

"If I knew then what I know now..."
Tips FOR parents of children and youth
with cerebral palsy, FROM parents



What is cerebral palsy (CP)?

CP is defined as a permanent movement and posture disorder caused by a disturbance in the fetal or developing brain. The underlying brain disturbances do not progress over time, but usually lead to limitations in activity for the child.

What did we do in this project?

Raising a child with CP is not always an easy task. Research exploring experiences of parents raising children with CP has uncovered advice and tips for new parents of children with CP to help them on their way through this experience. The aim of this tip sheet is to outline this advice so it can be used to help you in your journey of raising a child with CP.

What did we find?

Here is the major advice from the parents participating in this project:

Advocating



Getting the resources you need can be a struggle, whether it is at home, at school, or in the community. One way to help this process is to be a strong advocate for

you and your child. The following are ways in which you can be a successful advocate:

- Be assertive but polite; stay calm
- Try not to get discouraged
- Persevere! Your child is worth it
- Encourage your child to advocate for him - or herself - give them independence and the chance to take charge of their own lives
- Allow your child to make mistakes and to learn from them.

Education



Educating yourself in any way you can about your child's condition can help you prepare for the future and ask the right questions when the time comes. It is also

important for anybody working with your child, such as teachers and other community members, to be educated on your child's condition so that they understand your child's unique abilities and challenges. This can be done yourself and/or in partnership with your health care professionals.

Support Systems



Developing a strong support system can be helpful for both you and your child. Don't try to do it all yourself! Who to involve in this support system is up to you, but the following can help the process:

- Involve your family early on (including grandparents)
- Seek out other parents of children with CP for guidance and support
- Be a support for other parents of children with CP
- Build up a support network of family, friends, and neighbours.

Authors: Allison Reid BSc, MPT, Emily Brouwer BAKin, MPT, Shannon Clutton BKin, MPT, Heather Imrie BKin, MPT, Jan Evans PT, MSc Thames Valley Children's Centre, London Ontario, Dianne Russell PhD, Investigator, *CanChild* Centre for Childhood Disability Research, McMaster University, Hamilton Ontario, and Doreen Bartlett PT, PhD, Associate Professor, School of Physical Therapy, University of Western Ontario, London Ontario

Want to know more? Contact Doreen Bartlett djbartle@uwo.ca

Taking care of yourself

Although your child is important, you also need to be in the right mindset and stay healthy yourself, because that is good for the children! Here are some suggestions to ease your parenting demands:

- Make time for your partner and relationship – work together to raise your child
- Incorporate time to nurture your own needs
- Be honest about your feelings – guilt, anger, fear, anxiety – accept them (they are normal!)
- Keep a positive attitude – one day at a time
- If you start to feel worn out, seek support from family, friends and/or professionals.

Resources



Resources, no matter the type, are not always visible. Although they may be difficult to find, they have been shown to

be a tremendous asset to families. The following are ways in which you can ensure you are making the best out of what is available to you:

- Actively search out and use all the community and financial supports available to you
 - Ask other parents what supports and services they are using and tell other parents what supports and services you have discovered
- Consider involving your child in both inclusive and specialized (special needs oriented) community and school programmes to support both skill and social development.

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Working with others



Working with health care providers, educators, and others in the community can be overwhelming. A lot of new information is coming at you at once

and it can be difficult to sort through it all. To get the most out of these relationships, it is important to be comfortable and prepared:

- Ask questions and tell professionals what you and your child need and want – you know your child better than anyone
- Consider having an independent advocate join you at meetings; a second set of ears is helpful to make sure that you understand what is being said
- If you don't understand something, ask for it to be explained
- Observe your child's development closely in areas additional to his or her physical functioning (e.g. learning, reading, socializing). If you have concerns, ask for professional assessments
- Check that your child's equipment is comfortable for them to use in every setting
- Don't be afraid to seek out diagnoses for your child – they make it easier to access services and programmes
- Ensure that the health care professionals, educators and others are able to establish a rapport with you and your child
- Keep paperwork on file and make photocopies as necessary – it is common to need to fill out the same form several times – *CanChild* (www.canchild.ca) offers a "Keeping it Together" (KIT) organizational package for paperwork.

Lastly, parents suggested to "follow your gut", take it one day at a time, and appreciate the uniqueness of your child. One parent suggested keeping a journal so that you can see the progress being made.