

### **Key message**

*Parenting a child with global developmental delay involves a long-term commitment, but there are things you can do to make the journey easier. The end result can be more positive than you could have imagined at the beginning.*

For all parents, raising children is a journey, with many ups and downs along the way. For parents of children with global developmental delay, that journey can appear to be harder, and the final destination more uncertain.

Here are some thoughts on what to expect, and how to support yourself on the way.

### **The start of the journey**

- ***The start of the journey can be rocky.*** While you are trying to understand your child's needs and learning about your there is still is likely to be Confusion, anxiety, not knowing what to do or how to help
- ***These reactions are not pleasant, but they are normal.*** It would be worrying if you did *not* feel anxious and confused during these early stages.
- ***Things will settle down in time.*** As you learn more, it will become clearer what your child's needs are and what you and your family can do to meet them.

### **What to expect as things progress**

- ***There will be emotional ups and downs.*** Parents of children with developmental disabilities often describe the journey as an 'emotional rollercoaster', so you can expect to feel a range of different emotions, some positive and some negative, at different times in your journey. Just knowing that this is likely to happen can make it more bearable and understandable when it does.
- ***Transitions are likely to re-activate earlier feelings of uncertainty and anxiety.*** Every transition that your child makes – from home care being cared for by others, from preschool to school, from one class to another – will require adjustments on everyone's part. You and your child are likely to feel anxious and uncertain during these times. Take comfort from the fact that things usually settle down in time as new relationships and routines are established.
- ***No one can tell you what your child can or cannot achieve in time.*** This is because developmental disabilities do not have a fixed effect on children ,and



because each child develops differently. It is also because children's development partly depends upon the experiences and opportunities that they are given. It is up to you to discover what gifts your child possesses and how these can be nurtured.

## How to support yourself during the journey

- **Believe in yourself.** Parents of children with global developmental delay can feel overwhelmed and helpless, particularly in the early stages. It is important for you to have faith in your own ability to find ways to meet the needs of your child and family. With the right help, that ability will grow in time, along with the confidence to know you are doing the right thing for your child and family.
- **Look after yourself.** Just because you are the parent of a child with additional needs does mean you don't have needs of your own. These needs include having friends and interests of your own, as well as You'll be less able to respond to and care for your child and for other family members if you do not look after yourself.
- **Set yourself a pace you can manage.** The journey ahead is a long one, so don't start off at a sprint or you'll burn out before you have got very far. Only take on what you and your child can manage, and don't try and do absolutely everything.
- **Get yourself a support group.** Just as every child needs caregivers who are totally committed to them, so every parent and family needs a core group of people who care for and support them. This core group can include partners, family members, friends, or other parents of children with developmental disabilities. If you don't already have a core group of people who have your back, then connecting with other families who share similar experiences can become a valuable source of emotional support and an important part of looking after yourself.
- **Enjoy your child.** Find what your child enjoys doing and what you enjoy doing with them, and make sure these activities are a regular part of your life. You will find the many parenting challenges easier to deal with if you maintain a positive bond with your child.
- **Keep your family life as normal as you can.** Make sure your family still does all the normal things other families do – holidays, excursions, birthday celebrations. Don't let other people's expectations or judgments stop your child and family doing all the things that other families do.
- **Focus on what you can do now.** When facing uncertainties and feeling anxious, it always helps to tackle something that you can do in the here and now. Never lose sight of your long-term hopes for your child, but in the meantime focus on short-term goals, things you can work on now and that will



make an immediate difference to your life and that of your child. It is the accumulation of these short-term gains that leads to big changes overtime.

- ***Every now and then, take time to reflect your family's journey and your child's progress.*** While you are in the thick of things, it may be hard to recognise that you are making progress. It's only when you stop to look back that you can see the distance you have come, the challenges you have overcome, and the progress your child has made. So you should make sure you make time to do this every now and then. You may be surprised at how far you have come.

You may also be surprised to discover how much you have benefitted from the whole experience. Some families report that, although having a child with a disability is not something they wished for or would wish on anyone else, it has changed their family in many positive ways. Despite all the challenges, they would not have wanted their lives to have been different.

### Parental resources

- *Children and Young People with Disabilities (CYDA)*  
<http://www.cyda.org.au/>

Children and Young People with Disability Australia (CYDA) is the national peak body which represents children and young people (aged 0-25) with disability.

- *The Family Voices Podcast* Early Childhood Intervention Australia (Vic/Tas)  
<https://www.eciavic.org.au/resources/podcast-family-voices>

The Family Voices Podcast is a new series featuring casual conversations with families of children with disability and/or developmental delay and the professionals they work alongside. This podcast is an avenue for parents to share their individual stories of everyday life in a family with a child diagnosed with disability and/or developmental delay.

- Fialka, J. M., Feldman, A. K., & Mikus, K. C. (2012). *Parents and professionals: Partnering for children with disabilities*. Thousand Oaks, California: Corwin.
- Findlay, C. (2021). *Growing Up Disabled in Australia*. Carlton, Victoria: Black Inc.
- Griffin, J. (2021). *Day by Day: Emotional Wellbeing in Parents of Disabled Children*. London, UK: Free Association Books.

### Professional resources

- Carpenter, B. (Ed.) (1997). *Families in Context: Emerging Trends in Family Support and Early Intervention*. London, UK: David Fulton Publishers.



- Fialka, J. M., Feldman, A. K., & Mikus, K. C. (2012). *Parents and professionals: Partnering for children with disabilities*. Thousand Oaks, California: Corwin.
- Kausar, S., Jevne, R.F. and Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal of Developmental Disabilities*, 10 (1), 35-43.
- Keilty, B. with Kosaraju, S. and Levine, H. (2017). *Seven Essentials for Family–Professional Partnerships in Early Intervention*. New York: Teachers College Press.
- Kingston, A.K. (2007). *Mothering special needs: A different maternal journey*. London, UK: Jessica Kingsley Publishers
- Maul, C.A. and Singer, G.H.s. (2009). "Just good different things": Specific accommodations families make to positively adapt to their children with developmental disabilities. *Topics in Early Childhood Special Education*, 29 (3), 155-170.
- Solomon, A. (2013). *Far From The Tree: Parents, Children and the Search for Identity*. London, UK: Chatto and Windus.