no known reputable treatment is appropriate for and works on

100% of people. Be wary of any treatment that claims it is effective for all people with CP. Approach new treatments cautiously and with hopeful skepticism. If a treatment has a negative impact on your quality of life, you should seriously consider whether and why you wish to continue it.

**10 Do your healthcare providers have a clear understanding of your baseline of function and symptoms before starting your new treatment?** This understanding will support later evaluations and discussions about how well a treatment is working for you. It also will help with evaluating the severity of any side effects or worsening of symptoms that you had prior to the treatment.



Image by Odin Aerni.

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# Self-Advocacy in Healthcare

“My PCP has worked harder than anyone to study the medical journals and try to understand my situation with CP, but still it is all too clear that, though he indeed tries, he does not feel the experience that I have with actually dealing with CP.”

—John Borland, CP Research Network community research partner

Your voice is an integral part of your healthcare and the treatment you receive. We now turn to self-advocacy in healthcare settings, which is about making sure you have access to the information, health screenings, and healthcare facilities that you need to maintain your health and wellness. By advocating for yourself and participating in your healthcare communications across providers, you can improve your health outcomes and ensure that your goals are being adequately considered.



You can practice self-advocacy by expressing your needs, strengths, and challenges, and sharing your preferences with your healthcare providers. Clinicians report that **adults with CP who work side by side with their treatment team to identify and plan for their needs enjoy a higher quality of life.** For all people, with and without CP, being seen and heard builds self-esteem and self-fulfillment.

“Yes, I struggle with digestive issues, such as acid reflux that impacts all aspects of my life, from social functions to sleep. Recently I had tests run at the adult hospital. From the moment I rolled in and the admissions desk clerk asked my mother my name—I was treated as a child.”

—Benjamin Shrader, self-advocate and activist

“I’m not thrilled about [changes in my muscle and bone health] because I believe some of it could’ve been avoided had the medical community listened or realized that their standard diagnostic process may not work with someone with CP.”

—K Pleasant, Founder and Executive Director, Cerebral Palsy Positive ([cerebralpalsypositive.org](http://cerebralpalsypositive.org))



Image by Alexandr Hovhannisyanyan.

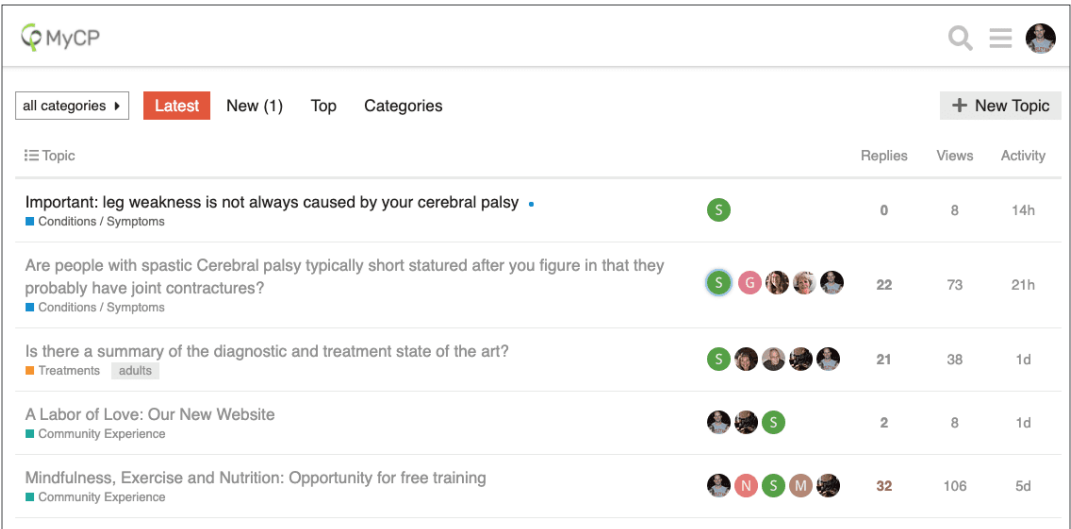
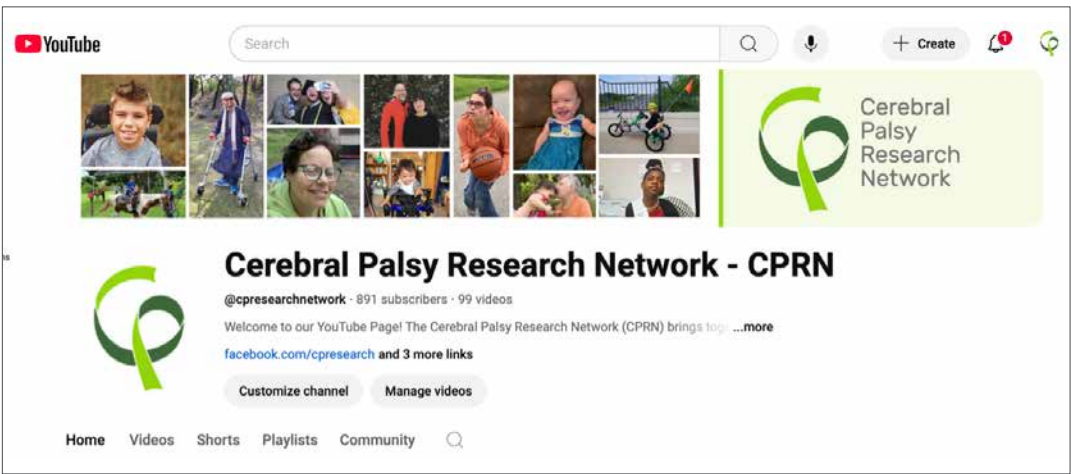
## Tips for Managing Your Own Healthcare

Here are some insights to help you stay organized and equipped to advocate for yourself or your loved one:

- **Educate your healthcare team:** Have a primary care physician, physiatrist, physical therapist, and/or speech therapist on your side. Health professional allies will help you self-advocate and educate the other medical professionals you encounter.
- **Track your records:** Find a way to keep track of your medical records and tests. Electronic medical record platforms such as MyChart ([mychart.org](https://mychart.org)) can help you stay organized. Reach out to your providers' support staff for access if you don't already use this feature.
- **Reference official health screenings:** See the American Academy of Family Physicians' guidelines for adult preventive screenings for the general population and discuss them with your providers ([aafp.org/family-physician/patient-care/clinical-recommendations/aafp-cps.html](https://aafp.org/family-physician/patient-care/clinical-recommendations/aafp-cps.html)).
- **Care coordination services:** Care coordination teams, offered by state programs or private providers, help you navigate healthcare systems and access resources to support your health and wellbeing. These teams can schedule specialist referrals, support communication among your providers, and help talk through your healthcare concerns. They may also support your transition to adult healthcare systems. Care coordination services are usually free and offered by states and private insurance carriers to people with chronic health conditions or complex care needs. Ask about eligibility criteria since definitions of these terms and access to programs may differ. Services vary by location and program, so ask for program details.
- **Share this toolkit with your providers.** They can get their own copy on the CP Research Network website at [cprn.org/our-toolkits](https://cprn.org/our-toolkits).
- **Share resources about CP:** Tell your providers about places where they can access information about people with CP, including our website [CPRN.org](https://CPRN.org), [AACPDm.org](https://AACPDm.org), [CPARF.org](https://CPARF.org), [UCP.org](https://UCP.org), and [CPresource.org](https://CPresource.org).
- **The American Academy for Cerebral Palsy and Developmental Medicine (AACPDm)** is a professional society for providers and other professionals who care for and support people who have CP. Their website includes a care pathways section with a combination of evidence-based information and expert consensus summaries for various conditions in people with CP: [aacpdm.org/publications/care-pathways](https://aacpdm.org/publications/care-pathways)

→ Sign up for the CP Research Network's monthly MyCP educational webinars at [cprn.org/mycp-webinar-series](https://cprn.org/mycp-webinar-series) to learn more about healthcare, research, and self-advocacy for people with CP. You can also view our library of past presentations on our Youtube channel [@CPResearchNetwork](https://www.youtube.com/@CPResearchNetwork).

→ Use online support groups like the discussion forum on [cprn.org/mycp/forum](https://cprn.org/mycp/forum). Because MyCP is not indexed by search engines, conversations there are not searchable on Google, and you can choose to be identified in your posts by a number rather than your name.



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# General Health for Adults with Cerebral Palsy



## Revisiting the Meaning of the Term “Cerebral Palsy”

As we begin discussing health topics in cerebral palsy, it's important that we establish what we mean when we say “cerebral palsy” or mention symptoms related to it. Cerebral palsy is approached differently in professional cerebral palsy societies, in clinical care settings with patients and families, and in public and social settings.

For our purposes, cerebral palsy (CP) is defined by the common characteristic of an early or infant brain injury that impacts the areas of the brain responsible for creating and coordinating movement. The injury or genetic change (an emerging area of study in CP) that causes these neurological disturbances is typically identified as cerebral palsy when the interference in brain development occurs before the age of two.

For more than a century, cerebral palsy has referred to the effect this injury has on movement, coordination, and posture. But over the last few decades, increased attention to the experiences of adults with CP has led researchers and clinicians to take a closer look at how

CP is defined—and how that definition impacts clinical care and overall support for people with CP. It's now more widely understood within the scientific community that the brain injury that causes CP may also cause additional conditions in some people, like vision and perception issues, and learning disabilities, which are sometimes referred to as **co-occurring conditions**. In many cases, these conditions are first identified by a person with CP or their family during childhood rather than being recognized by a clinician. Understanding what to look for can ensure you receive timely access to support and treatment.

This may be new information for you or your loved one, and if it is, we hope that it's helpful as you continue to seek care. As you do, it's important to keep in mind that while some clinicians know about these connections, many physicians, therapists, and educators do not. Talk to your providers to understand their approach to your healthcare, including their focus and specialties.

**“So, if we really want to focus on somebody's wellbeing, we need to see this global picture and we need to see the way all of these things are interacting together to affect somebody's mental health, their participation, their wellbeing.”**

—Dr. Heather Riordan, “Cerebral Palsy, Mental Health and Psychotropic Medications,” 2023 AACPD Community Forum

## How the State of Science for CP Impacts Your Healthcare

*The Adult CP Toolkit* was prepared carefully with community members and clinicians working together to present information about a diversity of health topics in CP. There are varying amounts of evidence and published literature

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for CP topics, and community and clinical concerns sometimes emerge before the data exists to inform official guidelines for screening, monitoring changes and treatment. **In these cases, it is especially important for you and your medical team to make individualized decisions.** Sharing this toolkit with your providers can help close knowledge gaps about adults with CP. As mentioned earlier, this toolkit's approach to adult healthcare in CP extends beyond musculoskeletal issues and related tone and movement symptoms to include broader health considerations:

1. We acknowledge that **different body functions may have been impacted** by your initial brain injury or disturbance in development (in some cases a genetic change may be the cause).
2. Although the initial brain injury is an event that does not worsen with time, it initiates a set of **physiological responses that impact different systems and functions of the body** during growth and development and can change over time. All the body systems (musculoskeletal, central nervous, cardiorespiratory, endocrine, renal, etc.) may be impacted, and often develop differently than in people without CP. As people with CP get older, these differences in their body systems can lead to changes in function as well as increased risk for potential lifestyle related conditions that will be much like early aging.
3. Sometimes **conditions and symptoms may be attributed to having CP when they may be separate issues.** It's possible another condition or problem that requires evaluation and treatment may be overlooked. A good example of this would be cervical spinal stenosis, which can be missed if physicians aren't familiar with its presentation in people with CP, and whose onset is sometimes earlier than in the general population.

## The Value of Primary Care

"My family doctor has gone out of his way to learn about CP and is doing the best he can to treat my needs. I also have several specialists who work with me, but most of them don't truly understand CP or my situation within it."

—Community advocate

"My friends in the community are constantly looking for general practitioners who know a thing or two about CP. This is obviously a field that needs to be developed further, but adults with CP need to know what to expect as they go through life. Sadly, we're currently in a position where patients and medical staff are finding this out together. It's definitely a field that needs further advancement and attention."

—Greg Moomjy, creative producer and Founder & Artistic Director of Opera Praktikos, New York's first disability-affirmative opera company ([operapraktikos.org](http://operapraktikos.org))

### The Role of Your Primary Care Provider

Your primary care provider (PCP) is the doctor who provides you with your medical home base from which other specialty care and treatment is often initiated and coordinated.

The term "primary care providers" refers to all medical providers who provide support for your preventive care and wellness and who treat common conditions such as an ear infection or respiratory illness. PCPs may include physicians, advanced practice nurses, and physician assistants, and they may be trained in different specialties, such as internal or family medicine. Some adults may think that they don't need a PCP if they are seeing specialists for their CP, but there is a lot more to your health than taking care of your CP.

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You may struggle to find a PCP or other health-care providers who are knowledgeable about caring for people with CP. There may be times when you need to educate your healthcare providers, or when you need to assert yourself or remind them of both your needs and your abilities. See page 70 for more information on self-advocacy.

Adults with CP have high rates of **chronic illnesses commonly seen in adulthood**, such as **high blood pressure, diabetes, obesity, heart disease, fragile bones, and kidney disease**. We don't yet know precisely why these chronic conditions are so common in people with CP, but your PCP is an excellent resource to screen for and treat these chronic diseases.

Early detection and proper treatment of these conditions improve outcomes. Adults with CP can learn more from their healthcare providers about the importance of physical activity, nutrition, sleep, and cardiovascular and respiratory endurance, as well as strategies for improving them. These factors play key roles in managing various health conditions adults with CP face. See "Physical Activity and Exercise" on page 96 for more information.

**Regardless of the different roles your providers play in your healthcare, it is vital that they all communicate together to provide you with the best possible care.** This is referred to as care coordination. Both self-advocacy and care coordination are crucial to the emotional, physical, and social wellbeing of each adult with CP.

**Care coordination** is the joint effort among a patient, their caregivers, and their providers to ensure that an adult with CP receives the care they need across multiple specialties (for example, orthopedics and neurology). This collaboration allows the person's healthcare to be managed holistically, with each provider considering the risks and benefits of procedures and treatments in light of other treatments the

person is undergoing. You can facilitate this communication by providing your PCP with updates from your specialist visits.

**Here is an example of the value of care coordination:** Let's say someone has been prescribed a medication for headaches by their primary care doctor with the potential side effect of affecting their balance and how they walk. Any specialists who evaluate the way the patient walks, such as a physiatrist or PT, should know about this medication to consider how it may be impacting the area of care and support they provide. Without this information, they may misinterpret changes in function as a different issue rather than the side effects of a recently started medication.

**Additionally, you can refer your PCP to:**

- The American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD), and their Care Pathways resources for clinicians: [aacpdm.org/publications/care-pathways](https://aacpdm.org/publications/care-pathways)
- Have them sign up for our monthly webinars: [cprn.org/mycp-webinar-series](https://cprn.org/mycp-webinar-series)



Direct your PCP to our monthly webinars:  
[cprn.org/mycp-webinar-series](https://cprn.org/mycp-webinar-series)

"The interesting thing is that I've not been treated medically for CP since I was 'released,' so to speak, from pediatric care and tracking of my CP at the age of 18. I get treatment for conditions that have resulted from my CP (for example, rehabilitation from my hip replacement surgeries, recovery from falls, and such) but not specifically for CP."

—John Borland, CP Research Network community research partner

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## Examples of How a PCP Can Support Your Health and Wellbeing

1. Providing dietary counseling
2. Managing unhealthy habits, such as use of tobacco or alcohol
3. Administering immunizations
4. Attending to reproductive healthcare
5. Detecting and managing chronic illnesses including diabetes, high blood pressure, high cholesterol, kidney disease, anxiety and depression, and heart disease
6. Screening for infectious diseases such as HIV and hepatitis
7. Providing cancer screening including for colon, breast, cervical, and skin cancer
8. Screening for problems with vision (more detailed vision screenings are handled by an eye care professional)
9. Caring for acute illnesses such as respiratory illnesses, rashes, bowel problems, and urinary tract infections

Your PCP is an excellent resource to screen for and treat chronic diseases like the ones mentioned above. You can find general preventive screening recommendations on the American Academy of Family Physicians' website: [aafp.org/family-physician/patient-care/clinical-recommendations/aafp-cps.html](https://aafp.org/family-physician/patient-care/clinical-recommendations/aafp-cps.html).

**While most of the recommended screening guidelines will apply to you, there are some screening procedures that need to be adjusted for people with CP because of differences in body structure and composition.** For example, most adults with CP have less muscle than people without CP. Tests that

are designed around an expected amount of muscle, such as your Body Mass Index (BMI), used to assess heart disease risk and obesity or some of the kidney measures may need a different interpretation or use of a different test for people with CP. Other tests may need to be on a different schedule in terms of how often a test is repeated or when to begin baseline testing. One example is the DEXA scan (assesses bone strength) which is usually done after a fracture or in later adulthood for the general population, but may be helpful to establish a baseline for bone health in adults with CP sooner. Work with your healthcare team to determine any adjustments to your health screenings and their schedules.

**We don't yet have all of the answers we desire or need for CP, but in the meantime there are areas where we can reduce the number of issues you may be facing as an adult with CP.**

For instance, many adults with CP do not receive common preventive health screenings that are recommended for the general adult population. There are many reasons for this, including physical barriers like inaccessible medical facilities or equipment (e.g., standard mammography machines—note that accessible versions exist), not having a primary care doctor to coordinate and track these screenings, and difficulty with transportation. However, health-care providers and local peers can help you find accessible facilities and machines or alternative screening procedures. Hospitals and clinics are increasingly addressing accessibility barriers, and new home-screening tools—like the Teal Wand, the first at-home Pap smear test in the US—are improving access to preventive care.

# Health Topics in CP

This next section covers a range of health topics for adults with CP to consider and discuss with their healthcare providers. There may also be other important and relevant health information to discuss that is not included here.

Speak to your providers about any concerns you have or changes you notice in your health and functional abilities, even if they are not covered in this section or elsewhere in this resource. Also, ask your healthcare providers to check updates in evidence that may affect the clinical care of adults with CP or how they address your specific healthcare needs.



- 1 Nutrition
- 2 Gastrointestinal (GI) function
- 3 Bladder health
- 4 Kidney health
- 5 Sleep
- 6 Cerebral/Cortical Visual Impairment (CVI)
- 7 Gynecological, Reproductive and Breast Health
- 8 Sexual Health and Intimacy
- 9 Physical Activity and Exercise
- 10 Fatigue
- 11 Pain
- 12 Bone Health
- 13 Muscle Health
- 14 Earlier functional decline
- 15 Falls
- 16 Tone management
- 17 Mental health

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# Nutrition and Eating, Drinking, and Swallowing

Diet and nutrition are hot topics for most individuals looking to manage their health. For people with cerebral palsy, many factors affect nutrition. Problems with eating, digestion, or access to appropriate nutritional food increase an individual's risk for malnutrition—which occurs at a higher rate in people with CP. Studies estimate that up to 58% of people with CP qualify as malnourished. For this reason, it's important for you or your care partners to be aware of and address these issues in order to prevent other health problems.

Swallowing is a complex neurological function that requires the coordination of nerves and muscles. Some people with CP struggle with swallowing beginning in childhood, while others may notice new problems as they age. Swallowing issues can range from trouble with certain textures to being unable to stop food or drink from entering the lungs—a disorder called **aspiration**. Aspiration is a serious condition that

can lead to pneumonias and chronic respiratory failure. In those cases, some people may need to rely on a **feeding tube** for some or all of their nutritional needs.

The stomach, the small intestine, and the large intestine are also sources of potential problems for people with CP. Those organs all require neurological input to move food through, extract nutrients, and remove waste products. Some people have gastroesophageal reflux (heartburn), vomiting, slow moving transit, and constipation, all of which can cause distressing symptoms that upset the digestion process.

While malnourishment tends to receive more attention from medical providers, some people with CP develop overnourishment or obesity issues as they age, which can cause health-related problems like heart disease and high blood pressure.

For proper nutritional care, you should work with medical providers and support staff who have experience with CP and how it can affect eating and nutrition. Because traditional measurements of nutritional status like body mass index (BMI) consider someone's weight in relationship to their height, these do not neatly fit people





with CP. An experienced CP provider will know that measurements of waist circumference compared to hip circumference have been shown to be a better assessment of nutritional status than BMI in people with CP. Additionally, specialists may assess swallowing function, treat digestive tract symptoms, or make specific dietary recommendations for supplemental nutrition. Thankfully, many options are available to care teams and families to customize solutions for balancing nutritional status.

### The Role of Oral Health in Getting Proper Nutrition

Issues with feeding and nutrition can start in the mouth where the breakdown of food and digestion begins. When your oral health is compromised and your teeth aren't able to do their job breaking down food, this can restrict the textures you can chew and impact your body's access to nutrients. It's important to monitor and maintain oral health by regularly incorporating supportive oral hygiene practices, such as brushing and flossing as directed by your dentist.








Ask your primary care doctor and dentist for ideas to improve your oral hygiene at home—and have them consult one another if needed. Sometimes adaptive toothbrushes, electric flossers, and water flossers (known by the brand name Waterpiks) can be very helpful. If you have difficulty during dental visits—for example, if you cannot transfer into an exam chair or if the dentist and hygienists cannot easily access all parts of your mouth—ask about alternative solutions. Some dentists specialize in caring for people with disabilities and may offer options like sedation to make the visit easier.

The American Dental Association website provides information for both people with disabilities and professionals about meeting the dental health needs of people with disabilities: [adanews.ada.org/ada-news/2022/august/ada-committed-to-helping-patients-with-disabilities-achieve-optimal-oral-health](https://adanews.ada.org/ada-news/2022/august/ada-committed-to-helping-patients-with-disabilities-achieve-optimal-oral-health).

## Changes in Eating, Drinking and Swallowing

Just as it's important to monitor your mobility and physical abilities, regular assessments of your eating, drinking, and swallowing are essential. These functions can change over time, especially as muscle coordination involved in these activities is affected by aging. Common assessments include a swallow study or an evaluation by a speech-language pathologist. Your primary care doctor may also be able to share eating, drinking, and swallowing strategies with you.

Eating and Drinking Ability Classification System from 3 years: descriptors and illustrations				
 <p><b>Level I</b> Eats and drinks safely and efficiently.</p>	 <p><b>Level II</b> Eats and drinks safely but with some limitations to efficiency.</p>	 <p><b>Level III</b> Eats and drinks with some limitations to safety; there may be limitations to efficiency.</p>	 <p><b>Level IV</b> Eats and drinks with significant limitations to safety.</p>	 <p><b>Level V</b> Unable to eat or drink safely – tube feeding may be considered to provide nutrition.</p>

Illustrations © Jane Coffey. Source: Sellers, D., Mandy, A., Pennington, L., Hankins, M., & Morris, C. (2014). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine & Child Neurology*, 56(3), 245–251. [doi.org/10.1111/dmcn.12352](https://doi.org/10.1111/dmcn.12352). Reproduced with permission.

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# Keeping Things Moving! Managing the Bowels, Bladder, and Kidneys

## Constipation

Constipation is a common problem in adults with CP, particularly for people whose movement is limited. Dehydration is a major risk factor for constipation. It also may be caused or worsened by being less mobile, eating a diet low in fiber, and neurological slowing of bowel function. Some medications, especially opioids, can also contribute.

People with CP or other physical disabilities will sometimes avoid liquids or delay bowel movements when access to an accessible bathroom is limited (such as during travel) or because they only have caregivers at certain times. While these strategies reduce the need to use the bathroom, they can negatively impact your health and comfort and lead to constipation or infections. Talk with your medical team about other solutions that can support your needs and overall wellbeing.

Constipation is not just annoying, it can also lead to serious complications like a bowel obstruction that require hospitalization.



Image by Tuân Nguyen Minh.

It is important to stay well hydrated and as mobile as possible! Creating a bowel program can be helpful. This may involve taking a medication or using a suppository at certain times of the day so that the bowels will empty at a convenient time. Laxatives and glycerin suppositories are commonly used to help keep the bowels moving. But nothing replaces water and movement!

“While I haven’t really gone for a GI screening, or seen a GI doctor, I’ve had problems with constipation all my life. And it’s gotten worse as I’ve become older. The number of suppositories I’ve taken on a weekly basis has dramatically increased since becoming an adult. Now that I’m seeing a nutritionist it is something I’m working on.”

—Community advocate

## Bladder Problems

CP can sometimes affect the bladder, making it either harder to urinate or causing frequent urination. Adults with CP often have risk factors for urinary tract infections, including not being able to fully empty the bladder, not receiving care in a timely manner, and dehydration. Constipation may play a role as well. Kidney stones are more common in adults with CP for some of the same reasons, and due to decreased mobility and taking medicines that affect calcium metabolism. Again, staying hydrated and mobile can help. Talk to your physician about your diet and medications to understand your risk for urinary tract infections and kidney stones. Also, be sure to tell them about any changes in urination, which may be caused by infection.

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## Kidney Disease

Adults with CP are at higher risk for chronic kidney disease. Bladder infections and kidney stones can contribute to this. Other risk factors are obesity, high blood pressure, heart disease, and diabetes, all of which tend to be more common in people with CP than in the general population. Kidney disease is a serious problem that can lead to the need for dialysis or a kidney transplant. The best way to avoid it is by adopting healthy habits such as a nutritious diet, regular exercise, and (again) proper hydration. Some over-the-counter pain medications such as ibuprofen (Advil) and naproxen (Aleve) can increase the risk of kidney disease if taken regularly. Acetaminophen (Tylenol) can be a good substitute for these as long as you do not have liver problems.

Work with your doctor to get your kidneys checked and remind them that people with CP typically have lower muscle mass, which can cause misleading test results that mask potential kidney problems. For people with CP, it's critical for providers to conduct more frequent screening and evaluate changes in kidney labs over time, which can provide more insight than a single reading that may appear normal for people with typical muscle mass. At this time there are no official recommendations to guide clinicians in screening for kidney disease in CP, but it's an area of emerging concern among adult providers.

So stay hydrated, stay regular, stay active, eat well and healthy, and work with your primary care doctor, and other healthcare providers, in monitoring for these problems.



## Sleep

Sleep is essential for good physical and mental health, but several studies show that many people in the general population have sleep-related disturbances. For people with CP, the problem is more common: 65% of the population report some kind of sleep disturbance.

**During sleep, many restorative functions occur throughout the body, mind, and brain, replenishing our energy. Because of this, addressing sleep-related disturbances may reduce some common complaints that interfere with daily life for people with CP such as fatigue, chronic pain, and body aches.**

When specialists work together on your behalf, they can help you sort through and address causes of sleep disturbance. They can strategize ways of breaking cycles where symptoms such as lack of sleep may worsen pain and worsening pain may disturb your sleep.

Your PCP may recommend testing to determine the source of your sleep disturbances. In some cases, you may be referred to a specialist for further evaluation.

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## Medical Reasons for Sleep Problems Include:

- Pain or discomfort
- Heartburn or reflux
- Breathing difficulties or sleep apnea
- Inability to change positions
- Problems with sleep/wake cycles
- Seizures
- Restless legs (movement of the legs when sleeping)
- Psychological factors (e.g., worrying about unfinished work or an upcoming event)
- Saliva aspiration

## Environmental Sleep Disturbances Include:

- Positioning while sleeping
- Noises
- Light (too much or not enough)
- Temperature (too hot or too cold)

## Practical Strategies for Improving Your Sleep

**Sleep hygiene** refers to keeping habits that support better sleep. This includes adjusting the environment (temperature, noise level, ambient light), sticking to a regular sleep/wake schedule and bedtime routine, and paying attention to physiological factors (exercise, timing of meals, caffeine use) to encourage better sleep. You can learn sleep hygiene strategies from a variety of professionals, including psychologists, your PCP, physical therapists, and occupational therapists, as well as sleep specialists.

## Sleep Medications and Herbal Supplements

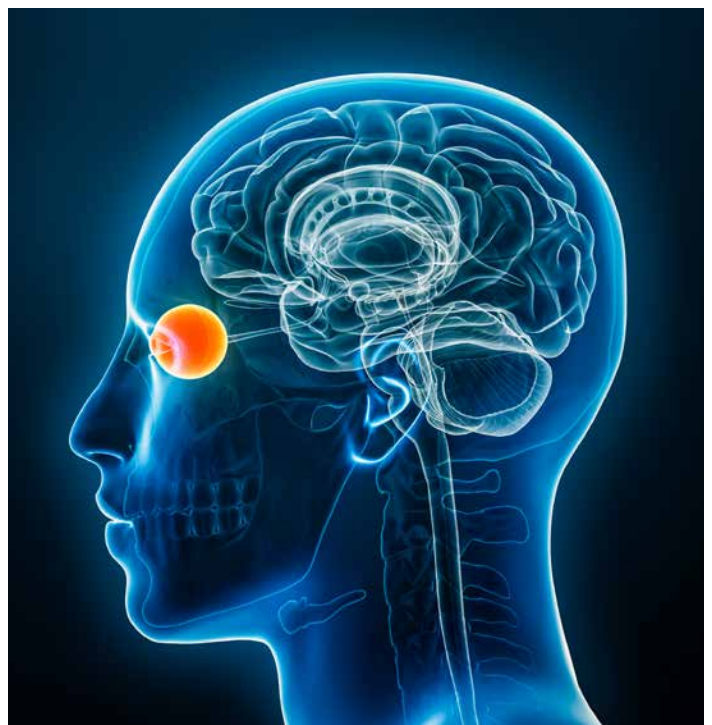
Medications and alternative or herbal remedies should be discussed with your healthcare providers as they can interact with other medicines, negatively impact other health conditions, or have undesirable side effects.

# Cerebral/Cortical Visual Impairment (CVI)

Around 40% of the brain is involved in processing vision. Cerebral visual impairment (CVI, also called cortical visual impairment) is caused by damage or interruption to the parts of the brain responsible for processing the visual information you take in through your eyes. Visual processing impairments are different from ocular impairments, which are based in the eyes and can sometimes be corrected with glasses or contacts. Because CP is caused by an early brain injury, CVI can co-occur with CP and may go unrecognized due to lack of awareness by eye care professionals and other clinicians.

**People with CVI typically show certain visual behaviors and traits, but the condition manifests differently in each individual.**

Common traits may include a preference for certain colors, improved vision when in simple or uncluttered environments, and difficulty recognizing faces and people.



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At the 2023 National Institutes of Health (NIH)'s first formal meeting on CVI, clinicians established five elements or characteristics of CVI:

1. The brain is involved in visual impairments.
2. Problems with vision are greater than expected based on the results of a traditional eye exam.
3. There are specific types of visual deficits that fall under the CVI umbrella.
4. While CVI may be comorbid with these, it is not a disorder of language or learning.
5. CVI is easily missed.

“We know from many first-hand accounts from adults who have learnt that they have CVI, that years of difficulties become explained. They become empowered by their new knowledge because . . . effective strategies to help in many areas can be implemented.”

—CVI Scotland, the Newcastle Adult CVI Inventory, Scoresheet & Advice



“I have not had the necessary intervention to help me understand my CVI and how it affects my mental, emotional, and physical being. Interventions, when I was a child, could have assisted me in developing strategies that could have better helped me manage day-to-day activities and gain meaningful employment. I have become accustomed to not realizing what strategies I use to compensate for my CVI as I perform these strategies unconsciously and automatically. I have struggled with CVI, without any support, for all of my life up until recently.”

—Dijana, participant in CVI NOW panel of adults with CVI sharing their experiences [perkins.org/adults-with-cvi-share-how-cvi-leaves-no-stone-unturned](https://perkins.org/adults-with-cvi-share-how-cvi-leaves-no-stone-unturned)

### Screening and Finding Support for CVI

CVI is usually diagnosed through a process of elimination when abnormal visual responses can't be attributed to eye problems alone. At this time, several measures are being used to understand and identify characteristics of CVI, but there is not yet official consensus on which tools to use, particularly for adults. Some researchers of CVI in adults have pointed to the Newcastle Adult CVI Inventory as a starting place. It's a tool you can discuss further with an eye care professional familiar with CVI:

[cviscotland.org/mem\\_portal.php?article=502](https://cviscotland.org/mem_portal.php?article=502).

“Empowerment is the knowledge that I have a condition that's getting to be known: There is a name for my condition. There is nothing wrong with me as a person. Knowing I can do something to make my life a little easier and that I can meet people in similar positions: That is empowerment.”

—Dagbjört Andrésdóttir, adult with CVI, from “Four Things to Know About CVI from Adults Who Have It,” CVI NOW [perkins.org/4-things-to-know-about-cvi-from-adults-who-have-it](https://perkins.org/4-things-to-know-about-cvi-from-adults-who-have-it)

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Ask local clinicians and family support organizations like Parent to Parent (a nationwide family support network) about resources they have for CVI. Neuro-ophthalmologists, developmental optometrists, and teachers of students with visual impairments (TSVIs) are also good professionals to contact for more information, as well as local schools for blind and visually impaired students.

### Are There Treatments Available?

Research has not caught up to the need for support for symptoms associated with CVI. **Because of a lack of clinician awareness, people with CP, including adults, may have CVI and not know it. There are a number of practical tools and apps that are easy to use and low cost or even free that support visual processing.** You can work with an eye care professional familiar with CVI and implement strategies to address related symptoms. Some apps that you can discuss with your clinician allow you to adjust lighting, isolate text, or adjust text color. You can also use audiobooks and text-to-speech programs to reduce visual fatigue. Introducing simple visual support strategies may help you even if we don't yet know all of the science behind why they may work.

“When my daughter was three years old, her occupational therapist told me that she had concerns about her vision, but she didn't understand what she was observing. My daughter already wore glasses and had been seen by multiple ophthalmologists since she was born. The therapist was adamant that they were missing something important. Eventually, we connected with vision professionals who helped us determine that the symptoms that weren't being captured through routine eye exams were associated with a lesser-known and researched condition referred to as (CVI).”

—Michele Shusterman, parent and community advocate

Consult with your medical team and eye care providers for more information and to understand any concerns or risks associated with introducing new vision protocols.

## Additional Resources

### *Cerebral/Cortical Visual Impairment (CVI)*

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Cerebral Palsy Alliance Research Foundation has a webinar dedicated to discussing and understanding CVI, “CP & CIV: A Community Discussion”: [youtu.be/wcREPdhWU44](https://youtu.be/wcREPdhWU44)

CVI Now hosted a panel of adults with CVI sharing their experiences, including their strategies, challenges, and a message about CVI: [perkins.org/adults-with-cvi-share-how-cvi-leaves-no-stone-untuned](https://perkins.org/adults-with-cvi-share-how-cvi-leaves-no-stone-untuned)

The National Eye Institute information page on CVI: [nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/cerebral-visual-impairment-cvi](https://nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/cerebral-visual-impairment-cvi)

Ophthalmology Times article about the five key elements of CVI identified by the NIH panel of experts: [ophthalmologytimes.com/view/nih-highlights-5-key-elements-of-cortical-visual-impairment-cvi-](https://ophthalmologytimes.com/view/nih-highlights-5-key-elements-of-cortical-visual-impairment-cvi-)

CVI Now Resource Center: [perkins.org/cvi-now/resource-center](https://perkins.org/cvi-now/resource-center)

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# Gynecological, Reproductive, and Breast Health

## Menstrual Health

Menstruation is a natural part of life, but for individuals with cerebral palsy, it can present unique challenges that require thoughtful consideration and proactive care.

Some of these issues include:

- menstruation-related pain (dysmenorrhea)
- excessive bleeding (menorrhagia)
- anemia
- reduced seizure control
- negative effects on hygiene
- negative effects on behavior, including irritability
- social isolation
- increased caregiver responsibility

Some people favor menstrual suppression—reducing how frequently have a period—to manage the burdens associated with menstruation. Menstrual suppression means that you use hormones to reduce the frequency and volume of periods and, in some cases,



to suppress periods completely. This can be achieved in many ways, including using birth control pills, the birth control patch, a contraceptive injection, or progesterone-containing implants. Each method has its own risks and benefits. Every person is unique, and tailoring approaches to individual needs is key to promoting a positive menstrual experience. By incorporating these considerations into your menstrual health management, you can navigate this natural aspect of life with greater comfort, dignity, and autonomy.

## Pregnancy Health

People with disabilities, including those with cerebral palsy, express similar interest in becoming pregnant to nondisabled individuals, and pregnancy rates in this group are increasing. Despite this, individuals with disabilities are often inappropriately discouraged from becoming pregnant or parenting. While there are data showing increased risks associated with pregnancy in individuals with disabilities, your decision-making process of whether or not to become pregnant should be individualized, and discussions with your healthcare providers should consider risks associated with you becoming pregnant as well as family-planning goals.

## Breast Cancer Screening

In the United States, breast cancer is the most common cancer among women, with an estimated one in eight women developing invasive breast cancer during their lifetimes. An individual's risk of breast cancer can vary based on factors such as age, ethnicity, lifestyle, and family history. Some ways to reduce your own risk of developing breast cancer include staying physically active, limiting alcohol intake, and maintaining a healthy weight.

Individuals with disabilities are less likely to be screened for breast cancer despite guidelines suggesting that screening should be equivalent to that of nondisabled individuals.



Recommendations for breast cancer screening may vary, but they can include a combination of clinical breast exams, breast awareness, and mammograms. For these tests, it's helpful for you to reach out to the clinic beforehand to let them know that you have CP and what kind of support you may need for your visit. Whether you walk independently, use assistive devices, or use a wheelchair, many of these tests require balance and stillness. Your clinic can work with you to accommodate your needs, make the exam easier for you, and reduce your stress.

Recently, there has been greater emphasis on the importance of breast awareness. This includes encouraging patients to become familiar with how their breasts normally look and feel and to report any changes to their healthcare provider.

Clinical breast exams are physical examinations of the breasts conducted by a healthcare professional to detect any abnormalities or changes. Recommendations for when to start clinical breast exams can vary. According

to the American College of Obstetricians and Gynecologists, people with breast tissue should be offered a clinical breast exam every one to three years during their 20s and 30s. The US Preventive Task Force suggests yearly breast exams and mammogram screenings beginning at age 40. For those who cannot access mammography due to positioning or other issues, ultrasound breast exams are available.

These recommendations are for individuals with average breast cancer risk; it's important to discuss your individual risk factors and preferences with your healthcare provider.

### **Cervical Cancer Screening**

The cervix is the part of the body located at the bottom of the uterus that connects the uterus to the vagina. Rates of cervical cancer vary significantly by geographic region, access to healthcare, and the implementation of cervical cancer screening programs. In the United States, cervical cancer incidence and mortality have decreased significantly in recent years, mainly due to widespread Pap smear screening and, more recently, human papillomavirus (HPV) vaccination.

HPV is a group of viruses, including certain high-risk types that are strongly linked to cervical cancer. It is estimated that 90% of cervical cancer is caused by these HPV types. You can be exposed to HPV through sexual intercourse and any skin-to-skin contact around your genitals, anus, or mouth.

The majority of sexually active individuals will be infected with HPV at some point in their lives. However, most HPV infections clear on their own without causing any long-term issues. Persistent infections with high-risk HPV types are more likely to lead to cervical cancer.

The availability of HPV vaccines has been a significant development in preventing cervical cancer. The HPV vaccine is recommended as

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early as age nine but can be given up to the age of 45. Vaccination against HPV is an important preventive measure to reduce the risk of HPV-related cancers.

It's important that you have a regular cervical cancer screening, such as Pap smears and HPV testing, to detect precancerous changes or cervical cancer as early as possible. Individuals with disabilities are less likely to be screened for cervical cancer than nondisabled individuals, so it's important to speak with your provider about addressing any barriers that may be preventing you from getting the screening you need. If you are uncomfortable with the idea of a pelvic exam or you had an unpleasant or perhaps painful experience, discuss your concerns openly with your provider so that you can identify potential solutions you may not have considered.

Typically, cervical cancer screening with Pap smears begins at age 21 and continues every three to five years until the age of 65. You and your health provider should work together to determine the frequency of your screenings in the context of your health history and risk factors for related problems, as well as your previous screening results and preferences. It is important to discuss all of these issues with your healthcare provider and make sure you get screened.

In 2024, the US Food and Drug Administration (FDA) approved self-collection procedures for HPV screening through a medical office or mobile medical clinic to increase the number of people who can be screened. In 2025, they approved the first HPV home-screening kit in the US, called the Teal Wand. A prescription is required for the home-use kit.

The risks and benefits related to screening methods for HPV should be discussed with your healthcare provider in order to determine which screening procedure is best for you.



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## Perimenopause

Perimenopause refers to a period of time—usually in a person’s 40s, but it can occur earlier or later—when changing hormone levels are leading them toward their final menstrual period. The age at which someone begins having physiological changes leading to their final period varies from person to person. This transition to no longer having periods is referred to as menopause.

During the perimenopausal time, many people (90%!) approach their medical providers with reports or complaints of hot flashes, vaginal and sexual changes, changes in their mood and sleep, and different menstrual cycle patterns. These symptoms can significantly impact a person’s quality of life but have often been overlooked by medical providers. Other symptoms such as changes in cholesterol levels and loss of bone may occur, increasing your risk for heart disease and osteoporosis. As a person with CP, you already are at higher risk for these conditions, so it’s important to speak with your medical provider about screening for them.

Perimenopause lasts for a different amount of time for each person. Traditionally, perimenopause includes early and late stages. The early stage can be defined by occasional skipped cycles and/or other hormonal changes or symptoms. The second stage often means greater menstrual irregularity, which can include months without bleeding or 60 days or more between periods.

Your medical provider should personalize the approach to treating your perimenopausal symptoms based on their type and severity, as well as your need for contraception to reduce the risk of pregnancy. It’s important to keep in mind that there isn’t an absolute way to know if a person undergoing perimenopause is infertile, other than experiencing 12 months without a period while they are off all hormones.

## Menopause

Menopause is a natural phenomenon of aging during which ovarian function shifts from a reproductive state to a nonreproductive state. It is caused by a decrease in estrogen and progesterone hormones.

The average age of menopause in the US is 51. However, some data suggest that individuals with disabilities may experience menopause earlier than nondisabled people.

Someone is menopausal when they haven’t had a period for 12 consecutive months. Vaginal bleeding should not happen after menopause; if you do experience postmenopausal bleeding, see your doctor immediately.

Symptoms of menopause are different for everyone. While some individuals may experience few symptoms, others may encounter significant changes that require medical interventions. Symptoms can include night sweats, hot flashes, weight gain, anxiety, and/or vaginal dryness, symptoms that may also occur with perimenopause.

The decrease in estrogen levels in menopause can also put individuals at risk for osteoporosis, heart disease, urinary tract infections, and skin breakdown due to skin thinning. People with disabilities, including CP, may be at greater risk for these conditions due to limited mobility or preexisting bladder dysfunction.

There are a variety of treatments for various symptoms of menopause. Speak openly with your provider about your treatment options.

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## Sexual Health and Intimacy

“It brings me to tears—oftentimes uncontrollable sobbing—to contemplate all that I have with my wife and what she sees and has clearly gained with me.”

—John Borland, CP Research Network community research partner

Relationships, intimacy, and sexuality are important issues that are often not considered or addressed for individuals with disabilities. Just like anyone else, people with CP have intimate relationships and sexual partners and should have access to information, education, and related healthcare support. **Having a disability alone does not mean that you will not or should not have the same liberties with regard to sexual intimacy, education, and expression as someone who is nondisabled.**



“Disabled young people are sexual beings and deserve equal rights and opportunities to have control over, choices about, and access to their sexuality, sexual expression, and fulfilling relationships throughout their lives. This is critical to their overall physical, emotional, and social health and well-being.”

—Dr. Sonali Shah, Associate Professor in Disability and Life Course Research, University of Nottingham

### Sex

Sex is a complex and taboo topic for many people. People with CP are often at a disadvantage when it comes to sex education. You may have received little or no information about sex or been taught things that are unrelated to your needs. There is a chance that you will face more obstacles with dating and lack guidance about how to navigate intimacy in ways that suit your body and needs. **Seek out resources that help you have healthy relationships with yourself and others.** Sex and reproductive health can have positive impacts on your life, identity, and self-esteem. People with cerebral palsy can and do enjoy the benefits of a healthy sex life.

**People with CP can have fulfilling sexual experiences.** Adaptive equipment like adaptive condoms, wedge pillows, and vibrators are available to support this, and being creative (for example, creative positions or using a body massager) can go a long way. You can talk to your partner or a trusted person or healthcare provider about your physical needs.



## Talking About Intimacy and Sex with Your Partner and Healthcare Providers

At times, symptoms of CP such as spasticity, contractures, or joint pain can interfere with sexual activity. Don't be shy about bringing this up with your partner. If you need help starting this conversation, your healthcare provider may be able to provide you with insight and support, address your concerns, and facilitate intimacy between you and your partner. If this is an area where they lack expertise, ask them if they can refer you to someone else who has this knowledge and can guide you.

Managing spasticity or changing your medications can help with your comfort and function. Many physical therapists, occupational therapists, and physiatrists have valuable expertise in positioning strategies that can increase your comfort. Pelvic floor therapists and other clinicians can also help you address pelvic pain and other concerns related to sex.

“Until very recently I didn't know I could [talk about sexual health with medical professionals], in the sense that I didn't know I could tell my parent or aide to leave the room so I could have the privacy to talk about these things with my doctor. Once I understood that, it's been very easy. And I have learned from my conversations with my doctor that because of the way our muscles work when we have CP, our bodies do different things when we're in bed. So I get Botox injections to help manage spasticity. This helps make intimacy easier for me, but I wouldn't have realized that had I not first understood that people with CP have the right to speak to their doctor in private.”

—Greg Moomjy, creative producer and Founder & Artistic Director of Opera Praktikos, New York's first disability-affirmative opera company ([operapraktikos.org](http://operapraktikos.org))



Most important, have open conversations with your partner about the best way to approach sex. Preparation, positioning, and good communication can make all the difference. Creativity and open communication are a lot of what makes sex meaningful and engaging—so talk it out, try new things, and explore what feels best for you both.

## “RESPECT me, the same as another woman.”

—K Pleasant, Founder and Executive Director, Cerebral Palsy Positive ([cerebralpalsypositive.org](http://cerebralpalsypositive.org))

### Sexuality

**People with CP, like all people, have a range of sexual orientations, preferences, and gender presentations.** People experience sexual development and desire at different ages and levels of intensity. Physical changes, dating, and the desire for sexual relationships are all part of this experience—this holds true for people with disabilities and nondisabled people. Exploring your sexual orientation and gender identity is part of creating a meaningful and authentic life. You deserve to be seen, respected, and affirmed, and it’s OK to correct people if they misgender or misidentify you. It’s also OK to come out—or not come out—whenever and wherever feels right for you, in your community, your family, or not at all. You might choose to come out only to yourself, to one person you trust, or in an online space—whatever works for you. The Trevor Project’s Coming Out Handbook can help you think about your identity and what coming out means to you: [thetrevorproject.org/resources/guide/the-coming-out-handbook](http://thetrevorproject.org/resources/guide/the-coming-out-handbook).

“Most healthcare professionals I have interacted with acknowledge that I can be sexually active but they aren’t really sure how to support

asexual individuals beyond recommending what they normally would for non-asexual people, and I think there’s still stigma and uncertainty around that particular identity as well. There needs to be more intersectional research around how to support disabled asexual people, and more acknowledgment that disabled people are valid in their aceness and it’s not a social reaction to prospective rejection or perceived ‘ugliness’ or what have you but a very valid identity in and of itself.”

—CP Research Network community advocate

### Consent

It is well established that individuals with disabilities are at increased risk for abuse and exploitation. Access to comprehensive sexual education is a human right that can reduce these risks. You should be taught how to set healthy boundaries and how to report any concerns about abuse. The Arc’s “Healthy Understanding of Our Bodies” resource ([thearcofhr.org/sexual-health-resource-hub](http://thearcofhr.org/sexual-health-resource-hub)) links to many websites and teaching materials that can help build a strong foundation for sexual health.

If you have concerns about someone’s capacity to consent and adequately understand the risks and potential consequences of engaging in sexual activities and relationships, your local Adult Protective Services (APS) agency should be able to offer related support, information, and sometimes referrals to other skilled local professionals. Keep in mind that discrimination laws vary by state and impact how to determine legal capacity to consent. Consult legal counsel for more specific information about how local and federal laws may apply to supporting both a person’s rights to sexual expression and their right to be free from sexual victimization.

### Reproductive/Sexual Health

As a person with CP, you may face extra challenges in accessing sexual healthcare because

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providers may dismiss your concerns and complaints, not make enough time to listen during a visit, or have exam rooms and equipment that are difficult or impossible to use with a wheelchair. Research has demonstrated that people with CP have higher rates of breast and cervical cancer but are less likely to receive screenings. Just like in other areas of your health, you need to advocate for your sexual health and access to the same care other people receive.

“I am asexual and I am physically very averse to reproductive health screenings, so that can be a mental challenge despite their being nothing inherently sexual about them. And there’s the physical challenge of getting gynecological screening when you have muscle issues. I think the mental hurdle makes the physical aspect worse. Everything else, though, is fine.”

—CP Research Network community advocate

Even if you are not currently sexually active, you are still at risk for reproductive health issues like cancer and should be seen by doctors regularly. You may have to advocate for preventive screenings such as Pap smears. For more information, see “Gynecological, Reproductive, and Breast Health” on page 86.

One major issue is finding accessible care. People who see a gynecologist, for example, may require accessible exam tables and movable stirrups. Accessibility in medical facilities is legally required by the ADA. Here is more

information about what the ADA requires in medical settings: [ada.gov/resources/medical-care-mobility](https://www.ada.gov/resources/medical-care-mobility).

Additionally, it may be helpful to ask your provider about the possibility of using a pre-medication like a muscle relaxant to help with stiffness and/or spasticity in your legs and hips during an exam.

### Prostate Exams

People with a prostate should have regular prostate exams. The American Cancer Society recommends starting around age 50, but talk to your provider to determine what’s right for you. **Remember that cancer and other health issues do not discriminate!** People with CP are just as vulnerable as those without, and it is important to take preventive steps and monitor your entire body.

### Sexually Transmitted Infections

Being sexually active comes with the risk of being exposed to sexually transmitted infections (STIs), which spread through sexual contact. These include gonorrhea, chlamydia, trichomoniasis, HIV, and others.

STI symptoms may include unusual discharge from your genitals, sores or bumps, itchiness and redness, pain while peeing, or abnormal vaginal bleeding—however, you may not experience any symptoms. Due to the access barriers and misconceptions discussed above, these infections may be under- or undiagnosed in individuals with disabilities. If you are sexually active, using barrier protection such as latex condoms offer protection against many of these infections. Ask your primary care doctor or gynecologist about screening for STIs, as many can be easily diagnosed and treated. If either you or your partner is infected, you both need to receive treatment at the same time to avoid reinfecting each other.

## Preventing Unplanned Pregnancies and the Spread of STIs

It's important to openly discuss options for preventing unplanned pregnancies and preventing the spread of STIs with your health-care provider and partner. There are many options to consider when it comes to birth control, but not all of them will also protect you or your partner from spreading STIs. Ask your primary care doctor or gynecologist for more information about what options are available to you and can help you address your physical needs and concerns.

When used properly, condoms can help prevent unplanned pregnancies and are highly effective in stopping the spread of many STIs. They are also widely available and cost effective. Talk to your primary care provider or other health professional if you have questions about which condoms may be best suited to the needs of you and your partner or how to use them.

The most common type of adaptive condom is a "pull" condom, which has a pull tab either on one or both sides to help pull it down. While these can be hard to find in the US, there are a few brands you can order online and through US retailers. We provide examples here not because we believe the brands to be superior, but because we found that these kinds of condoms can be hard to locate and we want you to have a place to start. Keep in mind that some condoms are made of materials that make them effective for preventing pregnancy but not STIs, so take your time and do your research. If you still have questions or concerns, talk to a trusted health provider.

## Adaptive Condom Brands

Easy Way Nature by Control: [controlfeelmakefeel.com/products/easy-way-nature-6-pcs](https://controlfeelmakefeel.com/products/easy-way-nature-6-pcs)

Uniq Pull: [uniqcondoms.com/en/producto/uniq-pull](https://uniqcondoms.com/en/producto/uniq-pull)

EXS Pull Condoms: [exscondoms.com](https://exscondoms.com)



Image by Slawek.

# Additional Resources

## Sexual Health and Intimacy

“Sexuality and Disability: Comprehensive Guide & Resource Directory” from Disability Resources: [disabilityresources.org/sex.html](https://disabilityresources.org/sex.html)

*Disability Intimacy: Essays on Love, Care, and Desire* by Alice Wong: [disabilityvisibilityproject.com/book/disability-intimacy](https://disabilityvisibilityproject.com/book/disability-intimacy)

*The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness* by Miriam Kaufman, Cory Silverberg, and Fran Odette: [simonandschuster.com/books/Ultimate-Guide-to-Sex-and-Disability/Miriam-Kaufman/9781573443043](https://simonandschuster.com/books/Ultimate-Guide-to-Sex-and-Disability/Miriam-Kaufman/9781573443043)

*A Quick & Easy Guide to Sex & Disability* by A. Andrews: [oni-press.myshopify.com/products/a-quick-easy-guide-to-sex-disability](https://oni-press.myshopify.com/products/a-quick-easy-guide-to-sex-disability)

Crippling Up Sex: [crippingupsex.com](https://crippingupsex.com)

“What I Wish I’d Learned in Sex Ed” by Carrie, from Autostraddle: [autostraddle.com/what-i-wish-id-learned-in-sex-ed-373066](https://autostraddle.com/what-i-wish-id-learned-in-sex-ed-373066)

Podcast by occupational therapists (OTs) about sex and disability: [otafterdark.com](https://otafterdark.com)

“Sexual Health and IDD Resources” from Kennedy Krieger Institute: [kennedykrieger.org/sites/default/files/library/documents/community/maryland-center-for-developmental-disabilities-mcdd/Sexual%20Health%20and%20IDD%20Resource%20Handout.pdf](https://kennedykrieger.org/sites/default/files/library/documents/community/maryland-center-for-developmental-disabilities-mcdd/Sexual%20Health%20and%20IDD%20Resource%20Handout.pdf)

“Let’s Talk About Sex: Sex and Relationship Education for People with Intellectual Disabilities” by Isabella Weber and Izzy Kaufman: [pmc.ncbi.nlm.nih.gov/articles/PMC8352484](https://pmc.ncbi.nlm.nih.gov/articles/PMC8352484)

“The Coming Out Handbook” from the Trevor Project: [thetrevorproject.org/resources/guide/the-coming-out-handbook](https://thetrevorproject.org/resources/guide/the-coming-out-handbook)

“Capacity to Consent to Sex: Legal Standards & Best Practices for Adult Protective Services” by Thomas F. Coleman, JD: [tomcoleman.us/aps-capacity-sex.pdf](https://tomcoleman.us/aps-capacity-sex.pdf)

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# Physical Activity and Exercise

## Overview

As you reach adulthood, you may notice you're not as active as you were during childhood. You may have decreased activity, do less physical therapy, or participate less in fitness programs. This section addresses how you can continue to be physically active into adulthood, because it is key to optimizing your abilities and to maintaining your health.

Exercise helps address conditions such as high blood pressure, hypertension, and high cholesterol. It also regulates sleep, reduces constipation, and can help you cope with stress, depression, and more. Not everyone likes to exercise. It's really difficult for some people with CP to do it alone, and many people have limited time and energy. On the other hand, some people absolutely love moving in whatever ways they can.



Work with members of your healthcare team, particularly physical therapists to help you establish a safe and meaningful physical activity plan, and perhaps one you enjoy. Annual physical therapy evaluations can keep track of your abilities and provide you with individualized exercises and help you build your routine of physical activity and exercise, choose activities and settings that you like, and exercise with people who motivate you.

**Remember, it is always important to share your goals with your physical therapist.** These can be things like improving balance, strengthening your legs, treating back pain, or developing a home exercise program. When you achieve these goals, you are typically discharged from therapy. However, if a new goal comes up, you can request a new referral from your healthcare provider. You'll want to maintain your mobility while still engaging in activities that interest you.

## Do I Really Need to Exercise?

Studies show that people with cerebral palsy may feel the effects of not exercising even more than those without CP.

People with CP will have different levels of fitness, which will provide a launching point for determining how much exercise they should get and at what intensity they should be working. Ask your PT or personal trainer for support in establishing an individualized exercise program. Again, before starting any new exercise program, check with your healthcare providers about any issues or conditions you may need to be careful of that relate to your individual health status.

## What Kinds of Exercises Can I Do at Home?

A physical therapist can help you develop an exercise program that you can do at home to get moving more.

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Movement should always begin slowly and gradually increase in speed. You should always stop a movement if it causes you pain. For adults with cerebral palsy who can stand with or without assistive devices, marching in place and walking are useful home exercises, and increasing the speed and time spent doing the movements will help your heart. Doing repeated motions from sitting to standing or going up and down one step can strengthen your leg muscles. The key is to move safely the way you usually do and increase the amount of time you spend moving.

For adults with cerebral palsy who are safer moving while seated or do not stand or walk, try reaching your knees to the ceiling or moving your legs in any way, making shoulder or neck circles, and doing trunk twists. These are useful exercises, and increasing the speed and time spent doing movements will help your circulation. If you're able, arm swings, twists holding a bag weighing a few pounds, and shadowboxing are other helpful exercises.

Another option for home exercise is online programming. The National Center on Health, Physical Activity and Disability (NCHPAD) has a variety of online videos that include yoga, seated exercise, and other programming: [youtube.com/@NCHPAD](https://www.youtube.com/@NCHPAD). NCHPAD also collaborates with the CP Research Network for their Mindfulness, Exercise and Nutrition, to Optimize Resilience (MENTOR) program ([cprn.org/mentor](https://cprn.org/mentor)), which is an eight-week online program that focuses on physical, mental, and emotional health for individuals with an existing disability or a recent diagnosis.



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# Physical Fitness for All: A Personal Perspective

By Steve Ferreira



My name is Steve and I have cerebral palsy. I am also a motorized wheelchair user. I have been involved in sports and physical fitness my entire life and have participated in team sports, such as wheelchair basketball and wheelchair rugby, and individual sports, such as track and field. I still do track and field competitively and specialize in shot put and club, a sport within track and field that is similar to the hammer throw.

When I was in middle school, my physical therapist motivated me by changing my traditional physical therapy program to working out with weights in the school gym. This was an eye-opening experience for me. Since physical education in middle school and high school were not adapted, this became my way of being involved in physical education with my peers.

In high school, other students would groan when they had to go to the weight room, but I could not get enough of lifting weights. In fact, when I graduated from high school, the physical education teacher gave me the Medallion Award for the graduating class. This award is for students who give their best effort, often in the face of special obstacles. This was an honor, because typically this award goes to a football or basketball player, and it was the first time that someone with a disability received the Medallion Award for physical education.





Physical fitness is still a large part of my everyday life. Being physically fit helps me stay in shape but also helps my mental wellness. I visit the gym at least four times a week, and I am motivated to excel. It has not always been easy.

At one point when I joined a local gym, the manager said to me, “What are you doing here? You’re in a wheelchair. You should not be here.” I proved him wrong, and I still work out at that gym a few times a week. I can use most of the equipment in the gym, but I do have to adapt how I use it. And, as of early 2024, I’m working on a project with some students from the UC Santa Barbara College of Engineering to build an adaptable cable machine for wheelchair users. The cable machine will be accessible by all so people with disabilities can work out side by side with their able-bodied peers. Physical fitness should be inclusive.

Cardio fitness is also important, and I have a handcycle that I use frequently. On days when it is raining (which happens quite a bit in the Seattle area), I have a bike trainer stand to use the handcycle indoors. I also use a rowing machine and stair machine for cardio. I can transition out of my wheelchair to access most of the equipment in the gym.

Physical fitness is important for everyone, but it is especially important for people with cerebral palsy. If our muscles are not used, they become weak. Exercise should be more inclusive, and people’s abilities should matter more than their disabilities.

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# Physical Therapy and Exercise

Physical therapists can help adults with CP to find exercises that support their functional fitness and that can help them navigate changes that accompany aging.

It's important to consult with a physical therapist and a member of your healthcare team such as your primary care doctor, before starting a new exercise program. They can go over any precautions you may need to take and what types of exercise are best suited to your needs. Exercise is not without risk. If you experience any pain or discomfort while working out stop immediately and communicate with your healthcare team.

## What to Expect from Physical Therapy Sessions

Everyone's goals for physical therapy (PT) will be different, so make sure to discuss your goals with your therapist. You should also discuss your abilities and preferences. They will assess your mobility and strength to see how well you're getting around and evaluate how that relates to your ability to participate in your community.



Your PT sessions may include a variety of exercises to improve strength, balance, and walking. If you are unable to walk, the therapist may focus on skills such as sitting postures, sitting balance, or transfers.

A physical therapist can also help you find a gym or adaptive fitness program in your community where you can continue exercising in addition to attending therapy and after therapy has concluded. This will help you maintain and perhaps improve your health and wellness.



NCHPAD has a directory of fitness centers and adaptive programs around the country: [nchpad.org/directories](https://nchpad.org/directories).

At a fitness center, it's especially important to have a personal trainer who specializes in working with people with disabilities. Look for a gym that employs someone who is a **Certified Inclusive Fitness Trainer**. These are fitness professionals who have the skills to develop and implement individualized exercise programs for people with physical, sensory, or cognitive disabilities.

## What If Your Physical Therapist Doesn't Know About CP?

If CP is new to your physical therapist, you can help them learn. Every person's experience with CP is different. Talk with your physical therapist about your experience and how your CP affects you. Direct them to websites like [CPRN.org](https://CPRN.org) and [AACPDM.org](https://AACPDM.org) where they can look for more information that may help them better understand and address your needs.

If you need a physical therapist, you can use the online directories from Choose PT ([choosept.com](https://choosept.com)) or the AACPDM ([aacpdm.org/providers](https://aacpdm.org/providers)) to search for one. If you cannot find someone who treats CP, look for a physical therapist who

treats neurological conditions. Providers who treat other neurological conditions will be familiar with managing some of the impairments you may experience because of your CP. For example, they may have worked with other adults who experience spasticity, muscle weakness, and limited range of motion. These physical therapists may also have experience in modifying functional activity and exercise around impairments.

### Will Insurance Pay for Physical Therapy If I'm Not Making Progress?

**Restorative physical therapy** focuses on regaining previous abilities based on a plan. When your goals are met, the therapy ends.

**Maintenance physical therapy** focuses on sustaining your current level of function and preventing or slowing the loss of function.

Many adults with CP may be enrolled in Medicare or Medicaid. They may still cover skilled therapy services when no improvement is expected. Maintenance therapy is included in their policies when skilled care is necessary to maintain function or to prevent or slow deterioration. This coverage applies to skilled nursing facilities, home health, and outpatient settings. You may have to work with your therapist to receive approval by Medicare or Medicaid to pay for maintenance therapy.

Health insurance may not cover maintenance therapy and most often has a set limit of visits. Some private insurance plans pay for wellness services and gym memberships, and you can use this to seek the help of a certified strength and conditioning coach. Consult with your physical therapist to create a transition plan.



## Additional Resources

### *Physical Therapy and Exercise*

The American Physical Therapy Association's ChoosePT: [choosept.com](https://www.choosept.com)

American Academy for Cerebral Palsy and Development Medicine providers directory: [aacpdm.org/providers](https://www.aacpdm.org/providers)

*Physical Activity Guidelines for Americans, 2nd edition*, from the U.S. Department of Health and Human Services: [health.gov/sites/default/files/2019-09/Physical\\_Activity\\_Guidelines\\_2nd\\_edition.pdf](https://www.health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf)

Centers for Medicare & Medicaid Services: [cms.gov](https://www.cms.gov)

# A Sample Exercise Program

The following information provides a general framework to consider in creating an exercise program for someone with CP. Although the studies reviewed to establish these ranges included no adverse events, it's vital to include your own history and unique health status when establishing an exercise program. Consult with your medical team before starting or resuming an exercise program after a period of inactivity to ensure you understand any necessary precautions to take or symptoms to monitor during activity.

EXERCISE	PROPOSED TARGETS
Cardio	<p><b>Frequency</b> → Start with 1-2 sessions/week and work up to 3 sessions/week</p> <p><b>Intensity</b> → Work to reach &gt;60% peak heart rate (see the American Heart Association's "Target Heart Rates Chart" at <a href="https://heart.org/en/healthy-living/fitness/fitness-basics/target-heart-rates">heart.org/en/healthy-living/fitness/fitness-basics/target-heart-rates</a>)</p> <p><b>Time</b> → Aim for at least 20 minutes each time → Increase the sessions per week and time as you can</p> <p><b>Type of Exercise</b> → Do activities that keep you moving steadily, like walking, biking, hand/foot cycling, running, swimming, propelling your wheelchair, or dancing → Community adaptive sports can be a fun option!</p>
Strength Training	<p><b>Frequency</b> → Aim for 2-4 sessions/week → Avoid lifting 2 days in a row—try doing it every other day</p> <p><b>Intensity</b> → Do 1-3 sets of 6-15 repetitions for each exercise → Try lifting weights that are about 50-85% of the most you can lift</p> <p><b>Time</b> → Keep up your training for at least 12-16 weeks</p> <p><b>Type of exercise</b> → Gym-based lifting equipment (e.g., leg press) → Free weights → Body weight exercises → Ask your doctor or physical therapist about closed kinetic chain exercises</p>

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## Types of Physical Activity to Promote Cardiorespiratory (Aerobic) Health

### Frame running

This is a type of adaptive running that uses a wheeled frame for support. The frame looks like a trike with large wheels, which surround the runner to provide stability. (For more, see “Introduction to Frame Running” at World Abilitysport: [worldabilitysport.org/sports/developing-sports/frame-running](https://worldabilitysport.org/sports/developing-sports/frame-running).)

### Using the stairs

Going up and down steps or climbing stairs can be more low-impact than running while increasing mobility and strength in your hip muscles.

### Cycling

Cycling includes using a road bike or stationary bike, which can be upright or recumbent.

### Handcycling and arm cycling

A handcycle is similar to a bicycle but is pedaled with the hands. Like a bike, it can also be upright or recumbent. Fitness Gear Scan has a guide to using an arm ergometer, which is like a stationary bike but for the upper body: [fitnessgearscan.com/arm-ergometers-a-comprehensive-guide-to-upper-body-workouts](https://fitnessgearscan.com/arm-ergometers-a-comprehensive-guide-to-upper-body-workouts).

### Wheelchair propulsion

You can find many helpful videos related to wheelchair racing online: [video.search.yahoo.com/search/video?p=wheelchair+racing+training+programs](https://video.search.yahoo.com/search/video?p=wheelchair+racing+training+programs)

### Indoor rock climbing

Rock Climbing Central has a guide to climbing with a disability: [rockclimbingcentral.com/climbing-with-a-disability-everything-you-need-to-know](https://rockclimbingcentral.com/climbing-with-a-disability-everything-you-need-to-know)

### Swimming/aquatic exercise

Exercising in water can be ideal for people with mobility impairments because it puts less stress on your bones, joints (where two or more bones connect), and muscles. Aquatic exercise is often a good option for individuals with cerebral palsy as a lifelong fitness activity. These workouts can be more gentle, but water also provides increased resistance that can help you build muscle and improve endurance. This kind of activity often takes place in warm water, which can help reduce pain in your joints and muscles and decrease spasticity and contractures. Options for aquatic exercise include swimming, aquatic yoga, resistance exercises, balance and range of motion exercises, assisted walking, and games.

### Summary

Movement and exercise help you maintain your health and wellbeing. For adults with cerebral palsy, it’s important to develop physical fitness and a sustainable physical activity plan whenever possible. Adults with CP have a high risk of earlier onset aging from both the way their bodies developed in childhood and their mobility limitations over their lifetime. Physical fitness, physical activity, and exercise can provide important ways to optimize your health and wellbeing now and for years to come.

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Exercise information (left) source: Verschuren, O., Peterson, M. D., Balemans, A. C. J., & Hurvitz, E. A. (2016). Exercise and physical activity recommendations for people with cerebral palsy [Table 3]. *Developmental Medicine & Child Neurology*, 58(8), 798–808. [doi.org/10.1111/dmcn.13053](https://doi.org/10.1111/dmcn.13053). Adapted with permission from the authors and Mac Keith Press.

# Additional Resources

## Exercise

American College of Sports Medicine, "Health-Related Fitness for Children and Adults with Cerebral Palsy": [digitalcommons.sacredheart.edu/pthms\\_fac/260](https://digitalcommons.sacredheart.edu/pthms_fac/260)

The National Center on Health, Physical Activity and Disability site provides an array of resources and opportunities around physical activity for people with disabilities: [NCHPAD.org](https://www.nchpad.org)

"Strength & Fitness Exercises for People with Disabilities" Instructable by user radiorental: [instructables.com/Strength-Fitness-exercises-for-people-with-disab](https://www.instructables.com/Strength-Fitness-exercises-for-people-with-disab)

Adams, H. P., Norton, C.O., & Tiden, H. M. (2005). *Aquatic Exercise Toolbox*. Human Kinetics.

The Academy of Neurologic Physical Therapy fact sheet on maintenance therapy and neurodegenerative conditions: [neuropt.org/docs/default-source/degenerative-diseases-sig/ddsig-fact-sheet-updates-2022/dd-fact-sheet-template---maintainence-care-\\_final.pdf](https://www.neuropt.org/docs/default-source/degenerative-diseases-sig/ddsig-fact-sheet-updates-2022/dd-fact-sheet-template---maintainence-care-_final.pdf)

"Skilled Maintenance Therapy Under Medicare," from the American Physical Therapy Association: [apta.org/your-practice/payment/medicare-payment-coverage-issues/skilled-maintenance-therapy-under-medicare](https://www.apta.org/your-practice/payment/medicare-payment-coverage-issues/skilled-maintenance-therapy-under-medicare)

The Centers for Medicare & Medicaid Services January 14, 2014 transmittal clarifying coverage of maintenance therapy: [cms.gov/regulations-and-guidance/guidance/transmittals/downloads/r179bp.pdf](https://www.cms.gov/regulations-and-guidance/guidance/transmittals/downloads/r179bp.pdf)

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# Fatigue

## How Common is Fatigue?

Adults with CP experience fatigue more often than people without CP. Fatigue also appears to be a complaint that occurs throughout the lifespan, possibly increased by changes that occur with early onset aging.

## How Does Fatigue Happen?

There are many reasons you may feel fatigue, including lifestyle issues (poor sleep, alcohol use, not enough physical activity, too much physical activity) or an underlying medical reason (vitamin deficiency, chronic infection, chronic obstructive pulmonary disease, diabetes, irritable bowel syndrome, medication use, and others).



Other sources of fatigue may not be physical but cognitive, as some people use a lot of mental effort to perform daily activities. For example, people with cerebral/cortical visual impairment may use a lot of extra energy just to get through the day trying to coordinate and process visual information (see the section “Cerebral/Cortical Visual Impairment” on page 83 for more information). Emotional fatigue may be present as well, and support is needed for this type of fatigue (see “Mental Health” on page 140). You should work with your physician to determine if any lifestyle or medical conditions are contributing to your fatigue.

One of the things that may also contribute to fatigue in adults with CP is that their muscles develop differently. As a result, it takes more effort and energy for people with CP to move as compared to their peers. **No wonder people with CP report fatigue!**

When the CP Research Network asked adolescents and adults with CP in a separate survey what contributed to their fatigue, they reported the following:

- Activity related factors
- General demands of life
- Lack of sleep/rest
- General health concerns
- CP-related factors
- Mental health concerns
- Environmental factors

“As I’ve had to source my own food and on occasion cook, I have to balance the stomach sensitivity I have with what is available. It adds to my exhaustion.”

—CP Research Network community member

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## What Can You Do to Improve Fatigue?

Unfortunately, there are no evidence-based interventions to reduce CP-related fatigue. However, extensive rehabilitation experience and some literature shows that people may benefit from **fatigue management**. Fatigue management uses specific strategies to help reduce fatigue and increase activities.

The **first step** is to work with your physician to identify lifestyle and/or underlying medical reasons that can be addressed. **Sleep problems** are highly correlated to fatigue, and assessing sleep as part of fatigue and pain management is important (see page 82 for more information on sleep). **Pain** is also related to fatigue, and pain management is an important part of managing fatigue (see page 107 for more information on pain).

The **second step** is to seek out resources and consult with specific health professionals such as speech, occupational, and physical therapists who can assist with your personalized fatigue-management plan. They may recommend equipment, lifestyle changes, or specific techniques to support you.

In one study, adolescents and adults with CP reported using these five strategies to manage fatigue:

- Rest or relaxation
- Sleeping or napping
- Adjusting or limiting their activities
- Being physically active
- Using specific adaptations or assistive devices for executing tasks

There is some scientific support for exercise as a way to manage fatigue and pain among adults with cerebral palsy who are ambulatory. People with multiple sclerosis also experience fatigue, and about 30 years ago, an evidence-based program was developed to help them manage it. A similar fatigue-management course was recently successfully adapted and used with adults with cerebral palsy. Although some multiple sclerosis-specific information may not apply, the information managing fatigue and conserving energy may be helpful—see the additional resources below.

## Additional Resources

### *Fatigue*

The National Multiple Sclerosis Society, “Fatigue and Multiple Sclerosis”: [nationalmssociety.org/understanding-ms/what-is-ms/ms-symptoms/fatigue](https://www.nationalmssociety.org/understanding-ms/what-is-ms/ms-symptoms/fatigue)

*Fatigue and Multiple Sclerosis: Evidence-Based Management Strategies for Fatigue in Multiple Sclerosis* by the Multiple Sclerosis Council for Clinical Practice Guidelines: [pva.org/wp-content/uploads/2021/09/fatigue1b772.pdf](https://www.pva.org/wp-content/uploads/2021/09/fatigue1b772.pdf)

*Fatigue: Take Control*, a six-part series from the National MS Society: [youtube.com/playlist?list=PL0606D967E1E961B4](https://www.youtube.com/playlist?list=PL0606D967E1E961B4)

# Pain and Pain Management

## How Common Is Pain and at What Ages Can It Occur?

Pain is the most common complaint among children and adults with cerebral palsy. It is also one of the most cited reasons by adults with CP for decline in function. **About 90% of adults with cerebral palsy report having a pain problem during adulthood and 70% report having chronic pain problems.**

In this section, you'll learn why people with CP experience pain and learn strategies for pain prevention and pain relief. Pain should be discussed with your healthcare team. Determining the source of the pain and addressing it early before it affects your daily life is essential to supporting your health, wellbeing, and best possible function as you age.

**The presence of new or worsening pain is a warning sign that should not be ignored. Pain lasting for three months or more is chronic pain.**



Image by Morgan Newnham.

The CP Research Network is actively pursuing research and quality improvement (QI) projects to better understand the types of pain people with CP experience and how to best address them.



Sign up for our MyCP community portal to take part in discussions about pain and other important topics. You will also have the opportunity to participate in research surveys like the one that helped identify pain as a top concern among adults with CP.

## Pain Screening

You may not be used to bringing up your pain during your doctor visits because you have been living with it most of your life and you don't think your provider can help. It is important to tell your provider about your pain, especially if it is getting worse and/or interfering with activities. Describe the location and what you are feeling (burning, stabbing, aching) so that your provider can suggest the correct treatments.

**“People just ignore the pain, and it is just always there, until it begins to prevent [you from] performing activities.”**

—Duncan Wyeth, retired Paralympic athlete & CP Research Network research partner

## Sources of Pain

There are many reasons why people with CP experience pain. Some studies suggest that neonatal exposure to pain—early life in the NICU with pokes, tubes, lights, and noises—can influence sensitivity to pain. Tight muscles, arthritis in joints, and pain from using a joint or body

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part too often or the wrong way (overuse syndromes) are common in CP. Pain among people with CP can include immediate pain after a procedure or pain lasting for more than three months such as headaches, stomachaches, knee or back pain, or just pain all over.

Pain that lasts more than three months is referred to as **chronic pain**. Different types of chronic pain can arise from the musculoskeletal system as well as other systems in the body such as the gastrointestinal system (the system responsible for digestion and the absorption of nutrients). Chronic pain may be widespread, or it may be local. Urinary tract infections, constipation, poor hydration, poor quality sleep, and lack of movement may contribute to chronic pain. It is important to get support to identify the cause and type of pain to reduce its impact on your function.

**“I have chronic pain, and I would gladly wish it gone, cured, away. Yet I also cannot spend all of my time pursuing cures, because I would never have a life.”**

—Alice Wong, *Disability Visibility: First-Person Stories from the Twenty-First Century*

### **What Are Some Ways to Manage or Address Pain?**

Once you have received an appropriate diagnosis or uncovered the reason for your pain, your treatment can target your underlying pain condition. In many instances, this will require a step-by-step multidisciplinary approach that includes a team of specialists. Treatments vary and may approach addressing pain in different ways.

### **Some examples of ways to manage or address pain include:**

- Improving lifestyle management, including nutrition, physical activity, stress management, sleep habits, and social connections
- Therapy, including PT, OT, and speech therapies
- Medications that change how the brain responds to pain signals or reduce inflammation that may be causing or worsening pain
- Adaptive equipment, particularly seating and positioning strategies
- Psychological interventions, including coping tools to support how you think about your pain
- Surgery that addresses the source of pain or assists with pain management, such as nerve blocks to disrupt pain signals

In the CP community, the word “therapy” is most often used to refer to physical therapy (PT), occupational therapy (OT), and speech therapy. It is also used to refer to mental health therapy. Context usually makes which type of therapy is being referred to clear. See the “Additional Ways of Addressing Pain” on page 112 for more information.

The best treatments for pain relief take a holistic approach, considering not only how your pain feels but also how it makes you feel in general, how it limits your activities, the consequences of those limitations, and how all of this affects your overall enjoyment of life. This approach includes options like **psychological therapies, stress management, mindfulness, sleep hygiene**, and both **pharmacological and non-pharmacological** treatments for pain.

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If you have pain and cerebral palsy, remember that it's important to **find the source** of your pain. Consult your physician and other providers—like physical, occupational, and speech therapists—for specific recommendations.

“I have much more pain now than I did when I was a kid. I’ve had chronic pain probably since I was a teenager (I’m 31). It feels like playing Whac-A-Mole a lot of days, like what’s going to hurt today? Pain and fatigue are the biggest reasons why I use mobility aids. My pain has also changed following two major orthopedic surgeries two years ago. These decreased pain in some areas and increased it in

others. For instance, the pain in my knees is greatly improved, but because my feet are in front of my knees for the first time in my life, I’m putting much more weight on my feet and ankles, and that hurts. I manage it by using my mobility aids as much as possible, and I’ve recently started wearing custom AFOs [ankle-foot orthoses] that have really helped my pain when standing and walking. Other than that, a hot shower can go a long way.”

—Cara Liebowitz, disability rights activist and writer



Image by Katelyn Wamsley.

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## Ideas for Targeting Pain Without Medication

There are a variety of ways that you and your providers may choose to address your pain. Non-pharmacological approaches (approaches that do not involve the use of medications) for pain management often take the form of **lifestyle changes for reducing and/or coping with pain.**

**These are changes you can make to your daily habits that may improve your health and well-being, including:**

- Exercise—both aerobic and resistance training
- Psychological approaches
- Stress management
- Therapies that may help you cope with pain
- Improving your nutritional intake and maintaining a healthy weight
- Improving sleep hygiene

**Other ways of addressing pain that do not include medication:**

- Biophysical agents (e.g., electrical stimulation, ice packs, hot packs)
- Posture management
- Joint protection
- Physical, occupational, and speech therapies to assist with lifestyle changes, assistive devices, and exercises

“When I was younger, my CP-related pain was in my knees, largely on the left side of my body, or in my legs when I walked a lot. Now, my body hurts more often and includes the right side of my body. However, as cliché as it may sound, allowing myself to rest has been one of the best pain management tools I’ve had.”

—Melissa See, author and disability consultant

## Exercise

Exercise targets all types of pain. In the general population and among people with chronic low

back pain, exercise has been shown to reduce pain more than no treatment, other standard treatments, or a placebo (false treatment). It can also lessen the impact of low back pain on daily activities. Additionally, there is evidence that exercise offers short-term pain relief for people with chronic pain from knee arthritis. Exercise provides an analgesic pain-lesening effect, and pain intensity is reduced for a period after exercise.

At this time, there is no evidence that these benefits differ for people with CP. Speak with your medical team about the kind of exercises that will work best for your body and align with your goals. Check in with your medical team before starting any new exercise program or restarting a program after a surgical or other medical procedure to determine whether you should take any precautions

“[My pain] gets better with exercise and worse with stress, which often have an inverse correlation in my life. I actually have an accountability system now and I am learning a sport along with my able-bodied peers, which has been motivating me to do the stretches I am more uncomfortable with in order to keep up and beat them.”

—CP Research Network community member

## Psychological Approaches for Managing Pain

### Stress management

Stress management is a collection of techniques and strategies to help people control their stress and improve their overall wellbeing. It can involve making changes to your life, preventing stress, and managing your response to stressful situations. The goal is to build resilience and improve the way you react to stressful things so you can have a balanced life and meet challenges head-on. Sometimes, these techniques are taught as part of psychological support services.

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## Mindfulness as a tool for stress reduction

Mindfulness is the ability to be fully present and observe the feelings and sensations in your body without judging them. It's a state of awareness that supports accepting what you're feeling by keeping your focus on the present moment. Many tools for supporting mindfulness are available online from mental health providers. Mindfulness has been shown to offer relief for low back pain, though it's still not clear if it is effective for knee pain. And it's worth noting that while mindfulness meditation can improve pain and depression symptoms and quality of life, additional well-designed, rigorous, and large-scale randomized controlled trials about these effects are still needed.

### Ways to practice mindfulness include:

- being as still as possible in your mind and thoughts
- focusing on your breathing
- observing the sensations in your body
- moving as intentionally as possible and concentrating on linking your movements with your breath
- trying any form of yoga, including chair, adaptive, or breathwork (pranayama)
- practicing gratitude and paying attention to what is working well for you

## Psychotherapy

Psychological therapies for chronic pain focus on improving how you feel physically and emotionally and how you function in social and daily life, rather than on resolving the pain itself. However, these treatments differ in what they approach, how long they last, and the particular goals that you choose. Psychological therapy takes a significant time commitment and several appointments, but many psychologists offer telemedicine so you can get care from home.

Research strongly suggests that people with chronic pain benefit from psychological treatments. Different approaches to therapy are



equally effective, and there are many different types of therapy to consider. When seeking support from a professional, ask questions about what methods they use and where you can find out more information about them.

### Below are three examples of therapies that may be used to manage pain:

- **Cognitive behavioral therapy** involves learning about pain, behavior, and mood, and developing strategies around relaxing, behavior, and communication, as well as ways to think about your pain.
- **Mindfulness-based therapy** helps you approach your pain without judgment and to see the physical side of pain separately from the mental or emotional side.
- **Acceptance and commitment therapy** focuses on accepting your pain and your emotions and thoughts about your pain rather than trying to control it.



## Nutrition and Weight

Your body weight can go up or down because of changes in your eating habits or activity levels. However, it can also change for reasons beyond your control, such as shifts in hormone levels. Ask your primary care physician or care coordinator about getting support from a registered dietician, who can help you learn about maintaining a healthy weight and nutritional status.

Extra weight can add stress to joints, muscles, and the heart, making movement take more effort. Increased weight can not only contribute to fatigue but also create more pressure and strain on your body parts, which can cause more pain. Sometimes weight loss, even in small amounts, may be helpful in reducing pain. However, being underweight or not getting enough nutrition can also harm your health and increase your risk of illness, problems with bone health, treatment complications, and pain.

## Sleep

Sleep and pain are closely linked, and poor sleep can increase pain sensitivity and make it harder to fall asleep. Sleep helps regulate inflammation, which can decrease pain sensitivity.

Positive sleep hygiene strategies may help reduce some of your pain. See page 83 for more information on sleep hygiene.

## Additional Ways of Addressing Pain

**Common pain management tools that rely on different energy sources** such as hot packs, electrical stimulation on your skin's surface, massage, and dry needling can be useful for different types of pain, including pain from stiffness, local pain, and nerve pain. Many therapists use these types of treatments to help people manage pain with success. In some instances, these approaches may reduce ibuprofen use.

**Rehabilitation therapy** options, including physical therapy, occupational therapy, and speech therapy can be used to manage pain. It can be very helpful to find a therapist who has experience working with people with neurological injuries. Physical therapy works on targeted strengthening, spasticity management, and neuromuscular rehabilitation to improve overall function. Occupational therapy helps with pacing, energy conservation, finding adaptive equipment, and upper extremity function. Speech therapy may help with pain related to the jaw or face.

**Posture management** for people with cerebral palsy involves using positioning techniques, specialized equipment, and exercises to keep the body aligned, prevent deformities, and improve movement and function. Regular changes in position throughout the day help you to avoid pressure sores and muscle stiffness.

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Your medical care team can provide specific strategies tailored to meet your particular needs. For example, regularly switching between lying on your back, stomach, and sides can prevent contractures and promote muscle flexibility. Specialized cushions, wedges, and foam rolls can stabilize the body in desired positions and reduce pressure points.

Some people need customized wheelchairs and seating systems designed to provide proper postural support and alignment.

**Reducing the stress on joints** will help most pain types. One major issue for joint stress is being overweight, and weight is difficult to manage when you have the mobility considerations that come with CP. However, losing 10 pounds can take 50 pounds of pressure off a painful hip joint, so if this is contributing to your pain, even small amounts of weight loss are valuable.

Other ways to reduce stress on your joints include lifestyle changes like using assistive mobility devices for longer distances, wearing a brace to protect a joint, using a cane, having someone else do things that may be harder for you to do, and using other forms of adaptive equipment or a service animal to assist you.

People with osteoarthritis and rheumatoid arthritis have challenges that are similar to people with CP, and programs that teach joint protection for people with these types of arthritis can be helpful.

### **Pharmacological Treatments for Pain**

Medication treatment options are varied and should be considered carefully in the context of all other medical conditions. Taking more than one prescription medication may lead to drug interactions that can cause serious side effects like sedation, trouble thinking clearly, and further problems with coordinating your movements.

Pain medications fall into two categories: non-opioid and opioid pain relievers. Opioids, which attach to opioid receptors to block pain signals, work well but are addictive and cause constipation. Non-opioids are all other drugs that can relieve pain. They work by different mechanisms and often have fewer side effects. These include acetaminophen, nonsteroidal anti-inflammatory drugs (NSAIDs), and antidepressants such as serotonin and norepinephrine reuptake inhibitors (SNRIs) and tricyclic antidepressants (TCAs). All have demonstrated efficacy in a variety of neuropathic pain conditions.

Several non-opioid drugs that are used to treat epilepsy may also be used to treat certain kinds of pain, possibly reducing the number of medications you need to take. You can talk to your healthcare team about whether this is a possibility for you. Local anesthetics are frequently used by adults with CP who have pain caused by nerve damage. Speak with your doctor for more information about the kind of pain you have and potential treatments.

All drugs have risks and benefits to weigh, and some drugs you may hear more about in the media than others (for all kinds of reasons), so be sure to consider these factors and more that may be relevant, when you evaluate and discuss your medical treatments with your healthcare team.

Opioids are recognized as the most effective and widely used drugs in treating severe pain. They are among the most controversial pain medicines, particularly because of their potential for addiction, tolerance build, and side effects. **Although opioids have indications for acute and chronic pain treatment, the Centers for Disease Control and Prevention's guidelines recommend use only if the expected benefits for both pain and function outweigh the risks.**

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Importantly, opioid medications are not recommended as a first-line treatment for pain except for short term use after surgery or severe injury. In particular, opioid medications have been shown to be ineffective at addressing widespread chronic pain.

Cannabidiol (CBD) is a hot topic, particularly for people with chronic pain. Some observational and clinical studies support CBD's effectiveness and safety in treating chronic pain; however, the scientific evidence is not strong enough to properly and safely determine dosage. While the FDA has not approved an application for cannabis for treating any disease or condition, it has approved one prescription cannabidiol, the drug Epidiolex, for treatment of some seizures. To date, this is the only FDA-approved cannabis-derived drug product. It has also approved three synthetic cannabis-related drug products for treating nausea from cancer treatments.

## Summary

**Pain should not be ignored.** There are many practical and lifestyle changes that can be included in your treatment plan for pain management. **It's important to accurately identify the source or sources** of your pain and address any coexisting conditions, such as sleep issues or stress, that may be making it worse. Pain is a complex issue. It often takes multiple visits to a provider (either medical or rehabilitative) and treatment approaches before you will start to notice improvement.

With the help of your healthcare providers, begin to actively engage in activities such as exercise, lifestyle changes, and joint protection as early as possible.

It's important to consult with your healthcare providers before beginning a new exercise routine so that you do not worsen your pain.

## Additional Resources

### *Pain and Pain Management*

Joint protection tips from the Arthritis Foundation: [arthritis.org/health-wellness/healthy-living/managing-pain/joint-protection/16-joint-protection-tips](https://www.arthritis.org/health-wellness/healthy-living/managing-pain/joint-protection/16-joint-protection-tips)

The National Center for Physical Activity and Disability (NCHPAD) has many videos on mindfulness: [youtube.com/@NCHPAD](https://www.youtube.com/@NCHPAD)

The Mindfulness, Exercise, Nutrition, and Resilience program by NCHPAD is a great online support program that can start you on your way: [cprn.org/mentor](https://www.cprn.org/mentor)

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# Aging and Musculoskeletal Management

## Functional Decline and Changes in Functional Ability

“Perhaps people with CP deal with this process a little sooner and at times a little more intensely, but everyone over time loses ability and tends to need more help. We all lose a certain amount of our independence as we get older.

I do miss being able to do what I used to do (I especially miss being able to canoe). It’s also difficult to see my capabilities slowly deteriorating and that I am becoming more limited in what I can do and need more help from others. I can no longer walk at all without assistive aids, or [without] hanging on to handholds. I try to adjust, but I like having a sense of independence.”

—John Borland, CP Research Network community research partner

You may have heard cerebral palsy is a nonprogressive condition. This means that the original injury that caused CP will not get worse over time. However, the effects of that injury on the body and living with CP can lead to changes as you age. As you get older you may experience changes in movement, speech, and activities of daily living.

Many people typically undergo a decline in functional abilities with aging, but adults who have CP seem to experience an **early onset aging process**. Changes in walking and other functional abilities can occur early in life and have been reported by adolescents with CP as well as adults with CP in their 20s, 30s, and 40s.



“I have not experienced changes in the way I move or my stamina. If anything, my stamina has improved since I frequently work out and lift weights.”

—Steve Ferreira, community advocate and Paralympic athlete

Between 2019 and 2024, the CP Research Network conducted surveys of adults in its community registry about function and pain. More than 60% of people who responded reported a decline in walking and other functional abilities as they aged.

Pain, fatigue, and changes in tone increase the risk for functional decline with aging. However, not all people with CP experience functional

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decline. Adopting or maintaining positive lifestyle habits play an important role in reducing the effects of aging for anyone, and definitely in people with CP. Maintaining an active lifestyle with supportive health habits like a healthy diet and good social connections are important.

“I want others to know that just because CP is not progressive doesn’t mean your function is stable. It changes over time, and what you can do at five years old, you can’t necessarily do at 25. This looks different for everyone because CP is not a uniform diagnosis. The sooner you understand this fact, the easier it’ll be for you to plan the accommodations you will need at every stage of your life.”

—Greg Moomjy, creative producer and Founder & Artistic Director of Opera Praktikos, New York’s first disability-affirmative opera company ([operapraktikos.org](http://operapraktikos.org))

### Understanding and Reducing Functional Decline

The functional decline experienced by adults with CP is not fully understood. Still, much evidence suggests that early onset aging is caused by a mix of physiological, social, and personal factors.

The nervous, musculoskeletal, and/or cardio-respiratory systems in people with CP develop differently. People with CP enter adulthood with lower bone and muscle mass, less strength, and less physical fitness than their peers without CP. This predisposes individuals with CP to early



onset chronic diseases, such as **sarcopenia** (age-associated loss in muscle mass), **high blood pressure**, **diabetes**, and **chronic kidney disease**. Seeing a PCP regularly can set you up for success as you age. Work with your PCP to ensure you’ve received all recommended **preventive screenings** for the general population. Talk with them about any symptoms or concerns you may have as well. Your PCP can coordinate your care and communicate with an interdisciplinary medical team to recommend evaluations and treatments to target your healthcare needs.

You can minimize common lifestyle choices that can lead to chronic diseases just by **developing a health and wellness plan** with your PCP and other healthcare providers such as a registered dietician or physical therapist. Adults with CP may also be at greater risk for joint problems, psychiatric conditions, and gastrointestinal disorders.

Having multiple health issues is not uncommon when you have CP, and that can be hard and sometimes overwhelming. Do the best you can to address them. Don't hesitate to ask your medical providers to help you tease apart and target these issues and any others, so that you access as much support as possible while minimizing their impact on your daily life.

If you experience any changes, seek **multidisciplinary care** through multiple providers to thoroughly investigate your symptoms, as the cause may be reversible.

Sometimes an orthopedic problem causes neurological problems. For example, cervical stenosis is a narrowing of the spinal canal that can cause paralysis of the arms and legs and changes in sensation and bladder control (see "Common Musculoskeletal Conditions in CP" on page 124). These symptoms may be reversible with orthopedic surgery if the cause is the compression of the spinal canal. Annual checkups to evaluate your functional abilities, how pain interferes with your activities, and what preventive strategies you can use will help optimize your mobility as you age.



## Supporting Your Health and Wellness Through MENTOR

The National Center on Health, Physical Activity and Disability (NCHPAD) offers an eight-week program called Mindfulness, Exercise, and Nutrition, to Optimize Resilience (MENTOR) to help build health and wellbeing skills:

[cprn.org/mentor](https://cprn.org/mentor)

"I absolutely love this program! It's wonderful and so beneficial. . . . I have truly enjoyed the exercise days!! It's amazing what we can do in a chair, and I'm more motivated to do it because of the class setting."

—Brooke Larrabe, MyCP member and MENTOR participant

If you join MyCP ([cprn.org/mycp](https://cprn.org/mycp)), you will be matched to surveys that are relevant to your experience with CP. You also will have access to summary information from your reported health status that you can share with your physician to support or enhance your clinical visits and care.



Join MyCP, our community portal, to find information, take part in research surveys, and connect with people on our discussion forum.

# Falls and Cerebral Palsy

Everyone experiences falls; however, people who have cerebral palsy experience them at a higher rate than those who do not have CP. This can be due to several factors, including weakness and balance impairment. It is reported that 53–97% of people with CP who walk fall each year, and these falls can result in injury, frustration, and restricting activities. At this time, limited research has been published about falls in adults with CP. Any fall should be evaluated by a medical professional to see if you need to be referred to therapists to develop programs that increase your strength and mobility or to evaluate your need for assistive devices.

More research is needed in this area, particularly to evaluate whether interventions reduce the frequency of falls. A study by CP Research Network researchers surveyed 381 people with CP, ranging from children to older adults (ages 5–76). It found that 86% had experienced at least one fall in the past year. Children aged 5–12 and individuals with moderate mobility impairment (GMFCS Level II) reported the highest fall rates. Most falls occurred while walking on uneven surfaces or when feeling fatigued.



Stay updated with the latest info on falls in people with CP through our MyCP webinars: [cprn.org/mycp-webinar-series](https://cprn.org/mycp-webinar-series)

## Falls and Aging

More than half of those surveyed (55%) experienced at least one serious injury due to a fall. The likelihood of severe injuries, such as fractures and concussions, increased with age. Among participants aged 50 and older, 80% reported experiencing a significant fall-related injury in the last year. Head injuries, including concussions and cuts requiring stitches, were among the most common types of traumas.



## The Emotional Impact of Falls

Beyond physical injuries, falls also have a significant psychological impact. Falling can be frustrating and embarrassing. Many people in the study said they lost confidence after falling. Older individuals and those with more mobility challenges (GMFCS Level III) were the most worried about falling. Because of this fear, some people avoided activities they enjoyed, which reduced their independence and mobility.

## Preventing Falls

Given the high risk of falls and injuries, the CP Research Network study emphasized the importance of proactive fall-prevention strategies, including:

- Regular fall tracking: Keeping a record of falls can help individuals and their healthcare providers identify patterns and develop prevention plans.
- Strength and balance training: Physical therapy and targeted exercises can improve stability and reduce fall risk.
- Environmental modifications: Making sure that home and public spaces are free of tripping hazards can significantly lower fall occurrences.
- Addressing mental health concerns: Support groups, counseling, and education on fall prevention can help individuals regain confidence and maintain an active lifestyle.

Falls remain a major concern for ambulatory individuals with CP, impacting both physical health and quality of life. This study underscores the need for greater awareness, proactive prevention efforts, and continued research into effective fall-management strategies. By working together—as individuals with CP, caregivers, and medical professionals—we can reduce fall risks and improve overall mobility and independence.

Read more about this study on our website: [cprn.org/understanding-the-physical-and-psychological-impact-of-falls-in-ambulatory-individuals-with-cerebral-palsy](https://cprn.org/understanding-the-physical-and-psychological-impact-of-falls-in-ambulatory-individuals-with-cerebral-palsy).

## Optimizing Bone and Muscle Health over Time

As you age, it's important to have your bones and muscles regularly evaluated, monitored, and cared for. Your skeletal system and muscles work closely together, each influencing the strength and function of the other. By keeping them in the best shape possible, you will be supporting your overall health and wellbeing.

### Monitoring Bone Health

Your skeleton is your body's framework. It gives your body its shape, protects your organs, and allows you to move. It also stores minerals and makes red blood cells. As someone with CP, your skeleton's health and integrity are key priorities that require ongoing monitoring and health management, particularly in adulthood.

Many people with cerebral palsy have fragile bones and reduced bone mineral density that increases the likelihood of fractures. This is a problem particularly for people with CP who



have limited ambulation (walking ability). Some of the risk factors for decreased bone mineral density (BMD) in adults with CP include reduced physical activity, reduced muscle strength, vitamin D deficiency, and taking certain medications. There are, however, ways of supporting your bone health, and it's important to discuss these strategies with your healthcare providers.

### Some experts recommend the following approaches to monitoring and supporting bone health when you have CP:

1. Having an initial bone density scan, known as a **DXA scan**, in early adulthood (some clinicians may say sooner) to establish a baseline bone mineral density (BMD) measure. DXA scans can help you and your provider understand what is happening with your bone health over time. Discuss ongoing screening frequency with your primary care doctor since official and specific health guidelines for people with CP have not been established yet.
2. Get regular physical activity as tolerated and in some cases under the supervision of your primary care doctor, therapist, or other specialists. Focusing on strengthening your muscles in particular (see the next section) will support maintaining your bone mineral density.

3. Calcium and vitamin D are important aspects of maintaining your bone health. You can get calcium and vitamin D from foods that you eat regularly, but people often need more. How much more? Clinician researchers aren't exactly sure, particularly when it comes to Vitamin D. Despite there being lots of published research on this subject, there are still many questions about the role of vitamin D in health, and bone health in particular. There are a number of official guidelines about daily intake for calcium and vitamin D for the general population based on age group and sex assigned at birth. You can discuss your specific risk factors with your PCP or another healthcare provider accustomed to treating people with CP. Ask them about their clinical opinion as it relates to your health.
4. Ask your primary care doctor to evaluate any medications you are taking because some may be associated with bone loss.



### Types of Physical Activity to Promote Bone Health

Your bones experience force when you move, and the amount, direction, and variety of that force impacts bone health. Sports like soccer, exercise that involves jumping, and intense exercise can promote bone health. Resistance training, cycling, walking, and swimming can be lower-impact options. There is growing evidence that bone formation in people with CP is different than in people who don't have CP. Bone development and structural organization happens during your childhood. Children with cerebral palsy usually experience inadequate bone development, which leads to weakened bones in adulthood.

**In the general population, bone fragility is often regarded as a women's health issue. However, for people with cerebral palsy, bone fragility is a health issue for all genders.**



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While everyone needs to be conscious of their skeletal health, this is especially true for people who have difficulty moving. Even if it is hard to move, you can find ways to move or be moved to promote skeletal health. **Movement is medicine for the skeleton.**

**Some examples of movement that support skeletal health include:**

1. Being pushed fast in a jogging stroller. The bumps and small movements of the body create new forces on the skeleton that can promote bone health.
2. Assisted aquatic exercise, which can help the person to move their body in new ways and engage their muscles.
3. Whole-body vibration machines—which can be a standing frame, tilt table, or seated bench—can increase skeletal health.

### **Fractures and Post-Fracture Health Issues**

Bone fragility often leads to **fractures**, which are breaks or cracks in the bone. **While many clinicians are aware that adults with CP are at high risk of fractures, fewer realize that young adults with CP are also at risk.** In fact, men and women with CP between the ages of 18 and 35 have a similar risk of nontraumatic fractures to that of older adults (65+) without CP.

Fractures are not just a bone problem. After a bone fracture, individuals can experience a decrease in mobility. The decrease in mobility can create new health issues or exacerbate ongoing issues.

If you have had a fracture and are recovering, talk to your doctor about using physical therapy (PT) and/or occupational therapy (OT) to help you become mobile again. While many people recover from fractures without therapy, rehabilitation is more important for adults with CP. Research suggests that post-fracture therapy can prevent complications down the road.

Fortunately, there may be several points along this process where individuals and clinicians can intervene to prevent, treat, or reduce the impact of these health issues.

### **Muscle Changes over Time**

Muscles are connected to our skeleton by our tendons. Tendons allow us to create force against our skeleton to produce movement. The close relationship between muscle and bone means that muscles play an important role in bone health, functional abilities, and decreasing the risk of cardiovascular disease through movement. As we get older, our bodies go through many changes: This is especially true for adults with cerebral palsy. One of these changes is a decrease in muscle size. Everyone loses muscle as they age, but people with CP begin losing muscle younger. Losing muscle means a decrease in strength.

“Although I have maintained an active lifestyle into my 70s, particularly in continuing to cycle several times a week, I have experienced muscle mass weight loss and my DXA bone scans have indicated a decrease in density over the past decade, but not a precipitous loss. This does impact my activities relative to strength-based tasks and increases my caution about sustaining possible fractures from falling.”

—Duncan Wyeth, retired Paralympic athlete



Photo by David Trinks.

## What Causes Loss of Muscle in Cerebral Palsy?

People with CP experience early muscle loss because they have a different muscle makeup or composition. As a person with CP, you have more connective tissue around your muscles, and your muscles contain more fat compared to people who do not have CP. **This means that people with CP start off with smaller muscles than people without CP.** Because of this, losing muscle will have a bigger effect on you.

## Inefficient Muscle Firing

Our brains talk to our bodies using chemical signals that travel through our nerves. These nerves connect to our muscles and tell them when to move and when to relax. In people with CP, this communication can be different. You might have trouble making certain muscles move because they are too tight (spasticity) or too loose (hypotonia). You might experience co-contraction, where two muscles that should work opposite each other, like hamstrings and quadriceps, both try to move at the same time. This can make things like walking more difficult.

## Decreased Physical Activity

Many people with CP are less active in adulthood. This may be due to **pain**, changes in **muscle tone**, and **fatigue**. When you are less active, you lose muscle mass. And when you lose muscle mass and strength, you often become even less active. This can become a problematic cycle.

## Why Is This Important?

Losing muscle can lead to less strength, balance, and endurance, which can affect your ability to walk, take care of yourself, work, and do the activities you enjoy. When you are less active, you lose even more muscle.

Being less active can also make your bones weaker and lead to early **osteoporosis**, which is a bone disease resulting in brittle, weak bones. Osteoporosis makes breaking bones more likely, which also results in decreased activity and more muscle loss and loss of function.

Older adults with CP who stay mobile and maintain their function often say this is due to regularly doing exercises that help with balance and strength.

People with CP often have more body fat compared to muscle than those without mobility issues. This means that your body mass index (BMI) may underestimate your true risk for heart disease. You should talk to your primary care doctor about different ways to look at your risk, such as measuring your waist-to-hip ratio. A DXA scan, which is an important test to evaluate your bone health, can also provide information about your ratio and fat to lean muscle to help you understand your risk. If your doctor orders a DXA scan, ask the about using it for body composition as well.

## What Can You Do If You Have Become Less Active?

If pain is stopping you from exercising, talk to your doctor. If your braces, crutches, or

wheelchair are causing you pain, talk to a **physiatrist** (also known as a physical medicine and rehabilitation specialist), **physical therapist**, or **occupational therapist**.

If changes in muscle strength or tone are making it hard to exercise, talk to a physiatrist about possible treatments. There are targeted physical therapy interventions that can help.

If you want to get stronger, steadier, or have fewer falls, talk to your doctor about doing physical and/or occupational therapy. It is important to do the exercises your therapist gives you at home, even after you finish your physical therapy treatment.

See “Exercise for People with CP” on page 102. It is best to check with your physician and therapy team before starting any exercise program.

### Summary

Adults with CP have differences in their nerve, bone, and muscle structure and function due to their early brain injury. This puts them at risk

for **early onset aging**, which means that they experience many of the chronic health conditions (cardiovascular disease, kidney disease, bone disease) that occur with aging and poor lifestyle choices (smoking, obesity, and substance abuse). There are specific physical exercises that can be done to improve muscle and bone health and function.

Be sure to talk with your doctor about bone health screening, prevention, and education as early as possible. **It is important to note that not all people with cerebral palsy will sustain a fracture, and for those who do, not all will develop a serious health issue.** You may need to inform your doctor about your risk of early onset bone fragility. If you sustain a fracture, talk with your doctor about taking your post-fracture health and recovery very seriously.

Be sure to access physical, occupational, and exercise physiologists for support in designing exercise programs and options that work for you and that you enjoy.

## Additional Resources

### *Optimizing Bone and Muscle Health over Time*

“Cerebral Palsy and Physical Activity,” from the Cerebral Palsy Research Network: [cprn.org/cerebral-palsy-and-physical-activity](https://cprn.org/cerebral-palsy-and-physical-activity)

“Live Well: Being Active,” from UP: The Adult Cerebral Palsy Movement: [upmovement.org.uk/live-well/being-active](https://upmovement.org.uk/live-well/being-active)

“Physical Activity and Fitness,” from Cerebral Palsy Alliance: [cerebralspalsy.org.au/support-by-age-group/18-30-years/physical-activity-and-fitness](https://cerebralspalsy.org.au/support-by-age-group/18-30-years/physical-activity-and-fitness)

“Benefits of Evidence-Based Physical Activity for People with Cerebral Palsy,” from Cerebral Palsy Foundation’s Cerebral Palsy Resource: [cpresource.org/topic/exercise-sports-recreation/benefits-physical-activity](https://cpresource.org/topic/exercise-sports-recreation/benefits-physical-activity)

“Exercise, Sports & Recreation,” also from Cerebral Palsy Foundation’s Cerebral Palsy Resource: [cpresource.org/topic/exercise-sports-recreation](https://cpresource.org/topic/exercise-sports-recreation)

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# Common Musculoskeletal Conditions in CP

The previous section discussed the importance of bone and muscle health. Along with your joints and connective tissue, these make up the musculoskeletal system. This system is central to many of the movement-related symptoms and conditions associated with CP, making it a key focus in long-term care and management.

In people with CP, the combination of having extra connective tissue (tissue that connects and supports other tissues and organs) and muscle weakness can contribute to joint stiffness and the development of deformities. Regular monitoring by orthopedic or rehabilitation doctors can help catch issues early so that treatments can be started to reduce the impact of progressive deformities.

Because of their bone structure, people with CP are at risk not only for fractures but also for other bone and joint problems. Bones respond to pressure, and over time, deformities can develop due to the uneven forces placed on the skeleton from muscle imbalances.

Repetitive use of muscles can result in overuse injuries, such as sore tendons (tendonitis), swollen and painful joints (bursitis), or pain and numbness from a nerve injury (neuralgia). Overuse injuries are common in adults with CP, particularly for people who rely more on certain muscles or joints due to spasticity or weakness in other areas. These injuries can have a big impact on your function and wellbeing. Understanding these challenges and using preventive strategies, including physical therapy, orthotic devices, and medical monitoring, can help manage these complications and enhance your overall quality of life as you age.



Orthotic devices, such as braces or splints, may be prescribed to support proper joint alignment and prevent further deformities. Spasticity management, especially focused treatments like botulinum toxin or phenol injections, may help you regain mobility.

People with CP experience additional skeletal stress, particularly on their hips and spine, due to their tone and movement patterns being different than those of people without CP. Although we have the science to understand how to monitor these issues in childhood, there isn't much information about screening or care for the hips and spine once someone reaches skeletal maturity. If you did not have hip surveillance where your hips were X-rayed and monitored on a regular schedule as a child and adolescent, this may be a particularly important conversation to have with your providers.

Below are some of the common bone, joint, and muscle problems experienced by adults with cerebral palsy. Your body is at much greater risk for these conditions than the general population. You need to take care of it, regularly see doctors, and be proactive in presenting changes in your body and symptoms to your medical team as they arise.

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## Osteoarthritis

Adults with CP may experience degenerative joint changes as they age. The constant stress on joints, combined with altered alignment and muscle imbalances, can lead joint surfaces to deteriorate. Osteoarthritis, a degenerative joint disease, is common in adults with CP. It can affect weight-bearing joints such as the hips and knees, causing pain, stiffness, and reduced mobility.

Some people with CP develop hip arthritis due to wear and tear at a younger age than those without CP. This can result in pain and limit motion. If you have changes in hip symptoms, you should discuss them with your physician. It may be appropriate to get X-rays and consult with an orthopedist about potential intervention.

Management strategies for osteoarthritis in individuals with CP may include weight loss, physical therapy, assistive devices, and, in severe cases, joint replacement surgery.

## Muscle Contractures of Upper or Lower Limbs

Muscle contractures are when muscles, tendons, or other tissues shorten and harden, which can cause joint deformities and stiffness.



These can occur when muscles and tendons become shortened and tight due to persistent spasticity or immobility. **Spasticity** is a hallmark feature of CP, in which increased muscle tone leads to stiffness and difficulty in controlling movements. Over time, the constant pull of tight muscles can result in contractures at the elbows, wrists, hips, knees, and ankles, limiting range of motion and making daily activities more challenging. Strengthening exercises and prolonged positioning, often with splinting or casting, can help manage contractures. In some instances, surgery may be recommended to release the muscle.

## Spinal Conditions

**Scoliosis**, a spinal curvature, can also develop over time in individuals with CP. It can emerge later in life even if an individual did not have a curve in their spine during childhood. Spasticity and muscle imbalances contribute to scoliosis, as the uneven forces on the spine can cause it to curve to one side. This is compounded by poor bone health. Scoliosis can lead to postural abnormalities, respiratory issues, and discomfort. Regular monitoring and intervention, such as bracing or surgery, may be necessary to manage the progression of scoliosis and prevent further complications.

Decreased movement and strength may also result in increasing kyphosis, an exaggerated forward rounding of the upper back, with the head protruding forward. This can cause stress on the nerves in the neck and may result in chronic pain. A physical therapist can provide exercises and may be able to suggest equipment to reduce the stress on the neck. The spine should be monitored by an orthopedic surgeon.

Some people with CP who walk most of the time may have always had an increased lordosis, an exaggerated inward spinal curve in the lower back. This occurs due to muscle imbalances around the hips, which cause an increased curve when walking. The lower back already

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absorbs a lot of stress during movement, and an increased lordosis adds to these stresses. This can cause chronic pain and arthritis. It may also result in stress fractures in the vertebrae, also called spondylolysis. A physical therapist can recommend movements and exercises to help improve flexibility and strength in that area.

**Cervical spinal stenosis** (a form of central stenosis) is a common but underdiagnosed condition in adults with CP. It involves a narrowing or compression of the spinal canal and/or the nerve passages in the neck. This condition can sometimes lead to myelopathy, a serious spinal cord injury resulting from severe compression. **Adults with CP are eight times more likely to develop myelopathy than the general population.** One large study found that the average age at which adults with CP developed stenosis was 54. For this reason, baseline screening for myelopathy is recommended around age 40. Adults with CP with contractions that cause abnormal head movements (dystonic head movements) may have a higher risk for cervical stenosis.

Discuss any symptoms such as changes in bladder function, numbness or tingling, especially in the hands and arms, or weakness. Significant changes in your movement pattern should be discussed with your providers. After a careful examination of your strength, sensation, and function, it may be helpful for you to have specialized imaging such as a CT scan or MRI of your neck or other areas of your spine.

At this time, there are no official healthcare guidelines for screening and monitoring people with CP for conditions like spinal stenosis and myelopathy. This makes it all the more important for providers who treat adults with CP to be aware of these progressive conditions. Their symptoms can sometimes be mistaken as features of CP, when in fact they are due to a treatable condition that requires attention. Discuss your risk factors and existing peer-reviewed research with your healthcare providers.

**Central stenosis** can also occur in other areas of the spine, such as the lumbar area, and may cause functional decline. It can lead to symptoms such as pain, numbness, tingling, and weakness in your neck, shoulders, arms, or legs, depending on what part of your spine is affected. Stenosis can also cause changes in bladder and bowel function and paralysis of the arms and legs if left untreated. Healthcare providers may mistake these symptoms for the effects of aging with CP, when in reality it is a treatable condition that requires attention and can make it seem like your CP is worsening.

**Foraminal stenosis** is a narrowing of the openings that your nerves pass through in your spinal bones. This can pinch or compress your nerves. Because it is caused by degenerative changes in the discs, joints, ligaments, and bones of the vertebrae, foraminal stenosis is common with aging, both in people with and without CP. Nonsteroidal anti-inflammatory drugs such as aspirin, ibuprofen, or naproxen are widely used to relieve pain and reduce inflammation. Cortisone injections, activity modification, physical therapy, and exercises can also provide relief. Movement can improve flexibility and strength, as well as reduce pain. Surgery may be required in severe cases, but it can generally be avoided.



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## Wrist and Shoulder Conditions

People with CP who predominantly use their arms for mobility—whether they use a wheelchair or walk with a walker or crutches—may develop overuse syndromes in the shoulders, elbows, or wrists. These include conditions like **torn rotator cuff**, **tennis elbow**, and **carpal tunnel syndrome**, which can cause pain, inflammation, and reduced function, making daily tasks more difficult. Strengthening and flexibility exercises can help those who rely heavily on their upper extremities maintain wrist and shoulder function. Over time, **subluxation** or **dislocation** of the joints may occur as muscles and tendons lose strength and elasticity. Treatment options include exercises, braces, and surgical stabilization. Therapists can also provide guidance on joint protection techniques. If you use a manual wheelchair, adding electromechanical assistance to your wheels (power assist) may decrease symptoms.

## Hip Conditions

Muscle contractures at the hip most often impact the hip flexors, which bend the hip, and hip adductors, which bring the knees together. These contractures can be addressed through reducing spasticity or through surgical procedures. Hip dysplasia is another condition that occurs when the hip joint has not developed properly and the socket is too shallow. Because the hip is a ball-and-socket joint, a shallow socket can cause the ball to slip out over time. The displacement of the femur head can lead to uneven leg length and limping, and may result in pain and arthritis. This can be corrected with surgery and occurs in both adults who walk and those who use wheelchairs. Total hip replacements are sometimes an option for hip dysplasia.

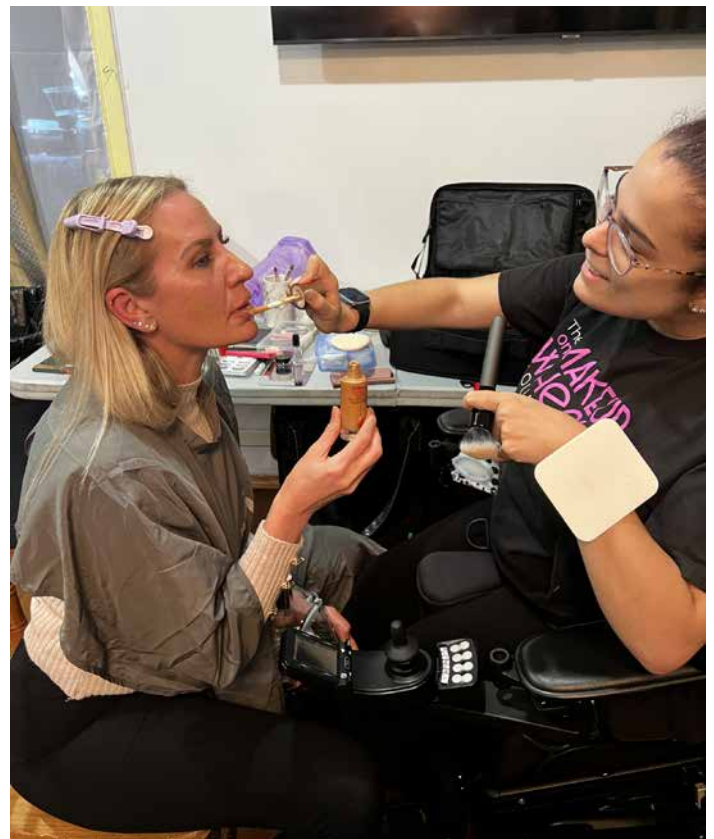
## Knee Conditions

The most common knee condition for people with CP is knee flexion contracture, in which the knee stays bent and cannot be fully straightened. This is linked to problems like

softening, tearing, and erosion of the kneecap (chondromalacia) and a kneecap that sits too high can easily dislocate (patella alta). Positioning, exercise, bracing, and surgery can address knee conditions.

## Foot Conditions

**Foot deformities** often progress into adulthood. Adults who have flatfoot or clubfoot may see progressive deformity and pressure sores over some regions of their feet. One of the most common foot deformities is a bunion, when the big toe joint is pulled out of place and a bony growth develops. This can cause the big toe to turn either sideways or downward. Proper shoes, specialized inserts or braces, flexibility exercises, and sometimes surgical intervention can be used to manage foot deformities.



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# The Surprise of Cervical Spinal Stenosis: A Personal Perspective

By Lisa Blumberg



Please note that this personal story is intended to give a sense of how Lisa felt as she discovered she has spinal stenosis. This essay is not intended as, nor should it be construed as, a way to diagnose the cause of your own symptoms. Consult with your doctor about any health concerns or symptoms you may have to determine their cause and how best to address them.

On Friday, March 23, 2018, when Janice, the pet therapy lady, came with a languid dog whose name evades me, I could still take some steps if I leaned my full weight on my walker. My internist had just told me that my MRI indicated the progressive weakness in my extremities was being caused by upper spinal cord compression from cervical stenosis. This totally surprised me. I was having pain now as my muscles tightened, but it wasn't in my neck or back. My posture was good enough. My doctor wanted to quickly set up a neurosurgery consult. Cautious by nature, I replied that I'd talk to my brothers and get back to her.

I was born with athetosis, one of the less common forms of cerebral palsy (CP). My physical disability was brassy and in-your-face, affecting my gait, fine motor skills, and speech. However, I always lived independently, worked at a corporate job every day, pursued many other interests, and microwaved supper quickly. For the past year, I had been coming up with shifting explanations for my slowly mounting difficulties. I was 65, so the frequent pauses in my steps were due to age. No, it was from my worn-out shoes. Wait, it had to be because of my walker, which I had started using recently (just by coincidence!) for stability. It was too low, too high, too stiff, and too wobbly. The handles weren't right.

In October 2017, I had seen my local physiatrist. He suggested more exercise, but I was already getting exercise. I worked out with a trainer twice a week. Later, I would read that the symptoms of cervical stenosis can be "subtle"—things like slowness in getting dressed.<sup>1</sup> In my case, this wasn't subtle. It began to take me two hours and then more.

Suddenly, it was taking me until midnight to clean up supper, then half an hour to walk to my room, and several to prepare for bed. I would not lie down until 3 or 4 a.m. My problem, I decided, was clearly lack of sleep, and indeed my judgment

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plummeted. In winter, I was in free fall as well as falling all the time, spending hours on the floor trying to get up. I had trouble flicking light switches. My internist did every lab test in the book. They all came back negative.

I started with a physical therapist, and she gave us a clue. “You are overcome by spasticity, but it is not coming from CP. It is coming from somewhere else.” My internist ordered the MRI.

During this dismal time, my brothers had been searching the internet, baffled by the lack of information on boomers with CP. On the day of my MRI results, though, they found a fact sheet put out by the American Academy for Cerebral Palsy and Developmental Medicine that stated that adults with CP may be at risk for spinal stenosis as they age. Refuting the common misperception that CP can get worse, it urged that any loss of function should be urgently investigated as possibly being spinal stenosis. Prompt treatment is essential; a 2017 study suggested that cervical spinal stenosis is a “hidden epidemic” for adults with CP, especially with those with athetoid CP.<sup>2</sup> Due to the “devastating” consequences of untreated cervical stenosis, it proposed active screening of people with CP over 50. We had had absolutely no inkling of any of this.



Photo by David Trinks.

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We went to Mass General because if I needed surgery, we wanted the A team. Going to the ER in another state on a Sunday night is probably not the best way to find a top specialist, but we had no other choice, and we were not disappointed. The diagnosis of severe cervical stenosis with myelopathy—my spinal cord was being choked—was quickly confirmed.

The doctors thought that the stenosis had been building up for years as I went about my active life, and then it flared. My only option was a laminectomy involving the removal of four cervical vertebrae and a fusion.

The operation, carried out urgently, went great, the neurosurgeon said. I was safe now. The surgical goal was to stop the spinal cord damage. I would need a lot of rehab to restore function. I spent six weeks at Spaulding Rehabilitation Hospital, where occupational and physical therapy filled my time and progress was measured by whether I could stand with a max, mod, or min assist.

I was home by May 2018, slowly relearning how to do the things I did before. I am very lucky. I have the huge support of family, friends, and coworkers and access to the best care. Yet my recovery is more arduous than it could have been had stenosis been on my radar. That is why I want to raise awareness. People who lead successful lives despite practical and social obstacles must not be stopped in their tracks.

*A graduate of Wellesley and Harvard Law School, Lisa Blumberg has worked as a corporate lawyer. She is also a writer and disability rights activist focusing on health-care issues.*

## NOTES

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Hung, C., Linhares, D., Matsumoto, H., Callejo, F., Kim, H., Roye, D., Dutkowsky, J. (2017). Cervical spinal stenosis in adults with cerebral palsy—a hidden epidemic? *Developmental Medicine & Child Neurology*, 59(3), 90–91. [doi.org/10.1111/dmcn.19\\_13512](https://doi.org/10.1111/dmcn.19_13512)

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# Treatments for Musculoskeletal Conditions

Now that we've covered common musculoskeletal conditions in CP, let's look at potential treatments and interventions you may hear about that could help manage them.

Talk to your healthcare providers about whether a surgical intervention or other treatment could be the right option to address your personal concerns and goals. Make sure your providers are clear about what you want to achieve, such as more efficient walking, improved sitting, or less pain.

## Common Orthopedic Interventions for Adults with CP

### Soft Tissue Surgery

- **Tendon lengthening:** A procedure to physically cut or lengthen tendons to increase their length, which can improve joint range of motion and function. Tendon lengthening allows for recovery of muscle strength after surgery. Children and teenagers usually respond better to this surgery than adults.
- **Contracture release:** Cutting away the shortened muscle, tendons, and other tissue surrounding the joint to allow the joint to move. This procedure may be done to make personal hygiene care easier, relieve pain, and/or improve positioning. It's important to understand that contracture release surgery will **permanently** reduce the strength of the muscles released but allow for free movement. Discuss this and any other potential trade-offs or concerns with your providers.



### Bone Surgery

- **Osteotomy:** Surgical cutting and reshaping of bones to improve alignment, correct deformities, and enhance function. For example, hip surgery may improve the positioning and location of the hip joint in the socket. An osteotomy may also enhance the rotation of the bones to improve gait. It takes longer for adults to regain their strength after surgery than for children, and recovery can last more than one year.
- **Joint fusion:** Permanently joining together two bones in a joint may be considered if a joint is unstable or severely deformed. Common types of joint fusion in adults include fusing the big toe joint to treat a bunion (when the big toe turns sideways) or painful bumps on the top of the foot called dorsal bunions.

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## Spinal Surgery

- **Laminectomy:** A surgery to treat central stenosis by removing bone spurs and/or part of a spinal bone. This helps open up the spinal column and relieve pressure on the nerves. Doctors may also remove abnormal disc material (a discectomy) during a laminectomy.
- **Scoliosis correction:** A major procedure that straightens the spine and aligns the hips and shoulders to correct an abnormal curve. The surgery can take several hours or longer if the area involved is large. During the procedure, the surgeon will make an incision to reach the spine and will use implants, such as rods, screws, hooks, cages, or wires, to help straighten it. They may also use bone grafts to hold the spine in place, move muscles aside, or remove joints between vertebrae. Special equipment is used to monitor the nerves that come from the spine. Given that adults with CP often have low bone mineral density and high likelihood of vertebral deformity, spinal surgery in adulthood is complicated. It is generally recommended in adolescence after growth is completed.

## Joint Replacement

**Hip or knee replacement:** Surgery to replace part or all of a joint with an artificial implant. For individuals with severe joint degeneration, this type of surgery may improve mobility and alleviate pain. Adults with CP have a higher risk of complications from this surgery compared to patients without CP. This includes greater chances of dislocation, infection, fracture, and implants becoming loose.

## Orthotics and Assistive Devices

Instead of or in addition to surgery, a complete approach to managing musculoskeletal issues in adults with CP may involve a variety of treatments, including orthotic devices, physical therapy, and assistive technology. An orthosis is a device that you wear, like a brace or a splint, to improve the stability or alignment of your bones, muscles, or joints. Learn more about assistive devices in “Opening Up Opportunities with Assistive Technology” on page 54.





CP can present in many different forms (spastic, dyskinetic, ataxic). These types of CP can occur in different combinations throughout the body, which can affect a person's functional abilities in unique ways. The approach to treating CP often focuses on answering these questions:

- How does the person move and which disorders of movement and tone are present?
- How do multiple movement disorders interact with one another to impact the person's function?
- Are there conditions related to movement that cause discomfort or pain?
- Are there conditions that may be present but not causing interference, pain, or functional limitations? Just because a movement disorder is present doesn't automatically mean it needs to be treated or that treating it would be helpful!

## Tone It Down! Spasticity and Abnormal Muscle Tone Management

**Muscle tone** is the amount of tension (that is, firmness or resistance to movement) in a muscle at rest. Muscle tone is what maintains our posture and keeps us upright when we are standing or sitting, and changes in muscle tone are what allow us to move. **Much of your health-care focus as someone living with cerebral palsy involves managing the symptoms and conditions related to having abnormal muscle tone and/or involuntary or extraneous movements.** Abnormal muscle tone can make it hard to move, but it can also make it hard to sit or stay still comfortably. Tone may change with aging and can cause problems for adults with CP.

When it comes to treating CP, you often hear about targeting or isolating certain muscle imbalances. This may include muscles that have too much or too little tone that impairs a person's ability to control and coordinate how they move or sustain their posture. Treatments may also aim to address pain from muscles not working together.

It's difficult to tease these pieces apart and determine how to improve symptoms without affecting function in some unintended way. However, screening and diagnostic tools for disorders of movement in CP have improved. For example, there have been recent advances in screening procedures for dystonia in people with CP in the US starting with our own network of hospital systems, and we now know that most people who have CP also have some dystonia. With awareness and changes like these, clinicians can learn how to better address related symptoms.

### Disorders of Tone in CP

**Spasticity** is the most common type of movement disorder seen in people with CP, affecting approximately 80% of the population. Spasticity is when muscles involuntarily stay stiff and tight due to central nervous system impairments that keep them overactive, causing increased muscle tone. It can interfere with posture and movement, cause pain, and limit function.



## Hyperkinetic Movement Disorders in CP

These are movement disorders in CP that involve involuntary movements that may repeat, have patterns, or be brief and/or random. These movement disorders such as dystonia may be hard to identify and therefore overlooked. The CP Research Network has been addressing this issue through quality improvement (QI) studies focused on improving the consistency and approach to screening for disorders such as dystonia.

There are some targeted treatments for certain dyskinctic forms of CP that focus on symptoms related to dystonia, chorea, and athetosis (chorea and athetosis are commonly seen together and referred to as choreoathetosis). However, these treatments are limited and may primarily focus on supporting positioning, posture, or pain relief.

**Dystonia** is a common hyperkinetic movement that is present in approximately 70% of people

with CP. Dystonia causes increased muscle tone (hypertonia) and involuntary muscle contractions and spasms that can lead to repetitive movements and abnormal postures. These movements are often activated through voluntary movement (movement you initiate) as well as being triggered by excitement or stress, or having someone move your body. Dystonia can affect just one limb or area of the body, or the entire body. It can be painful, disrupt sleep, and interfere with daily life.

Even though it's not always easy to detect dystonia, particularly in one office visit, because it's not always obvious, it's important to understand whether you have it. For more information about dystonia, download the CP Research Network's *Dystonia in CP Toolkit* from our website ([cprn.org/our-toolkits](http://cprn.org/our-toolkits)) or purchase a printed copy: [mixam.com/print-on-demand/67a679fab1eae2040e97d16f](http://mixam.com/print-on-demand/67a679fab1eae2040e97d16f).

**Hypotonia** is decreased muscle tone, so when a healthcare provider examines the limbs, they feel heavy and give no resistance (or less resistance) to passive stretch. This type of tone is most common in the chest and neck in people with CP, but it can also be seen in the arms and legs. Adults with CP may be at risk for falls and arthritis because of low tone. Hypotonia can be supported with therapies and bracing such as knee braces for walking and weighted vests for trunk stability.

**Ataxia** is not considered a disorder of tone. We include it here, however, because it is the only remaining primary form of CP that we have not mentioned. Ataxia is a less common form of CP and is often described as problems with coordination, balance, and targeting precise movements. A person who has ataxia has movements that appear wobbly or shaky. At this time, ataxia does not have a specific treatment, but related symptoms of hypotonia and walking instability are often addressed through therapy and bracing.

Learn more about how you can partner with us in advancing CP research by reading about our opportunities for people with lived experience: [cprn.org/partner-engagement-application](https://cprn.org/partner-engagement-application).

## The Impact of Muscle Tone Changes

Muscle tone changes, or changes in spasticity, are one of the primary reasons people with CP cite as causing functional decline. Changes in tone can also result in pain, balance problems, and falls. While the underlying reasons for these changes are not fully understood, changes in muscles, nerves, and brain activity have been documented with aging, and CP may contribute to these issues. Regardless of the cause, it's important to manage muscle tone in adulthood as it changes.

When considering tone treatments, it's best to choose functional goals to guide your choices and monitor effectiveness. You may need a combination of treatment options to reach these goals. Goals related to managing your tone can include things like improving wheelchair positioning, walking more efficiently, and increasing joint range of motion for activities of daily living, such as dressing. Treatment decisions should be driven by you working together with your health provider to choose the options that best support your goals. Below are some treatments that you may hear about.

## Treatments for Muscle Tone Disorders

The decision to undergo any treatment should be individualized, considering your overall health, goals, and functional limitations.

At this time, the amount and quality of evidence available to inform the management of involuntary movements or tone in people with CP, particularly in adults, is not enough to establish clear clinical guidelines. For this reason, we present information about treatments that are

considered some of the most commonly discussed in the context of tone management in CP. It is not meant to be an exhaustive list of treatment options, and clinical opinions may vary on using them and in what circumstances, but our intention is to provide you with a place to begin discussing tone management in CP with your healthcare providers.

It's important for you to work collaboratively with your healthcare providers to create an optimal treatment plan to address your particular needs, goals and concerns. Over time, the information relevant to this section will likely change and evolve as new evidence emerges about these treatments. Speak with your healthcare team about changes in knowledge about tone management and how it may impact your care.

## Therapies

Physical and occupational therapies are often key to successfully managing spasticity and dystonia. They can address a range of functional challenges—from targeted goals like improving the range of motion of a specific joint to broader aims like increasing your overall independence





in daily life. Physical and occupational therapies use many treatment options, but there's limited evidence about what works best for spasticity—and even less for adults with CP.

Current treatments focus on managing symptoms, such as providing support for maintaining posture and using oral medications to reduce involuntary movements.

Other potentially beneficial techniques include biofeedback, meditation, whole-body vibration, Pilates, yoga, and functional training. These techniques may help improve muscle strength, relax the central nervous system, support motor learning, and build endurance to reduce the effects of abnormal tone.

**Personalize** your combination of approaches. Finding a therapist focused on adults with CP can be challenging, but many providers are familiar with spasticity and dystonia and work with people who have chronic neurological conditions. These therapists may be able to help with your symptoms. Find physical therapists familiar with working with people with neurological conditions in ChoosePT's directory: [choosept.com/find-a-pt](https://choosept.com/find-a-pt).

**“Therapy is not a quick fix. It takes a while for some, but it's still worth it in the long term.”**

—Greg Moomjy, creative producer and Founder & Artistic Director of Opera Praktikos, New York's first disability-affirmative opera company ([operapraktikos.org](https://operapraktikos.org))

### **Bracing and Splinting (Orthotics)**

Splinting can help passively support a joint, providing a continuous stretch to combat increased muscle tone. Examples include using a removable hand splint while sleeping to keep the fingers straight or serial casting, using a nonremovable cast to progressively stretch a contracted joint.



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Braces, such as an ankle-foot orthosis (AFO), can also provide better functional positioning for activities like walking. For braces to be effective, they have to be worn regularly.

As the adult with CP, your perspective matters most. You know best whether bracing or splinting will be more comfortable for you, and which you will use more consistently.

## Commonly Considered Tone Management Medications

When it comes to medications, we still need more research and studies that compare the effectiveness of different drugs in meeting the needs of people with CP, but there are some that have been used repeatedly over the years that you may be more likely to hear about and we wanted to provide some basic information about them below.

**Baclofen** is commonly used to treat spasticity or dystonia. It is often the first-choice medication because it causes fewer side effects and medication interactions. This drug blocks messages from the spinal cord to help the muscles loosen up. Baclofen is generally well-tolerated, but it can cause weakness, sedation, or fatigue, which often limits dosing. Some patients report that it interferes with driving or the ability to concentrate at work. It has also been reported to decrease libido (sexual desire). You shouldn't stop taking it abruptly due to risk of serious withdrawal. It can be delivered by mouth or with an implantable device through a surgical procedure (see "Neurosurgical Procedures for Tone" on the next page). Baclofen is usually started at a low dose and gradually increased.

**Tizanidine** also works by reducing brain and nerve signals to the muscles, but at a different receptor. It also can cause sedation as a side effect, which again may limit dosing. Tizanidine can elevate liver enzymes and interfere with some antibiotics. Blood tests to determine liver enzyme levels should be done prior to starting

tizanidine and periodically while a person is taking it. Tizanidine is usually started at a low dose and gradually increased.

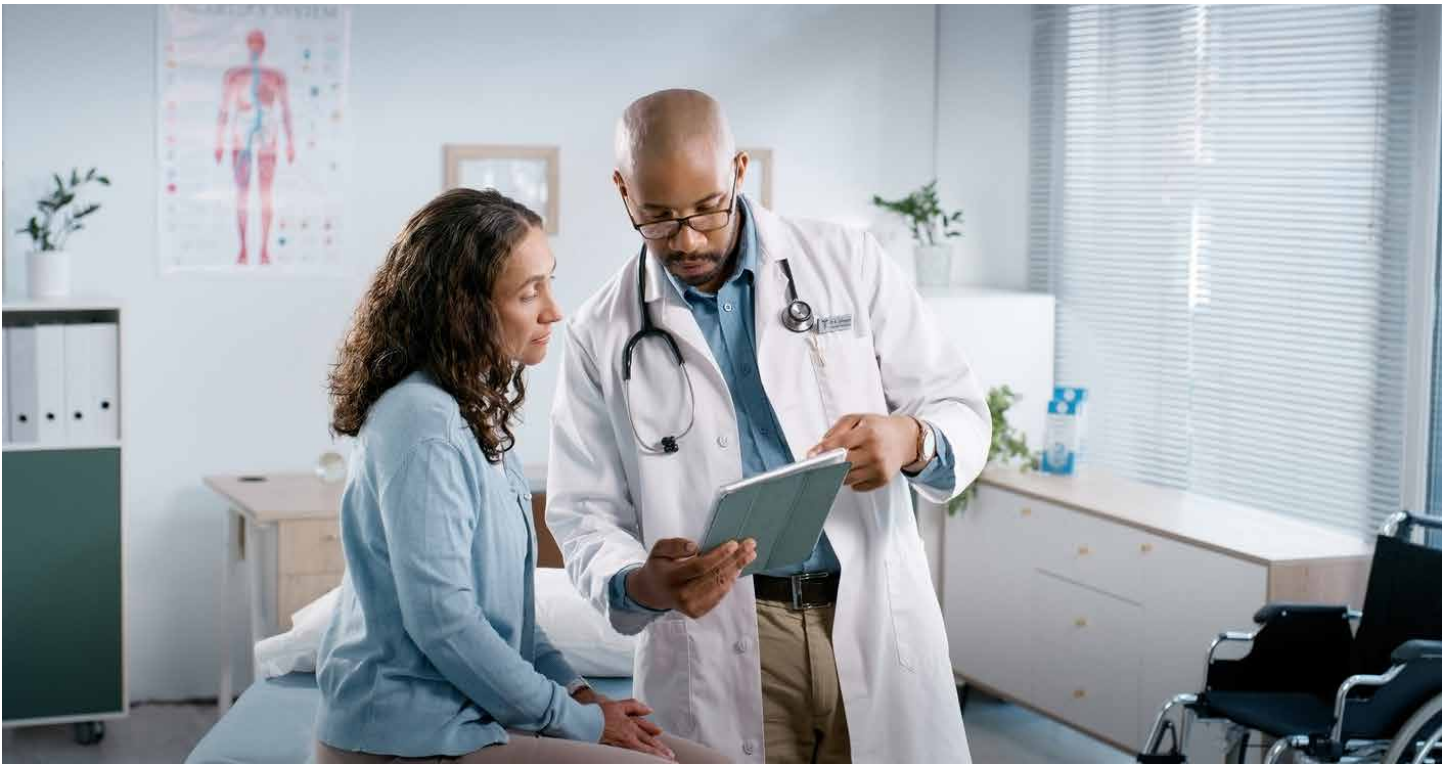
**Dantrolene** acts directly on the muscle itself by blocking calcium release. As a result, this medication is thought to cause fewer cognitive side effects, although there are still reports of it causing drowsiness and fatigue as well as weakness. It does carry a risk of liver toxicity, so use should be monitored with regular blood tests of liver enzymes before and during use.

**Benzodiazepines** also work by increasing inhibitory signals, but they carry the risk of cognitive side effects and oversedation. These medications have the potential for physiological dependence, posing withdrawal and abuse risks. Because of this, they are a controlled substance and not generally recommended as first-line treatment for spasticity or dystonia.

There is emerging evidence that cannabis-derived products reduce spasticity among people with multiple sclerosis, but research to support efficacy for reducing spasticity in other conditions is limited.

## In-Office Procedures for Targeting Spasticity

**Intramuscular botulinum toxin injections** are commonly used to treat spasticity or dystonia. These injections use the same botulinum toxin as cosmetic procedures, which is given in higher doses to treat limb muscles. The treatment blocks the signal from nerve to muscle. The effects of botulinum toxin are short, lasting only three to six months. This means the treatment requires repeated injections for continued benefit. Side effects include weakness and the risk of the toxin spreading to respiratory and swallowing muscles. This option works best for **focal spasticity**—spasticity that affects only one part of the body—with patient-specific goals.



### **Phenol Injections (Alcohol Blocks)**

Phenol is an alcohol that can be injected near a nerve, where it works by breaking down the proteins that make up the nerve. This disrupts the nerve's function and can reduce muscle stiffness. It can take effect almost immediately and can last from 4 to 12 months. Side effects include pain around the injection site and numbness of other nerves nearby. This option can be used to target easy-to-localize nerves and can be combined with botulinum injections.

### **Neurosurgical Procedures for Tone**

**Intrathecal baclofen (ITB)** delivers medication directly to the fluid-filled space around the spinal cord through an implanted, programmable pump with a catheter tube. This can be a great option for severe spasticity management, as it delivers medication close to the site of action rather than throughout the body, decreasing the likelihood of the cognitive side effects of oral baclofen. Intrathecal baclofen also carries the risk of withdrawal, which tends to be more severe than with oral baclofen. Withdrawal can occur if the medication in the pump runs dry or

if there is a problem with the tube connecting the pump to the intrathecal space. Therefore, the treatment can be a major commitment for patients and caregivers as it requires strict compliance and frequent follow-ups for pump refills.

**Deep brain stimulation (DBS)** is a surgical procedure that can help treat dystonia when other treatments have been less effective. During the procedure, electrodes are implanted into the brain (in the globus pallidus, a part of the basal ganglia) to help control abnormal signals that cause involuntary muscle contractions.

**Rhizotomy** is a nerve surgery to decrease high muscle tone. Rhizotomies are used to address a variety of concerns in people with CP, from pain to improving gait and function, or a combination of both. Deciding if this procedure is right depends on the patient's goals and on having a clear understanding of how they move and which tone or movement disorders they have, such as dystonia with spasticity. In some cases, people with more complex forms of CP (GMFC IV and V) may decide to trade some of their

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function for pain relief or improving the ease of navigating daily living needs such as dressing.

Although rhizotomies have traditionally been used in children with CP to address spasticity, some CP centers also perform the surgery on adults. As more data is collected about the outcomes from these procedures, particularly through our network, we may see broader adoption in the future.

You may hear people speak about different types of rhizotomy that distinguish how the surgeon approaches the spinal cord procedure. Selective dorsal rhizotomy, more commonly known as SDR (“selective” meaning specific nerves and “dorsal” meaning the nerves toward the back of the spinal cord), involves creating a small opening in the spine around the spinal nerves, then checking the sensory nerve roots for abnormal reflexes and cutting some of them.

Physical and occupational therapy are essential to improve functioning after selective dorsal rhizotomy, and most institutions prescribe an intensive outpatient or inpatient rehabilitation program after surgery.

For people with very severely increased muscle tone or dystonia that hasn’t been controlled or improved by medications or injections, ventral-dorsal rhizotomy (also called combined rhizotomy) may be considered. This involves cutting not only the sensory nerves but also some of the motor nerves that tell the muscles to move. Ventral-dorsal rhizotomy is typically only performed on people who have severely increased tone that has not responded to other treatments and who are dependent on others for most or all activities. Some hospitals use it to treat dystonia. Candidacy for this surgery, as well as surgeons’ comfort using this approach, varies.

## Additional Resources

“Dystonia in Cerebral Palsy Care Pathways” from the AACPDm is a great resource for your clinicians: [aacpdm.org/publications/care-pathways/dystonia-in-cerebral-palsy](https://aacpdm.org/publications/care-pathways/dystonia-in-cerebral-palsy)

*The Dystonia in Cerebral Palsy Toolkit* from the Cerebral Palsy Research Network provides parents, caregivers, people with CP, and clinicians who treat CP with insight into what having dystonia in cerebral palsy is like from the perspective of people with lived experience. It includes information about diagnosis, treatment, and current research. To access digital copies of our resources, including *The Dystonia in Cerebral Palsy Toolkit*, sign up for the CP Research Network’s community portal: [cprn.org/our-toolkits](https://cprn.org/our-toolkits)

*Tone It Down! Spasticity and Abnormal Muscle Tone Management*

“Dystonia in Cerebral Palsy: An Update on Our Progress” is a 2024 MyCP Webinar that highlights the CP Research Network’s ongoing work on dystonia in CP, developed in response to concerns raised by the community. This included creating community education materials and quality improvement initiatives aimed at addressing the absence of information, treatments, and understanding about dystonia in CP: [youtu.be/Wsy1s6edhVg](https://youtu.be/Wsy1s6edhVg)

Gillette Children’s. (n.d.) *Botulinum Toxin and Phenol (Injected Spasticity Medications)*: [gillettechildrens.org/conditions-care/botulinum-toxin-and-phenol-injections](https://gillettechildrens.org/conditions-care/botulinum-toxin-and-phenol-injections)

5.

# Mental Health

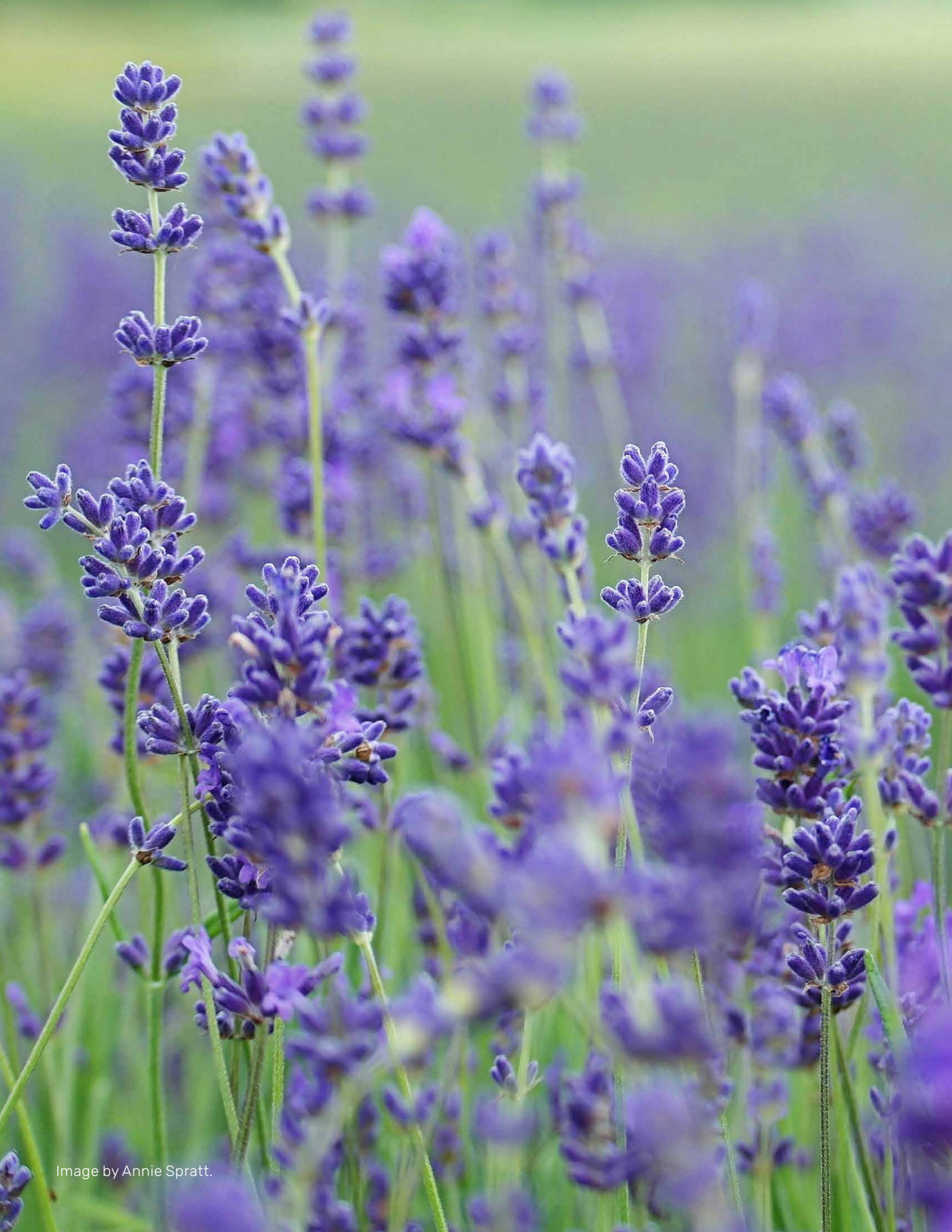


Image by Annie Spratt.

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# Emotional Wellbeing and Becoming an Adult: Tips to Be the Best You!

Going from childhood to adulthood can be hard for anyone. For people living with medical conditions and disabilities like cerebral palsy, navigating this transition can be especially overwhelming because it comes with a unique set of challenges on top of the usual ones. When facing so many difficulties, it's normal to struggle emotionally—and there are many ways to find help and support from professionals, friends, family, and other social support networks.

Being open about your struggles can lead to better support and care. Studies show that identifying and treating mental health and other health conditions early can reduce the severity—and possibly the duration—of symptoms. Being aware and seeking support are the first steps toward improving how you feel and your overall wellbeing.

Our mental health as human beings is impacted by many factors that are important to consider in evaluating and treating mental health conditions in anyone—not just people with CP.

## Some influences on mental health include:

- Circumstances or life events
- Biology and genetics
- Ongoing anxiety about feeling unstable in your environment—like worrying about falling, tripping, or navigating your environment
- Childhood experiences and related trauma
- Feeling socially isolated or disconnected from family and friends
- Physical factors such as sleep, nutrition, or physical pain
- Cultural and religious perspectives we feel connected to

At this time, we need more targeted research to understand how to best evaluate and treat mental health conditions and symptoms in people with cerebral palsy. It is especially important to consider how other treatments, particularly psychiatric medications, may interact with medications commonly taken by people with CP, as well as how they might affect movement-related symptoms—such as with balance, coordination, or changes in muscle tone—that can impact functional movements.

“When we think about strategies to approaching mental health in individuals with cerebral palsy, the first thing [is] we want to make sure the psychiatric symptoms are not due to an underlying cause like pain, intrathecal baclofen pump malfunction, shunt malfunction, common things like dental problems, ear infections, things like that.”

—Dr. Heather Riordan, “Cerebral Palsy, Mental Health and Psychotropic Medications”, 2023 AACPD Community Forum



Image by Priscilla Du Preez.

## Here Are Some Ways to Support Your Emotional Health

- **Find things you like to do.** There are so many options! Read or listen to music, audiobooks, or podcasts. Play a musical instrument or board games, garden or watch a great movie. Hang out with friends. Take deep breaths, go outside, or do exercises that feel good in your body. In some cases exercise has been shown to be even more effective than medication in improving depression and anxiety symptoms. If you are unsure what exercises are right for your body, ask your doctor or physical therapist.
- **Take care of your health.** Eat well, get enough sleep at night, and move or exercise in ways that are right for your body. Take your medications and attend doctor's appointments as scheduled. Ask for help if keeping track of your appointments and medications is challenging. Your doctor's office may have social workers and case managers that can help with introducing strategies for supporting your daily routine. There are also mood trackers that gently remind you to record your feelings, changes in your routine, and how often you are engaging in an activity. This information can help structure your day and provide valuable information to your care team. You may even notice that some activities are associated with improved mood or state of mind. This can give you insight into how to better support your mood and recovery.
- **Be with other people.** Being around and feeling connected to other people plays a key role in mental health. This can include seeing friends or family in person or connecting with people through online communities. Remember that staying safe is also important to your mental health. You deserve to be with people who are respectful and kind. Until you know someone well, meet in a public place where there are many other people around.

- **Get help if you need it.** Consider seeking support from a counselor or therapist. They can help you work through your feelings and identify potential resources and support for the problems you're facing. Ask your medical doctor for a recommendation or referral or call your insurance company to find a therapist that takes your health insurance. At the end of this chapter, you'll find a list of additional mental health resources.

"I have anxiety disorders and accompanying depression in addition to CP. It's anyone's guess whether that's because of CP or just a coincidence. What really made a difference for me was finding a therapist who is disabled herself and understands the ableism I face every day. I can talk to her about things like inaccessibility and she understands."

—Cara Liebowitz, disability rights activist and writer



The seven types of rest were created by Sandra Dalton-Smith, MD, a physician, researcher, and author.



Image by Tavin.

**Help is available.** If you or someone you know is struggling with suicidal thoughts or mental health, call or text the **US Suicide and Crisis Lifeline at 988** or reach out to one of the support resources listed below.

“There is hope, even when your brain tells you that there isn’t.”

—John Green, *Turtles All the Way Down*

### Helplines and Crisis Lifelines

#### SUICIDE AND CRISIS LIFELINE

Confidential emotional support to people in suicidal crisis or emotional distress  
24/7, free, available in English and Spanish  
Call or text 988  
Chat online at [chat.988lifeline.org](https://chat.988lifeline.org)

#### THE TREVOR PROJECT

Suicide and crisis hotline for LGBTQ+ youth  
24/7, free, available in English  
Call 1-866-488-7386  
Text START to 678-678  
Chat online at [thetrevorproject.org/get-help](https://thetrevorproject.org/get-help)

#### TRANS LIFELINE

Peer support for trans people in crisis  
Free, 24/7, available in English and Spanish  
1-877-565-8860

#### CRISIS TEXT LINE

Text-based crisis counseling  
24/7, free, available in English and Spanish  
Text HOME or HOLA to 741741

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA) NATIONAL HELPLINE

Information for individuals and families facing mental and/or substance use disorders  
24/7, free, available in English and Spanish  
1-800-662-HELP (4357)

If you live outside of the US, Find A Helpline is a resource that can connect you to help:

[findahelpline.com](https://findahelpline.com).

#### FOR CAREGIVERS

Suicide is Different provides guidance and free support calls for people supporting a loved one with suicidal thoughts: [suicideisdifferent.org](https://suicideisdifferent.org)

#### FINDING TREATMENT

Substance Abuse and Mental Health Services Administration (SAMHSA) treatment services locator: [findtreatment.gov](https://findtreatment.gov)

#### FIND A PSYCHOLOGIST

American Psychological Association  
Psychologist Locator: [locator.apa.org](https://locator.apa.org)

#### FIND A PSYCHIATRIST

American Psychiatric Association Psychiatrist Locator: [finder.psychiatry.org](https://finder.psychiatry.org)

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## Mental Health and CP

Each person has unique circumstances in their life that influence their mental health. As an adult with CP it's important to work with someone such as your primary care doctor who can help you target areas for treatment or support that may be negatively impacting your mental health. Whether you need help with managing sleep, nutrition, pain, social circumstances or difficult emotions, there are people and resources to help you establish and incorporate tools and strategies into your daily life to support your mental health.

In some cases you may find that mental health providers and specialists accustomed to treating people with brain injuries or disorders can offer important insight and information for managing your mental health. Talk with your primary care physician or other healthcare provider for more information, and the resources in your area that best align with your needs.

## Diagnosis and Treatment

**“Become your own advocate and educate your providers.”**

—Isabella Schultz, PhD, Rehabilitation Psychologist and cochair of the American Psychology Association (APA) Task Force on Guidelines for Assessment and Intervention for Persons Who Have Disabilities

Historically, cerebral palsy research has primarily focused on addressing motor impairments and related conditions. As pediatric neuropsychologist Seth Warschausky explains, “It is only in recent years that there has been recognition that cerebral palsy is a complex lifelong set of conditions that entail mental health risks.”

To address this, the cerebral palsy community requires additional and more appropriate screening tools for mental health than what is currently available. For example, tools that distinguish between symptoms of CP-related movement disorders and signs commonly



Image by Gabriela Popa.

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associated with mental health conditions (such as fatigue, slowed speech or movement, sleep difficulties, and pain and headaches) would support earlier and more accurate diagnosis. Increased education and awareness among clinicians about the mental health risks their patients with CP face is also essential.

When you experience new or ongoing symptoms related to your mental health, don't hesitate to reach out for help. While asking for support may feel uncomfortable or overwhelming, effective and timely interventions can make a real difference. You deserve care, support, and wellbeing—even if sometimes it doesn't feel that way.

If you are unsure of where to start seeking help, reach out to a member of your professional team who you feel comfortable communicating with even if they don't specialize in mental health or psychiatry. They may assist with referrals or coordinate support with other members of your clinical team. If your concern feels more urgent, look into local mental health services—or ask someone you trust to help connect you with the support you need and coordinate care. Visit your state department of mental health website for more information on local resources. If you need immediate support, you can call or text the national suicide hotline at **988** or call **911**.

## Additional Resources

### *Mental Health*

The Substance Abuse and Mental Health Services Administration's (SAMHSA) National Helpline is a free, confidential, 24/7, 365-day-a-year treatment referral and information service (in English and Spanish) for individuals and families facing mental and/or substance use disorders. 1-800-662-HELP (4357) [samhsa.gov/find-help/national-helpline](https://www.samhsa.gov/find-help/national-helpline)

"Cultural Dimensions: People with Disabilities" from the National Alliance on Mental Illness (NAMI): [nami.org/Your-Journey/Identity-and-Cultural-Dimensions/People-with-Disabilities](https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/People-with-Disabilities)

"Cerebral Palsy, Mental Health and Psychotropic Medications," a talk presented by Drs. Heather Riordan and Aaron Hauptman at the 2023 American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD) Community Forum: [youtu.be/OgZ1am3NDbo](https://youtu.be/OgZ1am3NDbo)

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## Final Thoughts from Our Community

To close this section—and our toolkit—we turn to the wisdom and experiences of members of our community living with CP. Their strategies, insights, and reflections offer valuable guidance on supporting your wellbeing.

### Recognize Your Strengths

“As someone whose life experience with CP predates most of the people around me, I can tell you that the situation for people with CP today is much better than it was when I was growing up. Rather than being viewed as being crippled and with no capability, people with CP today are much more viewed as being disabled . . . and are much more given the chance to—and are being raised in the expectation that they should—take risks and expand their capabilities.

“Do you realize how much better we adults with CP tend to be in terms of critical thinking—the ability to see deeply beneath the surface into how things work and why they work, and to see how things really are as opposed

to what others tell us they are—than the majority of able-bodied people tend to be? As compared to the rest of people, do you understand what great problem solvers we are?

“Really, this is empathy, the ability to feel other people and what drives and motivates them, and it seems that many people with disabilities—because we are outliers who only want to be recognized and accepted by others—have higher than average levels of this blessed ability.

“The point of what I am saying is that, yes, we have CP, we are disabled, and thus we struggle within our affliction with many difficulties and challenges. But because of our disability, because of our CP, we also have been blessed with gifts and abilities that most people who are not disabled tend not to develop, or do not develop to such a high degree.”

—John Borland, CP Research Network  
community research partner

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## Seek Community

“Find your CP people. Being a kid with CP is hard, but being an adult with CP is harder. There’s not a lot of programs out there for adults with CP. We’ve aged out of all our camps, rec programs, etc. You need to find other adults with CP who understand what you’re going through. I have an ongoing Facebook chat with a few other women with CP, and we can talk about non-CP things, but it’s nice to have them when I need to vent about doctors who don’t understand, or share pain management strategies, or get advice on CP-friendly exercise. I run the You Know You Have CP When. . . group on Facebook, and it’s so nice to have that community of people with CP of all ages, genders, life experiences, you name it.”

—Cara Liebowitz, disability rights activist and writer (Find the Facebook group at [facebook.com/groups/YouKnowYouHaveCPWhen](https://www.facebook.com/groups/YouKnowYouHaveCPWhen))



“Welcome to adulthood with CP. It’s a bumpy ride, but we can all help each other get through it.”

—Greg Moomjy, creative producer and Founder & Artistic Director of Opera Praktikos, New York’s first disability-affirmative opera company ([operapraktikos.org](http://operapraktikos.org))

## Parting Words from Our Team

Transitioning to and navigating adulthood is a personal and complex process that will look different for everyone. You may sometimes face challenges related to available resources, appropriate support, knowledgeable providers, or changes in your health. However, you can thrive as an adult with cerebral palsy in the areas that matter most to you. With additional research, time, persistence, and flexibility, you can achieve many or even all of your social, professional, and personal goals. You may need to give yourself more time and access additional support, but you can create a meaningful life. Sometimes connecting with people like yourself who have created fulfilling lives can provide you with a model and ideas for achieving your goals.

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Embracing independence, staying proactive about your health, and engaging in advocacy are all essential parts of this journey. Please join our MyCP community portal to access personalized resources, share your personal health experiences, take part in our research surveys on adults with CP, and connect with peers and researchers in our community forum. The CP Research Network also offers one educational webinar per month.



You can sign up to be notified of these presentations at [cprn.org/mycp-webinar-series](https://cprn.org/mycp-webinar-series).

We are here to connect with you during this journey, and we offer vital educational information and empowering opportunities to join us to advance the care, treatment, and outcomes to improve the lives of individuals with CP.

### **Know That Your Experience Is Valid and Embrace Solidarity**

“You are not alone. Your struggle is valid. And when you put words to it—a diagnosis, a shared experience—you will often find that your experience is more common than you think. Embrace solidarity and strength in numbers.”

—Benjamin Shrader, self-advocate and activist

“I know things feel uncertain and difficult and you can feel like you have to be perfect all the time to be valid, but you are amazing just by being yourself and you can figure it out. You have older people in the community to help you if you ever need so don't be afraid to reach out!”

—Fayza Jaleel, incoming medical student, Harvard University

### **Trust Yourself**

“Perseverance & persistence are key! If something doesn't seem right, trust yourself.”

—K Pleasant, Founder and Executive Director, Cerebral Palsy Positive ([cerebralpalsypositive.org](https://cerebralpalsypositive.org))

### **Define Life on Your Own Terms**

“Our world may be largely inaccessible, but that doesn't mean that we don't deserve to live rich, full, and independent lives, however that may look for us.”

—Melissa See, author and disability consultant.

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# Acknowledgments

## LEADERSHIP TEAM



Michele Shusterman



Mary Gannotti, PT, PhD



Jocelyn Cohen, JD



Cori Sparks



Cristina Sarmiento, MD



Jensine' Clark, MD



---

## **SCIENTIFIC REVIEWERS**

Ed Hurvitz, MD  
Linda Krach, MD

## **EDITORS**

Michele Shusterman  
Mary Gannotti, PT, PhD  
Jocelyn Cohen, JD  
Fayza Jaleel  
Patrick G. McPhee, PhD

## **CONTRIBUTORS AND SECTION REVIEWERS**

Nili Amir, MD  
Bhooma Aravamuthan MD, DPhil  
Kara Ayers, PhD  
Mohan Belthur, MD  
Lisa Blumberg, JD  
John Borland  
Liz Boyer, PhD  
Hank Chambers, MD  
Jensine' Clark, MD  
Jocelyn Cohen, JD  
Steve Ferreira  
Lynne Fogel  
Mary Gannotti, PT, PhD  
Heidi Haapala, MD  
Sandy Hanebrink, OTR/L, CLP, FAOTA, PLY  
Fayza Jaleel  
Maria Jones, PT, PhD  
Molly Lazarus, MA  
Cara Liebowitz, MA  
Ronna Linroth, OT, PhD, CCCP  
Liz Lucas, MD  
Greg Moomjy  
Jan Moskowitz, LCSW, CCLS  
Kathy Nelson  
Garey Noritz, MD  
Margaret O'Neil, PT, PhD, MPH  
Kari Pederson, MSW, LICSW  
Christine Petranovich, PhD, ABPP-CN  
Karen "K" Pleasant, MBA  
Dena Priluck, PT, DPT, NCS  
Jessica Prokup, MD  
Jackie Rapose, MSSA, LISW  
Monica Woll Rosen, MD  
Cristina Sarmiento, MD

Mary Schmidt, DO  
Melissa See  
Benjamin Shrader  
Carol Shrader  
Lisa Shusterman, PhD  
Michele Shusterman  
Alena Skinner  
Lorraine Sylvester, PT, PhD  
Sruthi Thomas, MD, PhD  
Debbie Thorpe, PT, PhD  
Daniel Whitney, PhD  
Christina Withers, DPT  
Duncan Wyeth, MA

## **COPY EDITOR**

Sara Carminati

Special thanks to John Borland, Duncan Wyeth, MA, and Mary Gannotti, PT, PhD, for all of their extra help and support throughout this project.

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