

# 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

South Australian Edition



Produced by the Children, Youth & Women's Health Service  
This is a Women's & Children's Hospital Foundation publication

## Acknowledgements

This resource has been adapted for South Australia from the original Victorian publication produced by interACT. Special thanks to Camille Heagney for her guidance and support throughout this process.

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

**Anna Malden (SA Coordinator)**

**Heather Ashmeade**

**Sue Cox**

**Wendy Duncan**

**Alana Francis**

**Elaine Gordon-Edwards**

**Michele Howard**

**Jon Jureidini**

**Paul Machet**

**Roxanne Perry**

**Peta Schmidt**

**Katie Tucker**

**Judy Underdown**

**Robyn Welsh**

**Ruth Willis**

Thank you to all of the individuals, parents, carers, families and organisations who have provided valuable input and feedback throughout this process.

We trust that the partnerships and relationships developed will continue to improve the care provided to the children of South Australia.

This publication would not be possible without the generous support of The Women's & Children's Hospital Foundation - the charity for the Women's & Children's Hospital in Adelaide, South Australia. Their ongoing support continues to improve patient facilities, purchase state-of-the-art equipment and fund life-saving research.

We would also like to extend our thanks to interACT for allowing us to bring this valuable resource to a South Australian audience. interACT is a group committed to helping parents, caregivers and service providers work together for the benefit of children with additional needs and their families. For more information on interACT contact [secretary.interact@gmail.com](mailto:secretary.interact@gmail.com)

**Disclaimer:** This information is presented by the Children, Youth and Women's Health Service (CYWHS) to provide health information for the benefit of the public. You should not use the information contained herein in place of your own health professional's advice or to diagnose, prevent or treat any health condition. Healthcare recommendations change often and every individual experiences health problems in a different way. Only your healthcare professional can advise you about you or your family's personal healthcare needs. We have made every effort to ensure the quality of information is correct. However, CYWHS does not guarantee the suitability, completeness, accuracy or authenticity of the information. References to other services are not necessarily endorsed or recommended by CYWHS. As the user, it is your responsibility to assess whether their services are suitable for you and your family. CYWHS cannot be held responsible for any action or claim that results from using the information in this brochure or any service referred to herein. No liability is accepted.

The South Australian Working Committee would like to dedicate this book to Anna Malden without whom the project would not have come to fruition.

© 2008

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 978-0-646-50597-8

# Contents

<b>Introduction</b>	2	<b>Who Will Help Us In The Community?</b>	
<b>Where Do We Begin?</b>		Case Management	44
Pre-Diagnosis	6	Early Intervention	46
Immediately After Diagnosis	7	Respite	47
Helpful Tips	8	Family Day Care and Child Care	49
Taking Control	10	Education (Schooling)	50
Consumer Feedback Policies	11	Preschool (Kindergarten) and School	52
Your Child's Voice	13	Community Agencies for Children with Disabilities	54
Hospital Admissions		Transport	56
- Public or Private	14	<b>How To Give Life Balance</b>	
Specialists	18	Key Sources of Support	60
Pharmacies	20	Paediatric Palliative Care	62
Developing a Care Plan for Your Child	22	Family and Friends	63
Emergency Medical Plan	23	Taking Care of Yourself	64
Calling an Ambulance	25	Caring for the Whole Family	65
Coping Strategies		The Non-Primary Carer's Perspective	66
- For Day to Day and Beyond	27	Siblings	67
Logistics	30	<b>Health Care Personnel Terminology</b>	69
Equipment	31	<b>Glossary</b>	75
Financial Considerations	32	<b>Publications</b>	79
<b>Going Into Hospital</b>		<b>Resources &amp; Services</b>	
Hospital Admissions		Advocacy & Support	90
- Hints and Tips	36	Counselling	94
Interpreters	40	Early Intervention, Respite & Recreation	95
Aboriginal Liaison Officers	40	Government	98
Transition	41	Interpreting & Relay Services	105
For Country Families		Medical & Health Services	107
- Attending Health Services in Adelaide	41	Transport	113

## 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 to the state of South Australia, 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)



Where do  
we begin?



## Pre - Diagnosis

**“Remember as a parent or a carer you are the most important and life changing influence on the world of your child.”**

*(B-J – parent)*

**“All children feel love, laughter and play, even when their ability may be limited their spirit reaches for the stars, so enjoy this journey with them.”**

*(Jewels – parent)*

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 or support person (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 special need. This can be a very stressful time as you are forced to face your child's diagnosis and everything that may lead from that. 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.

"Yes, the diagnosis may mean your child will be forever different to his or her peers, but that is ok. Your child is just 'a different kind of perfect', that's all."

*(Kimberlee – parent)*

"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 totally dependent on others for all of her life. What would happen to her in our old age? I was afraid, sad, and totally devastated. Nearly 12 months later I also became very angry. All these emotions, and more, bubbled to the surface from time to time during the course of our daughter's life but, gradually, I learned to feel happy and to have fun again. I guess that came with acceptance of our situation."

*(Karen – parent)*

"When my son was diagnosed I felt as if all my self esteem had disappeared. I could not see my future, and I felt like my family was a freak show for everybody to look at. All I could think about was his death and thoughts of this preoccupied everything I did."

*(Lisa E – parent)*

## Helpful Tips

“Trust yourself; as their mum you are in a unique position and you are powerful in your knowledge of your child. I was a first time mum but once I learnt to trust my motherly instinct it really benefited my son and those caring for him. Your instinct is often an early warning siren that something isn't right – listen to your instinct.”

*(Rachel – parent)*

“When our son was first diagnosed, I scoured the internet and the phone book, and contacted everyone I could. My husband didn't read anything. Later he did. Now I know that at the time he couldn't. Just because we parent the same child doesn't mean we cope the same way.”

*(Lisa B – parent)*

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 General Practitioner (GP)** you feel you can talk to, 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 with 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 careful: 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/email** to family and friends explaining what you know about your child's condition. Tell people in the letter/email how they can support to you and your family
- **Consider using the answering machine to screen calls at home:** You can easily spend all day and night returning calls. It is okay to only answer the phone when you feel like it. Alternatively, if you have a mobile phone at times you may choose to switch it off altogether and answer the phone when you feel like it. You can leave updates of the progress to date as the voicemail message on your mobile phone, so that friends and relatives do not need to keep ringing and feel that they know what is happening, especially in times of sickness and hospitalisation. It is a good idea to only give your mobile number to your friends and family

- **Choose who to tell about upcoming appointments**, as you may feel 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 How To Give Life Balance p59]
- **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
- **Contact agencies or organisations** who may provide specialist knowledge or advocacy related to your child's diagnosis. Most agencies provide excellent information on websites  
[Refer to Resources & Services p89]
- **Consider setting up a website** about your child where new information can be added 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 and who will not judge you
- **A social work or counselling service** may be a good source of support
- **Take each day as it comes** and, although it may be difficult, try not to think too far ahead. Don't try to take in too much information all at once. Only take in 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)*

*"Access and set up a website for your child. If treatment is intense and/or long it will save you having to repeat yourself numerous times to everyone wanting to know how things are going - they can just read updates on the website. It saves time and often - your sanity!"  
(Kimberlee – 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:

“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)

- **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 the doctor to draw pictures or write down and explain medical terminology
- **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 the 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, can prompt questions you may have planned to ask or take notes for you
- **Know how to contact your child's health care professional** for appointment changes, queries and after hours concerns. Write down telephone numbers or email addresses if available. Keep their business cards handy

# Consumer Feedback Policies

All health services dealing with your child are committed to providing safe, high quality health care. Feedback helps services understand your needs and informs them how to improve their services.

## It is important that you let services know if you:

- Feel concerned, disappointed, angry or upset with any aspect of treatment or care within a specific hospital, service or by a specific health professional
- Are worried about the service you have received or would like to provide ideas or suggestions on how things could be improved

## Services have a requirement to:

- Listen to you and understand your concerns
- Provide you with information and explanations
- Respond so that a better service can be provided to you and others

## If you have a suggestion, compliment, concern or complaint about any services you receive, you are encouraged to discuss it with:

- Staff member in the area involved
- Women's & Children's Hospital, Consumer Feedback Coordinator:  
Telephone (08) 8161 6710
- Flinders Medical Centre, Consumer Advisory Service:  
Telephone (08) 8204 5433
- Lyell McEwin Hospital, Patient Advisor/Consumer Complaints Officer:  
Telephone (08) 8182 9658

For other health services, find out who you can speak to about your concerns.

### What to expect

- Your suggestion, concern or complaint will be treated confidentially and with respect, passed on to the appropriate person and responded to sensitively and quickly
- The service will work with you to find the best way to respond to your feedback
- If there are immediate health issues that need action, they should be dealt with first
- You should feel confident that your complaint has been taken seriously
- You should know who is dealing with your complaint and how they will deal with it
- You should have information about the progress or resolution of your complaint within 30 days of making it
- There should be no negative responses to you because you have complained

If you are not happy with how your complaint is dealt with you can contact the South Australian Health and Community Services Complaints Commissioner [Refer to Resources & Services p89].

There may be community organisations that can also help you to make a complaint. For example, support organisations within the community will have processes through which you can address any grievances you may have. Always feel free to ring and speak with someone if you have concerns. Alternatively you can address your concerns to the appropriate person in writing.

### Access to Information

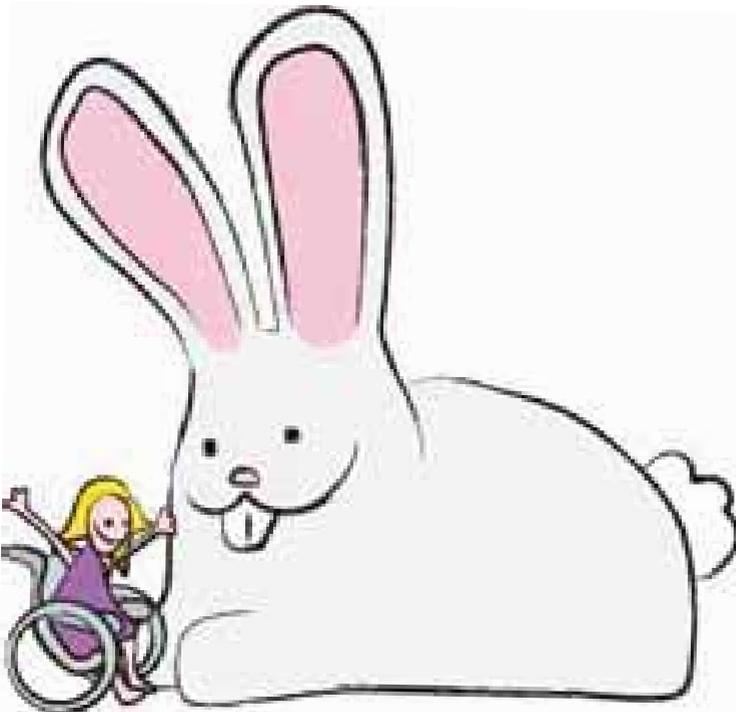
Under the Freedom of Information Act 1991 and the Code of Fair Information Practice you have the right to access and amend the personal and health information about your child. Please contact your health service for more information or a request form.

## Your Child's Voice

As a parent/carer, in time, 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, be persistent 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 cannot talk, 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.



**"In some situations you may need to tell health professionals that your child is not coping and will need a different approach."**

*(B-J – parent)*

**"Sometimes I felt like I was pushing too much on hospital staff to do procedures the way I knew would minimise trauma for my son. If I didn't push I felt I was letting him down. If I did I felt I was making a fuss. I found talking the issue through with staff helped them see why we needed things done the way we did and a better outcome for all."**

*(Rachel – parent)*

**"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)*

## Hospital Admissions - Public or Private

In Australia we are fortunate to have two healthcare systems - public and private.

**The Public System** is government funded, where your child will be treated according to how sick they are assessed to be. Doctors at various levels of training 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 and Paediatric units). A Consultant is always the head of a unit and oversees the care that Residents, Registrars and Interns (junior doctors) carry out on his/her behalf [See p69 for Health Care 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 (often called a Consultant). When admitted as an inpatient to hospital, your child's treatment will be managed by your chosen Consultant. Junior doctors will still be involved in the day-to-day care of your child. In the public system, specialists may rotate every week or two but in the private system the same specialist will be involved for the entire admission. In South Australia your child can be admitted as a private patient at any of the public hospitals that have children's wards, but there are no private hospitals with children's wards. 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.

Your private health insurance may also only cover the costs of your child's hospital stay. In general the charges from your child's treating doctor for visits and treatments carried out while they are an inpatient will be covered by your private insurance. Most South Australian hospitals have a "no gap" policy which means you should not be out of pocket for either the cost of the admission or for the charges of your treating doctor as long as your private health insurance policy covers these fees. If you are concerned please check with your treating doctor and your health fund about any out of pocket costs.

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.

For further information about being a private patient while in hospital, contact (during office hours):

- Women's & Children's Hospital, Admissions Information Coordinator:  
Telephone (08) 8161 6753
- Flinders Medical Centre, Private Patient Liaison:  
Telephone (08) 8204 3193
- Lyell McEwin Hospital, Private Patient Coordinator:  
Telephone (08) 8182 9253

“We chose to have private in public for the fact that we then had continuity of care and got to know our specialists really well. It has literally been a life saver.”

*(Rachel – parent)*

“We’ve been public the whole way through our journey and have been very impressed. We almost always see the same doctors in each department and have great continuity. We’ve never felt ‘let down’ at all by the public system.”

*(Kimberlee – parent)*

### As an Inpatient

Being a private patient benefits the hospital. The hospital receives additional funding from Medicare and Private Health insurance companies which it is able to redirect to upgrade equipment and improve services within the hospital.

Being a private patient does not mean your child will have a single room. It only means that you can choose your treating Consultant. In public hospitals single rooms are allocated based on the medical needs of a patient, for example if they are infectious.

Junior doctors will still treat your child because it is a public hospital. Private admission is worthwhile if you want to choose your own Consultant for continuity of care, 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. Most public hospitals in South Australia have a no gap policy which means that reimbursement from Medicare and Private Health Insurance funds is accepted as full payment for hospital inpatient charges. However, excesses and co-payments may still apply. If you are thinking of choosing to be a private patient, it is advisable to contact your health fund, doctor and hospital about any likely costs prior to your admission.

If choosing to be admitted as a private patient in a public hospital speak to your health insurance provider to ensure you choose the best option for you and your child.

### As an Outpatient

If you see your specialist 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 a good idea to ask about costs before you make appointments. You do not need private insurance to see a specialist privately. In fact private health insurance will not cover the costs of outpatient specialist appointments; however a rebate will be available from Medicare. You will be responsible for any payment above the Medicare rebate. This is usually called a gap payment. With Private Insurance Extras, you may get a rebate for some allied health professions, such as physiotherapy, speech pathology, occupational therapy, psychology and/or dentistry.

If you are using the public system for outpatient appointments, there will be no cost for the consultations. Some clinics will bulk bill, but there may be 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. Arriving late may mean your child has less time for their appointment
- **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. Some hospitals have crèches where your other children can be cared for while you are at your appointment. It is worth asking about this if you have other children who you will need to bring with you
- **Does your child need medicine?** Some medicines for children are only available from a hospital pharmacy. Some medicines may only be available at a subsidised price from the hospital pharmacy. Check with your doctor or the pharmacy staff regarding availability and cost. As waiting times at hospital pharmacies can be long (e.g. up to 2 hours) an option would be to leave your prescription at the hospital pharmacy and collect the medicines later. Some pharmacies offer a fax service for prescriptions, ask your local pharmacist about this.

If the medicines are available from your community pharmacy it may be more convenient for you to have a prescription to take there. However, prescriptions to take to your community pharmacy are not available from all outpatient clinics. If you prefer to get a prescription to take to your community pharmacy, an option would be to have the medicines prescribed by your GP. A prescription from your GP can only be dispensed at your community pharmacy

*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 and Genetics.*

*"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

## Referrals

- If your child needs to see a specialist, either a GP or another specialist will need to refer him/her. Referrals from GPs are valid for 12 months (unless marked otherwise). Referrals from other specialists are valid for only 3 months
- If your child needs to see the specialist beyond the date covered in the referral, you will need a new referral either from the original doctor or from another doctor who has seen your child
- 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

## Choosing Your Own Specialist

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/carers: word of mouth can be a valuable resource
- Would 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 or 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 free or may be bulk billed.

*Private consultations:* 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 private patient if a hospital admission is required and you have private insurance (make sure you check to which hospital your specialist is able to admit patients). If your child needs to be admitted and is admitted as a public patient, the hospital team can still take advice and speak to your private doctor. 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.

“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)

## 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/carers, 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.

## Specialised Paediatricians

Children with complex or chronic medical issues may need long term attention from a general paediatrician and/or one or more specialist paediatricians. There should be one doctor who is coordinating the care of your child even if multiple other doctors provide input.

## Pharmacies

“Our medication was often unusual and not readily available in our small community. We had to make sure the pharmacy had it in each fortnight we needed it. I forgot to phone ahead once (I had to give them 2 days notice) and ended up phoning 12 other pharmacies and driving over 120kms to get it.”

*(Rachel – parent)*

It may be helpful to go to the same community 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 at [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au) or call the PBS information line on Freecall™ 1800 020 613.

## Medication

- If your child is on regular medication(s) 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
- Make sure *you* understand everything you need to about new medication(s) and ask questions when you are unclear. Many medicines have a specific Consumer Medicines Information pamphlet which you can ask your pharmacist to supply
- Find out if your pharmacy offers a delivery service and use it to save yourself time
- Some 'over the counter medications' can be prescribed by your doctor so that you can obtain them 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 prescription faxed to your chosen pharmacy, and the original posted to them
- If your child is on multiple medications it may be useful to ask your pharmacist about administration aids such as a 'dosette'

*"Really get to know what medications your child takes: how much, when and why. Keep a list if needed."*

*(Kimberlee – parent)*

*"We have a great relationship with our local regional pharmacy. Our daughter's food is delivered there from Adelaide."*

*(Bill – parent)*

## Developing a Care Plan For Your Child

"I had a huge part in developing my daughter's care plan and notifying staff when changes needed to be made.

This way I knew nothing was missed. Our daughter's care plan went with her to pre-school and was used during hospital admissions by nursing staff."

*(Rachael – parent)*

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. The plan should be developed in partnership with you and others involved in your child's care.

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 flexible document that should be kept up to date so that it accurately reflects the care required by your child at any given time. It can be used in child care, school, respite and hospital. If your child needs to be admitted to hospital regularly speak to staff about developing a care plan for your child.

If your child's Care Plan is co-ordinated by his/her GP, he/she may be entitled to a Medicare rebate under the Enhanced Primary Care program (see below) or other programs. 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 called Action Plan or First Aid Plan)

An EMP is something you can prepare for your child with the help of professionals involved in your child's care. An EMP is a readily accessible document or process which is activated if your child has a medical emergency. It is specific to your child's existing medical condition(s). The information should be commonly known and shared by those coming into day to day contact with your child, 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/plan with written instruction of what to do in the case of a medical emergency, specific to your child's particular situation. In order for these instructions to be followed, it is essential that the document be:

- Up to date
- In close proximity to your child at all times
- Circulated to all of your child's carers and teachers

For some families, this measure can help 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 guidelines.

Your child's EMP can take any number of formats. Part of your care plan should include the Department of Education and Children's Services (DECS) health care plans (if applicable to your child) or any other plans used by the other services [See p50 for more information about DECS].

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.

"I wrote up an Emergency plan for my son's preschool (I was so nervous leaving him), and a letter to paramedics with all his relevant stats like a nurse handover. I also obtained a medic alert bracelet for him to wear to preschool. I then felt I had left my voice with him even when I wasn't there."

*(Rachel – parent)*

### Things to include in your child's EMP

- Child's name, date of birth and address
- Child's condition, treating hospital and hospital UR number
- 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/carers
- Name and contact details of doctor and/or specialist
- Authorised documentation from doctor/specialist attached: Yes/No

Many hospitals will have a special file or database of patients with complex health care needs. This file gives them quick and easy access to information if a child goes to an Emergency Department. Check with your doctor whether the hospital where your child is likely to be admitted has such a file and whether it is appropriate for your child's details to be entered into this file.

# Calling An Ambulance

## General questions callers will be asked after dialling triple zero (000)

- What is the exact address of the emergency?
- What is the phone number you are calling from?
- What is the problem? (What exactly happened?)
- Are you with the patient now?
- How many people are hurt or sick?
- How old is the patient?
- Is the patient conscious?
- Is the patient breathing?

The answer "no" to the last two questions results in the immediate dispatch of an ambulance response. Further questions will be necessary to enable ambulance staff to prioritise your request promptly and determine the appropriate level of care for you. Ambulance call-takers can also provide first aid advice to you over the phone.

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

## Calls to triple zero (000)

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

## 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.

## The Ambulance Cover Membership Scheme

This scheme protects patients from the costs of ambulance attendance and transport with one annual payment of \$58\* per year for single membership and \$115\* per year for family membership (\*at time of publication/conditions apply).

These fees cover 100% of the following services within South Australia:

- Emergency ambulance services
- Non-emergency ambulance services
- Air ambulance services

If you are a member of Ambulance Cover with SA Ambulance Service and require ambulance transport whilst visiting interstate, you will be fully covered for all emergency and medically justified non-emergency transport, except where a third party is responsible.

There is a 60 day qualifying period for all new or reinstated members requiring non-emergency ambulance transport or services and for people with a pre-existing condition. It is important to note that you are responsible for the cost of ambulance attendance and transport even if you did not call the ambulance yourself. Private Health Insurance may also cover the cost of ambulance services, so be sure to check with your provider.

For more information on how to get Ambulance cover visit [www.saambulance.com.au](http://www.saambulance.com.au)

## Emergency Medical Information Booklet

The Emergency Medical Information Booklet (EMIB) is a community service project from SA Ambulance Service and your local Rotary Club. The EMIB enables you to record your personal and medical information so that it is ready to use in an emergency. The booklet is usually kept on your fridge or in another clearly visible place to enable easy access for paramedics and ambulance officers who will need the information if they are called to your house. You can obtain the booklet by contacting SA Ambulance Service on 1300 13 62 72.

## Flagging pre-existing conditions

If your child has specific treatment requirements, please discuss this with your doctor who can advise if the ambulance service should be notified.

## 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 writing it down:** Get a large exercise book, diary or calendar for appointments, medications and anything else relating to your child. If you take a phone call from a service provider or a doctor, write it down, and then you can just refer to the book/diary/calendar instead of trying to remember everything.

**Keep a file:** Use a large folder or expandable file to store all your information so it is easy to find. Include all 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 and asthma)
- Respite organisations

**Look after yourself:** You will cope with everything so much better physically, emotionally, mentally and spiritually 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.

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 of yourself and what you can achieve
- **Use respite to have a break** before you wear yourself out
- **Involve yourself in recreational activities** away from your child, and make them a regular occurrence

"We bring a folder with essential information to all appointments including a business card holder with cards from all of our daughter's specialists and care providers. At home we have a complete filing cabinet for our daughter's records."

*(Bill – 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)*

"Returning to work part-time was one of the hardest things to do and maintain, but the best thing to do for me. My employer has been unbelievably understanding and accommodating."

*(Rachael – parent)*

"I needed to be with my son so I took 2.5 years off work and then only went back a couple of days a week. Do what you feel is right – try to trust your inner voice – it's often right."

*(Rachel – parent)*

"I kept missing my appointments because I had so many. A nurse suggested I put a reminder into my mobile phone calendar. This is now what I do every time I get a new appointment, and I haven't missed one since."

*(Craig – parent)*

"If you can't do all of the above, don't feel guilty, know that you can only do what is right for you now. Please try not to look back harshly on yourself – it won't help anyone."

*(Rachel – 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 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)*

- **Continue to talk about how you feel** with your available support network
- **You may want to keep working but you may want to reduce hours.** Talk to your employer about what is possible. Work may be a great outlet for you and be a place where you can be yourself
- **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 or support group exists for your child's condition** and what support services they may offer (e.g. Asthma Foundation of South Australia, Cystic Fibrosis South Australia). The health professionals looking after your child may be able to assist you with the local and national services that are available
- **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** openly 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** if you have had a tough day. Take some time out for yourself to do something 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 stress. Take the time to think about it
- **Take one day at a time**

"After 2 years I decided that it wasn't fair on my son that 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. I now believe that he will choose his time - not doctors, not text books or history, but him."  
*(Lisa E – parent)*

"I often felt guilty for not getting through all of my daughters early intervention activities every day. Expressing this to the Early Intervention team resulted in commencing team meetings where team goals were established and worked towards. This gave me a huge sense of achievement."  
*(Rachael – 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/carers to help transport your other children to and from school
- Accept genuine offers of help
- Have some frozen meals on standby at home: there are some great nutritious meals ready-made 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.

# 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.

Your health professionals will work together to decide what sort of equipment you and your child will need and they will arrange a referral.

At the Women's & Children's Hospital, equipment can be collected from Allied Health or the Home Equipment Centre. There is usually a small hire fee for equipment and a capped monthly charge for consumables. For more information about equipment and consumables provided at the hospital telephone the Home Equipment Centre on (08) 8161 6233.

Some children may be eligible to access services from Novita Children's Services. One of the services provided at Novita is the administration of the state-wide Independent Living Equipment Program for children, commonly referred to as ILEP. It comprises therapists 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. Equipment Service staff includes physiotherapists, occupational therapists, speech pathologists and therapy assistants. Where necessary, the Equipment Service links with Novita's Early Childhood, Child and Adolescent and Rehabilitation teams to ensure each child receives the most appropriate equipment for their needs. Further information about Novita's Equipment Service is available by telephoning (08) 8243 8302 or emailing [equipment@novita.org.au](mailto:equipment@novita.org.au)

If you need help with cost of equipment discuss this with your hospital or health centre [See Resources & Services p89].

## Financial Considerations

“Ask your social worker to help you find a way through the maze.”

(Rachel – parent)

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. Carer Payment is an income support payment. Carer Allowance is a supplementary payment which also provides your child with a Healthcare Card or you may be eligible for a Carer Allowance Health Care Card only.

- The *Carer Payment* can provide you with income support if, because of the demands of your caring role, you are unable to support yourself through substantial workforce participation
- The *Carer Allowance* is a supplementary payment that may be available to you if you are a parent/carer who provides daily care and attention for a child or adult with a severe disability, medical condition or someone who is frail or aged. Carer Allowance is not income and assets tested and may be paid in addition to wages, Carer Payment or other payments

If you are caring for a child under 16 years of age you may receive a fortnightly Carer Allowance plus a Health Care Card, or a Health Care Card only

- *Child Disability Assistance* is an annual payment to assist you with the costs of caring for a child with a disability

For more information visit [www.centrelink.gov.au](http://www.centrelink.gov.au) or call 13 2717 or ask at a Centrelink Customer Service Centre. You can ask for two publications ‘Centrelink - the basics’ and ‘Caring for someone?’

**Register your child for the Medicare Safety Net:** If you need to see a doctor or have tests regularly, you could end up with high medical costs. The Medicare Safety Net is designed to help you when you need it most. Once you reach a safety net threshold, visits to your doctor or having tests may end up costing you less.

All families need to register for the Medicare Safety Net, even if all your family members are listed on your Medicare card. You can register by:

- Downloading a form from [www.medicareaustralia.gov.au](http://www.medicareaustralia.gov.au)
- Registering online at [www.medicareaustralia.gov.au/online](http://www.medicareaustralia.gov.au/online)
- Calling 132 011
- Visiting your local Medicare office [See p20]

**Keep all receipts:** Realistically, there will be 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:

- Contenance 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 health professionals

**Parking:** You may be eligible for car parking concessions at some hospitals. Speak to the hospital staff about how to arrange this.

**Butterfly Cards:** At the Women's & Children's Hospital long-term patients and their families can be issued with a Butterfly Card, entitling them to 10% discount on food and drinks purchased from the Women's & Children's Hospital Cafes and purchases from the Health Information Centre. Patients and families entitled to the Butterfly Card include those who:

- Are expected to stay for more than one week
- Have frequent admissions, outpatient, and day patient or therapy bookings over 12 months
- Have five or more outpatient, day patient or therapy bookings in a 30 day period

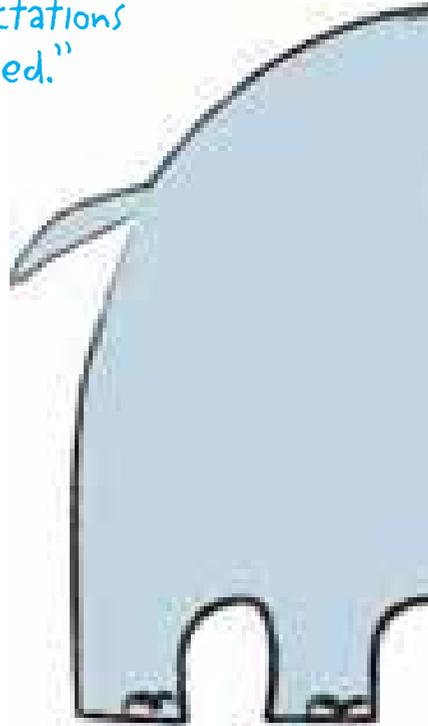
Ask your nurse or a member of your health care team to organise your card.

**Priority Listings for people with medical conditions:** It is possible to be placed on a priority list within essential services such as gas, electricity, water or telephone. This identifies your child to these services as requiring priority assistance. Further to this it will ensure your utilities are fully functional or repaired with the least amount of disruption and risk to your child's wellbeing.

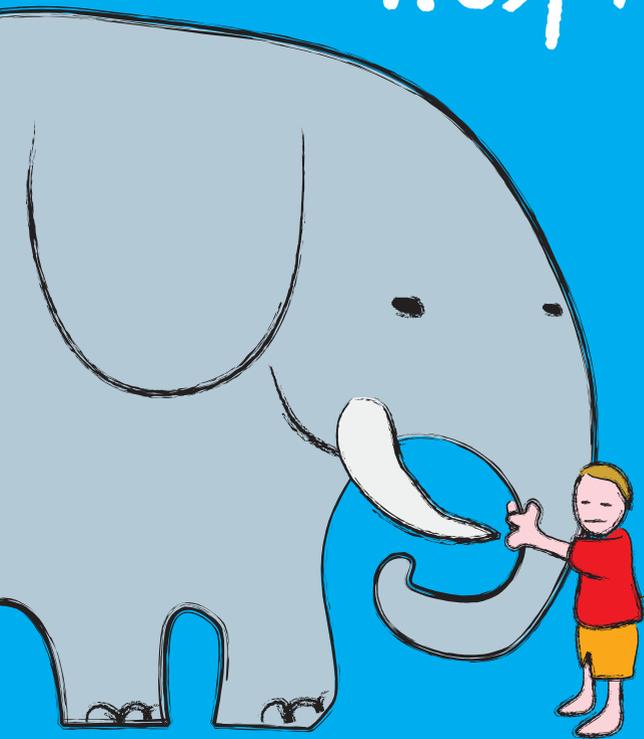
Not all companies will use the same terminology, nor will every service have this provision. Check with your individual utility providers to ensure their maximum assistance to you [For more information about Financial Considerations see Resources & Services p89].

“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

“My daughter became very fearful of doctors and nurses and what they were going to do. As she is visually impaired and can't clearly communicate, I developed a sign for her door asking people to introduce themselves and inform her what they were in her room for. This helped to prepare her.”

*(Bill – parent)*

“Taking my daughter's own books and toys to hospital helped us to make the experience as positive as possible.”

*(Rachael – parent)*

### Day Surgery

Many surgical procedures are done as day cases. Children often 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 who to contact if you are worried about your child.

### 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/carers are often so focused on their child that they don't think about themselves. So you don't forget things you may need, keep a bag packed with some basic items 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 need to take with you.

### What to take for your child

- Current medications: Do not assume that all your child's medication will be available at the hospital
- List all current medications and dosages/strengths. Always bring all your child's medicines with you so that the doctor can check exactly what he/she is taking and do this each time your child is admitted. This is very important for late or night time admissions since the pharmacy in the hospital may be closed and your child may need to use their own medication
- Lists of child's symptoms/doctors/appointments etc
- Nappies and clothes for discharge (nappies and hospital gowns are usually available on the ward during your child's admission)
- Equipment such as orthotics, glasses, hearing aids, splints, tube feeding equipment, spacers, ventilation 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)

## 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 (including clothes you can sleep in)
- 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 or other things to keep yourself busy

You won't have much storage space and it's unlikely to be secure. You are best to 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

"When my son was first born I took a knitting project to do at his crib in NICU. This was a special blanket I was working on for him. I made a rule for myself that I wasn't allowed to have dark thoughts about him while working on this blanket. It really helped me control my thoughts and limit my worry time – it gave me a break from my fears."  
*(Rachel – parent)*

"Getting a good night's sleep can be challenging when staying in hospital with your child. At times, the other children, monitors or nursing staff can be quite disruptive, so I always pack earplugs."  
*(Ronni – parent)*

“While my son was stuck in bed the nurse told me it was important to move his position in bed regularly to prevent bed sores.”

*(Kaye – parent)*

### Staying on the hospital ward

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/carers on the ward. Here are some questions you may want to ask:

- Is there an 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 a map of the hospital available for me to use?
- Where are showers and toilets for parents/carers 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)?
- Are there computers for me to use to access the internet?
- Is there parent/carer accommodation available?
- Are meal vouchers available?
- Are car parking concessions available for inpatient families and who do I see about that?
- Is there a play 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?
- Is there a crèche I can access for my other children?
- 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 in the ICU with your child is a little different to staying on other wards. For example:

- Security is greater and you will need to ring a doorbell and 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, or a one to two patient 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
- 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, or leave your mobile number with the nurse 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/carer accommodation. The nursing staff will ring you at home overnight if they are worried about your child
- 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
- The staff in the ICU are available to answer any questions, so if you are unsure of anything you are encouraged to talk it over with the staff
- When your child's condition improves, they will be transferred to a ward. Ward routines are quite different to the ICU, for example the Medical Team may only visit once a day and nursing staff may have a number of other patients to care for. It is often a good idea before your child is transferred to the ward to go and meet with the nursing staff and have a tour of the ward. Give yourself and your child some time to settle into the ward routines and ask as many questions as you wish

## Caring for yourself during your child's stay

- Drink lots of water and 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/carers 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.

- Social worker, counsellor, psychotherapist etc
- The hospital chaplain for spiritual and pastoral support
- Other parents/carers on the ward will have hints and tips on how they cope
- A play 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 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 who support Aboriginal inpatients and their families with the aim of ensuring their medical, practical and cultural needs are met while in hospital. The Aboriginal Liaison Officers can act as a cultural broker.

Aboriginal Liaison Officers 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

Ask at your health service if there is an Aboriginal Liaison Officer.

## Transition

When your child nears 18 years of age, doctors and other health professionals will need to “transition” (i.e. transfer) your child to adult services and specialists.

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. Ideally you should be actively involved in this process 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.

## For Country Families Attending Health Services in Adelaide

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 patients and visitors needing a place to stay there are many off site accommodation choices close to the hospital. Limited on-site accommodation may also be available. Aboriginal patients and their families may also choose from a number of Aboriginal hostels. Speak to your health care professional about this.

If you do not live in Adelaide 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 [See Publications p79].

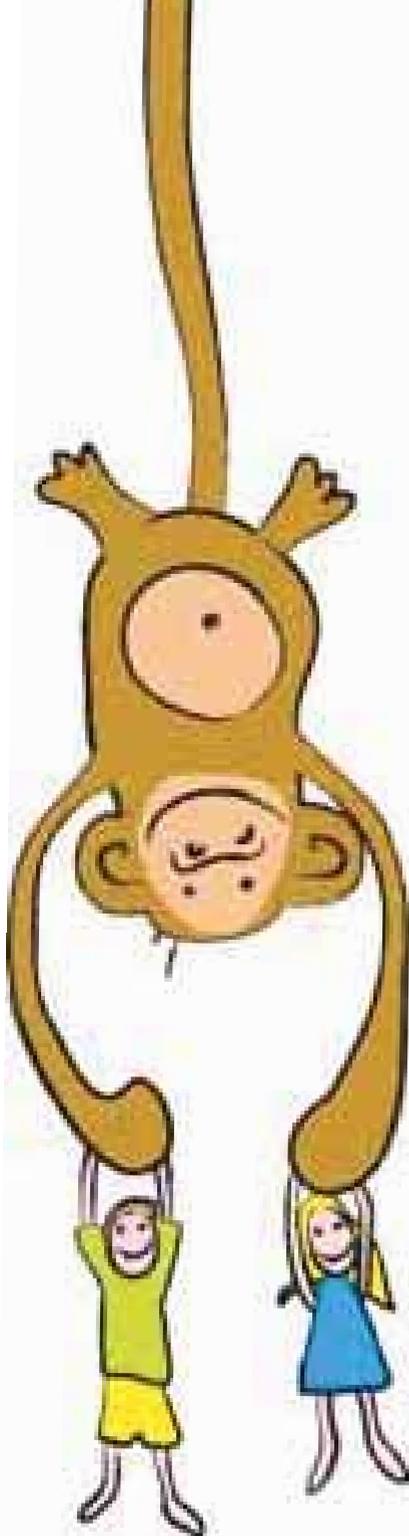
Get the referring doctor to sign a Patient Assistance Transport Scheme (PATS) form before you go to Adelaide and remember it needs to be signed again by the doctor in Adelaide [See p57 for more information about PATS].

“I learnt very early that there was a need to coordinate specialist appointments into blocks so I wasn’t travelling for one appointment. I found this helped minimise time away from home. Sometimes this took some organising and negotiating but it was more than worthwhile.”

*(Bill – parent)*

“Initially I was very nervous about travelling with my daughter, about forgetting essential equipment. I discovered writing lists helped ease my anxiety.”

*(Rachael – parent)*



“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?

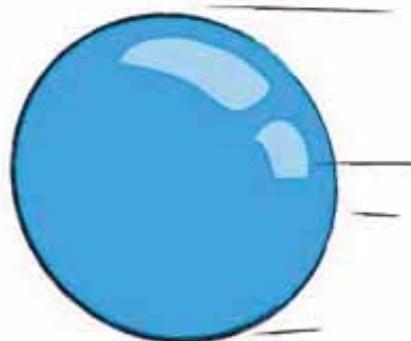
## Case Management

A Case Manager's role is to work with you, to make an assessment of your child's needs within the context of the family situation and co-ordinate ongoing services and support. Generally, a Case Manager will be affiliated with a particular organisation or program. Provided your child meets the eligibility criteria for case management, a Case Manager will be allocated to support the family by linking them into services such as:

- Specific home help from local councils
- Early intervention programs
- Recreation programs
- Schools
- Respite programs

They may also:

- Liaise between families and service providers
- Help to obtain equipment
- Provide information and advocacy
- Tap into funding options



Some case management programs exist at present. For example:

**Novita Children's Services:** Family Support Service staff work with families to coordinate the best services and support for the client. Novita's services are provided to children aged up to 18 years who are residents of South Australia and who have been diagnosed with either a permanent impairment to physical functioning or an acquired brain injury that:

- Has the potential to impact on their participation in life and
- Is likely to require ongoing support

Anyone can contact Novita's Central Intake Team on 1800 337 443 to enquire about eligibility or to refer a child for registration with Novita.

**Disability SA:** Child and Youth Service provides case management for children and young people who have a significant disability. Children from birth to school entry with significant global developmental delay or a condition associated with high likelihood of intellectual disability may be eligible for case management and family support as part of the Early Childhood Program. School age children with intellectual disability, and/or autism spectrum disorder may be eligible for case management and family support as part of the School Age and Youth Program.

Referral to these services can be made by parents, health professionals or other interested parties by contacting Disability SA Intake on 1300 786 117 or [disabilitysaintake@dfc.sa.gov.au](mailto:disabilitysaintake@dfc.sa.gov.au)

**Country Services:** Child Development Units (CDUs) coordinate care and services for families of children with special needs and/or developmental delay. These needs can vary from disability, learning, behaviour and medical needs. CDUs also offer a valuable communication channel between relevant agencies and health staff when case conferencing families needs.

CDU service models vary across South Australia ranging from multi-disciplinary teams providing coordinated assessment through multi-agency coordinated intake, assessment and therapy support by a resident or visiting Paediatrician. Contact your local Health Service for details and location of your nearest Child Developer Unit and resident and/or Paediatrician [See Resources & Services p89



## Early Intervention

“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)

“We have been involved with Early Intervention since our daughter’s birth. This really helped us to understand how to best help her reach her potential.”  
(Bill – parent)

Early Childhood Intervention is targeted at children 0-8 years of 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. child care, preschool

### Children, Youth and Women’s Health Service Early Childhood Intervention Consultants:

- This program provides a range of support and advice for parents of young children with a disability or developmental delay aged 0 to 8 years
- Early Childhood Intervention Consultants assist parents who may be worried about their child’s development

The Early Childhood Intervention Consultants offer a range of support and advice for parents including:

- Information about local services and support groups
- Assistance with accessing services and benefits
- Assistance in dealing with services for children with special needs
- Working to create a smoother transition between services
- Assistance with entering peer support ‘MyTime’ groups in South Australia [See p92 for more information]

Contact an Early Childhood Intervention Consultant through your local Child and Family Health Service on 1300 733 606 or the Early Childhood Intervention Program on (08) 8159 9400.

Families are central to all decision-making, including the choice of service, goals for therapy and program strategies for their child. The family, pediatrician or anyone concerned about a child’s development can make referrals for early intervention.

The Early Childhood Intervention Directory is produced by Disability Information and Resource Centre [See Resources & Services p89].

# Respite

Respite care is the temporary care of a person by someone other than the primary caregiver/s. Respite can occur in the home or at another location. Respite can be planned or in response to an emergency.

- **Respite can be the key to survival** in many instances, giving families a chance to have some 'time out'. It can also give families the opportunity to do things they would not ordinarily do when their child with additional needs is in their care
- **It is critical for your emotional and physical well being** that you have breaks from the intense demands of caring for a child who is sick, disabled or chronically ill
- **It is also important for the child's siblings** 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
- **Everyone in the family can benefit from respite**, including the child with additional needs. Often children go to places with their carers and do different things than they would ordinarily do at home. The variety can be pleasurable and stimulating for them
- **Respite facilities are usually heavily booked** and often have long waiting lists, so consider contacting them well in advance. Once you are on the books and using the service, make future bookings so that you can be sure to get planned breaks. Occasionally you can make an emergency booking, but strict conditions usually apply, and vary from service to service, depending on bookings, staffing levels and the mix of children booked in at the time

**"We have used 'emergency' respite to organise occasional weekends without our daughter in order to focus on being husband and wife and have quality time together."**

*(Bill – parent)*

“Without respite I would not have been able to return to work as traditional child care options were not suitable for our daughter.”  
*(Rachael – parent)*

### Centre Based Respite

This type of respite is provided in houses owned by service provider agencies. The child stays in the respite house and is cared for 24 hours a day by trained care workers. There are usually between 3 and 5 children in the houses at one time.

### In home care

This is provided by trained carers who come into the home. This form of care can be a great option for children who would be unsettled in an environment other than their own home. Some organisations provide in home respite through volunteers.

### Camps

Some organisations and respite providers offer camps during school holidays, be it for the child with special needs and/or their siblings. Trained staff and volunteers attend to the children and ensure that all medical and personal needs are met.

### School holiday programs

These programs are provided by some respite services, local primary schools and some local councils. For more information, contact these places directly [See Resources & Services p102].

## Family Day Care and Child Care

Family Day Care is provided by an approved and trained care provider in the care provider's home. Although the Department of Education and Children's Services (DECS) provides administration, support, training and monitoring, each care provider is self employed. The Family Day Care program in South Australia provides respite care as well as work related care for children with disabilities and additional training is provided as required to support children with specific health care needs.

Child care is provided in a child care centre by licensed and trained care workers. Child care centres may be government or privately owned.

Once you have decided on what type of care you want, you will need to meet with the relevant staff to discuss your child's special needs. They will be able to advise you of what supports might be available to support the inclusion of your child. They arrange for the care workers to be trained by the Community Health Support Program to provide the extra support that your child may need [See Resources & Services p89].

### The Community Health Support Program

The Community Health Support Program works with children who have complex health care needs in Family Day Care, child care, preschool, school and also respite, vacation care, out of school hours care and on camp. The program is staffed by Registered Nurses who develop Health Plans for children and train care workers who look after them.

## Education (Schooling)

### Department of Education and Children's Services (DECS)

DECS works in partnership with educators and health professionals to plan safe, reasonable and consistent health support for all children and students. This includes additional support for children and students with a health condition or care need which could impact on their attendance and participation in education and childcare programs.

Information on services and support is available from:

- The manager of the service your child is accessing  
e.g. child care centre, preschool, school
- Region support services  
[www.decs.sa.gov.au/speced/pages/specialneeds/intro/](http://www.decs.sa.gov.au/speced/pages/specialneeds/intro/)
- [www.decs.sa.gov.au/portal/community.asp](http://www.decs.sa.gov.au/portal/community.asp)
- *child health and education support services (chess)*  
[www.chess.sa.edu.au](http://www.chess.sa.edu.au) (for health planning information)
- List of services and resources [p89]

### Catholic Education South Australia (CESA)

CESA works with families and schools to provide educational opportunities for all children and students. This includes children and students with a health condition or care need which could impact on their attendance and participation. CESA provides advice to Catholic schools to assist in planning appropriate health support for students with a health or care condition.

In South Australia a cross sector agreement has formed the *child health and education support services (chess)*. The *chess* ensures that all preschools and schools have access to information and guidelines about the health planning process and health or care support.

Further information is available from:

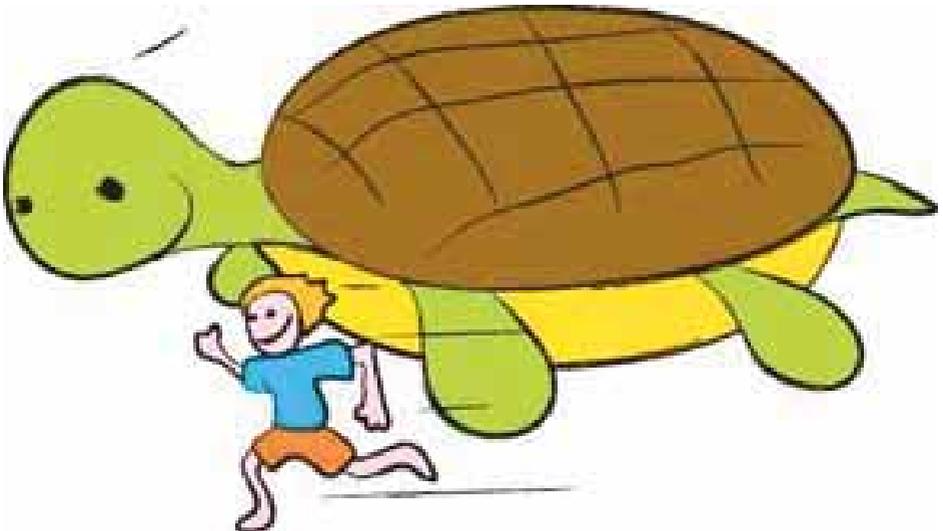
- The school
- *chess* [p98]
- CESA [www.ceo.adl.catholic.edu.au](http://www.ceo.adl.catholic.edu.au)

### Association of Independent Schools of SA (AISSA)

AISSA provides advice to Independent schools on planning and providing appropriate support for students with a health condition or care need which could impact on their attendance and participation. The AISSA is a signatory to the cross sector agreement for *child health and education support services (chess)* which provides guidelines about supporting students with health conditions.

Further information is available from:

- The school
- chess [p98]
- AISSA [www.ais.sa.edu.au](http://www.ais.sa.edu.au)



## Preschool (Kindergarten) and School

“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)

Starting preschool or school, or returning to preschool or school following an absence 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.

Before your child starts you will need to meet with the director/principal and let them know about your child’s special needs. They can discuss with you ways they can support your child and arrange referrals to the appropriate services. You may be asked to provide documentation about your child’s disability (e.g. reports) or health care needs (e.g. a health care plan describing recommended emergency and routine health and personal care support).

If your child requires assistance at preschool or school with complex health needs the staff can send a referral to the Access Assistant Program to arrange extra support for your child [See Access Assistant Program below].

Through careful planning, staff training, and other appropriate resources (e.g. health care plans) you can be assured that any staff coming into contact with your child will be informed of his/her individual needs.

Regular and ongoing case meetings with staff involved in your child’s education to discuss issues relating to your child’s overall development and progress, can be helpful and reassuring. These meetings are equally supportive of staff in their role, as some may have limited contact with your child. Even if they only see your child while doing yard duty, it is no less important that they know how to respond to your child’s needs [See p99 Resources & Services for further information about services DECS provides].

### The Access Assistant Program

The Access Assistant Program provides services to children with complex health care needs while they are at preschool and school. The Access Assistant Program provides support to children in government and private preschools and schools. Trained care workers attend school to support your child with their particular need (e.g. to give gastrostomy feeds, tracheostomy care, administer oxygen etc). For further information call (08) 8159 9400.

### 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, 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 judgment. 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 diary or 'communication book'. This book can be ideal for letting the teacher know of any extra relevant information regarding your child, whether it is changes in behaviour, specific observations or accomplishments made throughout the day.

### Meetings

Meetings with educational staff may feel quite intimidating, especially with two or three teachers. Consider making appointment times when you and your partner 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. It is beneficial for the staff to meet with those caring for 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.

### Siblings

Siblings of children with special needs will experience their own personal and emotional needs. It's important their needs are recognised. Siblings may need some extra support at school. They also may need a mentor to confide in or regular contact with a counselor/support group [See Siblings p67].

"My husband and I went to a few of our local schools for initial discussions with the special ed teachers and principals when our son was only 18 months old – just to see what their approach to us and our son was. We chose his school and put his name down for enrolment at 18 months based on their responses to our questions and projected needs. One school was ruled out immediately due to its approach to health with a very low immunisation rate – far too risky for our son."

*(Rachel – parent)*

## Community Agencies for Children with Disabilities

### Novita Children's Services

Novita Children's Services provides services for children with physical and multiple disabilities and acquired brain injuries aged 0–18 years. Novita provides therapy, equipment and family support services to children and young people across South Australia in metropolitan Adelaide and in rural areas via an outreach service. Novita also provides an Inclusion Support service that assists child care services to include children requiring additional support, such as children from culturally and linguistically diverse backgrounds, children with ongoing high support needs, indigenous children and children with disabilities. The Inclusion Support Program is available in the Mid North, Far North, Far West, Eyre Peninsula and Yorke Peninsula. Other families can access this service through Inclusive Directions. For further information call (08) 8243 8243. Website: [www.novita.org.au](http://www.novita.org.au)

### Disability SA

Disability SA provides a range of services to children and young people with disability aged 0-25 years. Services include:

- *Early Childhood Program* offers a range of therapy and family support services to young children from birth to school entry who have significant developmental delays or conditions associated with intellectual disability. Interdisciplinary teams based in the metropolitan area offer a range of services including developmental assessments and strategies for promoting a child's learning and development, groups and information sessions, strategies for understanding and responding to behavioural issues and links to other services and agencies. In country areas early childhood services are provided through community health
- *School Age and Youth Services* includes a range of services to children and young people (aged 5-25 years) diagnosed with an intellectual disability and/or autism spectrum disorder. Services in metropolitan areas include time limited case management, family support, information, strategies for promoting development, assistance with behavioural issues, support to access community services, sibling support, and assistance at transition times (e.g. starting school, leaving school)

Referral to these services can be made by contacting Disability SA Intake on 1300 786 117.

## Country Services

Health assessment and therapy services are provided across a number of South Australia's regional and rural areas by Child Health Teams based in Community Health Centres. These services offer a multi-disciplinary approach supporting positive growth and development for children whilst providing support and information for families. Contact your local Health service to locate your nearest Community Health Centre [See Resources & Services p89].



## Transport

### Red Cross Medical Transport

Red Cross provides a transport service for those experiencing difficulty accessing public transport, taxis or family support. This transport can support people in getting to and from hospital or medical appointments and some social support e.g. shopping. The service operates across the Adelaide metropolitan area as well as in the South East Country and Eyre Peninsula regions. The service has a registration fee and a small trip fee. Transport is provided by volunteers, usually in Red Cross vehicles.

For further information contact 1800 246 850 (free call) or (08) 8100 4500

Website: [www.redcross.org.au/sa](http://www.redcross.org.au/sa) or email: [sa\\_info@redcross.org.au](mailto:sa_info@redcross.org.au)

### 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) 3852 3300.

### Leukaemia Foundation Transport Services

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders. The Foundation provides courtesy transport within metropolitan Adelaide to treatment and other hospital appointments.

This service is specifically designed to relieve the pressure for patients who have difficulty accessing transport, or limited private transport options, such as the carer in the family having to return to work. The transport also minimises the risk of infection for patients who have a weakened immune system. It ensures patients arrive at appointments safely and on time, as well as providing a friendly face to greet patients.

The transport service runs from Monday to Friday from 8am to 5pm. To make a booking, please call (08) 8273 3500. The Leukaemia Foundation will try to accommodate all requests but asks that as much notice as possible is given. This service is free of charge. For further information visit [www.leukaemia.org.au](http://www.leukaemia.org.au)

### Patient Assistance Transport Scheme (PATS)

PATS provides part reimbursement to assist with travel and accommodation costs for clients who travel more than 100 kms (one way) from their permanent residence to the nearest medical specialist for treatment. An escort may be eligible for travel and relevant accommodation allowances if the need for an escort is medically endorsed.

PATS application forms are available from doctors' surgeries, hospital social workers and the regional PATS offices. A separate application form is required for each authorised return journey and original receipts and tickets must be supplied with the claim.

The scheme is not generally means tested although some exclusions and conditions apply. Please contact the nearest PATS office or free call 1800 188 115 to clarify any entitlement or for further information.

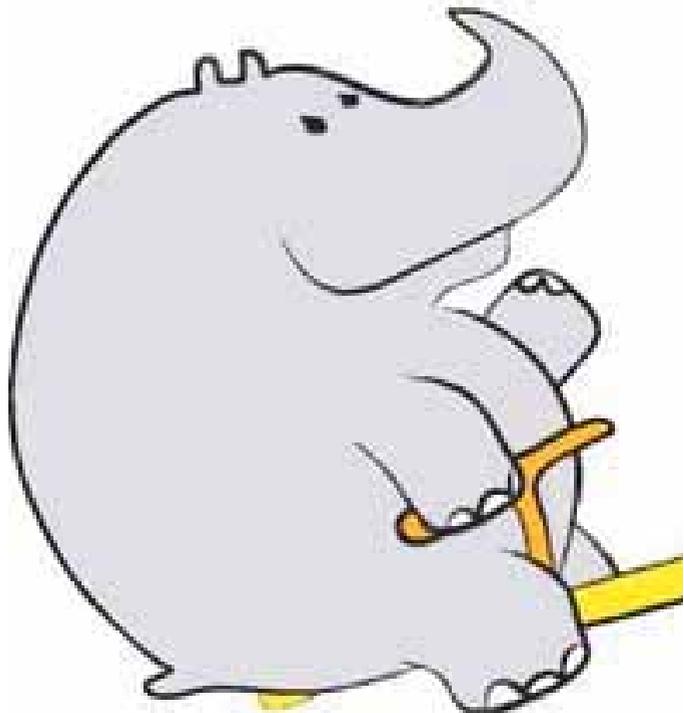
Each state and territory has a similar system. If you live interstate please ask your health care professional to guide you to the local scheme.

### South Australian Disabled Persons' Parking Permits

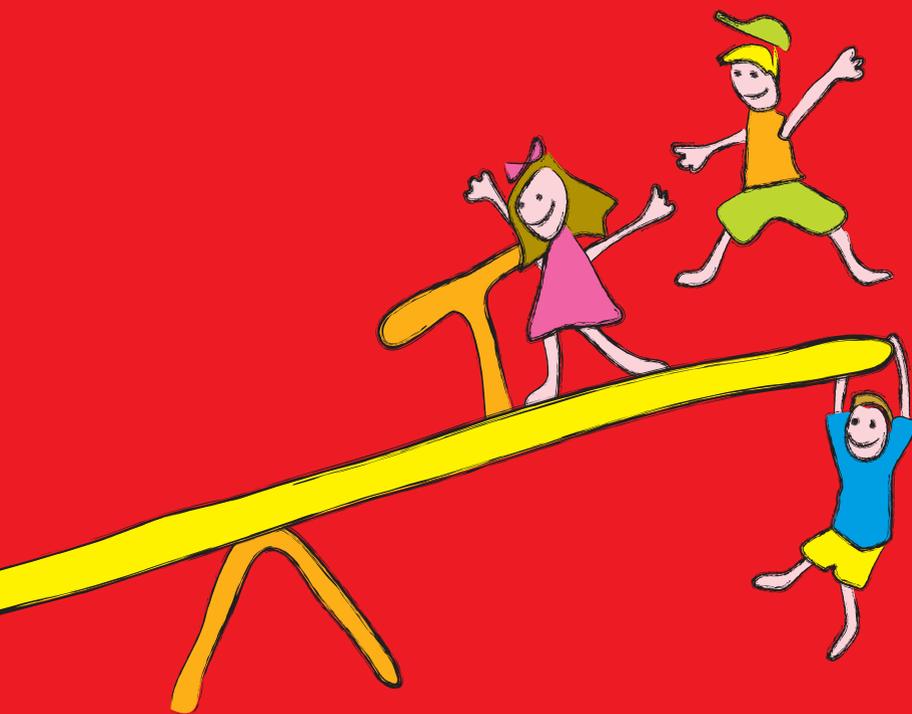
Your child may be eligible for a Disabled Persons' Parking Permit to make transport easier for you [Resources & Services p115 for more information].

“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 life balance



## Key Sources of Support

“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)*

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 Resources & Services p89]
- 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 (e.g. the MyTime Peer Support Groups)  
[See Resources & Services p89]
- Home Help may be available through your local council
- Contacting a ‘condition specific organisation’ (e.g. Epilepsy Association of South Australia and the Northern Territory Inc) 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 Practice Consultants who may be able to provide support and assistance. For example, the Children, Youth and Women’s Health Service has Clinical Practice Consultants located at the Women’s & Children’s Hospital. These Registered Nurses are able to provide excellent practical support for parents of children with complex/high medical needs, as well as advocacy, across the continuum of care

Below is a list of Clinical Practice Consultants at the Women's & Children's Hospital.

- Acute Pain Management
- Allergy
- Burns
- Cancer Care: Central Nervous System Tumours
- Cardiology
- Chronic/Complex Care Discharge
- Cystic Fibrosis
- Diabetes
- Endocrine
- Ears, Nose and Throat
- Gastroenterology
- Home Enteral Nutrition Service
- Infection Control
- Immunisation
- Metabolic
- Palliative Care
- Psychological Medicine
- Rehabilitation
- Respiratory
- Renal
- Stoma/Wound/Urology
- Transition to Home
- Transplant Coordinator
- Trauma

There may be staff working in similar positions within the general hospitals. Find out from your local hospital about the staff available to help your child.

- Staff within the hospital setting (e.g. Hospital chaplains, social workers, allied health professionals and Aboriginal liaison officers, Department of Psychological Medicine)
- 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 own religious community (e.g. church, mosque, synagogue) may provide practical help such as meals, cleaning or babysitting, as well as emotional and/or spiritual support
- Regular respite

## Paediatric Palliative Care

Support for families who are caring for their children with a life limiting illness is available from the Palliative Care Service at the Women's & Children's Hospital. This team of nurses, an art therapist, secretary and a doctor work across the hospital and in the community environments to provide support, care, resources and expertise. There is a 24 hour phone support service as well as home visiting and case management. You can receive help with your child and family through counselling, respite, care planning and activities to "Live Life to the Max!" The Women's & Children's Hospital Paediatric Palliative Care Service can be contacted on (08) 8161 7994 or through the hospital switchboard on (08) 8161 7000.

The Palliative Care Australia website has lots of resources including one called "journeys" which is for families of children who have life limiting illnesses. For more information visit [www.palliativecare.org.au](http://www.palliativecare.org.au)



## 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/email 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. Websites such as 'imthinkingofyou' (website: [www.imthinkingofyou.com.au](http://www.imthinkingofyou.com.au)) also link family, friends and communities in times of need.

**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 or mobile phone. 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 day is another battle, but it is also an opportunity to educate someone. Each time we are faced with a new battle, we just need to fight harder, speak louder and not give up."*

*(Lisa B – parent)*

*"During particularly stressful and upsetting times, I found frequent or long visits from family and friends very draining. Limiting numbers of visitors has helped us to have time out at these times. Learning to say no when visiting is not okay with you is also important."*

*(Rachael – parent)*

## Taking Care of Yourself

"Accept genuine offers of help - it makes friends feel useful and eases your load too."

(Kimberlee – parent)

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:

- Look after yourself. This 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/carers 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, some 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
- Take time out for yourself: retail therapy, pampering yourself, keeping a journal, craftwork, playing sport, catching up with friends

## 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 one 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 each other's needs.

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, mothers' groups etc).

Make your own choices about the best level of support for your family. If it feels more difficult than helpful, consider avoiding it.

"When a carer came to look after their sister, I would tell my other children 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) I was 100% committed to them in that time. They adapted quickly to this arrangement and planned what they wanted to do with me in this time. If, for some reason, they didn't want/need this time with me I would use it for myself. I would perhaps make an early start on dinner, but the children were always my first priority while the carer was in our home."

*(Karen – 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)*

## The Non-Primary Carer's Perspective

"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 take the attitude that nothing will happen to the primary carer, but life gives no guarantees for anyone or anything. Be aware of the basic day-to-day care requirements of the child, listen, ask questions about the condition and be available where possible. Try to be involved so that you and the child are comfortable and confident with another person, other than the primary carer."

(Tony – parent)

*Note: The person who does most of the care of the child is usually called the primary carer. Anyone else who helps with care is a non-primary carer. A 'non-primary carer' may be a member of the extended family, friends or community workers.*

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 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.

## Siblings

Parents of a child with chronic illness, disability and/or life-threatening illness will face a number of losses throughout the life of their child. A sibling, as an integral member of the family, will be subject to that same sense of loss. Without appropriate support and understanding, siblings risk their experience of loss being unrecognised which can have a significant impact on their emotional wellbeing.

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
- Embarrassment
- Fear
- Pressure to achieve
- Confusion
- Over protection or exclusion
- Heightened empathy
- Shame
- Anger or jealousy
- Increased responsibility
- Sense of achievement
- Denial
- Isolation
- Grief
- Understanding
- Independence
- Sensitivity

Many of these feelings affect children as they are growing up and siblings often continue to have concerns even as adults. It may be helpful to access existing supports for your other children. Like adults, they too need the opportunity to give expression to their feelings and the reality of their experience.

**Siblings Australia** was which was established in Adelaide in 1999, aims to:

- Increase awareness amongst parents, siblings and service providers of the concerns of siblings of children with special needs
- Increase the provision of services to families and, in particular, siblings
- Improve networking opportunities for families and siblings to support each other
- Enhance the inclusion of sibling support as part of 'core business' of relevant organisations

The organisation runs workshops for parents and providers on how to best support siblings. When funding allows, it also runs sibling support groups. It has a website which includes forums for siblings of all ages and for providers.

For more information visit [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au)

*"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)*

*"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)*

“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 way, but other people stare in a bad way...I have a friend who’s really nice to Elizabeth. My friends all understand but some don’t understand as much.”

*(Alice – sibling)*

**Big Brothers Big Sisters** is the leader in one to one youth mentoring both nationally and around the world.

They are:

- The longest-serving youth mentoring organisation in Australia and
- Supported by an international heritage spanning more than 100 years

YWCA’s Big Brothers Big Sisters of Adelaide is a community based mentoring program which provides young people (7-17 years), in need of additional support and friendship, with a caring volunteer mentor and positive role model. Big Brothers Big Sisters is based on the simplicity and power of friendship. Big Brothers Big Sisters contributes to an environment where the young person can develop positive self-esteem and life direction. For more information visit [www.ywca.com.au/programs/bigbigs.htm](http://www.ywca.com.au/programs/bigbigs.htm)

**Novita Children’s Service** psychologists can provide assistance to the siblings of Novita clients via Sibling Workshops and individual counselling. These interventions can be very valuable for children who may not want to burden their family with their problems and may feel more comfortable talking with others, especially other children who may be feeling the same as them. For more information, a list of helpful books and a brochure on ‘Sibling Concerns - How Parents Can Help’ visit [www.novita.org.au](http://www.novita.org.au)

**Disability SA** provides information and support to families about issues for siblings and what parents can do to help. The brochure ‘Children and Young People: Siblings of Children with Disability’ has helpful information including a list of useful resources and picture books for siblings of children with disability. For more information visit: [www.disability.sa.gov.au](http://www.disability.sa.gov.au)

**The Association for Children With A Disability (Victoria)** has a range of sibling resources including a booklet for parents called ‘Supporting Siblings: When a Brother or Sister has a Disability or Chronic Illness’, a series of three Sib Sheets and the Sibling and Your Shout websites for siblings. For more information visit [www.sibs.org.au](http://www.sibs.org.au)

# Health Care Personnel Terminology

**Medical Students**

Students studying to become a doctor.

**Intern**

1st year doctor.

**Resident/Resident Medical Officer (RMO)**

2nd or 3rd year doctor.

**Registrar**

Doctor training towards a specific speciality e.g. A Paediatric Registrar will be training in Paediatrics and a Surgical Registrar would be training in surgery.

**Trainee Medical Officer (TMO)**

This includes all doctors in training before they become a specialist.

**Fellow**

Qualified specialist or senior registrar doing further training prior to commencing own practice.

**Consultant**

Doctor who is a qualified specialist in a particular area. This person will be in charge of the team caring for your child.

**Mr/Miss (rather than Dr. title)**

Consultant Surgeon may use this title rather than doctor.

**Specialist**

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

**Paediatrician**

Specialist doctor working with children and young people only.

**Anaesthetist**

Doctor who is specialised in caring for your child during procedures where they need to be asleep. Among other things the anaesthetist looks after blood pressure and breathing during the operation and medicines for pain relief after the operation.

**Psychiatrist**

Psychiatrists are doctors who specialise in the prevention, diagnosis, and treatment of mental illness. Both psychiatrists and psychologists focus on reducing distress and enhancing well-being.

**Psychologist**

Psychologists undergo university training and supervised work to be registered to identify and treat problems that adults and children have both within themselves and with other people.

**Professor**

A role that includes teaching, research and work as a consultant in their area of expertise.

**Assistant in nursing or midwifery (AIN/M)**

An employee of the hospital who is in their 2nd or 3rd year of undergraduate education to become a nurse. They work under the direct supervision of a Registered Nurse.

**Enrolled Nurse (EN)**

A nurse who has undertaken a Diploma in Nursing through a vocational course. They work under the supervision of a Registered Nurse. Some have many years of experience.

**Graduate Nurse (GNP)**

A Registered Nurse who has undertaken a university degree in nursing or midwifery and is in their first year of work after university. They undertake a specific course run by the hospital that helps them apply their knowledge in the workplace.

### **Registered Nurse (RN)**

Provides direct care to patients and is the first 'step' of employment within nursing. A Registered Nurse may be new graduate or have many years of experience.

### **Registered Midwife (RM)**

A registered midwife has undertaken a specific course at university that allows them to be legally registered as a midwife and who in partnership works with the woman and her family during pregnancy, birth and the postnatal period facilitating early parenting.

### **Clinical Nurse (CN)**

A Registered Nurse who has developed significant clinical experience. They provide direct care to patients and support less experienced nurses in providing care or they may work with the Clinical Practice Consultant in a specialty area.

### **Associate Clinical Service Coordinator (AsCSC)**

An experienced nurse who has a specific role within the ward or health service to support the clinical service coordinator in the management of this ward. They also provide clinical care.

### **Clinical Service Coordinator (CSC)**

An experienced nurse who manages the ward or service, the staff, the resources and is responsible for the clinical standard of care.

### **Clinical Practice Consultant (CPC)**

An expert nurse who has specialised knowledge and skills in a particular area of practice, this may be asthma, cardiology etc. They support all nursing staff in developing skills in their particular area of practice and may also provide direct care to patients.

### **Nurse Practitioner**

A Nurse Practitioner is a Registered Nurse who has specific education in a particular specialty area. They use their advanced knowledge and nursing skills to provide individualised care.

**Nursing Director**

A Senior Nurse who manages a number of wards or services (Division) and is responsible for the professional standards of practice as well as the management of nursing staff.

**Director of Nursing (DON)**

A very experienced nurse who is professionally responsible for all nurses and midwives and standards of practice across a hospital or health region.

**Dietitian**

Dietitians have university qualifications in Nutrition and Dietetics. They understand the role food and diet plays in promoting good health and in the treatment of some conditions. They provide nutrition assessment and education and work with the Food Services Department in developing menus and in providing special diets and formulas for patients.

**Occupational Therapist (OT)**

Occupational Therapists are trained to work with people to overcome limitations. These may be caused by injury or illness, psychological or emotional difficulties, delays in development or the effects of aging. Occupational Therapists aim to assist individuals, groups or communities to maximise strengths and build skills to participate effectively in everyday activities.

**Pharmacist**

Hospital Pharmacists work with doctors and other hospital staff to ensure that medicines are used safely. In addition to the supply and control of medication within hospitals they provide education to parents and patients in relation to medicines and their use.

**Physiotherapist (Physio/PT)**

Paediatric Physiotherapists are trained to work with infants, children and their families to promote optimal movement, maximise physical function, manage respiratory conditions, assist with recovery post surgery, prescribe exercises to improve fitness and strength, educate people about their child's conditions and child development.

### **Speech Pathologist (Speech Path/SP)**

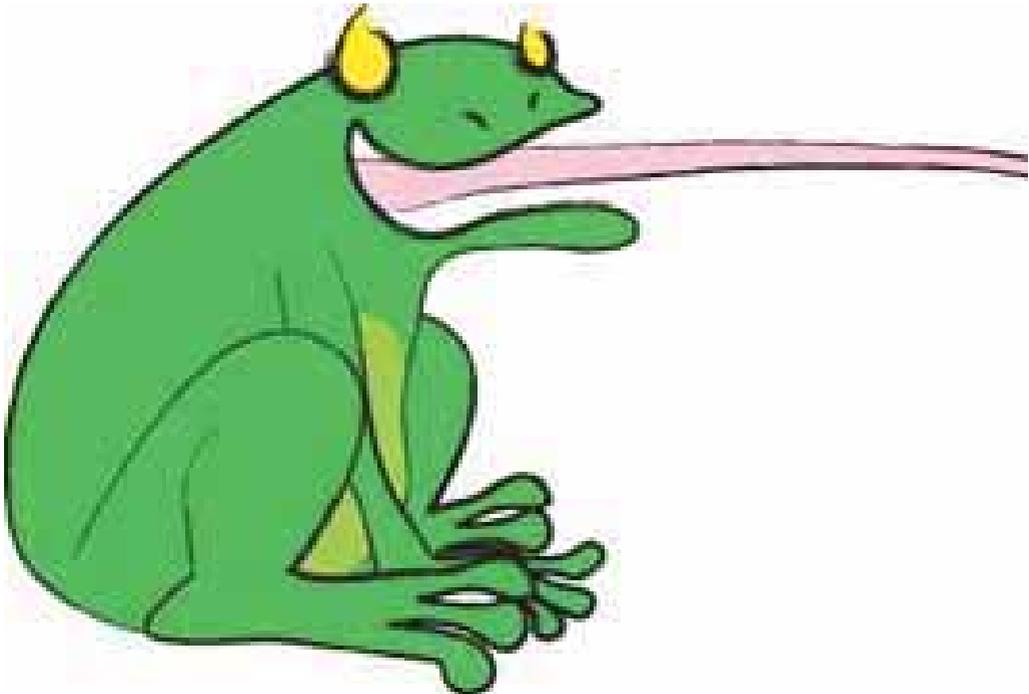
A speech pathologist has been trained to assess and treat people who have a communication disability. Speech pathologists complete a degree at university which encompasses all aspects of communication including speech, writing, reading, signs, symbols and gestures. Speech pathologists are also specifically trained to work with people who have difficulties with eating, drinking and swallowing.

### **Social Worker (SW)**

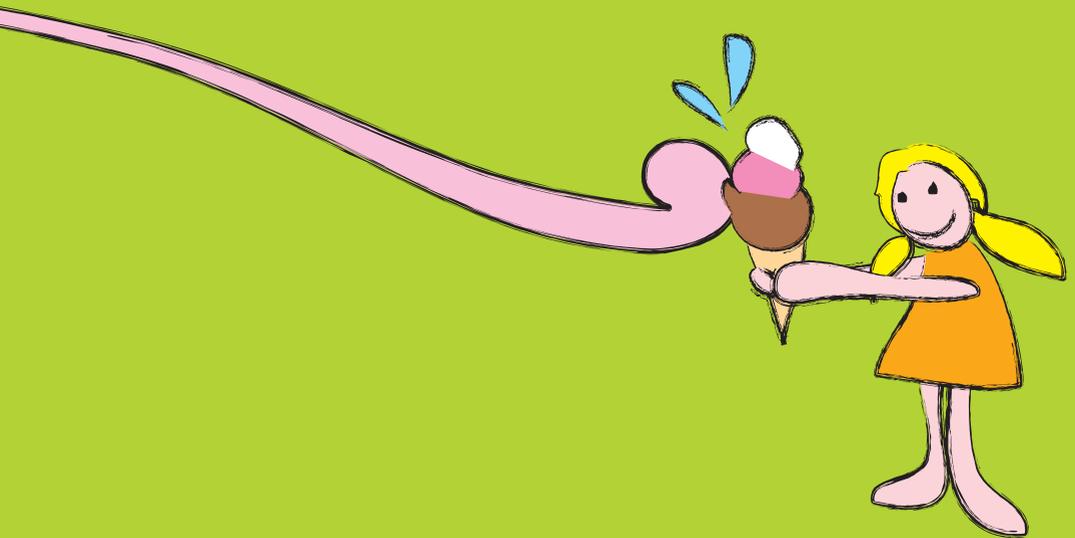
Social workers are trained counsellors who can help you and your family cope with the social and emotional effects of hospitalisation, illness, trauma and disability. They can help you with your concerns about your child's condition and offer information, advocacy and advice about a range of practical services.

### **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.



# Glossary



### **Allied Health**

Health professionals other than a doctor or nurse e.g. physiotherapist, occupational therapist, speech pathologist, dietitian, psychologist, counsellor, social worker, family therapist 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 stay with them while they are having treatment.

### **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 power to; to enable.

### **Inpatient**

A person admitted to hospital.

### **Meds**

Abbreviation of the word 'medications' for example tablets, syrups or other forms available to help treat diseases or conditions.

### **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.

**Paediatric**

Usually refers to a child or young person aged between 0-18 years.

**Play Therapy/Diversion Therapy**

A form of therapy 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**

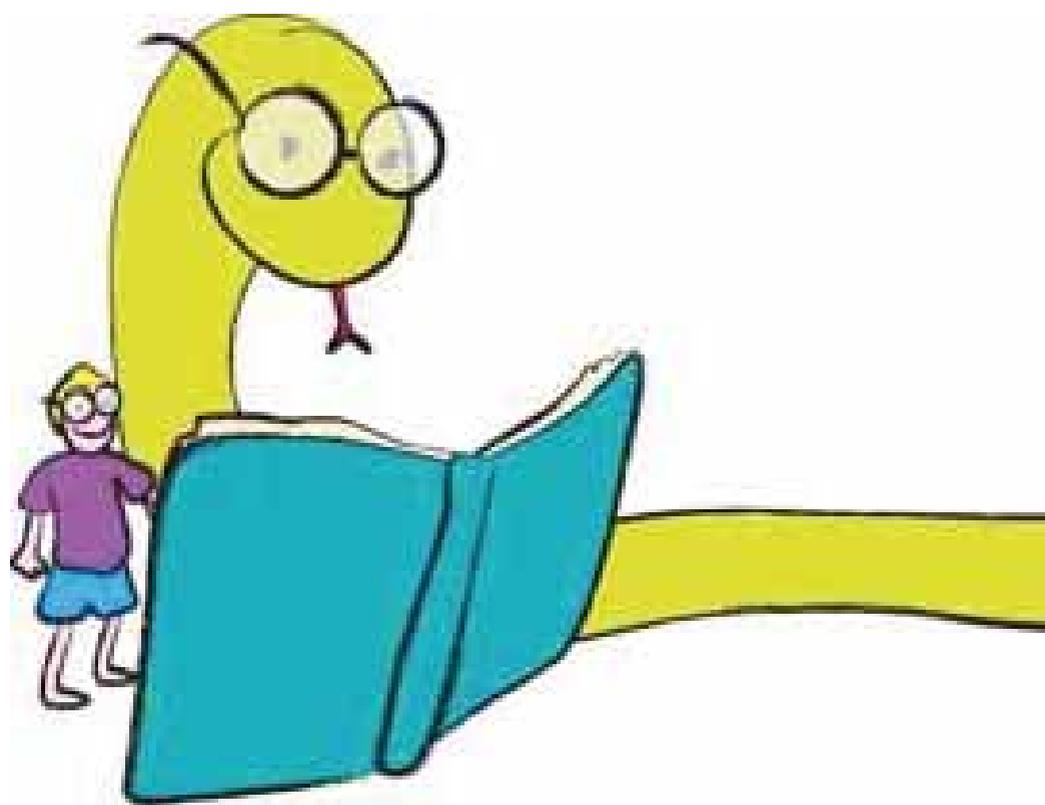
Respite care is the temporary care of a person who requires care. It provides a break for the primary care givers. Respite can occur in the home or at another location. Respite can be planned or in an emergency.

**Script**

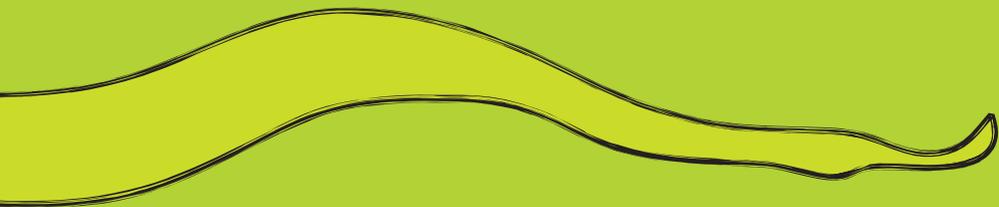
Abbreviation of the word 'prescription'. Written authority for the obtainment of a specific medication from a pharmacist.

**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



# Welcome To Holland

by Emily Perl Kingsley

©1987 by Emily Perl Kingsley. All rights reserved. Reprinted by permission of the author.

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"**Holland?!?**" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a **different** place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland.

# Celebrating Holland — I'm Home

by Cathy Anthony

(Follow-up to the original "Welcome to Holland" by Emily Perl Kingsley)

I have been in Holland for over a decade now. It has become home. I've had time to catch my breath, to settle and adjust, to accept something different than I'd planned.

©1995 by Cathy Anthony. All rights reserved. Reprinted by permission of the author.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger – the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

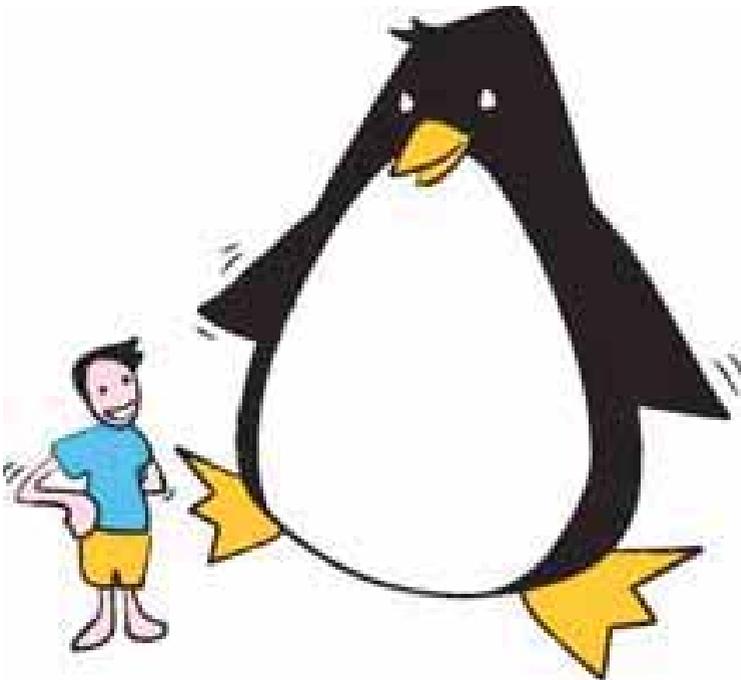
I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest.

And yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts. I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!



## For Parents

- **A Delicate Balance: Living Successfully with Chronic Illness**  
Wells, S  
1998, Plenum Publishing, New York
- **A Different Kind of Perfect: Writings by Parents on Raising a Child with Special Needs**  
Dowling, C., Nicoll and Thomas, B  
2006, Trumpeter, Australia
- **Building Links Directory: Service Providers for Children with Intellectual and Multiple Disabilities**  
Mieass, E and Mattschoss, L  
2008, University of South Australia and Suneden Special School
- **Coping with Your Child's Chronic Illness**  
Barrett Singer, AT  
1999, Robert D Reed Publishers, San Francisco CA
- **Directory of Services: For Children in the Limestone Coast Booklet**  
Government of South Australia  
2007, Country Health SA
- **'Doctor, I Feel Funny': How to Take the Stress Out of Being in Hospital for Patients and Visitors**  
Cameron-Hill, P and Yatesm S  
1999, Griffin Press, Australia
- **Easy for You to Say: Q & As For Teens Living with Chronic Illness or Disabilities**  
Kaufman, M  
2005, Firefly Books, US
- **For People from Out of Town Attending the Women's & Children's Hospital - Information Booklet**  
[www.wch.sa.gov.au/patients/facilities\\_support/outoftown/index.html](http://www.wch.sa.gov.au/patients/facilities_support/outoftown/index.html)
- **Listen. My Child Has a Lot of Living to Do: The Partnership Between Parents and Professionals in Caring for Children with Life-Threatening Conditions**  
Baum, JD., Dominica, F and Woodward, RN (Editors)  
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, EJ and Schultz, CL  
2001, MacLennan and Petty, Sydney
- **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**  
Topf, LN  
1995, Simon and Schuster, New York
- **You Will Dream New Dreams**  
- **Inspiring Personal Stories by Parents of Children with Disabilities**  
Klein, SD and Schive, K  
2002, Kensington Press, US
- **When Your Child is Ill: A Home Guide for Parents**  
Valman, B  
2002, Dorling Kindersley, Melbourne
- **Articles - A Parent's Perspective**  
'Welcome to Holland' by Emily Perl Kingsley [p80]  
'Celebrating Holland - I'm Home' by Cathy Anthony [p81]  
Website: [www.google.com](http://www.google.com)
- **Happy Kids books** form a range of Children's Health and Education Products specific to childhood conditions. Each book comprises 12 pages of interactive stories and puzzles for children. Central to each Happy Kids book is a character living with and learning more about their condition. There are currently 13 titles in the series, covering conditions such as epilepsy, diabetes, brain tumours and conductive deafness  
  
For more information contact Lisa Buchner:  
Mobile: 0414 253 542  
Website: [www.smartarts.net.au](http://www.smartarts.net.au) Email: [lisa@smartarts.net.au](mailto:lisa@smartarts.net.au)

*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  
2000, Harper Trophy, New York
- **Don't Call Me Special: A First Look at Disability**  
Thomas, P  
2005, Barton's Educational, London
- **Going to Hospital**  
Mitchell, M., Johnston, L and Keppell, M  
2005, The School of Nursing at The University of Melbourne
- **I Don't Want to go to Hospital**  
Ross, T  
2001, Picture Lion, 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
- **My Trip to Hospital – Brisbane's Royal Children's Hospital**  
[www.workingwonders.com.au/go/learn-more/publications/my-trip-to-hospital/my-trip-to-hospital](http://www.workingwonders.com.au/go/learn-more/publications/my-trip-to-hospital/my-trip-to-hospital)
- **The Visual Dictionary of the Skeleton**  
1995, Dorling Kindersley, London
- **My Many Coloured Days**  
Dr Seuss  
2001, Random House Children's Books, UK
- **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
- **When Molly was in Hospital:  
A Book for Brothers and Sisters of Hospitalized Children**  
Duncan, D  
1994, Rayve Publications, Windsor, CA

### For Siblings

- **Something has Happened:  
An Activity Book for Young Children**  
Irving, T  
2000, Skylight, NZ
- **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  
1998, Hodder Wayland, UK
- **When Someone has a Very Serious Illness**  
Heegaard, M  
1991, Woodland Press, USA
- **When Tough Stuff Happens:  
An Activity Book for Tough Times for 7-12 Year Olds**  
Irving, T  
2001, Skylight, NZ

## 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  
2006, (3rd ed) ABC Books, Sydney
- **Grief Counselling & Grief Therapy  
- Handbook for Mental Health Professionals**  
Worden, JW  
2004, (3rd ed) Brunner - Routledge, USA
- **Muddles, Puddles and Sunshine:  
Your Activity Book to Help When Someone has Died**  
Crossley, D  
2000, Hawthorn Press, UK
- **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 Bookshops

- **Disability Information and Resource Centre (DIRC)**  
195 Gilles Street, Adelaide SA 5000  
Telephone: (08) 8236 0555    TTY: (08) 8223 7579  
Website: [www.dircsa.org.au](http://www.dircsa.org.au)
- **Department for Families and Communities Library & Information Service**  
Strathmont Centre, 696-710 Grand Junction Road, Oakden SA 5086  
Telephone: (08) 8266 8556    Email: [disability.library@dfc.sa.gov.au](mailto:disability.library@dfc.sa.gov.au)
- **Relationships Australia Bookshop and Library**  
49a Orsmond Street, Hindmarsh SA 5007  
Bookshop Telephone: (08) 8245 8111  
Library Telephone: (08) 8245 8110  
Website: [www.rabooks.com.au](http://www.rabooks.com.au)
- **The Health Information Centre, Women's & Children's Hospital (Kermode Street Entrance)**  
Provides free information on a wide range of health topics. Staff can assist you to locate sources of information on specific health conditions. There are also resources for sale. Holders of the Butterfly Card receive 10% discount. The centre is open Monday to Friday 9.30am to 4.00pm.  
Telephone: (08) 8161 6875    Fax: (08) 8161 6885  
Email: [cywhs.healthinformation@cywhs.sa.gov.au](mailto:cywhs.healthinformation@cywhs.sa.gov.au)

You can also buy books online at the following Victorian Bookshops:

- **Open Leaves Books Melbourne**  
Telephone: (03) 9347 2355  
Website: [www.openleaves.com.au](http://www.openleaves.com.au)  
Email: [openleaves@openleaves.com.au](mailto:openleaves@openleaves.com.au)
- **Peoplemaking**  
Telephone: (03) 9813 2533  
Website: [www.peoplemaking.com.au](http://www.peoplemaking.com.au)  
Email: [books@peoplemaking.com.au](mailto:books@peoplemaking.com.au)
- **St Luke's Innovative Resources**  
Telephone: (03) 5442 0500  
Website: [www.innovativeresources.org](http://www.innovativeresources.org)  
Email: [stlukeir@stlukes.org.au](mailto:stlukeir@stlukes.org.au)

# 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 and case management services within the community to list, 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 (e.g. Diabetes South Australia, Cystic Fibrosis South Australia).

### **Big Brothers Big Sisters of Australia**

Big Brothers Big Sisters provides guidance and support to vulnerable young people, through one-to-one mentoring.

Telephone: 1300 4 MENTOR (636867), (08) 8227 0155

Address: 17 Hutt Street, Adelaide SA 5000

Website: [www.ywca.com.au/programs/bigsis.htm](http://www.ywca.com.au/programs/bigsis.htm)

Email: [bbbs@ywca.com.au](mailto:bbbs@ywca.com.au)

### **Companion Card Program**

The Companion Card Program is an initiative of the South Australian Government, jointly managed by the Department for Families and Communities and National Disability Services. This initiative promotes fairer ticketing for people with a permanent disability who have a lifelong need for a companion to attend community venues and activities.

Telephone: 1800 667 110

### **Defence Special Needs Support Group**

The Defence Special Needs Support Group is the only Australian charity dedicated to providing support, information and assistance to Australian Defence Force families who have someone with special needs. Programs include Host and Flexi Respite, Case Management, National Newsletter, local support groups and much more.

Telephone: 1800 037 674

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

**Disability Information and Resource Centre (DIRC)**

DIRC provides a free, friendly and professional information, referral and library service on all aspects of disability, to the people of South Australia.

Telephone: (08) 8236 0555 or 1300 305 558 (SA callers only)

TTY: (08) 8223 7579 (SA only) Fax: (08) 8236 0566

Address: 195 Gilles Street, Adelaide SA 5000

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

**Family Advocacy Inc**

The Family Advocate in your area can: provide information, help families gain access to services, support parent groups and networks, assist parents/carers to lobby for improved or new services, provide training programs for parents/carers and promote community involvement.

Telephone: (08) 8340 4450 or Country Callers: 1800 856 464

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

**Grandparents as Parents Project**

Grandparents as Parents Project provides a range of support services to meet the needs of grandparents who are the full time carers for their grandchildren. This includes counselling, support groups, newsletter, networking, parenting education and information and assistance to link with other support services.

Telephone: (08) 8241 9023

Website: [www.helpinghand.org.au//Service/Subprogram.aspx?p=22&id=18](http://www.helpinghand.org.au//Service/Subprogram.aspx?p=22&id=18)

**Independent Living Centre**

The Independent Living Centre is a state-wide information and advisory service on equipment and equipment related services to help individuals improve their quality of life and maintain their independence. Staffed by Occupational Therapists the service is available to all members of the public and is free of charge.

Telephone: (08) 8266 5260 or 1300 885 886 (SA & NT callers only)

Address: 11 Blacks Road, Gilles Plains SA 5086

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

Email: [ilcsa@dfc.sa.gov.au](mailto:ilcsa@dfc.sa.gov.au)

### **Make A Wish® Foundation**

Make-A-Wish® Australia brings magic and joy to children with a life-threatening illness by granting a cherished wish.

Telephone: 1800 032 260

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

### **MyTime Peer Support Groups**

MyTime is a new program providing local support for mums, dads, grandparents and anyone caring for a young child under school age with a disability or chronic medical condition. These peer support groups are an opportunity to put yourself first while your child is being looked after by a play helper. MyTime gives parents the chance to socialise and share ideas with others who understand the rewards and intensity of the caring role. Parents can meet regularly with people in similar circumstances to have fun, hear from others and find out about available community support.

Telephone: 1800 889 997

Website: [www.mytime.net.au](http://www.mytime.net.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 managers, volunteers and other families in a similar situation. Referrals can be made through the social workers at the Children, Youth and Women's Health Service.

Telephone: (08) 8267 6922

Address: 271 Melbourne Street, North Adelaide SA 5006

### **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 teachers and speech or occupational therapy if required.

Telephone: 1300 307 642

### **SANE Australia**

SANE is an independent national charity working for a better life for people affected by mental illness. SANE also has a website specifically for young people in families affected by mental illness ([www.itsallright.org](http://www.itsallright.org)).

Telephone: (03) 9682 5933 or

HELPLINE Telephone: 1800 18 SANE (7263)

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

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

### **Starlight Children's Foundation**

The Starlight Children's Foundation delivers innovative 'Distractive Therapy Programs' both within and outside hospital environments, with the endorsement and support of the healthcare profession. Programs are designed to be an integral part of the total health care of children providing positive distraction and entertainment and helping to reduce the stress and isolation of treatment and hospitalisation. Starlight grants wishes for children aged four to eighteen years, living with a serious or chronic condition who have been referred to Starlight by a qualified health professional. Starlight's other programs include: Starlight Escapes; Starlight Express Rooms; Starlight Express Vans; Starlight Fun Centres and Livewire.

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

### **The SA Continence Resource Centre**

The SA Continence Resource Centre is a state-wide continence information and advisory service, located at the Independent Living Centre. The service is staffed by Continence Nurse Advisors, providing information on continence management, continence services, continence funding schemes and continence products. This information is available to all community members and is a free service.

Telephone: (08) 8266 5260 or 1300 885 886 (SA & NT callers only)

Address: 11 Blacks Road, Gilles Plains SA 5086

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

Email: [continence@ilc.sa.gov.au](mailto:continence@ilc.sa.gov.au)

## Counselling

### **Kids Help Line**

The Kids Help Line is a free and confidential, 24 hour telephone counselling for 5 to 25 year olds in Australia. Online counselling is also available: Monday-Friday 3pm-9pm and Saturday-Sunday 10am-5pm.

Telephone: 1800 55 1800 (Counselling Line)

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

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

### **Lifeline**

Lifeline provides a 24 hour telephone counselling service.

Telephone: 131 114

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

### **Parent Helpline**

The Children, Youth and Women's Health Services Parent Helpline provides 24 hour/7 day telephone information support and referral for parenting issues.

Telephone: 1300 364 100 from anywhere in South Australia

### **Relationships Australia (SA)**

Relationships Australia (SA) supports families, individuals and communities to build skills, strengthen relationships and enhance wellbeing. Its holistic service range includes counselling, life and relationship courses, group work, a community library and specialised bookshop (also online [www.rabook.com.au](http://www.rabook.com.au)).

Telephone: (08) 8223 4566

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

## Early Intervention, Respite & Recreation

### **CanDo4Kids**

CanDo4Kids provide a range of community services to South Australian children and young people who have a sensory impairment including those who have a communication disorder. Services are provided to support the individual to become as independent as possible and to assist young people to have greater access to education and employment so that they can achieve an enhanced quality of life.

These services include: Early Intervention, Occupational Therapy, Family Support Services, Speech Pathology, Auditory Verbal Therapy, Auditory Processing Clinic, Recreation, Assistive Technology, Youth Work, Counselling, Mentor Program, Complex Case Management and Advocacy.

Telephone: (08) 8298 0900

Address: 28 King George Avenue, Hove SA 5048

Website: [www.cando4kids.com.au](http://www.cando4kids.com.au)

Email: [info@cando4kids.com.au](mailto:info@cando4kids.com.au)

### **Carers SA – Supporting Family Carers**

If you provide help or support to a family member or friend who has a disability, is frail/aged or has a chronic mental or physical illness, you are a carer, Carers SA can help. Help can come from Support Groups, Carer Counselling, Advisory and referral to appropriate Services.

Telephone: (08) 8271 6288 or 1800 242 636

Website: [www.carers-sa.asn.au](http://www.carers-sa.asn.au)

Email: [info@carers-sa.asn.au](mailto:info@carers-sa.asn.au)

### **Community Accommodation and Respite Agency (CARA)**

CARA is a not-for-profit organisation that helps South Australians with severe and multiple disabilities, and their families. They provide accommodation and respite opportunities for children and adults and are committed to helping people with disabilities and their families live full and rewarding lives.

Telephone: (08) 8347 4588

Address: 98 Woodville Road, Woodville SA 5011

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

### **Cora Barclay Centre**

The Cora Barclay Centre provides family focused Auditory-Verbal Therapy for children who are deaf or hard of hearing and wear hearing aids, cochlear implants or other listening devices. The Auditory Verbal therapists guide parents to teach their children to listen and acquire spoken language. The Centre offers early intervention services for 0-6 year olds and support services for school students up to the age of 18 years. Audiology services, professional counselling, family support and mentoring are also available. The Cora Barclay Centre also has a Parent Infant Program and a Music Group for the families of children under five years of age, both of which are open to the general public. These groups are run by registered teachers.

Telephone: (08) 8267 9200

Address: Elizabeth Forwood House,  
185 Melbourne Street, North Adelaide SA 5006

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

### **Disability SA**

Disability SA provides a range of services to children and young people with a disability aged 0-25 years. Services include:

- *Early Childhood Program* offers a range of therapy and family support services to young children from birth to school entry who have significant developmental delays or conditions associated with intellectual disability. Interdisciplinary teams based in the metropolitan area offer a range of services including developmental assessments and strategies for promoting a child's learning and development, groups and information sessions, strategies for understanding and responding to behavioural issues and links to other services and agencies. In country areas early childhood services are provided through community health

- *School Age and Youth Services* includes a range of services to children and young people (aged 5-25 years) diagnosed with an intellectual disability and/or autism spectrum disorder. Services in metropolitan areas include time limited case management, family support, information, strategies for promoting development, assistance with behavioural issues, support to access community services, sibling support and assistance at transition times (e.g. starting school, leaving school)

Referral to these services can be made by parents, health professionals or other interested parties by contacting:

Telephone: 1300 786 117

Email: [disabilitysaintake@dfc.sa.gov.au](mailto:disabilitysaintake@dfc.sa.gov.au)

### **Novita Children's Services**

Novita Children's Services is the main provider of services for children with physical and multiple disabilities and acquired brain injuries aged 0–18 years. Novita provides therapy, equipment and family support services to children and young people across South Australia in metropolitan Adelaide and in rural areas via an outreach service. Novita also provides an Inclusion Support service that assists child care services to include children requiring additional support, such as children from culturally and linguistically diverse backgrounds, children with ongoing high support needs, indigenous children and children with disabilities. The Inclusion Support Program is available in the Mid North, Far North, Far West, Eyre Peninsula and Yorke Peninsula. Other families can access this service through Inclusive Directions.

Telephone: (08) 8243 8243

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

### **Red Cross Carers Respite**

Red Cross provides a respite service for carers of frail or aged people, carers of those recovering from illness/hospitalisation or those who care for someone with a disability across the metropolitan Adelaide region. The service has a small hourly fee and is usually an in-home service providing companionship that allows carers who work countless hours and get very little 'timeout' to take a break. This break might be used for things like shopping, taking a walk, coffee with friends or even just a rest while knowing that the person they care for is being supported by a red cross volunteer.

Telephone: (08) 8100 4685 or 1800 246 800 (free call)

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

Email: [sa\\_info@redcross.org.au](mailto:sa_info@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 10 21

Disability, Sickness and Carers: 13 27 17

TTY: 1800 810 586 (toll free)

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)

There is an online message service where you can send a message to request a service or offer feedback. (Please Note: Due to the demand for services there may be a delay in calling you back or responding to your message.)

Website: <https://secure.centrelink.gov.au/sims>

### *child health and education support services (chess)*

The Department of Education and Children's Services has produced a range of resources to assist families and services with health support planning, including guidelines, planning and support guides and forms. For further information, resources or to download forms:

Website: [www.chess.sa.edu.au](http://www.chess.sa.edu.au)

Email: [info@chess.sa.edu.au](mailto:info@chess.sa.edu.au)

### **Child Care**

Child care is provided in a child care centre by licensed and trained care workers. Child care centres may be government or privately owned. Child care centres provide full-day or part-time child care for babies, toddlers, and children under the age of six years. Care for primary school age children before and after school and during school holidays may also be available in some centres. In some rural locations full-day child care is provided in the local preschool.

Website: [www.decs.sa.gov.au/families/pages/choosing/24140/](http://www.decs.sa.gov.au/families/pages/choosing/24140/)

### **Children's Centres**

Children's Centres provide a 'one-stop-shop' for young children and their families by bringing together a mix of services for children from birth to eight years and their families. At Children's Centres, qualified early childhood staff work together with families to provide quality learning and care to support children's development, health and wellbeing.

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

### **Department of Education and Children's Services (DECS)**

DECS is responsible for ensuring the provision of children's services and public education throughout South Australia. DECS' purpose is to engage every child and student so that they achieve the highest possible level of learning and wellbeing through quality care and teaching.

Telephone: (08) 8226 1000 or 1800 088 158 (free call)

Address: Education Centre (State Office), 31 Flinders Street, Adelaide SA 5000

Website: [www.decs.sa.gov.au/portal/community.asp](http://www.decs.sa.gov.au/portal/community.asp)

(information for parents and community)

Email: [decscustomers@saugov.sa.gov.au](mailto:decscustomers@saugov.sa.gov.au)

### Early Learning Program

The Early Learning Program provides support to parents of children from birth to 4 years of age who have:

- Limited access to resources and other children's services
- Recently arrived in Australia and speak a language other than English
- Cultural support needs

Early Learning Program Fieldworkers are Department of Education and Children's Services (DECS) employees.

The Early Learning Program has a focus on:

- Home-based literacy that helps parents of very young children with their children's language and literacy development. To be eligible, children need to be less than 4 years of age and experiencing some delay or difficulty in the development of language and literacy skills. Fieldworkers visit families for approximately one hour a week for two terms (negotiated with parents) and work directly with parents and children. They provide a 'hands on' program based on play, talking, stories and everyday activities around the home
- Providing materials, toys and advice to help parents assist children with special learning needs. Where possible Fieldworkers work with other early learning programs such as child care and playgroups to provide additional support for families with children who require assistance

Website: [www.decs.sa.gov.au/childrensservices](http://www.decs.sa.gov.au/childrensservices)

### Family Day Care

Family Day Care is home based child care for children from 0-16 years of age. The care is provided by approved care providers in their own homes. Care provider's homes must meet National standards and each Family Day Care scheme must be accredited under the National Child Care Quality Assurance and Accreditation system. Care hours can be negotiated to suit work, study or respite.

Website: [www.decs.sa.gov.au/familydaycare](http://www.decs.sa.gov.au/familydaycare)

## Hospital Education Services (HES)

*Women's & Children's Hospital:* HES provides a ward and classroom based service for children and students who are expected to be admitted for more than three days. The service is provided in a number of ways including:

- Specific educational packs developed by teachers for short term patients
- Programs to support children and students, within the guidelines of medical staff, to access the curriculum
- Liaison with schools to provide a continuity of curriculum

Interagency links are provided for students who:

- Have been discharged
- Have been recently referred
- Have long term health needs (dialysis, cystic fibrosis etc) requiring hospital treatment
- Spend extended time away from school usually at home

Internal hospital referrals are completed by medical staff. Sibling referrals are to be negotiated with the manager of HES. Interagency Links referrals can be made by hospital staff, schools, support services and others with written consent of the parent guardian.

*Flinders Medical Centre:* HES provides educational support and liaison for school aged inpatients at the Flinders Medical Centre.

- HES teachers facilitate a student's access to the school curriculum and can assist with the transition of students back into their own schools
- An 'outreach service' is available at the Flinders Medical Centre. Currently a visiting teacher services the Paediatric and Psychiatric ward two days a week, on Mondays and Thursdays
- HES can be accessed by all school-aged children who are likely to be in hospital for at least 5 school days or with frequent re-admissions
- Medical Professionals determine students who are appropriate to receive a teaching service

Website: [www.chess.sa.edu.au/HES/HES\\_Home.htm](http://www.chess.sa.edu.au/HES/HES_Home.htm)

### **Out of School Hours Care (OSHC) (includes Vacation Care)**

*Note: This may also be offered in Independent and Catholic Schools*

OSHC services provide quality care and recreational activities for school children in a safe environment. OSHC services offer a range of age appropriate experiences which encourage children to interact with friends, learn life skills, problem solve, develop skills and build confidence in a relaxed and supportive environment. OSHC services may provide care during some or all of the following periods: before school, after school, pupil free days and school holidays.

Most services are located in schools but some are located in community centres, recreation centres or child care centres. OSHC services located on state government school sites are required to meet the Department of Education and Children's Services South Australian Standards for OSHC. All approved OSHC services are required to register with National Childcare Accreditation Council and meet the requirements of the Quality Assurance System.

Fees for care are determined by each service and vary. The Department of Education, Employment and Workplace Relations approves OSHC services to offer Child Care Benefit (CCB) to families to assist with the cost of child care. Families should contact the Family Assistance Office on 136 150 to ascertain their entitlement to CCB and other assistance that may be available.

Once you have chosen an OSHC service, make a time to meet with the director to discuss your care requirements. The OSHC director will require information about your child's particular care needs so that appropriate support and resources can be accessed to best facilitate the successful inclusion of your child into the service. This may include applying for inclusion support funding, acquiring appropriate resources, arranging staff training as well as requesting health care and behaviour support plans.

For further information regarding OSHC in South Australia please visit the following website [www.decs.sa.gov.au/oshc](http://www.decs.sa.gov.au/oshc) or refer to your local White Page listings.

**Special Education Resource Unit (SERU)**

SERU provides a range of teaching and learning materials and specialised services which support children and students with disabilities and learning difficulties. These services are available to teachers, other professional workers and parents/carers.

The teaching and learning materials include curriculum, developmental learning resources (toy library), reference materials and journals and specialised and adapted resources.

Items can be browsed or borrowed online at <http://web.seru.sa.edu.au> (Click: Online Services/Resource Centre).

Telephone: (08) 8235 2871

Email: [admin@seru.sa.edu.au](mailto:admin@seru.sa.edu.au)

**Department for Families and Communities (DFC)**

DFC works with people who may be poor, vulnerable, at risk of harm or isolated, to connect them to choices and opportunities. The Department works with other agencies and provides direct services in housing, ageing, child protection, youth justice, disability, anti-poverty, adoptions, community services and domiciliary care.

Telephone: (08) 8226 8800

Address: Level 2, Riverside Centre, North Terrace, Adelaide SA 5000

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

### **Inclusive Directions**

Inclusive Directions is an Inclusion Support Agency that works in collaboration with childrens services in the community. The aim of Inclusion Directions is to promote inclusion and support families and children who have additional needs or come from diverse cultural backgrounds.

Inclusive Directions' role is to assist child care services to respond to the needs of all the children in their care. Available support includes: consultation and support around inclusive environments, program planning, assisting staff to identify professional development opportunities, supporting services to work in partnerships with families and community networks, access to funding through the Inclusion Support Subsidy and Flexible Support Fund, provision of Bi Cultural Support Program and access to specialised equipment.

For more information contact the nearest regional office:

North East Adelaide: (08) 8165 2900

South East Adelaide & Kangaroo Island: (08) 8358 2299

South East Regional South Australia: (08) 8725 0211

Riverland Regional South Australia: (08) 8582 3266

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

### **Health and Community Services Complaints Commissioner (HCSCC)**

The office of the South Australian Health and Community Services Complaints Commissioner.

- Helps people – service users, carers and service providers – resolve complaints about health and community services, including child protection services, when a direct approach to the service provider is either unreasonable, or has not succeeded
- Covers health and community services across the public, private and non-government sectors
- Handles complaints confidentially and impartially
- Monitors and reports complaint trends
- Makes recommendations to improve safety and quality
- Is an independent statutory officer

Hours: Monday to Thursday 10.00am to 4.00pm

Telephone: (08) 8226 8666

Toll Free: 1800 232 007

Address: PO Box 199, Rundle Mall, Adelaide SA 5000

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

## Interpreting & Relay Services

### ABC International Pty Ltd

ABC International Pty Ltd provides translating and interpreting services to both non-government and government clients including Commonwealth, Federal, State and Local Governments.

Telephone: (08) 8364 5255

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

### Deaf CanDo

Deaf CanDo the State's second oldest charity, provides services and programs which help to equip the deaf community with the tools, knowledge and confidence they need to live independently while having access to the full range of community services and facilities.

Deaf CanDo Auslan interpreters are highly qualified professionals who provide sign language interpreting services for deaf, deaf/blind and hearing impaired persons.

Telephone: (08) 8223 3335

TTY: (08) 8100 8205

Mobile: 0417 233 369 (emergency after hours)

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

Email: [interpreting@deafcando.com.au](mailto:interpreting@deafcando.com.au)

### Interpreting and Translating Centre (ITC)

ITC provides comprehensive, high quality, efficient, confidential and professional interpreting and translating services.

Telephone: (08) 8226 1990

Address: 24 Flinders Street, Adelaide SA 5000

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

Email: [itc@saugov.sa.gov.au](mailto:itc@saugov.sa.gov.au) or [saitc@bigpond.com](mailto:saitc@bigpond.com) (after hours)

### National Relay Service (NRS)

The NRS is an Australia-wide telephone access service provided 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.

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

- TTY users phone 133 677
- Speak and Listen (speech-to-speech relay) users phone 1300 555 727
- Internet relay users connect to the NRS  
(see [www.relayservice.com.au](http://www.relayservice.com.au) for details)

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

### **ONCALL Interpreters and Translators Agency**

ONCALL Interpreters and Translators Agency is the largest private interpreting and translating company nationally. Services are provided 24 hours a day seven days a week.

Telephone: (08) 8410 5111

Address: Level 1, 118 King William Street, Adelaide SA 5000

Email: [adelaide@oncallinterpreters.com](mailto:adelaide@oncallinterpreters.com)

### **Translating and Interpreting Service (TIS National)**

TIS National provides interpreting service to assist non English speakers to access government departments, community organisations and private businesses such as utility companies. The interpreting services is available 24 hours a day, seven days a week and can provide interpreting services in over 130 languages.

Telephone: 131 450

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

## Medical & Health Services

### Central Northern Adelaide Health Service (CNAHS)

This body is responsible for a large part of the health services provided by SA Health to this very large region. The region was established in 2004, bringing together the Royal Adelaide Hospital, The Queen Elizabeth Hospital, Hampstead Rehabilitation Centre, Breast screening services, Mental Health, the Lyell McEwin Hospital, Modbury Hospital, SA Dental Service and SA Pathology Services.

Telephone: (08) 8222 1400

Street Address: 207-255 Hampstead Road, Northfield SA 5085

Postal Address: GPO Box 1898, Adelaide SA 5001

Email: [cnahs@health.sa.gov.au](mailto:cnahs@health.sa.gov.au)

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

### Lyell McEwin Hospital (LMH)

LMH based in the Northern region of metropolitan Adelaide was opened in April 1959 and provides a wide range of health services which include obstetrics, gynaecology, adult medicine, surgical, paediatrics and intensive care.

The Paediatric Unit has 17 beds, for babies, children and adolescents from several weeks of age up to 16-17 years. Children who need to be admitted overnight are able to have a parent stay with them. The Children's ward also has a play coordinator who develops and organises a wide variety of age appropriate activities for children to keep them happy and busy while in hospital. The nursing staff have many years of paediatric experience and work very closely with the team of specialist paediatricians and allied health professionals.

Telephone: (08) 8182 9000

Address: Haydown Road, Elizabeth Vale SA 5112

Email: [info@lmh.sa.gov.au](mailto:info@lmh.sa.gov.au)

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

### **Child and Adolescent Mental Health Services (CAMHS)**

CAMHS in South Australia (CYWHS - CAMHS and SAHS-CAMHS) offer children, young people and their families confidential individual or family counselling and therapy, group sessions and information about mental health issues. All CAMHS staff are experienced in helping children and young people up to 18 years of age with emotional, behavioural or social difficulties. CAMHS services are provided by leading child and family specialists in multi-disciplinary teams that may include clinical psychologists, psychiatrists, social workers, mental health nurses, occupational therapists and speech pathologists.

#### *CYWHS-CAMHS (North):*

##### **Metropolitan Teams**

CAMHS Executive Unit: (08) 8161 7389

Adolescent Services Enfield Campus (ASEC): (08) 8269 3844

Behavioural Intervention Services (BIS): (08) 8365 0026

Eastern Region: (08) 8207 8999

Northern Region: (08) 8252 0133

Western Region: (08) 8341 1222

Northern Country Services: 1800 819 089

#### *SAHS-CAMHS (South):*

##### **Metropolitan Teams**

Flinders Medical Centre: (08) 8204 5412

Marion: (08) 8298 7744

Onkaparinga: (08) 8326 1234

##### **Inner Country Teams**

Mount Barker: (08) 8391 3922

Murray Bridge: (08) 8531 3901

Victor Harbor: (08) 8552 0600

##### **Outer Country Teams**

Riverland (Berri): 8582 4290

Mount Gambier: (08) 8724 7055

### **Children, Youth and Women's Health Service (CYWHS)**

CYWHS brings together acute and primary health care services for children, young people and women across the state. The Women's & Children's Hospital (WCH) is South Australia's main provider of specialist care for children with acute and chronic conditions and has the largest maternity and obstetric service.

The CYWHS is a state-wide Health Service, funded by the South Australian Department of Health, which includes the WCH and former Child Youth Health (CYH). The CYWHS South Australia's leading provider of health services for children, young people and women.

Telephone: (08) 8161 7000

Address: 77 King William Road, North Adelaide SA 5006

Email: [cywhs.webadmin@cywhs.sa.gov.au](mailto:cywhs.webadmin@cywhs.sa.gov.au)

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

### **Child and Family Health (CFH)**

CFH, a division of the Children, Youth and Women's Health Service, provides a range of services to families following the birth of a baby to support parenting and child development. A Universal Contact Visit is offered when a baby is a few weeks old, and can be provided in the clinic or at home. The community child and family health nurse will respond to issues (often related to feeding and settling) that arise when a baby is introduced into a family, undertake a 1-4 week health assessment, and provide advice or link you to appropriate services and supports in your community.

If parents/carers have concerns and require further information or support, they can call the 24 hour seven days a week Parent Helpline on 1300 364 100.

Telephone: 1300 733 606 for an appointment

Website: [www.cyh.com](http://www.cyh.com)

### **Women's and Children's Hospital (WCH)**

The WCH offers state-of-the-art services for women, children, young people and their families, the WCH is the specialist paediatric hospital in South Australia.

The WCH is publicly funded by the South Australian Department of Health, through the Children, Youth and Women's Health Service.

Address: 72 King William Road, North Adelaide SA 5006

Telephone: (08) 8161 7000

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

### **Country Health SA (CHSA)**

CHSA promotes health and well-being and provides hospital, residential aged care, community health, mental health and domiciliary care services from more than sixty locations throughout country South Australia. CHSA also manages the Patient Assistance Transport Scheme (PATS) which provides financial support to country residents for travel and accommodation.

Telephone: (08) 8226 6120

Fax: (08) 8226 7170

Street Address: Level 12, 100 Waymouth Street, Adelaide SA 5000

Postal Address: PO Box 287, Rundle Mall, Adelaide SA 5000

Email: [CHSA@health.sa.gov.au](mailto:CHSA@health.sa.gov.au)

### **SA Ambulance Service (SAAS)**

SAAS is the provider of emergency ambulance services in South Australia and is dedicated to providing the people of South Australia with the highest level of emergency medical patient care, treatment and transport.

Emergency call Telephone: 000

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

## SA Health

SA Health is the South Australian Department of Health and is committed to protecting and improving the health of all South Australians by providing leadership in health reform, policy development and planning. SA Health believe in health for all, with a focus on well being, illness prevention, early intervention and quality care.

SA Health leads and delivers a comprehensive and sustainable health system that aims to ensure healthier, longer and better lives for all South Australians. Included within SA Health are:

- Public hospital services
- Metropolitan and country health service delivery
- Responsibility for environmental health, communicable diseases epidemiology, health promotion and education
- The IMVS (Institute of Medical and Veterinary Science)
- Breast Screen SA
- Organ donation
- The Cancer Registry
- And many other services to the South Australian community

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

## Southern Adelaide Health Service (SAHS)

SAHS (Southern Health) was established in 2004 to bring together Flinders Medical Centre, Noarlunga Health Services and Drug & Alcohol Services South Australia. Repatriation General Hospital joined the region in July 2008. Southern Health serves a population of 330,000 people with an annual operating budget in excess of \$500M. More than 5,000 skilled staff provide high quality patient care, education, research and health promoting services.

Telephone: (08) 8201 7801

Fax: (08) 8201 7820

Address: Level 3A, Box 4, Sir Mark Oliphant Building,  
Laffer Drive, Science Park, Bedford Park SA 5042

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

### **Flinders Medical Centre (FMC)**

FMC is a 566-bed specialist referral public teaching hospital collocated with the Flinders University School of Medicine and the privately owned Flinders Private Hospital. The hospital is the major referral centre for acute care and emergency services in the southern region of Adelaide. It is one of two major trauma centres in South Australia, providing an around the clock emergency retrieval service to bring people to hospital by road or helicopter. The Variety Children's Centre at FMC provides a full range of services for children and young people from 0-18 years of age within a high caring environment.

Telephone: (08) 8204 5511

Fax: (08) 8204 5450

Address: Flinders Drive, Bedford Park, South Australia 5042

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

## Transport

### 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.

Address: PO Box 1201, Fortitude Valley, QLD 4006

Telephone: (07) 3852 3300 or 1300 726 567 (toll free)

Fax: (07) 3852 6646

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

Email: [mail@angelflight.org.au](mailto:mail@angelflight.org.au)

### Patient Assistance Transport Scheme (PATS)

PATS provides part reimbursement to assist with travel and accommodation costs for clients who travel more than 100 kms (one way) from their permanent residence to the nearest medical specialist for treatment. An escort may be eligible for travel and relevant accommodation allowances if the need for an escort is medically endorsed.

PATS application forms are available from doctors' surgeries, hospital social workers and the regional PATS offices. A separate application form is required for each authorised return journey and original receipts and tickets must be supplied with the claim.

The scheme is not generally means tested although some exclusions and conditions apply. Please contact the nearest PATS office or FREECALL 1800 188 115 to clarify any entitlement or for further information.

Each state and territory has a similar system. If you live interstate please ask your health care professional to guide you to the local scheme.

### **Plus One Free Companion Card**

The Plus One Free Companion card is designed to assist a wide range of people with physical mobility, cognitive, sensory or communication impairment(s), who cannot safely use public transport on their own, but could use public transport with the assistance of a carer.

Holders of a Plus One Free Companion card are able to travel on all Adelaide Metro bus, train and tram services throughout metropolitan Adelaide accompanied by a companion/carer. Whilst the Plus One Free Companion cardholder must be in possession of a valid Metroticket and concession card (if applicable), the companion/carer travels free of charge.

Telephone: 1300 360 840

Website: [www.ptd.dte.sa.gov.au](http://www.ptd.dte.sa.gov.au)

(click on 'Accessible Transport' and then 'Transport Assistance')

### **Red Cross Medical Transport**

Red Cross provides a transport service for those experiencing difficulty accessing public transport, taxis or family support. This transport can support people in getting to and from hospital or medical appointments and some social support e.g. shopping. The service operates across the Adelaide metropolitan area, as well as in the South East Country and Eyre Peninsula regions. The service has a registration fee and a small trip fee. Transport is provided by volunteers, usually in Red Cross vehicles.

Telephone: (08) 8100 4500 or 1800 246 850 (free call)

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

Email [sa\\_info@redcross.org.au](mailto:sa_info@redcross.org.au)

### **Royal Flying Doctors Service (RFDS)**

The RFDS of Australia is a not-for-profit charitable service providing aeromedical emergency and primary health care services together with communication and health education assistance to people who live, work and travel in regional and remote Australia.

Website: [www.flyingdoctor.net](http://www.flyingdoctor.net)

## South Australian Disabled Persons' Parking Permits

Your child may be eligible for a Disabled Persons' Parking Permit if they have a temporary or permanent physical impairment and –

- (a) Whose speed of movement is severely restricted by the impairment, and
- (b) Whose ability to use public transport is significantly impeded by the impairment

A permanent Disabled Persons' Parking Permit can be issued for up to five years. A fee applies.

A Temporary Disabled Persons' Parking Permit may be issued to a person whose physical impairment is likely to endure for more than 6 months but is not likely to be permanent. A fee applies. A temporary Disabled Persons' Parking Permit cannot be issued for more than 1 year without a subsequent application.

*What do you need to do?*

1. Obtain an application form for a Disabled Persons' Parking Permit available from –
  - Any Service SA Customer Service Centre, or
  - By telephoning the Service SA Call Centre on 13 10 84, or
  - Download a printable version of the Disabled Persons' Parking Permit form at [http://www.transport.sa.gov.au/pdfs/permits/application\\_disabled\\_parking\\_permit.pdf](http://www.transport.sa.gov.au/pdfs/permits/application_disabled_parking_permit.pdf)
2. Your doctor must complete the application form
3. Post or take the completed application form to any Service SA Customer Service Centre along with the required fee

### *Conditions and Benefits*

A Disabled Persons' Parking Permit -

- Is valid if the vehicle is being used for the transportation of the person, who is the holder of a permit
- Enables the vehicle to be parked for twice the period indicated on the sign, or for the period indicated on the sign and a further 90 minutes, whichever is the greater
- Allows the vehicle to be parked in parking spaces which are sign posted and have the people with disabilities symbol painted on the road surface (if a sign indicates that a time limit applies to disabled parking space there is no additional time allowed)

- Must be displayed on the inside of the windscreen of the vehicle on the side opposite to the driver's position so that it is easily legible to a person standing beside the vehicle

The holder of a Disabled Persons' Parking Permit is entitled to the same benefits when visiting another State or Territory as are available to permit holders in that place.

### **South Australian Transport Subsidy Scheme (SATSS)**

SATSS is a State Government subsidised taxi travel program for permanent residents of South Australia with permanent and severe disabilities who, because of their disabilities, cannot safely use public transport either independently or accompanied by a companion/carer.

Further information including eligibility criteria, entitlements and/or application forms are available from:

Telephone: 1300 360 840

Website: [www.ptd.dte.sa.gov.au](http://www.ptd.dte.sa.gov.au)

(click on 'Accessible Transport' and then 'Transport Assistance')

# Special Acknowledgements

This publication has been made possible through the generous contributions of ...



Women & Children's Hospital Foundation

---



interACT

Interact

---



