

# You Are Not Alone

## A Carer's Journey

A guide on caring for children with disabilities from birth to six years

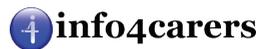


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## A Carer's Journey

We dedicate this book  
to our beautiful children  
Jaden and Jackson

'Our sons are our inspiration  
on our journey through life'

Michelle Rhodes and Tanya Dennis



## **You are Not Alone - A Carers Journey**

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# Real Love

You weren't like other children,  
And God was well aware,  
You'd need a caring family,  
With love enough to share.  
And so He sent you to us,  
And much to our surprise,  
You haven't been a challenge,  
But a blessing in disguise.  
Your winning smiles and laughter,  
The pleasures you impart,  
Far outweigh your special needs,  
And melt the coldest heart.  
We're proud that we've been chosen,  
To help you learn and grow,  
The joy that you have brought us,  
Is more than you can know.  
A precious gift from Heaven,  
A treasure from above,  
A child who's taught us many things,  
But most of all 'Real Love'

- Anon



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This book could not be completed without the support from our fellow carers and our family.

# Introduction

*You are Not Alone - A Carers Journey* is written by carers for carers.

As parents who care for children with disabilities, we felt compelled to compile our thoughts, ideas and experiences to help other families navigate their way through what can only be described as the 'maze' of disability services.

We have written *You are Not Alone - A Carers Journey* to provide guidance and advice to parents and carers centred on a child's early years, from birth to six years of age.

## **We want to help you and your family by:**

- Sharing information about other parents' and carers' personal stories and experiences
- Providing you with information and advice on services and support available
- Creating a website [info4carers.com](http://info4carers.com) from which you can download further information and find web links to access resources and services

We hope that *You are Not Alone - A Carers Journey* will be a reference guide for you during your journey as a carer. We do not assume that you need all the information that this book contains, but we hope that you can select the information that is most helpful to you and your family. We hope that this book will help make your journey a little easier.

*Note: Information provided in this book regarding services, support and resources applies to the state of Queensland only.*



# Dealing with diagnosis

## A mother's intuition

*The measure of love is to love without measure.*

- Saint Augustine

The ways in which parents learn that there is an issue with their child varies as widely as the disabilities themselves. Some know immediately that something is not 'right' while others may not realise this for several years. The latter can occur when an apparently healthy child is the first-born to a family, so there is no sibling with whom to compare progress.

It was 'mother's intuition' that led one of the parents who contacted us to realise her son was not reaching what she called the 'normal' milestones of rolling over

or sitting up, so she sensibly sought professional advice.

Another mother had a perfectly natural full-term birth and thought all was well. A few days later without warning her son turned blue with a seizure, the precursor to years of intensive treatment.

In another case, a mother was told immediately that her premature baby had irreversible brain damage and to take him home and love him. Six years later, the parents still do not know the full extent of his complex disability.

In every case, we have found that the knowledge that 'they are not alone' is a source of both comfort and practical help to these families as they face their carers' journeys.

## Andrew's story

Andrew was born prematurely in December 2003 at 30 weeks. He was diagnosed three weeks later with cerebral palsy and that was the day our lives changed forever.

From doctors to specialists and therapists – there was always someone for us to see.

Andrew cannot walk, talk or feed himself, but he always seems to communicate what he wants with looks, grunts and smiles. We are forever grateful for all that Andrew has taught us including patience, laughter, happiness, sorrow and strength – the list is endless.

We never dared to dream that Andrew would ever go to any school but now he goes to school at Xavier Conductive Education in Brisbane – and he loves it.

Andrew has a younger brother, Anthony, who was born in 2006. He has only known his brother with cerebral palsy so takes him as he is. I constantly wish that others would or could do the same.



Always follow your feelings as you embark on this special journey and remember, if something does not feel right – it probably is not.

You may sometimes be tired and lonely but you will make many new friends along the way. You will begin to seek information from these new friends, as they are going through the same journey as you. You share experiences that not even your family can completely understand - but that is okay.

No-one will ever really know what you are going through and patience is something you will suddenly have in abundance. You are your child's voice so never be afraid to speak up for him or her.

# Understanding your child

## Pre-diagnosis

A parent or carer is so familiar with their child that it is not surprising that they are usually the first to realise that something is not right. Take note of the 'gut feeling' and intuition that you feel, as they are

powerful tools that will aid you to get a diagnosis for your child. If you find it hard to find the right words to share your worries, you can contact service providers who can help and guide you but keep trying until you find what you need: don't give up.

You may feel a whole range of emotions throughout this process, and these feelings may come and go or you may grapple with them for a long period of time. Some of these emotions may be: blame, anger, confusion, grief, loss, shame, hope, isolation, exhaustion, relief and a copious amount of others. You have every right to be emotional as it is a very emotional time.

## Tips to help deal with diagnosis

- Keep a record of information regarding any issues that you notice about your child. This could be as simple as a notebook or diary in which you detail the types of behaviour that is concerning you. You may notice developmental, health, dietary, emotional and behavioural issues. Record the date, time, length, nature of behaviour and anything that you think could have brought on this behaviour. The brilliance of this tool is that you can have it on hand when you are at an appointment with a specialist or your general practitioner (GP). It makes it easy to share information, as all you have to do is pass over your records and it is all there for them to see. It can be a very valuable device on the road to getting a diagnosis.
- Have both you and your partner at appointment times, as it is important for both parents to feel equally involved in the process of diagnosis. You can both be briefed by the health care professional at the same time

and you can ask questions there and then. This is an ideal situation; however, it is not always possible. If you have to go without your partner or you are a single parent, it is a good idea to take along someone you are comfortable with to lend support.

- Build a strong support system around you. This can include family, friends, service providers, allied health practitioners and medical professionals. The important thing about those you choose is that they know the needs of your family and are available to support you through the process.

Unfortunately, you may not receive a diagnosis of your child's symptoms or behaviours straight away. Please be patient. It could take many tests and examinations before a child receives a diagnosis, if they do at all.



## Post-diagnosis

It is quite normal to feel a roller-coaster of emotions after a diagnosis has been made. These could include: fear, denial, anger, devastation, vulnerability and desperation. You may feel a sense of relief and this could be because the diagnosis represents an 'answer' to the questions that you asked health practitioners about your child. Or you may feel validated that the diagnosis of your child's condition is one that you suspected all along. You may also have feelings of grief as you mourn the dreams and expectations that you had for your child prior to their diagnosis.

- There is no right or wrong way to cope with a diagnosis and the way to do so is different for every person. This can cause friction between couples and families. It can be beneficial to seek support and advice from friends or professionals at this time. Just finding out the different ways that men and women react to complex matters can help.
- You may receive a wide range of reactions when you share the news of your child's diagnosis with your

friends and family members. While they may empathise with you, they may not be able to show empathy. Don't be surprised if some people don't know what to do or say and some may just do nothing, which may disappoint you. Some may deny the diagnosis and some will tell you stories of others they know or of celebrities who have received the same diagnosis. While they mean well, you have every right to tell them, 'Thank you but not right now', if you're feeling overwhelmed. There will also be those you will want to surround yourself with and those that will just be there with you, cry with you and just let you talk when you feel the need.

- Just remember, diagnosis or not, your child is amazing so celebrate every achievement, big or small. While it can be hard to stay positive all the time and there will be powerful emotions that come with having a child with a disability, there is still an abundance of happiness, joy, wonder, admiration and pleasure that your family will experience.

## Joanna's story

Already dealing with the fact that her son had cerebral palsy, Joanna was devastated to learn that he also had PPD-NOS (a form of autism). She went into grief, then shock and numbness, until she took the time to have a peaceful walk with her dog. This helped to clear her mind and allowed her breathing space to start to plan for the future. Respite is essential, Joanna says, and appointments with a counsellor

proved to be a blessing. Further down the track, after she had researched services and therapies, Joanna says she is blessed to have a wonderful son.

“He can do fabulous things and our bond becomes stronger by the day.

“Once we understand why our kids do what they do, we can find out how to empower them to be the best they can be.”

## Lisa's story

Lisa already had a two-year son when Jorge was born with a congenital brain abnormality and chronic epilepsy. Lisa recalls that the shock ‘rocked their world and she was crippled with feelings of resentment and inadequacy as a carer’. A year later a daughter was born, giving her three children with 37 months between them. When, 10 weeks later, her husband was sent to serve in East Timor for six months, she says she does not know how she managed.

She had run out of energy and felt she was starting to fail. Getting three young children in and out of the car several times a day in order to meet with the many therapists, as well as meet all their other needs, was just too much and depression set in.

At that point, Lisa knew she had to get help. She undertook a seven-day course endorsed by the Australian Depression Institute and this, she says, saved her life.

That week away, while her husband coped at home, taught her to appreciate the value of all experiences without labelling them good or bad, to recognise depressive thoughts and how to neutralise them.

Although Jorge's still has far to go on his journey, Lisa says she is no longer scared and is confident that she does her best every day. She offers this message to everyone in similar circumstances:

“To all of you Mums out there reading these words, I wish you all an abundance of love and light in your life. Be kind to yourselves! Do not be afraid to ask for help and, if you start to sink, grab a life raft. It does not have to be a week away with intensive therapy – it could be a bottle of wine and a really good friend who can listen.

“I don't know about you, but already my beautiful son has taught me more than I could possibly hope to teach him.”



# Adjusting to your child's disability

## Professional support

You may feel overwhelmed and exhausted being a carer and it's important to talk things through with a professional at some stage. Here are some definitions of the professionals you might consult and how they may be able to help you.

### **Counsellor**

A counsellor is someone who will listen impartially to you and can help make a difference to your life and your role as a carer. With a counsellor, you are in a safe, supportive environment, where you can talk freely and openly in a way that is rarely possible with friends or family.

Counselling does not involve giving advice or directing you to take a particular

course of action. Counsellors do not judge or exploit their clients in any way. You can attend one-on-one counselling, family counselling or group counselling sessions.

Remember, you can discuss any issue or topic you choose, such as anger, frustration, anxiety, depression, stress management, grief and loss, emotional support, coping skills, practical problem-solving techniques, health and wellbeing.

### **Social worker**

A social worker can help you in your role as a carer to better manage your daily, family or work life and help you to access government, social, health and other support services. A social worker can provide counselling support to help you with stress management, problem

solving, developing coping skills and help you to better achieve your goals and aspirations in life.

### **Psychologist**

A psychologist is an expert in human behaviour. Their treatments are based on changing behaviour and emotional responses without medication, in order to reduce distress and to enhance and promote emotional wellbeing. Psychologists can help you to better manage your emotions, thinking and behaviour. They also help people with mental health problems, such as anxiety,

depression, serious and enduring mental illness, addictive behaviours and childhood behavioural disorders.

### **Psychiatrist**

A psychiatrist is a medical practitioner who specialises in the prevention, diagnosis and treatment of mental illness. Extensive medical training enables the psychiatrist to understand the body's functions and the complex relationship between emotional illness and other medical illnesses. Psychiatrists can prescribe medication as well as utilising other forms of therapy.

## **A parent's story**

It wasn't apparent from the early months that there was anything amiss with our lovely little daughter. She slept a lot. I was revelling in my supremacy and how beautifully sorted my life was. I had worked hard during my twenties to establish my career; I had a brilliant job-share position, a good partner, good house.

Then my beautiful girl started to cry, and cry, and cry. We were quickly swept off into a daunting world of hospitals and specialist appointments: electroencephalograms (EEGs), magnetic resonance imaging (MRIs) and seizures. I was getting very little sleep; her big sister, all of two was not coping very well. The news kept getting worse and worse. "She is going to need a gastronomy tube and be fed through her belly," the doctor explained. That was hard to take. "Her condition is progressive."

We experienced many hospitalisations. Very dark thoughts circulated through my mind. I'd often find myself waking at 3am, to have a quiet, lonely sob. One morning, everything just seemed OK. I thought to myself, "Is this going to be my life?", and I answered "NO!" and I stopped crying. Then my daughter's seizure medication got sorted and she stopped crying. I sought help from a counsellor, and had my daughter's medication reassessed. I had avoided doing this because of some insane sense of personal pride.

Time has passed, my beautiful daughter has gained health and I truly feel blessed with this angel. I still have cycles of grief, but it seems easier to get through them.



## Loss and grief

The loss you may experience is real:

- Your child may be suffering from loss of health or frequent hospitalisations.
- You may lose your sense of self and being an individual. You may also lose your independence, privacy and time for yourself.
- You may miss out on employment and career opportunities and your financial security may be affected.
- You may have a sense of loss for the future you originally envisioned for your child and family.
- Siblings in the family may be experiencing grief and loss.
- You may have mixed feelings about being a carer and feel resentful about the changes in your life. These are normal feelings and reactions.

Grief is a natural response to a painful loss. It is not an illness. It is as much a part of emotional life as joy. Grief occurs not only through death. The immediate changes in your life and relationships that your child with a disability brings may be very frightening and stressful.

## How we grieve

It is important to recognise that we all respond to grief in our own way - men and women, different cultures, different inner beliefs. What is shared is the element of pain and suffering. Find compassion, for your child, for yourself. If you are grieving you may feel sick as well as emotionally upset. The different ways in which people respond to their situation

can sometimes cause tension between partners, other family members and friends. Seeking advice and support at this time can benefit all family members.

## Suppressed grief

Suppressing grief can lead to physical and emotional illness and these symptoms won't go away without the underlying grief being addressed. Even though it is important for you to take as long as necessary to learn to manage your grief, it is important to recognise when you need help and not be afraid to ask for it.

When you are grieving, you need support, patience, understanding and the opportunity to talk about your feelings of loss with others.

## Living grief and sorrow

Some parents and carers of children with disabilities may experience grief or feelings of loss at times throughout the entire lifetime of their children. This situation is known as 'living grief'. You may be constantly facing different circumstances or new events. You may feel this grief more acutely at the points of transition in your child's life. It is important to recognise that this is a normal phenomenon and that it is important to prepare yourself in advance for these transitional times.

## Stages of grief

Grief affects everyone differently. Listed below are the stages of grief that you

## Kelly's story

With two young autistic boys and seemingly endless futile battles to get help for them, it is little wonder that Kelly felt frustrated and emotionally distraught. She knew they could not be cured but found there was always hope.

Her turning point came when she resolved to educate herself about autism and found many opportunities to further

her children's development at home. Early intervention tailored specifically to each boy's needs included sign language, homemade visual aids, rhymes and music. All of these helped the boys reach learning milestones they had missed due to the unique challenges they faced.

"Autism is the road less travelled", says Kelly. "It has paths that bend unexpectedly but learning to anticipate them can make the journey less bumpy."

may experience and some suggestions to help you recognise and move through the grief process. The order in which you may experience these stages is not important; what is important is that you allow yourself to acknowledge and accept what you are feeling. Allow the process of grief to proceed and each stage will become further and further apart and become less and less intense.

### **Shock and denial**

In the first days after a major loss you may feel stunned, shocked and overwhelmed. You may feel frozen or hysterical. You may find it difficult to accept your loss and may find it hard to remember certain details of each day. All of what you experience is a way to give you time to adjust. What is significant about this stage is that shock and denial may happen without you being aware.

### **Anger**

Anger, frequently coupled with a sense of injustice, is a common reaction to loss and is often very intense. Anger can be directed at the lack of support from your

own family. You may become angry with God. You may feel that you are left to deal with situations on your own. Remember that people who don't give you support may be driven by other issues.

Anger is not wrong but if the feelings lead to destructive, damaging or violent behaviour, then it is the behaviour that is wrong not the feeling. Often we are angry at others and will try to find someone to blame for what has happened.

Yet, most commonly people direct anger at themselves and a feeling of guilt is the result. The 'if only' game may lead to feelings of guilt and anger at yourself. If unresolved, these feelings may become very unhealthy and lead to prolonged depression.

### **Bargaining and minimising**

Often when you go through the grieving process, emotions can be so intense that you can slip back into denial by entering into a bargaining agreement to minimise your pain. You may say things like: "If I keep busy my sadness will go away".

It is important to focus on the facts and not justify what happened. It is not necessary to know why it is, nor is it important to know exactly what has happened, just give the feelings associated some expression.

### **Despair**

It is common to sometimes feel overwhelmed by the anguish, pain and hurt of your loss. This could include uncontrollable crying, spells of deep silence, morose thinking and deep melancholy. Feelings of guilt, remorse, loss of hope and loss of faith and trust are also common.

You may need support to help you gain a different outlook during this time. Sometimes if people can't work through their feelings of despair, they may experience depressive thoughts and these can at times include ideas about harming themselves.

### **Acceptance**

There may come a time that you feel that you are reconciled with your situation and your loss. You may begin to reach a level of awareness and understanding about your loss. You can describe how you feel and problem-solve the issues involved in coping with your loss. You can also discuss your feelings with others and this assists you to handle your situation better.

You will begin to think rationally, and will begin to adapt to your current situation. Hopefully, you will be able to handle your situation with patience and self-confidence. Remember, you can start to accept your situation but still experience denial, bargaining, anger and despair.



You may need support from others to gain objectivity and clarity of thinking in order to reach the point of full acceptance. Those who have experienced similar losses can be a positive support during this time.

## **Gender differences**

There are a number of biological and social influences that may contribute to the different reactions of men and women when they experience grief. These influences can lead to men and women having different needs, wants and expectations and we can find our relationships struggling at a time when we need each other most.

In our society when faced with loss, men are generally considered to be stoic and strong and women are seen as nurturing and emotional.

By gaining a greater understanding of these differences, we may find there

is less conflict in our relationships and we are better able to support and be supported in times of loss and grief.

## Tips for moving on

- Only you can decide to move on with your life. Remember, grief may be lessened with acceptance.
- Instead of looking only at the negatives, use it as an opportunity to grow. You can either stay with negativity and drown or use it as a positive way to grow. Yet be patient and kind to yourself, it may take time.
- Alcohol and prescription drugs may prolong the grieving period.
- Remember, try to have balance in your life.
- Make time for yourself through meditation. Your brain needs to come to terms with your situation and your body is dealing with a lot.
- Exercise may help to lift your mood.
- Deep breathing or writing in a journal are safe ways to release angry feelings, blame or resentment.
- Try self help books and daily positive phrases and affirmations.
- Crying can be a great release – but beware as it can also become a habit.
- Seek help, speak to a friend or seek help from a professional counsellor.
- Start a new circle of friends through parents of other children with disabilities. Seek out people who can empathise with what you are going through.
- Attain the skills to learn to manage and deal with your situation. Understand the support you get may be different from what you expect.

## Angel MiMi

She was here at last a Granddaughter; it's a girl how lucky are we. We were full of joy and beside ourselves with glee.

Then the news came through, not everything is right. How anxious we were all through the night.

So many things had gone so bad. For weeks the news was nothing but sad.

Our hearts were broken for her mum and dad. Such brave young people for the problems they had.

Our darling baby Mia came home hospital free. A special little person she turned out to be.

So special to us who could see through her smile. In our hearts we just knew she would stay just a while.

Mi Mi was taken by the Angels when she was just four. We miss her but will remember her in our hearts forever more.

She was like a little Rose bud that could only bloom in heaven. We thank God for lending her to us and the time we were given.

The ache in our hearts will forever stay.  
The tears in our eyes we can wipe away.

*Helen Gray, Great Grandparent to  
Baby Mia (MiMi) Never Forgotten*



## Tommy's story

The heart-warming story of Tommy will resonate with everyone who has a child or cares for a child with a disability, from the shock, worry and grief experienced by the parents and the ultimate acceptance and understanding that provides hope – and moments of joy – for this family.

Tommy was born in April 2009 with IP36 Deletion Syndrome. The condition causes hypotonia (a floppy body), developmental delay, seizures, heart condition, inability to feed orally as well as hearing and vision impairment. His parents say nothing could have prepared them for this experience and that the grief that consumed them made them feel completely isolated from the world. But help was at hand in the form of a wonderful counsellor who had found them in the hospital.

“He helped us share our emotions and begin to understand that what we were feeling was actually grief. I often tell people that I am not sure how we would have got through those early weeks without this help and we realise how vital it is for anyone in a similar situation to talk to a professional very early on,” said Tommy’s mum Natalie.

Natalie, worried that she did not experience the love for her new baby she felt was normal, nor could she bond with him properly because he was so fragile - and both feelings made her feel guilty.

After a year, things improved dramatically. Talking frequently and opening her heart to sisters and girlfriends about her innermost fears proved a saviour and she

has experienced moments of pure joy.

“Every time Tommy meets a small milestone, we feel it is like Christmas and his fleeting smiles and giggles make every struggle worthwhile. The realisation that my baby was normal inside and has needs and emotions like any other baby was life-changing for me,” said Natalie.

“The grief has not gone away and the pain I feel at the loss of ‘normal’ is still strong – but it is easing. I have two wonderful little boys and a loving supportive husband. I count my blessings every day and realise that the early problems were all part of my journey to get to where I am today.”

Both parents admit that while no-one chooses to travel down the path of having a child with a disability, they feel they have learnt so much in a short time.

“The human spirit and the will to live are strong - even in a tiny boy who fights the odds every day. The kindness and support of strangers is overwhelming and we have really started to take notice of the little things that make life special,” said Natalie.

“Tommy may never crawl or sit up unaided or walk or talk – but maybe he will – and that is what we are working towards.”



## Dealing with the general public

*To speak or not to speak?*

*If it is not truthful and not helpful, don't say it. If it is truthful and not helpful, don't say it. If it is not truthful and helpful, don't say it. If it is both truthful and helpful – wait for the right time.*

- Buddhist Quote

Having a child with a disability of any kind can be challenging, and many people do not realise how thoughtless behaviour and comments can be hurtful.

One father wrote to us after his wife had been desperately upset by an acquaintance who asked, “Why does your daughter fall over so much?”

This little girl had already endured more than most people experience in a lifetime. Born with a condition that attacked her central nervous system, she also had a major brain bleed which necessitated surgery... the first of many serious procedures.

Four years of love and care saw this little girl take her first steps in a walking frame, and then two years later, without it. Knowing this background, that hurtful, insensitive question should have been rephrased as, “How wonderful that she is able to walk at all!”

The lesson for all of us is to say nothing unless we are familiar with the trials and tribulations of those that we are speaking to and to remember that a smile and a kind word can work wonders.



Many people do not really understand disability; they stare out of curiosity and ask questions that can be very direct and hurtful.

***Strength and unconditional love will guide you through difficult times. Hold your head up high and know that the love you share with your children will make all this worthwhile.***

Find the strength to educate others but keep your advice short and don't get emotional about your child. Always remember that our children can feel and hear what we are saying so it is important to keep their feelings in mind. Smile and reassure others that everything is all right, even when you really want to run away and scream at them!

Here are a few tips to help you deal with the general public:

- Be positive about your child.
- Don't dwell on the negatives and keep conversations short.
- Even if people are interested, it is always up to you to decide how much information to share with them.
- Never feel you need to explain your journey at all if you do not feel comfortable about it.
- Surround yourself with family and friends who understand you.



## Family dynamics

Balancing your needs as an individual, the needs of your marriage or partnership and the needs of your child can be a juggle, especially in the beginning. How well your family adjusts to having a child with a disability depends largely on yourself as a parent or carer. Children, other family members and friends all follow the parents' or carers' way of behaving and interacting with the child.

Having a child with a disability can put a great deal of stress on a marriage and family life. To begin with, there is the financial burden of having to pay for treatments and special equipment, there is the physical stress of moving and

feeding your child as they grow and of course the sheer emotional day-to-day issues of having a child with a disability. These continual demands may erode the time you spend with your spouse and other children, and can also diminish the amount of free time you have for yourself.

Some marriages, as Michelle's (opposite), grow stronger as a result of these shared stresses, while others break apart. It is almost impossible to predict how having a child with disability will affect a marriage, as each partnership is unique. It's vital to seek counselling if your relationship or family life is not coping under the stresses that you are facing.

## Michelle's story

In the first few years of dealing with our son's disability, my husband and I wanted to be physiotherapists, speech pathologists, occupational therapists, doctors and surgeons all rolled into one. We worked tirelessly and continuously wanting his cerebral palsy to get magically better.

Eventually, we realised how important it was for us to be parents first and therapists second and how our son wanted that too. We needed to show him that we loved him unconditionally, and accepted him for who he was and not measured him for what he couldn't do but rather for what he could do.

In order for us to be better parents, we had to nurture our relationship by spending more time together.

You can quite easily become so caught up in the needs of your child that you can start ignoring your partner and your marriage. Keeping your relationship strong and happy is one of the most important supports you can give your child.

Right from the diagnosis, we knew we had to face a challenging situation together. We decided to embrace the disability and work as a team.

To help each other, we would often ask what we could do to make a situation easier. Here are some of the things we do to enable us to handle our relationship and our child's disability:

- Make time for each other by spending a night out once a fortnight when we have a carer.
- Spend two or three weekends away together each year.
- Take turns spending time with our son on the weekends to enable the other parent to do duties or have a break.
- Find parents going through similar situations and have a catch-up.
- Give each other support by attending medical or therapy appointments together.

As time goes on, we are finding that our lives and our marriage have been greatly enriched by tackling all the challenges together with our son.

## Siblings

### **Understanding the needs of siblings**

When you have a child with a disability, you may find it challenging to meet the needs of all members of your family. And of course, you may also be dealing with a range of mixed emotions about the changes that have occurred in your family.

It is important to remember that your child's siblings will also have a mix of feelings and experiences. They may not have the understanding and emotional maturity to deal with what is happening around them. Their adjustment will be greatly influenced by the reactions of other people.



Siblings are likely to have the longest relationship of anyone with your child. If siblings are supported, they are more likely to develop stronger self-esteem and feel more able to deal with their experiences. They are likely to be more compassionate, tolerant of differences and more responsible. If every member of your family is supported, family connections will be stronger.

The information detailed here is based on Siblings Australia's contact with a large number of siblings, parents and service providers around Australia and overseas.

### Concerns of siblings

Brothers and sisters of children with disabilities may grow up in a situation of considerable stress. As a result they may:

- Lack understanding about the disability or illness.
- Have various fears and anxieties.
- Feel isolated.
- Feel resentment if a brother or sister receives more attention or is allowed to behave in ways they're not.
- Be embarrassed about their brother's or sister's appearance or behaviour.

- Experience shame about negative feelings.
- Feel they need to achieve, to be the 'good child'.
- Feel guilt over their own abilities and successes.
- Feel they have extra responsibilities.
- Have concerns about the future.

In order to better manage their family situation, siblings need:

- Information about their brother's or sister's disability.
- Opportunities to express their feelings.
- To feel special themselves.
- To feel competent and valued.
- Strategies to deal with difficult situations.
- Contact with siblings in similar situations.
- Social support.

### How can I help my children?

Many factors affect how a sibling adjusts. However, children's reactions are most influenced by the responses of people around them, especially you as a parent. In order to support your children try to:

- Find support for you and your family, both emotional and practical.
- Attend a parenting workshop run through Siblings Australia, Cerebral Palsy League or a relevant local group.
- Give children information about all aspects of the disability.



## Jessica's story

Dylan's loving parents did all they could to ensure that big sister, Jessica, aged two, would never be jealous of her new baby brother, even to the point of getting her her own baby doll to look after!

It all worked well for three weeks until Dylan started to experience major seizures, congestive heart failure and much more. By the age of 18 months, Dylan had been hospitalised 18 times and by the time he turned eight, this number increased to 40 and he had undergone eight surgical procedures.

This tough, ongoing situation was not only unsettling and broke all routines but also created an underlying level of stress and anxiety that showed itself in both predictable and unpredictable ways.

Jessica had to get used to Dylan disappearing into hospital for days and even weeks on end. When she was three, she announced she was going to be a doctor and make Dylan better! By the age of nine, however, she was in total meltdown. She tried to live up to her self-

imposed idea that she had to be perfect in order to balance out the fact that Dylan could not do a lot of things.

She constantly wanted to know every detail of what was going on but her parents realised it was up to them how much they explained about Dylan's genetic condition.

Today, Jessica's parents find that she is increasingly shouldering burdens but not sharing them. Remarkably for such a young person, she feels her parents have enough to deal with without having to deal with any of her problems.

Although this family works hard to manage the stress and anxiety associated with Dylan's disability, her parents are pleased that Jessica is a well-adjusted child who loves her brother, helps where needed and is very protective of him. Above all, she is proud of Dylan's achievements and is happy to talk about what is going on.

Jessica pays no attention to the fact that Dylan is different. To her, he is her brother and she loves him the way he is. Not a bad outlook on life really, and one from which we can all learn.

- Listen to your children and help them express their feelings.
- Set an example by showing it is ok to share difficult feelings.
- Watch for behaviour that might indicate stress.
- Help them learn skills to deal with difficult situations.
- Enable each child to feel special, spend 'one-on-one' time with them.
- Acknowledge their contributions to household activities but avoid giving them too much responsibility.
- Encourage your children to have contact with siblings in other families.
- Read books about sibling concerns; find books for your children that reflect the sibling experience – there is a list on the Siblings Australia website at [siblingsaustralia.org.au](http://siblingsaustralia.org.au).

## A caring family

No-one can dispute that Suzy has her share of challenges with her four boys. Each has problems ranging from heart murmurs, low grade muscle tone, constant reflux and vomiting, to eczema and asthma. Add to that fibril convulsions when one of the boys stopped breathing and finally, a baby with half a heart.

Not withstanding operations, spells in ICU, behavioural problems and much more, Suzy sums it all up by saying: "This family has had its fair share of ups and downs but I would not have it any other way. Every morning I wake up to find a different child cuddling me, and sometimes all of them at once.

"Children are young for such a short time before they grow up so spend every day making them smile."

### A poem

I am the eldest of four brothers,  
I have one mother and one father,  
Us kids all have our own conditions,  
Some worse than others.  
My youngest bro has half a heart,  
But it doesn't slow him down one bit,  
He plays with us all day long,  
And his heart is still really strong.  
We all look after each other,  
when sick or healthy,  
As we believe that team work,  
makes the dream work.

*By Samuel, 10 years old*



## Single parents

Having a child with a severe, or even slight, disability is heartbreaking. Very few people can truly understand the loneliness and the tiring day-to-day struggles.

Nevertheless, there are positive aspects for single parents, the first being that you can focus directly on your child's needs.

You also no longer have the responsibilities associated with being a wife or partner and that enables you to have more quality time for your precious child. However, being a single parent means that you may not have the day to day support that a partner can provide.

As a person who juggles so much every day, it can be very important to take some time out.

Sharing the care of your child, with grandparents, friends, partners or even overnight respite can be an absolute blessing. Having a night to yourself every now and again where you can have a full night's sleep is very restorative but even a relaxing evening with friends can make a world of difference.

Don't be afraid to talk to friends who share a similar experience because they often understand you and your difficulties so well that they can be a huge support in time of need.

Be gentle on yourself. You are the best person for your child and you need to be reminded what a good parent you are.

## Anneta's story

The excitement and joy at the birth of my grandchild was overshadowed by learning that my little precious bundle was a very sick little girl. It felt like my whole world had been ripped out from under me! I knew I had to be strong for my family.

I am a pensioner and live in far north Queensland and my family live in south east Queensland. For me, distance never stopped me from spending precious time with my beautiful girl. When I first saw my granddaughter, my heart broke at the sight of her, hooked up to machines and tubes. I wanted to hold her close and tell her how much love I had to give and that I would be there for her.

When I saw my family so heartbroken but full of love, devotion and caring for their beautiful daughter, I made a promise to myself to visit three or four times a year and whenever I was needed.

My beautiful granddaughter is doing very well. There are still milestones to meet and I am sure her quality of life will improve.

For example, one of her greatest achievements is that she now eats normally. It is a wonderful sight to see the family sitting down for meal. It is common knowledge that most of the important things in the world are accomplished by people who have kept trying when there seemed to be no hope at all and there is a saying which I always heed "Without faith nothing is possible; with it, nothing is impossible".

# Parents as advocates

## What is advocacy?

Advocacy is about promoting and defending your rights, needs and interests. In many instances, the advocate for a child is the parent or carer, or it could be an advocacy service provider, lawyer, volunteer or family friend.

Advocacy can change community attitudes and can help services providers and organisations be accountable and change for the better.

## How to be your child's best advocate

Advocacy means standing up for your child and if necessary, making a case for fairer treatment, more resources and better services, whether they be health services, education services or community services. Of course, it is important to educate your child on their rights so they can choose to possibly self-advocate when they get older.

Getting support so children can achieve better options and better lives has always been a huge challenge for parents and carers. Often the support and services that need to be provided to children and adults with disabilities or severe medical conditions are not forthcoming.

Here are some handy tips when dealing with advocacy service providers:

- Be positive
- Be clear on what you want
- Be honest
- Plan/list what issues are the most important to you and your child
- Gather any relevant facts, figures or documents to take to the meeting
- Don't try to talk 'jargon' – be yourself
- Listen carefully

*For more information on advocacy, please go to the Queensland Parents for People with a Disability website [www.qppd.org](http://www.qppd.org).*

# Francesca's story

The diagnosis of her daughter Lucia's rare one-in-three million autosomal recessive disorder saw Francesca's family in hospital for nine months. Lengthy and exhausting care failed to improve matters and after much research, Francesca heard of a clinic in Europe which could help.

The decision to try this last resort proved a turning point for the family in many ways. The daunting task of fundraising elicited wonderful, heart-warming support from family and friends.

"The outpouring of compassion for our daughter's predicament was overwhelming and provided us with opportunities to educate people about this rare syndrome," Francesca said.

But even better news was to come.

"The program was nothing short of a miracle and our life is much more manageable. We still face challenges but our daughter's increased confidence and the many positive outcomes give us the strength, determination and hope to carry on our journey."



## Health management

Your child's health journey may end up being a relatively straightforward one or it may be unpredictable, with many peaks and troughs. Remember, be positive and try to take things day by day.

Hopefully, this chapter will give you the tools you need to manage your child's health.

### Health issues

Every child is different and they can display a variety of symptoms depending on their condition.

Finding the right medical professionals to treat your child's health issues can be very difficult. Check with your general practitioner (GP), hospitals and other

health centres if they can refer you to a specialist who has experience in dealing with children with disabilities.

Ask other parents and carers for their GP or specialist recommendations as well.

Some common health issues that may arise when caring for a child with a disability or a medical condition can be:

- Eating and drinking
- Nutrition
- Dental
- Sleeping

Listed over the page are the specialists and allied health professionals that you may commonly encounter, including a brief description of how they can help you and your child.

## Eating and Drinking

### ***Paediatrician***

A medical specialist in children's health who can help you to manage your child's health needs and can prescribe medication. The paediatrician can also refer you on to other health practitioners.

### ***Speech pathologist***

An allied health professional who assesses a child's oral movement and swallowing skills. If the child's swallow appears delayed, the speech pathologist may write a reference for radiological assessment of the child's swallow.

### ***Gastroenterologist***

A medical specialist who can diagnose and treat your child's digestive system and can prescribe medication. They can help with managing vomiting, gastroesophageal reflux, gastrostomy tubes, nasogastric tubes, orogastric tubes, and advising on specialised feeding cups and utensils.

## Nutrition

### ***Dietitian***

An allied health professional who can assess and provide advice regarding nutritional intake, diet, type and amount of food, weight management, allergies, food intolerance, thickeners, formula and feeding pumps.

## Dental

### ***Paediatric specialist dentist***

A dentist who specialises in caring for babies' and children's teeth and gums and can prescribe medication. They advise on teeth grinding, foam biters, decay and cavities, malformation of teeth.

### ***Oral hygienist***

A health professional who helps with the care and oral hygiene of the mouth. They can advise on modified toothbrushes, specialised toothpaste and gels.

## Sleeping

### ***Physiotherapist***

An allied health professional who can help with sleeping positions and sleeping posture and can provide advice and programs to improve gross motor function, mobility and fitness.

### ***Occupational therapist***

An allied health professional who can provide advice on sleep positioning aids and ways to improve fine motor function and daily living skills.

### ***Sleep specialist***

A medical specialist who performs sleep assessments including overnight stays in hospital and can prescribe medication.

### ***Neurologist***

A medical specialist who monitors the brain and nervous system and provides advice and medication relating to seizure activity.

# Doctors and hospitals

Detailed in this section are a few tips on selecting a GP or specialist, information on preparing for medical emergencies, hospital admissions as well as regional assistance.

## Selecting your GP and specialists

- Your GP should be a reliable source of information and support for you and your family. Hopefully, you already have a local GP you feel comfortable with and who respects and understands your family's health needs. Don't be afraid to change to another GP if you feel you are not able to get the support you require.
- Your GP is often the first person that you would contact for most health problems. Ask as many questions as you like and never feel as if you are asking silly questions relating to your child's disability or chronic illness.
- If you have any major concerns about your child's development, ask your GP to refer your child to the appropriate specialist medical practitioner, such as a paediatrician, who is a doctor that specialises in caring for children.
- Many families who have a child with a disability or developmental delay find it helpful to have a paediatrician that they regularly consult with.



Paediatricians understand about the nature, severity, long-term outlook and causes of disabilities in children. They can also look out for associated conditions and manage any complications that may occur.

- All doctors and specialists should be able to explain things in detail and in words you can understand. You should be able to talk freely about your child's condition and needs with doctors and specialists as well as discuss your feelings and your family situation.

## Consultation room tips

- Don't feel rushed. Have all the information you need and all your questions answered before you leave.
- Take a friend or family member with you for support.
- Look at getting a second opinion if you are not happy.
- Prepare any questions you have before your appointment and mark them off when answered.
- Scripts can be provided by your GP for prescription medication. Ask your GP to issue you with repeat scripts for your child's regular medications, as going back and forth to GPs for scripts can be time-consuming.

## Calling an ambulance

Calling an ambulance can be a very stressful experience. If your child requires emergency intervention:

- Try to stay in control and don't panic as your child will sense it.
- If you can, get someone close by to do the calling, so you can remain with your child.

- Ensure that you give the emergency call centre the correct address and phone numbers.
- Try to be as detailed as possible when describing symptoms (e.g. breathing patterns, length and numbers of seizures etc). Something you might see as minor may make all the difference to the response time.
- When waiting for the ambulance to arrive, stay calm and continue to reassure your child.
- Give the paramedics space to access and treat your child, answering any questions they may have. Hindering them could delay treatment and transport to the hospital.

If you often require an ambulance, pre-pack a bag so you can grab it quickly. Things to pack may include:

- Your child's pyjamas, underwear, toiletries, medications, contact numbers, mobile phone and a small amount of money.
- Any medical aids (e.g. feeding, extension tubes, hearing aids, glasses) as well as any specialised formula.
- Your child's comforter, a toy or special blanket or pillow as this will reassure them and hopefully make their stay a bit more comfortable.
- Pre-packed food and drink for yourself to have at the hospital. If not, try to arrange for a family member or friend to bring you something at the hospital.
- A list of medications, including name, dosage and frequency that the medicine is to be given. Make sure this is updated regularly.

- Details of your child's routine, including meals, fluids and sleeping patterns. This can be handed to the nurses on arrival or in case of admission, put into your child's chart. It will also save you time explaining it to hospital staff that will be caring for your child.

## Hospitals

Your child can be admitted to hospital in a variety of ways. They may arrive at the hospital by ambulance or may be admitted to hospital by your surgeon, GP or by your hospital's outpatients' clinic. Having a child in hospital can be very distressing, especially if it is an unexpected admission, but hospital staff are there to help make your stay as stress-free as possible.

Here are some tips you may find useful:

- Where possible, plan your hospital trip in advance, whether you are driving or using public transport. You can ring the hospital and ask about car parking or common bus and train routes.
- Visit the local library and borrow some books about going to hospital that you and your child can read together. While you are there, log on to your hospital's website for information, virtual tours and lots



## Jaden's story

Jaden was born with no complications in 2003 but, two days later, he experienced breathing difficulties severe enough to turn his lips blue. This incident was explained as a 'minor choking incident'.

Jaden experienced a more serious attack three weeks later when he became very still, his eyes stared straight ahead and his body turned blue due to breathing difficulties. After a few minutes in the recovery position, and gentle rubbing on his back by his mother, his breathing returned to normal - but it was not destined to last.

And so began the exhausting cycle of ambulances, CT scans, MRIs, blood tests and spinal taps. Eventually, a chromosome test revealed Jaden had a genetic deficiency - 1P36.3 Deletion Syndrome.

Jaden's parents became expert at dealing with his seizures at home over the next three years when he averaged six attacks every day. Although an oxygen tank helped during the seizures, both parents endured long, sleepless nights.



Jaden's story is ongoing. He has a condition called global delay and needs constant care and support as he can't walk or talk.

Jaden's parents understand that part of their journey is constant hospital admissions.

"It doesn't get any easier but he has come to us for a reason and we believe he has taught us so many amazing things, and our journey is ongoing," say his parents.

of useful tips for making your child's stay easier. Sometimes the internet can be a good source of information, but if you have any concerns, always check with your doctor.

- Check with your doctor or admissions staff about whether you can take time-consuming admission forms home to fill in at your leisure.
- Keep a notebook on hand and jot down questions that you can ask the

doctor at any appointments.

- Make sure the doctor fully explains your child's condition and the procedure or operation. Sometimes, major hospitals will have printed handouts on procedures which you may find useful.
- Write down the name of a contact person from the ward where your child will be staying and the name of the doctor looking after your child.

This can be helpful for obtaining information about your child's condition or progress.

- Find out about hospital overnight rules and room facilities. Most hospitals will allow a parent to stay next to their child overnight, on a recliner chair or fold-out bed. There is usually a designated space for parents to make a cup of tea or coffee and heat up a meal while staying with their child. Shower facilities may also be available for parental use.
- Check hospital visiting hours so you can advise other family members. Just remember, bringing sick children to visit others in hospital is not recommended.
- Don't forget your Medicare card.

### **Specialty clinics**

Visiting specialty clinics can be a confronting experience and is a common occurrence for a child with a disability or medical issues.

Firstly, consult with your paediatrician and social worker within your hospital to find out more about specialty clinics offered. Your paediatrician and social worker can also help you to access referrals to other healthcare specialists and services, support, financial assistance and even parking benefits. It's important to understand that appointments can sometimes take much longer than planned.

Here are some tips to help you prepare:

- Try to allocate enough time between appointments during the day for lengthy clinic delays.

- Parking may be scarce, so investigate parking and public transport options.
- The specialist you see is your choice; if you do not feel comfortable or would like another opinion you are well within your rights to ask.
- Pack enough for your child's daily nutritional needs along with enough medication for all doses during the day. It's also a good idea to be prepared with your own snacks just in case there are no shops around.
- Clinics are often air conditioned and can get quite cold, so always have an extra layer of clothing available.
- Bring a support person along to appointments if possible, especially for times that you may be receiving results at your appointment.
- Rebook any follow-up appointments whilst you are at the clinic.
- Keep your receipt for any claims that can be made through Medicare or your private health fund.
- Before leaving the clinic, make sure that you are clear on all facts and if you are not, ask the specialist to go over relevant information.

You may not get all the answers you are looking for right away, nor will you always be happy with your first specialist or even with your child's diagnosis.

You may experience long waits, expensive bills and in some cases, little progress may be attained from specialist appointments. This can be very emotionally draining.

If you do encounter these issues, please understand that the frustration you feel is completely normal and never give up hope.

## Regional flight assistance

### Angel Flight

Not many of us think about the challenges faced by people who live in regional areas when they have to travel to city centres to attend appointments for treatment and hospitalisation. There are services available to help people in regional areas travel to and from hospital. Angel Flight is a flight service where pilots generously give their time and the use of their aircraft to transport patients to and from hospital for medical assistance and treatment.

Angel Flight also runs a ground service where volunteers transport patients to and from the airport. Health professionals are also on hand to assist with travel. To obtain more information on Angel Flight, speak with your social worker or visit [www.angelflight.org.au](http://www.angelflight.org.au).

### CareFlight Rescue

CareFlight Rescue is a not-for-profit organisation which provides rescue helicopters to the communities of south-east Queensland and northern New South Wales 24/7 at no charge to patients. On board every mission are a critical care doctor and paramedic ready for any emergency.

Their aim is to save lives whilst providing rapid response to those in need. Dedicated pilots and aircrew do an amazing job responding to emergencies within six minutes. Over the page is a story of one pilot's incredible experience! For more information on CareFlight go to [www.careflight.org](http://www.careflight.org).



### Helping regional Queensland families

Regional families often have to travel to larger hospitals for treatment. The Mater Children's Hospital's Paediatric Complex Care Service (PCCS) assists families to coordinate the special requirements of children with complex needs that live more than 50km outside the Brisbane area.

PCCS believes families who have access to relevant information and support networks will be better equipped to manage the issues associated with a child with complex needs. The PCCS can help families with a range of services such as:

- Notifying families of upcoming specialist appointments.
- Assisting with emergency travel and medical documentation.
- Assisting with accommodation near the hospital or Ronald McDonald House.
- Information on regional services.
- Attaining referrals to specialists.
- Information on specialised equipment.
- Helping with the transition from paediatric to adult hospitals.
- Organising palliative support.

To attain a referral for the PCCS, talk to your GP or contact the Mater Hospital. Please note, hospitals in other states may offer similar services.



## A pilot's story

Rob Bartolacci always wanted to be a pilot but fate saw him graduate in medicine as an anaesthetist. As a medical student, he had the opportunity to see first-hand the wonderful, lifesaving work undertaken by CareFlight.

In 1991, he started work with CareFlight, situated at Westmead in New South Wales where he has worked as an anaesthetist ever since.

Rob says that working for a charity is a great experience and that he and all

the crew are well aware of the unfailing support from fundraising, private donations and government funding as well as the dedication of the volunteers who work tirelessly to keep them flying.

Nothing is more gratifying than having former patients come back to visit. Such was the case when a 25 year old man walked into the helicopter base at Westmead and thanked Rob for saving his life. This same young man was just 15 when he had been involved in a horrific car smash in which a pole had wedged in his pelvis, causing him to lose all the blood in his body. Mercifully, Rob and the



team were able to replace it as quickly as he was losing it, as he lay trapped in the car, thanks to blood and blood products from nearby hospitals. Multiple operations followed but the outcome was positive.

Rob says the ambulance staff, police, volunteer rescue and hospital staff all contributed to this result. That includes the blood donors who gave freely of their blood, never knowing it would be used to bring a boy back from the brink of death.

Although he still does not have his pilot's licence, Rob regards himself as lucky to

have been trained to help people when they are at their most fragile. In a world filled with awful disasters he thinks it wonderful to find people ready to put the needs of others above their own.

"It is a privilege for me to work with CareFlight. I am lucky that it is something I love doing and along the way I have worked with some great people. It has also shown me that life is precarious and that in an instant, your world can change. Hopefully, it will never happen to you but, if it does, there will be someone there to help. To all those people, I give my heartfelt thanks," Rob says.



# Therapy needs and equipment

## Allied health services

Your child's disability will present many challenges for you and your family. But you don't have to face these challenges alone. There are many professionals who can help optimise your child's development.

The allied health professionals that you are most likely to come in contact with are physiotherapists, occupational therapists, speech pathologists and psychologists.

### **Physiotherapists**

Physiotherapists (physios) can provide assessments and therapies to develop a child's gross motor skills including sitting, crawling, walking and running. They can

prescribe equipment such as mobility aids, orthoses and splints to support body structure and function.

Physios develop programs to improve strength, balance, flexibility, endurance, coordination and overall development. They can also recommend specialised equipment and environmental supports.

### **Occupational therapists**

Occupational therapists (OTs) can assess and conduct therapy to help a child better participate in daily activities. They can help a child with dressing, grooming, bathing, toileting, play, learning and social interaction.

OTs can help a child to develop fine motor skills such as hand-finger coordination

and hand-eye coordination. This can involve throwing and catching, perceptual skills and sensory integration.

### **Speech pathologists**

Speech pathologists can help a child to communicate so they can better participate in daily activities. Types of communication include speech, augmentative and alternative communication. Speech pathologists also assess and support a child's eating, drinking and swallowing skills to improve overall development, health and wellbeing.

### **Psychologists**

Psychologists can assist in designing and implementing behaviour management programs. Psychologists often provide assessments to support school participation and personal development. They also provide counselling, positive behaviour assessment and parenting intervention.

### **Assessments**

Your child will need to be assessed by a therapist before they plan a program for them. The therapist will often review reports written by specialists and other professionals who have worked with your child. You may be asked about your pregnancy, your child's medical and developmental history.

Therapists will also assess your child by observing how your child moves, plays and interacts with you and other members of your family. They may also assess your child by conducting a number of standardised tests.

To measure progress, therapists may re-evaluate your child every six or twelve months. This can be a very stressful time for hopeful parents who may have 'test anxiety issues', watching their child perform and hoping things have improved.

The precise elements of your child's evaluation will depend on their age, degree of disability and how comfortable they are working with therapists.

Often therapists will work as a team if your child requires more than one type of therapy. It is a good idea for one of the team to act as a case manager so they can really get to know you and your child.

### **Funding**

Research shows that early intervention therapies from expert health professionals deliver real benefits to children with disabilities to help them develop to their full potential.



## A parent's story

After my first formal assessment I expected the physio to make specific predictions about my child's future abilities. I asked the big question, 'will my child walk?'. The physio replied that it was impossible for her to make any such prediction until my child had been involved in intensive therapy for some time, and that each child was different and progressed at different rates. As a

parent, I just wanted to know either yes or no! I felt upset, fearful of the unknown and still had to cling on to that little bit of hope.\*

*\*Often physiotherapists are one of the first therapists involved in assessing a child's postural and movement control. They are cautious about predicting a child's future skill level due to each child's developmental nature and potential for change.*

The Federal Government's *Better Start for Children with Disability* allows for more children to access intensive early intervention treatments. If your child is under 13 years of age and has been diagnosed with cerebral palsy, sight and hearing impairments, Down syndrome or fragile X syndrome, they may be eligible for services under *Better Start*.

The *Better Start* program includes funding direct to families for speech pathology, audiology, occupational therapy, physiotherapy, psychology, social work and education liaison services. In brief, *Better Start* includes:

- Up to \$12,000 for therapy services for children under six years of age.
- An additional \$2,000 for families in outer regional and remote areas.
- Medicare items for up to four diagnostic therapy services for children under 13 years.
- Medicare items for 20 therapy services for children under 15 years, provided a treatment and management plan is in place before the age of 13.

To attain therapy services through Medicare you need to visit your GP or consultant physician and attain a treatment and management plan for your child. You will then need to take this plan to your chosen allied health professionals to claim treatments through Medicare.

Go to [www.careraustralia.com.au](http://www.careraustralia.com.au) or to [www.fahcsia.gov.au](http://www.fahcsia.gov.au) to register for *Better Start* or obtain more information.

## Other therapies

There are many therapies available in Australia, each with its own aims and methods. Here are some of the better known ones:

### **Bobath or neurodevelopmental therapy**

Bobath follows a holistic approach to develop children's social skills, perceptual and intellectual abilities, eating, drinking and communication skills.

Individualised programs are developed and parents or carers are shown how to facilitate these in daily activities.

## Conductive education (CE)

CE aims to help a child improve their self-esteem, problem-solving skills, self-discipline and emotional strength. CE embraces a holistic approach to help each child to achieve greater independence and improved quality of life. It practises the concept of 'you will do it yourself'.

A program of routine activities, physical and educational tasks may improve fine motor skills, communication, gross motor skills and overall health and wellbeing.

## Hydrotherapy

Hydrotherapy offers the benefits of relaxation, movement experience, exercise, play and social interaction. For some children with cerebral palsy, the water environment may offer a level of movement and independence which they cannot achieve in any other environment.

Hydrotherapy involves a physiotherapist assessing each child's needs. The physio



## A parent's story

My little boy was only six months old when a formal assessment was done.

I watched in horror as the physiotherapist prodded and pulled him in all directions whilst he screamed continuously, not understanding what was happening to him.

He was so distressed his muscle tone increased and you couldn't bend him. This made it impossible to assess his movement skills properly.

Looking back I wish the assessment hadn't taken so long and that the therapist had spent more time gaining his trust and getting to know him beforehand.

I didn't realise how upset I would be witnessing this event and having to handle the bad news of his diagnosis on my own.

From then on, I decided that my husband or another family member would come with me to future appointments and that my son needed to be in a relaxed state to get any sort of accurate assessment.\*

*\* It is important for parents to be in a position to be able to prepare their child and themselves for assessments.*

*Asking a therapist what will take place and how to prepare their child will facilitate the assessment and result in a positive process and outcome for all involved.*

leads exercise sessions in a pool with parents and caregivers in attendance. The warm water is used to relax the muscles and the buoyancy of the water may assist with weight bearing. Regular hydrotherapy can increase strength, motor control, balance and coordination.

### **Body suits and kinesthetic orthoses**

This therapy focuses on the vestibular system, which is the body's sensory system that contributes to movement and sense of balance.

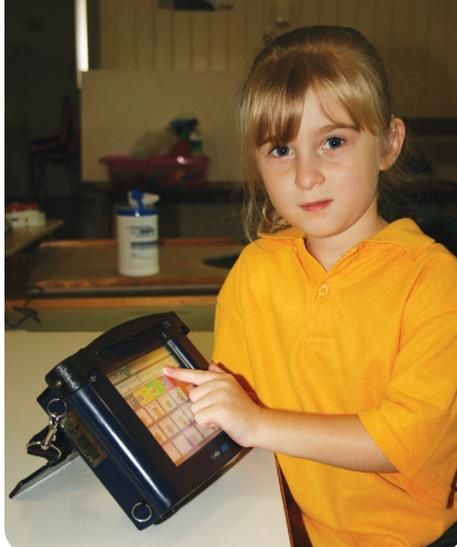
Theratogs, upsuits, and other forms of 'suits' help to provide sensory information to the skin, muscles, and underlying joints. Suits are designed to play a role in strengthening programs that help to recreate correct postural alignment, helping muscle tone, vestibular function and sensory perception.

## **Equipment**

Often parents are confused and overwhelmed with making decisions on what kind of equipment their child might need and also how to access equipment. It's a good idea to work collaboratively with your child's therapists and chosen equipment companies.

Your child may need various equipment and it is important to plan in advance as it can take a significant amount of time to work out the specific needs, apply for funding, organise appointments with therapists and wait for delivery.

A parent's comment: "I didn't realise it would take almost nine months for us



to get our son's first wheelchair. First it was making the decision on what kind of wheelchair and then we had numerous appointments to make modifications. We had to wait for the application forms to go through then the company took months to make it and then finally deliver it."

### **Different types of equipment**

Some of the equipment you may require includes:

- Communication devices/computers.
- Contenance aids e.g. nappies after five years of age.
- Daily living aids e.g. commodes used for toileting and showering, sleep systems, beds and eating utensils.
- Mobility aids e.g. wheelchairs and specialised walkers.
- Orthotics e.g. splints and leg wraps.
- Play equipment e.g. switch-adapted toys, modified bikes and swings.
- Therapy equipment e.g. therapy balls and roller mats.
- Seating and standing equipment e.g. specialised chairs for sitting and standing frames.

## Equipment trial services

You may find there are equipment trial services that are available in your area.

In Queensland, the Cerebral Palsy League has an equipment trial service run by Mylestones Mobility. This service allows therapists to trial equipment and accessories so they can help their clients choose the most appropriate equipment to meet their needs. Trial equipment is available for loan in one-week blocks, however exceptions can be made for regional clients. To learn more, go to [www.cplqld.org.au/mymobility](http://www.cplqld.org.au/mymobility).

## Accessing equipment

Here is a suggested outline of the steps involved in accessing equipment:

1. Discuss your child's needs with your therapy team.
2. Decide on a reputable and reliable company (often therapists can recommend a well-regarded company).
3. Research any government assistance or funding available e.g. Medical Aids Subsidy Scheme (MASS), Lions and Rotary Clubs.
4. Research any equipment trial services.
5. Consider any adaptations required at home or with your car before ordering and picking up the equipment.
6. Fill out appropriate order forms as soon as possible to reduce lengthy waiting periods.
7. Test the equipment in different environments such as at home or school to check whether it is suitable or needs further modifications.

8. Ask questions about delivery timeframes and other concerns. Questions could include:
  - When will my equipment be delivered?
  - Can I have a trial period of at least four weeks?
  - How long should the equipment last?
  - Is it guaranteed/under a warranty for a certain period?
  - Is free service provided if something needs repairing?
  - What type of training do you provide to help me use the equipment?
  - Is this training free of charge?
9. When picking up the equipment, have a therapist with you to ensure it meets the needs of your child. Often equipment is expensive and can take a long time to be sent back and modified, so it is important to take the time and get it right.

Please talk to your therapist about sourcing mobility equipment and assistive technology providers or in the first instance, you may like try the following organisations:

- LifeTec Queensland  
[www.lifetec.org.au](http://www.lifetec.org.au)
- Mylestones Mobility  
[www.cplqld.org.au/mymobility](http://www.cplqld.org.au/mymobility)
- Medical Aids Subsidy Scheme (MASS)  
[www.health.qld.gov.au](http://www.health.qld.gov.au)
- Spectronics  
[www.spectronicsinoz.com](http://www.spectronicsinoz.com)
- Technical Solutions  
[www.tecsol.com.au](http://www.tecsol.com.au)
- Freedom Health Care  
[www.freedomhmc.com.au](http://www.freedomhmc.com.au)



# Education and learning

## Playgroups 0-3 years

Education and learning through play is crucial for a child's development. Play groups give you the chance to meet other parents and carers in similar circumstances and allow your child to play and socialise with other children. Playgroups can also provide you with ideas on the types of play that you can do at home to help meet your child's needs and developmental milestones.

Some playgroups have a facilitator who can help parents and carers decide on activities. They lead children in activities so you can spend time focusing on

catching up with others in the group.

You may find the following websites useful:

- [www.playgroupaustralia.com.au](http://www.playgroupaustralia.com.au)
- [www.raisingchildren.net.au](http://www.raisingchildren.net.au)
- [www.mytime.net.au](http://www.mytime.net.au)

## Childcare 0-5 years

Preschools, kindergartens and childcare services can provide excellent learning opportunities for children with disabilities, special needs or chronic illness.

## Concerns with starting childcare

It is natural to have initial concerns when visiting the shops, a park or a playgroup with your child. It's important to acknowledge these concerns and work through them with friends in the same situation, family members or a counsellor. You may feel:

- Emotionally fragile as you see your child in a new setting, especially when they interact with other children without special needs.
- Frustrated that others don't understand your child's complex needs. Sometimes you may be hurt or puzzled by the attitudes of other parents or people associated with your childcare centre or playground.
- Worried that adults and children may not understand why your child behaves or moves differently when they look like all the other children.
- Concerned about whether other children will accept your child.
- Worried about safety issues when your child is playing with other children.
- Uncertain about trusting someone else to care for your child and 'letting go' for the first time.

## Strategies to overcome these concerns

To help teachers and childcare workers to understand the needs of your child, try putting together a management plan for your child's teacher and helpers. You can cover a range of relevant topics and even include photos demonstrating how to care for your child. For example, you could include a section on 'feeding' with photos and a written explanation on how to feed your child. You could also include

## A parent's story

The diagnosis of Angelman Syndrome was incredibly traumatic for our family and we didn't know what to do or who to talk to about options for our son Finn. As Finn was only 12 months old, we knew some form of early intervention was critical but we struggled to find information on different programs.

We managed to find programs overseas but could not find anything in Queensland. It was only when he was hospitalised with seizures that the complex care coordinator told us about a school-based early intervention program based on conductive education called the Xavier Special Education Unit, which was only a few suburbs from where we lived!

We enrolled Finn in Xavier straight away and he participated in the program right through to school age. We were so glad we 'stumbled' on to the school. Early intervention meant he benefited from intense programs that have helped him be the best he can be. It also enabled us to invest in the right type of effort and therapies to best aid his development.

His continued progress and improvement, despite his diagnosis, is encouraging.

His more settled nature (which is contrary to Angelman Syndrome) has validated our decision all those years ago.



sections on equipment, manual handling and transfers, and communication. You could also detail your child's behavioural and emotional issues and how childcare workers can best manage them.

Here are some tips to help settle your child into childcare:

- Before your child starts, organise a tour of the centre with your child to familiarise yourselves with the centre. Check if the setting is suitable, for example are the rooms accessible for wheelchairs, and have any of the staff worked with children with disabilities before?
- To help your child settle in, spend the first hour of each day with your child during the first week that they attend the childcare centre. This will help you feel comfortable with the running of the centre and slowly introduce the new environment to your child. It will also give you a chance to meet other children and refer to them by their names when communicating with your child.
- Arrange separate meetings with your child's carers, teachers and director so that you can provide as much information as you can and run through your management plan.

- Introduce yourself and your child to other parents and children in the centre. In this way, you are helping other parents and carers to feel comfortable speaking to you about your child and you can educate them about your child's special needs.
- Use a notebook or diary each day and place it in your child's bag. This can be used as a communication book between you and the centre. This is particularly useful if your child is non-verbal.

### **Funding**

The federal government's Inclusion Support Subsidy (ISS) provides funding to help childcare services to include children with ongoing high-support needs. All federal government-approved childcare services are eligible regardless of care type or location. Types of eligible childcare include:

- Family day care
- Kindergarten
- Limited hours day care
- Long day care
- In-home care, e.g. nannies
- Vacation care
- Outside school hours care

The ISS provides funding towards the costs of:

- Additional staff to increase the staff-to-child ratio.
- Relief staff, to cover for regular carers attending inclusion training.
- Specialist equipment e.g. hoists, change tables, toilets, support swings, positioning blocks chairs, and sensory mats.





### Early development programs

Education Queensland provides early childhood development programs and services for children prior to prep-age with a suspected or diagnosed disability with significant educational support needs. They provide services in the areas of intellectual impairment, autism spectrum disorder, speech-language impairment, hearing impairment, vision impairment and physical impairment.

These programs expose children to a variety of learning experiences, help to maximise potential, assess support needs and assist with transition to school.

## Starting school

When a child with a disability reaches school age, parents may consider different options for their education:

- Mainstream education

- Mainstream and special education unit support
- Special schools

### Mainstream education

Mainstream education is when children attend a regular classroom with other students who may not have a disability. For example, Education Queensland provides specialised programs and services to support students with disabilities with significant educational support needs in mainstream schools.

### Queensland Disability Services Support Unit (DSSU)

The role of DSSU is to enhance and facilitate inclusive education practices. DSSU is staffed by specialist teachers, therapists, nursing and guidance personnel. These specialists support students with disabilities to allow them to participate, learn and achieve the best possible educational outcomes.

Independent and catholic schools also provide inclusive education options. Each school varies in how much support it can provide for children with disabilities. It is important to research the school thoroughly before enrolling your child. Most of these schools have a website

## A parent's story

My son's first year of prep was a rollercoaster with lots of ups and downs. The teachers had to learn how to communicate with him, feed him, toilet him and manage his body movements.

I was really worried about his safety and

whether his needs could be met. I could have chosen a special school for him, but our dream for him was an inclusive learning environment.

After many months of working closely with the staff, I could finally see that they had a better understanding of my son and that he absolutely loved going to school.

that can provide information about the learning environment.

### **Mainstream and special education unit (SEU) support**

Students with disabilities can attend a mainstream or regular classroom and be supported by a school's SEU. Children gain extra support from SEU teachers who can help them with communication skills, physiotherapy and occupational therapy.

### **Special schools**

Special schools offer highly-specialised programs for students with an intellectual impairment whose educational needs are identified through an educational adjustment program (EAP).

Enrolment in a special school depends on a number of factors relating to student needs and available levels of support.

## **Learning and disability support**

A wide range of support services are available to assist parents and carers with information, programs and processes to help students with disabilities. Some of these services are outlined below.



## **A parent's story**

After researching schools in my area, I contacted a guidance officer for help and together we looked around at schools to suit my son's needs.

This whole process was confusing for me as I couldn't decide what sort of educational setting was best for my son.

Having the guidance officer with me was a huge help.

### **School transport assistance**

Check with your school if they provide a school bus or taxi for children with disabilities. You will need to ask for an application form for transport assistance.

### **Advisory Visiting Teachers (AVT)**

AVTs are teachers with specialist knowledge and skills, who support the educational programs of students with disabilities. They may visit students in the classroom on a regular basis and assist classroom teachers to support the needs of students. AVTs visit all government schools and some non-government schools. Non-government schools can access an AVT in the areas of visual impairment, hearing impairment and physical impairment.

### **Guidance officers**

School guidance officers can support and advise you when you are researching and deciding on a suitable school for your child. They can also help you through the process of the educational adjustment program explained below.

## Educational Adjustment Program (EAP)

As a parent, you will hear the term EAP when your child is beginning school and also throughout their schooling. It's important for teachers and parents to discuss who else may need to be involved in helping with your child's education and learning. You can attend an EAP meeting to discuss what other professionals may need to be involved and any actions being implemented to cater for your child's needs. Make sure you go to parent-teacher meetings regularly to keep reviewing your child's program.

For information on the EAP visit [www.education.qld.gov.au/students](http://www.education.qld.gov.au/students).

## Researching schools

Services to assist your child can vary depending on whether your child attends a state, catholic or independent school. Education Queensland and Catholic Education have specialist teams that can provide services for children with disabilities.



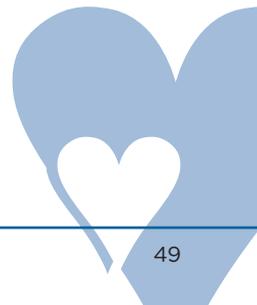
### Contacts

- Education Queensland  
[www.education.qld.gov.au](http://www.education.qld.gov.au)
- Catholic Education  
[www.qcec.qld.catholic.edu.au](http://www.qcec.qld.catholic.edu.au)
- Independent Schools  
[www.aisq.qld.edu.au](http://www.aisq.qld.edu.au)
- Directory of all Queensland schools  
[www.education.qld.gov.au/directory/schools](http://www.education.qld.gov.au/directory/schools)

## A parent's story

I felt overwhelmed when meeting with my child's therapists, teachers and teacher aides and discussing all the problems that they were experiencing with my daughter.

I was glad that my husband came along to support our concerns regarding our daughter. We worked together with staff on possible solutions to best support her needs and that was the first of many steps in the right direction.



# Heaven's Very Special Child

A meeting was held quite far from earth.

It was time again for another birth.

Said the angels to the Lord above,  
This special child will need much love.

His progress may be very slow,  
Accomplishments he may not show.

And he'll require extra care  
from the folks he meets down there.

He may not run or laugh or play,  
his thoughts may seem quite far away.

So many times he will be labelled,  
different, helpless and disabled.

So, let's be careful where he's sent,  
we want his life to be content.

Please, Lord, find the parents who,  
will do a special job for you.

They will not realise right away,  
the leading role they are asked to play.

But with this child sent from above  
comes a stronger faith, and richer love.  
And soon they'll know the privilege given

In caring for their gift from Heaven.

Their precious charge, so meek and mild  
Is HEAVEN'S VERY SPECIAL CHILD.



## Looking after yourself

The physical and emotional demands of caring for a child with a disability can be high and often carers put the needs of others before their own. It's important to remember to look after yourself and take time out for hobbies and outside interests. Try to keep your own needs balanced with the needs of your child, partner and family. If you don't, you may risk emotional and physical stress which will negatively impact on your life.

### Respite care

'Respite' means having a break from caring for your child. Some families have grandparents or friends who are willing to help out and provide an opportunity for you to have some time out. There may also be services in your local community

that receive funding from the state or federal government to provide respite. Depending on what is available in your area, you may be able to access:

- A respite care centre where your child can spend a night or weekend.
- A carer to look after your child at home while you go out.
- A carer to take your child on an enjoyable outing.

Some families use respite so they can:

- Spend time alone or as a couple.
- Spend time with their other children.
- Socialise with friends or just go shopping.

Not all families feel the need for respite while other families really value knowing

when they are going to have some time out from caring for their child. If you would like to find out more about respite services, please refer to our Resource Directory at [www.info4carers.com](http://www.info4carers.com).

## Sleep

Carers can often find it difficult to have a good night's sleep. Most carers get by on less sleep than the average mum due to the constant care their child needs.

Sleep deprivation may cause health problems such as insomnia, panic attacks, irritability, depression and anxiety, fatigue and a lowered immune system. Weight gain may be another side effect of sleep deprivation due to an increase in appetite that is sometimes caused by constantly changing sleep patterns. Your body's ability to regulate insulin production and sugar metabolism may also be affected, and this can lead to a higher risk of developing diabetes.

However, there is some good news! Lost sleep can be recouped – and in just a third of the time. For example, if you lose up to three nights sleep in a row, one unbroken night's sleep should leave you refreshed.

The most important thing to remember is carers need support to allow them time to recover and recoup to care again for another day!

### Tips to unwind

If your sleep is disturbed by having to care for someone, ensure you:

- Have a supportive bed that is conducive to sleep.

- Have some help so you can get an unbroken night's sleep at least one night a week.
- Cut down on tea and coffee in the evening.
- Take some time to relax, even if it's just for a short time every day – have a warm bath, go for a walk, read, meditate, do yoga or practice relaxation techniques.
- If you can't sleep, try not to lie there worrying. Get up and do something for 30 minutes that relaxes you like watching TV, listening to music or reading a book.
- Do some regular exercise.

## Fitness

Being 'fit' means being able to perform well in a variety of physically exerting circumstances. For most parents and carers, it means keeping yourself fit enough to cope with the physical demands of caring for someone.

If you run out of breath when doing simple tasks like walking up the stairs or if you experience knee, shoulder or back pain when lifting or moving your child, it's time to improve your physical condition.



Photo courtesy of Marina Pure Health Clubs  
[www.purehealthclubs.com.au](http://www.purehealthclubs.com.au)

Here are some easy steps to guide you to better fitness:

### **Step 1: Get the support of your loved ones**

Ask each loved one to help support and respect your wish to get 'fit' and your desire to lead a more healthy lifestyle.

### **Step 2: Incorporate more physical activity**

Try challenging your body by increasing the intensity of exercise. For example, if you regularly walk as part of your exercise regime, try running a portion of your walk, going a bit further each time or changing your route regularly.

### **Step 3: Do a variety of exercise**

Variety is the spice of life so make exercise fun by enjoying a diversity of physical activities throughout the week.

### **Step 4: Incorporate some strength training**

Doing resistance training two to three times a week can greatly improve the strength and tone of your muscles. You don't need to go to a gym to do this; you can work out to DVDs at home or use housework as a form of exercise.

Strong muscles are firmer and they help prevent debilitating bone and joint injuries. Doing strength training can increase your metabolic rate which helps with weight management. Did you know that a kilo of muscle will burn 50 to 100 calories a day whereas a kilo of fat will use up only about 5 to 7 calories a day?

### **Step 5: Give your body the right fuel**

Eating a balanced diet with all the essential nutrients will give you the energy needed to keep you going through the day. Drinking enough water throughout the day will also help avoid dehydration and prevent fatigue and headaches.

### **Step 6: Allow your body to rest**

When you start your exercise regime, make sure you get enough sleep to let your body recover and renew.

### **Step 7: Get a check-up**

Monitor your own health and wellbeing. Go to the doctor and dentist regularly to prevent or diagnose any health issues.

Remember, once you have achieved your desired fitness; continue with the steps that got you there. Wellness is a lifestyle!

## Other ways to get healthy

### **Physiotherapy and chiropractic services**

From time to time, you may experience sprains and strains associated with lifting, twisting, bending and pushing wheelchairs. To avoid injury, it is important to get advice from your allied health professional on how to move your child and how to use their equipment safely and properly.

Getting regular physiotherapy or chiropractic care can help to repair injuries and maintain health and wellbeing. Physiotherapists or 'physios' can treat muscular pain and develop programs to improve your strength, balance, flexibility and endurance. Chiropractors also treat muscular-skeletal issues including lower back pain, sciatica, shoulder pain, neck pain, headaches and limb pain.

### **Pilates**

Pilates is a great tool that you can use to nurture your mind and body. Pilates can help you to increase the strength of core muscles that are crucial to your wellbeing and the demands placed upon your body.

### **Nia**

Nia is a holistic fitness practice that allows you to tap into your creativity and discover new ways of moving. The Nia technique blends the movements of



dance, martial arts and healing arts into fun routines set to music.

One carer said, "I loved the way Nia made me feel after classes, my mind felt clearer and I could not believe I could dance that way. It took me back to being free and not so restricted."

For more information about various classes in your area you can search online at [www.niaaustralia.com.au](http://www.niaaustralia.com.au).

### **Other techniques**

You can also try a range of relaxation therapies like yoga, meditation, tai chi or massage to relax and unwind. For more details of fitness and health organisations in Queensland visit [www.info4carers.com](http://www.info4carers.com).





# Transport

Accessing information on public transport, wheelchair-accessible taxis and trains can sometimes be difficult, but it's important to research all the options available.

The Queensland Government's Disability Online website contains detailed information about the state's disability transport services and support. A few key points are outlined below, but for further details, visit [www.qld.gov.au/disability](http://www.qld.gov.au/disability).

## Subsidies

### Taxi subsidy scheme

The Queensland government's taxi subsidy scheme gives people with severe disabilities tax discounts. You can get half of your taxi fare subsidised, up to a maximum of \$25 per trip.

The Department of Transport and Main Roads issues membership for a maximum of five years. For details on how to apply visit [www.support.transport.qld.gov.au](http://www.support.transport.qld.gov.au).

### Vision impairment travel pass

This pass entitles holders to free travel on all participating urban public transport services including bus, rail and ferry within Australia.

To apply for a pass, complete an application form available from organisations that represent people with severe vision impairment.

### Australian disability parking permit

The Australian Disability Parking Permit (ADPP) is for people with severe mobility restrictions and is recognised in every state. It may be difficult for carers to get

## A carer's story

Having a disability parking permit makes getting out and about so much easier for me and my family. Disability parking bays are wide enough and long enough for my modified car and I get to park much closer to lifts and entrances.

But on the downside, I sometimes encounter some cranky people telling me off for using a disability parking space, especially when I have my child in his push chair. I take this in my stride and try not to let attitudes of people ruin my day. The only other negative is that I find there are not a lot of disability parking bays around in shopping centres or on the street when I need one.

Contact your local council about where disability parking spaces are located in your local area as well as for details of any parking privileges or concessions.



an ADPP permit; however, your doctor or allied health professional may be able to assist you in the process.

An ADPP allows a person with a permanent or temporary severe walking restriction to use designated parking bays located close to the entrances of shopping centres, hospitals and other public places.

ADPPs are issued for either a period of six to 12 months, or for a period of five years. To apply for an ADPP, you must:

- be unable to walk and always require the use of a wheelchair, or
- have your ability to walk severely restricted by a medical condition or disability.

Intellectual, psychiatric, cognitive or sensory impairment, does not qualify you for an ADPP unless your ability to walk is severely impaired too.

For more information on the scheme, visit [www.tmr.qld.gov.au](http://www.tmr.qld.gov.au).

## Modified vehicles

Vehicle modifications range from simple wheelchair hoists and racks on your car, to more complex hand controls. For more information about vehicle modifications:

- Talk to driver-trained occupational therapists
- Visit [www.jobaccess.gov.au](http://www.jobaccess.gov.au) for a list of products and suppliers or search for information under 'transport' on the [www.lifetec.org.au](http://www.lifetec.org.au) website for a list of products and suppliers.



## Choosing a vehicle

Buying a car or van with wheelchair access can be a challenging task. You need to make sure the vehicle is comfortable and safe for your child and that it also meets the needs of your family. Make time to research all your options, browse the internet and make contact with other people who have had their car modified.

The information outlined below was sourced from the Xavier Community Support Network at [www.xcsn.org](http://www.xcsn.org).

### *Vans*

Vans tend to be the most common style of wheelchair-accessible vehicle, as they generally have adequate headroom for someone sitting in a wheelchair and sufficient entry space through the rear.

### *Small commercial vehicles*

These vehicles are usually modified to incorporate a floor containing an internally-stowed ramp.

### *People movers*

People movers are modified so that the floor of the vehicle is lowered, allowing sufficient room for a person in a wheelchair. Some people movers, such as the VW Caravelle can be fitted with an electric wheelchair lifter.

For information on manufacturers, importers and retailers, visit:

- Just Buses  
[www.justbuses.com.au](http://www.justbuses.com.au)
- Flash Cab  
[www.flashcab.com.au](http://www.flashcab.com.au)
- Freedom Motors  
[www.freedommotorsaustralia.com.au](http://www.freedommotorsaustralia.com.au)

For general information on vehicle modifications, visit:

- Paraplegic and Quadriplegic Association of NSW  
[www.paraquad.org.au](http://www.paraquad.org.au)
- Association of Children with a Disability  
[www.acd.org.au](http://www.acd.org.au)
- Ebility  
[www.ebility.com](http://www.ebility.com)

## A carer's story

Getting our vehicle modified was perhaps one of the most daunting aspects of adjusting to our new life. I was worried that I had left it too long to attain a modified vehicle. I was also feeling confined to the house and that it was just too much effort to get out with the family.

The whole process seemed quite expensive and confusing. However, once I took the plunge, it was so liberating to finally get a modified vehicle and I felt life had started afresh for me and my family.

I highly recommend you seek the support of your occupational therapist to get started on researching modified vehicles.

# Home modifications

It's important to have a home which is comfortable and functional for all members of your family.

You may need to modify your home as your child gets older to enable wheelchair access and the installation of lifting equipment. This can be expensive. The Queensland Government offers a 'Home Adapt Loan' to enable eligible families to make necessary home modifications and loans range in value from \$5,000 to \$30,000.

## Applying for a loan

You will need to contact the Department of Communities who will send out an occupational therapist to assess your home and see if you are eligible for the loan.

For more information visit [www.communities.qld.gov.au/housing](http://www.communities.qld.gov.au/housing).





# Travel and recreation

## Air travel

The major airlines in Australia can cater for a wide range of needs. They can provide wheelchairs, preferential aircraft boarding, oxygen and facilities for guide dogs, and can also cater for special dietary requirements. Before booking, check the airline's website for medical forms and other paperwork that you may need to present.

Some airlines offer discounts to travellers with a disability. For example, Qantas accepts the Carer's Concession Card, issued by the National Information Communication Awareness Network, allowing the card holder and their carer to have discounted travel on Qantas domestic flights.

Most airports have wheelchair access, dedicated parking spaces, accessible toilets, telephones and high chairs.

Here are a few things to remember when flying, courtesy of the Victorian Government's Better Health channel [www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au).

Planning ahead can make your flight more enjoyable for you and your child. Suggestions include:

### Before you fly

- Make a list of questions to ask your doctor about how your child's condition may impact on your travel arrangements.
- Take your child to the doctor for a medical check-up.

# Annette and Liam's story

Travelling with a child with a disability has its challenges but you and your family can have fun-filled getaways, just like any other family.

Annette is the mother of eight year old Liam, who is severely disabled, uses a wheelchair, has epilepsy, is non-verbal and is fed through his abdomen via a gastrostomy tube.

Nevertheless, none of Liam's medical conditions have stopped the travel-loving family from having regular and interesting holidays. Liam has a delightful personality and loves to see new people, so Annette sees travelling as a positive move in the right direction for Liam's development.

"We want our family to travel, experience different cultures, see the world and escape from daily routines – just like any other family," Annette said.

Annette explained that while some airline policies and conditions can seem difficult

to comply with, her family have found that most staff are sympathetic and issues can be successfully negotiated.

For example, Liam was allowed to sit on his parents' laps during take-off and landing until he was six years old because they explained the standard airline harnesses were at risk of choking him.

Some of Annette's tips include:

- Be well prepared and book accommodation in advance to ensure it is accessible and meets your family's needs.
- Pack for all weather and eventualities.
- See your GP who can prescribe broad spectrum antibiotics and other medications which you can administer yourself if necessary.
- Travel insurance is a must and be sure to disclose all your child's conditions.

"In other words, don't let your child's disability be an excuse for not doing what other people take for granted. You can go anywhere you want and do anything you wish. If you want it to happen, it can – just be prepared!"



- Ensure immunisations are up-to-date and arrange vaccinations (if necessary) with your doctor.
- Ask friends or your travel agent for advice on child-friendly airlines.
- Discuss your child's medical or mobility requirements with your travel agent or airline before you fly.
- If you are travelling alone, ask the airline if it is possible to have an 'assistant' who will help you at each stop. For example, a staff member might collect your luggage for you.
- Arrange children's meals in advance.
- If you have a young baby, arrange with the airline for a bassinette.
- A car seat can be taken on board, but you will need to book a seat for it.
- If flying over a long distance, try to book an overnight flight to coincide with your child's sleeping habits.

### Carry-on bags

Make sure your carry-on bag holds every item your family is likely to need during the flight including:

- Change of clothes
- Change mat
- Nappies and baby wipes
- Tissues
- Nappy rash creams
- Bottles of milk
- Favourite snacks
- Dummy (if required)
- Spill-proof drinks
- Medications and paracetamol
- Toys and games

### On the plane

- Dress your child in a couple of light layers, so you can add or remove clothes as necessary.

## A parent's story

I often travel with my son who has a severe disability, and he also suffers seizures.

We had to get a medical clearance to fly with oxygen and also a doctor's letter for Qantas to allow us to fly.

I found that staff were experienced and treated us with respect.

We were usually first to board the plane, and staff were kind enough to help carry our luggage and extra medical bags.

- Don't hesitate to ask your flight attendants for help. For example, they may be able to warm bottles.
- Don't try to change your baby's nappy on your lap – plane toilets have pull-down change tables.
- Encourage your child to drink plenty of fluids to reduce the risk of dehydration.
- Offer toys one at a time, replacing each toy with a fresh one once your child shows signs of boredom.
- Younger children will appreciate having their favourite 'security' toy on the flight.
- To avoid fights over sharing, make sure each child has their own toys.
- Ask flight attendants for playing cards or colouring books and pencils, which many airlines supply free to young passengers.
- Older children may enjoy a trip to the flight deck. Ask your flight attendant.



## Accessible holiday accommodation

Accessible holiday accommodation caters to people with mobility restrictions. This type of accommodation normally includes zero or minimal stairs, easy access to all areas by wheelchair and railings in the bathroom. Before booking hotels, ask about their accessibility features and explain your child's requirements.

Tourism Queensland's website [www.queenslandholidays.com.au](http://www.queenslandholidays.com.au) lists accessible accommodation and attractions. It also has an *Accessible Queensland Guide* that provides information on services available for people with disabilities, including transport, insurance and personal care.

The websites below may also assist you in finding accessible accommodation:

- Take A Break  
[www.takeabreak.com.au](http://www.takeabreak.com.au)
- The Bed and Breakfast Site  
[www.babs.com.au](http://www.babs.com.au)
- Big Volcano - Gold Coast and northern NSW  
[www.bigvolcano.com.au](http://www.bigvolcano.com.au)

## Holidays and recreation

### Snow holidays

[www.disabledwintersport.com.au](http://www.disabledwintersport.com.au)  
This website lists ski resorts and holiday programs for people with disabilities. Specialised equipment is available to allow adults and children with disabilities to access the mountains and ski slopes.

### Horse riding

[www.rdaq.org.au](http://www.rdaq.org.au)  
Your child can have riding lessons and interact with horses in a myriad of ways through programs offered by Riding for the Disabled, a non-profit organisation which provides therapeutic, horse-related activities around Australia.

### All abilities playgrounds

[www.communities.qld.gov.au](http://www.communities.qld.gov.au)  
All abilities playgrounds are now opening across Queensland, where children of all ages and abilities can have fun and play alongside their friends and family. The new play spaces are being created by local governments in collaboration with the Department of Communities, local communities and industry specialists,





as part of the Queensland *All Abilities Playground* project.

These playgrounds encourage different types of play and apply innovative approaches in design to break down the barriers for children with a disability.

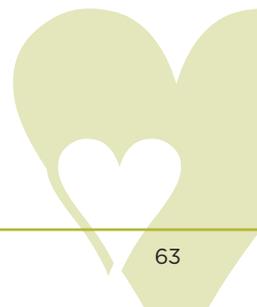
Families, parents and children with disabilities and other community members have been actively involved in the planning, design and implementation of the construction of the playgrounds. Activities range from a musical forest to a flying fox with a special harness, a

liberty swing and plenty of other sensory activities.

## A parent's story

It was scary initially to fly on a plane with a sick child, and we had to keep reminding ourselves that life must go on.

Firstly, we made sure that our son was well enough to travel and secondly, seeing his smile light up at new sights and experiences was enough to give us the courage to travel.





## Funding

Both the state and federal governments play an important role supporting carers and people with disabilities. This chapter details the type of support that is available for carers and their families to help make it easier for you to access support and services.

### Queensland government

**Department of Communities**  
[www.communities.qld.gov.au](http://www.communities.qld.gov.au)  
[www.qld.gov.au/disability](http://www.qld.gov.au/disability)

Disability and Community Care Services,

part of the Queensland Department of Communities, is probably your first port of call for information and advice on funding and services.

You need to meet certain criteria to receive services. Staff at your local Disability and Community Care Services centre can provide details on eligibility, services and how to apply.

**Medical Aids Subsidy Scheme (MASS)**  
[www.health.qld.gov.au/mass](http://www.health.qld.gov.au/mass)

The Medical Aids Subsidy Scheme (MASS) provides subsidy funding for a range of aids and equipment to

eligible Queenslanders. MASS aids and equipment help people to live at home and avoid inappropriate residential care or hospitalisation.

Aids and equipment are subsidised either on a permanent loan basis, through private ownership or through the purchase of consumables.

MASS provides subsidy funding towards:

- Communication aids - artificial larynges, speech generating devices and voice amplification devices.
- Contenance aids - disposable pads, nappies, reusable pants, catheters, sheaths, leg drainage bags and night drainage bags.
- Daily living aids - bath boards, mobile floor hoists, mobile shower chairs, non-mobile commodes, pressure reduction mattresses and transfer benches.
- Home oxygen - concentrator machines and cylinders.
- Medical grade footwear - customised and prefabricated footwear.



- Mobility aids - manual or power drive wheelchairs, wheeled walking aids and pressure reduction cushions.
- Orthoses - lower limb or spinal orthotic devices.

## Queensland discount cards

### Carers Business Discount Card

Almost 6,000 businesses in Queensland have signed-up for the Carers Business Discount Card to provide carers with discounts on products and services.

To be eligible for a Carers Business Discount Card, you need to live in Queensland and receive a Centrelink carer payment or carers' allowance.

### Companion Card

Having a Companion Card means you receive two tickets for the price of one when attending events or activities at participating venues.

Show the card when you buy your ticket and you will receive a second 'companion' ticket at no charge. This ticket is also exempt from booking fees and the cost of the ticket is covered by the business. The Companion Card is valid on public transport too.

The Companion Card is issued in the name of the person with the disability and is valid for five years.

The cardholder's companion may be a partner, family member, friend, volunteer or paid carer assistant.

To be eligible for a card you must:

- Be an Australian resident living in Queensland.
- Have a disability.
- Be unable to participate at most community venues or activities without care support.
- Need, or be likely to need, lifelong attendant care support.

The Companion Card is neither income nor asset tested and is recognised throughout Australia.

Find out about interstate programs on the National Companion Card at [www.companioncard.gov.au](http://www.companioncard.gov.au).

## Australian government

### FaHCSIA

[www.fahcsia.gov.au](http://www.fahcsia.gov.au)

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) funds:

- 'Better Start' - for children aged under six, diagnosed with Down syndrome, cerebral palsy, fragile X syndrome, or a moderate or greater vision or hearing impairment.
- 'Helping children with Autism.'
- Outside school hours care for teenagers with a disability.
- Disability parking scheme.
- Free AUSLAN interpreter service for medical appointments.

### Centrelink

[www.centrelink.gov.au](http://www.centrelink.gov.au)

Centrelink pays the disability support pension and a range of allowances, including:

- Carer payments
- Rent assistance
- Telephone allowance
- Utilities allowance
- Mobility allowance
- Education supplements
- Pharmaceutical allowance

### Health Care Card

If you are eligible for a Health Care Card, you will have access to cheaper pharmaceuticals and other savings, like bulk billing for doctors' appointments and childcare discounts.

You may be eligible for a Health Care Card if you receive a Centrelink payment.

### Continence Aids Payment Scheme (CAPS)

[www.bladderbowel.gov.au](http://www.bladderbowel.gov.au)

It is expensive managing a child's incontinence, especially when relying on incontinence products. The Continence Aids Payment Scheme (CAPS) provides payments to help you to meet some of the costs of continence products, like nappies and nappy wipes.

Your child may be eligible for the CAPS if they are five years of age or older and have permanent and severe incontinence due to an eligible neurological or other eligible condition verified by a health professional.



# Carer's Checklists

These checklists will help you identify the necessary steps you need to take to access services and support for your child as they develop. Not all points may apply to you and the list is not exhaustive. Please remember, your physical and mental health is important. Always seek help from your GP if you feel overwhelmed.

## Carer's checklist: 0-3 years old

- Attain referrals from your GP to a paediatrician, specialists or allied health professionals and relevant hospital clinics.
- Join support groups or establish relationships with families in similar situations.
- Contact charities that support and provide services for children with disabilities and medical conditions.
- Register with Centrelink for a carers' pension or allowance.
- Contact community support networks to access respite care, education and therapy.
- Register with relevant government departments.
- Seek out childcare services.
- Seek out schools for children with special needs.
- Start researching and applying for various funding programs.
- Research emergency respite services.
- Contact your local Carers Australia Association for information on support available.
- Apply for various carers' cards.
- Seek out youth and mental health groups for your child or for sibling support.
- Discuss equipment options and long-term home modifications with your local allied health team.
- Register with your state housing department if you require home modifications.
- Research training in relation to lifting and people handling.

## Carer's checklist: 3-4 years old

- Access an occupational therapist or physiotherapist knowledgeable about disability services to help you apply for equipment through a subsidy scheme.
- If your child needs support with their communication skills, talk to a speech pathologist who specialises in alternative and augmentative communication.
- Apply for funding for communication aids.
- Consult with your allied health professional to apply for disability parking permits.
- Start applying for taxi schemes.
- Contact the Australian Taxation Office to see if you might be eligible for tax concessions.
- Investigate how you can modify your home through various services and funding bodies.
- Discuss long-term equipment and home modification needs with your allied health professional.
- Start preparing your child for school. Some charities have education consultants who can link you to an Advisory Support Teacher.
- Research schools and attend open days for the ones you are considering for your child.
- Make an appointment with the head of each school to discuss your needs and the supports available.

## Carer's checklist: 4-6 years old

- Start applying for the Federal Government's Continence Aids Payment Scheme for nappies and continence products, if needed.
- Apply for flexible holiday programs through relevant schools and charities.
- Apply to various funding organisations, and please note that this is an ongoing process.
- Reapply for new pieces of equipment through subsidy schemes for equipment and aids.
- Research respite services - early introduction to respite services will allow your child to become familiar with care provided by others.
- Discuss respite care staff training needs with your allied health team.
- Discuss your child's school readiness needs and their social interaction skills with your allied health team and involve them in any goal-setting or service planning.

# Carer's notes



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# About the authors

## Tanya Dennis

Tanya Dennis (pictured right) is a strong advocate for disability rights. She is mother and carer of son Jaden who was born in 2002 and has 1p36.3 Deletion Syndrome. This is a chromosomal disorder which manifests as global delay, visual and audio impairment.

It was during Jaden's initial hospitalisation that Tanya began to see the challenges of life ahead and the need for some form of guidance. In order for Jaden to have the best life possible, she realised she would have to become his number one advocate.

In compiling this book, Tanya sought to provide a survival kit for other parents and carers to empower them with the knowledge to navigate the 'maze' that is disability services.

Tanya and her partner David Marler have also developed the website [info4carers.com](http://info4carers.com) that hosts the *You are Not Alone - A Carers Journey* eBook plus additional resources.

Tanya lives in Brisbane with David and Jaden.

## Michelle Rhodes

Michelle Rhodes (pictured left) is also a strong disability rights advocate and is mother and carer of eight year old Jackson, who has cerebral palsy. Cerebral palsy affects the way the brain controls the body's muscles resulting in speech, movement and posture difficulties.

Michelle is a qualified primary teacher, personal trainer and a swimming instructor for people with disabilities.

Michelle found that it was sometimes a struggle to find the right information about disability services, support and information. She hopes this book will become a ready resource and reference guide for Queensland parents and carers of children with disabilities.

She lives in Brisbane with her husband Peter and Jackson.







cerebral palsy league

