

4. Information about Parenting a Child with a Disability

- 1. Remember: All children including Children With a Disability have a right to; a.) make mistakes, and; b.) be teased;**

Charlotte Thompson writes of one of her patients, Jill Evans, (a patient with Spina Bifida) who said:

Children between third and sixth grade can be very cruel because they don't understand differences. By helping your child understand that kids grow out of teasing and letting them talk about it at home they can make it through this bad time.¹

- 2. Condition specific training and or information may be needed for parent's and others**

For example:

- a.) How to manage the condition;
- b.) Progression of the condition;
- c.) Implications of doing/not doing particular exercises or interventions;
- d.) The expected side-effects of particular drugs, or treatments;

You should check with condition specific organisations and other reputable sources, for this information.

- 3. Parents often feel guilty about the use of, or need for respite care;**

The use of respite is a widely recognised way of coping with the additional pressures of raising a child with a physical disability. In fact, far from being to the disadvantage of the child, research has shown that there are advantages for both the caregiver, and the child with a disability, particularly where the families manage the timing and use of respite and personal assistance services.²

In West Australian research,³ carer's "...were often seen as important in the care of the child and the family." (p.45.) and "A considerable number of parents did not feel they had sufficient respite time." (p. 44)

- 4. It is advisable to try to avoid behavioural problems by use of appropriate parenting techniques, skills, and or training, e.g. the "Triple P Parenting program";**

¹ P. 153, Thompson, Charlotte, (2000) Raising a handicapped child: a helpful guide for parents of the physically disabled [Revised and expanded edition] New York: NY, Oxford University Press ISBN 0-19-513253-x

² Caldwell, J., & Heller, T. (2003) Management of respite and personal assistance services in a consumer-directed family support programme. Journal of Intellectual Disability Research, 47 (4/5) 352-366.

³ Monterosso, L., Kristjanson, L., Phillips, M., Rowell, S., & Watson, M., (2005?) Paediatric Palliative and Supportive Care – Caring for Life: The needs of children and families in Western Australia. Churchlands, Western Australia: Edith Cowan University, School of Nursing, Midwifery and Postgraduate Medicine.

There are a number of sources of information and resources for assistance in relation to parenting and dealing with (and preventing) behavioural problems in children with a disability. These include; *The Stepping Stones Triple P Parenting Program* (The *Positive Parenting Program* modified for children with a disability.); *Resource Unit for Children with Special Needs, Inc*, the *Managing Challenging Behaviour DVD*, or any number of reputable resources available via the public library system, or bookshops. Some are listed at the end of this section.

When looking at “behaviour problems” it can be useful to look at the “ABC’s” or
Antecedents – or things/events leading up to the behaviour;
Behaviour – what *exactly* is the *identifiable* behaviour creating the problem;
Consequences – the end result of the inappropriate behaviour.

Without looking at, and dealing with, all three parts, attempts at behaviour modification are unlikely to be successful.

In the chapter “*How to stop Spinning: Understanding and Guiding your Child’s Behaviour*” in “*Special Children Challenged Parents*”, Dr Robert Naseef, says;

“Simply imagine he’s not your child. Everybody knows how to raise other people’s children”, or so it seems. Whenever I address a group of parents about how to handle the behaviour problems of children with disabilities, this statement never fails to evoke a round of hearty laughter. It’s so much easier for all of us, even experts, to discuss other people’s children. The balance between love and discipline is one of the toughest challenges of parenthood.”
(p. 89)

He provides a framework to address behaviour problems as follows;

Getting in touch with yourself. This is about being aware of your feelings about your child, and how this impacts on your interactions with them. He talks about the need to sometimes look at what child psychologist Saul Fisher has called the *pivotal areas* of everyday life. These can be described as those times or events when you get most upset, angry, frustrated, annoyed, sad etc. Part of it can be using whatever support systems you have, whether it is a support group of parents, a counsellor, or another parent of a child with a disability who you can “unload” with, to identify what they are, and why they are stressful.

Understanding what your child's behaviour means. As your child develops, and with greater experience with them, you could expect to understand that inappropriate behaviour indicates they are:

- Hungry;
- Scared;
- Overstimulated;
- Under stimulated or bored;
- Frustrated with not understanding;
- Avoiding something;
- Allergic;
- Feeling sick.

For children with limited verbal and nonverbal skills, they need to use behaviour as a form of communication this is known as *communicative intent*. However there can be problems if the behaviour is misinterpreted by the parent.

Strategies for Change. Here he talks about how (as with their non-disabled peers) there is a constant need to modify or “tweak” the methods used to deal with behaviour issues.

After talking about ineffective punishments, like;

- a.) Threats (that are not carried out);
- b.) Yelling, (which can teach children to only listen when voices are raised);
- c.) Insults and name-calling (which teach shame to the child);
- d.) Withdrawal of privileges (without reference to the problem behaviour);
- e.) Spanking, (most often a sign of parental frustration, and teaches children it is OK to be physically aggressive and or to be timid, passive, or afraid);

He says:

The goal of positive discipline is self-disciplined children who are responsible and cooperative at their own developmental level. An added value of using positive strategies to guide children's behaviour is that parents feel positive about themselves and their children. (p. 102.)

Stressing the Positive. Positive reinforcement of desired behaviour is the best way to avoid negative behaviour. Constant "attention" received for "negative" behaviour, will tend to reinforce it.

Setting Limits. Children need both positive encouragement, as well as limits. Limiting one or the other will create problems. Particularly for children with disabilities, creating unrealistic expectations is just setting them up to fail, and be disappointed.

It is necessary to be aware and understand the limitations the child has. Depending on the circumstances, these may be decided on after consultation with appropriate professionals (teachers, doctors, therapists etc).

Redirecting the Child. As for a young non-disabled child, sometimes it is appropriate to distract the child with an alternative (acceptable) activity.

Ignoring Inappropriate Behaviour. Although sometimes (like a temper tantrum at the supermarket checkout, with a large audience) easier said than done, e.g. this may be appropriate. There is no shortage of research to show that if you do not "reinforce" the behaviour, by paying attention to it, it may well go away.

Structuring the Environment. Sometimes referred to as *childproofing*, or *baby proofing*, the same techniques of avoiding, or limiting access to settings, or other "dangers" can be applied to a child with a disability (e.g. putting a padlock on a gate, so they cannot go out on to the road.)

It can also involve routine, so that the child knows that bath time follows dinner, and after bath time it is time for bed.

Giving Choices. This can be a case of "Which 2 of your toys do you want to take with you?", or "Which of these 3 choices of outfit do you want to wear tomorrow?", or "As we've only got time to go to one place, do you want to go to the beach or the park?"

Natural and Logical Consequences. This could be like having the (hungry) child who didn't eat their meal at the correct time, wait till their next meal to be fed, rather than give them a snack now.

Giving Breathers (Time-Out). Best used as a last resort. But can be effective for things like tantrums, and disruptive or aggressive behaviour.

However it needs to be used appropriately, otherwise the child does not learn to behave appropriately in the company of others. It also has the double benefit of also giving parents a chance to "cool down".

5. As a means of ensuring both parents are able to be involved, and knowledgeable about the child's disability and able to make informed decisions, there is a need to develop ways of appropriately sharing information about the child, their care, medical and any other related treatments or issues;

The following have been suggested by parents⁴ who have experience in this area.

- Develop a system for keeping all medical records together (perhaps a ring binder). Dividers within the binder can be used to separate information from each specialist.
- Keep a log of all conversations with providers (e.g., telephone, e-mail, fax) in your binder; include dates and times, names and contact information, the outcome of each contact, follow-up that is required, and who will do it and by what date.
- Keep a roster of the telephone and fax numbers of the professionals you are dealing with in the front of the binder so that you don't have to look up numbers each time you want to call.
- Ask for and keep copies of medical records and diagnostic information.
- Ask medical staff to show you (and other family members involved in the care of your child) how to use any special equipment that your child needs. Find out how you can get technical assistance *after hours* or how you might speak with other parents whose children are using the same medical equipment to learn more. (p.27)

⁴P.27, Santelli, B., Poyadue, F., & Young, J. (2001) The Parent to Parent Handbook, Paul H. Brookes Publishing Company Inc. Baltimore: MA.

6. Regardless of their disability, children need to do household chores to develop independence, and learn day-to-day survival skills, otherwise learned helplessness and self-esteem problems may develop

The following “25 Potential Chores for the Child With a Disability” are from a combination of sources, including *Rocky Bay* therapists⁵ and Charlotte Thompson’s book⁶, where she notes (amongst other things) that:

...a child with a disability or any other child can feel worthless or a burden at seeing others do all the work while they receive a “free ride”.

It is important for everyone in the family that the disabled individual does what is possible. Parents and siblings can grow to feel resentment if no contribution is made by the family member who is disabled. These feelings are often buried and may surface elsewhere in the family relationships. Siblings who are constantly forced to give and care for a brother or sister with a disability can themselves become emotionally disabled and shun close relationships later in life due to anger or fear of the sacrifices involved.

It does take time and effort for kids with disabilities to learn to do things around the house, but that’s not a good reason for their lack of chores. (p. 130)

While the child’s age, and degree and type of disability, as well as individual household circumstances will make some of these chores unsuitable, there are sure to be at least some chores from this list that the child with the disability can do, or act as a prompt for other ideas for chores.

⁵ Thanks to Rocky Bay therapists Di Andrewartha, Faye Broadhurst, Lisa Cattalini, Amanda Halfpenny, Aileen Huang, Shelley Smith, and Vivienne Travlos.

⁶ Thompson, Charlotte, (2000) Raising a handicapped child : a helpful guide for parents of the physically disabled [Revised and expanded edition] New York: NY, Oxford University Press ISBN 0-19-513253-x

25 Potential Chores for a Child with a Disability

Meal Related Chores:

1. If a parent is cooking - the child could read out the recipe
2. Peeling or preparing vegetables
3. Be involved in decision making i.e. what to have for dinner
4. Drying dishes (but may need to have a wheelchair height and accessible table);
5. Getting out, and putting away afterwards, crockery and cutlery, (need to ensure a suitable accessible cupboard);
6. Setting the dinner table;
7. Clearing up the table after the meal;
8. Taking rubbish out.

Pet related Chores:

9. Feed the pet/s (i.e. measuring and putting out food);
10. Walking the dog;
11. Brushing dog or cat (if it will sit on the child's lap);

Sibling/parent related Chores:

12. Keep younger siblings amused e.g. reading books;
13. Help younger siblings with homework;
14. Sort and fold washing, e.g. match socks, sort clothes into "owners", and take to appropriate room;

Communications Chores:

15. Get the mail (including junk mail) and open and sort it;
16. Ensure, medical and other appointments are on calendar/s (paper or electronic);
17. Download, and print condition specific information and newsletters, for parents to read at later time (e.g. a specific website, although may need to censor);
18. Ensure parents are aware of any school or other forms needing signatures or other information and are completed;
19. Type letters/emails/assignments for parents/siblings.

Self-management Chores:

20. Homework;
21. Exercises or other treatment tasks (eg physiotherapy) without prompting;
22. Tidying up room;
23. Returning things to where they belong.

General Household Chores:

24. Watering of plants with hose or small watering can;
25. Appropriate cleaning e.g. dusting, or cleaning of own hand basin.

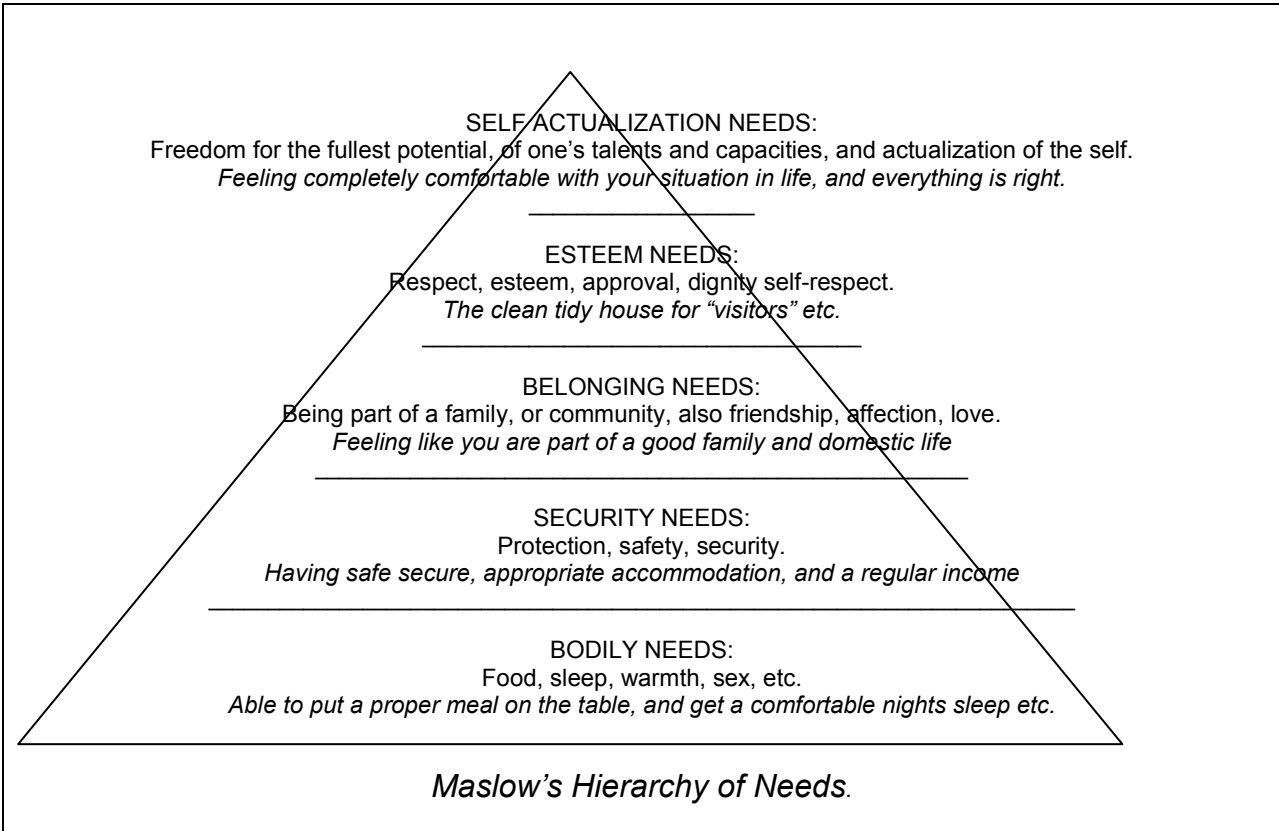
7. **It is not uncommon for parents to feel like their privacy is limited, and pressure to have a clean and tidy home for the constant "visitors" (e.g. health professionals and care support workers);**

It may be helpful to think of issues around privacy, and the need to have a clean and tidy home, in the context of “Maslow’s Hierarchy of Needs”. Abraham Maslow was a psychologist who developed his hierarchy to help explain human needs.

If you are struggling to “keep your head above water” as far as looking after your child, (or children) and maintain a household, and feel guilty about not qualifying for the “Good Housekeeping Award” this framework⁷ may give you a way to think about your situation. As well as help explain your order of priorities to others.

Basically his hierarchy says that we need to deal with fairly basic “lower level” needs like the need for food and shelter, before we can deal with “higher level” needs for respect, esteem, approval and dignity. Although it should be noted that even in non-disability settings it is rare for people to get to the “highest” levels of his hierarchy.

Since Maslow first devised it, he expanded it to have more levels, however many consider the five levels, to be the “definitive” description of the model, and it is certainly enough for this brief discussion.



⁷ Adapted from “Figure 2.10 Maslow’s need hierarchy” p. 62, Peterson, C. (1984) Looking Forward Through The Life Span: Developmental Psychology. Sydney: Prentice-Hall of Australia Pty Ltd.

8. Hospital visits (particularly in relation to operations) may disrupt the whole household routine, apart from being emotionally difficult for the parents and other family members;

You may well feel quite helpless and dependent on the hospital staff. There are some steps that can be taken to reduce the emotional disruption for the child and the household.

As a general indication of what to take, Princess Margaret Hospital says in their “Really Useful Guidebook to Princess Margaret Hospital for Children” (p. 6)

What to bring

- Any paperwork sent to you from the Hospital.
- Any special medical equipment your child requires.
- Medication, inhalers etc.
- Medicare card.
- Health Care Card, Veterans Card (if applicable).
- Private health fund membership details (if applicable).
- Clothing

Parents are responsible for washing their child’s clothes.

Please clearly mark all clothing and toys with your child’s name.

- Pyjamas (front-opening preferred).
- Shoes and slippers.
- Casual clothes for teenagers.
- Day clothes for patients on Ward 4H.
- A favourite toy.
- Toiletries.
- Tissues.
- Disposable nappies if needed.
- Schoolwork provided by your own school.

What not to bring

- Valuables, jewellery or large sums of money (The Hospital is not responsible for any lost property, theft or breakage).
- Electronic games or equipment (These can interfere with sensitive medical equipment).

The following suggestions are for planned admissions to hospital, rather than an emergency situation and are adapted from two sources.⁸

- A. For households with more than one child, there may need to be a pre-agreed understanding or “house rules” for the times the child with a disability is hospitalized. These could include things like; a.) Alternating between the parents as to who collects other children from school etc, and on the day’s not collecting children, that parent visits hospital; b.) Have pre-arranged “regular” babysitters,

⁸ Children’s Hospital at Westmead, (2005) The complete Parenting Guide: Caring for your Child from Toddler to Teenager, Carter, A. (ed.) Focus Publishing: Bondi Junction, NSW, and Le Fanu, J., (1998) The Family Encyclopedia of Baby, Toddler & Childcare. London: Robinson Publishing / Marshall Cavendish Partworks.

for when the parent/s go to the hospital, e.g. a particular aunt, uncle or grandparent;

- B. Be honest with the child, as to what to expect in hospital;
- C. When to tell the child about the pending visit, will depend on their age:
 - 1. For a child under 3, shortly before leaving for hospital (as they will be too young to understand longer concepts of time like “next week” or “tomorrow”);
 - 2. A child 3 or 4 can be told a few days before, and you could perhaps play games about going to hospital;
 - 3. Older children can be told a few weeks before, and will probably give it some thought, and ask questions;
- D. Try to take a favourite possession e.g. Teddy or other “Security Blanket”;
- E. If the child is sufficiently mobile, have them assist in packing or at least help decide on what clothes to take;
- F. Try to establish a belief in the ability of the doctors and medical staff to assist them;
- G. Reading children’s books about visits to hospital well before the event and explaining that hospital visits are a normal part of life for everyone (for various reasons) may assist;
- H. Try to treat the hospital visit as an “adventure” rather than being taken away from home;
- I. Tell them about how they will get to meet other children;
- J. Explain to the child what times you will be able to visit them and ensure you do;
- K. Explain to them that if they are really unhappy, the hospital will phone you, and you will try to either speak to them on the phone or come in for an “extra” visit;
- L. Find out if you can speak to the child on the phone;
- M. Prepare a list of contact phone numbers;
- N. Explain to appropriate hospital staff any special needs the child may have, e.g. favourite bedtime drink, any particular words or phrases they use when they need to go to the toilet, particular food likes or dislikes;
- O. Previous experience, age, and the type of procedure will determine how much of the following you need to explain to them beforehand, like:
 - (1) They should be prepared for the possibility of some pain or discomfort (admittedly a delicate balance between being realistic and creating too much concern) perhaps use “teddy” to play hospitals, to gently prepare the child for the possibility of some pain and discomfort;
 - (2) Whether they will be in a room of their own or in a more general ward;

- (3) When brothers or sisters will be able to visit;
- (4) That they may need to be “photographed” by a big machine for an X-ray, or scan;

P. In terms of visiting the following are recommended;

1. When visiting the child in the ward, play only with your child;
2. Try to limit the number of visitors at one time
3. Never leave without telling your child. When you have to go, explain why, e.g. need to get back to their brothers and sisters etc. Also tell the nursing staff so they can comfort the child if need be.

Q. Ask what if any programs the hospital has for the child to meet other children in the hospital;

R. Enquire as to whether there is anything in particular you can do to assist the child;

S. Respect the privacy and sensitivities of others in the hospital environment.

9. Parent’s of a child with a disability (like parents of children without a disability) need to be aware of, and balance, the positive and negative aspects of access to the internet

The internet and assistive technology offers young people with a physical disability an opportunity to interact with, and develop relationships with, others where the physical disability is “invisible”.

As Brigitte who is quoted in some research⁹ says:

It is nice to be able to sit in the privacy of my own home, go on-line and communicate with a stranger ... if my typing speed is queried I say I am new at this! On-line my disability is HIDDEN if I choose it to be. Why should I reveal such personal info when there is no need to? (p. 334.)

Elsewhere in the same research Sarah says in relation to whether or not having a disability makes any difference on-line:

No it doesn’t make a difference, but I don’t have to bring it up if I don’t want to! Where as most of the time meeting someone in person the disability is spoken about at some stage. Online you can chose not to even bring it up. (p. 333)

Or as Shaun says about disclosing his disability status:

I think it’s only relevant when you need to establish your credibility to talk about a subject relating to disability. For example, people don’t need to know that I have a disability if I am contributing to an analysis of the last All Black test, fine wines and food, movies, raising teenagers etc because it has no relevance. What might be more relevant is my gender, age, race, socio-economic status,

⁹ Bowker, N., & Tuffin, K. (2002) Disability Discourses for Online Identities. *Disability and Society*, 17 (3) 327-344.

parental status, academic background, where I live, who I know etc etc. (p. 335-336.)

There are a number of books and internet sites to assist parents in relation to appropriate internet access and use. (See the resource list at the end of this section for suggestions.)

Websites like the West Australian Education Department at <http://www.eddept.wa.edu.au> and the Yahooologans parent site at <http://yahooligans.yahoo.com/parents/checklist.html> have links to information about the subject, like "Creating a Family Pledge for Online Safety".

The Queensland Police Service suggests the following steps.

Children and the Internet¹⁰

The following suggestions are offered to protect your children from becoming a victim on the Internet;

- Keep your computer in a family room, not in a bedroom, that way you can supervise its use and what is being accessed
- Understand how the Internet works
- Understand parenting controls on your internet browser and how to block websites and emails
- Ask your internet service provider about how special software programs can be used to help protect your child.
- Explain how internet dumping works
- Don't allow your child to submit personal information on-line without your permission or knowledge of why they are submitting it
- Examine the privacy policy of a website and why the website may request personal particulars
- Explain what Agreements mean and the consequences of clicking on the "agree" button
- Try to interact with your child while they are on the Internet - expressing an interest can be both informative, reassuring and educational to both you and the child
- Encourage them to show you and tell you about anything that makes them uncomfortable when surfing the Internet
- Not everyone on the Internet is who he or she may seem. Changing your identity is an easy process and strangers on-line may be difficult to recognise.
- Familiarise yourself and talk to your child about who they contact on-line.
- Never allow your child to have an unsupervised meeting offline with anyone they meet on-line
- Educate your child on the dangers of opening mail, especially those with attachments

¹⁰ <http://www.police.qld.gov.au/programs/crimePrevention/eCrime/children.htm>

Resources:

American Red Cross: Disaster Services (ND) Disaster Preparedness FOR PEOPLE WITH DISABILITIES

http://www.redcross.org/services/disaster/0,1082,0_603_00.html

Amos, J., Green G., (ill.)(1998) Hospital Bath [England]: Cherytree Books.

Behaviour Home Page <http://www.state.ky.us/agencies/behave/homepage.html>

Carers WA <http://www.carerswa.asn.au/>

255 Walcott Street North Perth WA 6006

Phone: (08) 9444 5922 Fax: (08) 9444 8966

Email: info@carerswa.asn.au

24hr Carer Counselling Line: 1800 007 332

Civardi, A., (2005) Cartright, S., (ill.) Bates, M (ed.) Going to the hospital. London: Usborne Publishing.

Duncan, D., (1994) When Molly was in the hospital: a book for brothers and sisters of hospitalized children Rayve Productions.

Families of Spinal Muscular Atrophy <http://www.fsma.org/>

Family Internet Safety Pledge <http://www.surferbeware.com/safety/internet-safety-pledge.htm>

Fathers Network. [U.S.] www.fathersnetwork.org

Johnson, S. (2004) Keep your kids safe on the internet. New York: McGraw-Hill/Osborne. [ISBN: 0072257415]

Tarbox, K. (2000) Katie.Com: My Story. New York: Dutton/The Penguin Group.

Naseef, R., (2001) Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability, (Revised Edition.) Baltimore, MA: Paul H. Brookes Publishing Co.

Parent Project Muscular Dystrophy [U.S.] <http://www.parentprojectmd.org>

Princess Margaret Hospital Customer Service Unit (2005) The Really Useful Guidebook to Princess Margaret Hospital for Children

<http://wchs.health.wa.gov.au/general/visiting/1290.pdf>

Santelli, B., Poyadue, F., & Young, J. (2001) The Parent to Parent Handbook. Paul H. Brookes Publishing Company Inc. Baltimore: MA.

[See also the publishers' website <http://www.brookespublishing.com/>]

Temper Tamers Club <http://www.latrobe.edu.au/bouverie/kidsonly/ttc/index.html>

Triple P Positive Parenting Program <http://www1.triplep.net/>

