



# There's no such thing as a silly question

**A practical guide for families living with a  
child with chronic illness, disability, mental  
illness or a life-threatening condition.**

July 2017

This WA version of "No Such Thing As A Silly Question"  
has been funded by the Disability Services Commission

## Acknowledgements

This book has been adapted for Western Australia from the original Victorian publication produced by interACT.

We wish to thank the following people for their commitment and contribution to this book:

- **Mary Butterworth** – Developmental Disability WA
- **Leticia Grant** – Kalparrin
- **Dr Rachel Skoss** – Telethon Institute for Kids

We also extend our thanks to interACT for allowing us to bring this valuable resource to a West Australian audience. InterACT is a group based in Victoria and committed to helping parents, caregivers and service providers work together for the benefit of children with additional needs, from birth to 18 years and their families.

Our thanks to all the parents who have provided insight into living with a child with chronic illness, disability, mental illness or a life-threatening condition.

© InterACT

No part of “There’s No Such Thing As A Silly Question” may be reproduced or copied in any form or by any means without the permission of InterACT.

ISBN 978-0-646-47303-1 Design: the Wizarts



(08) 9340 8094  
[www.kalparrin.org.au](http://www.kalparrin.org.au)



(08) 9489 7777  
[www.telethonkids.org.au](http://www.telethonkids.org.au)



(08) 9420 7203  
[www.ddc.org.au](http://www.ddc.org.au)

# Table of Contents

## Introduction.....8

## General Information.....10

Pre-Diagnosis .....	12
Immediately After Diagnosis .....	13
Helpful Tips.....	14
Taking Control .....	16
Grievance Policies .....	17
Access to information .....	18
Your Child's Voice .....	18
Hospital Admissions – Public or Private .....	19
As an Inpatient.....	20
As an Outpatient.....	20
Specialists .....	22
Consultations: Public vs Private .....	23
Changing Specialist or Getting a Second Opinion .....	23
Specialised Paediatricians .....	24
Pharmacies .....	25
Pharmaceutical Benefits Scheme (PBS) Safety Net.....	25
Medications .....	26
Developing a Care Plan for Your Child.....	27
Enhanced Primary Care Program.....	27
Emergency Medical Plan (EMP) (also referred to as Action Plan).....	28
Calling an Ambulance .....	30
Ambulance Costs in WA .....	31
Mental Health Care Plans.....	32
Coping Strategies (for day to day and beyond) .....	33
Logistics .....	36
Equipment.....	38

Financial Considerations .....	39
--------------------------------	----

## Going into Hospital.....42

Hospital Admissions - Hints & Tips .....	44
Interpreters .....	49
Aboriginal Liaison Officers.....	50
Transition to adult services .....	51
Country/Regional Families Attending Health Services in Perth.....	52
Hospital Personnel Terminology.....	53

## Who will help us in the community? .....54

Child Health Centres.....	56
Child Development Service .....	58
Disability Services Commission and the NDIS.....	62
Early Childhood Intervention services.....	63
School-aged supports .....	65
Finding service providers.....	65
Challenging behaviours.....	66
Respite.....	67
Going to School .....	69
Confidentiality .....	70
Communication .....	70
Siblings.....	70
Transport.....	71
ACROD Parking Scheme.....	71
Western Australian Patient Transport Assistance Scheme.....	71
Angel Flight .....	71
Leukaemia Foundation Transport Services .....	72

## *How to Give Your Life 'Balance' .....74*

Key Sources of Support.....	76
Family and Friends.....	77
Taking Care of Yourself .....	78
Caring for the Whole Family.....	80
The Non-Primary Carer's Perspective .....	81
Siblings.....	82
Building Resilience in Your Family.....	85

## *Glossary.....86*

## *Publications.....90*

For Parents.....	92
For Kids .....	93
For Siblings .....	93
Bereavement Literature .....	94
Specialist Library.....	94

## *Resources & Services.....96*

Advocacy & Support.....	98
ConnectGroups.....	98
Continence Advisory Service of WA.....	98
Developmental Disability WA .....	99
Disability Discrimination Unit.....	99
Genetic and Rare Disease Network.....	100
Independent Living Centre.....	100
Kalparrin.....	101
Make A Wish Foundation.....	101
Midlas.....	102
My Time Peer Support Groups .....	102
Ngala.....	103
PWd WA.....	103
Redkite .....	104

Ronald McDonald House .....	104
Ronald McDonald Learning Program.....	104
SANE Australia .....	105
Starlight Foundation .....	105
TADWA (Technology Assisting Disability Western Australia) .....	105
Telethon Speech & Hearing.....	106
WA Companion Card Program.....	106
Counselling.....	107
Kids Help Line .....	107
Lifeline .....	107
Parenting WA Line.....	107
Relationships Australia .....	107
TCF - The Compassionate Friends.....	108
Carers Australia WA.....	108
Anglicare .....	108
Early Intervention.....	109
Ability Centre .....	109
Autism Association of WA .....	109
Disability Services – Early Years Metropolitan Program.....	110
ISADD WA .....	110
Kids Are Kids!.....	110
Next Challenge .....	110
Rocky Bay .....	111
Senses Australia .....	111
Skillbuilders .....	111
Telethon Speech & Hearing.....	111
Therapy Focus .....	112
Therapy, Learning & Communication – WA.....	112
VisAbility .....	112
Wize Therapy.....	113
Respite & Recreation .....	113

Activ.....	113	Interstate Patient Travel Scheme.....	124
Alkira Care Respite Services .....	114	Patient Assisted Travel Scheme .....	124
Avivo (formerly Perth Home Care Services).....	114	Royal Flying Doctors Service (RFDS) .....	124
IdentityWA Children’s Houses .....	114	Vehicle Modifications.....	125
Inclusion WA.....	115	Wheelchair Accessible MAXI Taxi.....	125
Lady Lawley Cottage (Red Cross).....	115		
Government .....	116		
Centrelink.....	116		
Child Development Service .....	116		
Disability Services Commission .....	117		
Department of Education .....	117		
Department of Local Government & Communities .....	117		
Health and Disability Services Complaints Office.....	118		
Interpreting & Relay Services.....	118		
Translating and Interpreting Service (TIS National).....	118		
W.A. Interpreters Pty Ltd. ....	118		
NABS.....	119		
National Relay Service (NRS) .....	119		
Medical & Health Services.....	119		
Child and Adolescent Mental Health Service .....	119		
Child and Adolescent Health Service .....	120		
Princess Margaret Hospital (PMH).....	120		
Perth Children’s Hospital .....	120		
King Edward Memorial Hospital.....	121		
Health Direct .....	121		
HACC – Home and Community Care.....	122		
Fiona Stanley Hospital.....	122		
Transport.....	123		
ACROD Parking Program .....	123		
Angel Flight Australia .....	123		

## Introduction

The aim of this book is to assist parents of children with chronic illness, disability, mental illness, or a life-threatening illness to find their way around the medical and community systems. This book will help parents identify and access the help and support they think is appropriate for them, their child and their family.

It also aims to provide insight into how parents can care for themselves and their families at a time when personal resources may be stretched to the limit. There are many resources available that address parenting, care issues and services available to families. The information presented here aims to sit alongside a range of other resources available.

It is not intended that this book be read from cover to cover, rather it is meant to be a resource book to be kept and referred to when needed.

Note: The terminology used in this book may differ from that used in other resource publications.

Information regarding services and resources is applicable for the state of Western Australia only, but may have a generic application in other states.

“Remember to enjoy your child for who they are and what they can do, rather than for what they are unable to do.”  
(Karen – parent)







*"Remember to enjoy  
your child for  
who they are and  
what they can  
do, rather than  
for what they are  
unable to do."*

(Karen – parent)



# *General Information*

*"I actually felt better when the diagnosis finally came, after 7 years of unexplained development delays it was almost a relief to know the reason! To have a name and a prognosis for what may be to come"*

**(Trisha T- parent)**

## *Pre-Diagnosis*

The time leading up to a diagnosis for your child can be unsettling and stressful. You may experience a range of emotions and a genuine sense of loss. Try not to be discouraged by the time, process, or lack of certainty around your child's diagnosis.

Remember too your 'gut feeling' can be a useful tool. Parents are so intimately attuned to their child that they can often tell when the slightest thing is wrong, even with a child who has no formal communication. Even if it is difficult to express your concern in words, don't give up. Seek service providers who will listen to and support you.

Do not underestimate the valuable anecdotal, observed and/or recorded information that you can provide to specialists, which may assist them in their diagnosis. Make a note of things that you notice about your child's health, behaviour and emotions. Keep a notebook or diary, and record things such as the time of day, nature and length of the episode/behaviour, its frequency, and any factors that you think may have contributed to the symptom/behaviour being displayed. Take this information with you to appointments, as it may be helpful for professionals in discerning what is causing your child's difficulties.

Regrettably, there will always be a small number of cases where a diagnosis is never obtained, however, the symptoms may still be treatable.

In this disorienting time, try to surround yourself with people from your personal circle of family and friends and also from within the medical and allied health professions, who have the capacity to be supportive of your child and your family's needs.

Consider making appointment times where both parents can attend together, so that two of you hear the same information first hand and both have the chance to ask specific questions. If this is not possible, or you are a single parent, consider taking an advocate (friend/family member/other health professional) with you.

## *Immediately After Diagnosis*

Immediately after diagnosis you and your family are likely to feel a variety of emotions including; denial, devastation, fear, vulnerability, desperation and/or anger. You may also experience a sense of relief in having a name for your child's condition and/or special needs. This can be a very stressful time as you are forced to face your child's diagnosis and its potential ramifications. You may experience some aspects of grief as you try to come to terms with the loss of the expectation you had for a healthy child.

Sharing the news of your child's condition will inevitably see people respond in a variety of ways. All will feel for you but not all may show this. Many will not know what to do or say and some will, in fact, not say or do anything. This can be very upsetting. Others may refuse to believe what you have been told or may cite examples of people they know, or have heard of, who have lived with a similar situation. It's important to realise this is all well-meaning but, if you find it all too stressful, it's okay to tell these people 'Thanks, but no thanks'. Others will just be there for you, may cry with you, and let you talk when you want. These are the people that you may want around you.

*"At first, our daughter's diagnosis consumed my thoughts during all my waking hours. All I could think of was that she was going to be dependent on others for all of her life. What would happen to her in our old age? I was afraid, sad, and overwhelmed. Months later I also became very angry. All these emotions, and more, bubbled to the surface from time to time, I learned later that this was a natural grieving process and eventually it brought acceptance of our situation."*

**(Sharon - parent)**

*"When my son was diagnosed I felt as though life, as I knew it, disappeared. I could not see my future as I had planned it, the dynamics of our family and our lifestyle had changed and I needed to find people who could understand how this felt"*

**(Trisha T - parent)**

*“When our son was first diagnosed, I scoured the internet and social media and contacted everyone I could. My husband didn’t read anything. Later he did. Now I know that at the time he couldn’t, he needed time to absorb & adjust first. Just because we parent the same child doesn’t mean we cope the same way.”*

**(Lily B – parent)**

## *Helpful Tips*

Immediately after the diagnosis you may feel overwhelmed and confused. Here are some suggestions to help put some stability and structure into your life at this point:

**Find a good General Practitioner (GP)** if you don’t already have one. You could ring your local general practice and ask them to recommend a readily available GP who will suit your needs. Alternatively, attend a clinic where there are GPs who are familiar with your situation, and bring them up to date on your child’s health needs. Your GP can be really useful for your whole family and can be a great coordinator if you are seeing a number of specialists.

**Use the internet wisely** as a source of information on your child’s condition. It might be helpful for gaining more information and understanding, but ‘be warned’: not all that you read on the internet is necessarily true or accurate. Always discuss what you have read with your child’s doctor(s) before acting on recommended medical management or alternative treatment therapies.

**Consider writing an open letter** to family and friends explaining what you know about your child’s condition. Tell people in the letter how they can be of support to you and your family and if appropriate, maybe even make suggestions about what they might avoid doing.

**Consider using the answering machine to screen calls**

– you can easily spend all day and night returning calls. It is okay to only answer the phone when you feel like it. Alternatively, at times you may choose to switch it off altogether.

**Choose whom to tell about upcoming appointments**

as you may be overwhelmed with phone calls afterwards, requiring you to retell the same story.

**Focus on looking after yourself and your immediate family**

– let other people support extended family and friends.

[Refer to pages 74-85 How To Give Life Balance]

**Consider providing your written or verbal consent to service providers.**

This will enable them to obtain information from doctors, hospitals and community providers you use, cutting down the number of times you have to repeat your child's history.

**Consider setting up a website** about your child where you can add new information as it comes to hand. Give the address to friends and family so they can get updates in a non-obtrusive way.

**Identify helpful supports**, such as a few key friends and family members who will be there for you unconditionally.

[Refer to our Resources/Services section, pages 96-125]

**Take each day as it comes** and although it may be difficult, try not to think too far ahead in the beginning. Don't try to take in too much information, only what is necessary and helpful at the time. Keep notes or a diary if it helps.

*“At first, I spent a lot of time worrying about the years ahead, but I realised that such thinking was unproductive. I learned to take a day, or even an hour, at a time.”*

**(Karen - parent)**

*“My mum has come to every major appointment since week 23. It helps to have someone else HEAR the information you are given. Once my paediatrician mentioned there was a problem, I found it very hard to hear anything else he had to say. I also misinterpreted some of the information in following appointments, which my mum later cleared up when we reviewed the appointment in the car going home.”*

**(Fi - parent)**

## *Taking Control*

When your child is diagnosed with a chronic illness, disability, mental illness or a life-threatening illness, you may feel overwhelmed and out of your depth. You will suddenly be thrust into the unfamiliar world of health professionals, and may feel that you have little power to contribute to the management of your child's condition. The following are some helpful suggestions from other parents who have been in the same situation:

- **Learn as much as possible** about your child's condition/illness and the treatment and management options. Knowledge and information are power and help to keep the lines of communication open and honest.
- **Make a list of the questions** you want answered, adding to it each time you think of one and take it with you to your child's appointments. Do the same in hospital and have the list ready for the doctors' ward round.
- **Don't be afraid to ask questions**, to disagree, or to challenge what medical, nursing or allied health professionals say. Ask for more detail, or for a simpler explanation if required. They are experts in their fields, and you are an expert on your child. See yourself as an equal part of a team who is managing the care of your child. If you feel you are not being heard, ask for an advocate to help you.
- **Determine your choices based on ALL your options.** You are your child's most important advocate. You also have the right to ask for a second opinion or to choose a different doctor.
- **Take another person with you to appointments:** they can help remember more about what was discussed, and can prompt questions you may have planned to ask.



# Grievance Policies

If you feel concerned, disappointed, angry or upset with any aspect of treatment or care within a specific hospital, or by a specific health professional, you are able to voice those concerns internally within the hospitals through the following channels:

- At **Princess Margaret Hospital (PMH)** address your concerns to the Child and Family Engagement Service: Phone (08) 9340 8315
- At **Perth Children's Hospital (PCH)** address your concerns to the Child and Family Engagement Service: Phone TBA
- At **Fiona Stanley Hospital** address your concerns to the Patient and Family Liaison Service: Phone (08) 6152 4013, Email: fshpatientfamilyliaison@health.wa.gov.au
- At other hospitals, enquire (through the Social Work Department) as to who is the appropriate person for you to speak with about your concerns.

If you have tried all the options available and are still not happy with the outcome you can contact Health Consumers' Council, phone 1800 620 780 or Email: info@hconc.org.au

Should the issue not be resolved internally, or you have a concern about a disability-related service, you can voice those concerns externally through The Health and Disability Services Complaints Office (HaDSCO). The HaDSCO's complaints resolution service is free, impartial and confidential. It encourages parties to discuss complaints and works towards mutually agreed outcomes. HaDSCO is generally unable to deal with complaints which are more than two years old or have already been determined by a court, registration board or tribunal. In these cases, referrals to alternative organisations may be suggested.

In the first instance, HaDSCO encourages complaints to be raised with the service provider. Complaints are generally resolved more quickly if service providers are offered a chance to address the issues. A complaint can be lodged by the service user or a nominated representative, for example, a family member, carer or guardian.

If this proves unsatisfactory, complainants should call HaDSCO's Assessment Team, Ph: (08) 6551 7600 to discuss the complaint. The HaDSCO Assessment Team will outline the options, explain the complaints process and organise a complaint form to be sent by post. Alternatively, complaint forms can be completed online or downloaded as a PDF, and returned by fax, email to mail@hadsco.wa.gov.au or post.

All complaints must be confirmed in writing. Once completed forms are received, HaDSCO determines how best to deal with the complaint and may contact the service provider.

Support organisations within the community will also have avenues through which to address any complaints or grievances you may have. Always feel free to ring and speak with someone if you have concerns or a grievance. Alternatively you can address your concerns to the appropriate person in writing.

*“My son made it quite clear that he didn’t understand the doctor. So he asked him – ‘Can you please talk in my language?’”*

**(Lisa B – parent)**

## *Access to information*

Under the freedom of information Act 1991 and the Code of Fair Information practice you have the right to access and amend the personal and health information about your child. Please contact your health service for more information and a request form.

## *Your Child's Voice*

As a parent, you will instinctively observe and understand your child’s needs, state of mind and level of discomfort or pain. Never underestimate your gut feeling if you think that something may be wrong. Even if you are unfamiliar with medical terminology, don’t give up in your interactions with health professionals when conveying concerns you may have about your child’s health. If your child’s condition is not easily identified, it does not mean that your concerns are not warranted. It might mean that more tests or observations are needed. Keep searching for the answers and don’t give up. Seek second and third opinions if necessary.

If your child has no formal communication skills, you will need to be his/her ‘voice’ when dealing with others. For younger children, you will be their ‘voice’ regardless. If your child can communicate in some way, allow him/her to play a part in care and treatment choices.



# Hospital Admissions – Public or Private

In Australia we are fortunate to have two healthcare systems - the public and private systems. Both the public and private systems have their advantages/disadvantages, but there are ways that you can utilise both effectively. Naturally, this will depend on your child's situation.

**The Public System** is funded by the government, where your child will be treated according to how sick they are assessed to be. In the public system, doctors of various levels will treat your child and you are not able to choose which doctor will provide your child's care.

The public hospital system is also a teaching system where students and junior doctors are taught medicine. When your child is admitted to the public system they will be admitted under the care of a unit e.g. Neurology, Respiratory Medicine. A Consultant is always the head of a unit and oversees the care that Residents, Registrars and Interns carry out on his/her behalf. [see section on Hospital Personnel Terminology]

**The Private System** is where you pay to be treated by the doctor of your choice. This doctor is a specialist in his/her field (Consultant). When admitted as an inpatient to hospital, your child will be treated by your chosen Consultant only, and you may choose which hospital you wish your child to be treated in. Remember, that most private health insurance companies will not reimburse you for hospital stays relating to pre-existing conditions until you have been a member for 12 months. They also have lists of preferred 'member hospitals' with whom they are affiliated.

Your private health insurance may also only cover the costs of your child's hospital stay. Your child's treating doctor may charge you for visits and treatments carried out while they are an inpatient. As these arrangements vary from doctor to doctor, please check with the treating doctor and your health fund about any out of pocket costs.

## As an Inpatient

Being a private patient doesn't necessarily mean your child will have a single room. It only means that you can choose your hospital and treating Consultant. Single rooms are allocated based on the clinical needs of a patient.

They may also be used to isolate patients with serious infections. There are few advantages to being admitted as a private patient in a public hospital. There is no difference in your care and Interns will still treat your child because it is a public hospital. Private admission is worthwhile if you want to choose your own Consultant, or if you want your child to be treated in a private hospital for elective procedures.

Your child has the right to be admitted as a public patient even if you have private health insurance. Public admission is advisable when your child gets sick and you do not know what is involved in treatment and tests.

If choosing to be admitted as a private patient in a public hospital you need to do your research. Check what post discharge supports will be available to your child. As a private patient your child may not be able to access programs such as Hospital In The Home or Post-Acute Care. This may impact on your child's length of stay in the hospital and effect the level of support you may be entitled to on discharge.

## As an Outpatient

If you see your Consultant privately for out of hospital appointments, you will have the advantage of him/her knowing your child's history (and getting to know you). The costs are usually greater, but some specialists bulk bill children with a disability or chronic illness, others reduce their rate. It is wise to ask about costs before you make appointments. You do not need private insurance to see a specialist privately. In fact, private health insurance may not cover the costs of outpatient specialist appointments, however some rebate may be available from Medicare. With Private Insurance Extras, you may get a rebate for some allied health professions, such as physiotherapy, speech pathology, occupational therapy, psychology, dentistry.

If you are using the public system for outpatient appointments, there will be no cost for the consultations, but there are often long waiting periods on the day and you may see a different doctor each time. If you need to see more than one doctor, it may be useful to try and book multiple appointments on one day, so you can reduce the number of trips to the hospital.

Here are some tips from parents who have had outpatient appointments:

- **Arrive early** to allow for your child's check in and weighing, if needed.
- **Bring snacks/activities for the waiting period**, especially for young siblings who may be with you.
- **Allow about 3 hours per clinic appointment** (to allow for parking, waiting, the appointment, any extras required by the doctor that day e.g. x-rays).
- **Try to get your other children cared for** on the day so you can concentrate on your child who is seeing the doctor.
- **If your child needs a prescription on the day**, ask if it will be available at your local pharmacy (an 'outside script'). This may be more convenient for you, especially if there are repeat scripts to be collected in the future. The alternative to an outside script is a prescription that is available only at the hospital pharmacy, which may be convenient to collect on the day you are there, but not if you have to collect repeat scripts at a later date.

**Note:** Sometimes with rare conditions or specialist clinics you may only be able to be seen in the public system, for example; Metabolic, Cystic Fibrosis, Genetics etc. As these are specialised areas it is often best that you are under the care of the public system. The doctors working in these units will have more experience in these areas. Often your case will need to be discussed with a team of health professionals. This can happen quickly and seamlessly under the care of these units.

*"I have moved between both the public and private systems for my son's care. I feel this has enabled me to get the best of both worlds. His consultants know him and me very well, which has proved very beneficial when caring for him when he has been unwell."*

**(Lisa E - parent)**



## Specialists

To see a specialist doctor, you will need a referral from either a GP or another specialist. Referrals from GPs are valid for 12 months, while referrals from other specialists are valid for 3 months. If your child needs to see the specialist beyond the date covered in the referral, then you will need a new referral from the original doctor.

It is your responsibility to ensure that your child's referral is current at the time of the consultation, although staff may remind you when you contact the specialist's office for an appointment.

If the specialist is likely to have a long-term involvement with your child, you may ask if he/she would accept an 'indefinite referral' from your referring doctor, as this will save you having to remember to update that referral on a regular basis.

If you have a preference, you can ask to be referred to a specialist of your choice. When choosing your child's specialist consider:

- The recommendations of other parents: word of mouth can be a valuable resource.
- Will you prefer a specialist who offers bulk billing?
- Are you prepared to travel the distance to the consulting rooms on a regular basis, if required?
- If your child is likely to be admitted to hospital, should you see a specialist who consults at the hospital your child is most likely to utilise?

## Consultations: Public vs Private

**Public consultations:** some specialists consult in the Outpatients Department of public hospitals. There may be delays on busy days and the length of the appointment may be limited. Public consultations are usually bulk billed.

**Private consultations:** you may see a specialist privately at his/her own rooms if you wish. In this case you have the advantage of being able to build a relationship with that person, and he/she can admit your child as a public patient if a hospital admission is required. With private appointments there are often shorter waiting times, appointments can be made sooner, and you have more choice of appointment times. Another advantage is that if you take your child to the emergency department, staff will phone your Consultant (or their representative) and liaise with them directly. Private consultations with specialists usually incur a charge, but some specialists may bulk bill in certain situations.

## Changing Specialist or Getting a Second Opinion

After an initial consultation, it is important to ask yourself:

*“Do I feel comfortable with this specialist?”* and

*“Can I see us developing a good working relationship with him/her?”*

If for any reason you are not satisfied with the specialist your child is seeing, you are entitled to request a referral to a different specialist. This can be difficult for parents, who may feel embarrassed or concerned that such a request will impact on the potential treatment of their child. It is crucial that you have trust and confidence in your child's doctor as well as good communication. Remember that you are your child's advocate. It is vital that you are able to work in partnership with your child's specialist to achieve the best health outcome for your child.

*“We were not happy with our daughter's first neurologist, for a number of reasons. I asked around and attended information sessions about epilepsy, and found another neurologist who, fortunately for us, was able to take our daughter on as a new patient. This new person worked well with us throughout our daughter's life, and we were glad we had made the change.”*

**(Karen - parent)**

## Specialised Paediatricians

Children with complex or chronic medical issues may need long term attention from a paediatrician. Your child may be referred to a paediatrician for an opinion on a particular problem and may only need a few consultations with a general paediatrician. In this case it may be worth requesting a referral to a paediatrician specialising in child development and/or disability, who can co-ordinate treatment for all your child's ongoing medical needs.

If you are not referred from within a hospital, your GP may refer your child to a paediatrician specialising in developmental medicine, perhaps one of your choosing. Be aware that many have long waiting lists, so look around, choose carefully and, if you wish, get recommendations from other parents. Many people believe that a developmental paediatrician is not necessary and that it is just one more specialist to see. But others are convinced that such a specialist plays a vital role in coordinating their child's care. It is, perhaps, something that you will discern only after a period of time, as you become more familiar with your child's needs.



# Pharmacies

It is helpful to go to a pharmacy where you can build and maintain a relationship with both the pharmacist and staff, as you will need to feel confident talking with them about your child and family's health issues. You also need to be able to trust their knowledge and their respect for your confidentiality. You are quite within your rights to shop around for a pharmacist/pharmacy that you are comfortable with, just like you would for a doctor.

## Pharmaceutical Benefits Scheme (PBS) Safety Net

If you or your family need a lot of medicine in a calendar year, the PBS Safety Net helps you with the cost of medicine. Keep a record of your PBS medicine on a Prescription Record Form (PRF) which you can get from your pharmacy. Each time you have a PBS medicine supplied, hand your form to the pharmacist so the supply can be recorded. Your pharmacy might be able to keep a record for you on their computer, but if they can't or if you visit different pharmacies, it is best to keep your own records. If you have a family, ask your pharmacist about combining the amounts you spend for your Safety Net total. (Please note that all medicines dispensed and paid for at a hospital pharmacy count towards the Safety Net Threshold. This should be discussed with the hospital pharmacy staff when you collect your medicines).

Once you or your family reach a Safety Net Threshold, you can apply for a PBS Safety Net card and your PBS medicine will be less expensive or free for the rest of the calendar year. Private prescriptions (non PBS) cannot count towards the PBS Safety Net. For more information about the PBS Safety Net, talk to your pharmacist, visit your local Medicare office, visit Medicare Australia's website ([www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)) or call the PBS information line on 1800 020 613

Private prescriptions may be claimed through Private Health Insurance. Make your decision as to which way you want to go based on these facts and your personal circumstances, not on what the pharmacist may say is easier.

# Medications

Some children will need a range of medications. The following might be useful things to consider to reduce the hassle in getting the required medications:

Make sure you understand everything you need to about new medication and do not be afraid to ask questions. Ask for the fact sheets so you can read the information at a time that suits you (if you need to).

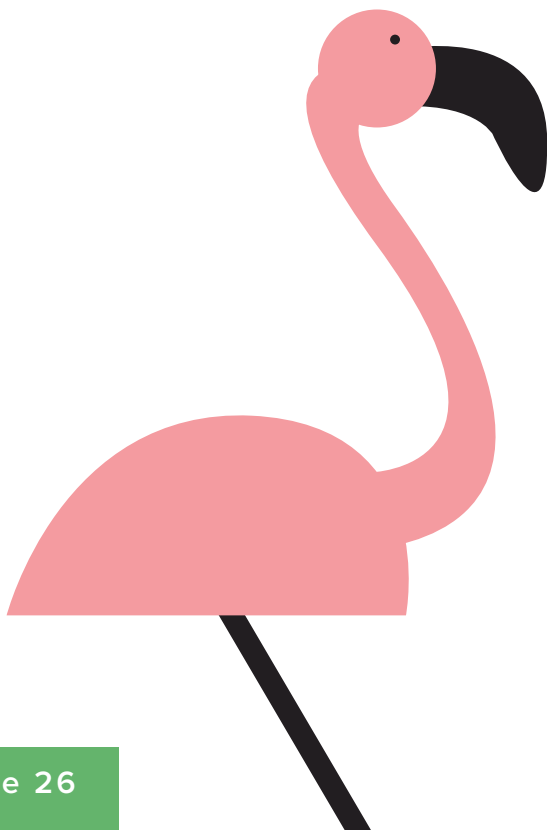
If your child is on regular medication make sure you find out if it will be readily available via your chosen pharmacy. If not, ask to have it kept in stock so that it is available for you when you need it.

Find out if your pharmacy offers a delivery service, and use it to save yourself time.

Some over the counter medication can be prescribed by your doctor so that you can obtain it at the reduced rate with a Health Care Card e.g. some laxatives, paracetamol, creams etc.

If your child needs medication urgently, it may be possible to have your child's script faxed to your chosen pharmacy, and the original posted to them.

If your child needs a lot of different medications at various times of the day, you or your pharmacist may be able to make up a webster pack (which puts the medications into different compartments for the time of day and day of the week). This makes it easier to remember what is needed at what time.



## *Developing a Care Plan for Your Child*

A Care Plan is a document that contains all treatments, therapies, nutrition, medications and routines specific to your child. It also includes emergency contacts, preferred doctors/specialists, primary hospital, and other relevant information.

Developing a co-ordinated Care Plan in conjunction with the programs, services, specialists, health professionals and allied staff involved with your child is recommended. The Care Plan is a fluid document in that it accurately reflects the medical management required by your child at any given time.

If your child's Care Plan is co-ordinated by his/her GP, he/she may be entitled to a Medicare rebate for services provided by aboriginal health workers, nurse educators, audiologists, exercise physiologists, dieticians, mental health workers, occupational therapists, physiotherapists, chiropractors, osteopaths, psychologists and/or speech pathologists. More information is available from [www.health.gov.au](http://www.health.gov.au) under "chronic disease management information".

## *Enhanced Primary Care Program*

The Enhanced Primary Care Program was introduced to provide more preventive care for older Australians and to improve the coordination of care for people with chronic conditions and complex care needs. Essentially, these plans aim to improve the quality of care by encouraging all health professionals to work together to improve patient outcomes. They are specifically for people with chronic health problems. Through these plans your child may be eligible for a number of Allied health appointments with a Medicare rebate. Speak to your GP for more information about what might help your child.

# Emergency Medical Plan (EMP)

*(also referred to as Action Plan)*

An Emergency Medical Plan [EMP] is a readily accessible document or process which is activated when/if your child has a medical emergency. It is specific to your child's existing medical condition. These plans are frequently requested by schools and childcare centres so that they are aware of your child's medical needs and your requested responses, in consultation with your GP/Specialist.

The information is commonly known and shared by those coming into day to day contact with your child (including siblings if appropriate), but it is of equal benefit and guidance to others e.g. ambulance paramedics, respite providers.

In addition to an EMP, your child's specialist may provide a letter with a written instruction of what to do in the case of a medical emergency, specific to your child's general presentation. In order for these instructions to be followed, it is essential that the document be:

- Up to date [reviewed every 3 months by the specialist]
- In close proximity to your child at all times
- Copied and circulated to all of your child's carers and teachers

For some families, this measure can reduce unnecessary hospitalisations. Without these authorised instructions, ambulance paramedics will have no choice but to treat and/or transfer your child to hospital as per their protocol. Your child's EMP can take any number of formats. It is not intended to be a comprehensive Care Plan, but a document and/or process which gives essential information in a concise format, to any person assisting your child in the event of an emergency, **specific to their existing medical condition**.

When you are developing an EMP for your child, include the following:

- Child's name, date of birth and address
- Child's condition and treating hospital
- Likely presentation/s e.g. seizures, apnoea, choking
- Triggers: heat, tiredness, certain foods
- Current medical management: (The best way to intervene and assist your child in the event of one of the above presentations)
- Specific circumstances in which an ambulance should be called
- List of current medication/s and dosages
- Allergies and/or allergic reactions
- Names and contact details of parents
- Name and contact details of doctor and/or specialist
- Authorised documentation from doctor/specialist attached: Yes/ No

# Calling an Ambulance

After you have rung triple zero (000), the dispatcher will ask the following general questions:

- What is the exact address of the emergency?
- What is your call back phone number?
- What is the problem? (What exactly happened?)
- How many people are hurt?
- How old is the person needing an ambulance?
- Is the person conscious?
- Is the person breathing?

The answer “No” to the last 2 questions results in the immediate dispatch of the maximum ambulance response. Further questions may be necessary, which will enable ambulance staff to prioritise your request promptly and determine whether the patient requires Intensive Care (MICA) Paramedic skills.

It may be helpful to have a copy of the above questions, along with answers, close to your telephone.

**Calls to triple zero (000)** – dialling 000 will connect you to emergency services from any fixed, mobile or pay phone and is free of charge. Calls to 000 can be dialled from a locked keypad of a mobile phone. Many newer digital phones require the user to dial 112, the international standard emergency number (see below). Consult your telephone company if you are uncertain how to access the 000 emergency network.

**The 112 Emergency Access Number** – when you connect to a mobile telephone service, the 112 International Standard Emergency Access Number is automatically activated, free of charge. It can only be dialled on digital mobile telephones, not on fixed lines (land lines) or from other technologies. Advantages of this number are:

- It can be dialled from anywhere in the world where there is GSM (Global System for Mobile Communications) coverage. This means that if you are out of your mobile phone company’s coverage area, but in an area that is covered by another mobile phone service provider, that network will carry your call.
- It will connect you to the local emergency number in whatever country you are in, to contact ambulance, police or fire services.
- 112 or 000 can be dialled while the keypad is locked
- You do not need to have a SIM card in the mobile phone to access this service

**Text-based emergency call service:** calls to 106 – this service is available to people with speech or hearing impairments, by dialling 106. This service is provided by the National Relay Service provider, the Australian Communications Exchange (ACE) and is for the exclusive use of those that rely on text-based telecommunications such as TTY and PC/ modem users. The number: 106 is not available for mobile text messaging users.

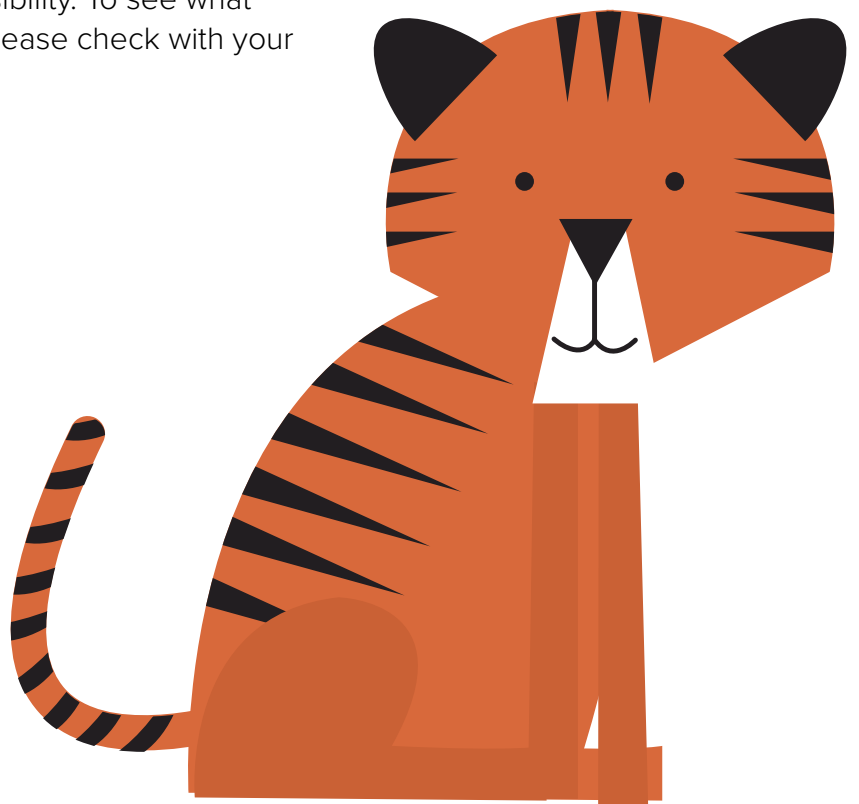
## Ambulance Costs in WA

In Western Australia only Aged Pensioners are entitled to free ambulance service, which are provided by St Johns Ambulance service. Pensioners receiving a Disability, Single Parent or Carers pension or other Centrelink pension may be entitled to a 50% discount on their ambulance account.

**Costs associated with ambulance services, whether emergency or not, will be incurred by the patient. This cost is not covered by Medicare, Healthcare cards, Pharmaceutical or Pensioner Benefit Cards. St John Ambulance operates a “user pays” system which means calling for an ambulance comes at a cost to the patient.**

## Currently fees

Fees for calling an ambulance in Perth vary, depending on the nature of the call out range from \$500 to \$932. Coverage can be obtained through private health insurers and is the individual patient's responsibility. To see what level of ambulance cover you hold, please check with your private health insurer.



# Mental Health Care Plans

Caring for a child with a chronic/life-threatening illness and/or disability can be stressful on families. It is important to consider the mental health and well-being of the child, of other family members, and importantly of the primary carer. Speak to your GP for more information about what might help.

The Better Access initiative provides better access to mental health practitioners (including Psychiatrists, Psychologists, and General Practitioners) through the Medicare Benefits Scheme. The purpose of the Better Access initiative is to improve treatment and management of mental illness within the community. The Better Access initiative is increasing community access to mental health professionals and team-based mental health care, with general practitioners encouraged to work more closely and collaboratively with psychiatrists, clinical psychologists, registered psychologists and appropriately trained social workers and occupational therapists. See [www.health.gov.au/internet/main/publishing.nsf/Content/mental-ba-fact-pat](http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-ba-fact-pat) for more detail.

If you would like more information about mental health, including how to find professional help and tips for good mental health, check out the following:

- [www.headspace.org.au](http://www.headspace.org.au)
- [www.bluepages.anu.edu.au](http://www.bluepages.anu.edu.au)
- [www.blackdoginstitute.org.au/public/gettinghelp/overview.cfm](http://www.blackdoginstitute.org.au/public/gettinghelp/overview.cfm)
- [www.mindhealthconnect.org.au/wellbeing](http://www.mindhealthconnect.org.au/wellbeing)
- [www.beyondblue.org.au](http://www.beyondblue.org.au)
- [www.actbelongcommit.org.au](http://www.actbelongcommit.org.au)
- [www.mindhealthconnect.org.au/tips-for-good-mental-health](http://www.mindhealthconnect.org.au/tips-for-good-mental-health)

If you are in a crisis, then use the following website and/or phone numbers:

- [www.lifeline.org.au](http://www.lifeline.org.au), phone: 13 11 14
- [www.kidshelp.com.au](http://www.kidshelp.com.au), phone: 1800 55 1800



# Coping Strategies

## (for day to day and beyond)

In order to cope with your child's disability/illness, and your family's changed circumstances, we have included some tried and true coping strategies. We have also suggested activities that will help to sustain you and your family.

Start by documenting: get a large exercise book or diary for appointments, medications and anything else relating to your child. If you take a phone call from a service provider or a doctor, document it, and then you can just refer to the book instead of trying to remember everything.

Keep a file (e.g. a large folder or expandable file) to store information in a logical and easily retrievable way. This can be a place to store information sheets from doctors, clinics, health centres, doctors' reports, test results, contacts for different aspects of your child's condition/treatment, medication leaflets, support groups etc. It may include:

- Equipment
- Medications
- Therapies
- Dietary requirements
- School
- Diagnosis (e.g. cerebral palsy)
- Other conditions (e.g. epilepsy, reflux, asthma)
- Respite organisations

Nurture yourself physically, emotionally, mentally and spiritually. You will cope with everything so much better if you are looking after yourself. Eat well, exercise and reward yourself even if it is just in a small way. By looking after yourself, you will be in a better position to look after those around you.

*"I now accept that I cannot do it all. Some things do have to give and I have become really good at prioritising things."*

**(Lisa E - parent)**

*"I have remained working (part-time) throughout the 6 years of my son's life. Not only has the income kept us in our own home but it has also provided me with a regular break from being at home and an entire life separate from being his mum. Working has brought a completely different dimension to my life and kept me sane in the process."*

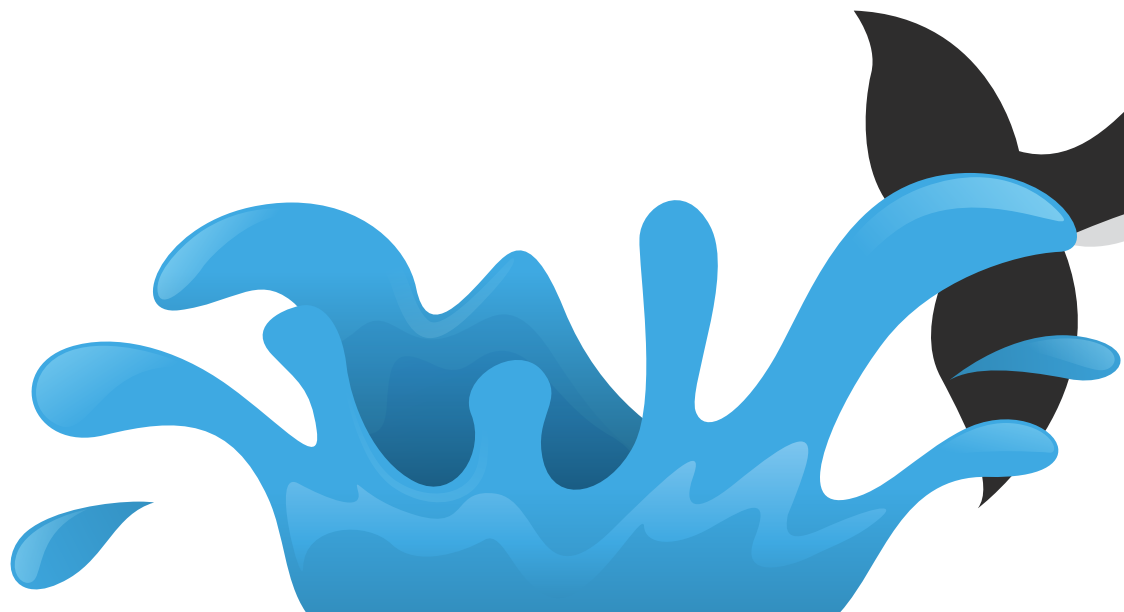
**(Lisa E - parent)**

*"I need time on my own out in the shed or under a car. Either I'm thinking about things or I'm doing something that takes my mind off things for a while."*

**(Tony - parent)**

Here are some tips from parents on how to achieve this:

- Be realistic: plan what you can, but try not to take on too much. Have reasonable expectations for yourself and what you can achieve.
- Utilise respite options and community support as early as possible.
- Involve yourself in recreational activities away from your child, and make them a regular occurrence.
- Continue to talk about how you feel and use all available supports.
- If you are working, keep working. This may be a great outlet for you and be a place where you can be yourself! It will help financially as well.
- Use the system: ask your specialist if there is anyone he/she would suggest you could contact for peer support.
- Investigate if a "condition specific organisation" exists for your child's condition and what support services they may offer e.g. Down Syndrome WA, Cystic Fibrosis WA. In WA 'ConnectGroups' has a database of over 700 Self Help and Support Groups for a wide range of conditions. To contact them, phone: (08) 9364 6909.
- Make sure to plan regular time out to do something by yourself (e.g. pampering, a hobby), with your partner (e.g. dinner, a movie), with your family (e.g. picnic in the garden, a walk, a drive to somewhere peaceful).



- Talk to your partner but be aware that they may deal with the same situation in different ways and that's okay.
- Keep a night at least once a month with your partner (or friend) where you may choose to not talk about disability/illness. It's important to still have fun.
- Plan a weekend away without children every now and then, by yourself or with your partner or a friend.
- Reward yourself with a treat when you make it through the day; a glass of wine, chocolate, watching TV, or something else you enjoy.
- Remember to enjoy your child for who they are and what they can do, rather than for what they are unable to do.
- Work towards your dreams: it's even more important now to have goals in life. They might take longer to come to fruition, but don't give up.
- Try to look for the positives in your situation with your child. You may find that you have grown and developed in ways that you never thought possible.
- Make important decisions carefully as you may be under considerably more stress.
- Take one day at a time.

*"After 2 years I decided that it wasn't fair on my son if we lived his life thinking he was always going to die. While he was here it was his right to live a full, active and happy life. This was my turning point."*

**(Lisa E – parent)**

*"Whilst I would change my son's diagnosis and prognosis in a second, I would never change what I have learned or the perspective this whole experience has given me. I live my life differently, and often feel that I have gained the wisdom and insight of an 80-year-old at a very young age. I will always be grateful for this."*

**(Lisa E - parent)**



## Logistics

**Get organised and delegate.** Here are some practical suggestions to help you maximise your time and maintain other commitments you may have, such as home, family and/or work:

- Get whatever you can home delivered
- Consider shopping online, if it is an option for you
- Email when you can, rather than go to the post office
- Pay your bills over the phone or internet
- If people want to help you, consider asking them to help with the housework, or if you can, get a house-cleaner in the short term
- Get another car seat installed in the car of grandparents (or someone else supportive) so they can help with picking up your child/children if necessary

**Have a plan in place for your other children** in the event of an unexpected hospital admission:

- Find people who are prepared to care for your other children should you have to go to the hospital, day or night
- Ask other parents to help transport siblings to and from school
- Accept genuine offers of help
- Have some spare frozen meals on standby at home: there are some great nutritious meals readymade and frozen in supermarkets.
- Ascertain whether your employer/partner's employer will allow time off for emergencies. Explain your circumstances. Most employers are very understanding and will endeavour to assist where possible.

**Don't wait for an emergency to occur** to organise these things. Plan ahead so as many arrangements as possible are already in place. Then, when you need it most, all you have to do is make a call to put the plan into action.

**Priority listings for people with medical conditions** – just as it is important to inform those coming in direct contact with your child of his/her support needs, it can also be helpful to inform those who provide direct support to your child in other ways. For example, a child may be reliant on medical apparatus that requires electricity. Some companies have priority listings, which are designed to help customers, or members of their household, who have a diagnosed life-threatening medical condition and whose life may be at risk without access to a fully operational utility service (e.g. gas, electricity, water or telephone). Essentially, you will be able to access priority assistance to ensure your utilities are fully functional or repaired in the event of emergency, with the least amount of disruption and risk to your child's wellbeing. Not all companies will use the same terminology, nor will every service have this provision. Check with your individual utility providers to ensure their maximum assistance to you.

# Equipment

Children with a chronic illness, disability, mental illness, or a life-threatening illness often require special equipment and medical items to enable them to leave hospital and be cared for at home and in the community. Equipment may help your child move around easier, assist with feeding or allow them to breathe more easily. Equipment may also include consumable items such as syringes, feeding lines and dressings and items which can be hired such as feeding pumps and suction units. In WA, the Community Aids and Equipment Program (CAEP)\* provides an equitable, accessible and consistent state-wide scheme for the provision of equipment and home modifications to benefit people with a long-term disability living at home in the community.

All equipment and home modifications funded by CAEP are provided to enhance the function, independence and safety of the equipment user; and to assist unpaid carers in their caring role. A range of basic and essential modifications and equipment required for activities of daily living and self-care are included within CAEP.

Discuss your needs and check your eligibility with your health professional (e.g. GP, OT, podiatrist). Your health professionals will work together to decide what sort of equipment you and your child will need and they will arrange a referral.

They will need to complete the CAEP referral form, and send it directly to the CAEP Service Provider.

*\*At the time of publication, WA is in transition to the WA NDIS from July 1, 2017 and it is anticipated that for people who are eligible for NDIS, equipment previously funded by the CAEP program will now be included in the individual's NDIS plan.*

*For specific information about the range of different types of equipment available, you can contact the Independent Living Centre WA (ILC). The ILC provides information and advice, assessment, training, funding and hire services that enable Western Australians of all ages and abilities to live more independent and fulfilling lives. ILC staff includes physiotherapists, occupational therapists, and speech pathologists with expertise, knowledge and skills to help children, families and carers to select, access and set up the most appropriate equipment to assist with mobility, communication and daily living. ILC links with Early Childhood, Child and Adolescent and Rehabilitation teams to ensure each child receives the most appropriate equipment for their needs and the hire service means you can often trial the equipment to ensure it meets the child's needs before purchasing. Telephone: (08) 9381 0600.*

# Financial Considerations

Caring for a child with an illness or disability can have significant financial implications.

**Centrelink:** You may qualify for extra Centrelink entitlements due to your child's disability or illness, namely the Carer Allowance, which provides your child with a Healthcare Card. Contact Centrelink – Disability, Sickness and Carers on 13 2717 or check [www.centrelink.gov.au](http://www.centrelink.gov.au) for more detailed information. Further information can be found through Carers WA ([www.carerswa.asn.au/](http://www.carerswa.asn.au/)).

Register your child for the Extended Medicare Safety Net, which you can do when visiting any Medicare Office. For a Guide To Understanding the Extended Medicare Safety Net visit [www.ama.com.au/article/extended-medicare-safety-net](http://www.ama.com.au/article/extended-medicare-safety-net). You can also register for the Pharmaceutical Safety Net.

**Keep all receipts:** Realistically, you will incur many extra expenses for your child's medical and support needs. Therefore, it is worthwhile keeping receipts, as you might be eligible for a tax rebate on your medical expenses at the end of the financial year. Keep receipts for items like:

- Continence aids
- Over the counter pharmaceuticals
- Nutritional supplements and Home Enteral Nutrition [HEN] program costs
- Contributions you make toward the cost of equipment
- Petrol and car parking expenses for specialist appointments and hospital visits
- Visits to doctors who do not bulk bill
- Private appointments with Occupational Therapists, Speech Pathologists, Physiotherapists etc.

**Parking Concessions:** You may be eligible for car parking concessions at some car parks (e.g. City of Perth Parking 1300 889 613) if you hold an ACROD permit.

Rural patients and families requiring long-term parking and who are staying overnight at Princess Margaret Hospital/ Perth Children's Hospital should contact the reception at the Social Work department to enquire about parking concession arrangements and eligibility.

**Life Support Equipment Electricity Subsidy Scheme** – this subsidy is available to compensate eligible people for the electricity costs of operating life support equipment at home who are dependent on specified life support equipment used in their homes under specialist medical advice and holders of concession cards that are means tested. The specified life-support equipment includes:

- Ventilator (VPAP or BPAP only)
- Oxygen concentrator – includes child concentrators; standard capacity (adult); high capacity “New Life Intensity” (adult)
- Feeding pump
- Suction pump
- Apnoea monitor (for children only)
- Nebuliser (for children only – when used every day for 1-2 hours/day)
- Heart pump
- Machine assisted Peritoneal Dialysis Equipment (cyclor or heater)

**Thermoregulatory Dysfunction Energy Subsidy Scheme** – this subsidy helps offset the energy costs associated with temperature control at the home of eligible people or their dependents with a thermoregulatory dysfunction. The subsidy is intended for people who hold means tested concession cards, (or the dependents of people who hold means tested concession cards) and who require heating and/or cooling to control the temperature in their homes under specialist medical advice. For further information, contact the Life Support Administrator at your electricity retailer.



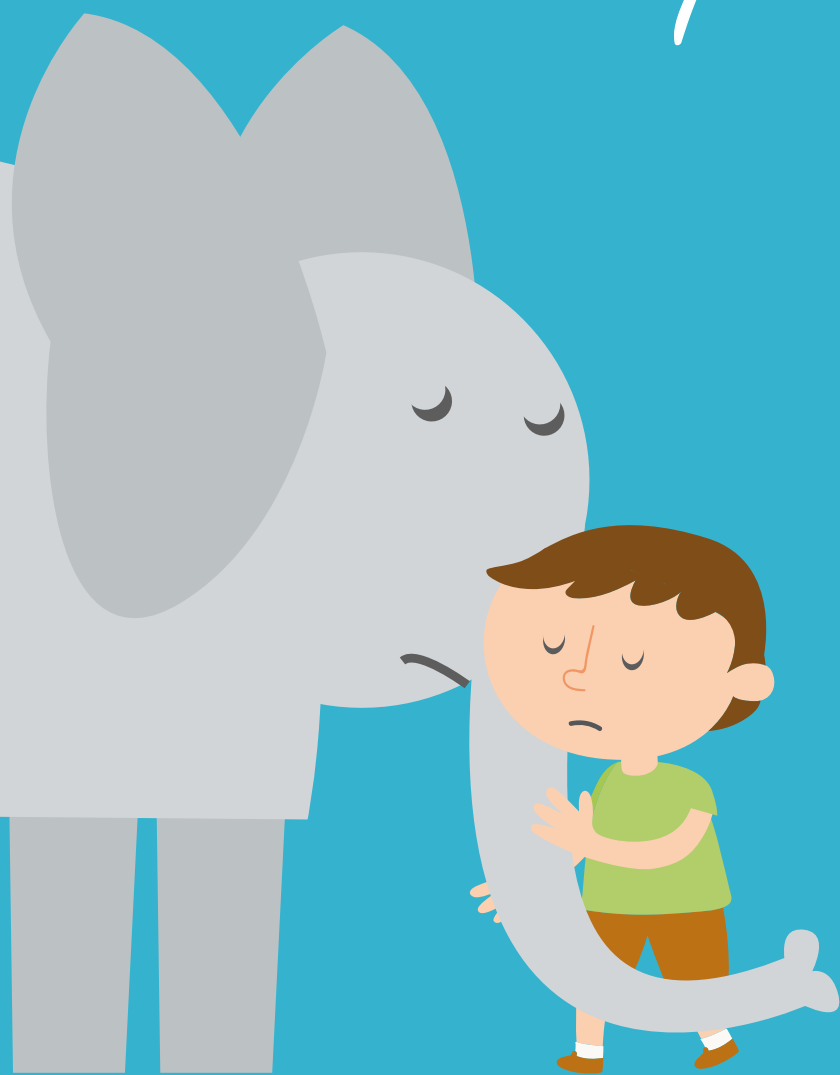


"Initially, taking my daughter to hospital was a frightening experience, full of uncertainty and worry. In time however, I became familiar not only with some staff, but also with the routine and the expectations of everyone involved."

(Karen – parent)



# Going into Hospital



# Hospital Admissions - Hints & Tips

**Day Surgery** – today many surgical procedures are done as day cases. With advances in surgical techniques and improved methods of pain relief, it has allowed patients to recover at home and only require a few hours stay in hospital after their surgery. Make sure you make arrangements at home to accommodate your child's recuperation. It may be useful to have a babysitter for other children, to have meals prepared and to have pain relief medication available at home. Before you leave hospital make sure you understand all the instructions given to you and that you know whom to contact should your child not be recovering as expected.

**What to take with you (for overnight or longer stays)** – staying in hospital with your child can be a stressful and worrying time. Understandably, parents are often so focused on their child that they think little about self-care and the things that will make their stay easier. Be sure to contact the hospital ahead of time, to confirm you have all the appropriate documentation for your child's admission. Calling on the day of admission is also advisable in case there are any last minute changes.

To reduce the inconvenience of forgetting even the simplest of items from home, it may be helpful to keep a bag packed with some basic supplies ready for an emergency trip to hospital, particularly for families who live some distance from the hospital, or who don't have someone to bring extra things in for them. Whether you have a bag packed or not, it is useful to have a detailed list of all the things you would like to take with you. In the anxious time before a hospital admission, parents can often find it difficult to think clearly about the details of packing.

The following items have been suggested by other parents and may be a helpful starting point for preparing your own packing list:

**What to take for your child:**

- Medicare card/private health care card
- Health Care card/pension concession card
- Maternal and child health record book “the Purple book”
- Details/contact numbers of your GP and or local Paediatrician
- Current medications: Do not assume that all your child’s medication will be available at the hospital.
- List all medications and dosages/strengths.
- Lists of child’s symptoms/doctors’/appointments etc.
- Nappies and clothes for day wear and discharge (nappies and hospital gowns may be available on the ward during your child’s admission).
- Equipment such as orthotics, hearing aids, splints, tube feeding equipment, etc.
- Your child’s special toy(s) and books for comfort and any other activities they might enjoy e.g. pencils and colouring book, puzzles, plain paper, sensory and communication toys/devices.
- Your child’s pillow, quilt, blanket, night-light, favourite drinking cup/bottle etc.
- Pyjamas (light weight) and slippers
- Toiletries – toothbrush, toothpaste, brush, comb, etc.
- Schoolwork provided by your child’s school

### What to take for yourself:

- Towel, hairbrush/comb, toothbrush and toothpaste, deodorant, cosmetics, sanitary products, shaving foam/ blades (electrical items such as hairdryers are not usually permitted for safety reasons)
- Medication and/or dietary supplements
- Comfortable clothes
- Your own pillow
- Pen and notebook to write down questions for hospital staff, to record information that you learn, and to write reminders for yourself
- Water bottle (dehydration can occur in warm, air-conditioned wards, and you may forget to care for yourself when you are busy with your child)
- Mobile phone and charger, and/or change for pay phone
- A list of phone numbers you are likely to want to call
- Cash for meals /snacks /car park
- Convenient meals to prepare for yourself in the parent facility (e.g. left-overs from home, pull-top tinned foods, microwave meals)
- Books and magazines to keep yourself busy
- You won't have much storage space and it's unlikely to be secure, so leave your valuables at home.

**Reducing your responsibilities** – try to arrange things at home so you can be totally devoted to your child when in hospital. For example:

- Try to put things in place to maintain the routine of life for those at home.
- If you can, arrange to leave your other children with relatives or friends, or have someone come to care for them at home.
- Accept offers of practical help from friends and family. Don't try to do it all.
- Put as many tasks/activities as possible on hold.
- Record a message on your telephone answering machine/message bank to briefly inform callers what is happening, so that you won't have to return calls, and callers know why you are unavailable.

**Staying on the hospital ward** – for safety reasons, usually only one parent/carer is permitted to stay overnight and siblings aged under 18 are not permitted to stay.

Once your child has been admitted to a ward and you have settled in, there are many things you will need to know. Nursing staff can be busy and may forget to tell you some things, so ask lots of questions, both of the staff, and of other parents on the ward. Here are some questions you may want to ask:

- Is there a parent information booklet that I should have?
- How do I go about getting a copy?
- Is there information specific to this ward that I should know?
- Is there a map of the hospital for me to use?
- Where can I find showers and toilets for parent use?
- Where can I get a meal/ snack?
- Where can I keep food brought from home?
- Where can I use my mobile phone?
- Where are public phones? Is there a change machine to get coins for the public phone?
- Where is the nearest Automatic Teller Machine [ATM]?
- Is there parent accommodation I can access?
- Are meal vouchers available?
- Are car parking concessions available for inpatient families and whom do I see about that?
- Is there a play therapist or a music therapist my child can access?
- Is there a playroom? Can I bring games to the bed?
- Is there a teacher/educational advisor I can access for my child?
- Are there volunteer visiting schemes?

Discuss with ward staff what care role you wish to play while your child is an inpatient. There are many tasks that may usually be done by nursing staff but that you may wish to do yourself. For example:

- Do you want to bath your child yourself, have a nurse do it, or do it together?
- Do you wish to give your child his/her medications?
- Do you want to change your child's nappies?

**Staying in the intensive care unit [ICU]** – staying on the Intensive Care Ward with your child is a little different to staying on other wards. For example:

- Security is greater, and you may need to identify yourself each time you enter the ward to be with your child.
- ICU is often a shared, open space with little privacy.
- Each child has a nurse to care for them on a one to one basis.

Try to take advantage of this arrangement to have breaks and care for yourself, in the knowledge that your child is in very good hands and closely monitored. Consider the following:

- Take regular breaks for food and rest when your child is stable. Ask if there is a pager to use when you leave the ICU area so that you can be contacted at any time.
- Try to get a good night's sleep, at home if it is close enough, or in the hospital parent accommodation.
- Do something relaxing at your child's bedside, such as reading or craft.
- Arrange for family and friends to come and do a few bedside shifts for you, to relieve the physical and emotional burden of doing it all yourself.

**Caring for yourself during your child's stay** – it is important to consider your own health and mental health needs while you are staying with your child in hospital. For example:

- Drink lots of water to reduce the chances of light-headedness and constipation
- Eat well-balanced meals whenever possible
- Have family or friends bring you meals and snacks; there is nothing better than fresh crunchy fruit and vegetables while in hospital
- Use the parents' room for a break
- Go for walks to stimulate your body and your mind
- Get sleep whenever you can (e.g. while your child sleeps, or while someone watches him/her).
- Seek support from others, including your own doctor, if you have ongoing problems sleeping



**Other sources of information** – apart from the ward staff, there are other sources of support and information to help you during your stay in hospital with your child. Depending on your needs and concerns, the following people/organisations may be valuable to talk to:

- The hospital chaplain.
- Social worker, counsellor, psychotherapist etc.
- Patient advocate.
- Other parents on the ward will have hints and tips on how they cope.
- A play / music therapist or teacher / educational advisor might be available to assist your child with activities.
- Hospital volunteers are sometimes available to help you by sitting with your child while you have a break.
- Support associations within the hospital (eg Kalparrin, Heart Kids at PMH/PCH).
- Support groups specific to your child's condition.

## *Interpreters*

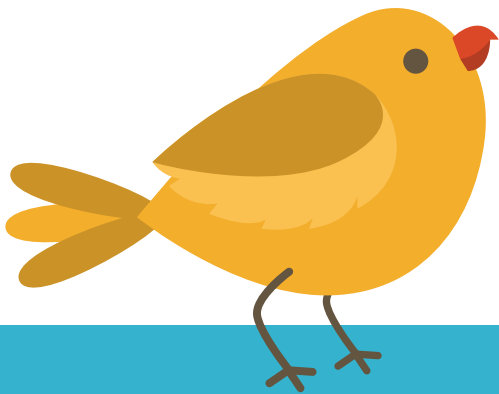
All Hospitals use interpreting services to provide communication with people when English is not their first language or for hearing impaired. If you require this service, please ask a hospital staff member.

# Aboriginal Liaison Officers

Some hospitals have Aboriginal Liaison Officers (ALO's) who support Aboriginal inpatients and their families with the aim of ensuring their medical, practical and cultural needs are met while in hospital. The ALO's can act as a cultural broker, and can assist with Aboriginal and Torres Strait Island patients and families with:

- Food
- Financial assistance
- Orientation of the hospital
- Warm clothing
- Accommodation
- Transport
- Community contact
- Discharge planning

There are ALO's at PMH/PCH and the new Perth Children's Hospital will have a dedicated Aboriginal Resource Lounge. Ask at your health service if there is an Aboriginal Liaison Officer.



## Transition to adult services

Throughout your child's medical management, it is important to keep in mind that you are (in most cases) dealing with paediatric services and specialists. When your child reaches 18 years of age, doctors and other health professionals will need to "transition" (i.e. transfer) your child to adult services and specialists. Children's services tend to be concentrated around the children's hospital, whereas in adult services, hospitals may have a range of different specialty areas.

Many health professionals, who have ongoing relationships with you and your family, may in fact start working towards this transfer at a much earlier age. At PMH/PCH this may commence from age 16, or earlier if instigated by the family. Ideally you should all plan this process together to ensure it is as smooth and stress free as possible. Your child will probably be comfortable and familiar with the paediatric staff and reluctant to change, so working towards an understanding that this is to happen when they become an adult is a positive first step. If the issue of transition has not been broached with you, feel free to initiate the discussion with medical and health professionals currently supporting you in your child's medical management.

It is important to know that support services in the community may also be required to transition your child from their programs when they reach 18 years of age.

## *Country/Regional Families Attending Health Services in Perth*

It can be hard if you need to travel a long way from home for medical treatment or services, especially if you or your child has to stay at or close to the hospital for some time. It can also be lonely if your family or your partner cannot be with you. Health care professionals understand this can be a stressful time and that staying in a strange city can be a bit overwhelming. For patient families needing a place to stay there are offsite accommodation choices close to the hospital. If you do not live in Perth or do not come into the city often, ask the hospital staff if there is a booklet with information on facilities close to the hospital as well as other useful information. Get the referring doctor to sign a Patient Assistance Transport Scheme (PATS) form before you go to Perth and remember it needs to be signed again by the doctor in Perth.

Ronald McDonald House Perth is conveniently located approximately 5km from the Perth City Centre and within easy reach of local shopping, train and bus transport. The House is situated directly across the street from the new Perth Children's Hospital in Nedlands. Until the transfer from PMH to PCH a regular shuttle bus is in operation between RMH Perth and Princess Margaret Hospital. Families must live at least 100kms from Perth and have a seriously ill child receiving medical treatment at Princess Margaret Hospital (PMH) or King Edwards Memorial Hospital. Admissions are made via a referral from:

- the Social Work Department and/or nursing staff of the attached hospital
- the patient's general practitioner
- an interstate hospital representative
- the local Patient Assisted Travel Scheme (PATS) office.

# Hospital Personnel Terminology

In the hospital, you will probably meet a range of people with different titles (and acronyms). To decipher what they all mean, here is a list:

## Medical

- Medical Students – 4th, 5th and 6th year students
- Intern – 1st year graduate
- Resident – 2nd or 3rd year doctor
- Medical Registrar – Hospital based doctor working in any medical specialty area
- Specialist Registrar – Hospital based doctor training in particular specialty
- Fellow – Qualified specialist doing further training prior to commencing own practice
- Consultant – Specialist Doctor
- Mr/Miss (rather than Dr. title) – Surgeon with patients admitted under their 'bed card'
- Professor – A role that includes teaching, research and work as a consultant in their area of expertise

## Nursing

- PCA – Personal Care Assistant
- Graduate Nurse – Nurse in their 1st year
- Clinical Supervisor – Level 2-3 nurse
- ANUM – Associate Nurse Unit Manager
- NUM – Nurse Unit Manager
- DDON – Deputy Director of Nursing
- DON – Director of Nursing
- Allied Health
- Physio/PT – Physiotherapist
- OT – Occupational therapist
- Speech Path/SLP – Speech pathologist
- Social worker
- Psych – Psychologist



*"Beyond the hospital experience, there will be a need to develop supports within the community. Many of these will be essential to enhance your family's quality of life."*

(Karen – parent)

Who will help  
us in the  
community?

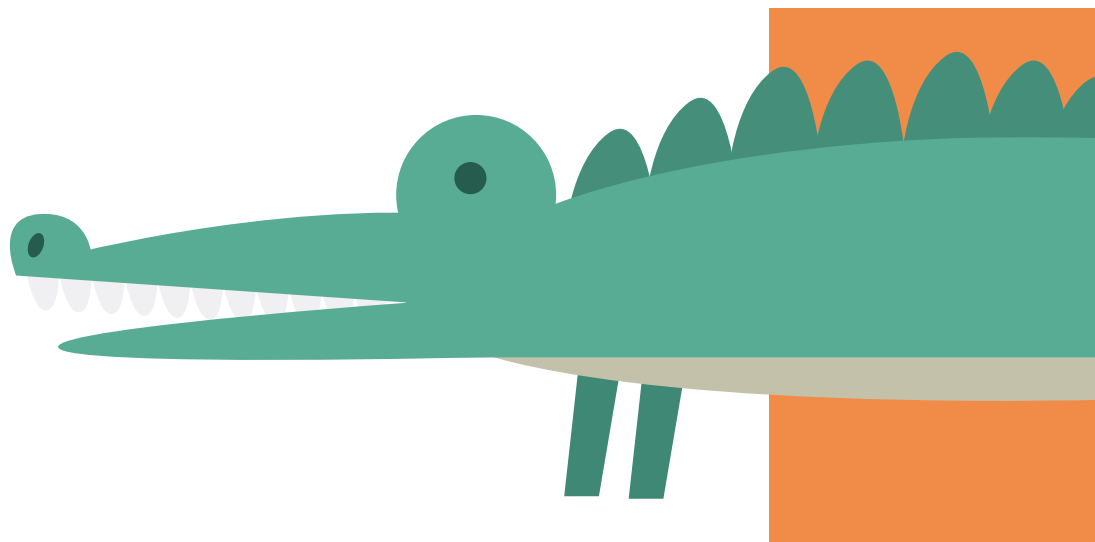
## Child Health Centres

Child health centres are staffed by registered nurses with qualifications in child and family health. They provide a range of services in partnership with parents and carers of babies and young children up to the age of 4 years.

Community child health nurses can assess children's health and development as well as provide information about many aspects of parenting, maternal and family health and healthy lifestyles. All services are free. You can ask for a free telephone interpreter if you need one.

Community child health nurses:

- assess baby and child health and development
  - after discharge from hospital
  - 6 to 8 weeks
  - 3 to 4 months
  - 8 months
  - 18 months
  - 3 years
- provide ongoing support for families and can offer information about many aspects of parenting, maternal and family health and healthy lifestyles
- provide information about immunisation and locations of free clinics in community health centres





- act as a link between hospitals and the community, working with family GPs and other health professionals when necessary
- work as part of a broader health team and can refer to:
  - Aboriginal and ethnic health workers
  - audiologists
  - dietitians
  - lactation consultants
  - medical officers
  - occupational therapists
  - paediatricians
  - physiotherapists
  - podiatrists
  - psychologists
  - speech therapists
  - social workers
  - specialised health educators.

For more information, regarding your local community, school or child health nurse:

- See inside your baby's purple All About Me book.
- Look in the phone directory under child health centres.
- Visit your nearest child health centre.
- Use the find a health service function on [www.healthywa.wa.gov.au/Service-search](http://www.healthywa.wa.gov.au/Service-search) by searching for service type, maternal and child health.



# Child Development Service

All children are unique and develop at different rates. It is normal for children to experience a range of social, emotional, and physical changes as they grow and develop. Some children benefit from additional support to develop their skills.

If you are concerned about your child's development, you are encouraged to talk to your child health nurse, school health nurse, or your general practitioner. They may recommend a referral to Child Development Services, or a range of other community services.

The Child Development Service (CDS) provides a range of services for children with or at risk of developmental difficulties and their families. Developmental difficulties may include problems with:

- coordination and movement (e.g. crawling, walking, writing and drawing)
- speech and language
- behaviour
- social and emotional skills (e.g. managing feelings, relating to others)
- play, early learning and attention

Child Development Service staff work in partnership with parents and families to meet the unique developmental needs of each child. Services are provided at a number of centres throughout the metropolitan area. Some services may be offered in the home or in a community setting.

Child Development Service staff also work closely with others that may be involved in your child's life, such as child health nurses, teachers, school health nurses, child care staff, school psychologists, and other health professionals. We may also refer children to other services where appropriate with parent consent.

Services may be provided by one or more of the following health professionals:

- **The Paediatrician or medical officer** who assesses children for developmental delays or difficulties and will discuss any concerns with parents/carers. The paediatrician may refer children to other team members or other medical or specialist services.
- **The Speech Pathologist** who works with children and their families to develop communication skills. This includes improving childrens' abilities to understand and use speech and language appropriately and to be understood by others.
- **The Physiotherapist** who develops programs to help children improve their physical abilities, gross motor skills, and co-ordination, looking at skills such as rolling, crawling, walking balance and ball skills.
- **The Occupational Therapist** who works to help improve childrens' play, fine motor skills, co-ordination (e.g. drawing, writing), sensory skills and self help skills (e.g. feeding, dressing) and how you can help to develop these at home and school.
- **The Social Worker** who can offer counselling and support to families. The social worker can also provide individual and family therapy, run groups for parents and children, link families to other resources, and discuss parenting concerns.
- **The Clinical Psychologist** who specialises in the assessment and treatment of childrens' behavioural, developmental, learning and emotional problems.
- **The Audiologist** who administers specialised paediatric hearing tests and helps to determine if a child's difficulties could be related to a hearing problem.
- **The Podiatrist** who provides assessment and treatment for concerns relating to feet and gait (walking pattern).

Other CDS team members you may meet include:

- Dieticians
- Play and Learning Therapists
- Therapy Assistants

Children who have not yet reached 16 years of age are eligible to be referred to the service. Your child may however, be ineligible for services if they are currently receiving developmental therapy services through another government agency (e.g Disability Services Commission) or if they have a diagnosed medical issue and are not at risk of a developmental delay. Children who are not eligible for Medicare, are ineligible for services through the Metropolitan Child Development Service. Families may consider private therapy in these circumstances.

Parents/legal guardians can make a referral to the Child Development Service if they are concerned about their child's development. Please provide as much information as possible on the referral form, and attach any other relevant information about your child's development. This information helps us to know which services your child may benefit from. You are encouraged to discuss your concerns with your child health nurse, school health nurse, school, or GP prior to referral to ensure that essential information is provided and that the most appropriate services are identified. A referral can also be made by other people including school staff, GPs, community health nurses and private practitioners, however your consent is always required.

Child Development Service contact details for all new enquiries:

Child Development Service Centralised Intake Team

Phone: 1300 551 827, Fax: (08) 9426 7676

E-mail: [childdevelopmentservice@health.wa.gov.au](mailto:childdevelopmentservice@health.wa.gov.au)

*The Child Development Service is not a crisis service. If a child is at imminent risk of harm to self or others, a referral to an appropriate service should occur as a matter of urgency.*

There are often waiting lists for Child Development Services. Some families consider accessing private services while they wait for their first appointment with the Child Development Service. If required, your child can still receive services from Child Development Services even if you decide to access private services. However, if your child is able to receive services through NDIS or the Disability Services Commission, then you are only able to access audiology and paediatrician services through Child Development Services.

Some children may also be eligible to receive a Medicare rebate for a limited number of private service appointments. You will need to discuss eligibility with your GP, who will provide you with a referral if your child is eligible. There may be a gap between the Medicare rebate and the fee for the private service. For more information, phone Medicare on 132 011.

When choosing a private clinician, it may be helpful to ask some of the following questions:

- What is your area of specialty?
- What age group do you usually see?
- What is your appointment availability?
- Where will the service be provided; home, school, clinic?
- What programs are offered? Is it on a group or individual basis?
- What will the appointment cost?
- Are you registered with Medicare/my private health insurer? Can you tell me how much the Medicare/private health rebate is?

You may also like to contact Parenting WA on (08) 6279 1200 or 1800 654 432 for information about other services and common issues related to child development and behaviour. Online resources can be found here: [www.raisingchildren.net.au](http://www.raisingchildren.net.au) and [www.pmh.health.wa.gov.au/health/child\\_development/resources.htm](http://www.pmh.health.wa.gov.au/health/child_development/resources.htm).

# Disability Services Commission and the NDIS

At the time of writing, WA is in transition from the existing DSC system to the WA National Disability Insurance Scheme, with full-scheme rollout beginning from July 1, 2017. It is anticipated that any child eligible for services from the current Disability Services Commission will likely be eligible for the WA NDIS. The following section is specific to children who are eligible for support through NDIS.

The WA NDIS and existing DSC system use a 'Local Coordinator' as the way families access the service system. The Local Coordinator helps families identify the types of supports that may be needed, and can link the person into other services if necessary. To see if your child is eligible for NDIS, please contact a Local Coordinator in your area:

Phone: 9426 9352

Email: [admin\\_LAC@dsc.wa.gov.au](mailto:admin_LAC@dsc.wa.gov.au)

WA NDIS supports are accessed after families have developed an individually focused 'plan' for their child. The Local Coordinator will help guide you through the planning process. You may also like to find out about the types of things people include in plans from peer-support groups, and disability-specific support organisations.

A range of resources have been developed to assist families to prepare for the planning process. You might find the following resources useful:

- Planning tool developed by WA Individualised Services – [www.waindividualisedservices.org.au/preparing-to-plan](http://www.waindividualisedservices.org.au/preparing-to-plan)
- Planning and Making Choices – [www.ddc.org.au/rise](http://www.ddc.org.au/rise)
- Making Changes Through Goal-setting – [www.ddc.org.au/rise](http://www.ddc.org.au/rise)
- Choosing what matters – Ideas for families – [www.ddc.org.au/rise](http://www.ddc.org.au/rise)

# Early Childhood Intervention services

Children 0-8 may benefit from 'Early Childhood Intervention' services. Early Childhood Intervention is targeted at children of preschool age. It aims to:

- Support families and promote the health, wellbeing and developmental needs of children with a developmental concern/delay, and/or disability.
- Improve the family's capacity to care for and manage their child's disability and/or developmental delay.
- Minimise the impact of the child's disability and/or developmental delay on the child and family.
- Enhance the access and inclusion of children who have disabilities and/or developmental delays into mainstream childhood services, e.g. childcare, preschool.

Early Childhood Intervention Services (ECIS) include:

- Assessment of the individual needs of the child and family
- Therapy and educational programs for children
- Information, education and support for families
- Training for parents to implement programs at home
- Co-ordinating the right combination of services to meet the child's needs
- Support to preschool and child care centres the child attends
- Transition support for starting school

Families are central to all decision-making, including the choice of service, goals for therapy, and program strategies for their child. The family, paediatrician or anyone concerned about a child's development, can make referrals for early intervention. You may choose to access a program that is specific to your child's condition, if available.

Early Childhood Intervention builds the resources and confidence of families, teachers and other caregivers to optimise the child's learning and development. The aim is to increase the child's participation and independence wherever they are, including at home, child care, parks, shops and schools. The team works with caregivers to develop strategies, routines and supports to maximise learning opportunities in daily routines.

*"We started Early Intervention even before we had received our daughter's diagnosis. The direct access to early intervention professionals and their knowledge and advice made such a positive difference to us as a family at a very difficult time in our lives. Meeting other parents in a similar situation to ours who understood how we felt in those early days was invaluable!"*

**(Ursula - parent)**

The team works with families and relevant people in the child's life, as a 'team around the child', with one team member being the 'Key Contact' who works with the family to identify, plan and work towards achieving goals. The Key Contact is the main person working with the family, but they have close communication with other team members. This means each child and family has timely access to a range of therapy supports.

To find out more about what makes a good early intervention service and other useful information, the following might be useful:

- Best practice guidelines: [www.ecia.org.au/resources/best-practice-guidelines](http://www.ecia.org.au/resources/best-practice-guidelines).
- Navigating the NDIS: [www.theinclusionhub.com.au](http://www.theinclusionhub.com.au). (Note that the inclusion hub is funded by the National Disability Insurance Agency, so there are some differences how to access NDIS supports).
- Starting out: [www.ecia.org.au/documents/item/155](http://www.ecia.org.au/documents/item/155)
- Autism Parent's Handbook: [therapyfocus.org.au/wp-content/uploads/2015/08/Autism-Parents-Handbook-2015.pdf](http://therapyfocus.org.au/wp-content/uploads/2015/08/Autism-Parents-Handbook-2015.pdf)
- ECIA family booklet: [www.ecia.org.au/resources/family-booklet](http://www.ecia.org.au/resources/family-booklet).





## School-aged supports

For children older than 8, the types of supports children need may be a little different from the early intervention supports. The supports will be focused on specific goals, so it is important to plan with your Local Coordinator so you can access the supports you need. For example, you may like to consider how your child can participate in a community activity (such as sport). During the planning process, your Local Coordinator might ask you about the type of support your child needs to participate such as a support worker. They may also ask whether the sporting club will need any help for your child to be able to participate, in which case they would give the club information about how to get that help.

When children are at school, the education system is responsible for the supports that a child needs to access the curriculum. You may go through a documented planning process with the school to develop an Individual Education Plan (IEP) for your child. You may like to think about if and how any of the goals in your child's NDIS plan can be coordinated with the IEP. For example, if you are including a communication device in the NDIS plan, it is good to make sure the school can incorporate the use of the device into the IEP, and access any professional development that teachers may need to support its use.

## Finding service providers

A number of different organisations provide early childhood intervention services. Some organisations have specific expertise for children with a particular diagnosis, while others work across a range of different diagnoses and needs. Your Local Coordinator can provide advice on organisations who provide services in your area, and how to choose what suits you. You may also like to look here:

[www.mycommunitydirectory.com.au](http://www.mycommunitydirectory.com.au).

Some children will continue to be eligible for services beyond early childhood intervention, throughout childhood. If your child has received early intervention services, you may want to talk to your team about the types of supports your child may need during their school years. As your child ages, there may be other organisations who better suit the support needs. The NDIS has an underlying principle of 'Choice and Control', so you do not need to feel like you can't change service providers or access services from a number of service providers.

# Challenging behaviours

Some children may experience challenging behaviours, and it is difficult to identify why the child needs to engage with that behaviour. Generally, the child is trying to communicate through their behaviour.

Positive Behaviour Support has a primary goal of increasing a person's quality of life, and a secondary goal of decreasing the frequency and severity of their challenging behaviours. Positive Behaviour Support is a comprehensive approach to assessment, planning and intervention that focuses on addressing the person's needs, their home environment and overall quality of life. Positive Behaviour Support is about working with families and carers to develop a shared understanding about why the person has a need to engage in challenging behaviour.

How does Positive Behaviour Support do this? Some of the ways it can assist includes:

- helping the person understand their daily life using clearer ways of communicating with them such as introducing a picture schedule.
- changing the environment to make where they live and work better for him or her (such as reducing high noise levels).
- improving the person's lifestyle so they have more interesting and enjoyable activities to keep them involved and connected with their community, such as helping the person gain employment and supporting recreational or other activities of interest.
- changing the environment so the person is involved in meaningful and positive relationships with others.

If your child is eligible for the NDIS, and may experience challenging behaviours, then you can get some help. You can talk to your Local Coordinator to see if the Positive Behaviour Support team at the Disability Services Commission would be of benefit. For more detail, see: [www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/services-supports-and-eligibility-new/services-services-provided-by-the-commission/therapy-services/behaviour-support-teams-](http://www.disability.wa.gov.au/individuals-families-and-carers/for-individuals-families-and-carers/services-supports-and-eligibility-new/services-services-provided-by-the-commission/therapy-services/behaviour-support-teams-)

Developmental Disability WA run a peer-support program for families of children who may experience challenging behaviours. Side by Side has been co-designed by families for families, and is a strength-based program which aims to build resilience, knowledge, friendship and support. For information, see: [www.ddc.org.au/side-by-side](http://www.ddc.org.au/side-by-side).

# Respite

Caring for a child with acute or chronic illness and/or disability can be physically, mentally and emotionally tiring and draining. Regular breaks, known as respite, may help relieve stress for the carer and the person receiving care. If you have other children, it is also important for them to have quality time with you.

Don't be afraid or ashamed to ask for respite care for your child. It does not mean you love your child any less, or that you are not coping. Nor does it mean you can't care for your child properly, rather that you are seeking to care for yourself and the rest of your family.

Within NDIS, respite may be talked about as building family resilience. It is important to consider the child at the centre – for example, planning for a support worker to participate in an activity in the community is one way for the primary carer to have one-on-one time with the child's sibling, or to take a little time for themselves.

There may be many ways to get help. For some, help comes from their natural networks, or from peer-support groups. Others may need to get help through a service organisation. The best option for you will depend on your circumstances. If your child is eligible for NDIS, your Local Coordinator can discuss your needs for these types of supports in your child's plan. There are several types of respite care including:

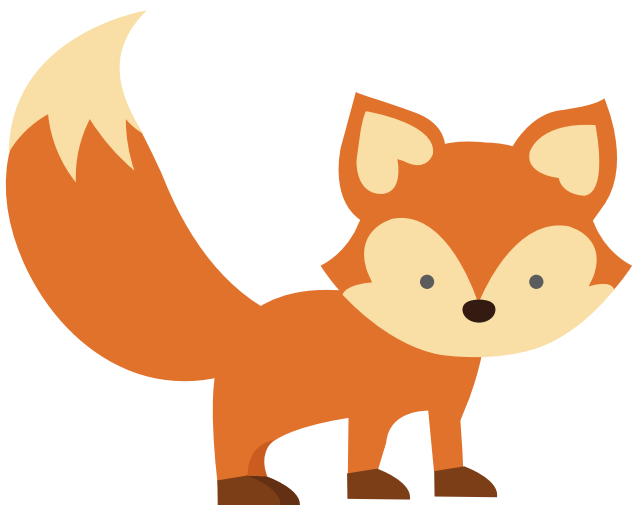
- **In-home respite care** - provides a respite carer to give support at home - day and night care is possible.
- **Centre-based day respite care** - provided at a centre.
- **Community access respite care** - can include social and activity-based outings.
- **Overnight or weekend respite care** - can be flexible, and can involve in-home care or a short stay with a host family.
- **Residential respite care** - involves a short stay in a live-in care facility.
- **Emergency respite care** - available following an unexpected event such as an illness, and may be available at short notice.

Call your local Commonwealth Respite and Carelink Centre on 1800 052 222 for help to find respite care services that meet your needs. Carers Respite Centres are run by a variety of community organisations and are located in metropolitan Perth and country areas. They can help you find services that provide respite support in your local community. For more information, call 1800 059 059.

You may also find some useful information about a range of respite options here: [www.specialaussies.com.au/what-next/respite](http://www.specialaussies.com.au/what-next/respite), including how to prepare your child for respite care, and questions for potential carers.

For children with life-limiting conditions who are not eligible for NDIS, there are limited respite options. At times, Hannah's House finds funding for these children. See [www.hannahshouse.org.au/why\\_hannahs\\_house.html](http://www.hannahshouse.org.au/why_hannahs_house.html)

Peer support groups can also be a valuable way to find support and build your natural networks. When families have been on a similar journey, they generally have a very good understanding of what you are going through, and may have good advice on other places to find support. There are a number of peer support groups that use social media to connect with each other. You may also find groups that meet through [www.peerconnect.org.au/resources/peer-networks/joining-network](http://www.peerconnect.org.au/resources/peer-networks/joining-network). Carers WA also run social support events, and provide 'short break' grants. For more information, see: [www.carerswa.asn.au/carers-wa-services/social-support](http://www.carerswa.asn.au/carers-wa-services/social-support).



## Going to School

Starting school is a major milestone for any child, but for a child with special needs, chronic illness and/or disability, the transition phase will carry extra tasks. At the beginning of each school year it is advisable to meet with the Principal and/or classroom teacher to discuss how your child's needs can best be catered for in the educational setting. Through staff training, professional development, and other appropriate resources (e.g. an Emergency Response Plan) you can be assured that any and all staff coming into contact with your child will be informed of his/her individual needs.

You may be asked to attend a meeting with your child's teacher and others (e.g. school principal, learning support coordinator), to develop a documented plan for your child's attendance at school. A documented plan is a support document for teachers as they plan, monitor, assess and evaluate the teaching and learning program for your child. The plans are often called different names, depending on the focus. For example, it may be called an Individual Education Plan (IEP), Individual Behaviour Management Plan (IBMP), Personalised Learning and Support Plan (PLSP), Individual Transition Plan (ITP) or Risk Management Plan (RMP).

Meetings with educational staff may feel quite intimidating, especially with two or three teachers. If possible, ask your non-primary carer or friend to attend with you. It is beneficial for the staff to meet both parents/carers of the child. The confidence that you gain in having a support person with you usually results in a productive meeting, with successful outcomes on both sides and an increased understanding about your child's specific individual needs.

Students with health care needs require a Health Care Authorisation which is not considered to be a documented plan. However, students with chronic, long-term or significant health care needs often require a documented plan to address their academic and social needs.

You may find the following resources useful:

- Starting school: [www.ddc.org.au/rise/](http://www.ddc.org.au/rise/)
- Department of Education: [www.education.wa.edu.au/web/at-school/resources-for-families](http://www.education.wa.edu.au/web/at-school/resources-for-families)
- Personalised Learning Support Plans used in Education – a guide for families: [www.ddc.org.au/rise/](http://www.ddc.org.au/rise/)
- Thinking ahead – learn how to advocate for your child at school: [www.ddc.org.au/rise/](http://www.ddc.org.au/rise/)

*“Each year we have a consultation with the new school level co-ordinators to explain our son’s chronic condition, his limitations and requirements. We also provide them with medical information sheets for their reference and understanding, along with our phone numbers and a request to keep us informed about anything that may puzzle them. Open communication is essential as we then feel that we are working as a team.”*

**(Neville – parent)**

## Confidentiality

In providing information to the school and its staff, it remains important that your child and family’s confidentiality is respected. Ascertaining the ‘need to know’ versus the ‘want to know’ can act as a helpful guide. Where possible, involve the child in this process. Children of all ages, whether they have special needs or not, do not like to be perceived as different. How respectfully they are treated, and how sensitively their personal health information is managed within the school setting, will influence the child enormously and ideally in a positive manner.

For adolescents in particular, we need to identify and acknowledge their mechanisms for coping and their resilience with illness/disability, as it is important in order to foster self-esteem and a sense of independence. It may be worthwhile to identify a significant other as a mentor whom your adolescent child can confide in without fear of discipline and/or judgement. In the school setting this person may be the counsellor, classroom teacher or school nurse.

## Communication

One of the most effective ways of exchanging information between the home and school settings is by way of a Communication Book, which is separate to a school diary. This book can be ideal for letting the teacher know of any extra relevant information regarding your child, whether it be changed patterns of behaviour, specific observations or accomplishments made throughout the day.

A Communication Book can also be important in recording if and when a child has had medication administered. Details of the time a medication is given and its dosage, particularly if it has been a result of a medical intervention, provide essential information for parents and caregivers.

## Siblings

Siblings of children with special needs will experience their own personal and emotional needs. It’s important their needs are recognised and validated. Consideration of the sibling experience within the school environment and implementing appropriate supports is warranted.

# Transport

## ACROD Parking Scheme

The ACROD Parking Program aims to support Western Australians with a significant mobility restriction to access the community. Permanent and temporary ACROD permit holders are able to park in the marked blue bays. For further detail, see: [www.app.org.au](http://www.app.org.au). Note that applications will need to be endorsed by your doctor or occupational therapist.

## Western Australian Patient Transport Assistance Scheme

The Patient Assisted Travel Scheme (PATs) provides a subsidy towards the cost of travel and accommodation for eligible patients travelling long distances to seek certain categories of specialist medical services. Applications for PATs need to be made by the referring medical practitioner, and must be lodged prior to travel at the patient's nearest health service. To find out more about the scheme, see: [www.wacountry.health.wa.gov.au/index.php?id=pats](http://www.wacountry.health.wa.gov.au/index.php?id=pats).

To be eligible for assistance, patients must be permanent residents in a WA Country Health Service region, travelling more than 100km one way to the nearest eligible medical specialist service including a Telehealth service, travelling more than 70km (each way) to access specialist medical treatment specifically for cancer or dialysis.

## Angel Flight

Angel Flight Australia is a charity that coordinates non-emergency flights for financially and medically needy people. All flights are free and may involve patients and carers travelling to and from medical facilities anywhere in Australia. Angel Flight passengers will fall into many categories including cancer patients requiring regular treatment a significant distance from their home, blood products requiring transport, an ambulatory patient needing aerial transport to specialist treatment and more. For further information, contact 1300 726 567 (Toll Free) or (07) 3620 8300.

## Leukaemia Foundation Transport Services

The Leukaemia Foundation provides patients and their families with courtesy transport to and from treatment. During treatment, a patient's immune system is weakened, so catching public transport may carry a risk of possible infection.

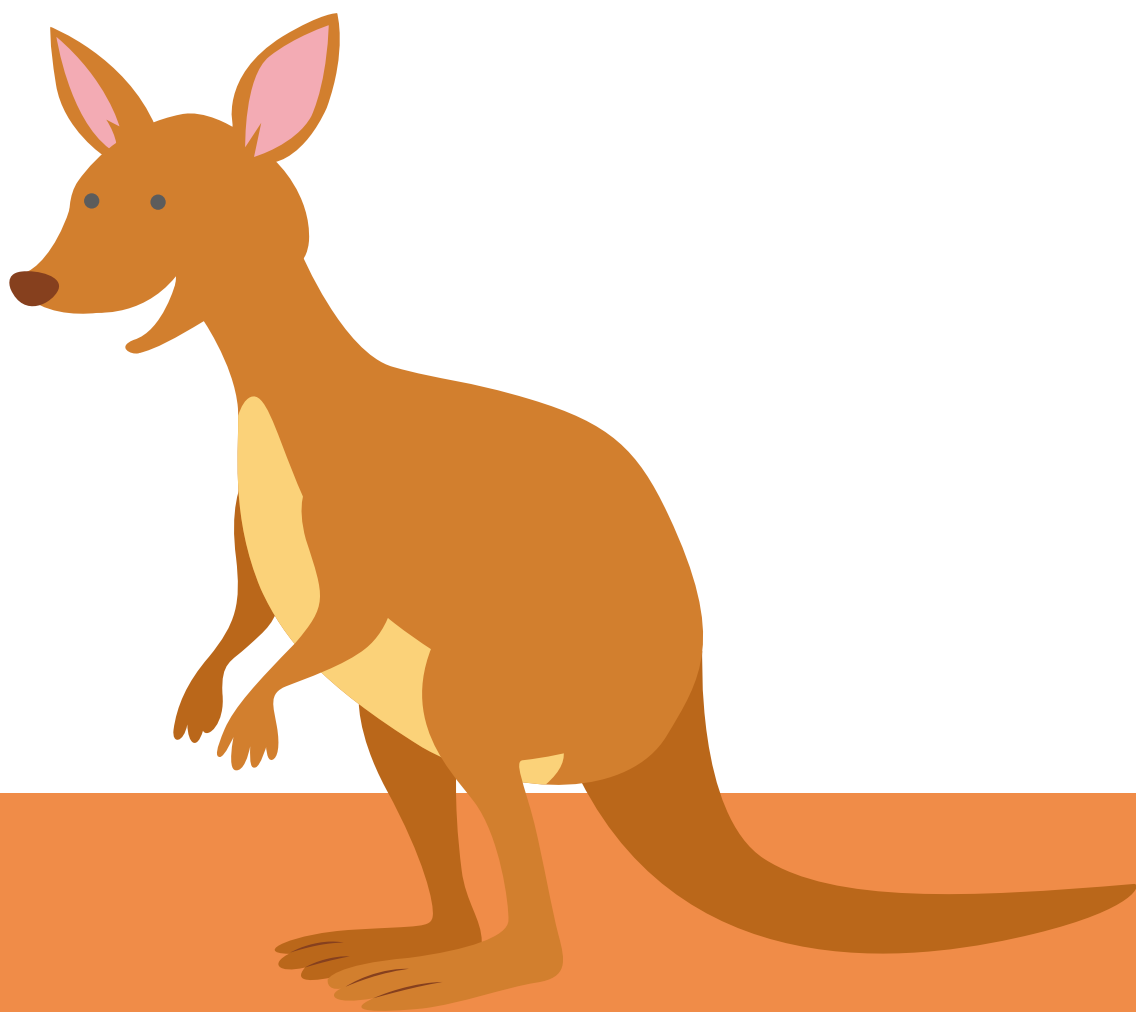
This service is specifically designed to relieve the pressure faced by patients who have difficulties accessing transport, or if patients have limited private transport options, such as the carer in the family having to return to work. It also ensures patients arrive at appointments safely and on time, as well as providing a friendly face to greet patients.

The patient transport program operates in and around the Perth metropolitan area, Mandurah and the South West region. They provide transport to and from treating hospitals in the South West region as well as to Perth for treatment.

The transport program usually runs on weekdays. To book the patient transport program, contact 1800 620 420. A minimum of 24-hours' notice must be given and if patients are unable to attend an appointment notification is required. This service is free of charge. For more details, see: [www.leukaemia.org.au](http://www.leukaemia.org.au).

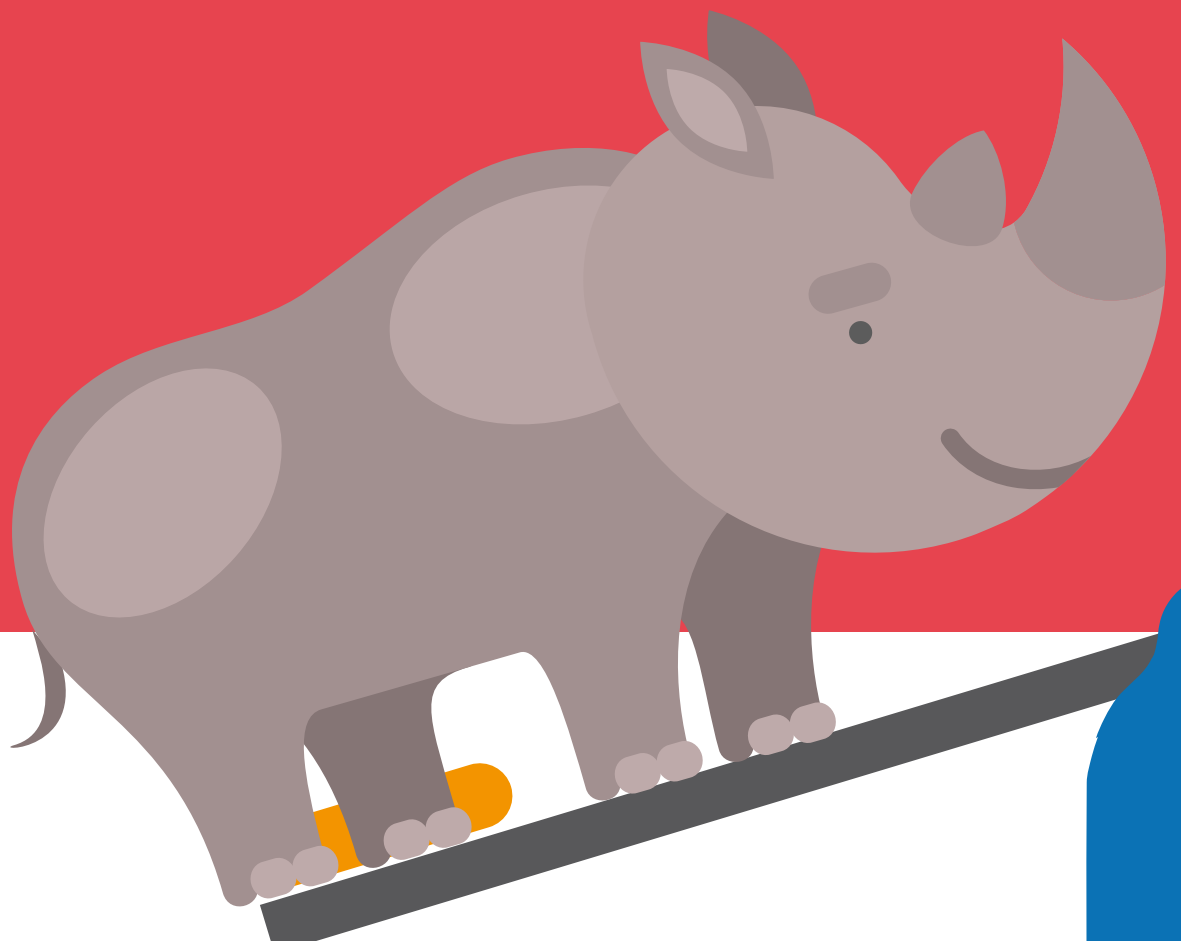






"We have worked it out between us. My wife goes to work. I stay home. Everyone has to sort out what's going to be the best way for them in their family."

(Nev – parent)



# How to Give Your Life 'Balance'



*“When my resources are stretched to the limit I delegate to my partner things like; physiotherapy, blood tests and the occasional specialist appointment. I give him a list of questions to ask, scripts needed, directions for parking and how to find the clinic. My mobile phone is always in reach. He returns with a new perspective on a Doctor’s visit and a new understanding of the hospital system. Each time he succeeds in getting answers to questions, and booking a new appointment, I become more relaxed and confident to hand over responsibilities to him. The more familiar he becomes with my role as primary carer, the better he is able to understand the condition and support me.”*

**(Helen – parent)**

## Key Sources of Support

It is important to utilise potential and existing supports. These may include:

- Family and friends: use their help, don’t try to cope by yourself
- Parent Support Networks / Parent to Parent (see: [www.peerconnect.org.au/resources/peer-networks](http://www.peerconnect.org.au/resources/peer-networks), Developmental Disability WA [www.ddc.org.au](http://www.ddc.org.au), and a range of social-media peer-support groups)
- Attending parent/family information sessions and/or support groups, whether disability specific or for general support. Support from people in a similar situation can be reassuring
- Home Help may be available through your local council
- Contacting the ‘condition specific organisation’ (e.g. Epilepsy Foundation) for your child’s condition, to find out how they can assist you and your family. Ascertain the facts of your child’s condition, when you feel ready to do so
- Some hospitals have Clinical Nurse Consultants who may be able to provide support and assistance.
- Staff within the hospital setting e.g. Hospital chaplains, social workers and allied health
- Family support workers and/or social workers through community organisations.
- A psychologist or counsellor specialising in disability and/or grief counselling.
- The Internet can be a great source of information however it is important to remember that not everything you read will necessarily apply to your child. Online support groups, Internet lists and discussion groups are good ways to talk to other parents of children with similar issues.
- Your church may provide practical help such as meals, cleaning, or babysitting, as well as emotional and/or spiritual support.
- Regular respite.

## Family and Friends

There are many ways in which family and friends can be involved and assist you when you have a child with additional needs, but they may be unsure of how to help. Try to get people involved so they can become familiar with your child and not afraid of his/her care needs. Taking up any offers of assistance can help to reduce stress levels.

**Communication** is very important, so that expectations are clear. There may be useful information sheets available that explain your child's condition. Circulating this information amongst family and friends may help them to understand your child's condition and how your family may be affected. This may also help you to avoid frequent repetition and explanations. Some parents have found it is helpful to write an open letter to family and friends, explaining their child's diagnosis, and what they would like other people to do, or not do, to say and not say.

**At busy times**, such as when your child is very unwell at home, or in hospital, keeping people up to date with your child's condition can be simplified by recording a brief but informative message on your telephone answering machine at home. Alternatively, organising a 'telephone tree' where each person calls 2 or 3 others until everyone is contacted, may be an option.

**Many families** experience a greater sense of loss when they do not get the support they expect from family and friends. To some extent 'life goes on' for other people. Understandably, they will not be affected by the diagnosis in the same way as you, because it's not their child. Some people will not be able to say or do what you would like. Given this, it is probably best to state your needs and be clear about your expectations of them. Try to keep communication lines open, but not at the expense of your emotional and physical health.

*"Every time someone asks about my child's condition it is an opportunity to educate someone. Each time we are faced with an obstacle we improve our advocacy skills, prioritise what's important and not give up."*

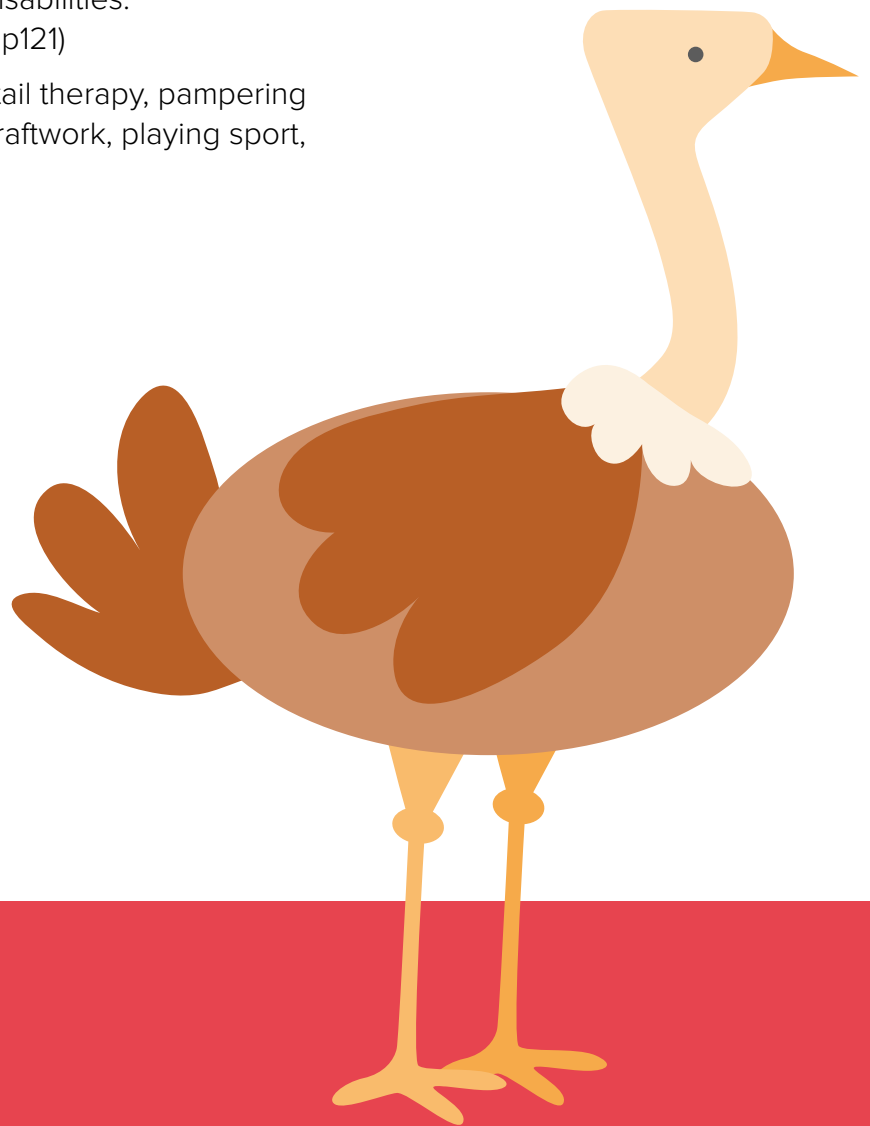
**(Alicia – parent)**

# *Taking Care of Yourself*

As a parent, it can be easy to focus on the needs of others and forget to 'care for the carer'. This can have far reaching effects on the rest of the family. Here are some helpful tips from parents;

- Keep as well as possible, to avoid minor illnesses which may add extra pressure to the family. Looking after yourself will better enable you to continue to look after others.
- Eat well-balanced meals where possible.
- Exercise regularly: walk, swim, or use exercise equipment at home. Balance this however with rest whenever possible.
- Access respite options.
- Get adequate sleep whenever you can. Sleep deprivation may compound existing stress. You may be able to schedule some sleep time while someone else watches your child, perhaps a carer or your partner.
- Role sharing at home can allow each person time to attend to their own needs such as rest, work or leisure activities.
- Consider talking to other parents who are in a similar situation, as this may help to reduce feelings of isolation. You may also find support groups helpful, either on the Internet, or in the community.
- Spending time with friends is important for emotional well-being.
- List some achievable priorities for each day, week, month, or year. For example:
  - Daily: a 10-minute coffee break, a walk around the block...
  - Weekly: a visit to a friend, time in the garden, a game of tennis...
  - Monthly: a manicure, an evening out with your partner...
  - Yearly: a weekend away, a trip to the snow, a big family get together...

- Set aside some time to spend with your partner, your children, or your whole family, no matter how brief. Plan some fun things to look forward to. This will help to maintain the bonds within the family.
- Ask for help when needed
- Accept support when offered, especially if it is helpful.
- Identify areas of life where you are overcommitted, and consider reducing your involvement or delegating tasks to relieve pressure.
- You may be eligible to apply for a Disability Parking Permit. This will enable you to use parking bays designated for people with disabilities.  
[See “Resources & Services” p121]
- Take time out for yourself: retail therapy, pampering yourself, keeping a journal, craftwork, playing sport, catching up with friends



*“When a support worker came to look after their sister, I let my other children know that this time was theirs to use with me however they liked. Regardless of what they wanted me to do (help with homework, play a game, read a book, kick a football, go out for a milkshake) I was 100% available to them in that time. They adapted quickly to this arrangement and planned what they wanted to do with me in this time. The siblings were always my first priority while the support worker was in our home.”*

**(Kate - parent)**

*“When I get home from work my wife has fed him. I shower him and put him to bed – the lifting is too heavy for my wife. She’s got trouble with her back from lifting him.”*

**(Nev - parent)**

## *Caring for the Whole Family*

This is just as important as it was before you were caring for your child with additional needs. Realistically, it can be harder to care for all family members in the same way as you used to. Be aware that change in the family (e.g. illness, disability) will have an impact on all members of the family. There may be significant changes in the relationships within the family, the roles assigned to family members, and perhaps also changes in the daily routine of the home. For example, your other children may have less time with you than they did before; you may get little time to spend alone with your partner; or perhaps you rarely sit down together as a family to share a meal. These changes can be unsettling, but with careful planning, you can do much towards meeting the needs of each other.

It is important to realise that each family member may react differently to the information received about your child. They may each deal with it very differently and may therefore need different supports. Where possible, and as appropriate, involve all family members in decision making processes. This is particularly important for your children, including the one with additional needs.

Consider accessing existing supports for family members (e.g. sibling programs, Big Brothers Big Sisters, Dads’ Days, Mothers’ Groups etc.) Make your own choices about the best level of support for your family. If it feels more onerous than helpful, consider avoiding it.





## *The Non-Primary Carer's Perspective*

People who find themselves in the role of the non-primary carer may also feel a range of emotions, including anger, denial, guilt, relief etc. These feelings may arise in response to the changes occurring in the home, and the challenges of accommodating the additional needs of the child. The non-primary carer may feel inadequate to provide the support needed by the primary carer or other family members. The new role may be overwhelming, particularly if different responsibilities and tasks are required. There may be a need to rearrange work and/or social commitments to allow for a reliable and consistent supporting role within the family.

Some people may willingly adopt their new role, but others may resent the changes and may fear the deterioration of family relationships. It may take time to learn and adjust to such role changes. Tasks may not be achieved as 'perfectly' or done the 'same way' they were previously. As the changing roles of others in the home are considered, the non-primary carer will perhaps be needed in ways that he/she has not been needed before. For example, he/she may become more involved with shopping, housework, siblings' homework, or the care needs of the child with additional needs.

Primary and non-primary carers will learn different skills and have new responsibilities. Remember that primary carers can also get sick, and may not always be able to attend to the child's needs. It is important that the non-primary carer understands the child's condition and is confident in the administration of medications, treatments and other daily care tasks. A carer from outside the family may need to consider tasks other than working with the child. Siblings may need more time and attention to balance some of what they may be missing out on, and non-primary carers are an obvious choice for accommodating such needs.

Note: In addition to the immediate family, a 'non-primary carer' may be a member of the extended family, friends or community workers.

*"When our daughter was in hospital for 6 weeks after her surgery, I was glad in a way that I could go to work, because it was a distraction from what was going on at the hospital. I also felt that I did not need to be there since her mother was with her. However, when I was at work, I would constantly worry about how things were at the hospital and how they were both getting on, especially when our daughter was in Intensive Care."*

**(Tony - parent)**

*"It is easy to take things for granted or have the attitude that nothing will happen to the primary carer, but life gives no guarantees. Be aware of the basic day-to-day care requirements of the child, listen, ask questions about the condition and be available where possible. Consider starting a list of information, a lot of dads wouldn't know what size shoes, clothes, nappies or medication doses their child would need if mum wasn't there"*

**(Nick – parent)**

# Siblings

Parents are not the only ones who must adjust to a child's illness or disability. Life changes for the entire family. As parents generally have to pay extra attention to the child with a chronic illness or disability, siblings may often feel neglected.

Some of the common feelings and experiences of siblings living with a brother or sister with a disability/chronic or life-threatening illness include:

- Guilt (that they are not sick)
- Anxiety about whether they will get sick
- Embarrassment
- Fear
- Pressure to achieve
- Confusion
- Over protection or exclusion
- Heightened empathy
- Shame
- Anger or jealousy over not being the centre of attention
- Increased responsibility
- Sense of achievement
- Denial
- Isolation
- Grief
- Understanding
- Independence
- Sensitivity

Parents need to be aware that while attending to the needs of your child with a chronic illness or disability, you may be neglecting – or creating unfair expectations for – your other children. At times, siblings may feel invisible unless they demand attention. However, siblings can learn to participate in the family and feel pride and love in helping their brother or sister with his or her health problem. The presence of a family member with a chronic illness provides opportunities for increased empathy, responsibility, adaptability, problem solving and creativity.

### Parents need to try to do the following:

- Establish some balance between the needs of your child with a chronic health problem or disability and those of your other children.
- Spend some time with each child individually when possible.
- Develop a special relationship with each one of your children.
- Keep in mind that siblings need to have honest information about the condition and to have their questions listened to and answered.

When there is a child with a chronic illness or disability in your family, your other children may experience negative effects. There are some warning signs that the siblings of your child with a chronic health condition or disability may need some attention. For example, a sibling may become:

- Anxious
- Depressed
- Withdrawn
- Angry
- Rebellious

They may also begin to:

- Lose interest in their friends
- Lose interest in activities that once brought pleasure (e.g. sport, music)
- Do poorly in school
- Push too hard to achieve
- Act out in other ways to get attention.

If you are concerned, ask your child's GP or paediatrician for help. He or she can guide you to local psychologists, social workers and/or support groups for siblings of children with chronic health problems or disabilities. You should not expect or attempt to solve these concerns related to the siblings of your child with a chronic illness or disability by yourself.

In WA, a range of organisations provide support targeted to siblings of children who either have a disability or life-threatening illness.

A sibling may not be the main person who looks after their brother or sister who has a disability but they usually have extra responsibilities and duties at home compared to other people their age.

*"It's awkward when people ask me if I have a sibling. I say I have a sister. They ask lots of questions about her, so I tell them. It's always the same reaction. I'm not ashamed of her at all. I'm actually really proud."*

**(Courtney - sibling)**

*"Sometimes my sibling takes it out on me if he is having a bad day in hospital. The staff emphasise his needs, but what about me?"*

**(Georgi - sibling)**

*"When I'm not with Elizabeth I'm just like everybody else. When I go places with Elizabeth I see some people who stare and that makes me angry. Some people stare in a nice, curious way, but other people stare in a bad way. I have a friend who's really nice to Elizabeth. My friends are all understanding but some don't understand disability."*

**(Alice - sibling)**

A young carer is someone aged up to 25 years who provides unpaid care and support to a family member who has a disability, chronic condition, terminal illness or mental illness.

The Carers Australia WA Young Carers program can offer supports, resources and activities.

For more details, see [www.youngcarerswa.asn.au/info-help/who-are-young-carer](http://www.youngcarerswa.asn.au/info-help/who-are-young-carer) or [www.siblingsaustralia.org.au/wa.php](http://www.siblingsaustralia.org.au/wa.php).

You may also like to consider getting a sibling involved in a mentoring program – for detail, see here: [www.aymn.org.au/program-state/wa](http://www.aymn.org.au/program-state/wa). Further information can be found from: Siblings of children with special needs – [www.siblingsaustralia.org.au/assets/resources/learning-links-article.pdf](http://www.siblingsaustralia.org.au/assets/resources/learning-links-article.pdf).



# *Building Resilience in Your Family*

Every family will learn how to embrace and show love for a child with a chronic health problem or disability. There is no right way or wrong way for siblings to live and grow together; rather, every family should strive for its own balance and determine what are some strategies and supports that help the child with chronic health problems and her siblings to thrive and be resilient.

The ultimate goal is to build internal strengths and coping skills in your child with a chronic health problem or disability and in all of the members of your family. Many factors will influence this process, including the course of the chronic condition and the external and internal supports and resources available to the child with special needs, her siblings, and the rest of the family.

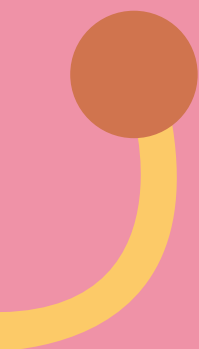
While most families with chronic health problems or disabilities struggle through times of fear and despair, many also develop an internal resilience, a creativity, and a closeness or cohesiveness that helps the children with and without chronic health problems and rest of the family to manage and cope together with the many stresses that may develop over time. Often as a result of these experiences, adults and children learn about their strengths and limitations, talk more openly, and learn new ways to solve problems which fosters mastery and pride.

In the months and years ahead:

- Continue to reassess the needs and goals for your child with chronic illness or disability, their siblings, and your family.
- Be willing to learn new skills, search for supports and make changes as needed that serve both the child with the chronic health problem, their siblings, and everyone else in the family.
- As much as possible, involve all of your children in shared decision making about any health care that affects them.
- Stay informed and give yourself credit for all the hard work you and your family have done and the resiliency you have developed in your family.



# Glossary



**Allied Health** – Staff other than a doctor e.g nurse, physiotherapist, occupational therapist, speech pathologist, psychologist, counsellor, personal care attendant, social worker etc.

**Bulk Bill** – Full amount of medical payment met by Medicare

**Clown Doctors** – Clown Doctors dose their patients with fun and laughter! Hospital can be scary, confusing or just plain boring for kids. Clown Doctors visit children in their beds or outpatient clinics.

**Counsellor** – A professional who provides advice and support in many forms e.g Individual counselling, relationship counselling, financial counselling, mental health counselling, rehabilitation counselling etc.

**Diagnosis** – Identification of a disease or condition by evaluation of physical signs and symptoms, history, laboratory tests and procedures.

**Discharge** – Going home after being an inpatient

**Elective** – Non-emergency situation i.e procedure takes place at a chosen time

**Empower** – To give or delegate power to; to enable or permit

**Inpatient** – A person being admitted into hospital overnight or longer

**Meds** – Abbreviation of the word ‘medications’ i.e tablets, syrups or other forms available to help treat diseases or conditions. They can be prescribed by doctors, complimentary therapists or pharmacists etc.

**Orthotic** – The design and use of external appliances to support specific muscles, promote a specific motion or correct deformities

**Outpatient** – A person who accesses hospital staff and medical management in a day clinic

**Paediatrician** – Specialist doctor working with children only

**Physician** – A person qualified to practise medicine, especially one who specialises in diagnosis and medical treatment as distinct from surgery



**Play Therapy** – A form of psychotherapy where a child plays in a protected, structured environment with games and toys provided by a therapist.

**Prognosis** – Prediction of the probable outcome of a disease based on the condition of the person, and the usual course of the disease in similar situations.

**Respite** – Provision of temporary care for a patient who requires care. It provides a break for the primary care givers. Respite can occur in the home, in the community or at another location. Respite can be planned or in an emergency.

**Script** – Abbreviation of the word ‘prescription’. Written authority for the obtainment of a specific medication from a pharmacist.

**Specialist** – A doctor who has completed extra training in a specific medical skill area.

**Symptoms** – An indication of a disease or a change in a condition.

**Technician** – A broad term used to describe someone who designs and helps you use specialised equipment available for people with disabilities. Technology can include environmental control devices, switches, mounting systems, computer hardware, accessories, educational and recreational software and communication devices.





# *Publications*

## For Parents

**A Delicate Balance: Living successfully with chronic illness.** Wells, S. 1998. Plenum Publishing New York.

**Coping with Your Child's Chronic Illness.** Barrett Singer, Alesia T. 1999 Robert D Reed Publishers, San Francisco CA.

**Easy For You To Say: Q & As For Teens Living With Chronic Illness Or Disabilities** Miriam Kaufman. 2005. Firefly Books, US

**Listen – my child has a lot of living to do! Caring for children with life threatening conditions.** Baum, J.D., Dominica, Sis F, Woodward, R.N. (eds) 1990. Oxford University Press. Oxford.

**Mum Says I'm Special, Aren't We All? Caring for Kids with Chronic Illness or Allergies.** Buchner, L. 2005 BAS Publishing, Australia

**Nonfinite Loss and Grief: A psychoeducational approach.** Bruce, E.J. and Schultz, C, L. 2001. MacLennan and Petty, Sydney, NSW.

**Siblings: Brothers and sisters of children with special needs.** Strohm, K. 2002. Wakefield Press, South Australia.

**The Art of Getting Well: A five step plan for maximizing health when you have a chronic illness.** Spero, D. 2002. Hunter House Inc, Alameda, CA.

**You Are Not Your Illness: Seven principles for meeting the challenge. 1995.** Topf, Linda Noble. Simon and Schuster, New York.

**You will dream new dreams - inspiring personal stories by parents of children with disabilities.** Klein, S.D and Schive, K. 2002. Kensington Press. US.

**When your Child is Ill: A home guide for parents.** Valman, B. 2002. Dorling Kindersley, Melbourne.

## A Parent's Perspective

- “Welcome to Holland” by Emily Perl Kingsley
- “Celebrating Holland” by Cathy Anthony

*Note: The above listing is only a small selection of books suggested for inclusion in this resource book. Most support organisations will be able to provide more comprehensive bibliographies, which are condition specific.*

## For Kids

**Bones: Our skeletal system.** Simon, S. 1998. Morrow Junior Books, New York.

**Don't call me special: A first look at disability.** Thomas, P. 2001 Hodder Publishing, London.

**I don't want to go to hospital.** Ross, T. 2001. HarperCollins Publishers Inc., London.

**Just for the day: A day's stay in hospital Melbourne:** Educational Resource Centre. 1994 Video recording, Royal Children's Hospital.

**The glow in the dark book of human skeletons.** Novak, M. 1997. Random House, New York.

**The visual dictionary of the skeleton.** 1995. Dorling Kindersley, London.

**My Many Coloured Days.** Dr Seuss. 2001. Random House Children's Books, U.K.

**When I'm Feeling Scared.** Moroney, T. 2005. Five Mile Press Pty Ltd, Australia

**When I'm Feeling Angry.** Moroney, T. 2005. Five Mile Press Pty Ltd, Australia

**When I'm Feeling Sad.** Moroney, T. 2005. Five Mile Press Pty Ltd, Australia

## For Siblings

**When Molly was in hospital: A book for brothers and sisters of hospitalized children.** Duncan, D. 1994. Rayve Publications. Windsor, CA.

**Something Has Happened: an activity book for young children.** Irving, T. 2000. Skylight, N.Z

**Supporting Siblings: When a Brother or Sister has a Disability or Chronic Illness.** Association for Children with a Disability. 2003. Australia.

**The Huge Bag of Worries.** Ironside, V. 1996. Macdonald Young Books, U.K

**When Someone Has A Very Serious Illness.** Heegaard, M. 1991. Woodland Press, U.S.A.

**When Tough Stuff Happens: An Activity Book for Tough Times for 7-12 year olds.** Irving, T. 2001. Skylight, N.Z.

## Bereavement Literature

Caring for Your Grieving Child - Engaging Activities For Dealing With Loss and Transition. Wakenshaw, M. 2002. New Harbinger Publications Inc. USA

Coping with Grief. McKissock, M and McKissock, D.1995. (3rd ed) ABC Books, Sydney

Grief Counselling & Grief Therapy - handbook for mental health professionals.

Worden, J.W. 2004. (3rd ed) Brunner- Routledge. USA

Muddles, Puddles and Sunshine: Your activity book to help when someone has died. Crossley, D. 2000. Hawthorn Press, U.K.

Shadows in the Sun: The Experiences of Sibling Bereavement in Childhood. Davies, B. 1999. Taylor and Francis USA

The Grief of Our Children McKissock, D. 1998. ABC Books. Australia

## Specialist Library

Activ Library is a major library for disability related information in Western Australia. Everyone is welcome – parents, families, carers, people with a disability and teachers and staff working in the disability field. They have more than 8000 items including books, DVDs, training materials, journals and selected websites. The collection has a strong focus on intellectual disability and autism, as well as other disabilities, health conditions, developmental delay and learning difficulties.

Address: 327 Cambridge Street Wembley

Telephone: (08) 9387 0458

Email: [library@activ.asn.au](mailto:library@activ.asn.au)

Website: [www.activ.asn.au/library](http://www.activ.asn.au/library)







# Resources & Services



*Note: While accurate at the time of printing, it is possible that certain contact details may change with time.*

## Advocacy & Support

There are too many 'condition specific' support organisations within the community to list here, however they are an excellent place to start and a wealth of information. Be sure to tap into these services – they exist to help you and your family. (eg Down Syndrome Association WA, Heart Kids WA )

### ConnectGroups

Connectgroups is the peak body for Self Help and Support Groups in WA with:

- Links to community networks and information.
- Assistance with group development and management.
- Support with community resources and services.
- Individual and group skills training.

They can assist families to connect with others in a support group or even assist you to establish one.

Address: 10A Almondbury Rd, Booragoon WA 6154

Telephone: 08 9364 6909

Website: [www.connectgroups.org.au](http://www.connectgroups.org.au)

Email: [info@connectgroups.org.au](mailto:info@connectgroups.org.au)

### Continence Advisory Service of WA

The Continence Advisory Service of WA provides education, advice and information to people with bladder and/or bowel health issues, their carers, families, health care professionals, support workers and special needs groups.

In 2013, the Continence Advisory Service of WA established a partnership with Therapy Focus to deliver PEBBLES. PEBBLES is a new continence management service for children aged 0 - 16 years with a disability. The service is the first of its kind in Western Australia and is available to eligible children throughout the state. The PEBBLES acronym stands for: Providing Education on Bladder and Bowel Health, Liaison, Expert Advice and Support.

Telephone: (08) 9386 9777

Website: [www.continencewa.org.au](http://www.continencewa.org.au)

Email: [pebbles@therapyfocus.org.au](mailto:pebbles@therapyfocus.org.au)

## Developmental Disability WA

Developmental Disability WA (DDWA) is the peak organisation in WA for people with intellectual and developmental disability, and their families and people who support them.

For over 30 years DDWA have been working to ensure that people with disability and their families live their lives their way. DDWA create lasting positive change by:

- supporting people with developmental disability and their families to have a strong voice
- partnering with others to develop more connected and inclusive communities
- influencing government and other decision makers

City West Lotteries House  
2 Delhi St, West Perth WA 6005  
Telephone: (08) 9420 7203  
Email: [ddcwa@ddc.org.au](mailto:ddcwa@ddc.org.au)  
Website: [www.ddc.org.au](http://www.ddc.org.au)

## Disability Discrimination Unit (DDU)

The Western Australian Disability Discrimination Unit is a part of Sussex Street Community Law Service Inc. They conduct a Disability Discrimination Outreach Service at St Mathews Church, Jull Street Armadale every second Wednesday morning by appointment. The DDU provides free information and advice to people who feel they have been discriminated against due to their disability.

Discrimination occurs when a person is treated less favourably than others. Discrimination can be direct or indirect and includes harassment and being asked discriminatory questions.

Direct discrimination is where a person with a disability is directly treated differently because of the disability.

Indirect discrimination is placing some conditions on a person with a disability that they cannot satisfy but that a person without a disability could.

### Who can complain about disability discrimination?

- A person with a disability
- A person on behalf of a person with a disability, such as a carer or parent of a child with a disability
- Associates, partners, friends, parents, carers and family members.

Phone: (08) 6253 9500  
Local Call: 1300 648 655  
Email: [Legal@sscls.asn.au](mailto:Legal@sscls.asn.au)



## Genetic and Rare Disease Network

GaRDN works to empower individuals and their families to reach positive health outcomes. They connect key stakeholders and service providers with people affected by genetic and rare diseases. GaRDN offer the 'Link Line' service which provides a supportive and confidential means of connecting individuals and families for whom no known genetic or rare disease support group exists.

Suite 5, Oasis Lotteries House, 37 Hampden Road,  
Nedlands 6009

Telephone: (08) 9485 8999

Email: [hello@gardn.org.au](mailto:hello@gardn.org.au)

Website: [www.geneticandrarediseasenetwork.org.au](http://www.geneticandrarediseasenetwork.org.au)

## Independent Living Centre

Independent Living Centre (ILC) enhances the independence and quality of life of people with disabilities by providing information and advice on daily living equipment. The Centre has a large range of aids for daily living and adaptive equipment on display.

- Assistive Equipment Services (AES)
- Community Allied Health Services
- Country Services
- ILC Hire
- ILC Training
- Technology and Communication
- Noah's Ark WA (toy library - [www.noahsarkwa.org.au](http://www.noahsarkwa.org.au))
- Occupational Therapy Driver Assessment

The ILC does not sell equipment. However, supplier and relevant service information can be obtained from the staff.

The Niche, Suite A, 11 Aberdare Road,  
Nedlands, WA, 6009 Australia

Telephone: (08) 9381 0600, 1300 885 886

Email: [general@ilc.com.au](mailto:general@ilc.com.au)

## Kalparrin

Kalparrin helps parents and carers of children with special needs to access services, resources and social support.

Kalparrin is a non-diagnosis specific service provider and assists families who are caring for children with a wide range of disabilities and special needs. These include physical and intellectual disabilities, autism spectrum disorder, genetic and rare diseases, developmental delays, mental health conditions, childhood cancers and chronic health conditions.

Parents and carers need quick access to information about how best to help their children and find the right therapy service providers, respite care options, education support, diagnosis specific groups, financial and legal advisors and funding opportunities which will help them get good care outcomes for their family.

Kalparrin also connects parents with one another to help them grow their support network. They do this through Kalparrin Families, WA's largest online peer support network which operates 24 hours a day and also by hosting a series of fun social events, carer wellbeing retreats and information workshops and seminars throughout the year.

All these activities provide a space, non-judgmental space where parents and carers can come together to make friends, get the information they need, learn new coping strategies and share the challenges, frustrations and joys associated with being a special needs parent.

In 2017 Kalparrin will be relocating to the Family Resource Centre at the Perth Children's Hospital. The address until then is:

Level 4, Hay St Building, Princess Margaret Hospital, Subiaco  
Telephone: 9340 8094

Email: [kalparrinwa@health.wa.gov.au](mailto:kalparrinwa@health.wa.gov.au)

Website: [www.kalparrin.org.au](http://www.kalparrin.org.au)

## Make A Wish Foundation

The Make A Wish Foundation grants wishes across Australia to children with life-threatening illnesses.

Telephone: 1800 032 260

Website: [www.makeawish.org.au](http://www.makeawish.org.au)

## Midlas

Midlas is a not for profit community organisation, accredited as a community legal centre with the National Association of Community Legal Centres. Midlas offers a range of free services for our eligible clients, including disability advocacy, financial counselling, tenancy advocacy, legal service, emergency relief and an information and referral service.

23 Old Great Northern Highway, Midland

Telephone: (08) 9250 2123

Website: [www.midlas.org.au](http://www.midlas.org.au)

## My Time Peer Support Groups

MyTime groups provide support for mothers, fathers, grandparents and anyone caring for a child with a disability or chronic medical condition. It's a place for you to unwind and talk about your experiences. It's a world away from appointments and therapy. It's support for you.

MyTime groups provide facilitated peer support to families raising children with complex needs. Peer support groups provide an opportunity for people who are living similar experiences to share those experiences and support each other. They typically consist of a group of people who share a similar—but not necessarily identical—life experience.

Telephone: (08) 9368 9368

Website: [www.mytime.net.au](http://www.mytime.net.au)

## Ngala

Ngala is a provider of Early Parenting and Early Childhood services with a passion for supporting and guiding families and young children through the journey of parenting. Services are supported by Ngala's interdisciplinary team including child health, midwives and mothercraft nurses, lactation consultants, psychologist, GP, and social workers. Services are available for families with young children who work or reside in Western Australia and our online information is available to everyone.

Services include:

- Ngala Parenting Line
- Community Centres
- Parenting Workshops
- Early Parenting Groups
- Consultations
- Day and Night Stays
- Childcare

Parents wishing to discuss these services should contact the Ngala Parenting Line which operates 7 days a week - 8am to 8pm

9 George Street, Kensington WA

Telephone: (08) 9368 9368, or Country Access: 1800 111 546

Email: [ngala@ngala.com.au](mailto:ngala@ngala.com.au)

Website: [www.ngala.com.au](http://www.ngala.com.au)

## PWd WA

People with disabilities WA provides systemic disability advocacy state wide and also Independent Individual Advocacy to have someone work alongside you when you think you have been treated unfairly or you are seeking a solution to a specific problem or issue.

Oasis Lotteries House, 1/37 Hampden Road,  
Nedlands, WA 6009

Telephone: (08) 9485 8900

Email: [info@pwdwa.org](mailto:info@pwdwa.org)

Website: [www.pwdwa.org](http://www.pwdwa.org)

## Redkite

Redkite supports children and their families through cancer by providing:

- **Financial assistance** to cover essential costs
- **Information, counselling and group support**
- Support to keep **education and career goals** on track
- Support through **grief and loss**
- **Diagnosis support packs** for children and young adults
- Support in hospital through **social workers** and **music therapists**

229 Stirling Hwy, Claremont WA 6010

Telephone: (08) 6188 2900

Website: [www.redkite.org.au](http://www.redkite.org.au)

## Ronald McDonald House

Ronald McDonald Houses are attached to major women's or children's hospitals around Australia, and provide a 'home-away-from-home' for families of children with serious illness, along with the support of experienced House Managers, volunteers and other families in a similar situation.

21 Monash Avenue, Nedlands, WA, 6009

Telephone: (08) 9346 9000

Website: [www.rmhc.org.au](http://www.rmhc.org.au)

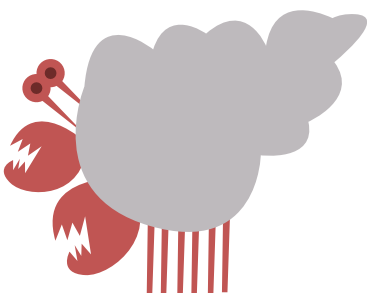
## Ronald McDonald Learning Program

A major concern when a child has a serious illness is that they may miss lengthy periods of schooling and fall behind their peers. The Ronald McDonald Learning Program provides comprehensive assessment to determine each child's learning strengths and needs. From the results an individual education plan is developed which includes tuition and speech or occupational therapy if required.

Learning Program Education Coordinator WA

21 Monash Avenue, Nedlands, WA, 6009

Telephone: (08) 9388 8607





## SANE Australia

SANE is an independent national charity working for a better life for people affected by mental illness and their carers.

HELPLINE operates Monday to Friday 9-5 AEST

HELPLINE Telephone 1800 18 7263

HELPLINE email [helpline@sane.org](mailto:helpline@sane.org)

Email: [info@sane.org](mailto:info@sane.org)

Website: [www.sane.org](http://www.sane.org)

## Starlight Foundation

The Starlight Foundation delivers innovative programs both within hospital environments, and outside, with their Captain Starlight, Starlight Express, Live Wire & Wish Granting programs.

Captain Starlight's role may seem simple - playing games, telling jokes and performing magic tricks - but it's a critical part of a child's overall care.

Designed to combat loneliness and isolation, Livewire connects teens and young people (10-20) experiencing serious illness or disability through creative workshops when they're in hospital, as well as via an online community.

Starlight also grants wishes for children aged four to eighteen years, living with a terminal, chronic or critical illness. Starlight Wishes make the impossible happen. A child can be referred to Starlight for a wish experience by a qualified health professional.

PO Box 385, Como, WA 6952

Telephone: 1300 727 827

## TADWA

### (Technology Assisting Disability Western Australia)

TADWA is a not for profit organisation established to deliver solutions for independence and safety for people with disabilities, older people and carers. Under the coordination of occupational therapists, TADWA designs, constructs or modifies equipment for people with disabilities.

371 Collier Road, Bassendean, WA 6054

Telephone: (08) 9379 7400

Email: [enquiries@tadwa.org.au](mailto:enquiries@tadwa.org.au)

## Telethon Speech & Hearing

Telethon Speech & Hearing Centre for Children is a not-for-profit, charitable organisation based in Wembley, Western Australia. Telethon Speech & Hearing (TSH) exists to support families, children, adults and carers offering:

- early intervention and school support programs for hearing impaired children,
- early intervention for children with speech and language delay or disorder,
- specialist paediatric audiological services,
- specialist adult audiological services and
- support services for adults with hearing impairment.

36 Dodd Street, Wembley WA 6014

Telephone: 9387 9888

Website: [www.tsh.org.au/programs-services/audiology-ear-health](http://www.tsh.org.au/programs-services/audiology-ear-health)

## WA Companion Card Program

The Companion Card is a card issued to people with a significant and permanent disability who require attendant care support from a companion to participate at most venues and activities. Cardholders present their card when booking or purchasing a ticket from a participating business. Participating businesses will recognise the Companion Card and issue the cardholder with a second ticket for their companion at no charge.

The Companion Card program has been running in Western Australia since April 2006. The program aims to provide a simple and consistent method of identifying people who legitimately require attendant care support to participate at venues and activities.

Telephone: (08) 9443 3107 or 1800 617 337 TTY

Email: [wa@companioncard.asn.au](mailto:wa@companioncard.asn.au)

Website: [www.wa.companioncard.org.au](http://www.wa.companioncard.org.au)

# Counselling

## Kids Help Line

The Kids Help Line is a free and confidential, 24-hour telephone counselling and online service for 5 to 25 year olds in Australia.

Telephone: 1800 55 1800 (Counselling Line)

Email: [counsellor@kidshelpline.com.au](mailto:counsellor@kidshelpline.com.au)

Website: [www.kidshelp.com.au](http://www.kidshelp.com.au)

## Lifeline

Lifeline provides a 24 hour telephone counselling service and a crisis support chat service each night from 7pm to 4am (AEST) via the website.

Telephone: 131 114

Website: [www.lifeline.org.au](http://www.lifeline.org.au)

## Parenting WA Line

The Parenting WA Line provides telephone information, support and referrals to parents, carers, grandparents, foster carers and families who are taking care of a child or children aged from pre-birth to 18 years. Parenting support officers can also provide information and referrals to local community support services and programs and courses offered by Parenting WA.

Contact the Parenting WA Line and speak with a parenting support officer from 9am to 5pm, Monday to Friday:

Telephone: (08) 6279 1200, or 1800 654 432

Email: [parentingwaline@dlgc.wa.gov.au](mailto:parentingwaline@dlgc.wa.gov.au)

Visit 'Parenting WA' on Facebook

## Relationships Australia

Relationships Australia is an organisation that offers resources to couples, individuals and families to help enhance and support relationships.

Telephone: 1300 364 277

Counselling: (08) 6164 0190

Website: [www.relationshipswa.org.au](http://www.relationshipswa.org.au)

### TCF - The Compassionate Friends

TCF provides support for bereaved parents, siblings and grandparents affected by the death of a child, through any cause.

Telephone: 08 9486 8711

Website: [www.compassionatefriendswa.org.au](http://www.compassionatefriendswa.org.au)

### Carers Australia WA

The professional counsellors at Carers WA are dedicated to helping carers build resilience in their caring role, by creating a balance between caring responsibilities and self-care. You can do this by phone, email, face to face or by skype.

Carers Counselling Line: 1300 227 377 (8.00am – 5.00pm)

### Anglicare

The Family Relationship Service for Carers offers counselling and mediation services to the family or carers of individuals with disabilities. The counselling sessions may be either one-on-one or via phone. They may include the whole family, depending on the client's preference. They can help families deal with stress, relationship issues and help resolve conflicts.

Appointments can be made by contacting Anglicare WA during offices hours 9-4pm, Monday – Friday.

Telephone: (08) 9263 2050, Country callers: 1800 812 511.

# Early Intervention

You can access early intervention services if you have an NDIS plan, WANDIS plan, Disability Services Commission funding, Better Start funding, Helping Children with Autism funding, Medicare or if you want to fund your own services.

Listed below are services providers who can assist families with early intervention therapies such as Speech Pathology, Occupational Therapy, Physiotherapy, Psychological support and ABA Therapy.

Under the NDIS in WA scheme launching across the state in July 2017 you can also elect to use your individual funding with a range of other service providers who are registered as NDIS service providers.

## Ability Centre (Previously The Centre for Cerebral Palsy)

For children with disability aged 0-7, our therapists focus on providing effective intervention from the earliest possible time. We do this by ensuring each child has the opportunity to develop, enhance and maintain skills in their home, pre-primary and community settings.

Services are delivered through individualised intervention initiatives that include opportunities for skill development for the child, and can include home visits or sessions at Ability Centre kindergarten visits, school visits, or visits to Child Care Centres – to provide information and support to staff and invitations to group programs

106 Bradford St, Coolbinia WA 6050

Telephone **(08) 9443 0211**

Website: [www.abilitycentre.com.au](http://www.abilitycentre.com.au)

## Autism Association of WA

Early Childhood therapy packages such as The First Steps for Autism program are designed for children aged zero to eight years of age and are tailored to meet the individual needs of each child and their family. You can choose to have therapy at our specialist therapy centres or in home, school and/or community environments.

215 Stubbs Terrace, Shenton Park WA 6008

Telephone: (08) 9489 8900, Country: 1800 636 427

Email: [autismwa@autism.org.au](mailto:autismwa@autism.org.au)

Website: [www.autism.org.au](http://www.autism.org.au)

## Disability Services – Early Years Metropolitan Program

For children diagnosed as vulnerable to intellectual disability, services are provided by an interdisciplinary team, using a 'team around the child' model.

71-73 Norma Road, Myaree, WA, 6154  
Telephone: (08) 9329 2403 or (08) 9329 2402  
Website: [www.disability.wa.gov.au](http://www.disability.wa.gov.au)

## ISADD WA

Providing early intervention services for children with any disability type, including unique services for autism.

50 Angove Street, North Perth, WA, 6006  
Telephone: (08) 9227 6888  
Email: [isadd@isadd.org](mailto:isadd@isadd.org)  
Website: [www.isadd.org](http://www.isadd.org)

## Kids Are Kids!

Kids Are Kids! provides a range of government funded programs (and privately funded services) to children and their families. Our programs offer high-quality Speech Pathology, Occupational Therapy, Physiotherapy and/ or Psychology services to support your child's skill development and increase their independence and participation in the community.

26 Parry Avenue, Bateman, WA 6150  
Telephone **(08) 9313 6566**  
Email: [info@kidsarekids.org.au](mailto:info@kidsarekids.org.au)  
Website: [www.kidsarekids.org.au](http://www.kidsarekids.org.au)

## Next Challenge

Individualised therapy with a Speech Therapist, Occupational Therapist, Physiotherapist, and consultant Dietician.

Units 3 and 4, 14 Main Street, Osborne Park WA 6017  
Telephone: (08) 9201 0707  
Email: [enquiries@nextchallenge.com.au](mailto:enquiries@nextchallenge.com.au)  
Website: [www.nextchallenge.com.au](http://www.nextchallenge.com.au)

## Rocky Bay

Provides services such as Physiotherapy, Occupational therapy, Speech therapy, Psychological support, Rehabilitation and skills development, Social work and Hydrotherapy.

13 Baling Street, Cockburn, WA 6164

Telephone: (08) 6399 4120

Email: [clinserv@rockybay.org.au](mailto:clinserv@rockybay.org.au)

Website: [www.rockybay.org.au](http://www.rockybay.org.au)

## Senses Australia

Providing early intervention services to children with a range of disabilities including physical, sensory and motor difficulties and intellectual disabilities.

11 Kitchener Avenue, Burswood, WA, 6100

Telephone: (08) 9473 5458 or (08) 9473 5459

Email: [Kelly.gurr@senses.org.au](mailto:Kelly.gurr@senses.org.au) or

[Rebecca.lamhut@senses.org.au](mailto:Rebecca.lamhut@senses.org.au)

Website: [www.senses.org.au](http://www.senses.org.au)

## Skillbuilders

Skillbuilders provides therapy support to children, including Occupational therapy, Physiotherapy, and Speech Therapy. They provide regular therapy programs, as well as specialised holiday programs and group programs. Skillbuilders also have an extensive range of therapy products.

Unit 1/24 Hammond Road, Cockburn Central, WA, 6164

Telephone: (08) 9417 4903

Email: [info@skillbuilders.com.au](mailto:info@skillbuilders.com.au)

Website: [www.skillbuilders.com.au](http://www.skillbuilders.com.au)

## Telethon Speech & Hearing

TSH provides a trans-disciplinary approach to meet the listening, speech and language, hearing, psychological and emotional, audiological, educational, and physical needs of children with a hearing impairment.

36 Dodd Street, Wembley, WA, 6014

Telephone: (08) 9387 9888, (08) 9387 9816, (08) 9387 9802

Email: [speech@tsh.org.au](mailto:speech@tsh.org.au), [jcoleman@tsh.org.au](mailto:jcoleman@tsh.org.au),

[pmonley@tsh.org.au](mailto:pmonley@tsh.org.au)

Website: [www.tsh.org.au](http://www.tsh.org.au)

## Therapy Focus

Qualified therapists work with young children aged 0-8, their families and carers to build on strengths and develop key skills. Support can include:

Play and social skill development, Communication skill development, Mobility and movement support, Toileting, self-care and hygiene skill development, Feeding and mealtime management, Sleep support, School readiness and transition support, Relationship development, Behaviour support, Sensory and emotional regulation, Development of routines and Provision of aids and equipment that support Early Childhood development

Suite 6, 1140 Albany Hwy, Bentley, WA, 6102

Telephone: (08) 6254 3200

Website: [www.therapyfocus.org.au](http://www.therapyfocus.org.au)

## Therapy, Learning & Communication – WA

*Interdisciplinary team including Occupational Therapy, Speech Therapy, Psychology, and Nutrition.*

10 Elcar Lane, Joondalup, WA, 6027

Telephone: (08) 9301 1154

Website: [www.tlc-wa.com.au/](http://www.tlc-wa.com.au/)

## VisAbility

VisAbility specialises in providing services for children who are vision impaired. A teamwork approach is used to

VisAbility also has orthoptists and orientation and mobility instructors with specialist training in vision impairment.

61 Kitchener Avenue, Victoria Park, WA, 6100

Telephone: 1800 VISION

Email: [seb.della@visability.com.au](mailto:seb.della@visability.com.au)

Website: [www.visability.com.au](http://www.visability.com.au)



## Wize Therapy

Wize Therapy provides physiotherapy, occupational therapy and speech pathology to young children with disability. Therapy services involve the provision of specialised services for infants, toddlers and children with developmental delay or an identified disability to maximise their participation in their chosen family, school and community activities. Individual therapy sessions can be provided, targeting specific goals e.g. in communication, mealtime skills, fine motor skills, mobility, balance, planning and organisation, social skills, gross motor skills.

Lots 4-6, First Floor Booragoon Commercial Centre, 175 Davy Street, Booragoon WA 6154

Telephone: (08) 9317 7932

Email: [info@wizetherapy.com.au](mailto:info@wizetherapy.com.au)

Website: [www.wizetherapy.com.au](http://www.wizetherapy.com.au)

## Respite & Recreation

There are several service providers who offer short term out-of-home accommodation as well as providing support in your own home or for recreation in the community.

### Activ

Activ provides a range of services including from respite, home and community care and recreational activities.

If you are a new customer wishing to access or enquire about respite services or seeking advice on eligibility, payment or funding, please call Activ **Client Services** on 1800 622 351. They will help determine your needs and can build a tailored program of services to suit.

Activ operates two short-stay residences dedicated to children's respite accommodation. The Variety Kitchener House is a 24 hour respite service for children 3 to 12 years of age and Variety Pelican Centre Garratt is a 24 hour respite service for children 12-18 years of age.

Telephone: (08) 9387 0555 or 1800 622 351

Email: [info@activ.asn.au](mailto:info@activ.asn.au)

Website: [www.activ.asn.au](http://www.activ.asn.au)



## Alkira Care Respite Services

Alkira Care provides community based respite care with innovative, flexible and individualised services 24 hours, 7 days a week. The facilities in South Lake Western Australia, is providing Short to Long Term Respite for children up to 18 years of age with Multiple and Complex needs requiring nursing care and support. Support in your home and community is available.

Bolderwood Drive, South Lake, Western Australia 6164

Telephone: (08) 9417 3015

Email: [info@alkiracarerespiteservices.com.au](mailto:info@alkiracarerespiteservices.com.au)

Website: [www.alkiracarerespiteservices.com.au](http://www.alkiracarerespiteservices.com.au)

## Avivo (formerly Perth Home Care Services)

Families and carers are vital in supporting a person with a disability. We support families and carers to access a break, by providing trained staff for in-home & in community support which can develop and strengthen carers in their role. Avivo also offer Carer Crisis Support 24 hours a day, all year round.

Telephone: 1300 620 267

Telephone: Carer Crisis Support (08) 6220 7529

Email: [hello@avivo.org.au](mailto:hello@avivo.org.au)

Website: [www.avivo.org.au](http://www.avivo.org.au)

## IdentityWA Children's Houses (Riverton & Nollamara)

Identitywa supports families and carers to have regular, planned breaks from their caring role. While families and carers have a break, children can stay in one of their where they can take part in activities of their choice at the home and in the community. These houses are located in quiet residential streets and have a warm and homely feel where your family member will feel at home. We have two children's support houses, one north of the river in Nollamara and one south of the river in Riverton.

In-Home Support is another way for you to have regular, planned breaks from caring for your family member. In-Home Support means a Family Support Worker will come to your home to provide assistance for your child and they can engage individuals in positive experiences both at home and in the community.

46 David St, Kensington WA 6151

Telephone: 9474 3303

Email: [reception@identitywa.com.au](mailto:reception@identitywa.com.au)

Website: [www.identitywa.com.au](http://www.identitywa.com.au)

## Inclusion WA

Inclusion WA works alongside community groups, sports associations and local government to make them more accessible for people living with disabilities & provides individually tailored information to people (and family members on their behalf) who want to get involved in their communities. This is where they do the research for you, providing you with a list of clubs and groups that you can approach yourself. Contact them and ask to speak to a Recreation Officer.

4/61 Walters Dr, Osborne Park WA 6017

Telephone: (08) 9201 8900

Website: [www.inclusionwa.org.au](http://www.inclusionwa.org.au)

## Lady Lawley Cottage (Red Cross)

Children are welcome to visit for a day, to stay overnight or for a week-long break. Our Cottesloe and East Fremantle facilities accommodation for overnight stays. We have a combination of single and double rooms combined with extensive outdoor play areas. Children are accommodated in one of three home-like units each with its own kitchen, lounge/dining room and outdoor play areas. Children can enjoy a host of educational fun including a sensory room, soft play area, craft room, external play areas and plenty of organised activities. There is a full program of fun activities on weekends and school holidays. Registered nurses can provide additional support if needed for children with complex medical needs.

In-home support includes assisting with daily living tasks, personal care, and preparing meals to suit the needs of each child, taking children to and from school, and helping to grow their confidence by taking part in recreational activities of interest, which also provide parents with networks and support.

8 Gibney St, Cottesloe WA 6011

Telephone: (08) 9318 2160

Website: [www.redcross.org.au](http://www.redcross.org.au)

# Government

## Centrelink

Centrelink is an agency of the Department of Human Services delivering a range of Commonwealth services to the Australian community. Centrelink is set up so that people can get much of the help they need in one place. The following telephone numbers will connect you with a Centrelink Call Centre from Monday to Friday between 8.00 a.m. and 5.00 p.m.

Appointments and opening hours: 13 1021 Disability, Sickness and Carers: 13 2717 TTY: Toll Free 1800 810 586

You can also register for a myGov account to access a range of government services, including Centrelink, Medicare and Child Support.

The Centrelink website contains a lot of information about services, together with a large number of publications available for download.

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

## Child Development Service

If you are concerned about your child's development, you are encouraged to talk to your child health nurse, school health nurse, or your general practitioner. They may recommend a referral to Child Development Services, or a range of other community services. The Child Development Service provides free services for children in the Perth metropolitan area who are experiencing developmental delays or difficulties. We have a team of clinicians who work in different areas of child development, such as Speech Pathologists, Occupational Therapists, Physiotherapists, Social Workers, Clinical Psychologists, Paediatricians, Therapy Assistants, Audiologists and Nurses. Depending on the child's needs, they may see one or more clinicians.

Child Development Service Centralised Intake Team

Telephone : **1300 551 827**

Email: [childdevelopmentservice@health.wa.gov.au](mailto:childdevelopmentservice@health.wa.gov.au)

Website: [www.health.wa.gov.au](http://www.health.wa.gov.au)

## Disability Services Commission

The Disability Services Commission is the State Government agency responsible for advancing opportunities, community participation and quality of life for people with disability. Services are planned around a person's individual needs and can include information and support about services in the community, WA NDIS, support specifically to help families and carers, support to live in the community, develop relationships, get involved in work or study and pursue leisure interests and help to develop skills and independence.

146–160 Colin Street, West Perth WA 6005

Telephone: 9426 9200 or 1800 998 214

Email: [dsc@dsc.wa.gov.au](mailto:dsc@dsc.wa.gov.au)

Website: [www.disability.wa.gov.au](http://www.disability.wa.gov.au)

## Department of Education

The principal responsibilities of the Department of Education is to provide and ensure access to high quality primary and secondary education for all West Australian children - including support for nongovernment schools.

Visit the website to find information on options for **children with special learning needs** including **specialist support for students with autism**.

151 Royal Street, East Perth, WA 6004

Telephone: (08) 9264 5233

Website: [www.education.wa.edu.au](http://www.education.wa.edu.au)

## Department of Local Government & Communities

Look for sections such as events, sports, arts, community directory, youth services, recreation and programs. Check out what's happening at your local library, rec centre, community centres and youth centre. Look for sections such as events, sports, arts, community directory, youth & family services, advice and support helplines, recreation and programs

Telephone: (08) 6551 8700

Email: [info@dlgc.wa.gov.au](mailto:info@dlgc.wa.gov.au)

Website: [www.dlgc.wa.gov.au](http://www.dlgc.wa.gov.au)

## Health and Disability Services Complaints Office

The Health and Disability Services Complaints Office (HaDSCO) is an independent statutory authority providing an **impartial resolution service** for complaints relating to health or disability services provided in the State of Western Australia. This service is free and available to the community in Western Australia and the Indian Ocean Territories (IOT). HaDSCO promotes leadership in the delivery of health and disability services via effective communication and supports improvement through complaint resolution.

GPO Box B61, Perth WA 6838

Complaints and enquiries Telephone: (08) 6551 7600  
or 1800 813 583

Email: [mail@hadsco.wa.gov.au](mailto:mail@hadsco.wa.gov.au)

Website: [www.hadsco.wa.gov.au](http://www.hadsco.wa.gov.au)

## Interpreting & Relay Services

### Translating and Interpreting Service (TIS National)

TIS National provides interpreting Services to assist non English speakers to access government departments, community organisations and private businesses such as utility companies. The interpreting service is available 24 hours a day, seven days a week and can provide services in over 160 languages.

Telephone: 131450

Website: [www.tisnational.gov.au](http://www.tisnational.gov.au)

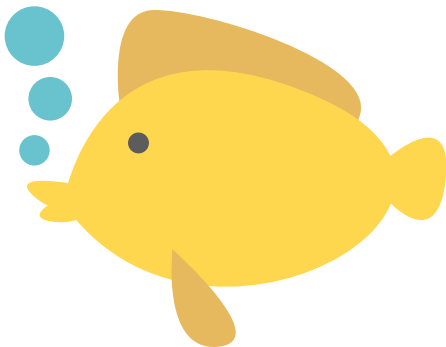
### W.A. Interpreters Pty Ltd.

They provide telephone interpreting, on-site or translation services. Clients include all major hospitals in Perth, such as Royal Perth Hospital, Osborne Park Hospital, Sir Charles Gardiner Hospital, St John of God Hospital, King Edward Memorial Hospital, Princess Margaret Hospital, the Disability Services Commission, and many other smaller organisations.

Address: PO Box 1119, East Victoria Park, WA, 6981

Telephone: (08) 9361 3248

Email: [admin@wainterpreters.com.au](mailto:admin@wainterpreters.com.au)



## NABS

The National Auslan Interpreter Booking and Payment Service (NABS) is funded by the Australian Government to provide interpreters free of charge to people who use sign language to communicate and would like to book an interpreter for private health care appointments (not available for public hospital appointments). This is a free service to Sign Language Users and Health Care Providers.

Telephone: 1800 246 945

Email: [bookings@nabs.org.au](mailto:bookings@nabs.org.au)

Website: [www.nabs.org.au](http://www.nabs.org.au)

## National Relay Service (NRS)

The NRS is an Australia-wide phone service for people who are deaf or have a hearing or speech impairment. It is also available to anyone who wants to call a person with a hearing or speech impairment, available 24/7.

Users who are deaf or have a speech or hearing impairment can call:

TTY/voice calls phone: 133 677

Speak & Listen (speech to speech relay) phone: 1300 555 727

Website: [www.relayservice.com.au](http://www.relayservice.com.au)

## Medical & Health Services

### Child and Adolescent Mental Health Service

The Child and Adolescent Mental Health Service (CAMHS) provides mental health programs to infants, children and young people up to the age of 17. This includes services in the community and in a hospital setting.

Children and families are referred to these services by their treating therapist, specialist, GP, school or other community organisation. Information and advice about accessing a CAMHS program is available by contacting a local **Community CAMHS** clinic.

For more urgent situations please contact the Acute Response Team on **1800 048 636** (24 hour service). In an emergency call **000** or take the child or young person to a **hospital emergency department**.

Website: [ww2.health.wa.gov.au](http://ww2.health.wa.gov.au)

## Child and Adolescent Health Service

The Child and Adolescent Health Service (CAHS) provides a comprehensive service supporting the health, wellbeing and development of young Western Australians. We aim to ensure that children and young people get the best start in life through health promotion; early identification and intervention; and patient-centred, family-focused care.

CAHS comprises:

Child and Adolescent Community Health ([ww2.health.wa.gov.au/About-us/Child-and-Adolescent-Health-Service/Child-and-Adolescent-Community-Health](http://ww2.health.wa.gov.au/About-us/Child-and-Adolescent-Health-Service/Child-and-Adolescent-Community-Health))

Child and Adolescent Mental Health Service ([ww2.health.wa.gov.au/About-us/Child-and-Adolescent-Health-Service/Child-and-Adolescent-Mental-Health-Service](http://ww2.health.wa.gov.au/About-us/Child-and-Adolescent-Health-Service/Child-and-Adolescent-Mental-Health-Service))

## Princess Margaret Hospital (PMH)

**Princess Margaret Hospital for Children** is WA's only dedicated paediatric hospital and major trauma centre. PMH provides tertiary (level 6) services for the state. It opened in 1909 with 40 beds, an operating theatre and a small outpatient department. Today, PMH is a 250-bed, internationally recognised tertiary paediatric facility that treats children and adolescents up to 16 from around the state. Each year, there are approximately 250,000 inpatient and outpatient visits. Princess Margaret Hospital will in 2017 be closing after 107 years of service to the community of Western Australia and will be replaced by the new Perth Children's Hospital.

## Perth Children's Hospital

The \$1.2 billion Perth Children's Hospital is being built on the **QEII Medical Centre** site in Nedlands, and will replace **Princess Margaret Hospital** as the State's dedicated children's hospital. As a leading paediatric hospital, it will provide the specialty medical treatment required for the most serious medical cases, as well as secondary services including inpatient and outpatient care and day stay care.

Website: [ww2.health.wa.gov.au](http://ww2.health.wa.gov.au)



## King Edward Memorial Hospital

The Women and Newborn Health Service (WNHS), is a part of the larger North Metropolitan Area Health Service. With dedicated staff and best practices based on the most current evidence-based medicine, WNHS continues to deliver first-class health care to women and infants in WA.

KEMH is the State's only tertiary maternity and gynaecological hospital and treated its first patients in 1916. Today more than 6000 births take place at the hospital every year and it is WA's only major referral centre for high-risk pregnancies. KEMH also has a state-of-the-art Special Care Nursery, designed to care for premature and sick infants. KEMH also cares for approximately 5000 women with gynaecological conditions each year

374 Bagot Road, Subiaco, Perth, 6008

Telephone: 08) 6458 2222

Website: [www.kemh.health.wa.gov.au](http://www.kemh.health.wa.gov.au)

## Health Direct

If you have an urgent medical condition, you are advised to either contact **Health Direct**, present to your nearest Emergency Department or contact your General Practitioner. Within Western Australia, 24-hour telephone health advice is available from **Health Direct** on:

Telephone: 1800 022 222



## HACC – Home and Community Care

The Western Australian Home and Community Care (HACC) Program is a joint funding initiative of the Commonwealth and WA State Governments which provides basic support services for eligible people of all ages with a disability and their carers to assist them to continue living independently at home. HACC support is designed to assist people with the greatest need and aims to maximise people's independence.

This includes providing basic support for people:

- to participate in social activity in a group or one-on-one.
- with everyday household tasks.
- to enhance nutrition, function, strength, independence and safety.
- to support independence in personal care activities such as showering and dressing.
- to keep up with essential activities such as shopping, banking and maintaining social contacts.

For information about the HACC Program and other community care services including: eligibility screening & referrals for individual assessment contact the Regional Assessment Service on:

Telephone: 1300 785 415.

## Fiona Stanley Hospital

As the major tertiary hospital in the south metropolitan area, FSH offers a high standard of patient care to communities south of Perth and across the State. A leader in clinical care, research and education, our hospital is supported by an innovative design that uses the latest scientific, technological and medical developments to help us provide the best possible care for our patients.

Paediatric services are located on level 3 of the main hospital and provides:

- a medium high risk (level 4) service providing care for planned and unplanned presentations of children and adolescents up to 16 years of age providing care for medical, surgical and some specialist conditions.
- a 20-bed ward including 2 respiratory isolation rooms with ensuites.
- 18 single bedrooms with ensuites.
- Facilities for parents to stay overnight with their children.

11 Robin Warren Drive, Murdoch, WA, 6150

Telephone: (08) 6152 2222

Website: [www.fsh.health.wa.gov.au](http://www.fsh.health.wa.gov.au)

# Transport

## ACROD Parking Program

The ACROD Parking Program aims to support Western Australians with a significant mobility restriction to access the community. No payment required.

To be eligible for an ACROD Parking Permit you must meet one of the following criteria:

- You are unable to walk and always require the use of a wheelchair, or
- Your ability to walk is severely restricted by a permanent medical condition or disability, or
- Your ability to walk is severely restricted by a temporary medical condition or disability.

All applications must be endorsed by your Doctor or Occupational Therapist.

For more information, please contact the ACROD Parking Program:

12 Lindsay Street, Perth WA 6000

Telephone: (08) 9242 5544

Email: [app@app.org.au](mailto:app@app.org.au)

Website: [www.app.org.au](http://www.app.org.au)

## Angel Flight Australia

This charity co-ordinates non-emergency flights, free of charge, for financially and medically needy people. Flights may involve patients or compassionate carers travelling to or from medical facilities anywhere in Australia. Angel Flight pilots do not carry medical staff or medical equipment and so do not act as an alternative to the Royal Flying Doctor Service (RFDS) or Air Ambulance in that capacity.

PO Box 421, Fortitude Valley, Qld 4006

Telephone: (07) 3620 8300 or Toll Free: 1300 726 567

Website: [www.angelflight.org.au](http://www.angelflight.org.au)

## Interstate Patient Travel Scheme

Patients who need to travel interstate to obtain essential specialist medical treatment not available in WA may be eligible for assistance under the Interstate Patient Transfer Scheme (IPTS). For further information about IPTS contact:

Department of Health  
Chief Medical Office IPTS  
189 Royal Street, East Perth, WA, 6004  
Telephone: (08) 9222 2474

## Patient Assisted Travel Scheme

(PATs) provides a subsidy towards the cost of travel and accommodation for eligible Regional patients travelling long distances to seek certain categories of specialist medical services. Applying for the Patient Assisted Travel Scheme is a simple six-step process that begins with having your doctor fill in the application form, and then lodging it via phone, fax, mail or in person at one of the participating regional health services.

If you require more information about PATs you can contact your local regional PATs office located in the Wheatbelt Region, Goldfields Region, South West Region, Kimberley Region, Pilbara Region, Midwest Region and Great Southern Region.

Website: [www.wacountry.health.wa.gov.au/pats](http://www.wacountry.health.wa.gov.au/pats)

## Royal Flying Doctors Service (RFDS)

The Royal Flying Doctor Service of Australia (RFDS) is a not-for profit charitable service and is one of the largest and most comprehensive aeromedical organisations in the world. Using the latest in aviation, medical and communications technology, they deliver extensive primary health care and 24-hour emergency service to those who live, work and travel throughout Australia.

Website: [www.flyingdoctor.org.au](http://www.flyingdoctor.org.au)

## Vehicle Modifications

There are a number of companies that do vehicle modifications.

### **Freedom Motors Australia**

13 Waterton Retreat, Ballajura, WA, 6066

Telephone: 0417 930 916

Website: [www.freedommotorsaustralia.com.au](http://www.freedommotorsaustralia.com.au)

### **TL Engineering Australia**

463 Bushmead Rd, Hazelmere, WA, 6055

Telephone: (08)92795466

Website: [www.tleng.com.au](http://www.tleng.com.au)

The ILC website also has a link to a list of suppliers.

Contact the supplier to get up-to-date information, or to make sure that a product is still available, to confirm prices and to buy products.

Website: [www.ilc.com.au/databases/search-products/](http://www.ilc.com.au/databases/search-products/)

## Wheelchair Accessible MAXI Taxi

Black & White Cabs currently has a fleet of over 150 Wheelchair Accessible Maxi Taxis. The Operators and drivers of our Wheelchair Accessible Maxi fleet have undergone extensive training to ensure we deliver a timely and safe mode of transport for passengers who depend upon the use of a wheelchair for mobility outside their home.

Black & White Cabs utilises considerable Call Centre resources for the management of our Wheelchair Accessible Maxi service. This includes the close monitoring of each and every Wheelchair Accessible booking to deliver service levels that meet or exceed the customer's expectation as well as the legislative requirements contained in our Taxi Service Contract with Transport and Main Roads.

Telephone: To book – Call 13 MAXI (136 294) and request a wheelchair accessible maxi.

Website: [www.blackandwhitecabs.com.au](http://www.blackandwhitecabs.com.au)

## Notes

[illegible]

## Notes

[illegible]

