

## INTRODUCTION

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

They're the days we'd rather not have, but at one time or another all parents of a child with a disability have experienced what social work consultant Kate Hooke calls the 'Black Days'. In this podcast, Kate looks at how parents can make those dark days more bearable.

## WHAT ARE THE 'BLACK DAYS'?

Hi. I'm Kate Hooke a consultant social worker with over 15 years experience working in the area of disability and health.

In the various parent groups I've run, it is amazing how often parents want to talk about the black days (or black weeks or month) with other parents who understand them, who have had them too.

The black days are those days when there seems to be no end to the troubles in sight.

When thoughts get jumbled, when emotions like guilt, sadness and fear of the unknown take hold and when everything seems hopeless and impossible.

It's difficult for many parents, and siblings, to admit to having black days. Sometimes it seems that society expects us to take on saintly, superhuman qualities when we have a family member with a disability.

Even though some parents may be reluctant to speak about them I can guarantee that almost all parents and family members affected by disability have had black days or week at one time or another.

For many parents the first black day or week was when their child was first diagnosed with a disability or when they started to notice that things were just were not right, or with the premature delivery of their baby.

(For some parents however, diagnosis can be a relief not a black moment, particularly if it has been a long and difficult path to get to that point.)

One mother told a group of parents that she called her black days 'scum pond' moments. She described what was usually a beautiful and largely calm pond that every now and then had a stone thrown into it. The stone caused many ripples and the scum from the bottom would rise up and muddy the pond.

She knew however, that over time the ripples would settle down and the scum would sink back to the bottom. The pond would once more be beautiful and calm. Many parents have found this a really valuable analogy and it an analogy that I actually use in my life.

## RECOGNISING AND COPING WITH THE 'BLACK DAYS'

Parents often talk about the black days as popping up at key times in their life.

One mother, for example, found her child's birthday each year difficult, as it was a reminder of the difference between what her child was able to do and what other children of the same age were doing.

Another mother found the first day of school each year difficult, as for her it marked the start of another year of training up yet another teacher to work with her child.

The causes of black days are as unique for each person as the strategies that they will use to work through them.

Many parents develop rituals to recognize the black days.

One mother took herself off for a massage when she was having a black day. She decided that if she was having a black day it meant things were obviously getting on top of her and she needed some TLC.

One father said he would try to go for a 5 km run if he was having a black day.

Another father however said that if he had a black day he needed to 'just keep pedalling', because if he got off the bike and had a rest he was worried that his black day might turn into a black week.

Over time, parents find what works for them when they are having a black day.

Support groups can be a great way for parents to learn strategies from other parents about how to cope with the Black Days.

Formal groups also help parents to develop a support network of people who truly understand what it is to have a black day.

These are the people we can ring, email or have a coffee with, when things start to seem overwhelming.

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Many parents have told me that their black days don't get less black as time goes on but they do get easier to manage – especially when parents know they have had black days before and survived them.

So, what are some of the best ways to survive black days?

Firstly, try to learn to recognise the signs leading up to a black day. It will make the darker times easier to manage.

Have some tried and tested strategies to help you manage the black days. Other parents are a great source of information in this regard.

Keep trying strategies until you find something that works for you but if nothing seems to work and you are feeling dark and helpless for long periods, you may need to talk to your local doctor.

Allow yourself time to grieve and have dark days. They are part of being human and are just as essential as the joyful and calm days. Allowing yourself to express these darker emotions

will also improve your physical health and put you in a stronger position to support your family and your family member with a disability.

Find a buddy who you can call on during a dark day or week.

Sharing your emotional burden, particularly with someone who understands what you're going through, can lessen it considerably.

Of course, if you are listening right now and need someone to talk to immediately, please call Lifeline on 13 11 14.

## 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](http://www.cpfoundation.com.au)