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Introduction

If you are a parent raising a child with special needs, this guide is written for you. Every day is a new experience. Every day you are challenged and tested, frustrated and rewarded. Some days you may find yourself using old strategies. Some days you may have the willingness and energy to try something new. Every now and then, you might take a chance, and road test a thought that has popped into your head and felt right.

And you learn. You learn about your child, yourself and the community in which you live. You learn how to negotiate, to fight for the rights of your child, to research, to plan. You learn how to manage, innovate and communicate. You make your way. You find success. This is knowledge born of experience. This is expertise.

The contents of this guide have been developed from the knowledge and experience of forty-one parents who are currently raising children with a disability. Ranging in age from 5 months to 13 years, these children have presented their parents with many challenges, obstacles, sorrows and joys.

Exhausted and inspired in turn, these parents have struggled with feelings of doubt, frustration and grief. They have celebrated their children's achievements, their own successes, and savoured life. They have discovered in themselves abilities and strengths that they did not know they had. They have lost their way and found it again and again.

It is this knowledge and understanding, these abilities and strengths that this group of parents would like to share with you.

To ensure confidentiality, the names used in this guide are not the real names of the people involved.

Structure of the guide

The Parent to Parent guide is made up of twelve separate chapters. Each chapter contains information about a different aspect of raising a child with special needs:

Chapter 1: The early days describes some of the feelings and events that you may experience during the early days and weeks following your child's diagnosis.

Chapter 2: Behaviour and your special needs child looks at some of the strategies that you can use when you are working with the behaviour of your child, such as social stories, time-out, progressive exposure, reinforcement, explaining why and routines.

Chapter 3: Dealing with specific behaviours gives examples of the way the strategies described in chapter 2 can be used to manage specific behaviours. Parents offer advice on dealing with aggression, bedtime, escaping, fear of specialists, bathtime, mealtimes, tantrums, showing affection and toileting issues.

Chapter 4: Getting social with your child explores some of the more social parts of your child's life. Parents provide practical tips on dealing with comments from the public; preparing your child for group social activities; dealing with loneliness and bullying; and managing school holidays. There are also some hints on how to manage day-to-day tasks such as shopping and banking.

Chapter 5: When your child asks 'Why am I different?' provides some ideas for answering your child's questions about their disability.

Chapter 6: Your family explores some of the issues that can arise within families when raising a child with special needs. Attention is given to the issues and needs of parenting partnerships, single parents, fathers and brothers and sisters.

Chapter 7: Friends and extended family discusses the response of family and friends to a child's diagnosis. It looks at some of the feelings and beliefs that can influence their behaviour, and provides some suggestions for creating and keeping positive relationships with them.

Chapter 8: Dealing with specialists provides practical tips for getting the most out of your meetings with the specialists who are involved with your child.

Chapter 9: Looking after yourself provides information about the things that you can do to keep yourself energised and healthy. This chapter also addresses issues related to respite care and looks at the pros and cons of support groups. At the end of this chapter you will find '10 hot tips for staying cool', for quick action when you reach boiling point.

Chapter 10: Getting organised describes a variety of activities that can help you to get organised. These include goal setting and planning, time management tips, and help with setting up an information file for your child.

Chapter 11: The things that make us strong presents parents' beliefs about the feelings, actions and events that have helped them to cope with raising a child with special needs.

Chapter 12: Resources contains up-to-date information about agencies, services and websites that may be relevant to you while raising your child. Some of the parents involved in the development of this guide have also volunteered a recommended reading list, consisting of resources that they found particularly useful.

How to use the guide

As the parent of a growing child, you are very busy. Balancing the physical and emotional needs of your child with those of other children, a partner, a job and extended family, all the while keeping a house and home life together, can leave parents with very little time to themselves. Reading can become a luxury, stolen in moments over coffee, or late at night as eyelids droop and sleep calls.

With this in mind, the Parent to Parent guide has been put together in such a way that it can be read in chapters, when you have only a spare few minutes or you want information on a specific topic.

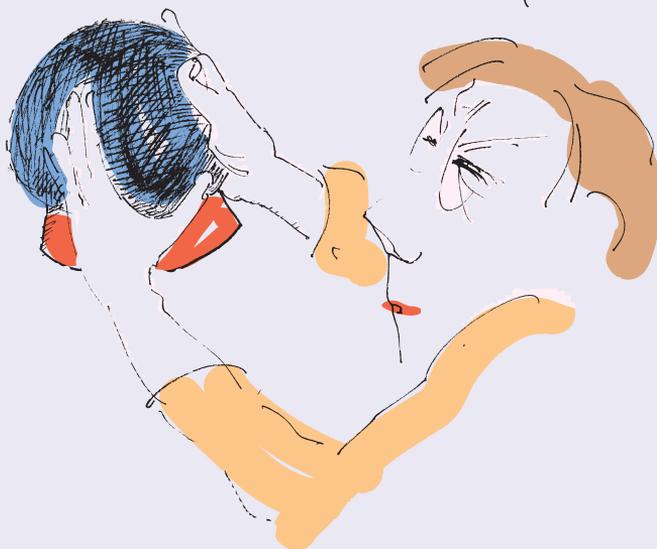
When you first receive the guide, have a look through the contents page, the index, and perhaps a brief flick through the pages, to get an idea of the different types of information included.

If there is a topic that you are immediately drawn to, or one that is about something you are facing at this time, you may like to turn to that chapter and read it more closely. For example, if you have an appointment with a specialist coming up, you may want to read the chapter on dealing with specialists. If you have just discovered that your child has smeared the contents of their nappy all over their bedroom and themselves, you might want to read about dealing with toileting behaviours—after a quick cleanup.

At the front of each chapter are some quick tips that can be read in moments when needed. More detailed information on each of these tips can be found inside that chapter.

CHAPTER
The early days

I wanted a Crystal Ball



QUICK TIPS

- *Be prepared to feel angry, sad and shocked when your child's disability is first diagnosed.*
- *Counselling may help you in these early days—you can safely talk about what you are feeling and get some help adjusting to the changes in your life.*
- *It may help you to collect information about your child's disability.*
- *You may need to put some time into finding out about the services that are available to you.*
- *Be prepared for new people to enter your life and your home. Remember they are there to help you.*
- *You may be able to get some help from other parents who are raising a special needs child. Allow yourself to talk openly to these people.*

The days, weeks and months following a child's diagnosis of a disability can be a difficult time for parents. Overwhelmed by conflicting emotions, parents can find themselves looking for answers, looking for support, and wishing that someone could reassure them that it will all work out.

The feelings

When your child is diagnosed with a disability, you can find yourself rocked by feelings of anger, sadness, loss and shock. Your natural hopes and expectations of a normally developed child are suddenly crushed, leaving you grieving the child that was not to be, and wondering about an unknown future.

I wanted a crystal ball that would tell me how it would all pan out. It was all very murky in the beginning. Our child was diagnosed with a disability in utero. Our whole lives were changing and it was all so unclear.

Greg, parent of a child with spina bifida

During the early days, your feelings of grief and anger can flow into your relationships with your partner, family and friends. You may feel that no-one can understand what you are going through, and you may feel lost and alone.

You are going to feel grief and anger, you are going to have trouble with your other kids, your partner, your family, your neighbours and your friends. You will come to a point where you realise that some friends are worth keeping and others you have to let go, and that's going to be hard. But you are not going to feel like this for ever.

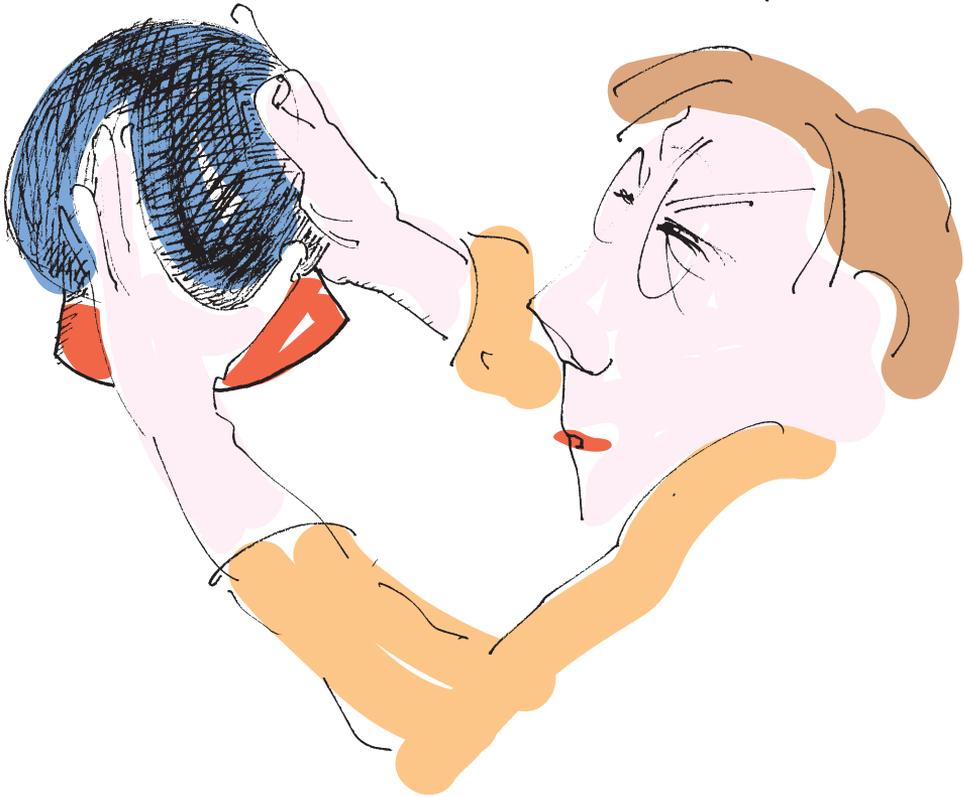
Catherine, parent of two children with autism and intellectual disability

Other parents have experienced this journey. They know how you are feeling, and don't want to pretend to you that this time is not difficult, is not awful. They want to let you know that these feelings do not last forever, that one day you will wake up and things will be better.

You can get negative and pessimistic but after a while you start to crawl out and go aaah, this is fun again.

Carly, mother of a child with a chromosomal abnormality

I wanted a Crystal Ball



You learn to stand on your own two feet with a child with a disability. It all feels normal now.

Elaine, mother of a child with autism

Counselling can be very helpful during the early days following a diagnosis of disability in your child. It can provide you with a safe place, where you can talk freely about some of the feelings that you are experiencing. A counsellor can also give you tools that will help you to adjust to the changes entering your life.

Whenever I've just felt like oh my God, if anything else goes wrong, I'm going to go berserk or something, I'd go and speak to [the counsellor], it was lovely just to have her to talk to. I think it's wonderful for anybody who's going into the process of getting a child diagnosed, because that is a horrendous time in anybody's life.

Kristy, parent of a child with autism

Collecting information

Soon after diagnosis, you may find yourself wanting to search for information about your child's disability.

Sources of this information can include paediatricians, specialists, service agencies such as Gateways or the Department of Human Services, community health centres, the internet and the library. You will find contact details for various agencies, centres and other sources of information in chapter 12 of this guide.

The amount of information that is available to you can be enormous and overwhelming. Parents who have already been through this process suggest the following:

- Focus on the information specific to your child's condition.
- Use reputable sources, such as associations relevant to your child's disability.
- Speak to other parents of children with the same condition and ask them to recommend resources they have found useful.

There are many benefits to be gained from being informed about your child's disability. You can learn about how your child will develop, gain insight into some of the issues that may arise for you as a parent and learn of the outcomes associated with your child's diagnosis.

However, for some parents, the knowledge collected during the early days following diagnosis can come at an emotional cost. While keen to learn more about their child's condition, parents are often faced with information that describes the more severe types of their child's diagnosed disability. They can develop fears and concerns about possible outcomes that may never actually occur for their child.

When my son was first diagnosed I wanted to read every book I could possibly find on it and I just read all day long. I found that a bit depressing because some books weren't that appropriate. It gets your mind thinking about all these possible consequences of your child's condition. If you've got a child that's high functioning a lot of the books that you read will be about children that are low functioning. The outcomes are vastly different, so it can be a bit depressing.

Charlotte, parent of a child with autism

When you are reading information about your child's disability, remember that:

- many resources are designed to provide information about the condition as a whole, and cover all ranges of severity of the disability

- only some of the information that you are reading may be directly relevant to your child
- the information describes your child's disability, not your child.

Finding out about services

Following your child's diagnosis, you will be put in to contact with some of the services that help parents of children with special needs. Parents who have already been through this process also recommend that you do your own research to find out what services are available.

Work actively with service providers to make the most of your service opportunities. Don't wait for them to come to you.

Lynne, parent of a child with cerebral palsy

Waiting for professionals to point you in the right direction can result in missed funding opportunities and delays in finding services that may be useful to you.

I didn't know about the toy library until two and a half years down the track. It was not until we swapped physios that she said, oh you've been going to Noah's Ark? I said what's Noah's Ark?

Lee, parent of a child with spina bifida

Tips for your search

- Speak to your paediatrician, early intervention team and case manager about the range of services that are available to you.
- Make contact with the association related to your child's disability.
- Work your way through the resource list provided in chapter 12 of this guide.
- Talk to other parents about the services and funding that they have used.

The Association for Children with a Disability has published an excellent guide to the benefits and services that are available for families of children with a disability. It is called *Through the Maze*, and copies are available from the Association.

Preparing for service provision

When parents become involved with therapeutic and support services, they are often unprepared for the number of people who suddenly enter their lives.

All of a sudden there are appointments to organise, people to meet, names to remember. There will be people coming into your home, building relationships with you, your child and other members of your family. You may develop a relationship with a particular service provider, only to experience a changeover to someone new as different agencies become involved.

You may feel as though your home and your life are being invaded. You may feel somewhat overwhelmed. Parents who have been through this experience empathise with you. They too have felt invaded and overwhelmed. They too have had to adjust to big changes in the way that they live their lives.

You have people in your home all the time and if you're not used to that, it can be fairly overwhelming no matter how non-threatening they try and be. They're usually very lovely people, they wouldn't be in the job if they weren't. It would be good for others to prepare you for this, because you don't realise that you have to have outside help.

Carol, parent of a child with arthrogypsis

Be prepared for new people to enter your life and your home. Try to focus on the positives of this situation. These people will be there to help.

Finding parents to talk to

Other parents who are raising children with special needs can be a valuable resource for you over the coming months and years. They can provide you with information about services and funding, strategies for dealing with issues that arise with your child and a sounding board for questions and concerns.

It's not until you're sitting there talking to another mum or dad and you ask, what do we do when this happens? Who do you ring when your world is falling apart? You realise personal experiences are what count. You don't always talk to people with kids younger than you, you get the other end of the scale where a lot of them have kids older than yours as well, so that's great.

Keely, parent of a child with autism

Experienced parents can be an important source of emotional support. They can appreciate and celebrate your successes and help you to realise that you are not alone in your struggles.

The helpful thing was just knowing that there was someone around to back you up because in the earlier days you don't feel confident, you don't feel as though you're going to be able to manage this.

Greg, parent of a child with spina bifida

One of the most commonly expressed regrets of parents, is that they did not talk to other parents during the days and weeks following the diagnosis of their child. It may seem strange to you that some parents feel reluctant to talk to, or meet other parents who are in a similar situation. On the other hand, it may be a reluctance that you recognise, as you too have experienced this feeling.

I would have liked to have known another parent going through this. But there's a real turmoil inside you, and you don't want to take that first step because every time you take a step down that path, you're actually acknowledging that they [the specialists] are right ... I eventually got into a discussion group with parents saying what they did with picnics and stuff like that [in regard to managing child behaviour]. To have had that earlier would have been fabulous.

Vicky, mother of a child with autism

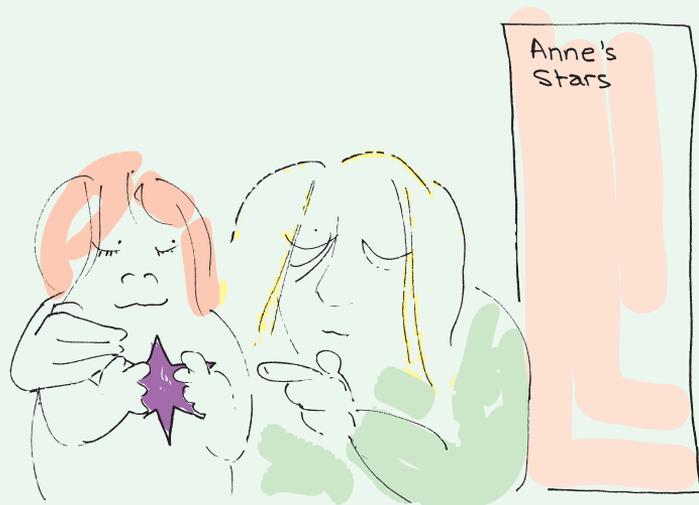
Connecting with other parents can provide you with emotional support, useful strategies and tips for navigating the service system. They can help you to come to terms with your child's disability and provide reassurance that life can, and does, go on.

Where can I find other parents?

Support groups can be a good starting point for meeting other parents. A list of regional support groups can be found in chapter 12 of this guide.

Some parents have found that their involvement in early intervention programs has enabled them to meet and become friends with other parents of children with similar needs. You may also like to try the internet. Chat rooms and noticeboards on relevant sites can put you in touch with other parents interstate or overseas.

Managing the behaviour of your special needs child



QUICK TIPS

- *It's likely that some of your child's behaviours will cause you problems. There are ways of changing these behaviours.*
- *In trying to change a problem behaviour it's important to work with one behaviour at a time.*
- *There are various strategies for dealing with problem behaviours presented in this guide: explaining why, positive reinforcement, progressive exposure, routine, social stories and time-out.*
- *Think about a behaviour that you would like to change and choose one of the strategies to try. Remember that it might take quite some time.*
- *Be consistent. It's important to always respond in the same way to that behaviour.*
- *Some behaviours are hard to change—you need to persist to get results.*
- *Try to work with your child's difficult behaviour in different settings.*
- *Tell yourself positive things to encourage you through the time of changing a difficult behaviour.*
- *Try to appear calm so that your child gets the message that their difficult behaviour is not getting to you.*
- *Get other family members to help with your everyday tasks while you are working to change your child's behaviour.*

The relevance of this chapter and chapter 3 will depend on the nature of your child's disability. These chapters are written for parents of children who exhibit some problem or difficult behaviours at times such as children with autism. For these parents, feeling moments of frustration and intolerance and experiencing failures as well as success—all this is *normal*.

Children act on instinct and are controlled by their basic drives. They tend to react rather than respond, are self-centred and wilful and often experience strong emotions that they are not quite sure how to manage. You are faced with the job of shaping all of this energy and will, of raising a child who behaves appropriately, interacts well with others and feels able to express the unique qualities that make them who they are.

As you know, this job is not easy.

Every day, and many times a day, you will find yourself setting limits and enforcing boundaries. Much of the time, your first attempts at changing your child's behaviour will be met with resistance. Your young child may simply ignore you, or look you calmly in the eye before resolutely digging in their heels. Your older child may push your buttons with uncanny accuracy, hoping for a reaction that will divert you from the task at hand.

The good news is that you are not on your own. The better news is that once your child has learnt some of the basic principles of appropriate behaviour, your life will get easier.

Preparing for behavioural change

There are certain behaviours that all parents recognise as a problem. They make life difficult for you, and can affect your child's ability to both care for themselves and develop relationships with other people. Common examples of these behaviours include aggression towards others, tantrums, problems with eating or an inability to give or receive affection.

Other behaviours are more open to individual interpretation. A behaviour that you find difficult to tolerate—for example, a child who jumps on the bed while whooping and screaming—may be viewed with tolerant amusement by another parent. Similarly, your child's habit of sneaking into your bed during the midnight hours may be viewed as problem behaviour by some parents and not others.

When you are preparing to tackle your child's difficult behaviours, there are two things that you need to decide:

1. What are the behaviours that cause problems for your child and those around them?
2. Which of these behaviours would you like to change?

Setting yourself up for success

Work with one behaviour at a time

Make a list of your child's behaviours that you would like to change. Arrange these in order of priority and importance.

Select one behaviour from the top (or near the top) of the list to work with. Set yourself a period of time to work only on this behaviour. How much time is needed will vary from child to child and across behaviours. A good rule of thumb is to start with three or four weeks and work from there.

Do not try to work with any other behaviours during this time.

Be consistent

You have to respond to a behaviour appropriately every single time, again and again until it is learnt. I see exhausted parents, who are tired and can't go on. But they have to. They have to be consistent or the behaviour will not change.

Julia, parent of a child with autism

Successful behavioural change depends heavily on your ability to be consistent and persistent in your response to your child.

Once you have decided on a target behaviour, it is important to respond consistently to the behaviour every time it is expressed. If your response is inconsistent, you are sending a confusing message to your child. You are telling them that their behaviour is okay sometimes and not others. The child will also become aware that sometimes, their defences of aggression, whining and tantrums are successful. An inconsistent response can actually make these behaviours happen more often.

In two-parent families, it is vital that both parents agree and are consistent in their response to their child's behaviour. If your child has regular contact with other family and friends, it is also important to involve them in the process. Talk to them about the

behaviour that you want to change, and let them know why this change is important to you. Explain the course of action that you have decided to take and ask them to continue working on your behalf while your child is in their care.

Be persistent

At some point in time, you may come across a behaviour that is highly resistant to change. You have selected your strategy, been consistent in your response and extended your time frame by two weeks—without success. You may feel frustrated, tired and stressed. You may be thinking of giving up. It is at this very point that you must persist.

Hang in there. It could be your response to the very next episode of your child's behaviour that makes the difference. Have another look at your strategy. Is there something that you may be able to do differently? Talk to other parents, read through this guide. Prepare for success.

Be prepared to work with the same difficult behaviour in different settings

Many children with special needs do not understand that the rules that apply to a particular behaviour in one setting, also apply to that behaviour in a different setting. Children can be very literal. If you have taught your child how to play appropriately with their brothers and sisters at home, your child may have learnt, 'this is how I play with my brothers and sisters at home', not 'this is how I should play with other children'. Equally, a child who has been taught that they have to sit down to eat their lunch at school may fuss and refuse to eat at home.

Be prepared to work with your child's difficult behaviour in a variety of settings.

This may involve going into these settings with your child and working with the behaviour 'on site'. Alternatively, meet with the people who look after or supervise your child in other settings. Talk to them about what you are trying to achieve and how you are doing it. Ask them to provide a consistent response to your child's behaviour while they are in their care.

It's all in the timing

Tired? Stressed? Worn out? This is probably *not* the best time to try out a new approach or strategy.

Try to identify times throughout the day when your energy and concentration levels are highest. These will be the best times to start working to change your child's behaviour.

If your child's behaviour occurs mostly in the 'mad hours'—in the morning before school, or in the late afternoon and early evening—use the quieter hours of the day to plan. Think about how you want to approach your child. Run through the things that you want to say and do in response to their behaviour.

If possible, get help with some of your 'mad hour' responsibilities from other members of the family. Keep a casual eye on your child and step in when they begin to express the behaviour that you want to change.

Self-talk

Positive self-talk is a great way to reduce parents' anxiety and stress. Imagine yourself standing near your child while they are having one of their best screaming tantrums. Start telling yourself 'I can't cope with this, I can't cope with this'. How do you feel?

Now, imagine yourself standing in the same position near your child, but as your child screams and thrashes about, you start telling yourself 'I can cope with this. I am achieving change'. Repeat this a couple of times. How do you feel now?

If these statements don't work for you, try to think of other statements that can help you to connect with your strength. The effect of using positive self-talk at difficult times can be quite remarkable.

Strategies for dealing with problem behaviours

You are standing on the brink of change. You have selected one of your child's difficult behaviours, set yourself a timeframe and committed to being consistent and persistent. Your self-talk is positive and motivated.

Now all you need is a strategy.

Following are several strategies that can be helpful when working with problem behaviours. Each has been tried and tested by other parents raising children with special needs. You may find that some of the strategies are familiar to you. Indeed, you may already have put them into practice. Other strategies may be new to you. Perhaps an idea that you have heard of vaguely, but were never quite sure about, is explained here.

Explaining why

When you act in response to one of your child's problem behaviours, provide your child with a simple explanation of why you are doing this.

It is a good idea to break your explanation down into three separate parts:

1. Tell your child that you are not happy with this particular behaviour.
2. Explain why you would like to change this behaviour.
3. Give your child an example of a preferred behaviour.

For example, you might say to your child: 'I do not like it when you draw on the walls. This makes a mess on the walls that takes a long time to clean up. We use paper for drawing on'.

When you use this approach, you are showing your child two things:

- actions have consequences
- when you want to change a consequence, you need to look at, and change, the action.

Your explanation should be given when the behaviour occurs, either before or after the disciplinary action that you have chosen to use.

After he'd come out of time-out we'd talk to him about why he'd been sent there, because there's no point in sending them willy-nilly after three minutes. There was that sort of debrief afterwards.

Julia, parent of a child with autism

Once you have been using explanations with your child for some time, you might like to encourage them to provide this explanation for themselves. Ask the child:

1. What did you do wrong?
2. Why was this wrong?
3. What are you going to do now?

Some parents may like to start off asking questions 1 and 3, and move on to include question 2 at a later date.

When you ask your child to think about their behaviour in this way, you are encouraging them to consider the effect of their behaviour on other people and teaching them how to come up with their own solutions to problems. These are two skills that will help them greatly in many areas of their lives.

Positive reinforcement and the use of rewards

The way it works

Any child behaviour that is rewarded is likely to be repeated. Any child behaviour that is ignored, or not rewarded, is likely to become less frequent.

Reward the good, ignore the bad. Sounds easy, doesn't it?

How we promote negative attention seeking

If you focus on the negative, you are going to get negative. If you focus on the positive, you get positive back.

Peta, parent of a child with autism

It is an unfortunate reality that parents tend to respond more frequently to their child's negative behaviours than their positive behaviours. Positive behaviours tend to increase the ease of living with your child. The day progresses more easily and with more harmony, as your child gets dressed, eats a good breakfast and plays well with siblings, all after a good night's sleep.

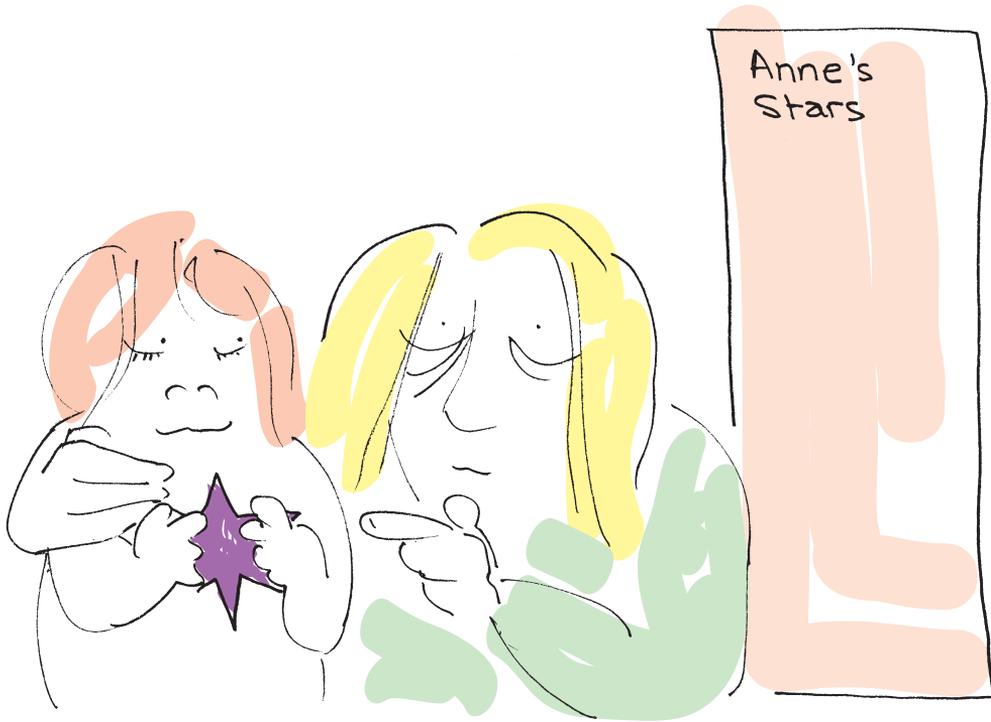
Each of these positive behaviours can pass by unnoticed and unrewarded, as you begin to have glimpses of the calm possibilities of future life. Then your child misbehaves. All of a sudden they receive a shot of focused, one-on-one attention. Their minds start ticking over, and it's a fair bet that they are thinking 'mmmm that felt good. I got what I wanted. I might do that again'.

Children seek the attention of their parents. Generally they will prefer, and act in order to receive, positive attention. However, when this is in short supply from stressed, tired or anxious parents, negative attention will do 'just fine'. From an early age, children can develop quite a range of behaviours that almost guarantee getting your attention. These include hitting, spitting, throwing and breaking things, diving on younger brothers and sisters and pulling the cat's tail, just to name a few.

One of your best tools for reducing this type of behaviour is to consistently notice and reward your child's positive behaviour.

Rewarding positive behaviour

There are several types of rewards that you can use to encourage your child's positive behaviours:



Emotional or social rewards

These include loving hugs, smiles, eye contact and praise from the observing parent. When giving verbal praise, remember to reward the behaviour rather than the child. For example, it is preferable to say 'great cleaning up Mary' rather than 'you are a good girl for cleaning up'. Otherwise your child may begin to use your response to their behaviour to determine their sense of self-worth.

Activity rewards

These centre around activities that your child likes. They may consist of extra computer time, an opportunity for some water play, an impromptu game of soccer in the backyard or reading a favourite story together.

Object rewards

These can include stickers, stamps, small toys, pocket money or the old favourite, good things to eat.

Star charts

A star chart is a piece of card that has a series of columns drawn on it. Each time you want to reward some behaviour you place a star or stamp on the chart. You can offer extra rewards or treats to your child for a certain number of stars.

Ignoring negative behaviour

Following the ideas of reinforcement, behaviours that are ignored, or not rewarded, will, after a while, become less frequent. However, it can be hard enough to ignore a persistent mosquito, let alone the obvious attempts of your child to drive you up the wall.

Selective blindness and deafness can be a great ally in these situations. Draw on your inner actor, hum a tune and go on with what you are doing. If you feel your heat rising, step around your child and head off into another area of the house to fold clothes or make beds.

Your primary goal in this situation is to give the appearance of unflustered calm.

Sometimes your child's behaviour will get worse in response to being ignored, and become destructive. If you find this too difficult to ignore, calmly approach your child and ask them to help you clean up the mess. If your child refuses, put your hand over theirs and guide their behaviour. Avoiding eye contact from your child during this task will deny them your direct attention, and prevent them from seeing how annoyed or angry you may be.

Hang in there. If you can hold out, and not reward negative behaviours with your temper or attention, your child will eventually get the message. The following example shows how a parent uses time-out and ignoring negative behaviours to achieve behaviour change in another parent's child.

I stopped a child stripping trees this year in one week. This is a very solid eight year old boy without any intervention up until this year. He used to get outside and he'd strip all the trees. He lived on a property and allowing him to go outside was his mum and dad's time-out. That works for them, but when he comes to school and strips the trees there and he goes down the street, it's got to stop there.

I use a chair in a room where there is no stimulation. I sit him down on the chair and say to him, if you touch the trees, you come inside. Touch the trees you come inside. It doesn't take them long to work it out. And I would say in a week I'd stopped it. If you leave it go once, then it's inconsistent. You pull them back and you pull them back and you pull them back.

I sat in there and the boy actually spat all over me but it was okay because he's still sitting. He knows I don't care what he does to me, he's going to sit, so he can kick, he can try and kick. I'll try and avoid it but I'm not going to focus on it because chances are he doesn't want to sit. If I focus on his spitting or kicking or hitting then I've lost it because he doesn't sit.

I focus on great sitting, he can spit at me but great sitting. I don't acknowledge that other stuff going on and he's never spat at me again. He's going to sit but anything he throws at me, it's okay because I'm asking him to sit. He doesn't want to sit, it's boring, but I'm not going to focus on the negative, we're just going to trial it again when he's outside and say right, no trees or we come back inside.

Other people have got offended and they go off. Then what are you going to teach the child, that every time you ask them to do something and they get down on the floor and they kick at you and they spit at you, you walk off?

Peta, parent of a child with autism

Diverting and redirecting negative behaviour

Diverting your child's attention can be a useful alternative when you are struggling to ignore the behaviour. As your child starts to get agitated, brightly suggest a race around the back yard, some water play or a video.

Some parents may have trouble with this technique, as they feel it will reward the attention-seeking behaviour of the child. However, the aim of the technique is to break the negative spiral of your child's behaviour. When used together with ignoring, it can give you a break and nip approaching tantrums in the bud.

Redirection is a similar idea that involves working directly with your child's behaviour, to move it in another direction.

My son always puts his hands in my face. So I put an object in them as he reaches towards me, or request him to sit on his hands or put them in his pocket. Successful 'hands down' is heavily rewarded.

Charlie, parent of a child with autism

Consistency is very important when using the reward or ignore approach to change behaviour. A reward needs to be given immediately after a positive behaviour is expressed. Equally, a behaviour you are trying to reduce needs to be ignored or redirected every time.

Progressive exposure

Progressive exposure is a strategy that you can use to help your child deal with situations that make them anxious or fearful. It involves gradually exposing your child to a feared situation a little bit at a time, over a long period of time. Little by little, your child becomes familiar with the situation and their feelings of fear, anxiety or being overstimulated are gradually reduced.

To use progressive exposure with your child, identify a situation that makes your child fearful or anxious. An example may be going to the supermarket. Identify what you would like to achieve. In this case, you may want your child to be able to cope with a trip to the supermarket to do some shopping.

Break the situation that you want to deal with down into very small parts. Gradually expose your child to stage 1 of the process, then stage 1 and 2, then stage 1, 2 and 3 and so on:

Okay Mark, we are going to go into the shop. I need a lollipop. We will get a lollipop each and then we'll go. After your child comes with you into the shop you say that was great Mark, you came with me into the shop to get a lollipop. I really like it that you did that.

When your child is able to deal with the first stage comfortably, you can move on to the next stage:

Okay Mark, we are going to go into the shop. I need a lollipop and some milk. We will get some milk and a lollipop each. And then we will go. After your child comes with you to the shop, you say that was great Mark. You came with me into the shop, I'm really proud of you.

When your child is okay with the second stage, move on to the third stage:

Okay Mark, we are going to go into the shop. I need a lollipop, some bread and some milk. We will get bread, milk and a lollipop for each of us. Then we will go.

Once again, reward your child for coming with you to the shop.

Continue this process until your child can comfortably deal with the situation as a whole.

Tips for using progressive exposure

- Progressive exposure works. But it does take commitment and time.
- The idea behind progressive exposure is to take your child to the edge of their comfort zone on each occasion, without allowing them to feel too frightened, anxious or stressed.

- Holding your child’s hand, or standing close to them during the process may help them to feel secure.
- Use lots of encouragement and positive rewards each time you expose your child to the situation that you are working with.

Our son is a phobic child. He’d scream every time a plane flew over and every time the train went past. Now at nine he can catch a train on his own if he has to. But you’ve got to break it down to the smallest pieces that they can handle and build on those. I’d take him to the end of the street here not far away from the train station. We’d watch for five minutes and the next time we’d watch for ten minutes, fifteen minutes, gradually building it up over six months. Then we’d stand on the platform and watch the train go past so we were very close and then from there we went on short trips. And it’s gradually extended out further and further.

Sharon, parent of two children with autism

Progressive exposure is particularly useful for helping your child to deal with situations that make them fearful or anxious as a result of over-stimulation. These situations will differ between children and can include travelling in cars, trains or planes, handling animals, supermarket shopping, showering or bathing, and exposure to music or noise. Parents of autistic children have also reported success when using this technique to help their child cope with the giving and receiving of affection.

Routine

A routine is a set pattern of behaviours that are developed to organise certain times of day, or days across a week. Routines can be developed for getting up and ready for school in the mornings, mealtimes and bedtimes.

An example of a morning routine might be:

- | | |
|-------------|---|
| 7.00–8.00am | Get up, watch a particular cartoon or show while eating breakfast.
Get dressed, brush your teeth and comb your hair. |
| 8.30am | Check through your school bag with mummy or daddy to see if you have everything you need. |
| 8.45am | Everyone into the car. |
| 9.00am | Drop off at school. |

Weekly routines will describe the set pattern of events that occur each week. These may include days for kinder or school, regular therapy sessions, meetings, and planned recreational activities for your child.

Children tend to respond very well to the structure provided by routine. It can help them to understand what behaviours are expected of them and the course of events that will make up their day. The use of routines is strongly recommended by parents who are raising children with special needs.

Establishing a routine is just essential with children with autism. They need that framework. They can predict what's going on in their life and they know what's coming next. It really reduces their anxiety level and that in turn reduces the tantrums and bad behaviour. As much as you feel like you're adapting your life around them it makes life a hell of a lot easier.

Charlotte, parent of a child with autism

Our whole life is routine.

Lana, parent of a child with Tourette syndrome and motor dyspraxia

Helping your child to learn a routine

A routine is learnt through repetition. Once you have developed an effective routine, it is important that the same set of behaviours are repeated at the same time, over and over again, until your child becomes familiar with them.

At the beginning, your child will need a lot of reminders to complete each step of the routine. They can often resist moving from one task to another and may display a range of behaviours that are designed to make your job more difficult. Common examples include whining, firm refusal, hitting, running and hiding.

Take a deep breath, take your child by the hand and lead them to the next task. Explain to them firmly that 'this is the way we do things in the morning/evening/bedtime'. Repeat the routine to your child: 'we do this and then we do that and then we go to school/have dinner/go to sleep'.

When you consistently repeat this over time, your child will learn and participate in the routine.

Weekly routines can be more difficult to teach because there is more time between different events. It is more difficult for your child to become familiar with the routine through repetition. One parent has come up with a great idea that can be used to deal with this problem.

Amy, who is mother of a young child with autism, has made up a separate calendar for each day of the week on her computer. The calendar is separated into time blocks, and uses pictures and symbols to mark the different events that will occur during a given day. The name of the day is shown clearly at the top of the calendar.

Each morning, Amy sticks a copy of the daily calendar to the wall at child height, so that her son can read it easily. In the beginning Amy led her child to the calendar every morning, and went through the different events that were going to happen that day. Now, he runs to the calendar to see for himself what will be happening that day.

Over time, Amy's son began to get used to the idea that certain events always happened on certain days of the week. He began to understand the weekly routine.

Routine: The double-edged sword

Some parents find that the use of routines can be a double-edged sword; both good and bad.

Their children can become so used to the security of a set routine, that disruptions can throw them off kilter, resulting in a backwards step in several areas of behaviour.

Like my elder son says, we don't have many friends over. Those friends blow out the routine.

Jill, parent of a child with Down syndrome

You can prepare your child in advance for any expected changes that are going to occur to their routine. A few days ahead of time, begin talking to your child about the event that is to occur and how this will affect their routine. Reassure your child that after this event has occurred, life and their routine will return to being the same as before. This approach can be useful for dinner parties, friends coming to visit or a trip to the movies.

Some parents argue that change and disruption to routine are a part of life. They feel that it is important that their child learns how to cope with disruptions and be more flexible in regard to their routine. In an effort to teach these skills, these parents will create situations that prompt their child to step out of routine. They will make sure that the child experiences a positive event because they were prepared to be flexible.

You have to have the boundaries there so that the child feels safety and security, consistency and all those feel good things so that they can get into a routine. The routine is what's got me through, but at the same time you have to leave a few holes in it and if the holes aren't there you have to make them. You deliberately take the boys to the pictures so that the session starts at five o'clock [they routinely have dinner at 6pm], so they have to have afternoon tea or something later. There are nice ways of challenging it that aren't hurting him.

Julia, parent of a child with autism

Social stories

A 'social story' is a simple story that contains pictures of your child demonstrating a behaviour that you would like them to adopt. Usually, a social story will consist of ten to twelve statements that relate to the desired behaviour. These statements describe the behaviour, place it in a specific context and describe what is expected of the child. Statements near the end of the story tend to focus on a positive reward given to the child who has demonstrated the desired behaviour.

For example, Charlotte was struggling with her child's practice of coming into his parents' bed during the night, often resulting in a game of musical beds for his parents.

Charlotte worked with an occupational therapist to develop a social story for her son that was about his sleep behaviour. The story showed pictures of her child going through his normal bedtime routine of bathing, cleaning teeth, reading a story and going to sleep. It then showed pictures of her son sleeping in his own bed until morning, and herself and her husband sleeping in their own bed.

The statements in the story followed the pictures. The first statements described the child's normal routine. The statements related to sleeping behaviour clearly pointed out that sleeping in your own bed all night was a very good thing—for children and mummies and daddies. The statements and pictures at the end of the story showed mummy and daddy rewarding their 'big grown up boy' for staying in his own bed with lots of cuddles.

The social story proved so successful in changing her son's behaviour that Charlotte has gone on to use social stories for other situations, with just as much success.

One of the reasons that social stories can be so useful is that your child becomes their own model for the behaviour that you would like them to adopt. Your child will enjoy seeing themselves in the book and can watch as they themselves demonstrate a behaviour and reap the rewards.

Some tips for constructing a social story

- Focus on one behaviour at a time.
- Keep your statements simple and aimed at the level of your child's understanding.
- Present your story over several pages, with one or two statements and a picture of your child on each page.
- The pictures of your child can be actual photographs or drawings, or a combination of the two. If using drawings, you might like to try putting photographic cutouts of your child's face on the drawing.
- Your child will expect everything to happen as it does in the story when they display the desired behaviour. Where possible, keep your statements real and exact. The aim of a social story is to describe a positive behaviour to your child, and show them the benefits that come from demonstrating this behaviour.
- Be careful in your use of emotional statements. It can be difficult to accurately predict the emotional response of other people such as brothers and sisters, teachers or friends at school who may be part of your story. If your story states that 'Jane's teacher is very happy with her because she sat quietly right through reading time', your child will expect this response from her teacher. If your child's positive behaviour goes unnoticed by the teacher, she may feel confused and angry. She may be less likely to practise the positive behaviour again because it was ignored. In this case it might be better to say that 'Jane got to hear the whole story because she sat quietly at reading time. Sitting quietly helped her to listen to what her teacher was saying'.

When can social stories be used?

Social stories can be used in many situations related to your child's development. Specific examples include toilet training, aggression towards brothers, sisters or friends, sleeping behaviour, and behaviour at school.

Social stories can also be used to prepare your child for special events, such as birthday parties, a hospital admission or changing schools. In this case, the social story will describe what is going to take place. It will show information about who the child will meet and some of the things that will happen. It can be helpful to include pictures of the hospital, school or party venue in the story.

How to use social stories

Social stories teach by repetition and familiarity. In order to be successful, they must be read to your child many times over. The more familiar your child becomes with the desired behaviour and the more they see pictures of themselves displaying that behaviour, the more likely they are to try it out for themselves.

For example, if your social story relates to sleeping behaviour, you need to read the story with your child in the early evening before beginning the bedtime routine. The story can be read again before lights out and again in the morning.

If the story relates to your child's behaviour at school, it can be read before school and at the school gate. Teachers can be involved in the process and asked to read the story to your child if he or she misbehaves in class. The story can be read again after school.

My son has had behavioural problems at school because he was touching kids while they're reading. We got someone from the Epic Centre down and he worked out social stories and that has been terrific. Anything that arises we just write a social story. He's taken out of class and another teacher sits down and reads it to him and then I have to read it to him at home before he goes to school and it's terrific. He goes back a completely different kid. I'd never even heard of social stories until now.

Jill, parent of a child with Down syndrome

This parent developed two social stories for her child. The first focused on her son's behaviour in regards to the teachers at the school. The second dealt more specifically with her son's behaviour towards other children.

Some of the statements included in the first story were:

At school my teachers are Miss B, Mr V and Mr B. At school we have rules. All the children do what the teachers say. Miss B, Mr V and Mr B are very happy when I do what I'm told. Miss B, Mr V and Mr B are very happy when I sit on the carpet and listen. When I do my work we are all happy. I am happy too. I will remember this story.

Some of the statements included in the second story were:

School is fun and I love playing with my friends. All children know the school rules. We all play nicely at playtime and lunchtime. I only touch people the right way. Alice and Nick touch the right way. When I play properly everyone is happy and my friends like me. This makes mum, dad and my teachers happy too. I will remember this story.

Time-out

Time-out refers to the process of removing your child from a situation for a period of time, usually when they are engaging in a problem behaviour. It can be a very effective disciplinary tool for parents who are raising children with special needs.

Typically time-out involves taking your child to another room in the house or another setting if outside. Some parents like to use a time-out chair. Your child will be required to stay put for a given period of time before returning to the area of activity.

Time-out can be used together with the behavioural reinforcement strategy of ignoring problem behaviour, which was discussed earlier. When your child responds to being ignored with negative behaviours of increasing frequency and intensity, you can lead them to their room and enforce some time-out for their reactive behaviour.

How to set up and use time-out

Decide on an area of the house that you would like to use for time-out. Ideally, this area should be really boring for your child. Some parents like to use a chair facing the wall in the hallway, or in a corner of the lounge room. Others use more industrial areas of the house such as the laundry:

We picked the dulllest room in the house, the laundry. Cleared everything out of the area that was likely to affect him and got a plastic chair, so there was nothing stimulating him there. It was boring.

Julia, parent of a child with autism

Most parents however, find their child's bedroom to be a very convenient location for time-out.

Decide how long time-out should be for your child. For young children three to five minutes is usually enough. For older children, you may like to extend the period to ten minutes. Enforce this time limit every time your child is sent to time-out. You may like to set a timer next to the child, and tell them that they can come out when the timer goes off.

Do not lock the door.

Once your child emerges from time-out, talk to them about what happened and why time-out had occurred. For younger children, repeat your explanation of why they were sent to time-out and suggest a different behaviour that they could use when this situation happens again.

You may like to ask older children to tell you why they were sent to time-out, and encourage them to think of other ways that they could behave in the same situation.

Reassure your child with a cuddle and a smile to let them know that the discipline is over.

Why time-out works

Time-out takes your child away from the scene of activity and cuts off their access to your attention, two experiences that they will find unpleasant.

When your child is consistently given time-out in response to a problem behaviour, they will slowly make the connection between their behaviour and its unpleasant results. This will generally have the effect of reducing the behaviour.

Another major advantage of using time-out is that it gives both you and your child time to cool off. After some much needed space, you may find that both of you are more able to look at how to solve the problem.

Possible problems with time-out

Me no time-out

Your child may not want to sit on the chair, or remain in their room for the set period of time-out. Each time your child moves from their chair or emerges from their room, put them back calmly and firmly. Let them know that they have to stay where they are for the time limit that you have set.

Demolition derby

Some children may treat time-out as an opportunity to tear their room apart. This is probably partly an expression of anger and partly a deliberate attempt to make you angry. Rather than giving up on time-out altogether, you might like to try one of the following approaches:

- Move the time-out space to another room.
- Work directly with your child's destructive behaviour.
- Remove all weapons of mass destruction, such as felt pens and heavy but moveable objects from the room.
- When entering the cyclone that was your child's bedroom, state clearly that you do not like it when your child does this and ask them to work with you to clean up the mess.
- Make a start and wait for your child to join in, perhaps putting your hand over their hand to show them what to do.
- If your child refuses, tell them that they will not be able to come out of their room until they help clean up.
- Once they start helping you, heap on the rewards for 'good cleaning up'.

Time-out works, and gives you a break. Try to do what you can to keep this valuable tool in your toolbox.

Time-out and the autistic child

Some autistic children may view being sent to a low stimulus environment where they are left to their own devices as quite a reward. If you have been using time-out for a while, and find your child reluctant to leave the time-out space or have seen an increase in your child's negative behaviours, it may be worth rethinking the use of this strategy. Rewarding positive behaviour, and ignoring or redirecting negative behaviour may be better options for shaping your child's behaviour.

Dealing with specific behaviours



QUICK TIPS

- *It's important to provide your child with simple, clear alternatives to being aggressive and to reward positive play.*
- *Some ways of helping your child develop regular sleeping patterns include establishing a routine at bedtime and staying with your child until they go to sleep.*
- *Using locks on just about everything is one way of dealing with the child who gets into everything, but everyone must remember to relock after use.*
- *If your child is an escape artist, you need to pay careful attention to possible escape routes. You may need to use restraints when out, and child or window locks in the car if possible.*
- *Using social stories or role plays is a good way of dealing with or preparing a child who is afraid of visiting the doctor, dentist or hospital.*
- *Encouraging water play and using goggles when washing hair may be useful for children who have a fear of water or bathing.*
- *Food that is refused by a fussy eater can be disguised or hidden, or rewards offered for trying new food.*
- *Setting a timer is one way of dealing with a child who dallies over their food.*
- *To make mornings a bit easier, develop a morning routine that your child can learn through repetition.*
- *How you deal with a tantrum will depend on the cause of the behaviour and whether the tantrum is severe or mild. Try to be aware of the triggers and warning signs.*
- *A star chart is a great way to help your child learn how to use the toilet. It's also a great way to motivate or reward other positive behaviours.*
- *You can help your child learn how to give and receive attention by such methods as teaching them to maintain eye contact and using progressive exposure to touch.*

Now that you know some of the strategies you can use to deal with your child's behaviour, you may be interested to find out how other parents have used these strategies, in combination with their own ideas, to deal with the problem behaviours of their special needs children.

Aggression towards brothers, sisters or other children

Aggression towards brothers and sisters and other children is a common problem that most parents will have to deal with at some time or another.

Strategies that parents have found successful when dealing with aggressive behaviour include: verbal explanation, providing your child with alternatives to aggression, time-out and rewarding positive play.

Verbal explanation

Talk to your child about their aggressive behaviour. Tell them that this behaviour is not acceptable and give your child the reasons why. For example:

Jesse, stop hitting your brother. Hitting is not acceptable in this house. When you hit your brother you hurt him.

Remember to keep your explanation simple and at the level of your child's understanding.

Alternatives to aggression

Your child may not want to give up their aggressive behaviour if they do not have any other way of dealing with their feelings of frustration and anger towards others. Therefore, it is very important that you provide your child with simple, clear alternatives to being aggressive.

Introduce your child to the idea of verbally expressing their needs and wants in an appropriate way. For example:

When someone annoys you, tell them, 'I don't like it when you do that' instead of hitting them or calling them 'stupid poo head'.

Encourage your child to look at different things that they can do physically in frustrating situations.

When your friend won't let you have a toy that you want, find another toy to play with for a little while. Your friend will finish playing with the toy soon and you can play with it then.

Think about the ways in which you deal with your own feelings of frustration. Can you teach your child any of your strategies?

Providing your child with alternative behaviours is an important last stage when you are using the verbal explanation approach to dealing with your child's aggression.

1. Tell your child that their aggressive behaviour is not acceptable.
2. Provide your child with reasons why.
3. Offer your child an alternative method of dealing with the situation.

Time-out

Time-out is a very useful strategy that can stop an increasingly agitated and aggressive child in their tracks. It involves removing your child from the scene of their behaviour and placing them in a less stimulating, secure environment for a set period of time, giving your child a chance to calm down and cool off.

Once they have calmed, you can discuss their behaviour with them, using the verbal explanation technique. Following your explanation, you may like to encourage your child to apologise to their sibling or any other children involved.

Rewarding positive play

Notice and reward your child's positive play with others: 'Great playing John'.

Pay particular attention when your child uses alternative approaches to aggression to get what they want: 'I noticed how you offered Julie one of your toys to play with when you wanted to play with her toy. I thought that was really great. I am really proud of you'.

Bedtime and sleeping

There are few things that can sap your energy as much as a child with a sleeping problem. Common difficulties faced by parents include: the child who is reluctant to go to bed, the child who wakes repeatedly through the night and the midnight run into mum and dad's bed.

The child who is reluctant to go to bed

The hours between your child's bedtime and your own are golden. Peace reigns in the house as you work to complete the tasks of the day. Then, it's free time. A glass of wine and a good book; a personal project; a favourite television show or some uninterrupted time with your partner—bliss!

For parents of a child who strongly resists bed, such thoughts of peace and time on their own can seem like a dream. Some children stubbornly refuse to go to bed, pulling out all the stops as they become increasingly tired. Others seem to pop out of bed as soon as they are put into it, again and again. Bedtime can seem like a war zone as parent and child pit their wills against one another.

Strategies that parents have found to be successful in dealing with a child who is reluctant to settle include: developing a routine, limiting or stopping daytime naps, talking about your child's day, staying with your child until they go to sleep, persistence and locking the door.

Routine

Work with your child to establish a regular bedtime routine. An example may include dinner, bath, clean teeth, story and lights out at 7.30pm. Try to keep your child's bedtime as consistent as possible. If your child can read the time, a clock can provide a handy aid for reinforcing that it is bedtime.

Putting a new routine in place will take some time. The key to success is to be consistent and persistent. Once the new routine has been put in place, it needs to be followed strictly, every night, until the child accepts that this is how it's going to be.

Our daughter Vanessa did not want to go to bed. We decided she needed to learn to fit in with us a lot more than she was doing. We persisted with a routine over months, months, months. It is now expected that Vanessa goes to bed between seven thirty and eight.

John, parent of a child with cerebral palsy and intellectual disability

Stop or limit daytime naps

A child who has a sleep during the day, and then finds it difficult to settle at night, may simply not be tired enough for sleep when bedtime approaches. If this sounds familiar, try reducing daytime sleeps or stop them altogether.

Talking about your child's day

Some children can find it difficult to settle at night because they are still wound up from their day. If you feel that this may be the case for your child, encourage them to talk about their day during the rundown to bedtime. A few minutes of discussion before your child's nightly story may make all the difference.

Staying with your child until they go to sleep

A child who is reluctant to go to sleep may drift off serenely when a parent stays beside them. However, you may find your child prolonging the experience of your one-on-one attention with conversation, questions and attempts to make you laugh. In this case, the strategy backfires. If you decide to use this approach, make it clear to your child that you are there to help them settle and go to sleep. If your child keeps talking or tries to get you to respond to them, then you must leave the room. If your child does not settle, return to the room, but make the conditions of your being there clear to your child.

Persistence

If your child gets out of bed once you have said goodnight, calmly return them to their bed and tell them that it is time to go to sleep. It is important to be persistent. Every time your child appears, walk them back to bed. Some parents find that an increasing firmness of tone can be helpful here.

Locking the door

Another option that parents can use to deal with a child who keeps getting out of bed, is to lock the bedroom door. This can be an uncomfortable choice for parents, even when they feel like they have tried everything else.

A specialist suggested that we put a lock on the door. I said, I can't do that, and he repeated, put a lock on the door. Three nights later, our son was sleeping through the night.

Sharon, parent of two children with autism

The child who wakes through the night

Most children will wake at some time during the night. Generally, they will have a wriggle or a scratch, before rolling over and going back to sleep. Some children however, do not go back to sleep and remain awake for some time before sleeping again.

Wakers tend to be one of two types: the quiet, non-intrusive waker and the waker who wants their parents up, *now*. The child who wakes and plays quietly with their toys before falling asleep again, does not usually present parents with any problems—apart from the possibility of an over-tired child the next day. It is the child who wakes up crying for mummy or daddy many times each night, or the child who gets up and turns on the lights, television and stereo, who can reduce their parents to quivering, sleep-deprived wrecks.

Strategies used by parents to deal with this sleeping problem include: setting a rule for quiet play, videos, locking doors and sedation.

Quiet play

Talk to your child about the way they behave when they wake up during the night. Let them know that their behaviour is not acceptable. Set a rule that your child has to stay in their room and play quietly if they wake up. Give your child an incentive to do this, for example, permission to watch a cartoon in the morning. Do not give your child this reward if they do not follow your rule.

Videos

If your child refuses to play quietly in their room when they wake, you may like to try setting them up on the couch with a pillow, blanket and video. The advantages of this approach are that, first of all, this is a quiet activity that will not wake the rest of the house and secondly, many children will fall asleep before the video finishes. The main disadvantage of the approach is that one parent will still have to get up during the night.

Locking doors

Locking your child's door will prevent them from getting access to the rest of the house when they wake at night. For some children, this will be enough to get their sleeping back on track after a short while. After all, the confines of the bedroom can be quite boring when you have had the run of the house. For others, a locked door will prompt mass destruction. If this is the case for your child, remove all items that could put your child at risk of injury and persist. You can encourage your child to help you clean up the mess in the morning.

A walk around the block

One parent developed a unique strategy for getting her child to stay in bed through the night and sleep.

He was so spasmodic. At one stage we couldn't get him to stay in bed. He'd be up, he'd have the heater, the computers, the telly or lights turned on at two o'clock in the morning. Mate no, get back to bed. So it was another hour trying to get him back and work on him and the other kids are going off. My elder daughter would say, oh come on I've got to work in the morning, so I'd have to take over. Sometimes I'd hop into bed with him and try and keep him quiet because the others hadn't had much sleep. In the end I thought right mate, you and me kid, the only way I could get him to stay in the bed was to take him for a walk that was on my terms around the block. This is what we did, you get out of bed mate, you're going for a walk, a walk, walk, walk.

I'd take him out there half past ten at night and he'd be screaming all around the avenue. He didn't like it. No, you stay in bed or you go for the walk. And it's on my terms. My pace, I've got your hand, I'm in control of this and you're walking. I'd take him for a walk right around our block and I'd make sure I went this way first because we had nosy people up the other way. Hopefully by the time I got to that stage he'd settle down. I notified the police. So if you hear this kid squealing, this is what it is and if you want to take him, by all means you go right ahead but this is behaviour management. You don't stay in bed and you're going for a walk. And so I'd bring him back and I'd put him into bed, tell him, get out of bed and you go for another walk, so he'd get out of bed, round we'd go and then at eleven o'clock, round we'd go again.

He got the message. It took about ten days. He got the message and he'd weigh it up, he'd go back to bed and think well, do I want to go for another walk or don't I and then next minute he'd be out here, so right, round we'd go again. Of course, he absolutely scratched the heck out of me, my fingers would be bleeding by the time I'd come in. Oh yeah it wasn't pleasant but he gave up in the end. And then we'd go in another cycle and another cycle after that. And then I only had to walk him once or twice but he knew, he knew. It was the only way I could get him into bed.

Lou, parent of a child with autism

Sedation

If you are all out of strategies, and your child is still not sleeping, talk to your child's doctor about whether or not it is appropriate to sedate your child at night.

We have tried a variety of things to no avail. Once a week I give him medication so I can get a decent night's sleep and his brother as well because that affects him. But yeah, bedtimes are a nightmare.

Melanie, parent of a child with dyspraxia and epilepsy

The child who comes into your bed

Parents can vary widely in how they feel about their child or children joining them in their bed during the night. For some parents, this is not a problem at all. Others put up with it because it means that they will get some sleep, rather than none at all. For some parents, it can be a real problem. A restless kicking child can take over the bed, and stretch out comfortably, while mum and dad cling to the far reaches of the mattress. Sleep is difficult and privacy impossible.

If you would like to get your midnight wanderer back into their own bed, all night, you might like to try one of the following techniques.

Social stories

Develop a social story for your child that focuses on their sleep behaviour. Show pictures of your child getting ready for bed and then sleeping in their own bed until morning. Include pictures of each member of the family staying in their own beds. Use simple statements to show that sleeping in your own bed all night is a very good thing. Finish the story with mummy and daddy giving their 'big grown up child' lots of cuddles and praise for staying in their own bed all night. Read the story to your child in the early evening, just before lights out and again in the morning.

Return your child to bed

Every time your child appears in your room, or slips under the covers almost unnoticed, return them to their room, straight away. It's going to take some work to convince your child that their own bed is preferable to the warm, comfortable security of your bed. Understandably, they will probably resist being evicted. Once again, success comes down to persistence.

Being persistent does not mean being overly rigid. If your child is sick or has had a nightmare, and wants to come into bed, it can be difficult to say no. A cuddle at these times can be very healing for both child and parent. However, children know a good thing when they are on to it. So you may find yourself dealing with phantom tummy aches and bad dreams as you wean your child out of your bed and back into their own.

The child who gets into everything

Little fingers can be very curious, and very destructive. Just ask the parent who has spent two hours cleaning the margarine and vegemite out of their child's ears, hair and clothes. Highly curious children can create havoc in what seems like seconds. Watchful and creative, they will hone in on any opportunity to touch, taste, unravel, break and smear.

This kind of behaviour needs a huge amount of supervision, leaving many parents exhausted by mid-morning.

One strategy that appears to help parents in this situation is the use of locks, locks and more locks. This can mean putting locks on the fridge, pantry, kitchen cupboards, washing machine, bedroom doors, laundry doors, laundry cupboards and the television cabinet. Essentially, you will need to lock everything that can either damage, or be damaged by, your child.

The main disadvantage of this approach is that it can be very inconvenient for other members of the household. It is also highly dependent on other family members remembering to relock everything as they go. However, these disadvantages should be weighed up against no longer needing to constantly watch your child.

My husband had a real problem in regards to putting locks through the house. So I left him with our child for the weekend, while I went off and did my own thing. He was very understanding after that.

Melissa, parent of a child with autism

The child who seeks to dominate and control their home environment

A child who tries to dominate and control their home environment may be doing so because they feel unable to control what happens in their day-to-day life outside of the home. Being able to control things at home can help them to restore their sense of feeling safe and secure. However, if your child's need to control is getting out of hand and making life difficult for you and other family members, it will need to be managed.

Compromise can be a good way to deal with this situation. Decide on certain activities or areas that it will be okay for your child to control. These may include

collecting the mail, packing their school bag, arranging the furniture in their room or managing a part of the vegetable patch. Let them know that these areas or activities are under their direct control. They get to set the rules and run the show.

Then, clearly define the areas and activities that your child is not allowed to dominate or control. For example, if your child always tries to control the television or video, point out that everyone has to share this equipment. Incentives can be used to help your child to manage their behaviour. Cooperation and sharing can earn your child extra time on the computer or a game with a parent. Attempts to dominate and control on the other hand can mean a privilege being taken away, or time-out.

The escape artist

Containing a child who wants to escape can be a constant challenge. Parents have to be vigilant, plan ahead and draw on physical aids such as locks, restraints, barriers and fences.

Securing your home

The most common method parents use to make their homes secure is to use locks. Locks on doors and windows. Locks on the sheds in the yard and any gates that provide access to the road. Fences are important, and should be high and in good condition. If you have a wooden fence, make sure that the smooth side of the fence faces inwards. Think about the layout of your home and yard. Look for possible escape routes, and put barriers or locks in place that will make them secure.

Educating friends and family is an important part of making your home secure. Locks and barriers will only work if everyone participates. Locks need to be relocked, and barriers need to be replaced as people go.

When you are out

A child on the lookout for an escape opportunity can make shopping trips a nightmare. Your main strategy for managing this situation is the use of restraints. The most common restraint used by a parent is a firm grip on their child's hand. This will work for children who are able to stand quietly beside you, or will not wander too far when you release your hold for brief periods.

If your child bolts the moment their hand is freed, a harness or lead may be needed.

We used to put a harness on him when we went out, because that was the only thing that he couldn't get out of. This particular harness is wonderful. It has crossovers and it does up at the back and it's light. It was the only way to keep him next to us. People probably thought I was awful walking around with a doggy lead but it was the only way to make sure he didn't bolt.

Judy, parent of a child with autism

Parents of young children may find it helpful to contact their early intervention centre for tips on restraining their child. One parent who did this found out about a specially designed pram harness to prevent escape.

Visiting a friend's home

Before you visit, explain your needs in regards to security for your child. Lock your friend's front door behind you as you enter. If your child is going to play in their backyard, check it to make sure that it is secure. If it is not, remain outside with your child and keep them in view throughout your visit.

You just constantly have to make sure that whatever situation they are in, they cannot get out. It doesn't matter whether it's in the house, or in the backyard, or at anybody else's house. You just always had to make sure that there was no way on this earth they could get out.

Amanda, parent of two children with autism

The playground

Look for playgrounds that are securely fenced. If you are taking more than one child to the park, try to take a friend or another parent with you so that there can be more than one set of eyes on the lookout. Encourage older children to look out for their brother or sister.

The car

The first time your child escapes from their seat belt and appears beside you, or opens the car door mid-travel can be heart stopping.

Sometimes something catches my son's eye out of the window, and he can be out of the seatbelt, window down, and almost out of the car in seconds.

Vicky, parent of a child with autism

There are several things you can do to manage this behaviour:

Child lock

Most cars have a small button or lever on the side of the back doors known as a child lock. When moved into position, this lock will disable the door handle, so that the door cannot be opened from the inside.

Window lock

If your car has electric windows, use the central locking facility near the driver to lock the car windows.

Set rules

Make it a set rule that the car does not move until seat belts are on. If a child releases their seat belt, immediately stop the car and repeat the rule.

Large car seats

Car seats have now been developed that can securely harness older children in the car. Contact your local council or disability service for more information in regard to these seats.

Toys and car games

Provide your child with some toys to play with on the journey. You might also like to play some car games, such as 'Spot the green cars', or 'Can you see any animals'. Some children might enjoy a parent-led game of 'I spy'.

When your child escapes

As a parent, it is natural to expect your child to answer you when you call out to them. However, experience has taught some parents that this is not always the case. Try to be very literal when you call out to your child:

You can be calling and calling but even now I'll call Mason's name and he won't answer. I'll say, Mason answer me please, and he'll say, yes. He won't say, what do you want. You always have to say, Mason can you answer me, so I'll know where he is because if I'm looking around and just calling him he won't think to answer.

Judy, parent of a child with autism

Why children like to escape

Some parents have observed that their escapee just wants to run. For these children, being contained in a house or a yard can be difficult. If you have the time and energy,

set your child some interesting physical activities in the yard. Challenge them to a race. For example, use a stopwatch to time how fast they can run around a particular route, such as to the back fence and back. If finances allow, a trampoline in the back yard can be a godsend. It can give your child the thrill of freedom and use up some of their excess energy.

The underlying strengths of your escape artist

Many escape artists are gifted problem solvers. Your attempts to contain them will be viewed as a challenge to be explored and solved. Indeed, some of these children can become so good at problem solving, that they make Houdini look like an amateur! While this ability is a strength that will serve your child well as they move through their life, it can create major headaches for parents who are trying to contain their child.

Locks on harnesses, doors and windows will need to be double locks. Supposedly child proof locks? Too easy. Equally, high fences will only be useful if there are no objects in the yard that your child can move and climb. A ladder in your yard? Yippee, escape and adventure beckon:

We had left a ladder against the side of our shed in the backyard. Our son shimmed up the ladder, over the roofs of two sheds, and was dancing on a third when we found him. We moved the ladder to where he was, but he ran back to his starting point as happy as Larry and got down the ladder. The good points were that we stayed calm, and then removed the ladder.

Vicky, parent of a child with autism

A problem solver enjoys a challenge. Another way to deal with your escape artist may be to change the focus of their challenge, from escape to something else. Check out your library or the internet for ideas about problem solving activities that you can set up for your child. You might like to collect some building materials, such as toilet rolls, icy pole sticks and pipe cleaners and challenge them to build a tunnel or bridge for toy cars. Look for a video game that involves a lot of problem solving. For a treat, set up a treasure hunt with simple clues, for example, 'Look at the bottom of the pole where mum hangs out the wet clothes' or 'You put your head on this every night after your story'.

Fear of visiting the doctor, dentist or hospital

Three strategies that parents have found useful when dealing with their child's fear or resistance to visiting a health professional are social stories, role playing and preparing the specialists.

Social stories

Social stories can be very useful when working with your child's fear of visiting a health professional. This story can be used to familiarise your child with the events that they are going to experience, the people they are likely to meet and the place that they will be visiting. You can also use the social story to reassure your child that you will stay with them throughout their experience.

Check with your health professional to make sure that your understanding of the events that are likely to occur is accurate. If possible, include actual photos of the clinic or hospital that the child will be attending, and the names of some of the people that your child will be meeting. A close match between your social story and your child's actual experience will improve your child's ability to manage any anxiety or fear that they may be feeling.

He had to have dental surgery at the hospital and so Judy did the social story, took photos at the dental surgery beforehand. And so he knew actually what was going to happen.

Ed, parent of a child with autism

Role playing

A similar activity that will increase your child's familiarity with the process of visiting a specialist is role playing. This involves physically acting out some of the things that will happen when your child visits the health specialist.

Using a visit to the doctor as an example, show your child how the doctor will look into their ears, listen to their heartbeat and look into their mouth. A toy doctor's kit can be a very useful aid when you are doing this.

Take turns with your child at being the doctor and the patient.

Preparing the specialists

You can work with your specialist and their staff to prepare a positive, user-friendly environment for your child. Contact the clinic at least two weeks prior to your child's scheduled appointment or procedure. Advise the staff of the nature of your child's disability and any special needs that your child may have. Request the involvement of staff who have had experience or training in working with special needs children.

Ask your health professional and their staff if they can suggest anything that will help minimise your child's anxiety or fear during their visit. If possible, meet with the staff who will be working with your child prior to your child's visit.

Our son needed an operation. It was a day stay. We knew that we were going to have a terrible time so we rang the hospital, let them know that our son had behavioural difficulties. Could we possibly have staff that were going to be able to deal with that, and weren't going to be aggressive because we sometimes find that people get upset because he's so upset. If people are willing to deal with him, it's much easier. We also got a disability nurse who had spoken to me beforehand about what she could expect from him and it was wonderful. They had a bed set up for us instead of a chair where they usually put the day stay surgery people. We also made sure that we had a doctor on call when we got home so we could get more sedatives because we had to travel for three hours. She'd already contacted the hospital as well. We felt like we handled that one really well.

Kristy, parent of a child with autism

Fear of water and bathing

When your child is frightened of water, getting them in the bath or washing their hair can be a nightmare. Here are a couple of simple techniques that you might like to try if you are faced with this situation.

Encourage water play

Put some water in the bath, and add some fun toys such as boats, plastic cups, trucks or soap pens (crayon-like sticks made out of soap).

Get into the bath while your child watches and start playing with the toys. Encourage your child to join you. Play with the toys together. Let your child draw all over themselves with the soap pens. (You might want to set a rule here that drawing on yourself is for bathtime only!) Get out of the bath together, and get dried.



After a few sessions in the bath together, you might like to suggest that your child gets in the bath on their own and shows you how they can bomb the boat with water from the plastic cup. Follow this pattern until your child feels comfortable about bathtime.

Goggles for hair washing

Many children fight having their hair washed because they do not like getting water in their eyes.

Elaine, mother of an autistic son, aged six, came up with a fun and successful solution to this problem: giving her child swimming goggles to wear while he was getting his hair washed. The goggles were introduced with slapstick humour and the child was given lots of positive reinforcement for both wearing the goggles and having his hair washed.

Getting your child out of the shower or bath

Some parents have the opposite problem to that described above, and have trouble getting their water loving child out of the shower or bath.

I tell my son that he has to get out of the shower soon. I tell him that I will count to 50 and then I will come in and turn off the shower. I count very loudly so that he knows when I am coming.

Judy, parent of a child with autism

This technique can be useful in many other situations, including getting your child off the computer or away from the television. After a few repetitions of the counting game, your child should get the message.

Mealtimes and eating

There are a range of problem child behaviours that can develop around eating, and behaviour at the dinner table. These include the fussy eater, refusal to sit at the table, and dallying over food.

The fussy eater

Most children will have preferences for some foods over others. Some children take this preference to the extreme, refusing to eat anything but a very limited range of foods. As a parent, it can be very frustrating to spend time selecting and preparing family meals, only to see your child turn up their nose at your offering and push their plate away.

Strategies for dealing with a fussy eater include compromise, hiding less-liked foods, using rewards, giving ultimatums and serving your child the food that they want.

Compromise

One way of dealing with fussy eating is to compromise. When preparing your child's meal, give a preferred food along with a small amount of a different food that your child has been reluctant to eat. This might consist of meat, carrots, broccoli or other vegetables.

Encourage your child to try this other food and be accepting if they refuse. Continue to present your child with at least one non-preferred food at each meal. You never know, one day they might try that carrot and discover a taste sensation!

I place a new food on his plate every night and encourage him to try it. Sometimes if the food is presented consistently over time he will adopt it as part of his repertoire.

Kristy, parent of a child with autism

Hiding food

Another strategy used by parents is to hide unfavoured foods, such as vegetables, in foods that their children like:

James won't eat fruit or vegetables. So I have to hide. If he needs some sort of goodness, it's hidden in his food so that he doesn't know it's there.

Barbara, parent of a child with autism

Hamburgers, pies and pureed soups are just some of the foods that offer a good hiding place for vegetables.

A similar idea is to disguise food. A piece of chicken that is refused outright, might be accepted when it is crumbed and cut into small pieces like chicken nuggets. Potatoes may get a very cool reception when they are mashed, but be wolfed down when they have been sliced and cooked in the oven as chips.

My son goes through phases where he only eats food of one colour. When he is on a particular colour, I use food dye to dye different foods that colour.

Elaine, parent of a child with autism

Rewards

Verbally reward any attempts that your child may make to try new foods—even if it results in them immediately spitting it out. Another way to use rewards for fussy eaters, is to use them as an incentive for eating core foods. For example, let your child know that if they eat their meat and potato, they can have some dessert, or an extra story before bed.

Giving ultimatums

Ultimatums about food have been given by parents for generations. A common one that is recognised and remembered by most people is 'eat what you're given or you go without'. The theory behind this ultimatum is that a child can refuse what they are given for only so long, before hunger makes them less choosy about what they eat.

While this may work in theory, it can be a lot harder to apply in practice. The will of a child can be very strong, as can be a parent's guilt over 'starving' their child. If you decide to use ultimatums, you have to stand by your word. Relenting and giving your child a preferred food after an ultimatum will not only reinforce their fussy eating, but also teach them that they can get what they want if they resist hard and long enough.

Giving your child what they want

Some parents will resign themselves to the limited food preference of their child and simply give them what they want. This approach will ensure that your child is eating something, and can mean peace rather than war at the dinner table.

The disadvantages of this approach are that you, as a parent, will need to cook two sets of meals each night. You may also have to deal with some arguing from your other children, when they realise that their brother or sister is having what they want for dinner, while they are facing liver and onion casserole.

The controlling eater

A small group of children will demand not only certain foods, but foods presented in a certain way.

You would make her a sandwich at home and she wouldn't eat it because it wasn't cut in the right shapes. She'd say, now I want six squares on my sandwich. I don't know how to cut six squares in a sandwich. I said, well Jane, they'll be rectangles. She said, well I don't want rectangles, I want squares. So then I'd cut an extra piece of bread into two pieces and she's got six pieces of bread.

Amanda, parent of two children with autism

If this is a behaviour that you would like to change, simply refuse to prepare the food in the way the child has requested. Initially, your child will probably refuse to eat the food. This may change if you keep refusing to meet their demands.

You could instead consider getting your child involved in preparing their own simple foods. Treat this as a problem solving exercise. Ask your child to show you how the food can be cut into the requested shapes or portions. It can also be an opportunity for your child to learn a basic living skill.

The child who refuses to sit at the table

Setting rules and gentle persistence are two strategies that parents can use to encourage a reluctant child to sit at the table.

Talk to your child about the behaviour that is expected of them at the dinner table. Set a rule that your child must sit at the table while they eat.

When you put the family meal on the table, bring your child to their chair and tell them that 'we sit to eat'. Encourage your child to look at how other family members sit to eat. When your child gets up from the table, gently and calmly return them to the table and repeat the rule 'we sit to eat'. After a few returns, let your child leave the table. Begin the process again the next night.

Do not force your child. A child who is dragged kicking and screaming to the table is unlikely to want to stay there.

Dallying over food

Some children not only sit to eat, but sit for a long, long time. They will pick, dawdle and push their food around, long after everyone else has finished their meal.

One simple idea that you can use to deal with this behaviour involves setting a timer. Explain to your child that you are setting a limit on the time that they can spend eating their meal. You may like to start with a time that is a little bit shorter than the time that they usually take and gradually work your way backwards.

Put a timer with an alarm on a nearby bench, set to go off at the end of the set time. When the alarm goes off, remove your child's plate from the table and put any uneaten food in the bin. Be prepared for some loud complaints about your action. Do not give your child anything else to eat that night. Repeat the process again over the next few nights.

Eating with hands rather than utensils

Teaching a child how to use a knife, fork or spoon requires patience, lots of encouragement, modelling and the use of the hand-over-hand technique.

Encouragement

Give your child lots of encouragement to use their knife and fork when eating a meal. Whenever your child picks up their utensils and tries to use them, give your child lots of verbal rewards. Talk to them about all the positives of using a knife, fork or spoon, for example, 'no messy hands'.

Modelling

Your child will learn from you and other people sitting at the table. Show them how you pick up a knife and fork, and how you use them to eat your meal.

Hand-over-hand

Stand behind your child's chair and place your hands over theirs. Gently guide their use of their utensils. This process will help your child to understand the grip and angles required to use their utensils effectively. Remember that using a knife and fork correctly is a complex task. It will take time and it will be messy. Preparing food that is easy to cut and pick up will help the learning process.

The child who will not feed themselves

Some parents complain that their children refuse to feed themselves, even though they have the ability and coordination to do this.

A child who can hold objects, open doors and scratch their face, can feed themselves. If they do not, it is because they have learnt that they don't have to. You will do it for them.

How children are taught not to feed themselves

A child can learn not to feed themselves during the early years of their life. At dinner time one night, they may look at the plate of food in front of them and refuse to eat. Their parent will offer verbal encouragement, but the child will not budge. So the parent picks up a piece of food and offers it to their child saying 'eat it for mummy, there's a good girl'. Initially, the child will enjoy their parent's positive attention and will eat the offered food to please them. The parent leaves the table thinking 'that worked, I got her to eat.'

The next time the child sits down to eat, she may refuse and look to her parent expectantly. After giving her verbal encouragement to eat—which has no effect—her parent feeds her again. The child eats and receives her parent's praise. This child has been taught that refusing to feed herself will get her undivided attention and praise from her parents.

Other children will learn not to feed themselves because they are slow or messy eaters. Time-pressed parents can find themselves taking over and feeding their child because it is easier or quicker.

I've got other people to get ready and other things to do and I haven't got time to be dressing her and feeding her but she won't eat her food by herself quickly.

Amanda, parent of two children with autism

There are three strategies that you can use to encourage your child to feed themselves: stop feeding them, give them the time and space to do it for themselves and reward self-feeding.

Stop feeding your child

Explain to your child that you feel it is time they learnt to feed themselves. Let them know that you will not feed them anymore. It is highly likely that your child will resist this turn of events and refuse to feed themselves. This is the time for you to remain strong. Tell your child that it is okay if they do not want to eat. Also tell them that you will put their uneaten meal in the bin and that they will not be able to have anything to eat until the next meal. Continue this process for the next few meals.

Giving your child time and space to learn

A child's first attempts at feeding themselves will be slow, laborious and messy. Give your child plenty of time to practise this skill. Stay with them and encourage their attempts. Try to close your eyes to the growing mess on the table, floor and your child.

He's learning to feed himself and that's really hard for me to sit back and watch that because he gets it everywhere. You know what it's like when you teach a toddler to feed themselves and he gets it everywhere, but he's getting there.

Sorrel, a parent of a 12 year old child with Down syndrome

Reward self-feeding

Whenever you see your child feeding themselves, give them lots of praise. Let them know how proud you are that they are developing this ability to be independent.

Mornings

Mornings are a hectic time in most households. Stress levels can rise when a child is reluctant to get out of bed and has to be pushed and pulled through the process of getting ready to leave the house.

There are a number of things that parents can do that will smooth the journey from bed to the front door.

Routine

Routines come into their own in the morning. A frantic disorganised household can become reasonably ordered when everyone knows what they have to do, in what order and at what time.

A basic morning routine for a child will involve getting up at a certain time, having breakfast, getting dressed, washing face and hands, brushing teeth and hair, packing or collecting their schoolbag and heading out the door.

Additions to the basic routine will vary from family to family. For some children, the morning routine will include medication and physiotherapy. For others, it will include toileting, putting on splints and feeding the cat.

When you are developing a morning routine for your child, consider all of the tasks that need to be completed by each member of the family before they leave the house. Make up a rough timetable that includes times to get up, bathroom and dressing time, therapy time if required and breakfast. When you have a feel for how things fit together, work up a specific routine for your child.

A routine is learnt through repetition. When you put a new routine in place, it is important that the same set of behaviours are repeated at the same time, over and over again, until your child becomes familiar with them.

At the beginning, your child may need a lot of reminders to complete each step of their routine. They will often resist moving from one task to another and may display a range of behaviours that will make your job more difficult. Common examples include whining, staunch refusal, hitting, running and hiding.

Take a deep breath, take your child by the hand and lead them to the next task. Explain to them firmly that 'this is the way we do things in the morning'. Repeat the routine to your child: 'we do this, and then we do that, and then we go to school'.

Persist, persist, persist. Your child will eventually find themselves moving into an organised routine that will make mornings easier for everyone.

Phillip has to catch a special school bus that arrives at 7.30am. I usually get up at 6.15am and get dressed. Never attempt to get kids ready for school in your PJs or you will get caught out. I turn on the TV and put up the volume. I get Phillip's breakfast ready first so if he gets up by himself he can sit right down and start on it. If he has not risen by then I go into his room with the dog, pull off his doona, open the blind and the window and get the dog to jump all over him. If this does not work I get his big brother to help me pull him out of bed. Phillip usually gets up before we get to this stage. I pack his lunchbox and put it on the table where he eats breakfast so that he can put it in his schoolbag himself. If there is anything else he has to take to school that day it is on the table so that he can put it in his schoolbag himself. While he is eating his breakfast I get his school clothes ready. When it is about 10 minutes before the bus arrives I take him to the toilet and then dress him while he finishes eating his breakfast. With schoolbag packed, breakfast eaten, or still eating, and dressed, we go wait outside on a foldup chair for the bus to arrive. This routine never changes. Most of Phillip's routines are as rigid as a steel beam.

Margaret, parent of three children, two of whom have special needs

Prompts

Some children find it difficult to move from one task to another independently, even when they are familiar with their morning routine.

Keep an eye and an ear out for your child's progress. If they are having trouble starting a task, remind them of what they need to do next. If they are still being too slow, you may like to work with your child briefly to get them moving on the task at hand.

Another way of prompting your child is to make up a series of pictures that show your child the things that they need to do to get ready in the morning. Put these pictures in a place where your child can easily see them and keep reminding them to look at the pictures.

Using incentives

Sometimes a child who is very capable of moving through their morning routine unaided, will not do it. They simply don't want to. The first prompts will be ignored. Follow-up prompts will lead to complaints that increase in volume. At this point, frustrated parents who are in a hurry may wind up the volume of their own prompts, and a battle begins.

One way to avoid the battle is to use incentives. A child who obstinately refuses to get dressed, may rush to throw on their clothes if they know that today is kindergarten day. Similarly, a chance to visit the horses in the corner paddock before school can have a child gulping down their breakfast before dragging you out the door.

Getting up early

Plan to get yourself and your child up at a time that enables you both to move in to the day without rushing or hurrying.

Be disciplined. Don't go for that extra ten minutes in bed.

Robyn, parent of a child with cerebral palsy and hearing loss

Your goal is to make the transition into the day as smooth as possible. The need to rush creates stress, which can in turn lead to flared tempers and slow progress.

It's important to stay calm at that time because it sets the tone for the rest of the day. So if I start out yelling at them at eight o'clock in the morning they're going to arrive at school and kinder feeling stressed and angry.

Amy, parent of a child with autism

Reducing your morning load

Do what you can to reduce your morning workload. Prepare lunches and iron clothes the night before. Empty and repack your child's schoolbag. Prepare your own bag with everything that you will need for the day. Completing a task the night before means one less task for you to do in the morning.

Carers in the home

Children who have severe physical disabilities can require a huge amount of care in the mornings. Feeding, toileting, bathing and dressing a heavily dependent child can be physically demanding and take a lot of time. Many parents find themselves exhausted before their day has really begun.

If you are in this situation, you may want to give thought to having a carer come in to your home for a couple of hours each morning to help you out.

We have somebody in the mornings, and this particular person has been with us for twelve years. She actually went to a four-day week about twelve months ago and we felt as much as we didn't want to lose her, we thought well we could afford to lose her for a day rather than lose her all together. She's called mum too, and she's like a sister to me. We share lots of things and they don't go out of this house.

Lynne, parent of a child with cerebral palsy

Tantrums

A child will tantrum when they are experiencing levels of frustration or stress that they do not know how to cope with. Triggers for tantrums include: a parent saying no to something that the child wants, other children who don't behave the way the child wants them to, or prolonged exposure to an overstimulating environment such as a shopping centre. A child can also tantrum in response to internal triggers. They may be frustrated that they can't communicate clearly or they have trouble completing a particular task.

Once a child has learnt that a tantrum will get them something they want, a new type of behaviour can emerge. You could call this the mild tantrum. It is a handy strategy that your child will pull out when they are mildly frustrated by a situation, and think that a little bit of action will get them what they want. In this case, the tantrum is more about pushing buttons and manipulating others, than feeling overwhelmed.

The method that you use to deal with a child's tantrum will depend on the cause of the behaviour and its severity.

How to tell the difference between mild and severe tantrums

A child who throws a mild tantrum will still have some control over their feelings and behaviour. They may shout and rant, but you will probably catch them throwing you a glance, just to check your reaction as they tip over the coffee table.

When a child is having a severe tantrum, they will be lost in emotions that are overwhelming them. They can be difficult to reach and extremely aggressive. Eye contact may be fleeting or non-existent. Some children can be so overcome by the storm of emotions that are sweeping over them that they will drop to the floor and kick and writhe.

Dealing with the mild tantrum

Provide a brief explanation

If your child is beginning to tantrum because you have said no to something that they wanted, provide a brief, simple explanation of why you said no.



Ignore your child and walk away

If your explanation is not accepted and your child begins to rev up, turn your back on them and walk away. Busy yourself in the kitchen or hang out a load of washing.

Do not give in

When you walk away from a child mid-tantrum, you may find that they come looking for you, only to continue where they left off. Many parents can buckle under the strain of a persistent tantrum and feel tempted to give in for the sake of peace. Remember, if you give your child what they want, you have just taught them that tantrums work.

Divert or distract your child

When you see a tantrum beginning to build, try to divert or distract your child: 'oh, did I just hear the mailman? Let's go look'. Some well-timed humour can also work wonders at this point:

A lot of the time with her it's humour. Like you'll do something stupid, you pretend to walk into something or trip over something or you'll go to put something on the table and you'll drop it and she'll laugh and you know you've broken it.

Nicole, parent of a child with Smith-Magenis syndrome

Stay calm

Try to stay calm or at least give the appearance of being calm, as you move around your child. Tell yourself 'I am the adult here, I can deal with this. This is just a temper tantrum'.

When you react and raise your voice to a child who is having a tantrum (as tempting as it may be), you will immediately increase the likelihood that they will tantrum again:

Oh guaranteed [repeated tantrums] if you yell at him. He loves that, he feeds off that kind of reaction, and if someone loses their cool with him he'll keep going back and doing whatever that was that made them lose their cool again and again and again because that's wielding his power.

Marley, mother of a child with autism

Time-out

Dealing with tantrums is stressful. If you feel your temper starting to rise, it might be a good idea to give your child some time-out. Make this a calm, controlled action. Lift your child gently and place them in their room. Tell them that they are not to come out until they have calmed down.

If you have already reached boiling point by the time you think of time-out, it is probably a better idea to head outside yourself, rather than approach your child while you are so heated.

After the event

When your child calms down, praise them for being able to regain self-control. Make an effort to reassure your child with a hug and an offer of an activity that you can do together.

Dealing with a severe tantrum

Stay with your child

A severe tantrum can be a frightening experience for a child. Stay with them, reassure them. Speak to them in a soothing tone. Let them know that mummy or daddy is there and in control.

Containment

A child who is emotionally and physically out of control can gradually calm if they are being held firmly. If your child will not allow you to hold them, stay close so that you can begin to touch them gently as the tantrum begins to ease.

Kyle was at his grandmother's just recently. She doesn't understand a lot of the things that he does and why he does them and she tends to treat him like a naughty little boy. And she tends to fuss, tell him not to do this and that so it overloads him. He was really quite cranky and so I had to go into crisis control after he had already smashed a window and put his fingers through, or his fist through a fly screen and smashed a couple of ornaments. I basically just grabbed him and held him. I actually get him in a lock when he's like this and gradually release it so he has the control. It took us about two hours to get him to completely calm down.

Melanie, parent of a child with dyspraxia and epilepsy

Another way to contain a child who is in the full flight of a tantrum, is to roll them up firmly in a blanket. If you decide to use this option, stay beside them and speak to them soothingly while they calm down.

While containment can be very effective for getting a child to calm down, containing them for too long once they have calmed can cause some children to get agitated again. Once your child's tantrum begins to pass and you feel their body relax, gradually release your hold.

Intervene and remove your child from the situation

If you see your child building up to a tantrum, try to intervene and remove them from the situation. A quiet suggestion of a treat in another room may encourage them to come with you.

Don't take it personally

A child who is having a severe tantrum is reacting to high levels of frustration or stress that have been created by their environment. Even though your child may be lashing out at you, the tantrum is not directed at you personally. Your child is out of control, and lost in their feelings.

It's frustration against the situation. It's not directed at me personally. It's really important to draw the distinction that although their behaviour might be shocking, it's not a personal affront at me.

Sharon, parent of two children with autism

When parents realise that they are not the target of their child's tantrum, they may find it easier to step into the role of being a calm supporter to their child.

Progressive exposure

If your child regularly responds to a certain situation with a severe tantrum, you could try using progressive exposure to increase their ability to cope in that setting. As the name suggests, progressive exposure involves gradually exposing your child to a situation that they find overwhelming, a bit at a time.

For more information on how to use this technique with your child, turn to the section in chapter 2 under Strategies for dealing with problem behaviours.

Toileting

Parents of special needs children can experience a variety of problems and challenges in relation to their child's toileting behaviour. Toilet training can be difficult, with children remaining incontinent for long periods of time before they learn to use the toilet.

Constipation can become a long-term problem for some children. Other children will open their bowels with ease, and use the contents to create rather unique works of art. For parents of children with a profound physical disability, toileting can become a demanding, difficult task that will have to be attended to each day of their child's life.

Toilet training

The strategies that parents use to toilet train a special needs child are generally the same as those used for other children. In most cases, the only difference will be that the strategies are put in place later for a special needs child, and are used for a longer period of time.

Strategies that parents commonly use for toilet training include: waiting for the child to indicate that they are ready, putting pre-trained children in underpants, modelling toilet behaviour and using timed prompts and star charts.

Child readiness

Most children will begin to give out certain signals when they are ready to be trained. These may include awareness that they are doing wee, or need to open their bowels, increasing interest in the toilet and the toileting behaviour of others, pulling at their nappy and taking off their nappy as soon as they have wet or soiled it.

Your child with special needs may indicate their readiness to be trained a lot later than your other children. It is not uncommon for children with special needs to get to the age of four without showing any signs of wanting to be trained. In these cases, parents will often begin toilet training anyway, in the hope of getting their child trained before they start kindergarten.

Put your child in underpants

Most disposable nappies are designed to draw moisture away from your child. Putting your child in underpants will increase their awareness that they are wetting themselves. Once they have this awareness, they can begin to learn the feelings and signs of *needing* to go to the toilet. These signs will eventually prompt them to look for a toilet.

During the first stages of training, try to give your child lots of water, to encourage a few accidents. They will learn the signs that they need to learn through experience.

Modelling toilet behaviour

Part of teaching a child to use the toilet is showing them how it is done. Take your child to the toilet with you when you go. Talk to them about the process of going to the toilet—whether you sit down or stand up, using toilet paper, flushing the toilet, washing hands afterwards.

For toilet training, I said to my husband he's got the anatomy that I don't so he's to take him to the toilet whenever he's able to and keep taking Jason to the toilet no matter what. Show him what you do when you sit down, what you do when you stand up. I said as tacky as that sounds, he's not emotionally connected to you so

you just show him that's what he needs to know. One day I just happened to walk in there and he's weeing in the toilet. I thought whooo, I didn't even know. I rang my husband up, guess what?

Peta, mother of a child with autism

Timed prompts

When your child is wearing underpants, take them to the toilet every half hour. Encourage them sit on the toilet for a minute and then let them go.

Many parents can make the mistake of asking their child if they want to go to the toilet, instead of actually taking them to the toilet. It is not uncommon for a child to say no when asked, only to wet or soil themselves a few minutes later.

Getting your child to sit

Some parents find it difficult to get their child to sit on the toilet long enough to have a wee, let alone open their bowels. Remember, your child is rewarded by your company. If you sit in the bathroom or toilet with them, read them a story or sing a song, your child may stay seated a little longer.

We're trying to get him to sit on the toilet at the moment and he won't but if you sing 'Old Macdonald had a farm' and go through about twenty animals, he'll sit there. But the minute you stop ...

Melissa, parent of a child with autism

Star charts

The use of a reward system can be very effective when you are teaching a child to use the toilet. One system that is commonly used by parents of children with special needs is star charts.

A star chart consists of a piece of card that has a grid, or series of columns drawn on it. Whenever your child uses the toilet successfully, they are awarded a star or stamp, which is stuck on the chart.

Extra rewards can be offered for a certain number of stars. For example five stars might earn your child a chocolate biscuit and ten stars a small toy.

When your child gets more practised at using the toilet, you can alter the system, so that your child has to work a bit harder for their reward. Instead of giving out a star every time they go to the toilet, reward them for going a half day, and then a whole day without having any accidents.

Changing the system will mean that your child will be receiving rewards less frequently. Daily rewards, or a reward every two days, will become a weekly reward. To prevent children from losing interest or motivation, it can be a good idea to increase the size of the less regular reward. For example, seven stars might earn your child a trip to the pool.

We gave small things for weekly effort, so if he only had one accident for the day we'd give him a star. As we went through, the rules changed a little bit. If he had no accidents he'd get a star. And for every week that he had seven stars he'd get a little toy from down at the airport. My husband would drive down there with him every week, give him this little plane from the airport. Once he had the idea that if he got forty stars, mum would give him this big train set that he'd had his eye on in the shop for ages. He'd put his star there and say, mum I'm closer, mum I'm closer. You can imagine what he was like when he actually got it. And by that time, he was trained.

Sharon, parent of two children with autism

Accidents

When your child has an accident, calmly remove them to an area where they can be cleaned up and changed if necessary. Remind them that they are learning to use the toilet now. If your child is using the toilet regularly and has an accident, you may like to ask them to help you clean up once they are washed and changed.

Regression

Toilet training does not happen in a straight line. Most children will take a few steps forward, and then one or two back. A child who has been using the toilet well, may suddenly begin to wee on the floor. A child who has been emptying their bowels on the toilet with no problem, may start withholding and waiting until their night nappy is on. This is a normal part of the toilet training process.

Try not to put your child back into day nappies when they start having accidents. The occasional step backwards should be expected, and training should go on as normal. If your child continues to have accidents, you may find it useful to return to star charts for a while.

Constipation and withholding

Chronic constipation can be a common problem among children with special needs. For some children, constipation occurs as a direct result of the physical effects of their disability. Other children will actively withhold their bowel contents, due to fear or

discomfort about emptying their bowels. A child's refusal to eat high fibre foods can also contribute to this problem.

Strategies that can help you to deal with constipation include: warm baths, adjusting diet, timed toilet trips, positive rewards and the use of laxatives.

Warm bath

Children who are constipated can become quite tense and tight in the lower region of their abdomen. This tension can make it even harder for them to go to the toilet. A warm bath can work magic on this area, relaxing and opening tensed muscles.

Follow-up activity

Sometimes a bath on its own may not be enough to get things moving. One parent has developed an interesting extra technique that has proven to be very successful:

I get her to run up and down the hallway, then on to the toilet. I give her a straw and she blows through the straw and she's been pushing a few out that way. If she blows through a straw really hard, you can see her little bottom push down like we would do.

Lee, parent of a child with spina bifida

Diet

Where possible, try to include lots of fruit, vegetables and other high fibre foods in your child's diet, and adequate fluids.

Timed toilet trips

Give your child lots of opportunities to open their bowels while they are at home. Set a timer and sit them on the toilet every hour for a few minutes.

Positive rewards

Whenever your child does use their bowels, give them lots of rewards. These may include verbal praise, extra time on the computer or choosing what the family will have for dinner.

Laxatives

If you have tried other strategies without success, you may want to talk to your child's GP about using a laxative to help manage your child's constipation.

Smearing

Smearing, or 'the art of poo', refers to a child's practice of collecting handfuls of their own faeces, and smearing it over nearby surfaces. Common locations include beds, walls, carpets and of course, themselves. While your child may find this experience enjoyable and satisfying, it will leave an awful, sticky, smelly mess for you to clean up.

Tips for dealing with your child's smearing behaviour include: staying calm, asking your child to help with the mess, reducing your child's access to their faeces, using social stories, giving rewards for appropriate behaviour and redirecting your child's behaviour.

Stay calm

When you discover that your child has smeared, try not to react. There is a good chance that your negative attention will reinforce this behaviour. It may help to step back from the scene for a moment, take a few deep breaths and allow the first waves of your reaction roll over you. Once you feel calm, or can act calm convincingly, re-enter the room.

Lead your child to the bathroom for a clean up, and change of clothes. While you are doing this, talk to your child about the behaviour that you would like them to use when they need to use their bowels. Try to focus on the behaviour that you would like them to develop, rather than the smearing.



Helping with the mess

Once your child is cleaned up, get them to come back and help you clean up their mess.

Reduce access

Cutting off your child's access to their bowel motions can be a very effective way to reducing smearing behaviour.

One good response to the faecal smearing is that my wife makes these boilersuits out of fabric. The best way to do it is Velcro up the back so that she can't reach around and open up. That's been the extinction of that behaviour.

John, parent of a child with cerebral palsy and intellectual disability

If your child tends to smear during the day, you could try dressing them in fitted overalls or a similar type of all-in-one clothing.

Social stories

Develop a simple story for your child that will teach them the appropriate way to behave when they need to use their bowels. Include pictures of your child sitting on the toilet, flushing the contents when they are finished and washing their hands. Finish the story with mummy or daddy giving them lots of praise for using the toilet. Read this story to your child regularly if they have begun to smear their faeces.

Verbal rewards

When your child empties their bowels into the toilet, rather than the floor or another location, give them lots of praise. If you are using a star chart, you could treat this as a two-star event.

Redirect the behaviour

Some children smear because they like the sensation of the goo between their fingers and the way it moves under their hands as they rub it on to a solid surface. Giving your child a substitute material that gives a similar experience may stop them from diving into their pants for paint:

I get shaving cream and let them run it all over a mirror. I try to divert them to that because they smear for a reason, there's usually an emotional side.

Gail, foster parent to a child with intellectual disability

Assisted toileting

Some children with special needs will require assistance with toileting throughout their lives. Successful management of their continence will require the use of aids, nappies and the constant support of parents and carers.

Equipment and aids

The primary continence aid used by many parents is nappies. When your child begins to grow out of the nappies that are freely available in supermarkets, talk to your early intervention worker about a source of larger nappies.

Ask your disability service provider to put you in contact with a continence nurse. This person will be able to provide you with up-to-date information about continence aids, and any funding that may be available to you.

Toileting a child with severe physical disabilities can place a heavy physical demand on parents. This will continue to increase as your child develops and grows. Find out about the lifting equipment and other aids that have been designed to reduce this load. Talk to other parents of children who are highly physically dependent. Ask them what equipment and aids they have used and found helpful. Find out about any funding that they may have accessed for this equipment.

Carers

Parents who are raising highly physically dependent children can often get a certain amount of in-home care. This support can be invaluable and give parents a break from the constancy of caring for a high needs child. Contact your local council and regional respite care network to enquire about in-home care. If you know of other parents who have access to in-home care, find out which services they use and how to contact them. Be proactive. Do not wait for services and funding to come to you.

Privacy

Children who are highly physically dependent can find it difficult to maintain privacy during toileting. Parents and carers need to remain mindful of this. It is through their actions that the child's right to privacy will be upheld, or compromised.

You have to put him in the shower chair, place him over the toilet and so you go ahead but you can't leave him there because he'd fall out. It doesn't matter how you strap him in, because of the equipment you just have to be there. So there's all those issues of his privacy and self-esteem and, and really you just don't want to be there and you think well does he really want me there? I'm his mother after all and a teenage boy doesn't want his mother so we always make sure that we put a towel

over him. We call it the modesty towel. So it's reinforcing social values. I think with kids with a disability you have to be continually reinforcing those things.

Lynne, mother of a child with cerebral palsy

When your child does not show affection

A lot of parent's communication and bonding with their child occurs through touch—a morning cuddle, a rub of their child's back, their child running to throw their arms around them because they haven't seen them for a few hours.

When a child does not give affection, or does not like to be held or touched, parents find other ways to develop this connection. More emphasis may be placed on talking with their child and expressing their affection verbally. Shared activities can take on a greater significance, as parent and child share space and interact with each other.

But touching can still be missed. For some parents, the lack of affection from their child can be devastating. It can leave them feeling disconnected, unloved and questioning their role:

I just thought this is really hard being a mum. I just kept showing him love but never got anything back, thinking this isn't what motherhood's meant to be like. That lack of responsive love that you know a normal baby just gives its mum and he just didn't give it. I always remember crying one day when he came up and hugged me.

Abbey, parent of a child with a benign brain tumour

The ability to give and receive affection can be learnt. It may not be as spontaneous as the affection given by another child and it may occur on the terms of the child rather than the parent. But the affection, the giving and receiving of touch will be there.

Strategies that parents can use to teach their child how to be affectionate include: teaching their child to make eye contact, sensory integration therapy, gradual exposure to affection and verbal explanation.

Making eye contact

It is through eye contact and scanning other people's faces that we learn what different emotions look like. We match what we see in someone's face, with the tone of their voice, the way they hold their body and their actions. In this way, we begin to understand and recognise feelings. Many children who find it difficult to give or receive affection can also find it difficult to maintain eye contact. A child who finds

it difficult to maintain eye contact, and who does not like to be touched, will have a more limited opportunity to learn about emotion.

The first step to teaching your child to be affectionate is to teach them to look you and other people, in the eye. A simple, effective technique that one parent has used to teach this behaviour to her autistic son, involves the use of well-timed rewards:

I started off with the basic stuff: Alex look at me and I held a lolly up to my eye. As soon as he looked, naturally at the lolly not my eye, I gave it to him. And I'd say look at me and it was just like dog obedience training. I got to the stage of, look at me and he'd just look at my eyes, great, and I'd hand over the lolly and then eventually we'd move over to different things.

Peta, mother of a child with autism

Sensory integration therapy

This technique refers to a process of gradually introducing your child to different sensations of touch, giving your child the chance to touch and get used to the touch of different things. You can use fabric, feathers, fur, shaving cream, slime, cotton wool and blocks—anything that will give your child a sensory experience when they hold it in their hands or when it is rubbed against their skin.

The aim of sensory integration therapy is to increase your child's tolerance to different types of sensory experiences. Even if your child does not like the feel of something, persist with it for a little while. Take your child beyond their comfort zone, but stop when they begin to become agitated. Try your child with this sensory experience again the following day.

Try to do some sensory integration therapy with your child each day. Take note of any sensations that they enjoy. You can use this experience as a reward, when your child is willing to hold or touch something that they don't initially like the feel of.

I think a lot of the sensory integrative ideas are really good because they actually do work. The kids really need that so much and I find Chris always benefited from things like that. He really likes being firmly rolled up in cushions and blankets and being squashed. He actually likes you to squash him as hard as you can, down under the foam mattresses.

Elaine, parent of a child with autism

Over a period of time, your child will learn to tolerate, and then enjoy a range of sensory experiences that they would have shied away from before. Once you have reached this point, you may like to start gradually exposing your child to human touch.

Progressive exposure to touch

Teaching a child to be affectionate will take a long time. Start with very small, light touches and work your way up from there. For example, you may want to start by stroking your child's hand briefly. You could include this as part of your sensory integration therapy with your child.

Initially, your child may pull away. Don't feel bad about this. Your child's dislike or fear of affection is what you are trying to overcome. Persist with a light stroke of your child's hand fairly regularly. When your child accepts this type of touch without becoming agitated and pulling away, move to a slightly larger show of affection.

Introducing gentle, brief tickling may work well at this stage. Always approach your child from the front so that they know you are coming. Give them a gentle tickle and let them go. If you have other children, make sure that your child can observe you tickling your other children and the fun that you are having together. Encourage your child to get involved with the play.

When your child is coping with a bit of tickling, you can begin to work your way towards a quick cuddle, and so on.

Marnie used to scream every time somebody touched her. She now loves a cuddle and adores a tickle. She'll ask for a tickle.

Joelle, parent of a child with autism

Once your child has developed tolerance for different degrees of touch, touch them a lot. Vary your touches through the range that your child can tolerate, and for varying periods of time.

I think it's like any wild animal, the more you handle them and the more you familiarise them with physical sensory stuff then the tamer they get.

Perry, parent of a child with autism

Verbal explanation

Talk to your child about affection and touch. Explain that family members and friends use touch to show each other that they care for them. And that this is what you are doing when you touch your child. When you feel that your child is ready for it, also talk to them about the different types of touch that are appropriate for other children, school friends, teachers and carers.

Getting social with your child



Q U I C K T I P S

- Consider using internet banking or shopping by phone or the internet to avoid having to take your child out and about if this causes problems.
- If you can, get someone else to look after your child so that you can do the day-to-day tasks on your own.
- When strangers say hurtful things about your child, you can try to explain your child's disability, just ignore it, confront the person or respond with humour.
- When taking your child on an outing, talk to them beforehand so they know what is going to happen.
- Going to the same place each time is a good idea, as is rewarding your child for good behaviour when you go out.
- Think about preparing your child in advance if they are going for a sleepover at a friend's house or away on a group camp.
- If your child finds it hard to make friends, you could reassure them about their self-worth and talk to them about any feelings of loneliness they may have.
- If your child is getting bullied or teased, you can help them by teaching them some strategies to use, talking to them about their feelings and working with their teachers and carers.
- It's a good idea to plan ahead for school and family holidays and get information about local holiday programs and activities.
- A family holiday might be difficult to arrange, but a setting that becomes familiar to your child is a good idea.
- Sometimes a holiday or outing apart from your special needs child offers benefits to all of your family. Don't feel guilty about doing that.

Your child in society

Dealing with comments from the public

There are times when the words of a complete stranger can stop you in your tracks. They can take your breath away and leave you feeling angry, sad, speechless or shocked. This happens because you are a strong, loving parent and because sometimes the words of strangers are unfriendly, judgmental and aimed at your child.

A stranger does not see your child for who they are or cannot appreciate the challenges you face every day. It can seem so unfair.

What people can say or do

Comments from the public can range from well-meaning to patronising to downright rude. Adolescents and young adults may copy your child's movements, or make fun of your child's difficulty with speech. Other adults may react to the inappropriate or aggressive behaviour of your child and make judgments about your attempts to deal with it.

I feel people are looking at me thinking, ooh, she's a bad parent.

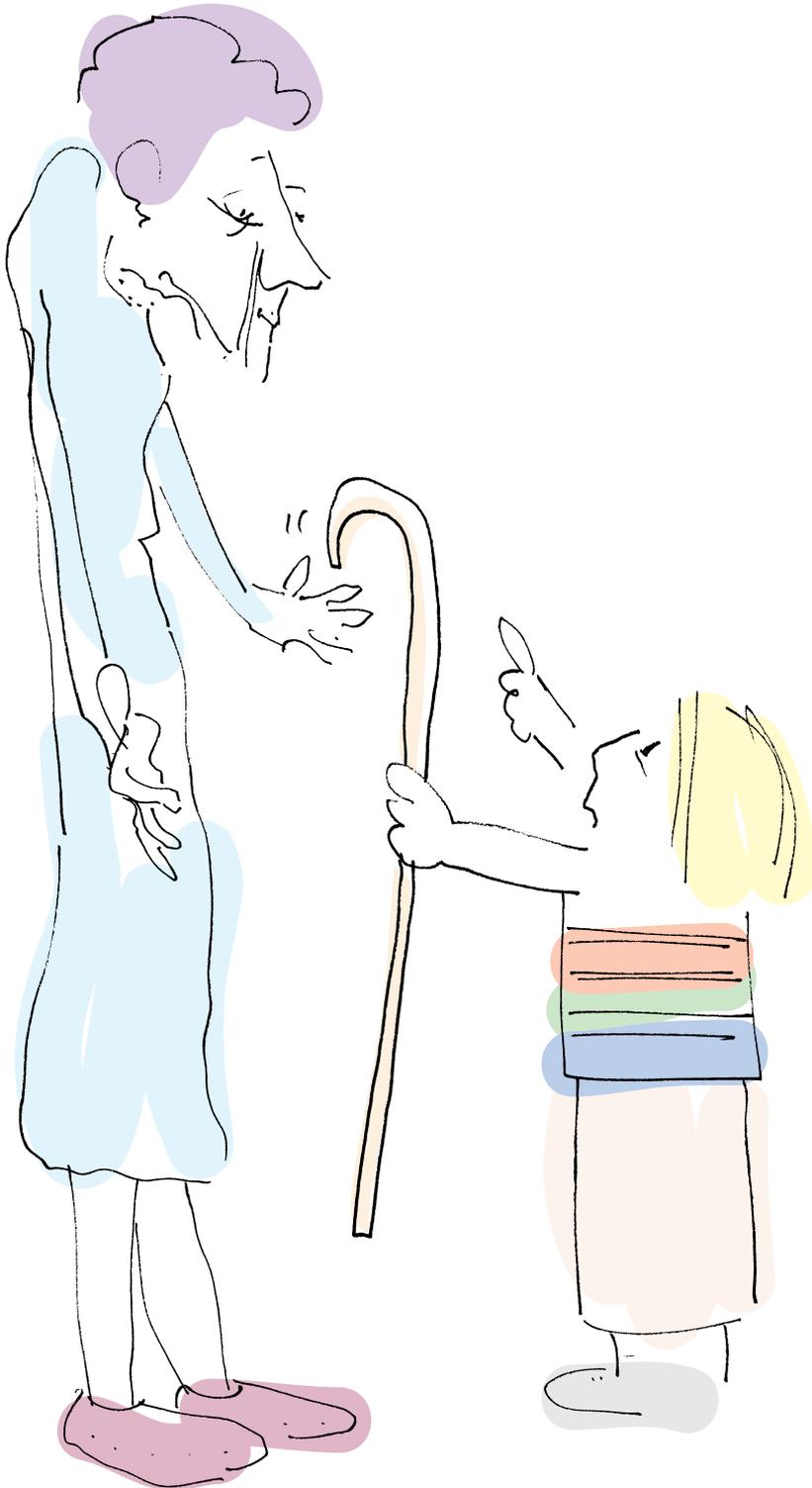
Charlotte, mother of a child with autism

To a certain extent, people in the wider community react to what they see. When they see a child with an obvious disability, they will generally be more accepting of that child's behaviour, movement and speech. Some people may stop and say hello, some people may smile, some will just walk by. A few may move to avoid your child, because they feel uncomfortable and are not sure what to say or do.

Adolescents on the other hand, can be less accepting. Perhaps this is because disability is so unfamiliar to them. Perhaps it is because they have not yet left the schoolyard, where differences are highlighted and picked on. One thing is for certain, adolescents who have spent time with a special needs child, either in the classroom or at home, are far less likely to make fun of other children with a disability.

In general, adolescents will only react to a child with a disability when they are with other young people their own age. This reaction can be a good cover for feeling uncomfortable. It can also 'earn them points' within their group of friends. If it is any consolation, most of these adolescents will grow up to regret and feel ashamed of this behaviour.

When a child does not appear disabled, the public does not always recognise the need to be understanding or accepting. As a result, your child's behaviour, and you, can be judged quite harshly.



Parents of children with Autism Spectrum Disorder report that this is a common experience for them. When their overloaded, overstimulated child begins to tantrum or become aggressive, they are faced not only with their child, but the tut-tuttings of onlookers who comment on their lack of control. Parents' attempts to manage their child's behaviour can also be judged and misunderstood:

Brent was having this major league temper tantrum about absolutely nothing and I basically picked him up and just sat him in the trolley and was just holding him there until he calmed down. I actually had this man walk up to me and tell me what a horrid mother I was and how cruel I was and how dare I treat that child like that. I turned around and asked if he wanted him. He said, I beg your pardon and I said, you take him for five minutes, you fix it and when you bring him back, you tell me why I am doing this. He just stood there and looked at me and said I beg your pardon. I said you know nothing about me, nothing about my son.

Keely, mother of a child with autism

Fortunately, there is understanding as well as criticism in the community. There are people who are sympathetic and caring. It is these people who will share a knowing smile, tell you that you're doing a great job and offer their help. These are the comments that you need to hang on to, because these people are seeing what is real.

How to respond to public comment

There are a number of different ways that you can respond to comments from the public. No doubt you have already tried out a few yourself.

Explain your child's disability

When you explain your child's disability to someone who has made a comment, you are letting them know that your child behaves, moves or speaks the way they do for a reason. Most of the time, your explanation will bring an embarrassed apology from the other person. Sometimes it will spark a sincere interest and willingness to understand.

Unfortunately, you may not always get a positive response when you take the time to explain about your child's disability:

You know these indoor play centres? We used to go to one that was near where we lived and they had party rooms that had these half-height doors. When you opened them they went click and when you shut them they went click. You can imagine an autistic child who has a fixation with doors and here's one that goes click. My God

he was in seventh heaven, forget the toys, all he wanted to do was open and shut this door. Well this woman got up from the table near the door and came over to me and said your son is driving me nuts. I said I'm sorry about that, he's autistic and the click of the door it's really quite interesting to him. Well she says, I don't give a damn, you better stop him. I said I'm sorry did you understand me, he's autistic and that's something that really intrigues him. She says, listen lady, I didn't come here to be annoyed by somebody else's kid.

Katherine, mother of two children with autism and intellectual disability

For some parents, a comment from the public is a chance to teach, to make people more aware of the disabilities that exist in our community.

I don't mind if somebody opens their mouth and tries to criticise if I have a child tantrumming, because that leads the way to education.

Peta, mother of a child with autism

Explaining takes time, effort, energy and a positive attitude. It is an act of giving. You are giving the other person a chance to learn and understand. After a long and difficult day, it can be hard to be positive and even harder to be generous. It is natural to get tired and feel angry:

I feel like I have to explain myself or my child, but at the same time I feel angry, and think, why should I have to explain myself? I constantly feel like there's an internal battle going on.

Amy, mother of a child with autism

At times like this, you may prefer to use one of the other responses described below.

Ignore it and walk away

How do you ignore something that offends you, and walk away? You think about it. You weigh up the pros and cons. Confronting and explaining can take time and energy that you may not have. Conflict can be draining. Do you think that talking to this particular person will increase their understanding? What would be the benefit to you and your child?

Sometimes you ignore and walk away because you don't know what to say. Your body has kept walking while your mind was trying to register what had been said or done. To react means turning back and chasing up the person. It can feel easier to walk on.

Ignoring the comment or action of another person does not mean shrugging off your feelings. If you choose to ignore and walk away, you may still feel angry, upset or stressed.

It is important to deal with this. Talk to others about the situation that has occurred. Express how it made you feel. You may find it useful to replay the scene over in your head, responding in different ways. Look at the positive outcomes of your choice. You have saved your energy and time. You have avoided conflict. You are choosing your battles.

Confront the person

Confronting the person can be tremendously satisfying. It can give you a chance to vent some of your feelings, and let the other person feel what it is like to be on the receiving end of public criticism.

My daughter was about five metres away from me and this young girl and her friends were walking in my direction. They just walked past her and of course she started doing this [copying her daughter's walk]. I went straight up to her and said some things to her. I just had so many things I could've rattled off to her that I didn't say, but she absolutely pooped herself to think she should've known better because she was probably in her early twenties. I was really cross but she couldn't keep her eyes off me wondering when we were going to get out of the place. I was so cross.

Lee, parent of a child with spina bifida

Another parent recalled telling someone that had offended her, 'well she's autistic, what's your excuse for being rude?'

Although it can feel good at the time, confronting people can also have its disadvantages. It can leave you feeling bad about yourself for lashing out. It can increase the potential for further conflict. It can also increase the other person's fear or misunderstanding of people who have disability. On the other hand, that person will probably think twice before speaking up again.

Humour

You have heard humour described as the best medicine. You know it can pull you out of a low patch and just sometimes, it can stop a tantrum in its tracks. Humour can also be a great way to deal with comments from strangers.

There are always these little old ladies that come up and start patting his hand and his head and that really freaks me out. I cannot cope with it. They go, oh the

poor thing, I'm so sad, oh you poor dear, how do you cope? I just want to punch their lights out. I know this is socially unacceptable and I'm really worried about the headlines in the local paper, Mother punches little old ladies' lights out. It doesn't look good. So I've developed the strategy. I thought I've got to use reverse psychology here and I just said, he's not poor, he's got more money in the bank than what we've got. We're the poor ones, we've got no money. Don't you feel sorry for us? I kept making a joke of it.

Lynne, mother of a child with cerebral palsy

The use of humour can release the tension that builds inside you when you are offended. It can surprise the other person and make them more open to further discussion about you and your child. It can take some of the sting out of your experience.

Humour can also be found in another person's response to you. One parent confesses:

It depends on my emotional state. Sometimes I say he's big for his age or he has a hormone imbalance. When I'm annoyed I say he has a brain tumour for the shock value and the change in people's responses.

Abbey, mother of a child with a benign brain tumour

The words of strangers can be intrusive and offensive. They can make you feel angry, frustrated and sad. Sometimes though, humour happens quite unexpectedly. When it does, laugh, enjoy it and be thankful.

Recognising yourself in the reaction of others

Think back to the time before you had a child with special needs. What were your thoughts when you saw a child screaming, or throwing things around? How did you feel when a child with a disability approached you or one of your children? It can be a challenge to try and walk in the shoes of someone who has made you angry or made you feel bad. Maybe, just maybe, you walked in those shoes and had those thoughts before experience became your teacher. Seeing these things in yourself can help you to cope with the lack of understanding in others:

I get really pissed off, and try to ignore them. Then I realise that I probably would have done the same thing before I had my son.

Sorrel, mother of a child with Down syndrome and intellectual disability

Parents may not be the only ones who find themselves changed by the experience of raising a special needs child:

My mum actually said it was probably six months [after our son was diagnosed] that she was in the bank one day and there was this little boy and he was going right off his nut. Mum said, you know it wasn't so long ago I would have stood there and looked at that child and I would have thought, why doesn't that mother just stop him. I don't even think that now.

Keely, mother of a child with autism

Show understanding to other parents in public

You know what it is like. You've been there. When you see another parent having a hard time, give them a smile, offer your help, tell them to hang in there. Your support will be appreciated.

Day-to-day tasks

Completing day-to-day tasks, such as shopping or banking can be very difficult when you are raising a child with special needs. Highly physically dependent children will require repeated lifting in and out of cars and wheelchairs. Children with behavioural difficulties can become overstimulated and act out. Escape artists will have to be constantly held and monitored.

If you are finding it difficult to complete day-to-day tasks, you may be interested in some of the following suggestions, which have been put forward by parents in similar situations.

Using the internet and your phone

Look into banking online. Talk to the people at your bank about how you can register for internet banking, and what services it provides. You may find that it saves you money as well as time. Talk to your local supermarket manager. Explain your situation and the difficulties that you can sometimes face when trying to get your groceries. You may be able to arrange to phone through an order and have it delivered to you at minimal cost. Some larger supermarkets also provide internet shopping and home delivery.

Preparing your child

If you are taking your child with you on an outing, prepare them beforehand. Talk to them about the sequence of events that will occur, from leaving the house to coming home:

If I had to take him along, I'd tell him about it as soon as I had the opportunity. So if I was picking him up from kinder and we had to go somewhere on the way home I'd tell him that as soon as I got to kinder. When we got in the car and I was buckling him in I'd tell him again. I'd say we've got to go there and then we'll go home. I virtually talk about it the whole way there because, if he knows what's happening then it really puts his mind at ease and he'll be much more compliant while we're doing that task.

Amy, parent of a child with autism

If you are preparing your child at home, you may find it helpful to use pictures or symbols when describing your outing to your child. Putting a reward somewhere in your story can also make your errands sound far more attractive.

While you are out, keep repeating your plan of action to your child. It is very important to stay as close to this plan as possible once you have left the house. This will build trust for when you use this approach again.

Take your child to a familiar place

Take your child to the same bank, or same supermarket each time—or as much as possible. Your child will become familiar with the building and the things that will happen while you are there. The bank or supermarket staff will also become familiar with you and your child. This can have two major benefits. The staff will be more likely to lend a helping hand if you need it and you are likely to feel more comfortable if your child begins to exhibit challenging behaviour.

Rewards for good behaviour

When your child comes with you on day-to-day errands and behaves well, reward their good behaviour. This can take the form of positive comments, hugs, a small toy or something nice to eat.

Rewards can also be offered to your child before you leave the house. At this point, the child is clearly informed that they will receive the reward only if they behave well. Most parents are familiar with the power of the chocolate frog. In your house it may be the toy car or stickers. Somehow, these objects have an ability to prompt amazing cooperation and real effort where mum and dad cannot.

When it comes to rewards, keep them small, keep them simple and definitely, definitely do not give the reward until the end of your trip.

When your child misbehaves

You've bitten the bullet, prepared your child and yourself and headed out with your young one in tow. There in the middle of the supermarket, your child has dropped to the floor and is working up to a major tantrum. What do you do?

- Try to understand the cause. Go through a mental checklist. Is your child hungry or thirsty? Are they tired, bored or overstimulated? Offer food or drink. Give them a specific job to do or something to handle. If they are overstimulated, speak to them calmly and quietly and use the strategies you have developed to bring them back to balance. If your child is not settling easily, tell them clearly that you will be leaving very soon and mentally edit your shopping list to the essentials.
- Ignore the behaviour. Some parents find that completely ignoring their child's behaviour can give them enough time to complete their task.
- Contain and remove. When your child becomes very distressed and aggressive, you may feel that the best option is to remove them from the environment or activity that is upsetting them.

Shopkeepers will come and help me carry him to the car when he is having a bad episode. We remove him to the car and harness him in, so we get someone to help.

Kristy, mother of a child with autism

- Do day-to-day tasks on your own. If your child's physical disability or behaviour makes doing day-to-day tasks almost impossible, try to find time to do them on your own. This can be done while your child is at school or during respite.
- If your child is below school age and you don't use respite, involve your partner, family and friends. If you are parenting with a partner, you can ask them to do the shopping on their way home from work. Approach your parents, brother or sister to look after your child for a morning or afternoon. Alternatively, offer to swap one or two hours of childminding each week with a friend.
- If you are able to complete day-to-day tasks on your own most of the time, consider taking your child out with you once per week or fortnight. This will give them an opportunity to interact socially with the wider public and to develop a presence within their community.

... but by the same token I think he needs to be out and about. So we take him shopping and you know places he's seen and where he interacts with people because that's important for him too.

Carole, parent of a child with arthrogryposis

Childhood activities and friends

As your child begins to develop social independence, a new world of experience and challenge will open up. There can be the excitement of the first sleepover, the thrill of camp, as well as the heartbreak of bullying and loneliness. Within this section, you will find some hints from parents for dealing with each of these situations.

Preparing for sleepovers

Your child's first invitation to sleep over at a friend's house can be exciting and a little scary. Immediate concerns crop up: Do you know the other child's parents? Do they know about the special needs of your child? Are they able to cope with your child's needs? Will your child be okay?

While these thoughts are running through your head, your child is looking at you expectantly, eyes shining, hoping for a yes. What do you do?

Take some time

If you have any concerns about the sleepover, tell your child that you would like to take time to think about it, before giving them an answer. Let them know that you can see this is important to them, but that sleepovers can be a big thing for mums and dads too, and that you need to talk about it.

Look at the care needs of your child

Does your child have any care needs that are likely to arise while they are staying away overnight? If they can manage these needs themselves, do they need prompting? Do they have any needs that will have to be met by the parents of the other child?

A common issue that causes concern for parents is incontinence. If your child commonly wets the bed, has accidents or wears a nappy, you may be unsure how these situations can be managed when you are not there. If your child requires medication, can you trust another child's parents to give it to them? Alternatively, you may have a child who experiences fits that can be triggered by stress. Can another set of parents deal with this?

Talk to your child about their friend

Ask your child if their friend knows about the special needs that your child may have. If they do not, you might like to suggest that your child and their friend have their first sleepover at your house. In that way, your child's friend can see your child's needs being met in a calm and practised way. It can get them used to the fact that your child has to do certain things at a certain time or in a certain way.

Talking to the parent

Do you know the parents of your child's friends? If you do not, it might be a good idea to arrange a meeting between at least one from each set of parents before the sleepover takes place. Talk to the other parents about your child. Let them know if your child has any needs that will have to be managed while they are staying with them. Make it clear as to what they would have to do to help your child to manage their needs.

Sleepovers have only just recently started happening. My daughter wanted to stay at friends and I'd say, you can't because you wet the bed. I spoke to her paediatrician and he said, well why not? He said, I think you'll find that most people will gladly get up in the middle of the night, but I didn't want to put that on other people. I think the problem was more mine than my daughter's so I did go down that line and told people, oh yeah, well all right, and they wake her at eleven and two and six and that's fine.

Roma, parent of a child with VATA

Encourage the other child's parents to voice any concerns that they may have over this. If they are okay with it and you feel okay with them, then the stage is set for the sleepover to go ahead.

Doing it in stages

Some parents feel more comfortable approaching sleepovers in stages. The first step may consist of having your child's friend over to your house on one or two occasions. If you are friends with the other child's parents, you too may like to sleepover with your child at their friend's house. When everyone is feeling comfortable with the situation, you can then move on to independent sleepovers.

Keeping in touch

Once your child is at their friend's house and settling down for the night, the reality of sleeping away may set in. Confidence can fade, leaving your child wishing for you and home. Talk to your child about this before the sleepover. Let them know that these feelings are okay and that they can call you any time, for either a pick up or a talk.

Getting ready for a camp

Organised group camps can be a great experience for your child. Within a safe, closely supervised setting, your child will be introduced to a variety of new activities, experience the thrill of being away on their own and have a chance to meet and play

with other children. Camps can also be great for mums and dads, giving them a well-earned break from the day-to-day care of their special needs child.

Because most camps involve two or more days away from home, some preparation may be needed to make sure that your child is indeed a happy camper.

Talk to the camp leaders

Make a time to meet with at least one of the leaders well before the camp is due to begin. Ask them to provide you with details about how the camp will be structured. What are the facilities like? Where will the children sleep? How will the meals be organised? What activities will be conducted? How will the children be supervised?

Ask the leader if the adults who will be supervising the camp have any experience working with special needs children. Talk to them about your child's needs and any concerns that you may have. Let them know if you have any ideas about things that can be done to help your child to feel comfortable at camp.

We worked with the cub leaders to make sure that everything that they could possibly do to plan it for him and make it easier was thought about. So where they normally have a rotating time to have tea, the group that my son was in had a fixed time so that he knew that, for argument's sake, six o'clock was tea time, twelve o'clock was lunchtime, seven o'clock you get out of bed. His cub leader made sure that the whole day was planned to a precise routine.

Keely, parent of a child with autism

It can be useful to talk to the camp leader about your expectations of the camp and the leaders, at this time. Would you like them to contact you if your child scrapes their knee or has an argument with another child? What would you like the leaders to do if your child becomes teary and homesick? Sorting out these issues can give you peace of mind and help the camp leaders to feel more comfortable about dealing with these issues if they arise.

Let your child know what to expect

When you have a good idea about what will be happening on the camp, share your knowledge with your child. Talk them through the camp, from getting on the bus, to you meeting the bus when they get home. Let your child know about some of the people they will meet and some of the things they will be doing while they are away. If your child has particular needs that will have to be managed by other people while they are at camp, talk to them in detail about who will help them and what will happen.

Encourage your child to share any feelings that they may have about going on the camp. Discuss all the good things that your child will experience and some of the things they might feel while they are there. Work with them on a plan of action if they feel homesick or get scared at night or if they feel left out. You might also like to share your own stories of fun that you had at camps when you were their age.

Start with a sleepover

If your child has never slept away from home before, you might like to arrange a sleepover with a friend before the camp, to see how they go. If the sleepover is at your house, you could set up a tent in the backyard for some camping practice. Depending on your child's age and level of comfort about sleeping outside, you may like to share the tent or offer to leave the outside lights on.

Going along on the first camp

Your child's first camp is a big deal. A positive experience will build their self-esteem and set them up to feel confident and excited about future camps. If you feel that your child is highly anxious about going to the camp or that the camp leaders are concerned about their ability to meet your child's needs, you might like to consider going along. Having you there the first time can help your child to feel secure and comfortable. Camp leaders can also learn how to deal with any situations that may arise for your child.

The first year I attended camp with her, which seemed to ease everyone's mind. Everyone felt comfortable enough for me to stay home on the next camp.

John, parent of a child with cerebral palsy

When your child finds it difficult to make friends

Most children will experience loneliness at some point in their lives. They will spend playtimes and lunchtimes on their own because no-one wants to play with them. They will sit alone in class because no-one wants to work with them. They may attempt to join in with other children only to be told to go away or that 'we don't like you'.

Sadly, a child with a disability is likely to have these experiences more often and for longer periods of time, than children without disabilities, particularly when they are integrated into the mainstream school system or other mainstream activities.

How will you know if your child is lonely?

Parents often assume that their child will tell them if they are feeling lonely or that no-one wants to play with them. This is not always the case.

I was not aware of any issues until a friend of mine helped at kinder and said that no-one played with my child—they had decided he was a baby because he couldn't talk and they weren't going to play with him. You hear their experience termed in an observer's words and it cripples you.

Vicky, mother of a child with autism

Talk to your child about their everyday experiences at school. Ask them who they play with or sit next to in their class. Does your child like the way other children play with them? Ask your child if there is anyone at school that they really like. Does your child think that these children like them back?

Sometimes children will tell you who they played with, but not tell you that they felt a bit left out by their friends, like they were not welcome. You may like to ask your child how playing with their friends makes them feel or if their friends sometimes make them feel bad. Children who find it difficult to make friends, can sometimes accept lower quality, less positive friendships in preference to being on their own.

A handy source of information about your child's social experience can be teachers at their school or kindergarten, and if you use them, the staff at residential respite care facilities.

How to respond to a lonely child

One of the most important things that you can do for a lonely child is to reassure them of their self-worth. Let them know that they are interesting, talented and fun to be with.

Encourage your child to express their feelings about the behaviour of their school friends if they are not being accepted. Show them that you understand their feelings and, if you feel it is appropriate, share some of your own experiences of loneliness as a child. Let your child know that these feelings and their loneliness will pass.

Explain to your child that people who are a bit different can often be excluded or picked on by other children. This can be for any reason, such as because they wear glasses or stutter, or because they are overweight or not good at sports.

Let your child know that everyone is different in their own way. Sometimes people look, move or speak in a way that is different to other people. Sometimes people are different because they think or feel differently to other people. Everyone has things that they do well and things they don't do so well.

If you know of any role models with the same disability as your child, tell your child about them. These role models may have achieved in the fields of sport, art, drama, science, technology or community service. They may be located in your town or in

a country across the world. Inspire your child and yourself with the stories of these people who are also different. Reassure your child that it is okay to be different, even if their school friends don't act like it.

Continue to work with your child on the development of their social skills. When you can, observe them at play with other children. Look for any behaviours that may make it more difficult for your child to make friends. Make working with these behaviours a priority.

Working with teachers

You may like to meet with your child's teacher to discuss your child's social integration. Are there any strategies that the teacher could use to improve social interaction with other children in the kindergarten and school?

There used to be a problem at the kindergarten where none of the kids would sit with Jack. So now they've got name tags and every child has to sit where their name tag is. They change them every lunchtime, therefore Jack gets a variety of different people to sit with. He fortunately has really lovely teachers that have understood and they've just decided to put these things in place for everybody. It happened with other children too, not just Jack, because we have a Down syndrome boy at our kindergarten as well, so both of them were singled out.

Kristy, parent of a child with autism

I've basically gone up there a few times to show them what happens when Jesse is getting agitated and told them to just back off, just try and stay away from him. Now they know that when Jesse is flapping his hands or clapping his hands, it doesn't necessarily mean that he's excited or happy. It means get out of the way quick. The teacher has been reinforcing it really well.

Melanie, parent of a child with dyspraxia and epilepsy

Preparing your child for loneliness

Few parents actively prepare their children for loneliness. The very thought of it can be confronting. Some parents may feel that they are dealing with this issue by teaching their child social skills and working with teachers and carers. Other parents may choose to deal with it if it happens, in the hope that it will be a rare occurrence for their child.

Your child will develop positive, fulfilling friendships with other children. Along the way, they will also experience periods of rejection, exclusion and loneliness. It is important to prepare them for this. Talk to your child about loneliness. Let them know that it is

something that everyone experiences from time to time. Tell them that these times will come and go, that it's okay to experience these things.

Explore the strengths and positives of having time to play alone, as well as time to play with friends. Ask your child to think of different things that they can do on their own that they enjoy. Talk to them about doing these things when their friends do not involve them in their play.

You are your child's protector, champion and friend. Let them know that you are there to support them when they are having problems with their friends. Encourage them to talk to you. Show them that they are loved just as they are.

When your child gets bullied or teased

When a child is different, they are at risk of being bullied or teased by other children. This experience can leave them feeling embarrassed, rejected and confused. When it continues to happen, it can begin to affect how they feel about themselves.

Children like to be liked. When they first experience teasing and taunts from other children, they may not understand why these children are not being very nice to them. They may feel unsure about what to do. Some children walk away from the teaser, head down and hurting, while others react with anger and aggression, either at the teaser, or later at other children, siblings or pets. These children are hurting too.

It is natural to want to be there to protect your child from the taunts and insults that are directed at them. But you cannot be there all the time. Teaching your child how to deal with this experience on their own can give them useful tools for dealing with the many obstacles they will face as they grow and develop.

Giving your child tools

Work with your child to develop a number of different tools or strategies that they can use when they are being bullied or teased by other children. These can include walking away, saying something to the children who are teasing them, looking for a teacher or adult to protect them, talking to you about what is happening to them and telling a trusted adult how they are feeling.

Things that your child can say to someone who is teasing them may be 'I don't like it when you say that to me' or 'please don't do that to me, it is not very nice'. Ask your child if they can think of things that they could do in this situation and add their suggestions to the list.

Talk to your child about how they can combine these different strategies. For example, walking away can remove them from the situation, but they may still have some bad

feelings inside. Sharing these feelings with you or another adult that they can trust can help these feelings to go away.

When your child understands the different things that they can do, encourage them to practise using them. Play a game where you take turns to tease each other (gently) and use the strategies that you have been learning. Give your child lots of praise for their responses.

One parent taught her son how to take these strategies with him when he goes to school or to another situation where there will be groups of children:

You know we've used emotional toolboxes, you know this invisible case that my son takes around and gives him ideas about what he can do in certain situations.

Sharon, mother of two children with autism

Talking about feelings

Talk with your child about their experience of being bullied and teased. Ask them to describe the situation to you, the sort of things that were said, how your child responded, how they felt. Let them know that you understand how they are feeling. If they have responded in a constructive way, praise their behaviour. If they have not responded in a constructive way, ask them if there is anything that they could have done differently in that situation. You may also like to ask your child what they think should happen to the children who teased or bullied them. Encourage your child to vent their feelings of anger and distress.

This process of going over the experience and exploring your child's feelings is called *debriefing*. It can help your child to let the event go, and move on.

Why do children tease?

Talk with your child about some of the reasons why children tease. Sometimes children tease your child because they are different. Sometimes they tease because they don't understand your child's disability and sometimes they tease your child because they are unhappy about something in their own life.

Let your child know that it is okay to be different. Talk to them about role models who have achieved great things, who have the same differences as they do.

Depending on the nature and age of your child, you may even suggest that they work with a teacher to develop a talk for their class about their disability. The class can learn about all the ways your child is the same as they are, as well as the ways they are different.

Let your child know that some children tease and bully because they are unhappy themselves. Ask your child to think about a situation at home where they might argue with their brother or sister or tease a pet because they are unhappy about something else. For example, you may have told your child that they couldn't watch a particular video that they wanted to watch and a short while later they poked their sister, or pulled the cat's tail. This may not have had anything to do with their sister or the family cat, but had everything to do with how your child was feeling.

Why aggression or lashing out doesn't work

When your child lashes out at a child who is teasing them, they are doing two things: firstly, they are increasing the likelihood that the other child will hit them or that they will be punished by an observing adult, and secondly, they are rewarding the behaviour of the child who is teasing them. A strong response to the teasing or bullying of another child will almost guarantee that this child will do it again.

Increasing your child's self-esteem

Reassure your child of their self-worth. Let them know how wonderful, talented and interesting they are. Work with your child to develop a positive sense of self that can protect them from the words that are being directed at them.

Working with teachers and carers

When your child is being teased or bullied in a particular setting such as school, you can work directly with the staff to target this issue. Meet with your child's teacher and the principal to discuss the problem. If your child has identified the children who are teasing or bullying them, ask the principal and teacher to talk to the children and possibly, their parents.

Our principal's terrific. I just went up there and he said, I'll put a stop to it straight away, and those boys were sat down with the principal and my son and they just talked about disabilities. They're the best of mates now.

Jill, parent of a child with Down syndrome

Some children may not feel comfortable with this approach, fearing the possible fallout from the other children when they are next in the playground.

Another alternative is to work with the principal and teachers to improve the culture of acceptance in the school. You could ask the school staff if they are aware of any strategies that can be put in place to improve the situation. If you have the time, do your own research.

The problem of bullying has come under the spotlight in recent years. A lot of information about how to deal with this issue is now available. Contact the Department of Education, the Association of Children with a Disability and other disability services, and ask them for resources on this topic. Have a look on the internet for resources related to the bullying of children with special needs in schools. Put forward any ideas that you may come up with.

Campaign for disability awareness

Ignorance and a lack of familiarity can lie behind a lot of teasing and bullying. Although it is not always the case, most children who tease or bully other children with disabilities have not had a personal experience with disability. Parents can work against this lack of knowledge by raising awareness of disabilities within the school setting. This can take the form of providing information, putting up posters or having speakers come in and talk to the children.

Children's knowledge and familiarity with disability can also be increased by getting them involved in more interactive activities. There are puppeteers who tour schools putting on educational performances that focus on disability and acceptance. Teachers can introduce role play in the classroom, where children get to experience what it is like to have a range of disabilities for a period of time. Some parents have encouraged the development of group activities in the school, involving the participation of both disabled and non-disabled students:

At show and tell time, John would go and teach the grade the signs we'd learnt so in fact he was teaching something that they otherwise wouldn't have the opportunity to learn. They did a signing choir, they performed at the opening of this year's Hearing Awareness Week. John and all his mates signed 'What a wonderful world' and they got to the bit where they said 'they're really saying I love you', he was pointing to me in the audience. It was the most amazingly emotional thing you could ever go through as a parent. They're just learning to sign 'Mary's boy child'. The grade twos, in front of hundreds of parents, will get up there and sign.

Robyn, parent of a child with cerebral palsy and hearing loss

There are many things that you can do to raise awareness about your child's disability and disability in general. If you are interested in becoming involved, get in contact with the organisations or service providers listed in chapter 12, to find out how you can get started.

Creating a diverse social group for your child

Your child will form their social group from the people that they meet on a regular basis. This group may include children from your child's kindergarten or school, children of family friends and extended family and children that they have met at organised activities.

Some parents find that, over time, their own social group changes. Increased contact with other parents of children with special needs can lead to the development of new friendships. You may find that these parents understand and sympathise with you in a way that some of your older friends, who do not have children with special needs, cannot. You may also feel that these parents are more accepting of your child and their behaviour. The drift towards the company of other parents and away from some of your previous friends, can feel natural.

You find a lot of the time that the people you mix with the most are other people with autistic kids, like it or not, because it's just easier to mix with other people that have similar problems and understand yours. So I guess it reduces your social circle and it reduces the sort of outings that you have with your family.

Katherine, parent of two children with autism

If your child attends a special development school, mixes with the special needs children of your friends and attends activities organised by disability services and organisations, their social experience may consist solely of interacting with other special needs children and their parents. This can be of concern to some parents:

Children whose social interaction occurs solely within special development schools and home can be socially disadvantaged. Encourage your child to spend time around other same age children [who do not have special needs] who can role model behaviours and social rules for them.

Nicole, mother of a child with Smith-Magenis syndrome

If you are concerned that your child's social experience is too limited, consider getting them involved in activities within the wider community. These can include music, dance or drama groups, sports or other interest groups and established organisations such as cubs, scouts, brownies or guides. You may think about becoming involved in the leadership or organisation of one of these groups. It will give you an opportunity to connect with your child in a different way and keep you on hand to help smooth your child's integration into the group.

Holidays

School holidays can be a difficult and demanding time for parents and children. The sudden change in routine can throw everyone in the family out of kilter. Working parents may struggle to find adequate child or respite care during the holiday period. Children who have become attached to the routines of school can find the sudden loss of structure very difficult and may begin to act out with aggressive, reactive behaviours.

Planning for school holidays

Planning ahead is your best tool for dealing with school holidays.

- Look into the available respite services long before the holidays are due to commence. If you can, try to arrange for at least one day of respite per week.
- Look into the holiday programs that are available. Are there any that you feel your child would enjoy?
- If your child can cope with visiting parents and other relatives, explore the possibility of a holiday sleepover or visit.
- Make up a plan for each day of the holidays. Mark respite care, holiday programs and possible sleepovers on your plan. Look at the recreational centres, parks, playgrounds and adventure centres in your area. Can you include any of these in your plan? Prepare a list of activities that you can do on your days at home. These can include painting, cooking, building a cubby house, clay modelling or making a garden. Make sure you have collected all the supplies you need prior to the holiday.
- If you are working, get in early to schedule annual leave during school holidays. These periods are often in high demand among working parents.
- Look for resources that can help you plan your holiday period. Books and internet sites that suggest a variety of different activities for children can be invaluable.
- Contact your local council, and any service providers that you are involved with. Ask them if they have any information on holiday resources that might be of use to you.
- For local information, get a copy of the *School Holiday Survival Kit for Parents of Children and Adolescents with a Disability*. The kit is published by MacKillop Family Services, and is an excellent resource for the Geelong, Bellarine Peninsula and Surfcoast areas. It provides information on care options that are available during the holidays, holiday programs, camps, recreation centres, support groups and support services.

Planning a family holiday away

Can you remember your last trip away as a family? Barely? You are not on your own. The difficulty of caring for a special needs child in an unfamiliar place and the sheer cost of taking your family away, leaves many parents opting for holidays at home.

One safe, relatively low cost option that families could consider is a camping holiday within a structured caravan and camping park. Many parks are becoming more aware of the holiday needs of families with young children and provide securely fenced recreational areas such as playgrounds and pools. Larger parks may offer additional features such as a games room, tennis courts and plenty of space for riding bikes.

When you find a place that you like, keep going back. The familiar setting will help your child to make the transition from home to holiday. It will also give your children and yourselves an opportunity to develop friendships with other people who are regular visitors to the park.

We have a caravan on a site in a camping ground near Mildura. The caravan is a safe option, because we can enclose the children securely at night. It's one place where the kids will go to bed and they can't get out. We usually have a baby monitor on us, so they can still talk to us, and we'll go down and sit by a campfire and drink and carry on. The people down there are probably our true friends, because we can spend so much time with them.

Sharon, mother of two children with autism

It's a couple of years now that we've been going and the kids all make friends quickly and we hardly see them. Last year, my disabled son also made a couple of friends.

Vicky, mother of a child with autism

Holidays and family outings apart

Having a child with special needs can place a limit on the activities and places that a family can enjoy. This can become an issue when there are other children without special needs in the family and when family interests involve activities that their child with special needs cannot participate in.

We are coming to the realisation that we can't do things as a family, that our other children are missing out.

Jo, mother of a child with intellectual disability and epilepsy

Some parents deal with this issue by leaving one parent at home with their special needs child, while the other parent goes out with the rest of the family. Other parents choose to place their child in respite care, so that both parents and the other members of the family can have some time together:

We cannot access the beach, camping or hiking, the things we love doing, with our son. We have holidayed separately for years now. Due to the sheer care load, a holiday is not a holiday if our child comes. We tried this when he was younger and ended up in hospitals in every state we were visiting.

Peter, father of a child with cerebral palsy

He simply refuses to sleep in a strange bed, in unfamiliar surroundings. If possible, I usually put him into weekend respite so that the rest of us can go on a short holiday.

Margaret, mother of a child with Down syndrome and autism

The decision to exclude your special needs child from a family activity or holiday can be difficult. If you are considering this option, you may find yourself struggling with feelings of guilt and loss: guilt because you are leaving your child with other carers while the rest of the family has a break; loss because you have had to give up yet another dream—of a family holiday together. It may help you to consider the benefits that the respite care will bring to the other members of your family, including yourselves.

Raising a child with special needs requires enormous energy. It can be exhausting, and feel relentless. It is important that you find ways to nourish and re-energise yourself as both an individual and a parent. If the high care needs of your child prevent you from doing this at home, then a holiday apart from your child may be necessary to give you much needed time and space. It can be a chance to spend more time with your partner and other children. It can also give you an opportunity to take up activities or interests that you otherwise put aside.

CHAPTER

**When a child asks
'Why am I different?'**

QUICK TIPS

- *There are no right or wrong answers to this question, but it's a good idea to plan how you would answer if or when your child asks.*
- *Encourage your child to express any feelings they have about their disability.*
- *Talk to your child about their strengths and abilities too.*
- *Tell your child about individuals with a similar disability who have been successful in some way—they will be good role models for your child.*

Children are very good at catching their parents off guard—a sudden smile, a joke, a sign of unexpected understanding. It is not surprising then, that many parents find themselves wordless when their child turns to them one day and asks ‘why am I different?’ Other versions of this question might include ‘mummy, what is autistic?’ or ‘daddy, why won’t the other kids play with me?’

So, how do you answer?

The first and most important point here is that there are no right or wrong answers to this question. The second is that each parent’s response will vary according to their child’s age, development, temperament and disability. That said, this chapter contains some basic guidelines that you may like to use when *planning* your response to your child.

Explaining cause and effect

Try to provide an explanation of your child’s disability that’s suitable for the child’s age and that includes information about causes and effects. This might include a discussion of any known physical causes of the disability and the way it might affect your child’s body, thinking, emotions and behaviour. You might find it helpful to use pictures where appropriate or include references to other children that your child knows who have a similar disability.

Here’s one way of explaining to a child of 8 or 9 years about their intellectual disability:

Some things inside your head work a bit differently to the way things work in other people’s heads. This means that you can’t do some things in the same way that other children your age do them. Sometimes it might take you a bit longer to learn how to do something and you might need some help to learn it. But that’s okay. It is a part of the beautiful person that you are. Your mum and I are so proud of you.

Here’s how a parent explained autism to a child of 11 or 12 years:

He said, so what does it [autistic] mean? I actually didn’t know what to say to him for a little while. Because he’s so good at computers I actually said to him, what it means is that you’ve got a Mac brain in a PC world. It doesn’t matter, you have information, you process it, you come up with an end result. You can have two people using different methods but they still come up with the end result. So it really doesn’t matter,

it just means that you process information differently. And that was something that he could understand, because as far as I'm concerned yes, he's different but then I'm different and so is his brother and so is every person in the street. Every person is different.

Julia, parent of two children with autism

Talking about their feelings

Encourage your child to express any feelings that they might have about their disability, themselves and any responses that they get from friends, family, teachers and members of the public. Sometimes your child may experience feelings that they find difficult to talk to you about. At other times, you may find it difficult to deal with, or respond to, emotions that your child does not want to explore with you.

Counselling can provide your child with a safe, secure environment in which to explore feelings or situations that they have experienced. A counsellor might also be able to provide you with tools that can help you to respond to the changing emotional needs of your child.

Identifying your child's strengths and abilities

As a parent, you have keenly observed the development of unique strengths and abilities in your child. Your escape artist has revealed a well-developed problem solving ability. Your autistic child demonstrates an enviable logic and can program any appliance in the house. Your child with intellectual disability plays a great game of netball and loves to sing.

Share these observations with your child regularly. Write a talent list. Work with them to develop a sense of self that includes characteristics such as talented, unique, warm, funny, focused, loved, as well as disabled. Children (and adults) love to hear about the things that make them special.



Finding role models

We have all had the experience of being inspired by individuals who have achieved success, often against great odds. You might like to do some research on the achievements of different individuals who have a disability similar to that of your child. These individuals may be located in your town, or in a country across the world. They may be world famous, or famous within their home community. They may have achieved in the fields of sport, art, drama, science, technology or community service.

Sharing the stories of these individuals with your child can be a source of inspiration to both your child and yourself:

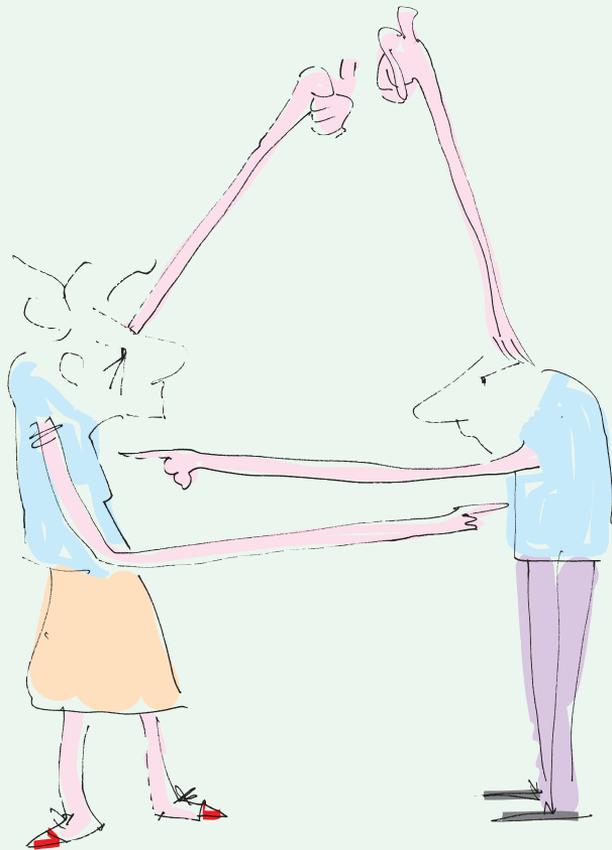
When you see other children with autism and what some can achieve as adults—you see what Dane Waites has been able to do with the weightlifting—and it's just wonderful. It gives you a bit of hope.

Judy, parent of a child with autism

Look at some of the biggest inventors in the world and some of the top artists in the world and they're autistic.

Joelle, parent of a child with autism

CHAPTER 6
Your family



Q U I C K T I P S

- *Make your relationship with your partner a priority:*
 - *make time for each other*
 - *talk to each other about who will do what in the family*
 - *try to take some time-out so that you can do some things together*
 - *support each other through the bad times.*
- *If you are a sole parent, work on establishing a support system.*
- *Parents of a special needs child often feel the loss of the child that might have been and it may take time to learn to accept that.*
- *Fathers can play an important role in parenting but might need some time to gain confidence in caring for their special needs child.*
- *Sometimes it's hard for brothers and sisters of a special needs child. Try to spend some quality time with each member of your family.*
- *Try to make sure that your other children feel that they are special too.*
- *Encourage your friends and other family members to give attention to your other children, as well as to your special needs child.*
- *Talk to your other children about their feelings.*

Bringing up a child with special needs will have an impact on each member of your family. It will influence the way you relate to your partner and your other children, it will shape your parenting and it will change the way each of you experiences the world.

Your partnership

If we were starting over again, certainly one of the things that I would be saying to couples is that this is really going to stretch your relationship and you need to work things out and put things in place to support your relationships. Relationships come under enough pressure, but disability is ten times the problem.

Peter, parent of a child with cerebral palsy

Although it can be a difficult thought for parents of a newly diagnosed child, it is important to understand and be realistic about the stress that raising a child with a disability will place on your partnership. A common mistake made by many parents is to direct all their energy into other areas of their family life and neglect the maintenance of their relationship with their partner until major problems begin to emerge. This is natural and understandable, particularly when you are both trying to come to terms with the shattering realisation that your child is disabled.

However, your partner will be your primary support through this experience. Together you will form the framework within which your child, or children, grow and develop. Maintaining this relationship is of vital importance to both of you and to your whole family.

Building a strong partnership

Making your relationship a priority, investing in it and maintaining it, will all work to strengthen your relationship.

Make a commitment

Talk to your partner about the importance of your relationship. Make a commitment to each other to try to keep the lines of communication open and to talk about minor problems before they become major problems. Be realistic about the fact that life is going to get very stressful at times. Acknowledge that this will put pressure on the relationship, but commit to being there for each other, to stay and work it through.

Clarify your expectations

Families need an income to survive. In most cases, one parent will take on the primary role of income support, while the other parent will take on the primary care role in the home. For some people, these roles will overlap, with the parent in the primary care role taking on part-time work, and the parent working full-time increasing their role within the home.

It is important to work together with your partner to clarify each person's expectations about who will do what in your lives together. Although it may seem petty to break expectations down to the specifics of shopping, cooking, bedtimes, organising childcare or managing the accounts, spending time on these issues can prevent resentment and frustration building up later.

Set goals

You and your partner form the head of your family. As such, you are responsible for steering the family in the direction that you want it to go. Make a time to discuss the things you want for your family and yourselves. Begin to look at strategies to make your goals happen.

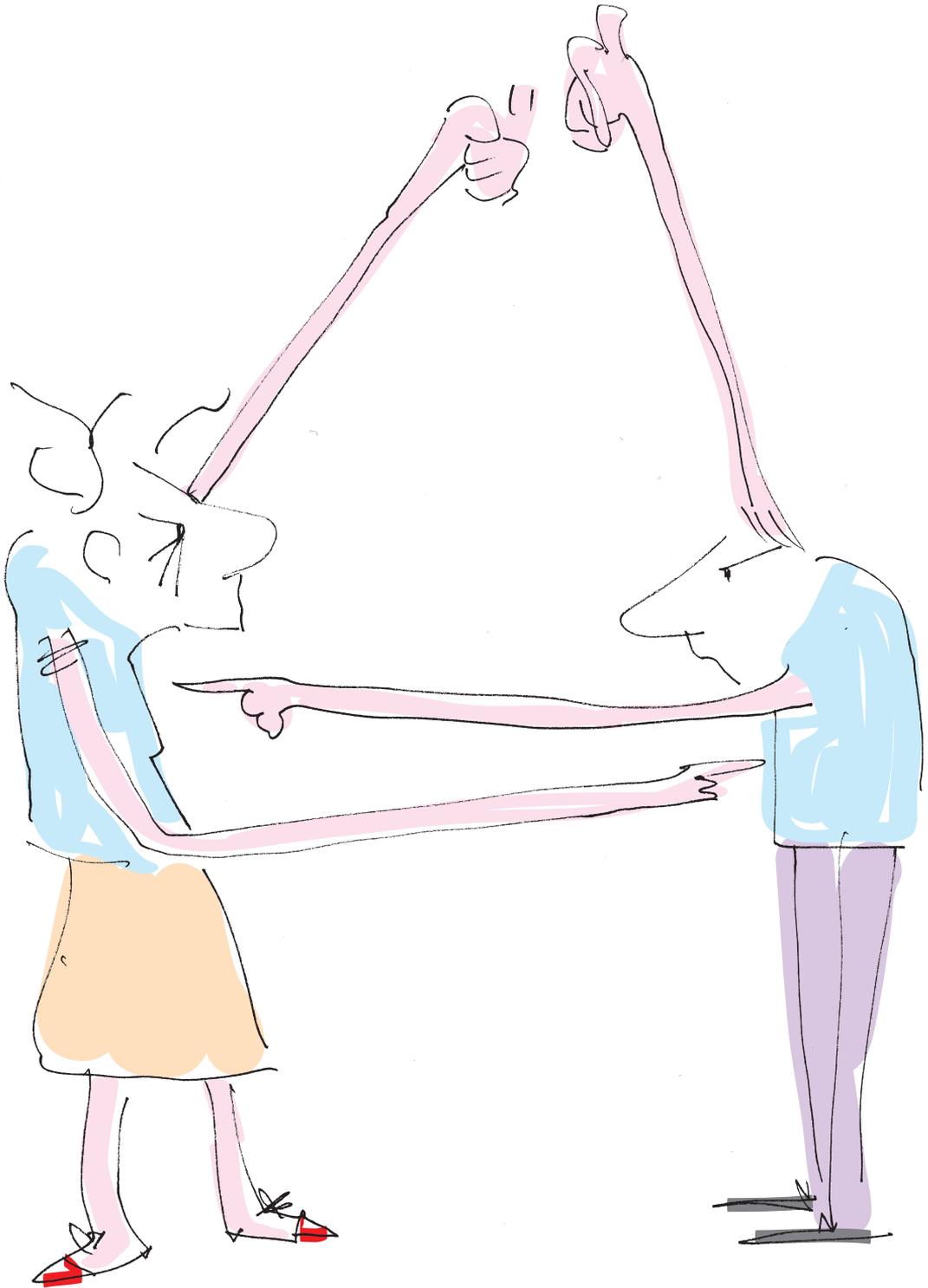
Plan to take time-out

All parents need time-out from being parents. Couples need time together, and as individuals, we need time for ourselves. Plan ahead to make time for each of these things. Find out about the sources of respite that are available to you. Start thinking about family and friends you can call on. Once you've decided on an activity or occasion, make the childcare arrangements and confirm them, so your plans can go ahead.

Look for an activity that you can enjoy together

Have you ever heard the saying 'couples that play together, stay together'? Life can get very serious. Working, raising children, running a house and trying to socialise with friends can leave couples little time to spend together. Desperate for a night off, you organise a carer and head out for dinner. But then you continue to talk about your children, your work, your serious life. Sound familiar?

One way couples can get a real break together and have fun at the same time is to take up an activity that they can enjoy together. Indoor rock climbing, dancing, theatre, pottery and billiards are just a few of many activities that can be done in one or two hours, at night.



Acknowledge each other's input

When you are feeling tired, stressed and resentful of the demands on your time, it can be easy to get into the argument about how much you do, while implying this is more than your fair share. If you find yourself doing this, take a moment and step back. Think of five great things that your partner contributes to your life together. Share your list with them. Then think of another five. You will begin to appreciate the effort that you are both putting in. Yes, there are some issues here that you need to work through, otherwise you wouldn't be having the argument. But you seem to make a good team and a good team works things out together.

Support each other through the bad times

Don't kid yourself, there are going to be bad times. You are going to go through periods when you feel depressed or frustrated or angry. You are going to have days when you just can't take it anymore. Keep talking to each other about how you are feeling. Be prepared to step in and help. Take over for each other so that one of you can get a much needed sleep or a few hours on your own.

When problems arise between you

Talk to each other first. Look at the problem and explore different ways that you might manage or deal with it. Don't be afraid to use a counsellor to help you sort through feelings and issues. Sometimes that independent, confidential third party can really make a difference.

Characteristics of a strong relationship

What are the characteristics of a strong relationship? Parents whose relationships have survived the early years of raising a child with special needs, say that they:

- recognise each other's strengths and contribution to parenting
- plan ahead and set goals together
- work as a team
- present a united front for their children and others—and disagree in private
- get counselling when they feel it is needed
- make time to talk things over (often on the run)
- support each other rather than turning to people outside of the relationship
- value and respect each other
- encourage one another
- attend church and worship together
- give each other time-out

- take time-out together
- have fun as a family
- see each other as their primary source of strength and support.

Sole parenting

Many relationships do not survive the pressure and strain of raising a child with special needs. Often one parent is left to bring up their child almost completely on their own. This is an enormously challenging task.

For some parents, it is also a relief. Separation can mean the end of long periods of hostility, tension and conflict in the home. Parents may feel like they can get on with the job of raising their children without the second job of trying to hold together a relationship that is failing.

The first twelve months following a separation can be the most difficult for single parents. It will be a period of picking up the pieces and working out how this new life will be structured. There will be intense emotional upheaval for both the parents and children, as each member of the family struggles to accept, and then adapt to, the change that has occurred.

In the best case, parents can still work together after the separation to develop goals, plan strategies and ensure consistency in their shared parenting. But this is not always possible. Therefore, the first priority of a newly-single parent is to establish a comprehensive support system that includes immediate and extended family, friends, respite care, play groups and parent support groups. The second is to begin planning. Now more than ever, it will be important to think ahead, prepare and get organised.

Counselling can provide vital support during this process. A good counsellor can help parents to explore and deal with the many feelings that they are experiencing. They can work with them through the separation or divorce in order to get the best possible outcomes for the children. A counsellor can also provide parents with valuable tools for managing stress and help them to discover the strengths that they will need as they take on their new role.

Fathers

The experience of having a special needs child will have a tremendous impact on all fathers. They will get angry and grieve. They will feel confused and lost. They will struggle to come to terms with what is happening within their life. They will experience all of these things while trying to fulfil their role as supporter, protector and provider.

Despite this, many fathers feel that they do not have a voice in the resources that are provided for them.

There needs to be something specified for fathers in particular. One thing I've always found is it's not overly addressed to males, it just seems like some of the groups I've been to with Denise don't encourage fathers, it's like an afterthought.

Paul, parent of a child with a brain injury

A father's grief

The diagnosis of a disability in your child can have an immediate and profound impact on how you view your life. Natural hopes and dreams can be shelved, as you try to learn and understand more about your child. After a time, you may review some of these hopes and dreams and see that they are still attainable. Others will no longer be possible, and you may feel a sense of loss.

The potential child

One of the first losses that many fathers experience is that of the potential child, created in your mind during the months of pregnancy and early life—the child you would teach to fish, ride a bike, drive a car, the child who would invite you to a tea party with their dolls, or ask you for help with their homework, the child who would grow into an independent man or woman, self-assured and successful.

It is a loss that most fathers learn to deal with and accept over time. But it may never go away completely.

It's been hard because with any kid you want to play with them and there's that loss. I think I've worked through now that it's not going to happen, but there is still that feeling. I guess when other kids his age go through those transition stages or you meet a kid that's twelve, you think, I could be doing these sort of things with him. So not being able to do the boy type activities, or just activities in general, is very difficult.

Peter, parent of a child with cerebral palsy

Adjusting to fathering a child with special needs

Fathers enjoy, and are greatly rewarded by, the warmth and affection of a close emotional bond with their children. They are also rewarded by their child's ability to achieve and excel in different areas of their life.

Fathers tend to compare. When you take them down to the park, you see the other children playing cricket and football and you know that your son can't do those things and he behaves very oddly and tends to chase other kids. You can't expect him to be like other normal children, so you've got to work with that.

Ed, parent of a child with autism

Part of adjusting to fathering a child with special needs involves resetting your expectations to fit within the reality of what is possible for your child. Your child will still achieve and excel, though it may be in different ways and different areas than you expected.

As you get to know your child, you will come to understand more about where their strengths, their talents, their interests and their limitations are. Draw on your knowledge to construct goals and aspirations that are suited to your child.

The irony is he's real sports-minded whereas [his non-disabled brother] is quite the opposite. The day I saw him in a wheelchair and onto a basketball court, I realised for the first time in his life he was on a level playing field, because the mobility wasn't an issue any more. It was his own skill level with what he'd do from here up. And you know he just loved that and I guess we've built on the basketball, we've gone to little aths and swimming and other stuff.

Greg, parent of a child with spina bifida

Look for role models with a disability that is similar to your child's. These may be individuals who have achieved in the fields of sport, art, drama, science, technology or community service. Without doubt, they will inspire you and give you and your children ideas about what's possible.

Involvement in parenting

When fathers are the primary source of income to a family, the time that they spend with their children can be limited to one or two hours in the morning or evening, and weekends. The primary parenting role is often left to the mother, who spends greater amounts of time with their children. Although major parental decisions are discussed, most of the day-to-day decision making occurs in the father's absence. Some fathers feel quite comfortable with this. Others find themselves in conflict between accepting the limitations of being the provider and wanting to take on a larger parenting role with their children.

One way in which fathers can increase their involvement in parenting, is to encourage a team approach to the setting of parental goals.

Setting goals

Goal planning sessions generally involve some in-depth discussions regarding your child's development. They can give you a chance to remain in touch with aspects of your child's development that you are unable to witness while you are at work. They can also give you and your partner an opportunity to talk about the beliefs and priorities that underlie your individual approaches to parenting.

Working together, parents can set mutual goals for their children and decide on the strategies that can be used to achieve them.

You've got to be able to set goals together and work together as a team and it is a real team. You see in a lot of relationships where the discipline of the child is one parent saying one thing, the other parent is saying another, and if that was a disabled child it just couldn't work.

Will, parent of a child with Down syndrome and hearing problems

When you parent in different ways

Some fathers who try to become more actively involved in the day-to-day care of their child can find themselves challenged, rather than welcomed, by their partners.

Paul: I think the father is an afterthought in the early days. We had a few arguments. She said to me you're doing this wrong. It doesn't necessarily matter if I'm doing it wrong.

Denise: I used to say to him, no you've got to do it this way, and I was just as new as he was so how come I knew more than him? He had to point it out to me, how come you're some expert?

Paul and Denise, parents of a child with brain injury

The fact is that each parent has their own parenting style, even if their approach, goals and beliefs are similar. While these differences can sometimes cause conflict between parents, they can also meet different needs and bring out different qualities in your child. For example, one parent may focus on the development of physical skills and playfulness, while the other may focus on emotional development and creativity. The result is a child who receives well-rounded encouragement and opportunities to learn.

Experience beats fear

On the other hand, some fathers can feel quite nervous about their ability to care for their children. They may be concerned that they will be unable to meet their child's needs or that they will get it wrong at a crucial moment.

Knowledge is born of experience. By putting yourself in the situation of caring for your child on your own, you will learn how to meet their needs. Through experience, you will come to learn what needs to be done at the crucial moments. Talk to your partner and other parents about the strategies that they use. Work up a list of ideas that can help you to deal with the variety of different situations that can arise with your child and keep it handy. This list will be of benefit to both parents.

It's a visual reminder of things you can do, instead of trying to keep it all up there.

Brad, parent of a child with a chromosomal disability

Share your child's life

Make an effort to become involved in different aspects of your child's life. Help with researching your child's condition. Look into services that are available to help you. Go along on visits to the doctor or meetings with teachers if you can. Your partner will be thankful for your support and involvement with these activities. If your child has developed recreational interests outside the home, go along and watch or participate. Set aside some regular time for you and your child to spend together.

Have fun with your child

A great way to increase your involvement in parenting your child is to seek out ways that you can have fun together. Are there any activities that your child enjoys that you can get into? Do you have any interests that you can share with your child? These may be things that you can do at home, such as soccer in the backyard, playing on the computer, drawing, cooking or chess. They can be sports or hobbies, or something passive like listening to music.

Start off with an activity that your child already enjoys. Your child will (generally) appreciate your attempts to come into their world to connect with them. Although you may find it a bit of a struggle to stay interested in their games, try to hang in there. The sparkling eyes of your child will be worth it.

Comfort your child

Children love the safe, secure feeling they get when they are comforted by dad. Reach out to your child when they are sick, sad, lonely or frightened. Get up to them in the night. Stroke their head and calm their fears.

When she was sick with an eye operation, I stayed home from work and I was up in the middle of the night when her eye got infected to the point where it was closed. It actually helped me bond with her more. Normally it's always been mum, mum, mum, mum, but dad looked after her that time and now dad's pretty popular.

Paul, parent of a child with a brain injury

Support

Many fathers feel that their opportunities to receive support are limited. Men who have partners will tend to draw much of their support from this relationship. Men who are without partners or involved in an unhappy relationship, can find themselves feeling isolated and adrift, unable to talk to, or confide in, friends, and not sure who to turn to.

The response of male friends

The response of male friends following your child's diagnosis may vary widely. Some fathers experience a rapid loss of male friendships at a time when they need them most:

Most of them don't touch me like the plague and don't talk to me, don't make the effort, or they're typical blokes and they'll say, how's Pip, is she all right? Yeah, that's about as far as they want to know. So it was certainly an eye opener where you thought any loyalties lay. I've usually got pretty right pre-conceived ideas on how things should be and then to find out that that's not how they were, we were really shocked. So I wrote them off.

Paul, parent of a child with a brain injury

Others find that their friendships strengthen and become a source of emotional support:

I've been fortunate to have some close male friends, and we certainly are quite open in our chatting in relationships about everything and anything, which is great. I think that's something important, to keep up contact with people as much as possible. It is very easy just to become a recluse.

James, parent of a child with an intellectual disability

Agency-based support services

Fathers who decide to approach a care service for support can often find that these services are staffed almost solely by women. This can be a discouraging thing for men

who are seeking the strength and understanding of other men. It is this experience that has prompted one father to start studying towards a social work degree, so that he can eventually take up a role supporting men in this situation.

There isn't much around to help men. When you go to a service, you only see women. There aren't any one-to-one dad's groups. That's why I decided to go back to school and do social work, so I can help other dads.

Perry, parent of a child with autism

Counselling

Some fathers find counselling very useful. They indicate that it has helped them to deal with dark emotions, such as grief, loss and anger that previously they have been keeping under tight control. Some fathers also comment that counselling has given them ways to strengthen their relationship with their partner:

It has been difficult for me over the years to communicate some of these thoughts and feelings to my wife. I think that's something that develops with practice. Blokes do have trouble doing it and I think that it's important to perhaps see a psychologist individually more than as a couple. If your relationship is strong you can cope a lot better with things and we've gone through a lot of ups and downs. If things are not well between the two of you, you are very vulnerable and little things turn into big things and if there's a lack of communication or things are unhappy, basically you just want out.

Peter, parent of a child with cerebral palsy

If you are interested in learning more about counselling services that are available to you, turn to chapter 12 of this guide.

Brothers and sisters

The expectations placed on a child who has a brother or sister with a disability can be greater than those placed on other children. This child will be asked to cope with the unequal sharing of parent time, watch as their brother or sister receives different treatment from family and friends and deal with unkind teasing from other children. In many cases, the social life of this child will also be affected, with their disabled brother or sister putting limitations on where the family can go and what they can do.

The balancing act

Maintaining harmony in a house often requires a finely tuned juggling act from parents. Your child with special needs will require large amounts of your time and attention. Your other children will observe this and at a certain point or age, begin to ask why they do not get the same amount of one-on-one attention as their brother or sister. Later these requests can become contests and for some children, pitched battles.

There are several things that parents can do that may help to promote a sense of fair play among their children.

One-on-one

Try to provide each child with some quality one-on-one time each night, or as regularly as possible. This will be a period of time that is set aside and totally devoted to your non-disabled child. Let them know that this is their time and that they can have a say in how it is spent. It might involve reading a story, doing some art, playing a computer game or having a talk about the child's day.

If you have access to respite care, consider using some of it to spend time with your children who do not have special needs. Take them out somewhere or support their involvement in a sporting team.

It's important about having a routine just scheduling time to be with my son on his own, where we can have a chat about his day and find out what's going on in his life. We have a bit of time on Tuesday afternoons, a bit of time together before we pick Jordan up from day care.

Amy, parent of a child with autism

My daughter plays netball on a Monday night. It took me a long while to organise respite and really the only respite I use is for the Monday night netball.

Jo, parent of a child with intellectual disability and epilepsy

Balance the needs of family members

When you are raising a special needs child, you can begin to feel as though they sit at the centre of your family, drawing the majority of family time and resources. At the same time, less demanding and relatively healthy family members can feel pushed to the outer circle.

It is important that parents remain mindful of the needs of each of their children when making family decisions. A child who feels that their voice is being heard and

considered will feel less resentful than a child who is constantly required to give way to the priority of their disabled brother or sister.

I'm not going to compromise the family's structure and activities of other members of the family because she's not coping. I'm sorry about that, we'll do everything within our power to assist her to get through her day but no one else is going to miss out because she's having a bad day. That's not fair.

Nicole, parent of a child with Smith-Magenis syndrome

Treating your children the same

Where possible, try to be consistent in the expectations of behaviour that you have for each child and how you approach them. Watching a brother or sister get away with behaviour that others would be punished for can be very difficult for children.

One mother views her determination to treat each of her children in the same way as a preparation for life:

Anthony's different, that's cool, I accept that, that's fine. I've never had a drama with that but I can't see why any child, any person regardless of who they are or what dramas they have, should ever be treated differently to anybody else and if I do that in my own home then I know that my kids are going to go out there and that's how they're going to treat the rest of the world. If Anthony's brought up to believe that okay, he's different to other people but he still has the right to expect to be treated exactly the same as anyone else, that's got to go a hell of a long way for him.

Keely, parent of a child with autism

You're special too

A child with a disability can often receive treatment from a variety of different specialists, such as speech pathologists, occupational therapists or physiotherapists. To another young child, this can look suspiciously like extra attention. Quick to identify injustices (particularly those involving themselves), the young child may set up a protest about all this added attention that they are *not* receiving.

Parents need to understand that it is difficult for many young children to grasp the lasting nature of their sibling's disability or the impact that it will have on their life. Children care about the here and now, and what they see is that the other child is getting more than they are.

One way of addressing this issue is to allow your child to become involved in their own special activity. Talk to your child about the fact that everyone has the right to

have some of their own unique experiences that they do not have to share with other brothers and sisters. Ask your child to nominate (within reason) an activity that can be theirs alone. Swimming, karate, a musical instrument, cubs or brownies would all fit the bill nicely. When your child next complains about the special attentions being received by their disabled brother or sister, gently remind them that they have their own special things that they do too.

Seeing the bright side

Encourage your children to identify some of the positive things that they experience because they have a brother or sister with special needs:

There are heaps of rewards for having Will in the family, like you get the best parking spots. We went to the Olympics, which was just sensational. We had the best seats in the house, so I keep reminding our son that if we didn't have [his brother], we would have been up in the rafters at the swimming.

Bob, parent of a child with spina bifida

Explaining to your child

Irrespective of the techniques that you use to balance the attention that is given to your children, there will be times when your child with special needs requires higher levels of monitoring, attention and care than your other children. Talking to your children about their brother or sister's disability can help them to understand why they need more of mum and dad's attention at different times.

Keep your explanation simple for younger children. The aim of your discussion is to let them know that their brother or sister has some things that are wrong with them, and because of these things they cannot do this or that. Explain to your children that mummy and daddy have to give their brother or sister lots of help to do some things.

It is likely that you will need to have this discussion with your children several times throughout their young lives. As they gain understanding and maturity, you can gradually increase the complexity of your story.

Older children may appreciate learning more about the cause of their brother or sister's disability and how this affects their behaviour or ability to do different things. You could also talk about the longer term outcomes of your child's disability. This greater understanding may bring the added bonus of your child becoming more involved in the care of your special needs child.

A situation that eases with time

Many parents report that competition for their attention and the associated bickering between children can start to ease as the children get older and move into their teens:

Our elder son is thirteen, two years older. Earlier, you could see the jealousy and he really paid out heavily on his younger brother because of the attention that he used to get. But now I think he sees it in a whole different light. He's branching out a bit himself and being more independent. I think he's a great brother and we acknowledge that and we reward him for that.

Greg, parent of a child with spina bifida

Fighting and bickering

There are few things that can get under the skin of a parent like the constant fighting and bickering of their children. Although annoying, bickering is a natural part of the process that children go through when they are learning to get along with other people. It is one of the ways that children learn about boundaries, ownership and problem solving.

What parents can do

- Give your children some time to sort it out themselves. If your children are getting out of control or are at risk of harming each other, it will be time to step in with some parental action.
- Encourage your children to talk about the cause of their argument. Lead them through the process of looking at each person's view and ask them if they can suggest any solutions to their problem. You may have to help out here at first. Stay with your children until an agreement is reached.
- If tempers are too heated for rational discussion, send each child to a different room to cool off. Once each child has calmed down, bring them together to discuss the situation.
- Encourage sharing behaviour between your children. Reward your children with praise, whenever you observe them playing well together, sharing, or problem solving—'great decision making kids! That's a great way to work it out'.

Copying the behaviour of a sibling with a disability

Sometimes parents will observe their younger children copying the behaviour of their older, special needs brother or sister. For example, the younger brother of an autistic child may experiment with rocking or flapping their hands.

What parents can do:

- Ignore the behaviour. As a parent, you have an enormous power to influence or shape the behaviour of your children. When you give a behaviour your attention, your child will naturally want to express the behaviour again in order to get more of your attention. In most cases a behaviour that is ignored will gradually fade.
- Expose your child to other young children who do not have a disability. Before young children reach the age of kindergarten or school, their social interaction is largely limited to family members and the children of close family friends. Humans learn socially appropriate behaviour from those around them. A child who spends a lot of time with another child who has a disability will assume that their behaviour is normal. Copying that behaviour is a natural part of social learning.

When your younger child begins to meet and play with other children their own age, they will learn that the behaviour they have been copying is not like the behaviour of other children. At this time you can expect to see a reduction or complete change in the behaviour that has been copied.

We're just hoping that most of it he'll grow out of, and that he'll realise as he gets older that it's not appropriate and that his brother is actually ostracised in public for some of the things he does. I think that he's too young to realise the public view.

Kristy, parent of a child with autism

Achievement and reward

When a child with special needs experiences success, it is an occasion for celebration. There is much praise from parents, friends and family and the child's achievement is discussed at length. This can be confronting for another child, who often has to work much harder to earn their rewards:

I guess that it's a bit of a problem for us, when at most sporting events he only has to turn up to get a medal, because that's the way disability is, like there's only the two of them in the pool, they're both in different categories, so they both win. That's especially one of the things that Chris has trouble with—[his brother] gets applauded whereas anyone else has to perform.

Bob, parent of a child with spina bifida

All parents will notice and reward the significant achievements of their children. Fewer parents will pay attention to the smaller, day-to-day successes that mark a child's

growth and development. Try to take note of some of the smaller achievements and successes of your non-disabled children. Let them know that you have noticed and that you are very proud. You may like to reward them with some one-on-one time over a game or a celebratory icecream. The rewards that you provide for these successes don't have to be big. The big thing for your child will be that you noticed.

The different behaviours of friends and family

Some parents report that friends and family tend to treat their children differently. Grandparents may rush in the door, eagerly looking for their special needs grandchild, giving their non-disabled grandchild a quick hug and ruffle of the hair on the way.

Friends may visit the house bringing a present for your special needs child, each time he or she returns from a visit to the hospital. Yet they will not think to include a little something for your other child. People that you meet on the street may ask about the wellbeing of your special needs child and ignore your other child standing beside you. Finally, some family members and friends may exclude your special needs child from activities and invitations offered to other members of the family.

Parents who observe these differences in the way that their children are treated wonder about the effects that it will have.

I think he would've found it really hard too because she had quite a few visits in hospital. In the first couple of years people would come and buy her something and him with nothing or just constantly ask, oh how's Amy instead of saying, how are the kids going, and this is in front of him. But he doesn't talk about it much.

Lee, parent of a child with spina bifida

If you feel that one of your children is being favoured over the others and you are not happy about it, there are a number of things you can do:

- Treat your children the same (where possible). Let friends and family know that you would like them to do this too.
- Speak with friends and family directly about their behaviour. Let them know that it concerns you and tell them why.
- When a friend asks how your special needs child is going, let them know how all of your children are going.
- When someone wants to invite some of your children somewhere or get some of them involved in an activity, give them permission so long as they include all of your children.

Bullying

Children who have brothers or sisters with special needs can become the target of bullying in the schoolyard.

Response to bullying

Children's responses to bullying and to their brother or sister can vary widely. Some children may become ardent defenders of their sibling, challenging bullies and the children who tease. Other children may become embarrassed or uncomfortable about being seen with their brother or sister:

I do think it's been tougher on our daughter, she feels like everyone's picking on her because she's got a brother with a disability. It's actually affected her sense of self a lot more than it's affected her brother. She gets embarrassed walking through the schoolyard with him because people are staring at her.

Robyn, parent of a child with mild cerebral palsy and hearing loss

Explore their feelings

Talk to your child about the experience of being bullied. Ask them how it makes them feel within themselves, about the bullies and about their brother or sister. Let them know that their feelings of anger, stress, fear or embarrassment are all natural responses to this situation.

Why children bully

Talk with your child about some of the reasons that other children tease or bully. Sometimes children tease because they can't cope with the fact that their brother or sister is different. Sometimes they tease because they don't understand or feel a bit frightened of their brother or sister's disability. Sometimes they tease because they are unhappy about something in their life.

Strategies to deal with bullying

If your child is being bullied or teased about their brother or sister, ask them how they deal with it. Are they happy with their strategies? Talk to your child about a range of responses that they can give when they are being bullied. These may include walking away, saying something to the children who are teasing them, looking for a teacher or adult to protect them, talking to you about what is happening to them, and telling a trusted adult how they are feeling.

For more detailed information on what you can do when one of your children is being bullied, turn to chapter 3 of this guide.

Support for brothers and sisters

Being the brother or sister of a child with special needs can be difficult. Through their experiences at home, at school and in the community, they can feel different from other children the same age. Some children will struggle to adjust to this difference and may find it difficult to make friends.

My daughter does lack self-confidence and she does think that she's different because she has a brother with disabilities. She's not like other kids because she hasn't got the self-confidence and she hasn't developed social skills. She is very shy. She hasn't developed real close relationships.

Peter, parent of a child with cerebral palsy

Socialising with other siblings

Siblings of a child with special needs may benefit from spending time with other children who are in the same situation. If you have other friends who have a child with a disability in their family and other children around the same age as your own, consider getting together every now and then. Look into the availability of sibling support groups and ask your children if they would like to visit one to check it out.

Expressing their feelings

Encourage your children to talk about any feelings that they may have about their disabled brother or sister. Explore how their experiences affect them at home, at school and when they are out in the community. It is important that you are very accepting of what your children say to you during these discussions. They are talking to you as their parent, not the defender of their disabled brother or sister.

If you feel that your child is experiencing emotional problems but is not able to talk to you about them, consider getting the help of a counsellor. Your child may feel more able to share their feelings of anger, stress, resentment or loss with someone outside of the family. They will also be able to discuss any feelings that they may have about you as a parent and other members of their family more freely.

Acknowledge their achievements

Children can sometimes feel that their parents are too taken up with their disabled brother or sister to notice that life is sometimes difficult for them. Let them know that you notice, that you see them helping and trying hard to be supportive. Thank them. Family is a team effort and everyone puts in, in their own way. Your children will glow with your recognition and you'll feel good too.

Friends and extended family



Grandparents can help ...
time out for mum

Q U I C K T I P S

- *Expect that some of your friends and other family members will not be able to cope when you get the diagnosis of your child's disability. Some will feel very awkward about it and not know how to respond.*
- *Encourage your child's grandparents to become involved with your special needs child.*
- *You can help your friends and family to overcome any uncertainty they feel about spending time with your special needs child by talking to them about what to expect and how to deal with certain behaviours.*
- *Give your friends and family opportunities to learn. Experience with your special needs child will help friends and family to feel more comfortable with them.*
- *Make time for your own friendships. You may also make new friendships with other parents of special needs children.*

When parents of special needs children are asked to comment on the things that help them to cope, the support of family or friends is often high on their list. These parents talk of family rallying around them, holding them close, asking what they can do. They describe friends who offer practical help, respite and a shoulder to lean on when things get tough.

They support me in different ways, whether it's just listening to me, coming and sitting with Erica, me dropping her off while I get a break or mowing the lawns. People have got different little ways that they can help out.

Lee, parent of a child with spina bifida

At the time of the accident there was one girl, a really good friend who came not long after the accident and saw John in ICU. We both cried and she was just so supportive, like the whole town. As soon as they knew about it, there was this social worker who organised meals for us. The whole town raised money for John, over a thousand dollars. They put it into a trust account for him so when he's old enough we can use that money for him. It was just wonderful.

Megan, parent of a child with acquired brain injury

Unfortunately, this is not the experience of all parents.

Where did they go?

A diagnosis of disability in a child can be very confronting for some people. Certain friends find it difficult to cope and feel unsure of what to say or do. They may begin by thinking 'we'll just give them some space and then contact them when they're ready'. But days become weeks and friends realise that contacting the parents will now require explaining and apologising. They realise that they will have to face the anger and disappointment of a close friend who they know they have let down. For these friends, it can be easier to avoid the conflict and drift away.

When a family has a child with a disability most friends just sort of drift off and in fact most family members drift off.

John, parent of a child with spina bifida

For the parents, this is an added loss on top of the bombshell that has already rearranged their lives. Many parents recall this period as a time of sorting out just who their real friends are.



Grandparents can help ...
time out for mum

I have to say that, yes you might not have as many friends but then you just sort the good from the bad a lot quicker when you have a disabled child or you get cancer or something. The people who are genuine are going to come to the forefront.

Hope, parent of a child with Down syndrome

Dealing with friends who don't know what to say

Lost in the grief and anger that can follow a child's diagnosis, few parents will have time for friends who search awkwardly for words. Sometimes friends will say something that can sound thoughtless:

It was just a really hard time and no matter what anyone said at that time it wasn't the right thing anyway.

Jessica, parent of a child with Trisomy 13

I don't know what response I want from people and what I want people to say. I don't know what could come out of their mouths that would be better. I just know it'll come out so atrocious, and I just don't want to deal with it.

Anna, parent of a child with brain damage

It is a big ask for parents to be forgiving of someone else's difficulty at this time. Perhaps the realisation that your friends are trying can take some of the sting out of their inappropriate words.

Just try and not take things that people say to heart and not take them the way sometimes it sounds. Try and interpret how they mean it as opposed to how it's coming out of their mouth and sounding terrible.

Rose, parent of a child with chromosomal abnormality

If you can, reassure your friends. Let them know that you see them reaching out to you. It will help your friends feel more comfortable around you and keep the door open for communication and support.

Dealing with fear

Sometimes family and friends may withdraw from both you and your child out of fear, fear that your child will have a seizure while they are visiting, or fear that they will be faced with a particular behaviour that they do not know how to cope with. This fear can be magnified when your child has serious health issues.

They would say when we were in hospital, if you want us to come and help you. But I don't need help when we're in hospital, I need help when we're at home. I think that comes from people being uncomfortable. No one wants to be minding Jade and have her die—that's the bottom line. I don't want it either but I think it could happen and that dictates a lot of the help you get I think.

Kim, parent of a child with a genetic syndrome

One of the best ways that you can deal with fear is through education and communication. Talk to your family and friends about your child's condition. Provide them with some clear information that is not written in medical language. Encourage them to ask questions, and watch the different things that you do to take care of your child. If your child has behaviour problems, teach your family and friends the best way to deal with these behaviours.

Talk about the possibility of your child getting sick or possibly dying while in the care of another family member or friend. Ask your family and friends if this is a concern for them. Encourage them to discuss what they are feeling.

If a situation arises with your child while friends or family are present, you may like to ask them to get involved. Experience is a great teacher.

While [the grandparents] were apprehensive, they wanted to know what to do if our daughter had a seizure. We'd say, here you do it because we know what to do. That's been really good, they've been fantastic support and they have a great relationship with her.

Rose, parent of a child with a chromosomal disability

Sometimes, even your best efforts will not reduce the discomfort of family and friends.

You can't force them to understand. All you can do is provide multiple opportunities for learning.

Robyn, parent of a child with mild cerebral palsy and hearing loss

Denial

Denial is a way of coping. It helps people to shut out an event or situation that's too much for them to deal with. When someone is in denial, they will literally deny reality. This will come out in comments like 'that isn't happening, I don't see that, there's nothing wrong here'.

A common early response from grandparents is to withdraw slightly and downplay the disability of their grandchild or question the diagnosis. These responses are typical of someone who is experiencing denial.

For a while [my husband's parents] seemed to pull back when we would talk about issues to do with it. It didn't really sink in, the severity of it, and it felt almost like we were trying to get attention from them. I just wanted them to deal with the fact that he wasn't normal, that he did have this thing wrong with him.

Jodie, parent of a child with a severe endocrine disorder

There were a few arguments I had with my mother. She was saying 'there's nothing wrong, blah, blah, blah' before we found out that he was autistic. Once she knew about it and she'd watch Dylan, she realised that there was something there. I just

don't think she wanted to see that there were problems because it was her first grandson.

Barbara, parent of a child with autism

Over time, a person in denial will begin to come to terms with what is happening in their life. Grandparents may begin to acknowledge the disability of their grandchild and re-connect with your family. They may begin to seek out information and open themselves to developing a close, mutual relationship with your child.

As a parent, you can help with this process in a number of ways:

1. Try to recognise denial when you see it. Understand that denial is an automatic coping mechanism, not a deliberate decision to withdraw or reject.
2. Give your parents gentle encouragement to become involved with their grandchild.
3. Always speak factually about your child's condition. Do not make concessions for your parents because you think they can't handle it.
4. Talk to your parents about your understanding of your child's disability and the probable outcomes.
5. Provide your parents with information about your child's condition that is not written in medical terms.
6. Keep the lines of communication open.
7. Be patient. Your parents will probably come around eventually.

Maintaining friendships

Raising a child with special needs can be time-consuming and draining. The energy that it takes to meet your child's needs and those of the rest of your family, can leave you too tired to put energy into your friendships.

Quite often I feel like friends take up my time and it annoys me if I get on the phone and they want to chat and I know I'll have kids throwing a tantrum in the background and obviously explaining, sorry, I've got to go, and they just won't shut up. Sometimes you have to be quite assertive with them. I feel quite bad that I'm not maintaining those friendships adequately. I really should try and make it a priority just like exercising I suppose, otherwise I'll wake up one day and I'm old and I've got no friends and I'll be pretty miserable I think.

Amy, parent of a child with autism

For other parents, social activity becomes restricted because of the high physical care needs of their child or their difficult behaviour.

Friends are really hard. We couldn't socialise with this child needing twenty-four seven care, plus the stress. I couldn't be bothered with visitors plus they didn't understand, not having a clue.

Carly, parent of a child with Trisomy 13

Because of these difficulties, parents of children with special needs can be at risk of becoming socially isolated.

At times it is very easy to become a recluse. It is just too hard to get out, just too hard to do this, too hard to talk about. The child tends to dominate the conversations when you're at home and when you're out.

Peter, parent of a child with cerebral palsy

Friendship is not just about support. It is about fun. It's about enjoying yourself. It's about letting go for a while—all things that you, as a parent, very much need:

Not matter how restricted your time is, and especially the entertaining and things like that, still try, never give up even if it's just absolutely impossible sometimes. Your true friends will accept your kids however they are and they'll keep coming back.

Melanie, parent of a child with dyspraxia and epilepsy

Making new friends

Following the diagnosis of your child, you will probably come into more contact with other parents of children with special needs. Among these parents, you may find individuals that you click with, where the talk is easy and the understanding mutual. Consider making new friends and be open to the possibility that your life can expand as it changes.

Dealing with specialists



Q U I C K T I P S

- *There are some ways of making the most out of a visit to a specialist:*
 - *write down a list of questions beforehand*
 - *audiotape the meeting (with permission) or take notes*
 - *ask the specialist to talk in language you can understand.*
- *Remember that you're an expert on your child too. Tell your specialist if what they say doesn't sound right for your child.*
- *Don't be afraid to ask questions.*
- *You may be able to choose a different specialist if you're not satisfied with one you see.*
- *It's a good idea to ask for copies of your child's reports.*

A specialist is someone who has a high level of knowledge and training in a specific area. Specialists who work in areas related to children and disability include:

Paediatricians:	child health and development
Speech pathologists:	speech
Neurologists:	brain function
Orthopaedic surgeons:	bones, muscles and movement
Ophthalmologists:	vision
Otolaryngologists:	ear, nose and throat
Gastroenterologists:	digestive tract
Urologists:	urinary tract
Endocrinologists:	function of hormones

Depending on the age of your child and their disability, you will become involved with one or more of these specialists during the early years of raising your child.

Getting the most out of your meetings

Your specialist can be an excellent source of information and advice about your child.

To get the most out of your meeting:

- write down a list of questions to ask
- request permission to record your meeting on a tape recorder
- take notes
- ask your specialist to explain in words that you understand.

Your list of questions

Prepare a list of questions that you would like your specialist to answer about your child. Take this with you to your appointment. Try to be assertive with your specialist and let them know that you have some questions or concerns about your child that you would like them to answer during your meeting. As appointment times with specialists can be quite short, ask your most important questions first, in case you run out of time.

Audiotaping and taking notes

Meetings with specialists can be quite intense. In a short period of time you get a lot of information and the answers to many of your questions. It can be helpful to record

your meeting in some way. Some specialists will allow you to take a tape recorder into your meeting. You can then listen to the tape when you get home and make notes about the information that was provided by the specialist.

If your specialist is not comfortable with this, take someone with you who can take notes. As a last resort, take notes yourself. Remember, it will be difficult enough to keep an eye on your child, participate in the conversation with your specialist and get some of your questions answered without having to write notes as well.

Understanding your specialist

Unfortunately, quite a few parents come away from a meeting with their specialist feeling a little overwhelmed and unsure of what the specialist has actually said.

These people are so knowledgeable and they are using all this language that you don't know and you think, oh my God, I don't know what they are talking about.

Rose, mother of a child with a chromosomal abnormality

Ask your specialist to speak to you using words that you can understand. If they drift off into complicated medical explanations during your meeting, ask them again.

Remember they are there to provide a service to you:

Demand your specialist talk to you. You can feel like you're pushed to the background and they'll tell you in a roundabout way what they're doing and what they intend. They don't explain it properly. Make them sit down and explain everything.

Melanie, mother of a child with dyspraxia and epilepsy

Working together: recognising your own expertise

Your specialist is an expert in your child's physical condition. You are the expert on your own child. Together you can work as a team. When you meet with your specialist, talk to them about your knowledge of your child. Let them know that you have come to them to get information that will help you to raise and care for your child.



When your specialist is talking with you, compare what they are saying against your own knowledge of your child. When you agree with them, let them know. When you disagree with something your specialist says or does, trust your instincts and speak up, even if it means challenging medical opinion.

I stood up to the medical specialists, disagreed with them on certain points. I knew my baby better than they did. They thought they knew more about my baby because they know more about the disease. This was not accurate.

Carly, mother of a child with chromosomal abnormality

You need to go in very focused and calm and explain your case. Keep explaining, saying no, that's not how it is, if they paint this picture that doesn't marry to what you're seeing.

Nicole, parent of a child with Smith-Magenis syndrome

Select the right specialist for you and your child

You have a choice about the specialists that you work with. A good specialist will provide you with expert information about your child's condition, disability or stage of development. A great specialist will also listen to what you have to say and consider your knowledge of your child:

We have got a really good rapport with our specialists and they really listen to what we've got to say. My husband and I will go to some together or I'll go on my own with her. If we see any changes in her, we let them know and then they'll take it on board, which is great. They see her once every six months, we see her every day and see the changes and what's going on, so they really do respect and trust us but we have to trust them as well.

Lee, mother of a child with spina bifida

If you are referred to a specialist that you don't like or feel that you cannot relate to, you can look for someone else. Talk to other parents about their experiences with different specialists. Ask other health professionals for their thoughts. When you find someone you like, let other parents know too.

Collecting reports

Each time you go to a specialist, ask the staff at the front desk to send you a copy of your child's reports. They may be required when you apply for funding, school entry, integration workers or other disability services. They can also help you to update new specialists and caseworkers that become involved with your child.

If you don't receive the report within a few days, contact the specialist's office and repeat your request and persist until you get what you are asking for.

Be annoying. Let them know that the easiest way to get rid of you is to give you what you want.

Melanie, parent of a child with dyspraxia

It can be a good idea to keep all of your child's records together in a secure location. See chapter 10 for tips on setting up a file for your child.

CHAPTER 9

Looking after yourself



QUICK TIPS

- *Caring for a special needs child is hard work. It's important to look after yourself too.*
- *Counselling might help you to deal with some of your feelings and give you strategies for dealing with stress and looking after yourself.*
- *Try to put some time aside for yourself each day, even briefly. Use that time for an interest you particularly enjoy.*
- *Every now and then pamper yourself a little, or a lot.*
- *When people offer to help, take up their offer. Suggest something that they could do that would help you.*
- *To help you stay positive at the end of each day, write down three positive things that you have experienced that day.*
- *Consider using respite care for support and to have a break.*
- *Try going to a parent support group. If you don't like one, try another.*

Why self-care is important

Caring for a child with special needs can be exhausting. It can require constant effort, daily management of very difficult behaviours and basic tasks such as eating, sleeping, toileting, bathing and dressing.

He can't get out of bed himself. So we've got to get him out, get him to the toilet, get him cleaned and dressed and have breakfast. At night he can't move in bed so if you lay him on his side he will stay on his side. So he wakes up a couple of times and asks to be turned. You've got to get up and he might do that two or three times a night.

Carole and Greg, parents of a child with arthrogyposis

You can tell a twelve year old perhaps, there's a hotpot on the stove, look when you cross the road, that's not how to treat a dog, or any things that occur. I don't want to say poor us but it's extraordinary the sort of things that we do and deal with minute by minute. It's constant vigilance.

John, parent of a child with cerebral palsy and moderate intellectual disability

During the daily care of your child, you will be organising services, dealing with your child's health and therapy needs, organising funding and developing strategies to help your child work towards the achievement of different goals. You will be doing all this while trying to balance the needs of other family members, run a household, and for some parents, work as well.

No wonder you feel tired.

Parents who do not care for themselves can be at risk of burnout. They can begin to feel overwhelmed by the demands placed upon them. Exhausted and increasingly negative, their ability to cope with stress will drop. They may find themselves yelling more, eating more or drinking more in an effort to cope. Sleep can become difficult and their relationships with their partner, children and friends can suffer.

If you run on a treadmill the whole time, eventually your body will give out and what you've got to do is learn to relax yourself, whether it's walking along a beach, I don't care what it is, you've got to find ways of relaxing.

Joelle, parent of two autistic children

How do you relax? How do you re-energise and resource yourself? What stops you from burning out?

Ideas for looking after yourself

Counselling

Many parents resist the idea of counselling. They feel that they should be able to cope on their own or that the support provided by their partner, family or friends should be enough. On the other hand, parents can also feel that they have to put on a brave face for the other people in their lives and find it difficult to explore or express the darker side of their feelings.

Counselling can provide parents with an outlet for difficult, heated, uncomfortable emotions. It can give them a safe place to explore some of their feelings about the changes brought into their lives by the birth of their special needs child. A counsellor can also help parents to manage stress, communicate, strengthen their relationships and protect their sense of self.

Counselling has been the best thing that I've done. It gives me an opportunity to talk about how I am feeling, helps my marriage by giving me strategies on how to start talking together, how to approach subjects that I am too scared to ask about. My counsellor encouraged me to stop worrying into the future, to deal with today, this week. That's what I do now.

Lee, mother of a child with spina bifida

Engage in hobbies and interests

Do you have any hobbies or interests? Make time for doing these things. Instead of flopping down on the couch at night, pull out your sketch pad or tie some fishing flies. Pull out that book you've been wanting to read, plan a creative project.

You may be reading this thinking that you are just too tired at the end of the day. Just try it and you may find that giving time to your own interests energises you when you least expect it.

Some parents find that they can make some time and space for a hobby or interest during the day:

I spend an hour every afternoon for me. I design clothes and do stuff like that. I set the hour aside and turn off the phone and do all sorts of things. I might set my child up doing something or give her just a piece of rest time where she doesn't have to do anything.

Sharon, parent of two children with autism

Think about setting aside some time for yourself as part of your daily routine. You can tell your child that this is mummy's time or daddy's time. If you take the same time each day, your child may gradually learn to give you this time as well. Children's videos can come into their own in this situation.

Some parents have hobbies or interests that take them out of the house. Look at your sources of formal and informal respite care. Commit to using some of your respite hours for yourself.

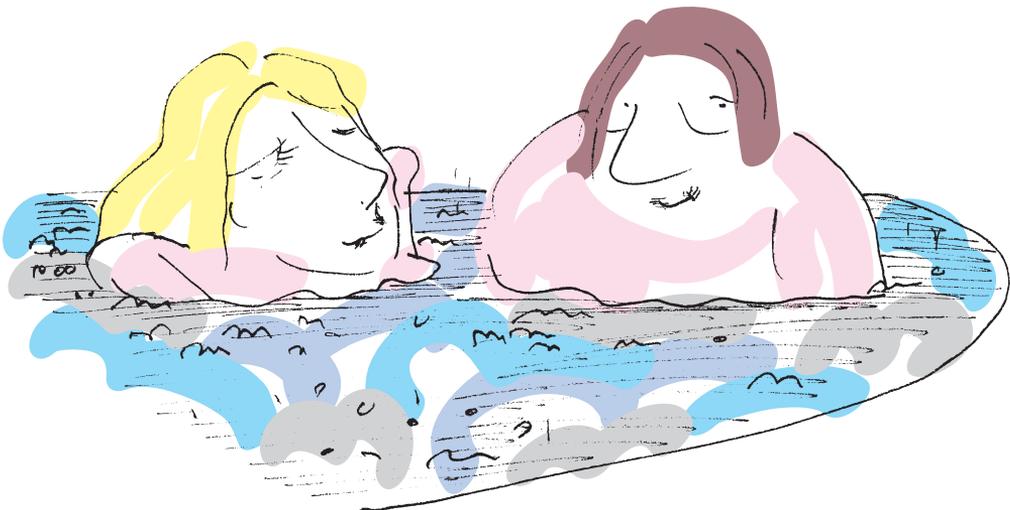
Pampering

Pampering yourself gives you a double bonus of time to yourself and a feeling that you are being rewarded. Look at the different things that you can do to pamper yourself. A visit to your hairdresser once a month, a massage, a bottle of wine with dinner, some great chocolate or an old favourite, the candlelit bath.

Pampering that involves some sort of bodywork can be especially good. Feelings of stress, tension and anxiety can be stored in your muscles, making you feel tight or sore. Massage and other therapies such as reflexology, bower therapy, rolfing or yoga can help you to release this stored up tension and relax.

Physical activities

Another way to release feelings of stress or tension is to burn them off. Get physical, get moving. Walk, swim, surf, play golf, dance or join a gym. Physical activity can be particularly good for parents who are feeling housebound with their special needs child.



Regular respite

Think about all of your sources of respite. These may include paid carers, friends and family members. Look at how you can organise these resources to obtain regular respite care.

Many parents find themselves using their respite care to devote time to other children or complete day-to-day tasks for the home. Consider devoting some of this time to yourself. It may feel a bit selfish or decadent at first, but you deserve it. You need to have some time for yourself.

Reflection

Some parents find it helpful to keep a journal. It can give them a place to express all of their feelings and reflect on their day. Others find that meditation helps them to stay calm and gives them a break from the chaos of day-to-day life. Meditation can also teach parents the benefits of detachment or stepping back.

When you are feeling highly stressed and frustrated, you can often find yourself responding through your emotions. This can mean yelling or reacting in the heat of the moment. Stepping back from the situation and taking a breath, can help you to look at things in a new light. It can allow you time to think as well as feel.

Self-affirmation

You are working hard and doing a great job. Remind yourself of this. Remember to acknowledge your talents, strengths and gifts. Allow yourself to enjoy the feeling you get when others compliment you on your strengths and skills.

Sharing your feelings

Try to be open with the people in your life about how you are feeling. Let them know about your hardships, frustrations and doubts, as well as the good parts of your day. When you open yourself to expressing how you feel, you are also allowing other people in. It can be a gateway to comfort, understanding and support.

Staying positive

Sometimes parents can get so caught up in the daily management of their child's disability, that they can lose sight of their child. Take note of your child's strengths, abilities and particular talents. Celebrate positive changes in your child's development and progress.

At the end of each day, write down three positive things that you have experienced that day. These might include a responsive smile from your child, a success on the road to managing a difficult behaviour or a piece of art work given to you by your child. They might include a caring comment from a friend, a remembered moment of laughter, a caring act from one of your other children or a breakthrough in your understanding or learning. They could include getting that job done that's been waiting on the backburner, getting the house in order or feeling the sun on your face when you stop for a moment and take a breath.

Try to fight negative thinking. One or two negative thoughts may pass. But negativity has a way of feeding itself. It can become a mindset that affects your mood and how you see the world. One mother was told about a simple technique that she has found very useful for limiting negative thoughts. It involves lollies. Every time you start to have a negative thought, grab a lolly and start to chew. While you are chewing, start to make a ribbon from the lolly wrapper. Tear it as finely as you can to make a long ribbon. When the ribbon is finished, force yourself to think about something else.

It wasn't that there was a Mintie, it was just that she'd given us a really concrete strategy for getting out of that pit. Over the next couple of months I used to chew a lot of Minties, but I got past the stage where I was thinking about it every hour and then I got past the stage where I was dwelling on it every day.

Katherine, parent to two children with autism

Take up offers of help

When friends ask you if there is anything they can do to help, say yes. Make up a list of things that friends could do that would help. This might include such things as cooking a couple of meals, doing some ironing, looking after one or more of your children, mowing the lawns or dropping books or videos back to the library. Take your friends' offers at face value. They want to help.

The value of study or part-time work

At times you can get so involved in being a parent and partner, that you begin to forget what it feels like to be you. Investing time in things that interest you, setting goals for yourself and taking on activities of your own provide you with opportunities to re-energise yourself.

Two ways in which you can put these ideas into practice include taking up a course of study or commencing part-time work:

I suppose my study is very much 'me' time and that probably helps me cope more than anything else.

Keely, parent of a child with autism

I think going back to work was really good because it takes your mind off your problems, it gives you more depth to your life and your lifestyle and your time, something else to do.

Abbey, parent of a child with a benign brain tumour

Time with your partner as a couple

If you are sharing the parenting of your child with your partner, try to make time to do things as a couple every now and then.

We have got an understanding with both sets of grandparents that we have two nights a year that we spend away from our children. One of them is my husband's work's Christmas party. We always go to that. We always stay overnight, we can let our hair down. The other time is our wedding anniversary. We always, always go out for our wedding anniversary. We always have that time on our own. I think that's fair.

Sharon, parent of two children with autism

My husband and I are rock and roll dance teachers, we got into the rock and roll, loved it. I know that every time I get out now if I'm teaching rock and roll or if I'm at a dance, my husband and I are usually together. It's time I've got invested in him away from the kids.

Peta, parent of a child with autism

Spending time alone with your partner can give both of you an opportunity to reconnect and touch base with the 'us' that existed before you became a family. It can also help you to recognise the 'us' that still exists in your everyday life.

Respite care

Respite care services exist to provide you with support and the opportunity to take much needed breaks. You can use respite care for a few hours at a time, whole days and overnight. Longer periods of time can also be arranged.

Respite care can take place:

- in your home
- in activity centres
- in residential respite care facilities
- on outings with your family or other groups of special needs children.

The decision to use respite care

For some parents, the decision to use respite care is simple and straightforward. They realise that they need help, they see that these services are available to them and they use them. For other parents, this decision is more difficult and emotional. They weigh the advantages that they will receive from the use of respite services against their fears that this experience will be emotionally harmful for their child. These parents think about what it is to be a parent and wonder if using respite care means that they may be letting their child down.

This conflict can be particularly strong for parents who are thinking about placing their child in residential respite for a weekend or longer.

I finally decided we needed to do something, that we needed space. I got the forms and the case manager of that area said, oh wow, this is a big step for you. I sat down one night to fill it out and I went to bed with a migraine and I wanted to physically vomit. I really felt that I was letting my son down, that I had failed as a mother. I was really paranoid that if this got out to human services they were coming to get him, that they'd deem that I'm a terrible mother and I've failed.

Lynne, parent of a child with cerebral palsy

Fortunately, most parents go on to discover that respite care is great for both parent and child.

When I am talking to others, I say the hardest part is organising it and doing it for the first couple of times. But you need it. It's wonderful once you've got it, you'll never let go of it.

Melissa, mother of two children with autism

Things to consider when making your decision

- A rested, refreshed parent is more fun to be around than a tired, stressed parent.
- Coping, problem solving and optimism are all easier to achieve when you are rested and refreshed.

- Your child has a right to develop relationships with other people.

Like any child, yours needs to form relationships with other people. You're not the only person on the earth that's going to enjoy your kid.

Carly, mother of a child with chromosomal abnormality

Introducing your child to respite care

Children can sometimes feel reluctant to go to a respite care centre, just as they can feel reluctant about starting kindergarten or school. Parents should not necessarily take this behaviour as a sign that their child is not ready for respite care.

Children tend to be wary of unfamiliar settings, particularly when they realise that mummy and daddy won't be there with them. They can express their concerns by saying 'I don't want to go, I want to stay with you', or clinging to you with a firm grip when you drop them off.

One way to combat your child's anxiety is to provide them with a gradual orientation to the centre.

Orientation to day care

Start off with a short visit to the centre with your child. Introduce your child to the centre staff. Ask them to introduce your child to one or two of the children who attend the centre. Spend some time playing with your child in the centre, and then leave.

The next time you visit the centre, follow the same process, staying for a longer period of time. Keep doing this until your child will move away from you and play independently with the toys and play equipment when you arrive. At this point, you can begin the other part of the orientation process by gradually leaving your child in the centre for longer periods of time.

Initially, take your child to the centre as you have been doing. Stay for half an hour, then announce you are leaving for a little while. Return in half an hour. Repeat this process until your child is comfortable seeing you go and feels secure in the respite setting. For some children, this outcome can be achieved within three or four weeks. For others, it can take a few months.

If you have tried a slow and gentle orientation to respite care and your child is still deeply upset by the experience, you may have to put respite care on the backburner for a while.

Preparing your child for longer stay respite

A social story can be a useful tool for parents who want to prepare their child for a weekend or a longer stay in respite care. Typically, a social story will consist of ten to fifteen statements relating to your child's stay in respite care. These statements will let your child know when they are going, how many nights they will be staying, what sort of things will happen, how their day will be organised and when and where you will pick them up. If possible, include pictures of the centre, your child and yourselves in the social story.

Social stories reduce your child's levels of anxiety and stress by making their approaching stay in respite familiar to them. It is important that their experience in the centre is the same or similar to what they have been lead to expect, so try to do some research before you write the story to make sure your statements regarding the timetables and activities of the respite centre are correct.

Read the story with your child regularly during the days leading up to their stay. Meet with the staff at the respite facility and ask them to continue reading the story to your child throughout their stay. One set of parents have shared their experience of using a social story with their son:

Judy made a little booklet and it set out a social story. It told him what date he was going and what day of the week it was, that he would sleep there, how many days and how many nights and the various things that he would do. He would be able to take all his Nintendo and Game Cube games with him and be able to play with them at night after school. It didn't say that he would enjoy it because if he didn't enjoy it then he would say, that's not true, that didn't happen. I didn't put anything in that wasn't actually going to happen.

I said he'd go each day from [the centre to school] not on the bus, he'd go with the workers. They'd take him and a friend and other children to school and then come home. He'd come home on Friday on the bus after school not to [the centre], but mum and dad would be waiting for him and they'd be very glad to see him.

We went over that with him and it was great. He understood so long as he knew when he was going and when we were coming back. We had to be back by the time we said otherwise it would be trouble, but he coped very well. They said he behaved very well, he was very good there. Previously, he didn't like [the centre], didn't want to go beyond about two days, but he went for about a week.

Colin and Judy, parents of a child with autism

For more detailed information on how to write a social story for your child, turn to chapter 2.

Working with care providers

Respite care workers will have experience in working with children with special needs. However, they will not have experience in working with your child. Make a time to meet with the carers who will be looking after your child. Talk to them about your child's likes and dislikes, talents, abilities and needs. Discuss the different rules that you put in place at home and whether or not you would like your child to have these continue in the respite setting.

Give the carers a rundown on some of the situations that may arise with your child and let them know how you would like them to deal with these situations. You may like to prepare a document for the carers that they can refer to while your child is with them.

Where to find respite care

Contact the following services to learn more about the respite care services that are available to you:

- Association for Children with a Disability
- Community Health Centres
- Disability Services
- Home and Community Care Program
- South West Access Network (now known as Mpower)
- Your local council
- Commonwealth Carer Respite Centre

You can find contact details in chapter 12.

Support groups

When you are raising a child with a disability, you need to have access to support, understanding and information. A parent support group has the potential to contribute to each of these needs.

A good support group will provide you with an opportunity to:

- meet other parents
- talk freely among people who understand and empathise
- share some of your experiences and feelings

- receive support and encouragement
- discuss relevant issues
- have a laugh
- pick up new strategies
- learn from the experiences of others.

I would say the most useful thing is talking to other parents. It helps you understand that you're doing the same things as other people, that you make the same mistakes but you're doing the same good thing, that other people are feeling the same things, angry sometimes or really sad or they resent their husbands or whatever it is.

Jo, parent of a child with epilepsy and intellectual disability

Support groups are affirming and people speak the same language and express the same degree of frustration with, for example, doctors or health services generally or other institutions and schools. Sometimes you come away with a different approach or strategy.

Michael, father of a child with cerebral palsy

It must be said that support groups are not for everyone. Some parents find it difficult to listen to the emotional and often traumatic stories of other group members, when they are already struggling to deal with their own. Other parents feel that support groups focus too much on the grief and anger and do not move on to adapting and being positive.

They tend to get hijacked by everyone that's got their favourite horror story of what little Freddy's done. Okay you've let out the steam, now get on with it. I don't think a lot of parents actually get past that. They use the previous behaviour as a justification for why they're tired and why they're like they are.

Julia, parent of a child with autism

Support groups can be a tremendous source of understanding, information and strength. If you have never gone to a support group before, give one a try. They may not be for everyone, but they might be right for you. Also, different groups will have different dynamics. If you don't enjoy your first experience with a support group, don't give up on the idea all together. With a bit of looking around, you may find a group that you like.

10 hot tips for staying cool

All parents will experience times when they have just had enough. They have exhausted their patience, their tolerance and their ability to clench their jaws. A volcanic eruption threatens.

Here are ten things that you can do when you want to run out of the house screaming:

1. Put on music and dance like no-one is watching.
2. Walk laps of the backyard (try a cartwheel when you have cooled off a bit).
3. Call Lifeline.
4. Sit on your front steps and cry.
5. Call a friend to come over.
6. Tackle the weeding, then pick some flowers.
7. Fold socks.
8. Climb a tree.
9. Jump on your child's trampoline.
10. Repeat the following: 'My child is pushing my buttons to get a reaction'.

Stop beating yourself up. You are doing a great job. You *can* cope. Take a moment to breathe. Revisit your strategies. Try something new.

Getting organised



Q U I C K T I P S

- *Planning and setting priorities will help you to get organised and stay that way.*
- *Write up and display the weekly schedule where all family members can see it.*
- *Set goals for all members of your family and plan how to achieve them. Small steps at a time will pave the way to success.*
- *Keep an information file for your child so you and others can always find information when it's needed.*
- *Have a list of telephone contacts handy and give it to other carers.*
- *Swap tips about getting organised with your friends and other parents of children with special needs*

It takes time to get organised. It can involve going through all of your cupboards and drawers to collect the bits and pieces of information that have been tucked away over time. It can require you to draw charts and reschedule your day-to-day tasks. It can prompt you to re-examine your goals and identify new priorities in your life. However, it is worth it.

There are many things that you can do to improve your feeling of being organised. Four suggestions that have been put forward by parents who are raising children with special needs include learning more about time management, setting goals, developing a telephone contact list for your child and organising the storage of information related to your child.

Time management

Getting to appointments, managing a house, going to work, playing with your child, shopping, banking, helping out at school, touching base with your partner, finding time for yourself—it is a juggling act that only multiplies when you have more than one child.

How do you fit it all in?

Set your priorities

Setting priorities requires you to look at the time and resources that you have available and to compare this with the list of things that you would like to achieve. When the number of tasks on your list exceeds the time and resources that are available to you, you must make some decisions about what you can and cannot do.

The first step in this process is to sort through the list of things that you want to achieve. Work out which items are 'must do', 'can do' and 'want to do'. Highest priority is given to the 'must do' items. When it comes to 'can do' tasks, try to give preference to those activities that will benefit your family the most. *Always* include at least one of the 'I really want to do' items in your priority list. Making time to do something that you really want to do, either for yourself or your family, will nourish you and make you feel good.

The second step in this process of setting priorities is to accept that you may not have the time or resources to do everything you want to do right now. Important things that do not make your immediate priority list can be put on the backburner until time and resources allow you to look at them again.

Every now and then, it is important to rethink the priority that you have given to different activities or tasks. Are your priorities still working for you? Are you satisfied with the choices you are making? If not, it might be time to rearrange your priorities.



Plan ahead

It's amazing how much stress is taken out of your life when you plan ahead.

Sharon, mother of two children with autism

Planning ahead is an essential part of effective time management. It can help you to save time and maintain a sense of order in your life.

Some practical tips for planning ahead

- Bath your children, make school lunches and iron clothes the night before. This can take some of the rush and stress out of getting ready in the morning.
- Plan a weekly menu and buy groceries in bulk.
- Make friends with your freezer. Prepare double-serve meals and freeze half for another night. You might like to set aside an afternoon for cooking once per week or fortnight, when you can prepare three or four evening meals at once.
- When scheduling more than one appointment for your child, try to arrange them on the same day or afternoon where possible.

- Plan ahead for major events such as Christmas and birthdays. This can involve putting money away each week, buying one or two gifts per month throughout the year, and cooking and freezing ahead.

Planning ahead for a health crisis

Parents who are raising children with special needs can be faced with very sudden changes in their child's health, which may require immediate, high level medical attention.

Although it can be impossible to predict these emergencies, parents can put plans in place to help them deal with a crisis when it happens.

- Develop a management plan. A sudden, severe crisis can cause high levels of stress, panic and confusion. It can be difficult to think clearly or make decisions, particularly when the crisis occurs during the middle of the night. It can be a great help to be able to grab a management plan, where some of the necessary thinking has already been done. Your plan should include:
 - a statement that clearly describes your child's disability
 - a list of the people who need to be called, and in what order
 - the name of your child's doctor and specialists
 - emergency telephone numbers, including the ambulance, hospital, and relatives and friends who can come at short notice to care for your other children.
- Meet with your specialists and emergency health professionals to develop a flowchart of procedures to be followed in different circumstances.

We decided then that we'd have a flowchart of procedures we would do under what circumstances. It's reviewed annually with our paediatrician and our specialist. It's current and so if our daughter goes in an ambulance without us, this document is handed over and the paramedics are authorised to fulfil that procedure straightaway. Every year we have a meeting with the ambulance service and review all that. There are medications on there that paramedics couldn't deliver, for example. Only MICA could. So we write it down and have a cover letter from our paediatrician so that paramedics could deliver medication that was needed.

Nicole, parent of a child with Smith-Magenis syndrome

- Review your management plan and flowchart after the health crisis. Was it effective? Could it be improved?

- Provide copies of the management plan and flowchart to family members and carers who look after your child.
- Write down your established home routines and keep copies in a place that can be located easily. If you are suddenly called away with your child, family, friends or carers will be able to locate the list and continue family routines (as much as possible) while you are away.

The Commonwealth Carers Resource Centre has an excellent emergency care kit that can be used to develop an emergency plan. If your child has a medical issue you could think about getting a Medi-alert bracelet from your chemist or ambulance service.

Know your schedule

Keeping track of your appointments and planned activities is important for effective time management. Some parents find it enough to keep a large diary or calendar for recording their various appointments. While this keeps the organising parent informed, it also leaves them with the daily responsibility of telling other family members about planned activities.

One strategy for making sure that the whole family is aware of their daily and weekly schedule, is to use a large wall chart. These charts can be a laminated piece of card with the days and times for a one week period:

Date:

	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
9am							
10am							
11am							

At the beginning of each week, write in the appointments or activities scheduled for that week. At the end of the week, wipe the board clean ready for the following week's schedule.

A suggestion made by one parent who uses this system, is to prepare laminated cards for regular appointments. These may include therapy sessions, visits to a health clinic, kinder or school, support groups or swimming lessons. These are stuck to the board with small Velcro spots that have been placed on various squares of the board.

Place your laminated board on a wall in easy view of the entire family and near the phone. In this way, you can make a quick visual check when planning appointment

times over the phone and everyone in the family can keep track of the planned events for the week.

Tips from the internet

The internet can be a good source of information about time management. A quick search can reveal a range of sites devoted to this topic.

Goal setting

Goals give us focus and direction. They give us a map of where we want to go and can shape the decisions that we will make in order to get there.

We made a series of six month plans and as each one approaches, we're pretty much off and running on the next period of time. The current one is running until the middle of next year at which time there may be some really dramatic changes which means we just make choices and dispose of or reconfigure the things that we have already.

John, parent of a child with cerebral palsy and moderate intellectual disability

Goals for each member of the family

Raising a child with special needs is, for most parents, exhausting and consuming. It can begin to feel as though your child sits at the centre of your family, drawing the majority of family time and resources. At the same time, less demanding and relatively healthy family members can feel pushed to the outer circle.

Setting goals for each member of the family as well as the family as a whole can help you and your partner feel there is some form of balanced perspective and forward planning.

We see our child as part of the family, not the focus of it, a special child, but no more special than any other member of the family.

Hope, mother of a child with Down syndrome

Goal setting exercises can help family communication and give you insight into the particular needs and hopes of each family member. It can also provide an opportunity for family members to have input into the changing life of the family.

Steps for setting and achieving goals

1. Decide on timelines for your goals. Some goals can be achieved in a few months, others can take much longer. As a general rule of thumb, it is a good idea to start with short-term goals, and move to the development of long-term goals when you are more practised.
2. Ask each member of the family to come up with one or two short-term goals. These should be realistic and achievable in six months or less. As a family or between parents, decide on a small number of family goals that can be achieved during this time period. This may involve some working out of priorities.
3. Break each goal down into a series of smaller sub-goals, then make a list of tasks required to achieve each sub-goal.
4. Record these tasks in your diary or on a goal sheet such as the one on the next page. While timelines can be hard to keep, they are an important part of achieving your goals. If nothing else, the process of breaking goals down, setting tasks and applying timelines can give you a clear and realistic idea of what needs to be done and how long it is going to take to do it. The desire to keep to a timeline can be a motivating force—particularly when working towards a long-term goal.
5. When planning large goals that consist of several sub-goals, you might find it helpful to record your goal setting activities on a 'goal record'. This is a table that has enough space for your goal, sub-goals, tasks and timelines. An example of a 'goal record' is provided on the next page.
6. Remember to consider respite and support services in your goal planning. They can help in terms of time, funding and useful information.
7. Check back on your goals and your progress every few months. At the end of the time period such as six months, hold a family meeting where everyone can review their goals and set new goals for the coming six months.

Example of a goal record

Goal	Sub-goal	Tasks	Timeline	Date to complete
Making the home escape proof	Decide on target areas to be secured	Go through the house and yard and look for possible escape routes. Talk to members of the family about escape routes they remember their brother or sister using.	1 week	
	Decide on a method for making each area secure	Find out about different methods of locking or securing areas in the home. Find out about methods for securing yards and outdoor spaces.	2 weeks	
	Decide who will do the work, you or a contractor	Identify the jobs to be done by yourself or a contractor.(You may choose to contract all or some of the jobs.)	2 days	
	Purchase the materials you need or make contact with a contractor	Make a list of materials that are needed and where to get them. Set time aside to buy needed materials. Make a list of the jobs to be done. Complete work on list. OR Make a list of possible contractors. Contact and ask for quotes. Decide on the contractor(s). Complete works as requested.	1 day 1 day 1 hour 3 weeks ½ day ½ day ½ day 1 week	
	Completion of job		5-7 weeks	

Set up an information file for your child

As you are no doubt aware, in a short period of time, it is possible to gather a lot of information and paperwork about your special needs child. Without a set plan for dealing with this information, it may end up in drawers, on shelves, in between the cookbooks or on top of the fridge (for a start). Finding the information when you need it can be frustrating and time consuming.

So where do you start?

1. Collect all of the information and paperwork that you have in regards to your child. Search in all the usual places, including bags, the car's glove box, the 'everything' drawer and that stack of papers near the phone.
2. Sort the information into different categories. These may include doctor and specialist reports, newsletters, forms and information related to school, Centrelink paperwork, information about funding opportunities, business cards and contact details of specialists and allied therapists, carer information and equipment suppliers.
3. Put each pile of papers into a separate, clearly-labelled manila folder.
4. Place all of the folders into a file drawer, cupboard or vertical file set aside for this purpose, or even a sturdy cardboard archive box. These are available from office suppliers for just a few dollars.
5. Once a month, check all of the usual places for information that may not have made it to the file.

Telephone contact list

You may find it useful to set up a telephone contact list that relates specifically to your child with special needs. We have provided an example on the next page that you may like to adapt to your particular needs.

Copies of the list, or parts of the list, can be given to teachers, carers, friends and extended family.

Contact list

Name _____ **Medicare no.** _____

Healthcare no. _____

Contact type	Contact person	Address	Telephone/ fax	Email	Notes
Emergency contacts					
Hospital emergency department					
Paediatrician/ doctor					
Early intervention					
Education			Session times		
Playgroup					
Kindergarten					
Primary school					
Noah's Ark Toy Library					
Family support					
Counsellor					
P.A.S.S.					
Support group					

Contact type	Contact person	Address	Telephone/ fax	Email	Notes
Health					
General practitioner					
Hospital children's department					
Health centre					
Maternal and child health nurse					
Specialists					
Paediatrician					
Neurologist					
Therapies					
Physiotherapy					
Speech therapy					
Medical supplies and equipment					
Orthotics department					
Chemist					

The things that make us strong



Q U I C K T I P S

- *A positive mindset can help you through the difficult days.*
- *Time-management skills may make life easier.*
- *Good communication skills are important.*
- *Being flexible will lower your stress levels.*
- *Supportive relationships with family and friends can assist.*

Thoughts from other parents

When asked to reflect on the things that made them strong, parents raising children with special needs offered the following thoughts:

- A positive mindset can help you through the difficult days:
 - have faith
 - realise that you can do this
 - love your child and believe in their rights with the knowledge that they did not ask for their condition
 - be persistent in exploring every avenue
 - practise resilience—the ability to bounce back after tough times
 - see the funny side (where possible)
- Time-management skills may make life easier:
 - be organised
 - plan ahead to avoid potential stressors
 - prioritise
 - stick to a routine
 - take it one day at a time
- Good communication skills are important:
 - practise patience and tolerance
 - don't take no for an answer
 - place a high value on feelings
- Being flexible will lower your stress levels:
 - think laterally
 - improvise when necessary
- Supportive relationships with family and friends can assist:
 - trust your partner to do their bit
 - recognise that your partner's skills complement your own
 - accept the help of supportive family and friends.

Few of us are born with these skills. Most of us learn them over time.

A final message to you

You are already successful.

You have learnt to cope with stress, exhaustion and endless obstacles.

Trust in your own abilities.

Learn whenever you have the chance.

Be inspired by the knowledge and experience of other parents around you.

Share what you know.



CHAPTER

12

Resources



Alphabetical list of services

This section provides a list of some of the resources that are available in the Geelong, Barwon and south-west Victorian region. These details were correct at the time of printing.

Agency	Description	Phone	Website
Arts Access	Arts and cultural activity for disadvantaged people and people with disabilities	9699 8299	www.artsaccess.com.au
Association for Children with a Disability	Information, advocacy and support for families of children with a disability	1800 654 013 Warrnambool 5561 39200 Geelong 5221 2984 Colac 5232 2001	www.acd.org.au
Attention Deficit Disorder Victoria	Services for people with Attention Deficit Disorder	1800 233 842	
Australian Drug Foundation	Information on alcohol and drug problems and prevention	1800 069 700	www.adf.org.au
Australian Hearing	Hearing services information	13 17 97	www.health.gov.au/hear
Australian Law Online	Family law hotline	1800 050 321	www.law.gov.au
Autism Victoria	Autism services information	9885 0533	www.autismvictoria.org.au
Autismhelp.info <i>(An initiative of Gateways Support Services)</i>	Website with information on autism		www.autismhelp.info
Barwon Disability Resource Council	Advocacy and information for people with a disability	5221 8011	www.bdrc.org.au
Barwon Family Resource Centre	Information, counselling and referral service	5243 0980	
Barwon Health	Hospital, rehabilitation, residential and community services	5226 7111	www.barwonhealth.org.au
Barwon Health Swanston Centre 24 hr crisis line	Services for people with mental health issues	5226 7410	

Agency	Description	Phone	Website
Barwon Health Paediatric and Adolescent Support Service (P.A.S.S.)	Counselling and support service for children, adolescents and families living with chronic illness and/or disability	5226 7204	
Barwon Primary Care Forum	An alliance of Barwon Region community and health services	5260 3610	www.barwonpcp.org.au
Barwon South West Carer Respite Centre	Carer respite service for Barwon South West region	5222 2477	
Bethany Family Support	Family counselling and referral	5278 8122	www.bethany.org.au
Better Health Channel	Community health information website		www.betterhealth.vic.gov.au
Better Hearing Australia	Services for people with hearing loss	5221 1042	
Brain Foundation Victoria	Support to people and families living with the effects of Acquired Brain Injury	1800 677 579	www.brainfoundation.org.au
Cancer Helpline	Telephone counselling service for people affected by cancer	13 11 20	www.cancervic.org.au
Care Ring Crisis Line	Telephone counselling service	13 61 69	
Carer Respite Centre	Respite information and assistance	1800 059 059	
Carer Resource Centre (Also Carers Victoria)	Information on carer issues and resources	1800 242 636 9650 9966	www.carersvic.org.au
Centacare Catholic Family Services	Family and counselling services	5221 7055	
CentreLink	Registration for financial and childcare assistance	13 27 17	
Child Care Access Hotline	Referral and listing of available child care services	1800 670 305	www.ncac.gov.au
Child Support Agency	Child support information and applications	13 12 72	
Children's Therapy Services	Therapy services for children with disabilities	5221 1078	

Agency	Description	Phone	Website
Citizen Advocacy	Advocacy and support service	5221 8033	
City of Greater Geelong Child Care	Geelong region Child care centres (see listing in Geelong white pages under City of Greater Geelong)		
City of Greater Geelong Community Child Health/Maternal Child Health	Geelong region Maternal and child health centres (see listing in Geelong white pages under City of Greater Geelong)		
City of Greater Geelong Disability Services	Information on services for people with disabilities in the Geelong region	5227 0270	
City of Greater Geelong Extended Care	Respite care service	5227 0721	
City of Greater Geelong Home Maintenance	Assistance with repairs for safety for eligible clients	5227 0722	
City of Greater Geelong Parenting Service	Website with parenting information and articles		www.geelongaustralia.com.au/parenting/parent.html
City of Greater Geelong Toy Libraries	Listing of local toy libraries	5227 0270	
Commonwealth Carers Resource Centre	Information on carer issues and resources	1800 242 636	www.carersvic.org.au
Commonwealth Carer Respite Centres	Respite care service	1800 059 059	
Community Centres in the yellow pages	Locally based health and community service		www.yellowpages.com.au
Community Connections (Vic) Ltd	Community information, services and programs available to families of children with disabilities	1300 361 680	www.comconnect.com.au/services
Community Friends of Red Cross	Volunteer visitors to carers for emotional support	5229 1564	
Community Health Centres in the yellow pages	Locally based health and community service		www.yellowpages.com.au

Agency	Description	Phone	Website
Community Health Centres	Locally based health and community services	Belmont 5260 3333 Corio 5273 2200 Newcomb 5260 3333 Surf Coast 5261 3001 Colac 5230 0180 Birregurra 5236 2000	
Continence Advisor	Information about continence issues and assistance	5260 3333	
Continence Helpline	Continence information	1800 330 066	www.contfound.org.au
Cystic Fibrosis Victoria	Information, advocacy and support for people with cystic fibrosis and their carers	9686 1811	www.cysticfibrosisvic.org.au
Cottage By The Sea	Respite care service	9813 0646	
Deaf Society	Services for people with hearing loss and deafness	5221 4100	www.vicdeaf.com.au
Department of Human Services (<i>Disability Services</i>)	Disability services of the Department of Human Services	Freecall 1800 675132 Barwon 5226 4540	www.dhs.vic.gov.au/ds
Department of Human Services (<i>Specialist Children's Services</i>)	Services for young children with disabilities or developmental concerns	Barwon 5226 4540 South West 5561 9444	www.dhs.vic.gov.au
Diabetes Australia–Victoria	Information and support for people with diabetes	1800 640 862	www.dav.org.au
Dieticians at Barwon Health Centres	Nutrition and healthy diet advisors at Geelong Community Centres	Belmont 5260 3333 Corio 5273 2200 Newcomb 5260 3333 Surf Coast 5261 3001	
Dieticians in yellow pages	Nutrition and healthy diet advisors		www.yellowpages.com.au

Agency	Description	Phone	Website
Disability Online	Website information for people with disabilities, their families and carers		www.disability.vic.gov.au
Disability Rights and Advocacy Service	Assistance for people with a disability who need someone to stand up for their rights	5221 8033	
Disability Services (<i>City of Greater Geelong</i>)	Services for people with a disability	5227 0270	
Down Syndrome Association	Support for people with Down Syndrome, their families and carers	9486 2377	www.dsav.asn.au
DPS Publishing	Residential Care information		www.dpspublishing.com.au
E PIC—Educational Programs for Infants and Children	Early childhood intervention service	Bundoora 9446 9022 Heatherton 9551 7960	
Epilepsy Foundation	Services for people with epilepsy	1300 852 853	
F inancial Information Service	Centrelink information on financial matters	13 23 00	
Fire	Emergency service	000	
G ateways Support Services Inc.	Barwon South Western region Disability services agency	5221 2984	www.gateways.com.au
Geelong Advertiser	Geelong newspaper	5227 4300	www.geelonginfo.com.au
Geelong Community Legal Service	Free community-based legal advice and resource service to disadvantaged residents	5221 4744	
Geelong Hospital	Acute and emergency care	5226 7111	
Geelong Kindergarten Association	Preschool group employer	5222 6965	www.gka.org.au
Glastonbury Child and Family Services	Support services for families	Colac 5231 4740 Geelong 5222 6911	
H eadway Victoria	Services to people living with acquired brain injury	9642 2411	www.headwayvictoria.org.au
Home and Community Care (<i>City of Greater Geelong</i>)	Assistance with housework and personal care	5227 0726	

Agency	Description	Phone	Website
Independent Living Centre	Display of products to assist people with disabilities in living at home, including Comtech—software and hardware, equipment hire and resource library	9362 6111 1800 686 533	www.yooralla.com.au
InfoXchange	Electronic services directory with news and events regarding disability		www.infoexchange.net.au
InfoXchange Australia Service Seeker	Statewide search facility for InfoXchange	9486 9355	www.vic.serviceseeker.com.au
Karingal	Support services for people with a disability	5229 3488	
Legal Aid	Assistance with legal representation		www.legalaid.vic.gov.au
Leisure Networks Association	Recreational opportunities for people with disabilities	5222 3911	
Libraries in the Yellow Pages	Public lending of book and audio visual resources		www.yellowpages.com.au
Lifeline	Crisis telephone counselling service	13 11 14	
Lifeworks	Telephone counselling service	5222 3172	
Local Council in the yellow pages	Local government		www.yellowpages.com.au
MacKillop Family Services (<i>Barwon</i>)	Family welfare agency and disability services	5278 9211	
Mental Illness Fellowship of Victoria	Support services for people with a mental illness	5229 8827	www.mifellowship.org
Mental Health Department	Mental Health Publications ordering contact number	1800 066 247	www.health.gov.au/hsdd/mentalhe
Migrant Resource Centre	Services for people from culturally and linguistically diverse communities	5221 6044	
Mood Disorders Group	Support services for people with a mental illness	5222 5999	
Motor Neurone Disease Association of Victoria	Support services for people with motor neurone disease	1800 806 632	www.mnd.asn.au

Agency	Description	Phone	Website
Mpower <i>(formerly South West Access Network)</i>	South West regional services and information to people with disabilities, families, carers and service providers	5561 8111	www.mpower.org.au
Multiple Sclerosis Society	Support services for people with multiple sclerosis	1800 287 367	www.msaustralia.org.au
Muscular Dystrophy Association	Information and assistance for people with muscular dystrophy and neuromuscular diseases	9370 0477 1800 656 MDA	www.mda.org.au
Neighbourhood Houses in the yellow pages	Local centres for adult education		www.yellowpages.com.au
NICAN	Information on recreation, tourism, sport and the arts for people with disabilities	1800 806 769	www.nican.com.au
Noah's Ark Inc.	Family resource & toy library	5229 5327	
Office of Hearing	Hearing aid information	1800 500 726	www.hearing.com.au
Office of Hearing Services	Information about hearing aids via teletext	1800 500 496 TTY	
Office of the Public Advocate	Information about powers of attorney and guardianship	1800 136 829	
ParaQuad Victoria	Support for paraplegics and quadriplegics	9415 1200	
Parent Line	Telephone counselling and advice for parents	13 22 89	
Pathways	Support for people with a mental illness	5229 8295	
Playgroup Victoria	Information on playgroup locations in Geelong region	5222 3263	
Physiotherapists in Barwon Health Centres	Assessment for mobility issues and aids in Geelong health centres	Belmont 5260 3333 Corio 5273 2200 Newcomb 5260 3333 Surf Coast 5261 3001	
Physiotherapists in Yellow Pages	Assessment for mobility issues and aid		www.yellowpages.com.au
Police	Emergency service	000	

Agency	Description	Phone	Website
Psychologists at Barwon Health	Counselling and psychological assessments	Belmont 5260 3333 Corio 5273 2200 Newcomb 5260 3333 Surf Coast 5261 3001	
Relationships Australia	Counselling service	1300 364 277	www.relationships.com.au
Respite South West	Internet site with information about respite issues for people living in South West Victoria	5561 8127	www.respitesouthwest.org.au
Scope Victoria	Information and support for people with physical and multiple disabilities (formerly Spastic Society of Victoria)	5221 5444	www.scopevic.org.au
Scope (Vic) Respite	Respite care service	5243 9180	
St Laurence Community Services (Barwon) Inc.	Case management for people with complex community care needs	5223 1111	
St Laurence Community Service Centre—Family Services	Family support services	5221 6128	
St Laurence Disability Services	Support services for people with a disability	5275 2665	
Spina Bifida Association of Victoria	Support services for people living with spina bifida	1800 686 533 9362 6111	www.sbav.org.au
STAR	Support and advocacy for people with intellectual disabilities	9650 2730	
Strengthening Parent Support Program	Parent advocacy and support services available through Gateways and Mpower	Barwon: Gateways 5221 2984 South West: Mpower 5561 8111	
SWAN (now known as Mpower)	Services and information to people in South West region with disabilities, families, carers and service providers	5561 8111	www.mpower.org.au
Taxi Directorate	Half-price taxi information	1800 638 802	

Agency	Description	Phone	Website
The Bouverie Centre	Counselling service	9376 9844	
V ery Special Kids	Victorian organisation that aims to improve the quality of life for families who have a child with a progressive life-threatening illness.	5224 2385	www.vsk.org.au
Victorian Aids and Equipment Program	Disability equipment availability and hire	1800 783 783	
Victorian Deaf Society	Services and information for the deaf		www.vicdeaf.com.au
Victorian Parenting Centre	Parenting advice and services	9639 4111	
Villamanta Legal Service	Free statewide community legal centre for people with disabilities	1800 014 111	www.villamanta.org.au
Vision Australia Foundation	Services for people who are blind or vision impaired	5221 4100	www.visionaustralia.org.au
Vision Information Line	Services for people who are blind or vision impaired	1800 331 000	
Volunteer Resource Centre	Training and placement of community volunteers	5221 1377	www.geelongvolunteer.org.au
W heelchair Sports Victoria	Sports club for people in wheelchairs who share a love of sport	9473 0133	www.wsv.org.au
Whole Woman	Women's health website—Barwon South West region		www.wholewoman.org.au
Y ellow pages	Phone directory		www.yellowpages.com.au
Yooralla	Services and assistance to Victorians living with a disability	9650 4077	www.yooralla.com.au
Yooralla Recreation Services	Recreation services and activities for people living with a disability	9607 3501	www.yooralla.com.au

Quick reference to counselling, respite and parent support services in Geelong and south western Victoria

Counselling services

Barwon Health	5273 2200
Bethany Family Support	5278 8122
Care Ring Crisis Line	13 61 69
Centacare Catholic Family Services	5221 7055
Lifeline	13 11 14
Lifeworks	5222 3172
Parent Line	13 22 89
Relationships Australia	1300 364 277

Respite care services

Barwon South West Carer Respite Centre	5222 2477
City of Greater Geelong Extended Care	5227 0721
Commonwealth Carer Respite Centres	1800 059 059
Mpower (<i>South West Access Network</i>)	5561 8111
Scope Respite	5243 9180

Parent support groups

For information on parent support groups in the region contact the Strengthening Parent Support Program at Gateways on 5221 2984 or Mpower (*Warrnambool*) on 1800 806 093

Parent advocacy

Association for Children with a Disability	1800 654 013
Barwon Disability Resource Council	5221 8011
Citizen Advocacy	5221 8033
Disability Rights and Advocacy Service	5221 8033

Other services

Schools

Barwon Valley Specialist School	5221 5444
Colac Specialist School	5231 1055
Hamilton Specialist School	5572 3077
Hampden Specialist School (Cobden)	5595 1995
Nelson's Park Specialist School	5278 3620
Portland Specialist School	5523 2218
Warrnambool Specialist School	5561 1711

Playgroups

Maternal and Child Health (City of Greater Geelong)	5227 0270
Child Care Access Hotline	1800 670 305
Playgroup Victoria	5222 3263

Written resources

<i>Emergency Care Kit</i> Commonwealth Carer Resource Centre	1800 242 636
<i>Hanging in there</i> Paediatric and Adolescent Support Service Barwon Health	5226 7204
<i>Helping You and Your Family</i> Association for Children with a Disability	1800 654 013
<i>School Holiday Survival Kit for Parents of Children and Adolescents with a Disability</i> MacKillop Family Services (Barwon)	5278 9211
<i>Through the Maze</i> Association for Children with a Disability	1800 654 013
<i>Who can I turn to?</i> Lifeline Geelong Inc.	5222 2255

Books recommended by parents

- Attwood, Tony & Wing, Linda (1988) *Asperger's Syndrome: A Guide for Parents and Professionals*, Jessica Kingsley Publishing.
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- Hoopman, Kathy (2003) *Haze: An Asperger Novel*, Jessica Kingsley Publishing.
- Meyer, D (ed) (1997) *Views from our Shoes: Growing up with a Brother or Sister with Special Needs*, Woodbine House.
- Rogers, Dale Evans (1992) *Angel Unaware*, Fleming H. Revell, a division of Baker Book House Co., Grand Rapids, Michigan USA.

Websites recommended by parents

www.flylady.com

Personal online coach for time and home management skills
(subscription required)

www.mugsy.org/wendy

Personal autism story located on the website of the National Autistic Society of Surrey, UK

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Parent to Parent

This guide will be a fantastic resource full of handy information.

I wish I'd had it when my child was first diagnosed

Julie, mother of a child with special needs

