

A sick child needs you to be strong

Having a child with a long-term illness or disability is always difficult to manage. While we grieve and struggle with serious illness in ageing parents, there is something so much harder when we see a child of our own afflicted with a major illness.

Is it because as parents we often seem masters, to our young children at least, of every situation?

But when a child is diagnosed with leukemia, cystic fibrosis, multiple sclerosis or any long-term illness, parents can't make it better or make it go away.

Feeling powerless to make a much-loved child better is something every parent dreads. Yet many parents face these situations, and have to learn how to manage.

Parents may put themselves through the agony of wondering whether they are responsible for the child's illness, and think back over all their youthful misdemeanours and wonder if their past behaviour has led to their child being sick. They may wonder if they have been neglectful, or if the child's illness is a case of the old-fashioned fire-and-brimstone idea about divine retribution.

Parents may blame each other and feel that if only their spouse had done this or that the illness would not have happened. The trouble is that we are so caught up in scientific thinking and needing to find a cause for everything that happens, that we forget that sometimes bad things just happen to good people.

So toss out the window all those thoughts of blame, past behaviour and torturing yourself about "why".

The task now is to think about what is happening and what are the difficulties we must find a way of facing.

One of the most important parts of dealing with a child's illness is to explain it to them, because they need the knowledge of what is happening and the ramifications it may have.

Obviously, how you explain the illness or disability will depend on the child's age. Then you need to be open about what the limitations are, but also what the possibilities are to thrive and enjoy life.

Parenting a sick child is about leadership – you need to explain what the parameters are, and say "these are the areas we can't manage, but here are all the things we can still do".

It's a matter of helping the child to learn to live with the limitations of the illness, rather than letting them become distressed and angry because of what they can't do. All life has possibilities, even for sick kids.

For a counsellor, the three basic rules are these: deal with and dissolve any issues of blame or guilt for the parents about the child's illness; communicate with the child about what is happening to them; and find out what resources there are that can help.

You need to be strong for your child and support them. This might mean finding an older buddy with a similar condition, or accessing agencies for older kids with disabilities that can help them find work and which offer emotional support.

If a sick child throws huge tantrums, it's important to challenge them, and not because they are ill. Ask them if they like themselves when they behave like this – chances are they will say no.

Finally, parents need time out too. It's important for Dad to get a break and go to the footy or for Mum to go out for coffee with friends. So don't feel guilty about using respite care, even if your child may want you 24 hours a day.

Let the extended family help out here. You also need support so you can continue being a parent, and respite breaks are essential for you to carry out your vital role successfully.

Survival tips

- Be open about the illness with your child
- Focus on the possibilities as well as the limitations
- Do something for yourself so you can recharge the parenting batteries.