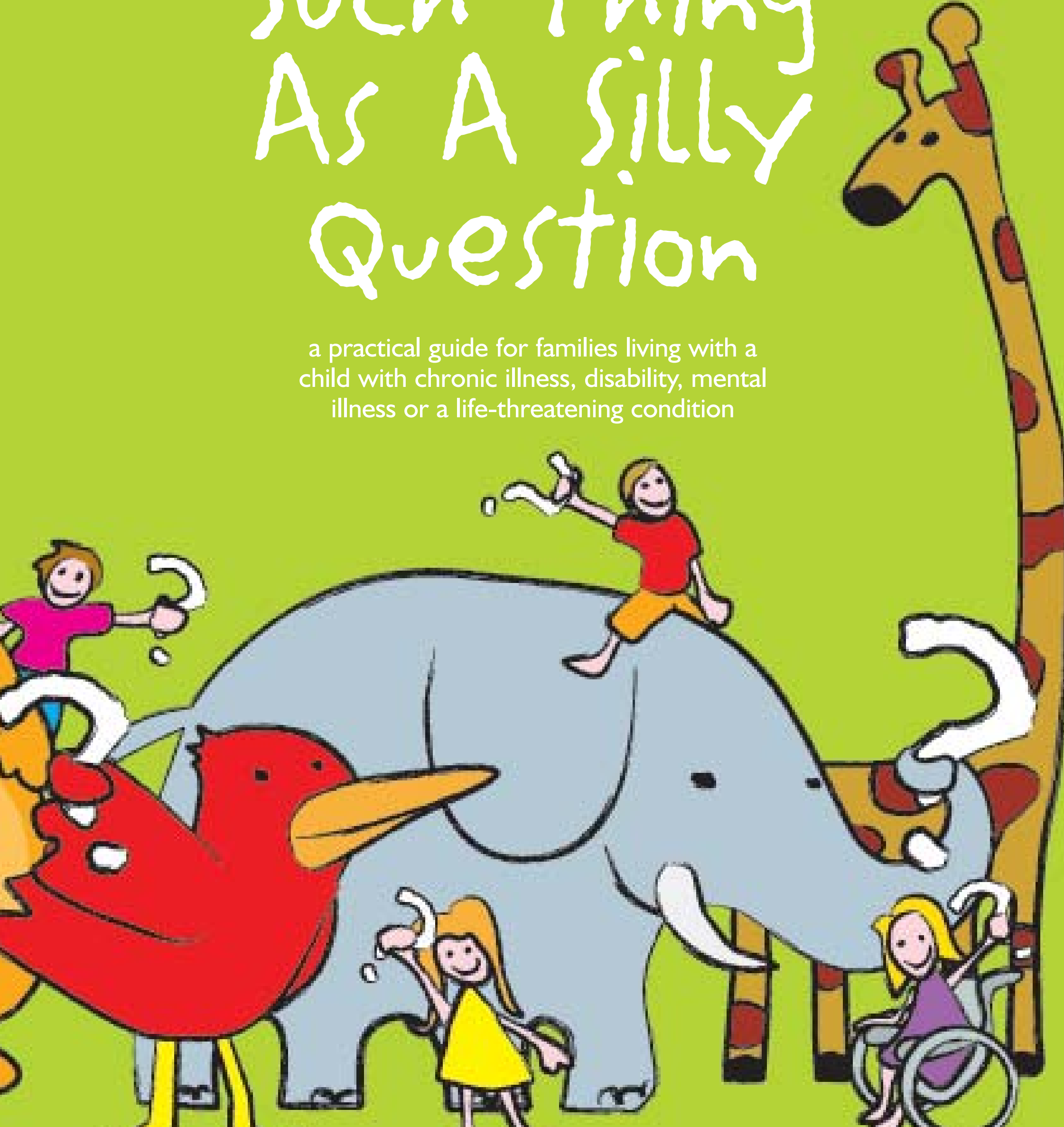
There's No Such Thing As A Silly Question

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



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Produced by interACT

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very special kids.

THE GANDEL CHARITABLE TRUST

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

The interACT committee would like to dedicate this book to Camille Heagney without whom the project would not have come to fruition.

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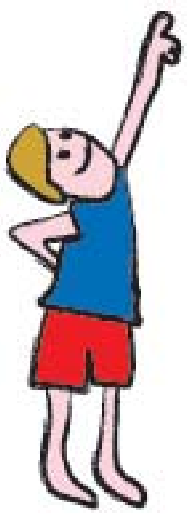
Contents

Introduction

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

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

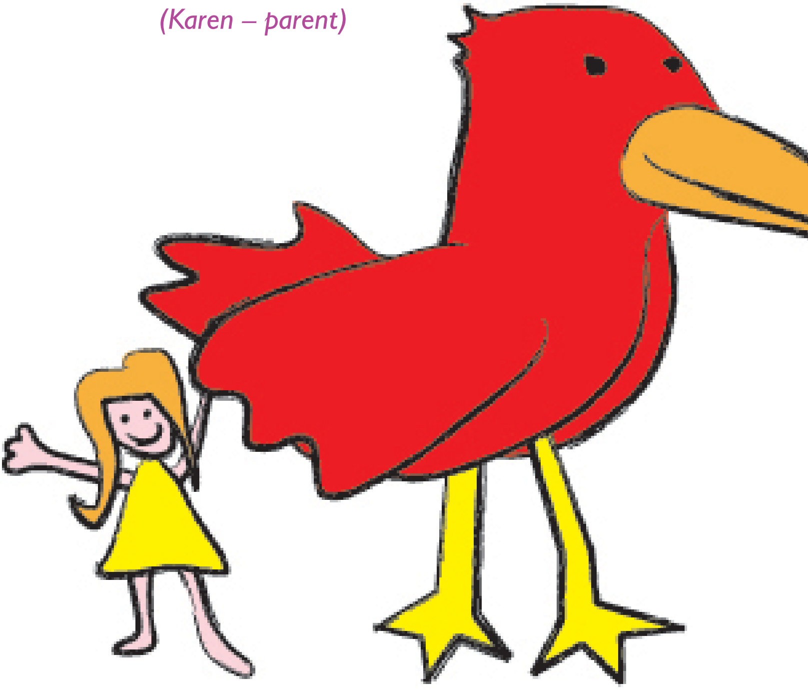
It is not intended that this book be read from cover to cover, rather it is meant to be a resource book to be kept and referred to when needed.



Note:
The terminology used in this book may differ from that used in other resource publications. Information regarding services and resources is applicable for the state of Victoria only, but may have a generic application in other states.

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

(Karen – parent)



Where do we begin?

Pre - Diagnosis

"I wished someone would have told me that I would be happy again, that I would sleep again and that this raw pain would ease and that I would dream new dreams"

(Lisa E - 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 wrong with your child.

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

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

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

Immediately After Diagnosis

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

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

"At first, our daughter's diagnosis consumed my thoughts during all my waking hours. All I could think of was that she was going to be 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

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

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

- **Visit the Health for Kids Network website:** You will find an online database of child/adolescent-friendly GPs registered with the 'Health for Kids Network' at www.healthforkids.net.au. HFK has developed this database, in conjunction with Southern Health, with the aim of linking families without a GP to a child/ adolescent-friendly GP in their area. Remember too, you may visit several GPs before you find one with whom you feel comfortable.

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

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

> "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)*

- **Consider using the answering machine to screen calls:** you can easily spend all day and night returning calls. It is okay to only answer the phone when you feel like it. Alternatively, at times you may choose to switch it off altogether and answer the phone when you feel like it.
- **Choose whom to tell about upcoming appointments**, as you may be overwhelmed with phone calls afterwards, requiring you to retell the same story.
- **Focus on looking after yourself and your immediate family:** let other people support extended family and friends.
  [Refer to How To Give Life Balance p55]
- **Consider providing your written or verbal consent to service providers.** This will enable them to obtain information from doctors, hospitals and community providers you use, cutting down the number of times you have to repeat your child's history.
- **Consider setting up a website** about your child where you can add new information as it comes to hand. Give the address to friends and family so they can get updates in a non-obtrusive way.
- **Identify helpful supports,** such as a few key friends and family members who will be there for you unconditionally.
  [Refer to our Resources/Services section p77]
- **Take each day as it comes** and, although it may be difficult, try not to think too far ahead in the beginning. Don't try to take in too much information, only what is necessary and helpful at the time. Keep notes or a diary if it helps.

> **"At first, I spent a lot of time worrying about the years ahead, but I realised that such thinking was unproductive. I learned to take a day, or even an hour, at a time."**
>
> *(Karen - parent)*

Empowerment

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

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

> "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)*

Grievance Policies

If you feel concerned, disappointed, angry or upset with any aspect of treatment or care within a specific hospital, or by a specific health professional, you are able to voice those concerns, internally within the hospitals and externally through the Health Services Commission.

Internally

- At the Royal Children's Hospital [RCH], address your concerns to the Consumer Liaison Officer: Telephone (03) 9345 5676
- At Monash Medical Centre [MMC], speak with the Complaints Liaison Officer: Telephone (03) 9550 2745
- At other hospitals, enquire (through the Social Work Department) as to who is the appropriate person for you to speak with about your concerns

Externally

- Write to the Health Services Commissioner
  Level 30, 570 Bourke Street Melbourne Victoria, 3000
  Telephone: (03) 8601 5200
  Toll Free: 1800 136 066
  Fax: (03) 8601 5219
  Email: hsc@dhs.vic.gov.au

Support organisations within the community will also have avenues through which to address any complaints or grievances you may have.

Always feel free to ring and speak with someone if you have concerns or a grievance. Alternatively you can address your concerns to the appropriate person in writing.

Your Child's Voice

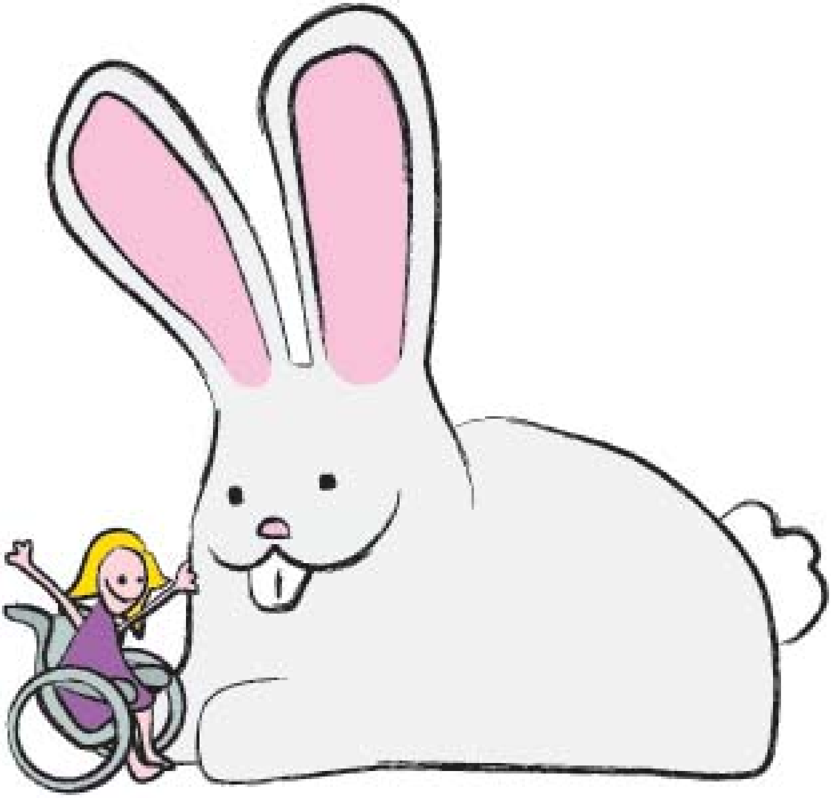
"My son made it quite clear that he didn't understand the doctor. So he asked him – 'Can you please talk in my language?'"

(Lisa B – parent)

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

If your child has no formal communication skills, you will need to be his/her 'voice' when dealing with others. For younger children, you will be their 'voice' regardless.

If your child can communicate in some way, allow him/her to play a part in care and treatment choices.



Hospital Admissions - Public vs. Private

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

The Public System is basically a free system (funded by the government), where your child will be treated according to how sick they are assessed to be. In the public system, doctors of various levels will treat your child and you are not able to choose which doctor will provide your child's care. The public hospital system is also a teaching system where students and junior doctors are taught medicine. When your child is admitted to the public system they will be admitted under the care of a unit e.g. Neurology, Respiratory Medicine. A Consultant is always the head of a unit and oversees the care that Residents, Registrars and Interns carry out on his/her behalf. [see p38 for Hospital Personnel Terminology]

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

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

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.

As an Inpatient

Being a private patient doesn't necessarily mean your child will have a single room. It only means that you can choose your hospital and treating Consultant. Single rooms are allocated based on the clinical needs of a patient. They may also be used to isolate patients with serious infections.

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

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

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

As an Outpatient

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

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

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

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

> "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)*

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

Specialists

Referrals

- If your child needs to see a specialist doctor, either a GP or another specialist will need to refer him/her. Referrals from GPs are valid for 12 months. 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 from the original doctor.
- It is your responsibility to ensure that your child's referral is current at the time of the consultation, although staff may remind you when you contact the specialist's office for an appointment.
- If the specialist is likely to have a long-term involvement with your child, you may ask if he/she would accept an 'indefinite referral' from your referring doctor, as this will save you having to remember to update that referral on a regular basis.

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

Consultations: Public vs Private

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

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

Changing Specialist or Getting a Second Opinion

After an initial consultation, it is important to ask yourself, "Do I feel comfortable with this specialist?" and "Can I see us developing a good working relationship with him/her?" If for any reason you are not satisfied with the specialist your child is seeing, you are entitled to request a referral to a different specialist. This can be difficult for parents, who may feel embarrassed or concerned that such a request will impact on the potential treatment of their child. It is crucial that you have trust and confidence in your child's doctor as well as good communication. Remember that you are your child's advocate. It is vital that you are able to work in partnership with your child's specialist to achieve the best health outcome for your child.

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

Specialised Paediatricians

Your child may be referred to a paediatrician for an opinion on a particular problem and may only need a few consultations with a general paediatrician. Children with complex or chronic medical issues may need long term attention from a paediatrician. In this case it may be worth requesting a referral to a paediatrician specialising in child development and/or disability, who can co-ordinate treatment for all your child's ongoing medical needs. Children with developmental delays/disabilities may be referred to the Developmental Medicine Department at the Royal Children's Hospital, where paediatricians and other specialists will monitor all aspects of their care.

Monash Medical Centre has a Developmental Disabilities Clinic, where medical and allied health staff provide an assessment service only. On completion of assessment, the patient is referred to other relevant health care professionals or to services within the community for ongoing treatment and management. There is a spina bifida clinic that does, however, provide assessment and ongoing management for its patients.

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

Pharmacies

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

Safety Net Card

- This is an official record of all the national health prescriptions you have had filled and the associated costs incurred. When your medical out-of-pocket expenses exceed a designated amount, the medicare rebate increases to reduce your payments.
- Have your pharmacist maintain a record, if you only go to one pharmacy. If you use another pharmacy (even occasionally) keep the card yourself and ask for the sticker from each script to attach to your card.
- All family members can be on the one Safety Net Card or, if you wish, the child/children with Health Care Cards can have a separate Safety Net Card.
- The benefit of having separate Safety Net Cards for children needing regular medication is that the threshold is reached sooner, as it is lower for those with Health Care Cards.
- When you have the whole family on one Safety Net Card you have a much higher threshold to reach before you go onto cheaper scripts.
- If you actually go over your threshold without realising you can be refunded the extra amount you paid for scripts through Medicare. You can pick up a brochure from Medicare outlining what the threshold is for those with and without a Health Care Card.
- Private prescriptions may be claimed through Private Health Insurance.

Make your decision as to which way you want to go based on these facts and your personal circumstances, not on what the pharmacist may say is easier.

Medication

- If your child is on regular medication make sure you find out if it will be readily available via your chosen pharmacy. If not, ask to have it kept in stock so that it is available for you when you need it.
- Make sure *you* understand everything you need to about new medication and *do not* be afraid to ask questions.
- Find out if your pharmacy offers a delivery service, and use it to save yourself time.
- Some over the counter medication can be prescribed by your doctor so that you can obtain it at the reduced rate with a Health Care Card e.g. some laxatives, paracetamol, creams etc.
- If your child needs medication urgently, it may be possible to have your child's script faxed to your chosen pharmacy, and the original posted to them.

Developing a Care Plan for Your Child

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

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

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

Emergency Medical Plan (EMP)

(also referred to as Action Plan)

An Emergency Medical Plan [EMP] is a readily accessible document or process which is activated when/if your child has a medical emergency. It is specific to your child's existing medical condition. The information is 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 with a written instruction of what to do in the case of a medical emergency, specific to your child's general presentation. In order for these instructions to be followed, it is essential that the document be

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

For some families, this measure can reduce unnecessary hospitalisations. Without these authorised instructions, ambulance paramedics will have no choice but to treat and/or transfer your child to hospital as per their protocol.

Your child's EMP can take any number of formats. It is not intended to be a comprehensive Care Plan, but a document and/or process which gives essential information in a concise format, to any person assisting your child in the event of an emergency, **specific to their existing medical condition.**

Things to include in your child's EMP

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

Calling An Ambulance

General questions callers will be asked after dialling 000

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

The answer "No" to the last 2 questions results in the immediate dispatch of the maximum ambulance response. Further questions may be necessary, which will enable ambulance staff to prioritise your request promptly and determine whether the patient requires Intensive Care (MICA) Paramedic skills. **It may be helpful to have a copy of the above questions, along with answers, close to your telephone.**

Calls to 000

Dialling 000 will connect you to emergency services from any fixed, mobile or pay phone and is free of charge.

Calls to 000 can be dialled from a locked keypad of a mobile phone. Many newer digital phones require the user to dial 112, the international standard emergency number (see below). Consult your telephone company if you are uncertain how to access the 000 emergency network.

The 112 Emergency Access Number

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

Advantages of this number are:

- It can be dialled from anywhere in the world where there is GSM (Global System for Mobile Communications) coverage. This means that if you are out of your mobile phone company's coverage area, but in an area that is covered by another mobile phone service provider, that network will carry your call.
- It will connect you to the local emergency number in whatever country you are in, to contact ambulance, police or fire services.

- 112 or 000 can be dialled while the keypad is locked
- You do *not* need to have a SIM card in the mobile phone to access this service

Text-based emergency call service: calls to 106

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

The Ambulance Membership Scheme

This scheme protects patients from the costs of ambulance attendance and transport with one annual payment of $60* per year for single membership and $110* per year for family membership (* at time of publication).

These fees cover 100% of the following services within Victoria:

- Emergency ambulance services
- Non-emergency ambulance services
- MICA (Mobile Intensive Care Ambulance)
- Air ambulance services

For members who require services while interstate, it is important to note that you are only covered for transportation to the nearest hospital.

There is a sixty-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.

Patients with a health care card (whose parents are in receipt of Carers' Allowance) automatically have ambulance cover within Victoria.

Private Health Insurance may also cover the use of ambulance services, so be sure to check with your provider.

Coping Strategies for Day to Day and Beyond

"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)

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

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

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

It may include:

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

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

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

- **Be realistic:** plan what you can, but try not to take on too much. Have reasonable expectations for yourself and what you can achieve.
- **Utilise respite options** as early as possible.
- **Involve yourself in recreational activities** away from your child, and make them a regular occurrence.
- **Continue to talk about how you feel** and use all available supports.
- **If you are working, keep working.** This may be a great outlet for you and be a place where you can be yourself! It will help financially as well.
- **Use the system:** ask your specialist if there is anyone he/she would suggest you could contact for peer support.
- **Investigate if a "condition specific organisation" exists for your child's condition** and what support services they may offer e.g. Asthma Victoria, Cystic Fibrosis Victoria.
- **Make sure to plan regular time out** to do something by yourself (e.g. pampering, a hobby), with your partner (e.g. dinner, a movie), with your family (e.g. picnic in the garden, a walk, a drive to somewhere peaceful).
- **Talk to your partner** but be aware that they may deal with the same situation in different ways and that's okay.
- **Keep a night** at least once a month with your partner (or friend) where you may choose to not talk about disability/illness. It's important to still have fun.

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

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

"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)

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

(Lisa E - parent)

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

Logistics

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

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

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

- Find people who are prepared to care for your other children should you have to go to the hospital, day or night
- Ask other parents to help transport siblings to and from school
- Accept genuine offers of help
- Have some spare frozen meals on standby at home : there are some great nutritious meals 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.

Financial Considerations

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

Centrelink: You may qualify for extra Centrelink entitlements due to your child's disability or illness, namely the Carer Allowance, which provides your child with a Healthcare Card.

Contact Centrelink – Disability, Sickness and Carers on 13 2717 or check www.centrelink.gov.au for more detailed information.

Register your child for the Medicare Safety Net, which you can do when visiting any Medicare Office. For a Guide To Understanding the Medicare Safety Net visit www.ama.com.au/web.nsf/doc/WEEN-6494TL. You can also register for the Pharmaceutical Safety Net [See p19].

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

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

Parking Concessions: You may be eligible for car parking concessions at some hospitals. For example, when your child is an inpatient at the Royal Children's Hospital for three or more days, you may obtain a Parent Discount Parking Card which gives a discount rate from the third day. If your child receives a disability allowance you can receive a car park discount card valid for 1 year. Cards are available from the Information Desk in the front entry building. At Monash Medical Centre, use your blue outpatient booklet for a reduced parking fee when attending outpatient appointments, as a public patient. If your child is an inpatient, your admitting nurse can give you a form that entitles you to park for a week for the cost of a day ticket. If your child is receiving treatment from another hospital, be sure to enquire about parking concession arrangements and eligibility.

Special Equipment: In Victoria, a 'life support concession' is available to users of eligible life support machines and members of their households, provided they hold Commonwealth Concession Cards. Electricity and/or water concessions may be available depending on the equipment used. Please note that a concession can only be claimed if the energy account is in the name of the concession cardholder.

Both electricity and water concessions are available to users of:
- Haemodialysis machines.

Electricity concessions are available to users of the following machines:
- Ventilator for life support – polio only
- Oxygen concentrator
- Intermittent peritoneal dialysis machine

Machines *not* eligible for concession include:
- Continuous positive airways pressure (CPAP) machine
- Ventilator (not for life support)
- Ventolin nebuliser

For further information, contact the Life Support Administrator at your electricity retailer, or the account enquiries telephone number on your water agency bill.

Priority Listings for people with medical conditions

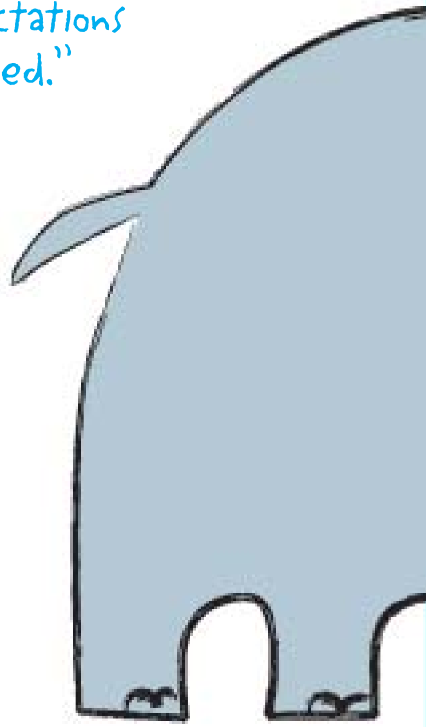
Just as it is important to inform those coming in direct contact with your child of his/her support needs, it can also be helpful to inform those who provide direct support to your child in other ways. For example, a child may be reliant on medical apparatus that requires electricity.

Some companies have priority listings, which are designed to help customers, or members of their household, who have a diagnosed life-threatening medical condition and whose life may be at risk without access to a fully operational utility service (e.g. gas, electricity, water or telephone). Essentially, you will be able to access priority assistance to ensure your utilities are fully functional or repaired in the event of emergency, with the least amount of disruption and risk to your child's wellbeing.

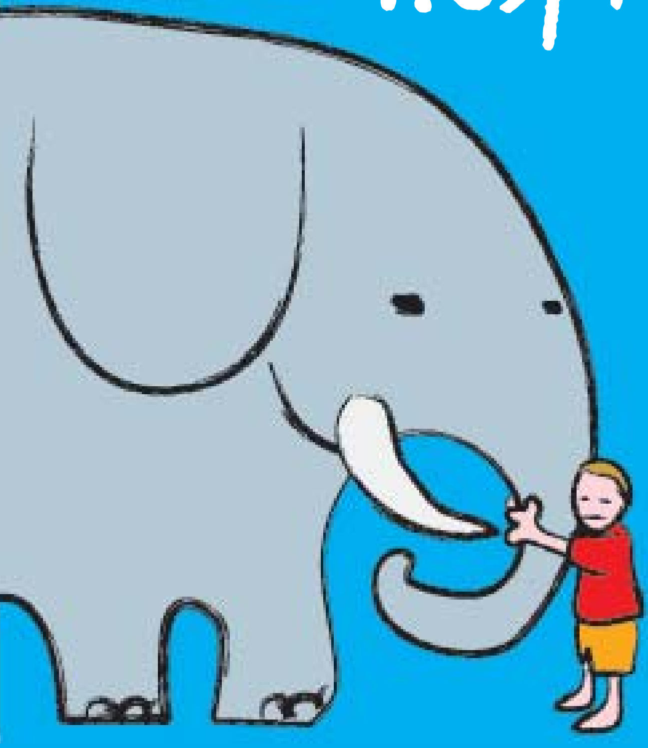
Not all companies will use the same terminology, nor will every service have this provision. Check with your individual utility providers to ensure their maximum assistance to you.

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

(Karen – parent)



Going Into Hospital



Hospital Admissions - Hints & Tips

Day Surgery

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

What to take with you (for overnight or longer stays)

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

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

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

What to take for your child

- Current medications: *Do not* assume that all your child's medication will be available at the hospital.
- List all medications and dosages/strengths.
- Lists of child's symptoms / doctors / appointments etc.
- Nappies and clothes for discharge (nappies and hospital gowns may be available on the ward during your child's admission).
- Equipment such as orthotics, hearing aids, splints, tube feeding equipment, etc.
- Your child's special toy(s) and books for comfort and any other activities they might enjoy e.g. pencils and colouring book, puzzles, plain paper, sensory and communication toys/devices.
- Your child's pillow, quilt, blanket, night-light etc.

What to take for yourself

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

Reducing your responsibilities

Try to arrange things at home so you can be totally devoted to your child when in hospital. For example:

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

Staying on the hospital ward

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

- Is there a parent information booklet that I should have? How do I go about getting a copy? Is there information specific to this ward that I should know?
- Is there are map of the hospital for me to use?
- Where can I find showers and toilets for parent use?
- Where can I get a meal/ snack?
- Where can I keep food brought from home?
- Where can I use my mobile phone?
- Where are public phones? Is there a change machine to get coins for the public phone?
- Where is the nearest Automatic Teller Machine [ATM]?
- Is there parent accommodation I can access?

- Are meal vouchers available?
- Are car parking concessions available for inpatient families and whom do I see about that?
- Is there a play therapist or a music therapist my child can access?
- Is there a playroom? Can I bring games to the bed?
- Is there a teacher/educational advisor I can access for my child?
- Are there volunteer visiting schemes?

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

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

Staying in the intensive care unit [ICU]

Staying on the Intensive Care Ward with your child is a little different to staying on other wards. For example;

- Security is greater, and you may need to identify yourself each time you enter the ward to be with your child.
- ICU is often a shared, open space with little privacy.
- Each child has a nurse to care for them on a one to one basis. Try to take advantage of this arrangement to have breaks and care for yourself, in the knowledge that your child is in very good hands and closely monitored.
- Take regular breaks for food and rest when your child is stable. Ask if there is a pager to use when you leave the ICU area so that you can be contacted at any time.
- Try to get a good night's sleep, at home if it is close enough, or in the hospital parent accommodation.
- Do something relaxing at your child's bedside, such as reading or craft.
- Arrange for family and friends to come and do a few bedside shifts for you, to relieve the physical and emotional burden of doing it all yourself.

Caring for yourself during your child's stay

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

Other Sources Of Information

Apart from the ward staff, there are other sources of support and information to help you during your stay in hospital with your child.

- The hospital chaplain
- Social worker, counsellor, psychotherapist etc
- Patient advocate
- Other parents on the ward will have hints and tips on how they cope
- A play / music therapist or teacher / educational advisor might be available to assist your child with activities
- Hospital volunteers are sometimes available to help you by sitting with your child while you have a break

Interpreters

Interpreters are available 24 hours a day at the Royal Children's Hospital to assist where communication or understanding may be compromised due to cultural or language difficulties. Currently RCH has interpreters for the following languages;

Arabic, Assyrian, Auslan, Cambodian, Cantonese, Chaldean, Croatian, Greek, Italian, Korean, Lebanese, Macedonian, Malay, Mandarin, Persian/Farsi, Polish, Serbian, Signed English, Somali, Spanish, Teo-Chew, Tigrinya, and Vietnamese. Interpreters for minority languages spoken in Sudan, Burma and East Timor are also available. The Interpreter Service can be contacted on (03) 9345 5026 or (03) 9345 5998. Services are free of charge.

Monash Medical Centre [Southern Health] can provide interpreters for the following languages: Bosnian, Cambodian, Chinese, Croatian, Greek, Italian, Spanish, Turkish and Vietnamese. If you require an interpreter for another language, the Interpreter's Service will contact an external agency for support. For more information contact (03) 9594 6666

Transition

Throughout your child's medical management, it is important to keep in mind that you are (in most cases) dealing with paediatric services and specialists. When your child reaches 18 years of age, doctors and other health professionals will need to "transition" (i.e. transfer) your child to adult services and specialists.

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 all plan this process together to ensure it is as smooth and stress free as possible. Your child will probably be comfortable and familiar with the paediatric staff and reluctant to change, so working towards an understanding that this is to happen when they become an adult is a positive first step. If the issue of transition has not been broached with you, feel free to initiate the discussion with medical and health professionals currently supporting you in your child's medical management.

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

Hospital Personnel Terminology

Medical

Medical Students
4th, 5th and 6th year students

Intern
1st year graduate

Resident
2nd or 3rd year doctor

Medical Registrar
Hospital based doctor working in any medical specialty area

Specialist Registrar
Hospital based doctor training in specific specialty

Fellow
Qualified specialist doing further training prior to commencing own practice

Consultant
Specialist Doctor

Mr/Miss (rather than Dr. title)
Surgeon with patients admitted under their 'bed card'

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

Nursing

PCA
Personal Care Assistant

Graduate Nurse
Nurse in their 1st year

Clinical Supervisor
Level 2-3 nurse

ANUM
Associate Nurse Unit Manager

NUM
Nurse Unit Manager

DDON
Deputy Director of Nursing

DON
Director of Nursing

Allied Health

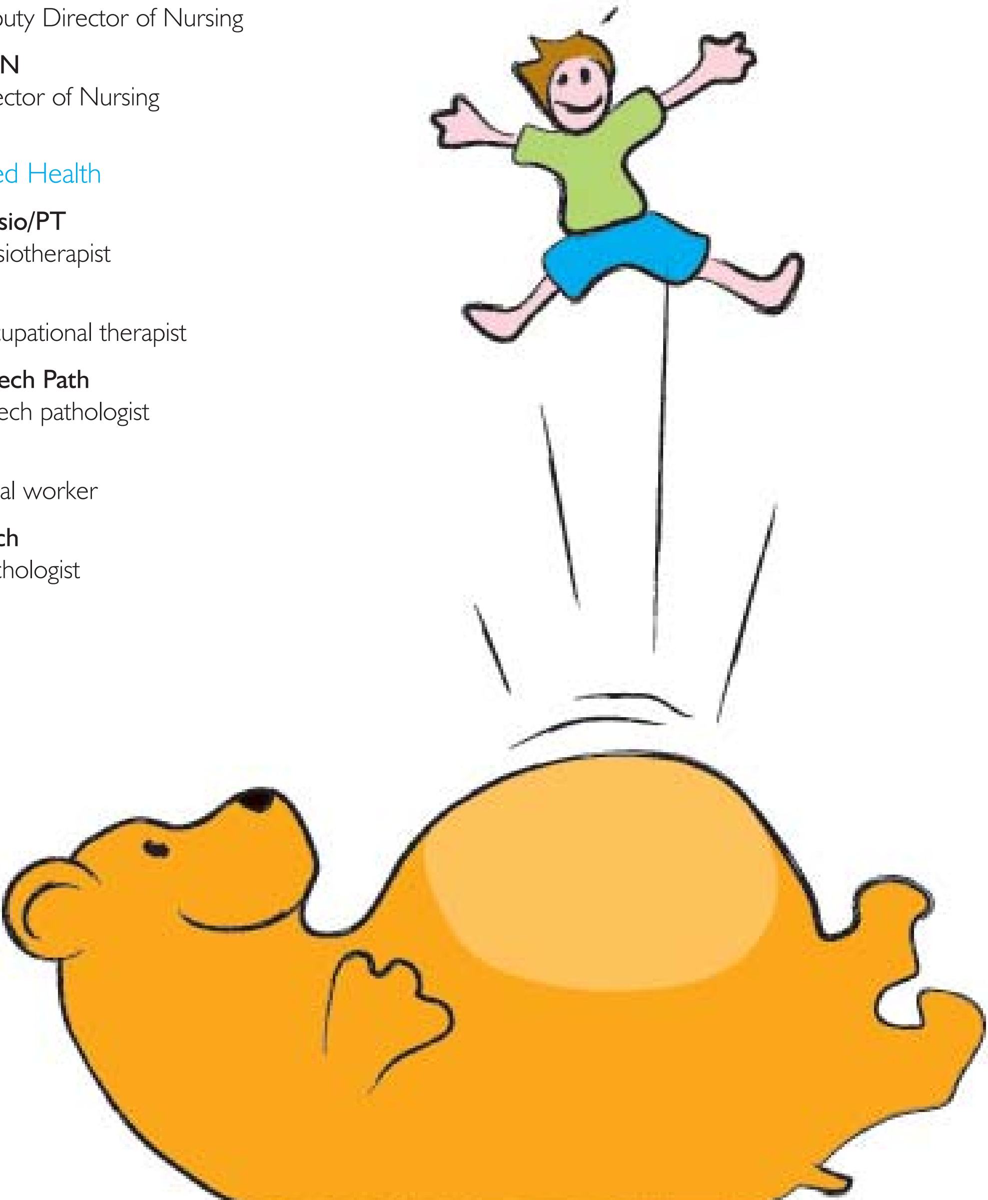
Physio/PT
Physiotherapist

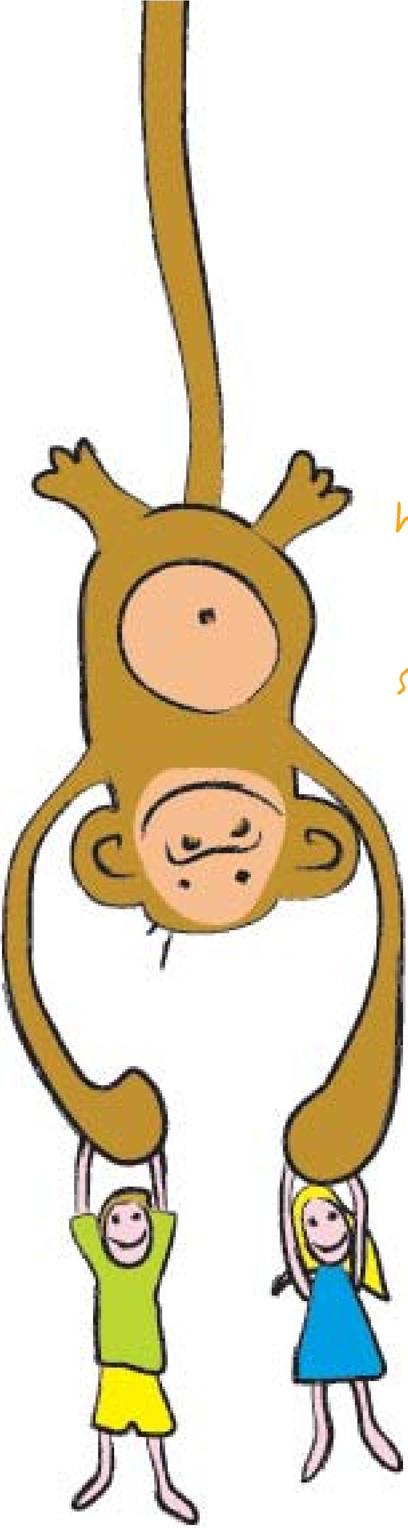
OT
Occupational therapist

Speech Path
Speech pathologist

SW
Social worker

Psych
Psychologist





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

(Karen – parent)

Who will help us in the community?

Case Management

A Case Manager's role is to work with a family, to make an assessment of their child's needs within the context of the family situation, and to co-ordinate ongoing services and supports. 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

Many different case management programs exist at present.

Children from birth to 6 years with a severe disability may be eligible for case management with attached brokerage funding through the 'Early Choices Program'.

Once children reach school age, they move from the 'Early Choices Program' to the 'Making a Difference Program'. If a child has not yet received case management, they may become eligible for the 'Making a Difference Program'.

Children from birth to 18 years with high/complex medical needs may be eligible for case management and funding from the Family Choice Program, available through the Royal Children's Hospital and Monash Medical Centre. The case managers from these programs meet with families to develop individual plans to assist them. Brokerage funding, which is an amount of money allocated to the child/family on the program, is applied by considering each family's specific needs through their plan, and can cover items like extra home help, incontinence aids, counselling, hire of equipment, etc.

Non-recurrent funding (i.e. a one off payment) may also be available (e.g. to top up the cost of equipment or training of carers).

Referral to these programs is via the health professional or through self-referral. Like most programs, they usually have extensive waiting lists so it is recommended to make enquiries as soon as possible. To find out more, contact your local Department of Human Services (DHS) or the Association for Children with a Disability.
[See Resources & Services p78]

Funding may also available from sources such as the Regional Disability Support Initiative (RDSI), DHS - Client Services, Philanthropic Trusts, the Variety Club and Service Clubs such as Rotary and Lions.

Early Intervention

Early Childhood Intervention is targeted at children of pre-school age. It aims to:

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

> **“I have accepted my daughter’s diagnosis and disability a long time ago and I love her just the way she is. However, what I continue to find extremely difficult and frustrating is the constant and ongoing need to fight for services and equipment and having to go out ‘begging’ for funds to cover gap payments for necessities like wheelchairs, standing frames, etc.”**
>
> *(Ursula - parent)*

Early Childhood Intervention Services (ECIS) include:

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

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

You may choose to access a program that is specific to your child's condition, if available. You may also have a choice between a program where you stay and participate, and one where you leave your child in the care of others. It is recommended you enrol your child as soon as his/her needs are identified, as waiting lists are likely.

The availability of early intervention programs will depend on the area you live in. There are centre-based programs your child may attend and there are also home-based programs, usually provided through Specialist Children's Services (SCS), which is part of the Department of Human Services (DHS).

Specialist Children's Services (SCS) is a team of early childhood intervention professionals with specialist skills and training in working with children from birth to school age, who have multiple or additional needs. Team members may include occupational therapists, physiotherapists, speech pathologists, psychologists, and educational advisors. SCS provides services at childcare, playgroup or preschool, or on an individual basis at home.

In general there are few centre-based programs that accept very young children (i.e. only a few months old).

Be aware that if you are receiving a service (e.g. physiotherapy, occupational therapy and/or speech pathology) from one program, be it centre based or in-home, you will be *ineligible* to receive the same service from another program.

Many Special Developmental Schools (SDS) have early intervention programs, which accept children from the age of 2 years and 8 months, but it is advisable to make early enquiries. As these SDS programs do not require parents to stay, they can provide valuable respite for parents, while their child participates in a structured early intervention program.

The Department of Human Services provides information about programs on the Early Childhood Intervention Service.
[See Resources & Services p87].

There are also some published guides to help you, depending on the area in which you live.

The 'Early Childhood Intervention Directory'
is produced by DHS Southern Metropolitan Region;
www.dhs.vic.gov.au/regional/southern.

'The Respite Resource Guide for Parents and Carers'
produced for the Eastern Metropolitan Region of Melbourne, is available from Villa Maria Carer Services or Respite Information and Development in the East (RIDE).
[See Resources & Services p88].

'Through The Maze'
A Guide to Benefits and Services for Families of Children with a Disability is produced by the Association for Children With A Disability.
Phone: (03) 9500 1232 or 1800 654 013, or www.acd.org.au.
[See Resources & Services p78].

> "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)*

Respite

Respite n. a temporary intermission; suspension of labour; stop; reprieve; interval of rest or relief [Oxford Dictionary]

- **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 demand that caring for a child who is sick, disabled or chronically ill may brings
- **It is also important for the sick 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 booking levels, staffing levels and the mix of children booked in at the 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.

- Carers may be from your local council or specific respite providers such as Interchange or Yooralla.
- Some organisations provide in home respite through volunteers. It is important however to distinguish between carers and volunteers. Carers are specifically trained in the care needs of your child. Volunteers on the other hand, may not have any medical expertise or training.
- Extended Families Australia (EFA) is an association that provides opportunities for mature-aged people to develop loving and caring 'grandparent' relationships with children who have a disability. Established in 1978 as the Foster Grandparents Scheme, EFA matches a volunteer with a child, providing valuable companionship and support for the child and his or her family through regular visits.
  See www.extendedfamilies.org.au or Telephone: (03) 9650 7216

Day programs

These programs provide respite/care services offered outside the home for a nominated time each week. For example, Ringwood Biala offers care for children from birth to six years of age, for five hours once a week for families registered with them.

Residential care

This involves your child living away from home for one or more nights. For example, Villa Maria has a number of houses in Melbourne staffed overnight with trained carers. In some cases the children attend their normal day programs at school, and return to the respite house in the afternoon for dinner and an overnight stay.

Very Special Kids

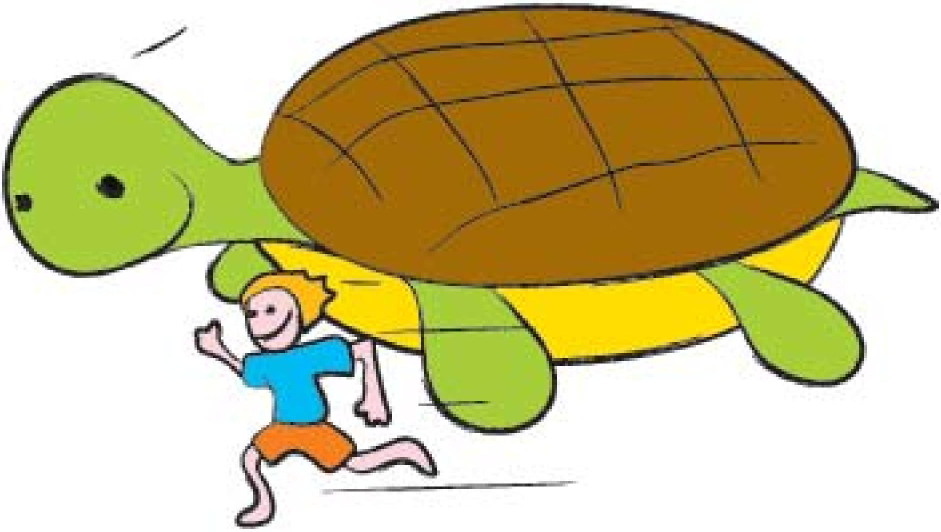
Very Special Kids supports families throughout their experience of caring for children with life-threatening illnesses, from diagnosis through to recovery or bereavement. Support services include counselling, sibling support, bereavement support, trained family support volunteers and care at *Very Special Kids' House* - Victoria's only and Australia's first hospice for children (offering respite, transition and end-of-life care). Other services include family camps and activities, parent activities and newsletters. [See p89]

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.



Going to School

Starting school is a major milestone for any child, but for a child with special needs, chronic illness and/or disability, the transition phase will carry extra tasks.

At the beginning of each school year it is advisable to meet with the Principal and/or classroom teacher to discuss how your child's needs can best be catered for in the educational setting. Through staff training, professional development, and other appropriate resources [e.g. an Emergency Medical Plan] you can be assured that any and *all* staff coming into contact with your child will be informed of his/her individual needs.

Regular and ongoing Case Meetings [or Parent Support Group PSG Meetings] with *all* staff involved in your child's education, to discuss issues relating to your child's overall development and progress, can be incredibly 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.

Confidentiality

In providing information to the school and its staff, it remains important that your child and family's confidentiality is respected. Ascertaining the 'need to know' versus the 'want to know' can act as a helpful guide. Where possible, involve the child in this process.

Children of all ages, whether they have special needs or not, do not like to be perceived as different. How respectfully they are treated, and how sensitively their personal health information is managed within the school setting, will influence the child enormously and ideally in a positive manner.

For adolescents in particular, we need to identify and acknowledge their mechanisms for coping and their resilience with illness/disability, as it is important in order to foster self-esteem and a sense of independence.

It may be worthwhile to identify a significant other as a mentor whom your adolescent child can confide in without fear of discipline and/or judgement. In the school setting this person may be the counsellor, classroom teacher or school nurse.

Communication

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

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

The Non-Primary Carer

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

Siblings

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

> "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)*

Transport

Red Cross Medical Transport

The Australian Red Cross provides a free transport service to and from hospital or a medical appointment for people without a car who cannot use public transport or afford a taxi. This service covers the Melbourne metropolitan area including the Mornington Peninsula. Wheelchairs are unable to be accommodated. Transport is provided for the person having treatment and his/her carer.
For further information contact (03) 8327 7868.

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

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

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

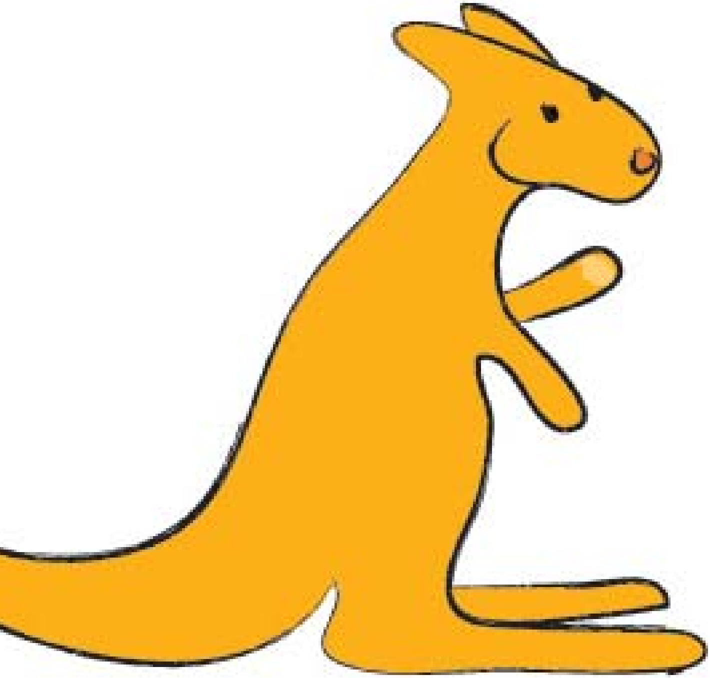
Victorian Patient Transport Assistance Scheme

The Victorian Patient Transport Assistance Scheme (VPTAS) assists rural Victorians with travel and/or accommodation costs incurred when travelling long distances for medical/dental treatment.

To be eligible for assistance, patients must be Victorian residents, have a current referral to the nearest medical/dental specialist or approved place of treatment, and have to travel more than 100 kilometres (one way) or an average of 500 kilometres per week (if receiving treatment in a block of at least five weeks) - known as Block Treatment Subsidy - from their home to the location of treatment.

Application forms are available from most doctors' surgeries, hospital social workers and DHS regional offices.

If your child is accessing medical services in Victoria, but your family resides in another state, it is worth finding out what similar schemes exist. Consider contacting the Department of Health in your state.



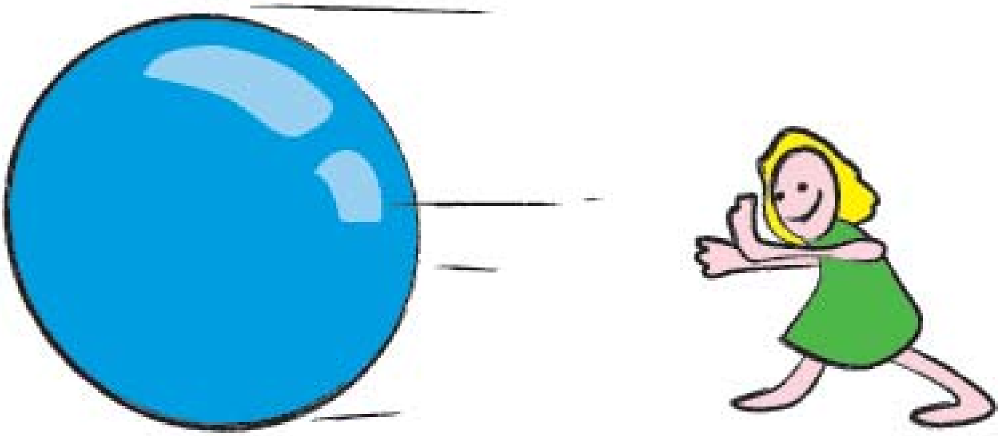
Victoria Disabled Persons' Parking Scheme

A statewide Disabled Persons' Parking Scheme currently operates in Victoria. The Scheme provides for two permit categories with varying parking concessions, based on the applicant’s need for assistance.

Under category one, permit holders with significant intellectual or ambulatory disabilities who meet the eligibility criteria are entitled to park a vehicle in a special bay reserved for people with a disability only, for the specified time only, or may park a vehicle in any ordinary area or bay for twice the specified time (upon payment of any initial parking fee, if applicable).

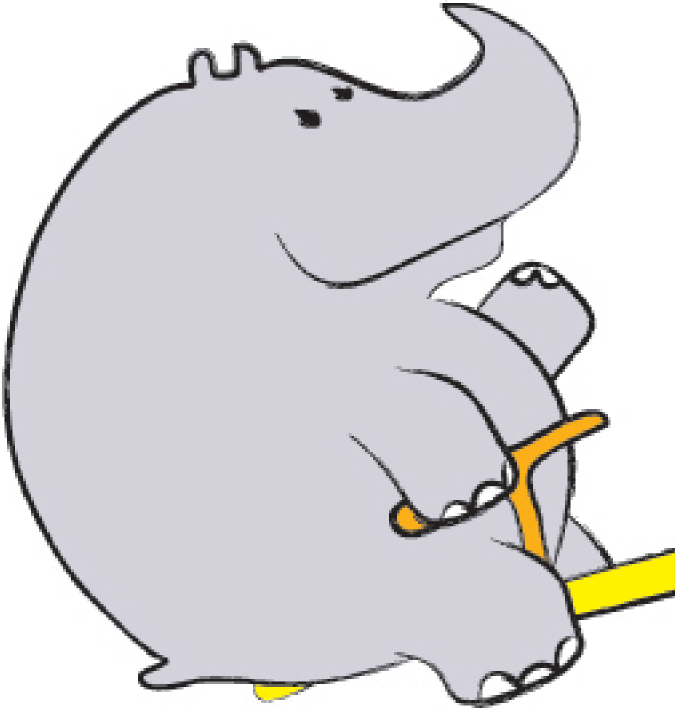
Under category two, permit holders who require rest breaks when walking may park a vehicle in any ordinary area or bay for twice the specified time (upon payment of any initial parking fee, if applicable). The permit label should be carried by the permit holder when he/she is not being transported in a vehicle. Permits must not be left on display when the vehicle is not engaged in the process of transporting a permit holder.

Category two permit holders are not permitted to park in special disabled persons' parking bays. For more information see www.vicroads.vic.gov.au.



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

(Nev – parent)



How to give life balance

Key Sources Of Support

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

- Family and friends: use their help, don't try to cope by yourself
- Parent Support Networks / Parent to Parent
  [See Resources & Services p77]
- Attending parent/family information sessions and/or support groups, whether disability specific or for general support. Support from people in a similar situation can be reassuring
- Home Help may be available through your local council
- Contacting the 'condition specific organisation' (e.g. Epilepsy Foundation) for your child's condition, to find out how they can assist you and your family. Ascertain the facts of your child's condition, when you feel ready to do so
- Some hospitals have Clinical Nurse Consultants who may be able to provide support and assistance. The Royal Children's Hospital, for example, have a Clinical Nurse Consultant for Developmental Disabilities, who can provide excellent practical support for parents of children with complex/high medical needs, as well as advocacy, while the child is an inpatient
- Staff within the hospital setting e.g. Hospital chaplains, social workers and allied health
- Family support workers and/or social workers through community organisations such as Very Special Kids, Villa Maria, Scope
- A psychologist or counsellor specialising in disability and/or grief counselling
- The Internet can be a great source of information however it is important to remember that not everything you read will necessarily apply to your child. Online support groups, Internet lists and discussion groups are good ways to talk to other parents of children with similar issues
- Your church may provide practical help such as meals, cleaning, or babysitting, as well as emotional and/or spiritual support
- Regular respite

> "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)*

Family and Friends

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

Communication is very important, so that expectations are clear. There may be useful information sheets available that explain your child's condition. Circulating this information amongst family and friends may help them to understand your child's condition and how your family may be affected. This may also help you to avoid frequent repetition and explanations.

Some parents have found it is helpful to write an open letter to family and friends, explaining their child's diagnosis, and what they would like other people to do, or not do, to say and not say.

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

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

> "Every 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)*

Taking Care of Yourself

As a parent, it can be easy to focus on the needs of others and forget to 'care for the carer'. This can have far reaching effects on the rest of the family.

Here are some helpful tips from parents;

- Keep as well as possible, to avoid minor illnesses which may add extra pressure to the family. Looking after yourself will better enable you to continue to look after others.
- Eat well-balanced meals where possible.
- Exercise regularly: walk, swim, or use exercise equipment at home. Balance this however with rest whenever possible.
- Access respite options.
- Get adequate sleep whenever you can. Sleep deprivation may compound existing stress. You may be able to schedule some sleep time while someone else watches your child, perhaps a carer or your partner.
- Role sharing at home can allow each person time to attend to their own needs such as rest, work or leisure activities.
- Consider talking to other parents who are in a similar situation, as this may help to reduce feelings of isolation. You may also find support groups helpful, either on the Internet, or in the community.
- Spending time with friends is important for emotional well being.

- List some achievable priorities for each day, week, month, or year.
  For example:
  Daily: a 10-minute coffee break, a walk around the block…
  Weekly: a visit to a friend, 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.
- You may be eligible to apply to your local council for a Disability Parking Permit. This will enable you to use parking bays designated for people with disabilities. [See Resources & Services p97]
- 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 the needs of each other.

It is important to realise that each family member may react differently to the information received about your child. They may each deal with it very differently and may therefore need different supports.

Where possible, and as appropriate, involve all family members in decision making processes. This is particularly important for your children, including the one with additional needs.

Consider accessing existing supports for family members [e.g. sibling programs, Big Brothers Big Sisters, Dads' Days, Mothers' Groups etc.]

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

"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

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

Some people may willingly adopt their new role, but others may resent the changes and may fear the deterioration of family relationships. It may take time to learn and adjust to such role changes. Tasks may not be achieved as 'perfectly' or done the 'same way' they were previously.

As the changing roles of others in the home are considered, the non-primary carer will perhaps be needed in ways that he/she has not been needed before. For example, he/she may become more involved with shopping, housework, siblings' homework, or the care needs of the child with additional needs.

Primary and non-primary carers will learn different skills and have new responsibilities.

Remember that primary carers can also get sick, and may not always be able to attend to the child's needs. It is important that the non-primary carer understands the child's condition and is confident in the administration of medications, treatments and other daily care tasks.

A carer from outside the family may need to consider tasks other than working with the child. Siblings may need more time and attention to balance some of what they may be missing out on, and non-primary carers are an obvious choice for accommodating such needs.

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

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

(Tony - parent)

"It is easy to take things for granted or 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."

(Nev – parent)

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.

> "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)*

The Association for Children With A Disability (ACD) has produced an excellent resource called 'Supporting Siblings: When a Brother or Sister has a Disability or Chronic Illness'. The 46-page booklet outlines common sibling responses from early childhood through to adolescence. With a focus on strategies that promote coping and resilience in siblings, social factors that impact on life experiences are also considered in terms of how they contribute to the ability of siblings to cope with their situation.
For more information see www.acd.org.au/siblings/supporting.htm.

A Sibling Program Directory which lists programs across Victoria that are suitable for young people is also available through their website. For more information see www.acd.org.au/siblings/directory.htm.

A website called 'Your Shout', which was made by and for adolescents who have a brother or sister with a disability or illness, has also been developed by ACD. 'Your Shout' invites adolescent siblings to share their stories and experiences. For more information see www.yourshout.org.au

Big Brothers Big Sisters is a program which provides mentoring for children aged 7-17 years, by trained volunteers who commit from 2-6 hours a week to their Little Brother or Sister, for at least twelve months. The role involves doing simple activities that enhance the friendship and contribute to an environment where the young person can develop positive self-esteem and life direction.
For more information see www.bbbs.org.au.

Siblings Australia was originally established in 1999, as the Sibling Project, within the Department of Psychological Medicine at the Women's and Children's Hospital, in Adelaide. It 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

For more information see www.siblingsaustralia.org.au

> ”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)*

Glossary

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

Bulk Bill
Full amount of medical payment met by Medicare

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

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

Discharge
Going home after being an inpatient

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

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

Inpatient
A person being admitted into hospital overnight or longer

Medical
A physician (doctor)

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

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

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

Paediatrician
Specialist doctor working with children only

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

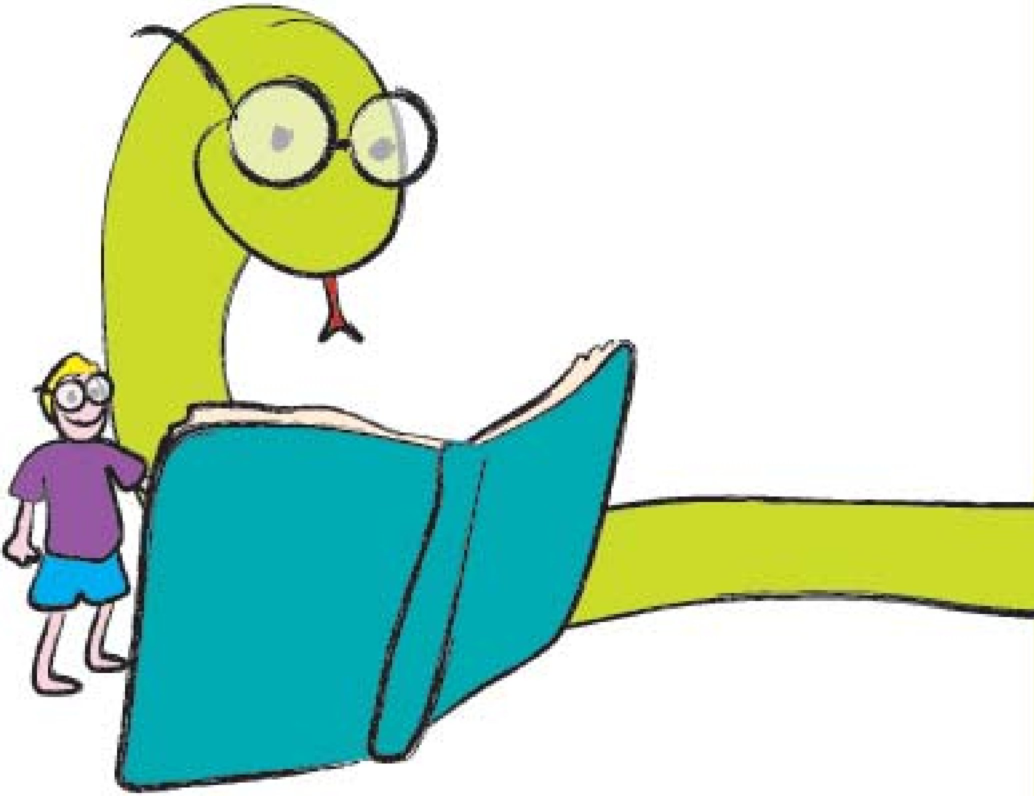
Prognosis
Prediction of the probable outcome of a disease based on the condition of the person, and the usual course of the disease in similar situations

Respite
Provision of temporary care for a patient who requires specialist care or supervision that is normally provided at home

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

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

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



Publications

For Parents

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

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

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

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

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

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

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

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

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

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

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

- **Articles - A Parent's Perspective**
  "Welcome to Holland" by Emily Perl Kingsley
  "Celebrating Holland" by Cathy Anthony
  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 **Email:** lisa@smartarts.net.au

- **Parent To Parent: Raising Your Child With Special Needs**
  A joint publication of Deakin University and the Department of Human Services (Barwon-South Western Region) – this document provides advice, information and strategies from parents for parents, about raising children with special needs. A list of resources specific to the region is available.

  www.deakin.edu.au/dhs/parent_to_parent/

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

For Kids

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

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

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

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

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

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

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

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

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

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

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

For Siblings

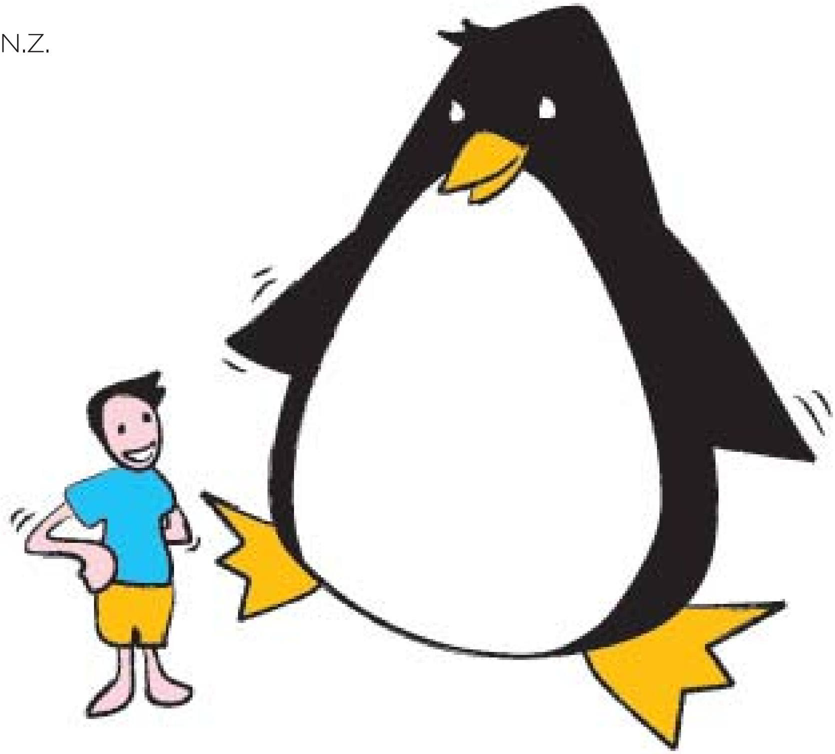
- **Something Has Happened: an activity book for young children.**
  Irving, T.
  2000. Skylight, N.Z

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

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

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

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



Bereavement Literature

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

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

- **Grief Counselling & Grief Therapy**
  - handbook for mental health professionals.
  Worden, J.W.
  2004. (3rd ed) Brunner- Routledge. USA

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

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

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

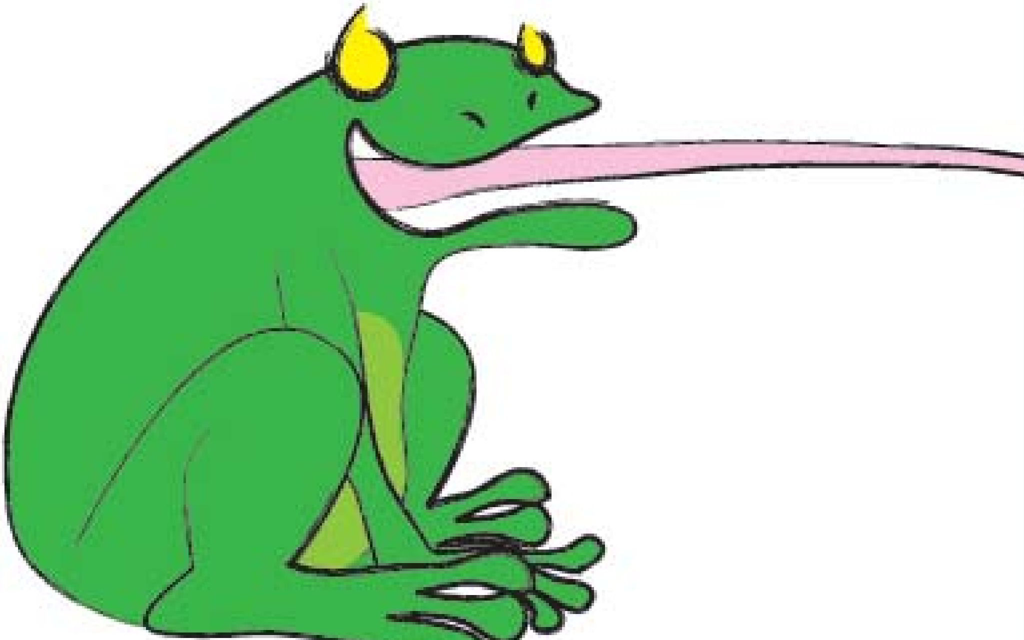
Specialist Bookshops

- **Open Leaves Books Melbourne**
  79 Cardigan Street
  Carlton 3053 Victoria
  Telephone: (03) 9347 2355
  Fax: (03) 9347 1430
  Email: openleaves@openleaves.com.au

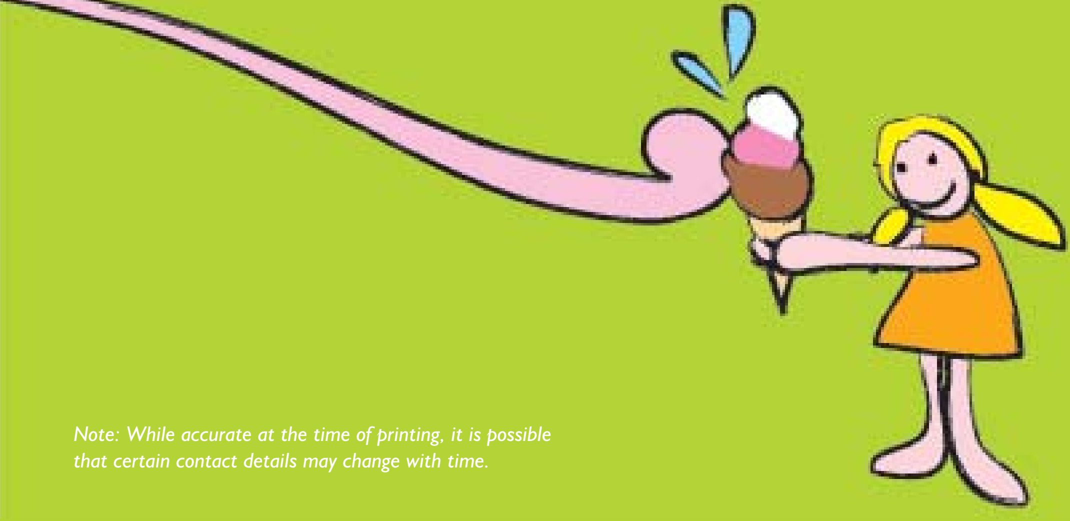
- **Peoplemaking**
  375 Camberwell Road
  Camberwell 3124 Victoria
  Telephone: (03) 9813 2533
  Fax: (03) 9813 2533
  Email: books@peoplemaking.com.au

- **St Luke's Innovative Resources**
  137 McCrae Street
  Bendigo 3550 Victoria
  Telephone: 5442 0500
  Fax: 5442 0555
  Website: www.stlukes.org.au/resources
  Email: stlukeir@stlukes.org.au

- **The Resource Centre for Child Health and Safety** is located in the main building, first floor of the Royal Children's Hospital, Melbourne, and is open to the public Monday to Friday 9:00am - 4:30pm (excluding public holidays and a Christmas break.) Email queries to chic.bookshop@rch.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 here, however they are an excellent place to start and a wealth of information. Be sure to tap into these services – they exist to help you and your family.

Able Australia

Able Australia provides information, support, advocacy, and respite care for people with a multiple disability, including deafblindness.

Address: 616 Riversdale Road, Camberwell, VIC 3124
Telephone: (03) 9882 7055
Website: www.dba.asn.au
Email: info@dba.asn.au

ACD - Association for Children with a Disability

A non-profit organisation providing information, support and advocacy for Victorian children with a disability and their families.

Address: Suite 2, 98 Morang Road, Hawthorn, VIC 3122
Telephone: (03) 9500 1232 or Toll Free 1800 654 013
Fax: (03) 9500 1240
Website: www.acd.org.au
Email: mail@acd.org.au

“Through The Maze” is a resource booklet available free of charge by mail, and can also be viewed on the ACD website via the “Information and Support for Families” link. A comprehensive services listing may also be accessed through this site.
www.acd.org.au/information/keycontact.htm

Big Brothers, Big Sisters of Australia

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

Address: PO Box 468, Richmond, VIC 3121
Telephone: (03) 9427 7611 Fax: (03) 9427 9568
Website: www.bbbs.org.au Email: bbbs@bbbs.org.au

ChIPS – Chronic Illness Peer Support

ChIPS is a Chronic Illness Peer Support program for young people living with any type of chronic illness or medical condition. The program is based in Melbourne at the Centre for Adolescent Health, Royal Children's Hospital.

Address: Centre for Adolescent Health,
2 Gatehouse Street, Parkville, VIC 3052
Phone: +61 3 9345 6616
Telephone: (03) 9345 6616
Website: www.rch.org.au/chips/index.cfm?doc_id=295

EFA - Extended Families Australia
(formerly Foster Grandparents Scheme)

Extended Families Australia (EFA) is an association that provides opportunities for mature-aged people to develop loving and caring ‘grandparent’ relationships with children who have a disability.

Address: 177 Glenroy Rd, Glenroy, VIC 3046
Telephone: (03) 8311 4044
Fax: (03) 9300 3358
Website: www.extendedfamilies.org.au/
Email: efa@extendedfamilies.org.au

Independent Living Centre (Yooralla)

Yooralla's Independent Living Centre (ILC) enhances the independence and quality of life of people with disabilities by providing information and advice on daily living equipment. The Centre has a large range of aids for daily living and adaptive equipment on display. The ILC does *not* sell equipment. However supplier and relevant service information can be obtained from the staff.

Address: 705 Geelong Road, Brooklyn, VIC 3025
Postal address: P.O. Box 1101, Altona Gate, VIC 3025
Telephone: (03) 9362 6111 or Toll Free 1800 686 533
TTY: (03) 9314 9001
Fax: (03) 9314 4825
Website: www.yooralla.com.au/ilc.php
E-mail: ilc@yooralla.com.au

Make A Wish Foundation

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

For more information:
Telephone: 1800 032 260
or visit: www.makeawish.org.au/

MOIRA Key Cards

These cards are produced in a handy and portable format, and are individually laminated to protect them from spills and other damage. They provide helpful and relevant information about your child when he/she is away from his/her primary care givers.

For more information visit:
www.moira.org.au/keycards.html

Parent Support Network

The Association for Children with a Disability (ACD) works closely with a network of Regional Parent Support Co-ordinators. These workers provide information and support to parents of children with a disability, including links to local/regional parent support groups and workshops. Regional Parent Support co-ordinators are also available to provide emotional support to parents at times of critical need.

Regional parent support co-ordinators across the state of Victoria can be found in the ACD publication "Through The Maze" or at www.acd.org.au/support/regional.htm

Redkite

Redkite supports children and their families through cancer by providing emotional guidance, financial relief and educational services.

Address: PO Box 3037, Auburn, VIC 3123
Telephone: (03) 9813 5020 or Toll Free 1800 1334 771
Website: www.redkite.org.au

Ronald McDonald House

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

Address: 28 Gatehouse Street Parkville VIC 3052
Telephone: (03) 9345 6300

OR

Address: 33 Kanooka Grove Clayton VIC 3168
Telephone: (03) 9562 6223

Ronald McDonald Learning Program

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

Telephone: 1300 307 64

SANE Australia

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

Postal Address: PO Box 226, South Melbourne, VIC 3205
Telephone: (03) 9682 5933 (HELPLINE Telephone 1800 18 7263)
Fax: (03) 9682 5944
Email: info@sane.org (HELPLINE email helpline@sane.org)
Website: www.sane.org

SCOPE

Scope is a not-for-profit organisation providing disability services throughout Melbourne and Victoria to children and adults with physical and multiple disabilities. Information, support and assessment services are available. Scope is committed to overcoming the personal, structural and attitudinal barriers that prevent those with disability from participating in community life and works to make our community more inclusive, more accessible and more welcoming.

Box Hill Office

Address: 830 Whitehorse Rd, Box Hill, VIC 3128
Postal Address: PO Box 608, Box Hill, VIC 3128
Telephone: (03) 9843 3000
Fax: (03) 9843 2030

Glenroy Office

Address: 177 Glenroy Rd, Glenroy, VIC 3046
Telephone: (03) 8311 4000
Fax: (03) 9306 6654
Email: contact@scopevic.org.au

Starlight Foundation

The Starlight Foundation delivers innovative 'Distractive Therapy Programs' within 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. Starlight also grants wishes for children aged four to eighteen years, living with a terminal, chronic or critical illness. A child can only be referred to Starlight for a wish experience by a qualified health professional.

For more information
Telephone: (03) 9663 3300
or visit www.starlight.org.au/

Support Groups Directory

The Royal Children's Hospital Resource Centre for Child Health and Safety provides contact details for more than 200 Victorian support groups and other community organisations. The listing can be accessed online at www.rch.org.au/chas/support/index.cfm?doc

TADVIC (Technical Aid to the Disabled)

Under the coordination of occupational therapists, TADVIC volunteer members design, construct or modify equipment for people with disabilities. This service is provided where no commercially available solution will meet their needs. There is no charge for the TADVIC service. Clients are asked to reimburse the volunteer for any cost of materials and travelling expenses incurred.

Address: TADVIC Co-operative Ltd,
C/- Royal Talbot Rehabilitation Centre, 1 Yarra Boulevard, Kew, VIC 3101
Telephone: (03) 9853 8655 or Toll Free 1300 663 243
Fax: (03) 9853 8098
Website: www.tadvic.asn.au
Email: info@tadvic.asn.au

Taralye
(Advisory Council For Children With Impaired Hearing)

Taralye aims to promote the linguistic, educational and social outcomes of deaf children through innovative early intervention services and research. Services offered include information/advice/referral; therapy/counselling; clinic; medical specialist/surgeon; early childhood intervention.

Address: 137 Blackburn Road, Blackburn, VIC 3130
Telephone: (03) 9877 1300
Fax: (03) 9877 1922
Website: www.taralye.vic.edu.au
Email: taralye@edumail.vic.gov.au

TLC for kids

Provides urgent assistance and immediate distractions for sick children in hospital needing “rapid Tender Loving Care”.

Address: Suite 1, 99 Curzon Street, North Melbourne VIC 3051
Telephone: (03) 9328 5903 OR 1300 361 461
Email: www.tlcforkids.org.au

Victorian Companion Card

The Companion Card promotes the right of people with a disability, who require a companion, to fair ticketing at Victorian events and venues. The Companion Card also entitles Cardholders and their companions to travel without charge on all train and tram services and all metropolitan bus services, country trains, coach and town bus services.

Telephone: 1800 650 611
Website: www.vic.companioncard.org.au

Victorian Continence Resource Centre

The Victorian Continence Resource Centre provides information on incontinence and continence assistance programs.

Telephone: (03) 9816 8266
Website: www.continencevictoria.org.au

Vision Australia

Vision Australia provides a range of services including information, advice, referral, counselling, early childhood intervention, medical support, occupational therapy, physiotherapy and pathology.

Address: 454 Glenferrie Road, Kooyong, VIC 3144
Telephone: (03) 9864 9222
Fax: (03) 9761 2455

Yooralla

Yooralla helps Victorian children and adults with disabilities, as well as those who have acquired disabilities through accident, ill health and age. Yooralla provides community access, independence and employment services, as well as residential care, respite care, and carer support services.

Address: Level 2, 244 Flinders Street, Melbourne, VIC 3000
Telephone: (03) 9650 4077
Website: www.yooralla.com.au
Email: yooralla@yooralla.com.au

Counselling

Australian Centre for Grief and Bereavement
The Australian Centre for Grief and Bereavement offers a bereavement counselling service.

Address: McCulloch House, Monash Medical Centre,
246 Clayton Road, Clayton VIC 3178
Telephone: (03) 9543-9449

Care-Ring (formerly Crisis Line)
Care-Ring provides 24 hour telephone crisis counselling service.

Telephone: 136 169

Genetic Support Network of Victoria (GSNV)
The GSNV provides information, advocacy, support and counselling for families and individuals affected by a genetic condition.

Address: 10th Floor, Royal Children's Hospital,
Flemington Road, Parkville, VIC 3052
Telephone: (03) 83416315
Website: www.gsnv.org.au
Email: info@gsnv.org.au

Griefline
Griefline provides a 24 hours Telephone Support Service (7 days).

Telephone: (03) 9596 7799

Hopeline
Hopeline provides counselling for families facing life-threatening illnesses.

Telephone: 1300 36 4673

Kids Help Line
The Kids Help Line is a free and confidential, 24 hour telephone counselling and online service for 5 to 18 year olds in Australia.

Telephone: 1800 55 1800 (Counselling Line)
Website: www.kidshelp.com.au
Email: admin@kidshelp.com.au

Lifeline

Lifeline provides a 24 hour telephone counselling service.

Telephone: 131 114
Website: www.lifeline.org.au

Parentline

Parentline provides 24 hour telephone advice and referral for parenting issues.

Telephone: 132 289

Relationships Australia

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

Telephone: 1300 364 277

The Bouverie Centre (Victoria's Family Institute)

The Bouverie Centre is a statewide integrated clinical, academic and consultation agency specialising in family approaches in mental health service provision. The Bouverie Centre provides a range of programs to individuals and family members, service providers and agencies.

Address: 50 Flemington Street, Flemington 3031
Telephone: (03) 9376 9844

TCF - The Compassionate Friends

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

Telephone: (03) 9888 4944
Website: www.compassionatefriendsvictoria.org.au

Early Intervention, Respite & Recreation

Access for All Abilities (AAA)
Through Sport and Recreation Victoria, the Victorian Government provides funding to a network of community-based organisations that assist local sport and recreation organisations to develop environments in their community that include, and are accessible to, people with disabilities. For more information visit
www.sport.vic.gov.au/web9/srvdirectory.nsf/AAAProviders

Biala Box Hill Incorporated Early Intervention Centre
Address: 10 Rose St, Box Hill, VIC 3128
Telephone: (03) 9899 0508
Fax: (03) 9897 3467

Carers Victoria
Carers Victoria provides services to support carers in their caring role, as well as education, training and advocacy programs to increase awareness of carers and carer's issues.

Telephone: 1800 242 636

ECIS - Early Childhood Intervention Service
(Department of Human Services)
Early Childhood Intervention Services (ECIS) support children with a disability or developmental delay and their families, from birth to school entry. ECIS provides special education, therapy, counselling, service planning and coordination, assistance and support to access services such as kindergarten and childcare

Telephone Toll Free 1800 783 783 (9am - 5pm Monday - Friday)
Website: www.ecis.vic.gov.au
(select the link to 'Our Services' to search for statewide services by name or by region)

Interchange Victoria

Interchange Victoria is a community based, not-for-profit organisation that provides support to families who have a child with a disability. Interchange provides respite and social support through the help of volunteers. Programs include; in-home respite, host care, youth groups, school holiday programs, camps and sibling and family activities.

Address: Head Office,Suite 6, Ashley House,
75 Ashley St, Braybrook, VIC 3019
Telephone: (03) 9396 1118 or Toll Free 1300 300 436
Fax: (03) 9396 1613
Website: www.interchange.org.au/

Noah's Ark Toy Library

Noah's Ark provides early childhood intervention services to promote the health, well being and developmental needs of children with additional needs, while supporting the whole family. Counselling for parents, referrals, information, toy library, occupational and speech therapy, physiotherapy, play groups and camps are available.
A small annual fee for these services applies.

Address: 28 The Avenue, Windsor, VIC 3181
Telephone: (03) 9529 1466
Fax: (03) 9529 7061
Email: noahsarkvic@ozemail.com.au
Website: www.noahsarkvic.org.au/services_fam.asp

Regional Carer Respite Centres (CRCs)

Provides information about respite services and assistance in organising respite, including emergency and after hours respite.

Telephone: 1800 059059

RIDE (Respite Information and Development in the East)

RIDE is a free service provided by Yooralla. RIDE provides information about respite options available in the Eastern Metropolitan Region (EMR) of Melbourne, and supports the development and enhancement of respite services in the region.

Copies of the EMR "Respite Resource Guide" are available by contacting RIDE.

Address: 6 Ellingworth Parade, Box Hill, VIC 3128
Telephone: (03) 9895 7004 or (03) 9895 7005
Fax: (03) 9689 1699
Website: www.yooralla.com.au/ride.php
Email: ride@yooralla.com.au

Ringwood Biala

An outreach program of the Ringwood Uniting Church, the respite program at Biala is designed to give the parents of special needs children with development delay or disabilities, one day a week relief from the constant and ongoing role of being responsible for their child. Volunteers provide one-on-one care for the children.

Address: Cnr Greenwood Ave and Station Street, Ringwood, VIC 3134
Telephone: (03) 9870 6033
Email: church@ringwood.unitingchurch.org

Very Special Kids

Very Special Kids supports families throughout their experience or caring for children with life threatening illnesses, from diagnosis through to recovery or bereavement. Support services include counselling, sibling support, bereavement support, trained family support volunteers and care at *Very Special Kids' House.* - Victoria's only and Australia's first hospice for children (offering respite, transition and end-of-life care.) Other services include family camps and activities, parent activities and newsletters.

Address: 321 Glenferrie Rd, Malvern, VIC 3144
Telephone: (03) 9804 6222 or Toll Free 1800 888 875
Fax: (03) 9822 1252
Website: www.vsk.org.au
Email: mail@vsk.org.au

Villa Maria Society (Disability Services)

Villa Maria's Disability Services provide services to cater for people of all ages with a variety of impairments or disabilities. Services include providing accommodation for people with disabilities, early childhood intervention, pre-school, primary and secondary education, facility-based respite care for children with disabilities, and adult day centre activities. Flexible support programs are available to assist people with a disability in a wide variety of ways.

Address: 6 Studley Park Road, Kew, VIC 3101
Telephone: (03) 9853 5377
Website: www.villamaria.com.au

Government

Centrelink

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

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

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

https://secure.centrelink.gov.au/sims

DE&T - Department of Education and Training

The principal responsibilities of the Department of Education and Training are to:

- Provide and ensure access to high quality primary and secondary education for all Victorian children - including support for non-government schools
- Ensure that all Victorians have access to high quality training and further education services necessary for the social and economic development of the state
- Link training and further education to employment, especially in high skill areas and areas of skill shortage
- Ensure that Government policies and service delivery reflect and meet the needs of all young Victorians.

Address: 2 Treasury Place, Melbourne, VIC 3002
Postal address: GPO Box 4367, Melbourne, VIC 3001
Telephone: (03) 9637 2222 or Toll Free 1800 809 834
Fax: (03) 9637 2626
Website: www.det.vic.gov.au
Email: edline@edumail.vic.gov.au

DHS - Department of Human Services, State Government of Victoria

The Department of Human Services is committed to ensuring that all Victorians have access to quality services that protect and enhance the community's physical, mental and social well-being.

Address: Level 18, 555 Collins Street, Melbourne, VIC 3000
Telephone: (03) 9616 7777
TTY: 1300 131 525
Fax: (03) 9616 8555
Home page: www.dhs.vic.gov.au/
Office for Children: www.office-for-children.vic.gov.au
Disability Services Division: hnb.dhs.vic.gov.au/ds/disabilitysite.nsf
Email: disability.services@dhs.vic.gov.au

Health Services Commissioner

The Health Services Commissioner is an independent health ombudsman. The role of the office is to assist health service users to resolve complaints about health service providers and improve the quality of health care. The Health Services Commissioner can accept complaints about anyone who claims to provide a health service. The Health Services Commissioner is not an advocacy service but assists in mediating or conciliating complaints. If you have trouble resolving your complaint directly with the provider, they can assist you.

Address: Level 30, 570 Bourke Street, Melbourne VIC 3000
Telephone: (03) 8601 5200 or Toll Free 1800 136 066
Fax: (03) 8601 5219
Email: hsc@dhs.vic.gov.au

Specialist Children’s Services (SCS)

Along with Early Childhood Intervention agencies, Specialist Children's Services is funded by DHS and provides services to families with a child (from birth to school entry) with a disability or developmental delay. They aim to promote the health, well being and development of the child, and to ensure that families have access to a range of early childhood support services.

Located in each of the DHS regions across Victoria, SCS comprise a multidisciplinary team of professionals such as occupational therapists, physiotherapists, psychologists, social workers, speech pathologists, and educational advisers. To find the SCS office in your region go to www.dhs.vic.gov.au.

Interpreting Services

Translating and Interpreting Service (TIS)
TIS provides a telephone interpreting service for families to access government and community utilities and services.

Telephone: 131450

VITS Language Link
VITS provides a telephone interpreting service for families. For more information and to obtain the fee schedule;

Telephone: (03) 9280 1955

VIC Deaf Auslan and Interpreting Services
For more information on Auslan or interpreting services go to www.vicdeaf.com.au

Telephone: (03) 9473 1117 or (03) 9473 1118

Medical & Health Services

Child and Adolescent Mental Health Service (CAMHS)
CAMHS provides outpatient mental health services for children and adolescents from birth to 18 years, and families, who are experiencing emotional, behavioural and social difficulties. They also offer an inpatient service in a residential setting for therapy and treatment to adolescents aged 12 -18 years. Specialised assessment services are also available. Mental Health Services in Victoria are area based.

For information on a Mental Health Services nearest to you, go to www.health.vic.gov.au/mentalhealth/services/index.htm. This link takes you to the Mental Health Website where you can select any suburb in Victoria and it will provide you with contact details for mental health services in that area.

Department of Developmental Medicine

Based at the Royal Children's Hospital, the Department of Developmental Medicine is committed to the care of children with disabilities and their families, within the hospital and in the community. It conducts and promotes educational programs and research in the area of childhood disability. Services provided by the Department include management, consultation, liaison/outreach, and advocacy.

Address: Flemington Rd, Parkville, VIC 3052
Telephone: (03) 9345 5898
Fax: (03) 9345 5871
Website: www.rch.org.au/cdr
Email: cdr.dept@rch.org.au

HACC – Home and Community Care

The Home and Community Care (HACC) Program provides funding (from the Victorian and Australian governments) for services which support frail older people, younger people with disabilities and their carers.
Telephone: (03) 9616 8424
Website: www.health.vic.gov.au/hacc

Health For Kids Network

The Health for Kids Network is a network of GPs interested in child and/or adolescent health. A web-based directory allows hospitals, community health centres or other agencies to identify local doctors for families who do not already have a regular GP. There is an online library of useful information on child and/or adolescent health.

Website: www.healthforkids.net.au
Email: admin@healthforkids.net.au

Metropolitan Ambulance Service (MAS)

The Metropolitan Ambulance Service (MAS) provides pre-hospital emergency care as well as patient transport across Victoria. The MAS manages the statewide services of Air Ambulance Victoria and the Ambulance Membership scheme.

Website: www.ambulance-vic.com.au/
In an emergency call 000.

Monash Medical Centre (MMC)

Monash Medical Centre (Clayton Campus) is one of the state's major teaching and referral hospitals. It is the largest within Southern Health (Victoria's largest metropolitan health service) providing specialist care to the state's southeast. Clayton Campus focuses on medical services requiring complex and multi-disciplinary activity and significant technological support.

The Moorabbin Campus has developed as a less intensive hospital offering a range of services including elective and short-stay care, with a strong emphasis on women's health. For more information visit: www.monashmedicalcentre.com.au

Clayton Campus

Address: 246 Clayton Rd, Clayton, VIC 3168
Telephone: (03) 9594 6666
Fax: (03) 9594 6111

Moorabbin Campus

Address: Centre Rd, East Bentleigh, VIC 3165
Telephone: (03) 9928 8111
Fax: (03) 9928 8752

Nurse On Call

Nurse-On-Call, a Victorian Government health initiative, is a phone service that provides immediate, expert health advice from a registered nurse, 24 hours a day, 7 days a week.

Telephone: 1300 60 60 24
(for the cost of a local call from anywhere in Victoria.)

RCH – Royal Children's Hospital

The Royal Children's Hospital is a specialist paediatric hospital and provides a full range of clinical services, tertiary care and health promotion and prevention programs for children and adolescents. The hospital is the major specialist paediatric hospital in Victoria, and also cares for children from Tasmania and southern New South Wales and other states around Australia and overseas.

Address: Flemington Rd. (corner of Gatehouse St.),
Parkville, VIC 3052
Telephone: (03) 9345 5522
Website: www.rch.org.au/ (click on the 'Contacts' link for useful phone numbers, RCH floor maps, and a street map)

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 Toll Free: 1300 726 567
Fax: (07) 3852 6646
Website: www.angelflight.org.au
Email: mail@angelflight.org.au

Multi Purpose Taxi Program

The Multi Purpose Taxi Program helps Victorians with severe and permanent disabilities use taxis at an affordable rate. The program is coordinated by the Victorian Taxi Directorate. For more information or to obtain an application form, see Multi Purpose Taxi Program in the A-Z Index on the website.

Address: Level 14, 80 Collins Street, Melbourne Vic 3000, Australia
Telephone: (03) 9655 6666
Website: www.doi.vic.gov.au

Red Cross Medical Transport

The Australian Red Cross provides a free transport service to and from hospital, or a medical appointment, for people who cannot use public transport or afford a taxi.

Telephone: (03) 8327 7700
Website: www.dhs.vic.gov.au/concessions/guide/g_healthcare.htm

Rural Ambulance Victoria (RAV)

Rural Ambulance Victoria (RAV) provides pre-hospital patient treatment in emergency and non-emergency situations and ambulance transport services, along with various public education services, across regional Victoria.

Telephone: (03) 5338 5000
Fax: (03) 5338 5211
Email: rav@rav.vic.gov.au

Vehicle Modifications

There are a number of companies that do vehicle modifications. However, some may do so only in a specific range of cars e.g. Mercedes, Kia. Contact the following businesses directly, or see "Disabled Persons – Equipment" in the Yellow Pages.

Capital Special Vehicles

Address: 12 Capital Drive, Dandenong, VIC 3175
Telephone: (03) 9794 8888

Norden Body Works

Address: 60-62 Bennet Street, Dandenong, VIC 3175
Telephone: (03) 9793 1066

Fleetworks Mobility

Address: 11 Vickery St, Malvern East, VIC 3145
Telephone: (03 9569 3166

Veh Quip

27 Amay Crescent, Ferntree Gully, VIC 3156
Telephone: (03) 9758 7276

Victoria Disabled Persons' Parking Scheme

Statewide Disabled Persons' Parking Scheme operates in Victoria. The Scheme provides for two permit categories with varying parking concessions, based on the applicant's need for assistance. Application forms are available from municipal councils. Permits will only be issued to established residents of a municipality. You or your agent must complete the first part of the application form, and the relevant medical practitioner should complete the rest.

Address: 60 Denmark St, Kew, VIC 3101
Telephone: (03) 9854 2666
Fax: (03) 9854 2918
Website: www.vicroads.vic.gov.au (For information on parking permits click on the following menu items - Roads and Projects > Road and Traffic Management > Victoria disabled persons' parking).

VPTAS - Victorian Patient Transport Assistance Scheme

The Victorian Patient Transport Assistance Scheme (VPTAS) aims to assist rural Victorians with travel and accommodation costs incurred when travelling long distances for specialist medical/dental treatment. Eligibility depends on Victorian residency, current medical referral, and distance travelled for treatment.

Telephone enquiries may be made through the Department of Human Services Regional Offices.

Email: secretary.interact@gmail.com

For further information visit the VPTAS website:
www.health.vic.gov.au/ruralhealth/aservices/vptas.htm

Notes

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