

## COLUMN / CHRONIQUE

# Consumer Health Information Column

Submitted by Dorothy McLachlan

### Preamble

By way of a brief introduction, I am a Consumer Health Information Technician and health literacy consultant with Alberta Health Services. My position is with AHS Libraries and my office is in the Red Deer Regional Hospital Centre. My education and experience are not in library services but rather as a paralegal, public educator, and facilitator. My role with Alberta Health Services involves assisting patients, their families, staff, and the general public to find good-quality health information in a variety of formats and from a wide range of venues.

### Musings

#### Health literacy – as a parent

Let me just say up front that back in 1992, I had no medical training whatsoever and have only now added a Medical Terminology Certificate to my resume. At that time, pregnant with my second child, I was thinking about the usual things. Would the child be healthy? Would it sleep through the night as quickly as the older sister did? My second daughter was born August 1992 and she was diagnosed with a congenital heart defect. She slept all the time, barely able to stay awake long enough to feed.

We were referred to a Pediatric Cardiologist at the University of Alberta Hospital in Edmonton and so began our 3-three-year long journey into the unknown. Armed with an initial diagnosis of AVSD (atrial ventricular septal defect), I spent many hours in the teaching hospital's medical library while my tiny daughter was in the pediatric intensive care unit.

I cringe when thinking back to those hours that I literally hounded the staff in that library while I studied the workings of the heart, from conception to birth, and the many different abnormalities that can occur. That very stressful time was likely the beginning of my personal health literacy quest. I knew I *needed* information and where to *access* it, that I had to *understand* it enough to ask appropriate questions of the doctors assigned to my daughter's case and then *use* that information to make the best decisions for my daughter and our family.

Fast forward 20 years, and I am now immersed in the field of consumer health and health literacy. I recognize that not all parents have my personality, the confidence to question medical personnel and I admit to a higher degree of tenacity and stubbornness. Unfortunately, the need to be

able to do these things becomes paramount as you learn to advocate for your child who is counting on you. Being strong enough to push through your own fear and focus on acquiring the necessary information is a monumental task at a time when you are not at your learning best.

Health literacy is about communication. It is not limited to the communication between patient and clinician, nor is it only between other health professionals and the public. It encompasses any and all communication where health is the issue and information exchange is the priority. Medical library staff are called upon to act as "information conduits", gently and tactfully leading parents like us to resources that may or may not be understandable and then be encouraging when the nerves set in about not having enough information and being paralyzed by indecision.

I am very sure that I was in no condition to do this back then, so a very belated, but heartfelt "Thank You" to the library staff who helped me.

#### Health literacy research – University of British Columbia/ Public Health Agency of Canada project

As some of you may remember, early in 2011, a call went out on the health literacy listserv for information and feedback on the state of health literacy in Canada. The information was being collected by researchers at the University of British Columbia on behalf of the Public Health Agency of Canada. Researchers then posed questions directly to interested parties and groups:

1. What do you see as the emerging opportunities and responsibilities for your organization to address at this time in the area of health literacy?
2. Who do you see as the key players in advancing health literacy in Canada?
3. What recommendations do you have for the Public Health Agency of Canada in moving forward to address health literacy? In what ways could the Public Health Agency of Canada help your work on health literacy?

Following that, contractors were asked to gather positive examples of health literacy in practice in the field from across the country. The examples were translated into case vignettes reflecting current and recent health literacy related work and (or) existing interventions in health literacy.

Canada falls sadly behind the United Kingdom, Australia, and the United States in this area and the results of this research and potential for narrowing that gap are inspiring.

**Website:**

"Health Literacy Consulting"(<http://www.healthliteracy.com/>) is the brainchild of Helen Osborne, a leading health literacy expert in the United States. From her website, you can access health literacy tips, articles, and books and sign up for her free monthly newsletter.

**Sights, sites, and cites****Books (sights)**

Wild, Cheryl, R.N., B.S.N. Heart defects in children, what every parent should know. Wiley Publishing, New York. 1999. 143 pp. softbound. ISBN 1-56561-166-7.

This book is aimed at parents of babies who are newly diagnosed as the one in a hundred born with a congenital heart defect. It provides basic information to nonmedical parents who want, and indeed need, to understand what is happening to their baby. The information is concise without including medical jargon, and it includes diagrams and aims to fill in the gaps that doctors do not always have time to do. It will provide enough background that parents will be better equipped to ask specific questions of the health care team, making them better prepared for the months ahead. While it does not cover *all* of the defects, it does include the seven most common ones. It may be slightly outdated in terms of medical research and advances, but nothing has been recently published that would make it obsolete. The Heart & Stroke Foundation of Canada does not publish anything on childhood heart defects. The American Heart Association does and it is available on their website.

Dempsey, Sharon. Extreme parenting, parenting your child with a chronic illness. Jessica Kingsley Publishers, London, U.K., and Philadelphia, Pa. 2008. 184 pp. softbound. ISBN 978-1-84310-619-7.

In the author's words: "to care for a child with a chronic illness is parenting at its most extreme" and in her book, she then proceeds to outline how to counteract the effects of that challenge. From her personal experience with a son diagnosed with a brain tumor, the book chronicles from diagnosis, through hospitals and treatments, to support and education and when hope fades, end-of-life issues. She deals with communication and day-to-day life in a well-written and thoughtful way.

Canfield, Jack; Hansen, Mark Victor; McNamara, Heather; Simmons, Karen. Chicken soup for the soul – children with special needs. Health Communications Inc.,

Deerfield Beach, Fla. 2007. 322 pp. softbound. ISBN-10: 0-7573-0620-9.

Always a favorite, this collection focuses on the heart-warming stories of real families and their real children who are special. It is about parents reaching out to other parents to share their children's triumphs and overcoming barriers in school, at home, and in the community.

**(Web) sites****International**

[www.diabetes.org.uk](http://www.diabetes.org.uk) and [www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com)

Both of these pages offer valuable information, slightly different from what is available on the Canadian Diabetes Association website ([www.diabetes.ca](http://www.diabetes.ca)). On the UK site, the right-hand column offers the links that will be of greatest use to health librarians assisting patrons in searches. Check out the 250+ recipes that are diabetes friendly or being able to offer all of the consumer information in 20 different languages. On the site for children, you will find an unbelievable amount of information, links to books, articles, support groups, and conferences.

**National**

[www.virtualhospice.ca](http://www.virtualhospice.ca)

This awardwinning Canadian website provides information on palliative and end-of-life care for the patient and the caregivers. It is interactive in that it allows visitors to ask a question directly to a professional and receive an anonymous reply on the site. It is one of an elite group of websites to tackle this difficult subject in a meaningful and efficient manner. Programs and services are listed by province and by topic, making it very user friendly. From a health literacy perspective, the information there is ample white space, text size adjuster, and common language in most cases. For parents who experience the loss of a child, the support and information are invaluable at a time when close friends and family might not be able to help.

[www.aboutkidshealth.ca](http://www.aboutkidshealth.ca)

From the Hospital for Sick Children in Toronto, this website covers everything for the parents and the child. They have just launched a multilanguage component to the site that adds a much needed service to our immigrant population in Canada. There are videos on the workings of the human body for everyone and a special section "Just for Kids" that contains age-appropriate information on health.