# Children and Youth with Complex Cerebral Palsy

## Care and Management

**Edited by Laurie J. Glader and Richard D. Stevenson**

A practical guide from Mac Keith Press

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# Chapter 21

## Through the eyes of parents

Michele Shusterman,
Carol Shrader and Jennifer Lyman

As a pediatrician or family doctor, you may be the medical professional that interacts the most with the family of a child with cerebral palsy (CP). How you relate to the family and the insight and resources you have to offer can make a big difference in how they approach and experience life. This chapter is written by Michele Shusterman, founder of CP NOW a nonprofit organization and CP Daily Living blog, with contributions from Carol Shrader and Jennifer Lyman. Like Michele, Carol and Jennifer are mothers of young people with CP as well as community advocates. Michele is the parent of a 10-year old girl, Jennifer is the parent to a 12-year old boy and Carol is the mother of four children, two of whom are 20-year old young men with CP. We have chosen to compose this chapter as though we were sitting talking to the medical professional about this topic, in a personal, casual and direct manner.

Parenting an infant and young child can be challenging for all caregivers. Adding a complex form of CP to the typical challenges of raising a child makes life even more complicated. When developmental and medical issues first become apparent, at birth or sometime afterward, family members struggle with a wide range of practical, emotional and social problems.

The most important thing you can do as a clinician is to approach the family with a helpful attitude. Physicians and therapists who demonstrate humility, honesty and receptivity to parents' feelings and perspectives empower families to help their child.

First-time, as well as experienced, parents initially feel lost and unprepared to meet the unique physical, emotional and developmental needs of a child who has a diversity of medical conditions. When there are complex medical issues, parents can feel caught in a game of 'whack-a-mole'; as soon one problem is addressed, another critical issue pops up to take its place. Spontaneity is replaced with the need for planning and flexibility, and families are immediately thrown into a world that is unfamiliar and frightening. Parents may be spending most of their time trying to figure out how to meet their child's most basic needs and feeling that they and their child are not making progress. Parents are in a constant state of worry about the child's eating, sleeping, bowel habits and movement. In some cases, the family is doing all they can to avoid another visit to the hospital. They may feel tremendous tension and anxiety trying to meet their existing obligations at work and at home. The parents' own needs often take a back seat.

The combination of emotional, physical, and financial strain can be overwhelming, especially as parents repeatedly adjust different facets of their lives in response to their child's needs. How parents learn to cope with the fact that their child has medical problems impacts not only the child but the whole family.

*As their physician, you can acknowledge the difficulty of the situation and help them identify the specific areas of where they are feeling the most pressure and anxiety.*

By having this focus, they can begin to strategize and address those areas of concern.

## Emotional impact

Grieving the loss of the child they thought they would have is common for parents of a child with CP. Grief takes many forms and is a process that each family member moves through at their own pace. Personal histories, strategies for coping and the support available all affect how someone grieves and how long that grief lasts. Many parents have shared with me that they still grieve from time to time many years out from their child's diagnosis. I include myself as one of them. As a physician, you can help families by letting them know that grieving is normal, takes time, and is part of the journey toward acceptance. By being patient and understanding with parents you will be able to encourage them to understand and deal with their grief.

*If you are concerned about how a parent or family member is coping with their grief, or how the grief may be influencing the care of the child, it may be helpful to recommend counseling.*

Reassure parents and other family members that there is no shame in seeking guidance and support from a professional counselor or member of their clergy. Approaching the parents with compassion, rather than judgment, is key to getting parents to accept your help.

## Considerations to support family life

It is often hard for others to relate to a family who has a child with a complex medical condition. As the parents struggle to cope with the child's care they are likely to be less available for family and friends, often just struggling to keep their heads above water. It is common for others to pull away from the parents. It may be that they do not know how to be helpful or that they feel unsure about how to interact with the family. Families are vulnerable to feeling isolated and unsure about the support available to them as their time becomes more consumed with caring for their child. They are likely to miss out on social events they used to enjoy because they find it too difficult to attend.

The family must figure out how to educate others about their 'new normal' while facing the fact that not everyone will be accepting and supportive. It takes time to navigate these changes in social connections and it may involve working through pain and grief in the process. It may be necessary for the family to transition to a different or more expanded network of friends and people who relate to what they are experiencing. In the interim, parents and siblings will feel vulnerable and may need extra encouragement and support. Single parents have unique challenges and can be particularly at risk for being overwhelmed and isolated.

As a physician, you can help parents understand that family and friend issues are common and that there are ways to deal with them.

## Offer families your ear

You can go a long way in helping parents by being a good listener – actively listening without judgment. By inviting parents to share their authentic feelings in a safe place, you may be offering them a rare opportunity to let their guard down. This in itself is a great gift to offer parents and it gives you the opportunity to more clearly identify where the family may need additional support or perhaps counseling. As a clinician, you will not have all the answers to a parent's questions, but you can become a trusted advisor and collaborator dedicated to helping the family organize themselves and their approach to caring for their child. Parenting a child with a disability requires tremendous flexibility with lots of unknown variables. Having a physician who offers consistent support gives parents much needed comfort and stability. This can be a challenge for a busy practice, and takes teamwork on the part the social workers, nursing staff and others, but it is invaluable for these families.

## Help parents learn to take care of themselves

Helping parents learn to take care of themselves can be a daunting task. Here is a specific example from my own history:

> *Ever since my daughter's diagnosis of CP 10 years ago, I have struggled with the ongoing tension between wanting to seize opportunities to encourage her greatest potential and wanting to make our lives about more than just therapy and treatment. When she was very young I kept seeing all of the activities and peer interactions she was missing out on and I felt I needed to fight harder against her CP. I spent most of my day thinking about my daughter and making mental lists of what I needed to do to support her health and development. I thought I had no time to consider and address my own needs. As she got older, however, I had to let go of this thinking as I saw that my daughter continued to get further behind her peers, even as I pushed the daily limits of her energy and the energy of our family to overcome her problems. Her peers began to run and develop fine motor skills when we were still working on crawling.*
>
> *Once my daughter began kindergarten, my husband and I realized that we needed to change how we approached each day. We did not have nearly as many hours to dedicate to therapy and she was very tired after a full day at school. There were also additional developmental needs that became apparent and required our attention. Some of these problems included addressing a visual processing disorder and figuring out how she could successfully learn in a classroom setting. Ultimately, learning to take care of myself became a process that began with me experiencing the limits of my own power and honoring my daughter's need for fun and relaxation. Embracing her limitations and mine become easier with time, practice and greater acceptance of my daughter's disability. I now spend much less of my time and energy thinking about how to make her symptoms of CP go away. We focus more on helping her plan and achieve her individual goals in a timeline that is best for her and our family.*

It's important to realize that simply telling parents that that they must take care of themselves is often ineffective.

Most parents realize they need to take better care of themselves but do not know how to make the time to do it. They often become consumed with their child's daily needs and even when they have a few moments or longer for a break, they may spend that time thinking about their child and family. As a physician, you can recommend parents create a schedule where there is designated time for fun together as a family, as a couple and time alone.

## Foster the child's independence

How to foster independence in a child is an issue for all parents. For parents of a child with a disability, it can be especially confusing. How much help should the parent offer the child? Humans are hardwired to respond to an infant as soon as they begin to cry by offering them nourishment, comfort or maybe bringing a toy closer within reach. When a child has experienced medical trauma, or is demonstrating developmental delays, the parent often feels more compelled to cater to the child and help them minimize their frustration and pain. While this perspective is understandable it can also interfere with the child's development and growth. When parents view the child as incompetent or incapable of even trying to do things independently, they stop looking for and creating those opportunities for their child.

Over time this dynamic can lead to learned helplessness where the child responds to the parent by being unable to perceive or work toward her or his own competencies. Even the child with a disability who relies heavily upon a caregiver or technology for navigating her or his day, must be given opportunities and choices to push themselves. It is difficult for parents to figure out how much room to give the child to explore and to experiment. If the child meets with failure, should the parent encourage the struggle or assist and after how long? Parents may need the ongoing assistance of their Early Intervention and therapy team to arrange the child's environment so they can practice working toward mastering tasks that are at their level. These opportunities are unique to the child but they may involve learning to use supportive equipment and devices which improve the child's independent access to the world. Given the appropriate boundaries, parents can foster confidence and competence in their child by giving them the chance to work through aspects of their daily activities on their own.

With my own child, I break down all of her activities of daily living into smaller segments (sometimes even parts of segments) where she can challenge herself while having opportunities to succeed. I have learned over time that by providing ongoing opportunities for my daughter to take responsibility for negotiating as much of her day as possible, I am influencing her personality development. Sometimes this becomes more important than mastering the specific tasks themselves. The alternative to finding ways to foster independence and confidence in the child is to risk having a child grow up expecting everyone around them to cater to their needs (and getting angry when people do not respond as their parents do) rather than taking ownership and responsibility for what they can do.

## Tips for Parents of Children with Complex CP

Below are some tips that have helped me free up some of my emotional and mental energy and some of my time. They have acted as guideposts for helping me approach my daily life with the intention of creating more balance.

1. **Pay attention to how much intellectual and personal energy you are giving toward finding answers for your child.** Be sure to carve out times during the day to simply be with your child, other family members, or spouse without thinking about CP and the challenges your child faces.
2. **Don't sacrifice reason and good sense to help your child.** New therapies will constantly be presented as ***the*** treatment for CP. Before trying a new therapy, make a list of the sacrifices the treatment will require you and your family to make. Weigh the emotional and financial costs and the physical, safety, and unknown risks the treatment will present against the possible benefits for your child. Remember that a treatment without any known risks does not mean it is risk free. Discuss these issues with people you trust and your child's medical team. Set time commitment limits and financial limits and be aware of your expectations about the treatment.
3. **Your child will have his or her own developmental timeline.** When you compare your child to other same aged peers, you may subliminally approach your child with disappointment and he or she may perceive this as something he or she is doing wrong. Focus on the positive points, the things that are working and the small, incremental steps that lead to putting together larger developmental pieces.
4. **Assess and honor your child's physical and cognitive energy limits each day.** These may change daily. You know your child best. Don't be afraid to speak up if you think what is best for your child is different from what the experts advise.
5. **Be aware of what is driving your approach to your child's therapy/developmental support program.** Be honest with yourself and look out for guilt, fear, and hopelessness that are motivating you to push your child and other family members too much. This may be difficult territory to sort through and balance, but is often part of the emotional journey that is a necessary step to accept the CP diagnosis. Remember, it's your child who ultimately has to participate in the therapy and integrate all the information that comes from your therapy planning.
6. **Creating a balanced schedule becomes easier as your child's developmental picture becomes clearer.** Over time, as you and your professional team have had a chance to observe your child, you will have a better understanding of how to focus your time and which therapies and treatments work best for your child. In addition, you child's clinical team may use the Gross Motor Classification System (GMFCS, see Chapter 1) to help guide decision making around goals and treatments.
7. **Focus on what your child does well and what they like.** Integrate interests with opportunities for development. For instance, perhaps a child likes the water. Swimming is an activity that your child can enjoy while also developing their motor skills.
8. **Explore respite resources in your area** including what is offered by local parent-to-parent offices, churches or other religious centers, and state programming that allows for in-home support for your child. Some US states offer programs through Medicaid/TEFRA/Katie Beckett that allow for parents to have respite hours. Additionally, your area may have medical day care centers which offer out-of-home respite programs. Contact your local Health and Human Services Agency for more information.

## Support siblings

Carol Shrader

Often the child with a disability is not the only child in the family. Family dynamics are not a benign issue. Parents often struggle to find the balance in caring for their child with special needs in relation to their other children. They can err on the side of ignoring the typically developing child or bounce as far as glorifying the typically developing child while ignoring the child with special needs. Finding the balance is key to successful family dynamics that encourage relationship and compassion on all fronts.

> *When my triplets – two of whom have cerebral palsy – began preschool, I was stunned at our first parent-teacher meeting. The preschool teachers' faces looked a bit less than inviting as I sat across from them and their tone was serious and commanding of my attention.*
>
> *'Claire doesn't share.'*
>
> *I almost choked. Claire, my only daughter? The triplet sibling of two boys with cerebral palsy? A child whose very life has required her to share since the womb. Are you kidding me?*
>
> *'She sits with her legs in a V-shape in front of Benjamin and Mason. She keeps the toys they want to play with in the V and will not let any other children share them.'*
>
> *My heart swelled with pride, even as my head wanted to roar. I took a deep breath before saying, 'This is not called "not-sharing". This is called protecting her brothers. Benjamin and Mason cannot get the toys they like or keep them if someone else grabs them. Claire is simply ensuring they have a chance to play also.'*
>
> *It was the first time I realized educating the world on how siblings of children with special needs behave would be as important as educating the world about my boys.*

Encourage the parents of your patients by reminding them that they are not alone in the tug-of-war they are experiencing. Cerebral palsy colors our home life. It colors our family. It colors our life experiences. And likewise, it will color the lives of the families you serve. Often siblings are more mature than their peers, with a level of empathy that is unmatched.

> *When the triplets were teenagers, one of my sons had a major surgery. As soon as he was released from the hospital, his triplet sister left for a mission trip abroad. Claire struggled with feelings of guilt, of leaving the family when they needed her assistance. We pushed her out the door. She called with a heavy heart:*
>
> *'Mom, these teenagers want to talk about boys, about clothes and about what kind of car they drive. I want to scream that my brother just had major spine surgery and is fighting to recover!'*

Even still, the needs of the sibling are important and can be fairly basic. In a recent panel of now-adult siblings of children with special needs, a facilitator asked my daughter and her peers to name the one thing they wish their parents had known they needed as children. Every single sibling listed the same thing: one-on-one time with the parents.

> *Claire: 'My brothers needed so much undivided attention from my mom, and though I didn't need her to get dressed, I craved that one-on-one time, too,' Most people with at least one other sibling can relate to this, but when your siblings have disabilities, I think this desire for alone time is even stronger. It took so much for my parents to plan time out for just me that every time they did it was as if they were telling me, "You are special. You are valued. You are loved."'*

Often, parents are running from therapy to therapy, doctor to doctor, with educational meetings thrown in. The idea of time alone with one child is a foreign concept. And yet, these siblings are clear with their message.

> *When the triplets were 8, we had another child. Cate was 2-years-old when she climbed down from her high chair and up on the wheel of Benjamin's wheelchair and wiped the dripping ice cream from his chin. She was 4 when I stopped her little fist as it flew toward a little boy's face who had told her that her brother was weird. Cerebral palsy definitely colors her world.*

Encourage your parents to allow the siblings to take some ownership in the disability. Three-year-old Claire knew inherently to form a V-shape with her legs and protect her triplet brothers. When Cate was 4 she knew the same.

When the anxiety level increases in a home – due to therapies, pending surgeries, illnesses – the child with cerebral palsy and the parents are not alone in feeling apprehensive. The siblings feel the stress as well. Younger siblings can benefit from pre-operative appointments with a Child Life Specialist who can help them process the upcoming event. Remind your parents that anxiety can manifest itself in many ways in siblings – anger, sadness, jealousy, and even a seeming lack of compassion.

Finding the balance between caring for the typically developing child and the child with special needs can be a challenge. However, if communication lines are open, if all the children know that home is a safe place for expressing emotions, feelings, fears, then even though the balance might not be any easier to achieve, it is at least less toxic.

Finally, encourage your parents that the life lessons and skills learned in growing up in a family colored by cerebral palsy are priceless.

> Claire *(to a group of parents): It is because I'm a special needs sibling that I'm most fulfilled when volunteering with children and adults with disabilities. Oh my goodness, I have gotten to know and serve some simply incredible people,' 'It is because I'm a special needs sibling that I'm working towards becoming an occupational therapist to serve these amazing children. And it is because I am a special needs sibling that I understand the challenges, yet also believe that being a member of my amazing family has made me who I am.*

Because Cate is younger, because she is not one of the three, and perhaps because we have the advantage of her perspective, we have tried things that forced the boys to watch. She has challenged us to try things outside the wheelchair-accessibility bubble. She has forced us to be creative in including the boys, in trying new things and in realizing it is ok for the boys to occasionally have to sit on the outside looking in. But the main thing she has done is make us realize as a family that the primary focus does not always have to be on the disabilities in our home. Sometimes, the focus can be on softball. Or ballet. Or fishing.

Being the sibling is not painless. Being the sibling is not without cost. Claire, at 17, was still the little girl wanting to sit with her legs in a V-shape in front of her brothers and protect them from those who would steal their toys – or even their joy.

## Talk about quality of life

What is quality of life? The World Health Organization defines it as 'an individual's perception of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards and concerns' (WHO 1995). Most parents want the highest quality of life possible for their child and therefore the conversation about quality of life is important to have. Supporting a good quality of life for a child with complex CP means different things to different parents and individual children. For some parents these feelings may be tied to what they hear directly from their child about what is important and fulfilling to them. It can be especially challenging when the child is unable to clearly communicate what is important and fulfilling. In addition, parents have their own personal values and expectations about what a good quality of life means for their child. Wherever possible it is important to understand the perspective of the child as well as the parents. There may be cases where what the child wants is different from what the parents want. It is helpful to highlight those dynamics so they can be addressed. If parents and children can agree on goals, moving forward is enhanced.

It was very reassuring to me to hear recently that there have been several studies that repeatedly demonstrate that a child with CP's self-reported quality of life is like that of their peers who do not have CP. According to the SPARCLE study, a large-scale study investigating the quality of life of children and adolescents who have CP, self-reported quality of life does not change with the type of CP or severity when it comes to psychological well-being, self-perception, social support, school environment, financial resources and social acceptance (Colver 2006). The following quote from Albrecht and Devlinger cited in one of the SPARCLE papers particularly struck me:

> Possibly, from the perspective of a non-disabled adult imagining what it would be like to be disabled *would be upsetting* [my emphasis], but probably not from the perspective of a child whose sense of self from birth incorporates their impairment and who embraces the growth, development and living with the same excitement as most children' (Stockman 2009).

Families can find the SPARCLE (2017) study and the papers linked there at http://research.ncl.ac.uk/sparcle/

These results do not mean there are not areas of specific concern for children with CP, but they can bring relief to a worried parent.

> *I never thought about my daughter's quality of life in a broad context. Looking back, I can see that my husband and I instinctively addressed aspects of our daughter's quality of life by considering parts of her day and how much variety she is getting with her activities, interactions and movement. As parents, we have worried about and monitored how much time our daughter spends at home and in the same room and in the same piece of equipment. We balance these concerns with her energy levels, our energy and her requests for what she would like to do with her day.*
>
> *We periodically sit down together as a family and discuss our daughter's goals and how she feels about school, therapy, time with her friends and family, and what she likes or does not like about her activities. Sometimes we struggle to keep up our physical energy to support our ideas and our daughter's, for what she would like to do with her day. This has led us to purchase different equipment that makes transferring her easier. We have also increased the number of hours we have additional help. It has been very useful for us to identify specific goals around what we all feel constitutes a good quality of life for our daughter and setting up our weekly routine to work toward meeting those goals.*

When discussing quality of life with families, it is important to discuss the child's mental health because children with CP are at higher risk of mental health disorders than their peers without CP.

> *My daughter has struggled through periods of intense anger and anxiety. Thankfully we sought the support and guidance of a psychologist to help us learn how to help her cope with and move through these feelings. Along the way we learned that much of her anger was tied to issues such as insomnia, pain, frustration with feeling different and side effects*

> *from her epilepsy medication. I have also learned that anxiety, in particular, is common among children with CP. Given how obviously heightened her nervous system responds to noises, crowded areas and new activities, I wonder how her early brain injury may have increased her susceptibility to anxiety and made it more difficult for her to manage her feelings.*

Many children with CP may experience these same feelings and issues or they may have secondary conditions, such as communication difficulties, that lead to emotional outbursts. Encourage parents to meet their children where they are and seek the professional support they need when it comes to their emotions, behavior, movement, learning and social skills. If children receive support and acceptance at home and in their community, the emotional difficulties will be easier to manage.

## Encourage participation in recreation and leisure activities

Jennifer Lyman

Helping children with complex forms of CP find meaningful recreational and social opportunities often feels like an uphill battle for parents. Traditional childhood activities and programs aren't usually geared toward including those with significant disabilities, especially physical ones. There are frequently issues with physical access to activities (i.e. the terrain, inaccessible bathroom facilities, etc.) and it can sometimes be difficult to adjust the pace and nature of an activity to facilitate a child's participation. There can also be problems with how program directors and other families and children relate to kids with significant disabilities. Despite these challenges, there are successful programs and there are also strategies for establishing inclusive programming and fostering social interaction. When the child feels strongly about being included in an activity, a family's efforts to facilitate that inclusion can feel well worth the time and energy. At the same time, there is also the opportunity to rethink what constitutes participation and recreation for the child.

If a family or individual child is trying to find a way to include their child in a program or activity it is often very helpful to look at successful existing programs, even outside of the local area. It is not always necessary to re-invent the wheel – parents or interested program directors can benefit from others' ideas about successfully adapting a program and including a child with complex physical disabilities. An example of an existing program is the *Ballet for All* program that was developed in Syracuse, New York by Dr. Nienke Dosa, Dr. Lisa Neville and their team (see Sports, recreation and leisure in the Information and resources section for more information). They developed a manual for facilitating the participation of kids with CP in dance programs, including wheelchair users. Another example is Miracle League, a popular adaptive sports program available in many places in the US.

At the same time, while structured activities and adaptive sports may appeal to some children with CP it may not appeal to others. My son participated in an adaptive baseball and a ballet program but he didn't like either one. I realized that just like any other child, some things he liked and some things he didn't.

Just because it was an activity designed for children with disabilities, it didn't mean that my son would want to be a part of it. If a family needs ideas for creating opportunities for recreation you, as the primary medical provider, can help them by guiding them to consider what the family enjoys doing together and what is fun and fulfilling for the individual child.

Social media also offers a wealth of information. Through social media, parents can discover successful programs and approaches that can be used to create a local program or provide insight about including a child in an existing program.

Parents can benefit from trying to find a balance between advocating for their child to be included, and identifying and celebrating the many ways their child is participating already. Both families and physicians often adopt the mindset of trying to find activities that mimic or are a variation of what a typically developing child would be experiencing. Participation and recreation is approached through the lens of seeing how closely the child with disabilities can come to experiencing an activity or social interaction the way their peers do. Thinking about participation and recreation in this way is a natural tendency and it makes sense in some situations, but it can be frustrating when the gaps are too big. It is helpful to encourage parents to embrace the idea that the child with complex physical limitations will experience life in their own unique way and at their own pace. This acceptance requires a shift in the parents' thinking and can be very painful territory. Parents may need help in navigating this new way of thinking.

Our family has learned that it is important to slow down and appreciate what we can do together. If parents are spending significant time and energy fighting for accommodations so their child can participate, the result may ultimately be unfulfilling, exhausting, or worse, cause their child anger and resentment, especially if the child was never interested in participating in the first place.

You may be surprised to hear that some families and children, like ours, may find joy in things like simply hanging out together and listening to music or cooking. By helping the family identify their collective and individual interests, you can help them decide how to approach their free time, rather than becoming lost in someone else's ideas of what recreation and leisure should like for them. Some families may feel relieved to hear that it is OK to slow down rather than trying to look like other families.

> *For our family, before our son was born, we were avid whitewater kayakers, mountain bikers and skiers. We enjoyed camping and going on long hikes. After he was born and after the first few years of addressing his complex medical needs, we knew that the activities we enjoyed likely wouldn't be activities that he could do with us on a regular basis. We had to redefine what 'meaningful opportunities' looked like, and identify the best opportunities to enjoy ourselves. If we didn't take this approach we would constantly feel like we were coming up short. Families of children with disabilities benefit from seeing their child and their experiences on their own merit and not compared to what other families experience.*
>
> *We still offer our son opportunities that are adventurous and fun. He participates in an adaptive skiing program, he attends overnight CP camp each summer and some day we will take him whitewater rafting, but these are all events, not the day-to-day activities that he enjoys and that sustain him. Instead, we as a family go downtown and listen to music or walk around, we hang out, relax and he rides his trike and we go swimming, an activity that is relatively barrier free. We go for drives and go fishing. He is on the school soccer team. His classmates push him on the field and he loves cheering for them from the sidelines. These are all meaningful activities for him and us.*

I have learned to carve out specific time for participation and recreation for my son aside from his exercise and therapy time. Some families may find ways of combining the two that are satisfying, but we prefer to separate them. My son still has 'therapy' and I still make sure that he gets his strength and cardio activity whether it be from tricycle riding during physical education at school, using his gait trainer or having him practice his swim skills before he can play. But when it comes time to family time, we prefer to slow down.

I have worked with his therapists and his physicians to find equipment that will allow him to participate in ways that are comfortable and that he enjoys. He has a camp chair that we take almost everywhere so he can get out of his wheelchair and hang out with us. He uses water wings or a life vest in the pool so he can swim independently. He began using powered mobility at an early age to help him learn to develop the skills necessary to get to where *he* wants to be. If he wants to ride his tricycle, I am always happy to go for a long, slow walk while he rides. Often, we find ourselves chatting with friends and neighbors who we don't get to see and this gives my son an opportunity to meet new people. These are all examples of how we have facilitated my son's participation in recreation and leisure activities. He finds these opportunities fulfilling and they make him happy.

Recreation and leisure time for people with complex CP is a tricky endeavor, but with an open mind, creativity, persistence and a generous perspective, it can be a source of great pleasure and satisfaction for the whole family.

## Plan for the future

Thinking about the future of a child with CP can be confusing and worrisome to parents. It is a complicated topic involving the person's unique abilities and limitations, family dynamics, financial resources and community resources.

### *Making predictions*

Countless parents have told me that their child's doctor or therapist said their child would *never* speak, stand, learn, use a power chair, feed themselves, walk, or have meaningful relationships. But then the child accomplished what the parents were told the child would never do. When parents hear what their child cannot or will not ever be able to do, they can easily lose hope for their child's future. There are so many variables that contribute to what a child with CP can learn, that it is impossible to know for certain what can be achieved.

As a medical professional it is important that you encourage parents to be open about the future. Do not make specific and absolute predictions about a child's development.

### ***Start with the child's interests***

One of the most helpful pieces of advice we received as parents of a child with CP came from a developmental pediatrician who saw our daughter when she was 3 years old. He asked us to begin exploring and focusing on what *interested* our daughter. Was there an area of interest or a talent we could help her develop? This guidance was invaluable for many reasons, including helping us to shift our vision toward what was working for our daughter instead of what was working against her. It forced me to approach my daughter with curiosity rather than worry which was a different experience for me. It did not take me long to identify that she loved music.

> *We have continued to surround my daughter with music. She doesn't go anywhere without her wireless headphones and she uses music throughout her day as a way of entertaining herself, relaxing and making her therapy and exercise routines fun. Last year we asked her if she would like to take music lessons. She immediately said she wanted to learn to play the piano. Truthfully, with her limited fine motor skills I was doubtful we could make it work. But, I have learned to expect to be surprised and to set her up for success as best as I can. There is no harm in trying a new activity. Often this means rethinking conventional ways of participating and breaking down movements until she can comfortably work through them at her own pace. Even if we try an activity and it ends up not working out, we usually learn something helpful in the process about what kinds of support and technology she needs or what activities are more easily adaptable for her. Once in a while we all decide it is best to let something go, but if our daughter is very persistent we will keep trying to facilitate her participation.*

> *Fortunately, her school's music instructor had a background in special education and was eager to teach our daughter. The first time I sat in on one of her lessons I was in shock. It was beautiful to watch. Despite how hard she had to work to coordinate her vision and hand movements (with arm support from me and hand support from her instructor), she loved it. She has continued to improve and looks forward to her weekly lesson.*

For me, it doesn't matter if piano becomes a part of my daughter's future. What matters is that facilitating her participation in something that interests her has allowed her to have a creative outlet that brings her great joy. Surprisingly, it also improved her fine motor skills. I share this example because parents need to be open to creating opportunities to develop their child's interests. By doing this, parents help their child learn to establish a lifelong habit of goal setting and learning about what kind of support they need to meet those goals. It also gives a message that, despite the child's limitations, meaningful goals can be achieved. Experiences like this enhance a positive, forward-looking attitude in the child.

### *Anticipate transition to adulthood*

As a medical professional, you can help the parents, with the input of the individual with CP, to consider the future when the time is right. As the child gets older, this discussion becomes more pertinent (see Chapter 18 Transition). The timing of the conversation depends on the family, the child, and resources available in the community. When discussing the future, you may find that some parents unload a host of concerns whereas other parents may ask to delay the conversation until a later time. Whenever possible make sure you invite the perspective of the individual who has CP, as appropriate. Practical considerations play a role in when you choose to have these discussions especially when time is needed to arrange transitions for housing, adult medical care, education and vocational training.

Children with CP, like other children often have ideas about their own future. Check in with the person periodically to see how their goals are developing and changing. At the age of 10 my daughter already has some clear goals and ideas for herself. She wants to live in her own apartment with assistance, in a nearby city and go to college to become a doctor like her father. Her ideas and goals may change over time and whether or not she can achieve them depends in part on what support is available to help her. As she gets older, our family will need support from professionals who have guided families before us as well as from families who have already been through this transition.

People with complex CP have different impairments and barriers to employment and participation in life activities. Some parents of young children may already be concerned about what kind of future their child will have and what choices are available to them. Will they need to live at home? Will they want to? If so, what does that mean about the larger family's future and needs? If they live in a group setting who will take care of their medical needs? What kind of financial plans does the family need to arrange for the future? You can help families by connecting them with information about options available for housing and medical care in your community.

There is a nonprofit organization in Australia called Fighting Chance that was started by Laura and Jordan O'Reilly, the siblings of a young man who passed away from complications related to CP (http://fightingchance.org.au). Laura was frustrated with the lack of vocational opportunities available to her brother Shane after he finished high school. Together she and her brother Jordan started Fighting Chance. Fighting Chance provides opportunities for meaningful social participation, employment, work experience and skill development to young people with the most significant disabilities in their community. This is an example of how families can advocate for change and how communities can develop programs that provide meaningful opportunities for people with significant disabilities.

## Conclusion

There are many examples of adults with complex forms of CP who have created meaningful lives for themselves with the help of technology, social and community support. As described in the example above, advocacy for people with disabilities is changing the way society thinks about and supports people with CP. The result is exciting new possibilities that will help those with complex CP lead fulfilling lives. As a provider you help families evaluate the various options that become available for their loved one and encourage or even partner with caregivers to continue to advocate for more so that each individual with complex CP can live up to their potential with whatever supports they may need.

### Key Points

- As a clinician, you will not have all the answers to a parent's questions, but you can become a trusted advisor and collaborator dedicated to helping the family organize themselves and their approach to caring for their child.
- Support families in their unique grieving, including accepting changes in their expectations about parenting, social life and daily routines.
- Most parents realize they need to take better care of themselves but do not know how to make the time to do it. Here you will find strategies for guiding families to create more balance in their daily life.
- How to foster independence in a child is an issue for all parents. For parents of a child with a disability, it can be especially confusing with an ongoing tension of empowering the child versus not frustrating them too much.
- Finding the balance between supporting the typically developing child as well as the child with CP is key to successful family dynamics that encourage relationship and compassion on all fronts.

- Supporting a good quality of life for a child with complex CP means different things to different parents and individual children. If a family needs ideas for creating opportunities for recreation have them consider what the family enjoys doing together and what is fun and fulfilling for the individual child.
- Thinking about the future of a child with CP can be confusing and worrisome to parents. It is a complicated topic involving the person's unique abilities and limitations, family dynamics, financial resources and community resources.

## Information and resources

It is important to have a wide range of reliable information to offer parents about many topics related to CP. However, parents vary in how they handle information about CP. Some parents want lots of information and articles to review; others want to know as little as possible. It can be helpful to check in with parents to see where they are and how they are most comfortable receiving information. Some families may wish to have you point out or provide resources to read about a condition on their own and then discuss it with you later. Others may want to discuss their concerns (and yours) in depth. And for some families it may be helpful to let them know in advance about a discussion you would like to have. Keep in mind there will be some parents who react with anger at the information you provide. This could reflect an inability to deal with the pain associated with their child's problems.

The resources below can both educate parents and reassure them that other parents have successfully navigated the same issues they are facing.

*CP Tool K*it, https://cpnowfoundation.org, is a comprehensive diagnosis resource guide for parents and caregivers.

*CP Daily Living*, http://cpdailyliving.com, is a comprehensive resource website and blog created to share information and resources about CP. It also documents our journey as a family and share how we navigate difficult issues our daughter faces and that we face as a family. The CP Daily Living website includes a support resource section that includes online and local resources for families based in the US: www.cpdailyliving.com/disability-information-by-state/.

*Inspire*, https://www.inspire.com, is a popular online health community network with individual pages dedicated to specific conditions.

*Hope for HIE*, http://www.hopeforhie.org, is US-based and offers education and support resources for families whose children have been diagnosed with hypoxic ischemic encephalopathy. They also have a Facebook page where families can interact with one another.

*Mommies of Miracles*, www.facebook.com/MommiesofMiracles/, is a popular Facebook page for families who have children with complex medical needs. They also have local online discussion groups throughout the world.

*Preemie World*, http://preemieworld.com, has books, videos, and other products and tools to help families adjust to life beyond the neonatal intensive care unit NICU (neonatal intensive care unit). They write newsletters for professionals and families, publish an international directory of support groups and preemie resources, and run an online preemie support forum through *Inspire*.

*The Four Walls of My Freedom: Lessons I've Learned from a Life of Caregiving*, by Donna Thompson. http://www.donnathomson.com. Donna is the parent and caregiver of her adult son who has a very complex form of cerebral palsy, and is also the primary caregiver to her mother who is living with Alzheimer's. She also hosts a popular blog and Facebook page called, 'The Caregiver's Living Room'.

*The Six F-words Framework Poster*, https://worldcpday.org/wp-content/uploads/2016/06/WCPD_2016_Six_F-Words_for_Cerebral_Palsy_Poster.pdf, is a very helpful visual guide to have in your office and to hand out to parents to refer to in order to assess how parents are balancing life for their child and family. The six 'F-words' for cerebral palsy are Function, Family, Fitness, Friends, Fun and Future.

*How to Make and Keep Friends*™ book series by Donna Shea and Nadine Briggs. http://www.howtomakeandkeepfriends.com. These books provide quick, easy tips to help kids manage their feelings. The series was created as a resource to support the social success of children at home, at school and on the playground.

### *Respite*

In the US, free respite may only be available through state-based Medicaid Waiver programs. Parents will need to apply and qualify for respite care, so keeping a list of local phone numbers and websites related to accessing respite services is invaluable to families.

*TEFRA/Katie Beckett Medicaid Programs*, http://cahpp.org/project/the-catalyst-center/financing-strategy/tefra/.

*Home and community-based services*, https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html. States can develop home and community-based services waivers (HCBS Waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting. These programs often include respite services.

*United States Department of Labor – Disability resources*, https://www.dol.gov/odep/topics/disability.htm. In the US you can find information and links to many local services and agencies on this website.

### *Siblings*

*ForeverSibs*, https://www.facebook.com/pg/ForeverSibs/about/, is a nonprofit whose mission is to 'honor and recognize the unique role of brothers and sisters with rare diseases/disorders and autism through social support and education, thereby decreasing their anxiety and isolation'. It offers sibling support on Facebook, twitter and by mail for siblings of people with cerebral palsy and other conditions.

*Sibshops*, https://www.siblingsupport.org/sibshops, is a US-based program offering online, print, workshops and state, by state-based support to siblings of individuals with special needs.

### *Sports, recreation and leisure*

Here are some resources for adaptive sports and recreation programs as well as examples of programming supporting the participation and inclusion of people with physical disabilities.

*Ballet for All* is a ballet dance program for children with cerebral palsy developed by developmental pediatrician Dr. Nienke Dosa and occupational therapist and dancer Lisa Neville. They offer a resource guide for dance assistants to understand cerebral palsy and how to work with children to include them in a ballet class. You can find their resource guide for dance assistants here: http://bbi.syr.edu/projects/Fit-In/docs/BalletForAll_Web_Tagged.2015.pdf.

*Best Day Foundation, https://bestdayfoundation.org*, is a US-based nonprofit dedicated to providing safe, fun adventure activities, like surfing, sea kayaking, snowboarding and more, to children with special needs.

*Blaze Sports America*, http://blazesports.org, is an international organization offering a variety of camp, recreation and adapted sport activities, including golf, fencing, swimming, and more, for children with disabilities and veterans.

*Challenged Athletes Foundation*, http://www.challengedathletes.org/resources/, offers a comprehensive state, by state adaptive sport guide.

*CP Daily Living*, http://cpdailyliving.com/activities/, has a recreation resource section with links to many programs, organizations and other lists that families may find helpful.

*Miracle League*, http://www.themiracleleague.net, offers adaptive baseball, soccer, basketball and other league programming throughout the US.

*Serious Fun Network*, https://www.seriousfunnetwork.org, actor Paul Newman has sponsored camps throughout the world that include and focus on the needs of children with cerebral palsy and other disabilities or illnesses.

*Tri My Best Triathlon*, trimybesttriathalon@gmail.com, is a community-based physical fitness opportunity run by volunteers for individuals with developmental disabilities. There are several locations throughout the US that offer this program. For more information, send an email to the address listed above.

*Variety Children's Charity*, https://www.varietypittsburgh.org, Variety's signature program is the 'My Bike' Program, which provides adaptive bikes individually customized to eligible children with disabilities.

*Very Special Camps*, http://www.veryspecialcamps.com, is a specialized directory dedicated exclusively to camps that serve individuals with one or more of a wide range of special needs.

### Transition

*Fighting Chance*, http://fightingchance.org.au, is an Australian nonprofit founded by Laura and Jordan O'Reilly, the siblings of a young man who passed away from complications related to cerebral palsy. The organization works to create comprehensive and meaningful employment, social, educational, and community-based opportunities for individuals with disabilities.

*Got Transition*, http://www.gottransition.org, seeks to empower patients, families and health care providers through comprehensive resource and training programs designed to assist with the transition from pediatric health care to adult health care for individuals with disabilities.

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