

2. Communication Skills

1. If you don't already have them, you may need to develop the communication skills for dealing appropriately with the medical professions, and other support service providers.

This may mean developing assertiveness skills, or the ability to be an advocate (for your child) in the hospital, medical, or other setting, to avoid scenarios where it could otherwise result in a less than satisfactory outcome, become confrontational or a “battle of wills”.

At the start of his book on “Emotional Intelligence” Daniel Goleman¹ quotes the ancient philosopher Aristotle:

Anyone can become angry—that is easy. But to be angry with the right person, to the right degree, at the right time, for the right purpose, and in the right way—that is not easy.

In a more formal sense, it has been said that “*Emotional intelligence is the ability to perceive and express emotions, to understand and use them, and to manage them to foster personal growth.*”² This can be applied to interpersonal communication with health and medical professionals as it involves going from being “Reactionary” to “Responsive”. Robert Naseef, in *Special Children: Challenged Parents*³ refers to the continuum from being *Passive* to *Assertive* to being *Aggressive* and a classic self-help book *Your Perfect Right*, by Michael Emmons and Robert Alberti. They talk of different types of problem solving.

Passive problem solving involves allowing your wishes, thoughts, ideas, to be dealt with in whatever way the *other person* sees fit;

Aggressive problem solving means *you* disregard the other person's rights, feelings, wishes etcetera, by attacking the other person, and establishing a climate of fear.

Assertive problem solving involves thinking and acting in a manner that backs up the legitimate rights of their child with a disability, without putting down the other person's thoughts, feelings or expertise. “The assertive parent is both respectful and self-confident while requesting the services that his or her child needs.” (p. 235)

While it is now widely recognised that to be effective, there needs to be a partnership between parents and professionals, it is also important to ensure that the child with a disability, increasingly becomes involved in the decision making. Otherwise, as one researcher noted, “Lack of inclusion of the choices of young people can result in ‘accidentally-on-purpose’ losing splints or not doing exercises.”⁴

¹ Goleman, Daniel, (1995) Emotional Intelligence: Why it can matter more than IQ. London: Bloomsbury Publishing Plc.

² Salovey, P.; Mayer, J. D.; Caruso, D, (2003) Measuring emotional intelligence as a set of abilities with the Mayer-Salovey-Caruso Emotional Intelligence Test. In S. J. Lopez, & C. R. Snyder, (Eds.), Positive psychological assessment: A handbook of models and measures. (pp. 251-265) Washington, DC: US: American Psychological Association.

³ Naseef, Robert, (2001) Special children, challenged parents: the struggles and rewards of raising a child with a disability (Revised Edition.) Baltimore: Ill., Paul H Brookes Publishing Company ISBN: 1-55766-535-4

⁴ Bricher, G., (2001) p. 246. “If you wanted to know about it just ask”: Exploring disabled young people's experiences of health and healthcare. Unpublished doctoral thesis, University of South Australia.

Some of the health care recommendations from the same South Australian study looking at the experiences of young people include that health practitioners should;

1. Treat each young person as an individual;
 2. Recognise that young disabled people need to be involved in health care decision making;
 3. Use appropriate language;
 4. Work with parents to assist young people to develop their skills in health care decision making;
 5. Recognise that mobility choices are social as well as practical;
 6. Start to question how much treatment is enough;
 7. Start to define success;
 8. Challenge professional perceptions of disability;
 9. Develop links for young disabled people with disabled adults and peers.
- 2. Be prepared to take somebody else along with you (to medical and related appointments,) as an advocate who is not as directly involved as this can sometimes reduce the chances or effects of “information overload”, and not “taking in” important information.**

“Information overload” can be a particular problem for conditions like *Duchenne Muscular Dystrophy*. But for any of the conditions resulting in a physical disability, there is the “double-edged sword” of wanting and needing as much information as possible, at the time of diagnosis, and at other treatment stages, but risking being so overloaded that you cannot cope, or make use of the information received.

It may be worth considering using an advocate or have a trusted friend or relative come with you to initial appointments.

Although written by a scientist⁵, in the context of treatment *for himself* of an uncommon cancer, the same principles can be applied to situations about treatment, and medical practices related to a physical disability.

Despite wanting to be an active participant in treating my cancer, this out-of-body experience reminded me that when dealing with a dread disease, at times an advocate is essential -- even for the most rational of scientists. Having [his wife] Terry’s eyes, ears, and mind working at the same time mine were was valuable in itself, as it allowed me to bounce ideas off her later and helps us make better decisions about my treatment. But when my unconscious took over in an effort to take in information about my condition, Terry was my lifeline, my

⁵ Schneider, S., (2005 *The Patient from Hell: How I worked with my doctors to get the best of modern medicine and how you can too*. Cambridge, MA: De Capo Press / Perseus Books Group.

sole source of information about what had happened. She would brief me afterwards, when I was ready to hear the information, and she would comfort me as well. Through her I learned that having an advocate is not a sign of weakness but an indication that the patient is using all resources available in the hopes of being restored to health.

I highly recommend that all patients try to get advocates. In choosing an advocate, you should decide what level of interaction with medical personnel fits your personality, knowledge base, and medical situation. Find an advocate who can intercede at the level you want and help you think ahead about questions you should ask and requests you should make. Of course your advocate should be someone you trust with very personal information and feel comfortable interacting with, so friends and family members are often ideal. (p. 58-59.)

- 3. Because doctors and other health and support professionals sometimes perform a “gatekeeper” role, by being the people who “authorise” services, you may from time to time need (by doing your research) to be able to “sell” a particular type of intervention, or a particular service provider to one of these “gatekeepers”;**

This can also involve being an educator of the professionals who may well have a number of area's to keep up to date on, where as a parent, you will (presumably) only have the one. Also you will know of the individual circumstances of your case, and how this may well benefit from a particular intervention.

It may be that you have initially heard about a new resource, treatment or other source of benefit for your child with a disability, that your specialist or other service provider has yet to hear or read about. You may have heard about it via a technical journal you have studied via the internet or some other source, or from a fellow parent via a support group (face to face, or on-line) this is your chance to be an advocate for the child's welfare, or benefit, and empower yourself.

- 4. For all families (particularly those where the parents have separated) there is a need to find way's of sharing information between the parents;**

Even for families where the parents have not separated, there is the need to keep track of information related to the child's treatments and related information.

Sometimes in families where the parents have separated there may be a belief that information is sometimes used as a “bargaining tool” or “reward”, between the separated parents. The following have been suggested by parents who have experience in this need for information sharing.

- Develop a system for keeping all medical records together (perhaps a three-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.
- Find out what you can do to make a hospitalization experience less scary for your child.⁶

5. Dealing with the responses of other's to your child with a disability is something that you will need to deal with time and again

In a wide range of situations, there is the need to deal with the reactions of others. For all these settings it may be worth looking at, and thinking about the various issues, and strategies, as described in "Facing the Crowd" by Deborah Fullwood and Peter Cronin⁷ and summarised in Appendix B: Dealing with possible stigma and embarrassment.

⁶ P.27, Santelli, B., Poyadue, F., & Young, J. (2001) The Parent to Parent Handbook. Paul H. Brookes Publishing Company Inc. Baltimore: MA.

⁷ Fullwood, D., & Cronin, P., (1986) Facing The Crowd: Managing other people's insensitivities to your disabled child. Melbourne, Victoria: Royal Victorian Institute for the Blind.

Resources:

Cerebral Palsy Association of Western Australia Ltd. (1995) How can I help? : Information for friends and relatives of a child with cerebral palsy. Coolbinia, W.A. ,

Goleman, Daniel, (1995) Emotional Intelligence: Why it can matter more than IQ. London: Bloomsbury Publishing Plc.

Kids As Self Advocates Advocacy Tips

<http://www.familyvoices.org/KASA/KASA%20Advocacy%20tip%20sheet.2006.doc>

Kids As Advocates Tips on Preparing for a Doctor's Appointment.

<http://www.familyvoices.org/KASA/KASA%20Tips%20on%20Preparing%20for%20a%20Doctor.2006.doc>

Naseef, Robert, (2001) Special children, challenged parents: the struggles and rewards of raising a child with a disability (Revised Edition.) Baltimore: Ill., Paul H Brookes Publishing Company [ISBN: 1-55766-535-4]

Sandler, Adrian, M.D. (2004) Living with Spina Bifida: A Guide for Families and Professionals. (Updated Edition. With a New Preface by the Author.) NC: University of North Carolina Press [ISBN 0-8078-5547-2]

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Thompson, C., (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)

