

INTRODUCTION

Hi and welcome to the Cerebral Palsy Foundation's ParentWise Podcast series. I'm Robyn Cummins.

Today, Liz Foy, who has many years of experience working with families who have a child with a disability, talks about how parents of newly-diagnosed children with a disability can build a strong and effective network of support with family and friends.

STARTING OUT

Hi. I'm Liz Foy.

Networks of informal and formal support can be a vital source of strength and encouragement for parents of children with a disability.

For parents who've just received the news that their child has a disability, it's extremely tempting just to bunker down and avoid talking to others all together.

Although it's a tall order amongst the initial shock and confusion of a diagnosis, talking to others about the situation and being as clear as you can about the sorts of support that you and your partner would find helpful are the first steps to building lasting and open networks of support.

There's no doubt that your family and friends will want to support you but you may need to show them how. You need to take the lead and guide them to respond in ways that will help you most.

Try to be as specific as you can about the help that you need. For example, 'What would really help us, is if you could do the shopping or mind the other children'.

Your friends and other family members will be blessedly relieved when you can offer them specific requests for practical help, because then they have a clear mandate and permission to do something.

Your family, especially your parents will take time to adjust and understand.

Working with families over the years, I've observed that the grandparents of the child with a disability need special consideration because it seems that they experience a kind of 'double grief'.

In other words, they have an extraordinary feeling for their grandchild's situation but they also feel enormously for the distress of you, their own child.

Your parents will want to be strong for you but may also need support from their own networks. So, let them help you in practical ways.

Giving a clear explanation of your child's disability to your family and friends will help them to understand and to support you.

They may be inclined to falsely reassure or to diminish the significance of the problem.

You really should discourage this by explaining the facts.

It is not always about looking for solutions.

So, let those who support you just be there to take the journey with you. Just staying in touch and listening will often be enough.

You know, when you feel anxious and upset and sensitive, you may feel that others cannot really understand what you are going through.

Unless they have a child with a disability, you are right, they can't.

But don't push others away. Value their attempts to support you, even if their words and actions often seem clumsy.

In the early years, it's natural that you will seek out and pursue whatever treatment is available for your child.

At some point however, you'll take a decision to stop battling the disability.

This will free you to decide to enjoy your child for who they are and to help them be the happiest person they can be.

When you take this step, those who support you will follow your lead.

Strangers also can give you tremendous support.

Through the web, you can find complete strangers - who you may not be able to see or hear, often from other English-speaking countries across the other side of the world – who are facing the same issues and concerns as you.

You will come to see that there is a common parental experience of disability which has universal themes.

Through sharing the experience of being in the same boat, you can feel connected and understood.

It's interesting that the greatest power of the parent support group, whether on the net, the telephone or face-to-face, is not the support you receive, but in fact the support you give.

There is healing power in the process of helping others who are going through similar, or perhaps even more challenging, experiences.

Exchanging information and ideas with other parents will also help you to recognise and acknowledge that you are becoming an expert in this human experience, with skills and knowledge to share.

It's equally important to try to find health professionals and medical personnel you can relate to easily and who you feel you can work in partnership with.

Therapists and doctors, who have wisdom and compassion, will relate to you as a person and support you to understand how you can best help yourself as well as your child.

Again, one of the most difficult things for parents in working with professionals, or talking to family members and friends, can be communicating their needs clearly and assertively.

If you are having difficulty expressing your needs to others, try this little assertiveness formula.

Rather than telling the other person what they're feeling and trying to put words in their mouth or explaining their feelings to them, you just need to describe how you're feeling.

So, if you give a neutral description of what's happening like, 'When you come over and fold the washing ...' Then describe how you feel about it. For example, 'I feel a little bit upset because I feel as if I should be doing it myself'.

Then you go on to say what you'd prefer, 'What I would really like is if you just ask me what would be the most helpful'.

The benefits of this approach are that you don't blame the other person and you own your own feelings (and they can't argue with that).

Then go on, as graciously as you can, to say what you'd prefer them to do in a positive and constructive way.

Using an assertiveness formula like this one often clears the air because, as we all know, if we don't say things about something we feel, it can hang around in the air and cloud our most important relationships.

Remember too that sometimes the most powerful forms of support come not from others but from within yourself. Support and nurture yourself by:

- Optimising your health with regular food, sleep and exercise
- Focusing on your strengths and using your networks of support to help you highlight your strengths as a parent of a child with a disability and as a person.
- Training yourself to think optimistically – viewing the world through a more optimistic frame can make an enormous difference.
- Enjoying the moment. The future will then be more inclined to look after itself and you'll have time to notice your daily achievements and your child's milestones.

Again, it's other parents in your support network who have children with a disability who will understand the importance of little things and little achievements that you will be able to celebrate.

CLOSE

Thanks for listening. We hope you've found these strategies and ideas useful.

You can download or listen to more episodes in the ParentWise Podcast series at the Cerebral Palsy Foundation's website - www.cpfoundation.com.au