Consumer health information

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Consumer health communities of practice: now meeting in a town near you?

As many of you know, CHLA is affiliated with CHIPIG, the Consumer Health Information Providers Interest Group. This active group, composed mostly of consumer health librarians working in “bricks and mortar” libraries, meets in person in the Toronto area several times a year. CHIPIG allows out-of-town members to join meetings by teleconference. You can learn more about CHIPIG and how to become a member on the CHIPIG Web site, http://www.chla-absc.ca/chipig/.

Some consumer health information providers living outside the Toronto area have found it difficult to network and find professional support through teleconferences alone. Recently, a group of Ottawa professionals—consumer health librarians, medical librarians, and a clinical educator with a nursing background—got together to form a new community of practice. Our first meeting was held in December at the Canadian Lung Association offices. We plan to meet several times a year to share ideas and experiences, to review relevant research, and to find ways to collaborate and learn together. We will invite members from several disciplines, including health educators, health writers, and health professionals.

If you live in the Ottawa area and have an interest in consumer health, please feel welcome to join our group. If you live outside Ottawa and you are part of a similar group, we’d love to hear from you too. We’d like to get a better idea about other ad hoc or formal groups with an interest in consumer health. Please contact me at melaniewise1@gmail.com.

Book review


For most people, going to the hospital is akin to visiting a foreign and unwelcoming country. The hospital is full of things strange and unfamiliar: unusual sights and sounds, a foreign language, new customs, arcane rules. The Essential Hospital Handbook is intended as a travel guide to this unfamiliar place, written for family members of seriously ill adult patients in Canadian and US hospitals. The book offers explanation and practical advice to help family members accompany, advocate, and care for their loved one through a hospital stay.

Our guide on this hospital journey is Toronto-based journalist Patrick Conlon, a fellow traveller; Conlon was inspired to write the book after his partner Jim was hospitalized with an acute life-threatening illness. Galvanized by his experience, Conlon writes with an advocate’s passion that medical care must be patient-centered, and family members must be welcomed and included in decisions about their loved one’s care.

As its title suggests, Conlon’s book does contain “essential” information: an explanation of how hospital care is delivered in several departments, the roles of hospital staff, the daily routine (washing, changing dressings), and how family members can help with these activities. It includes chapters on surgery, living wills, and the intensive care unit (ICU), and three chapters on the recovery ward and preparing for discharge. The chapter on hospice care provides a clear explanation of the physical signals that death is approaching and discusses patients’ physical, social, psychological, and spiritual responses to the end of life. The book includes reference material interspersed throughout its pages: a dictionary of medical terms, a list of common medications and their uses, explanations of medical tests and their purpose, and definitions of medical specialties. One imagines that readers might use sticky notes to mark these reference items and flip back to them often. It also offers templates family members can photocopy and fill in: charts to track a patients’ care, questions to ask the surgeon, a checklist to prepare for discharge, an outline to follow to lodge a complaint, and a sample agenda for a family meeting.

Apart from the essentials, The Essential Hospital Handbook also contains more reflective passages about the history and culture of hospital care. Its chapter on the ICU refers to Florence Nightingale’s contributions; a discussion about emergency care explains the etymology of the word “triage” (from the French trier, to sort). Parts of the book read like a “behind the scenes” tour of hospital life; in one section, the author defines euphemistic medical slang like “ward x” (the morgue), “vitamin H” (Haldol, a tranquilizer given to combative patients), and “stream team” (urology department). These historical and cultural insights are interesting, though arguably not “essential”.

The book aims to empower family members to be as involved as possible in their loved one’s care, and it offers encouragement and tools to do so. Its tone is pitch-perfect, sensitive without being sentimental. By providing so much information in an encouraging tone, Conlon demystifies a scary place and equips family members with the knowledge
and confidence to get involved in a myriad of ways. Highly literate readers will find The Essential Hospital Handbook a helpful guide. But while most family members likely want to participate in their loved one’s care, one wonders how many have the wherewithal to do so to the degree the book suggests. Many people have work commitments and other caregiving duties that prevent them from staying at the bedside for as long as is described in the book. Relatively few people have the time or ability to keep a parallel medical chart for their loved one. And many potential readers will struggle with the book’s sophisticated language and vocabulary.

The book’s writing level is a concern for a guide that could be useful to a wide audience. For example, many definitions eschew lay language in favour of something unnecessarily opaque: the definition for “oncology” is four lines long, with the word “cancer” appearing only at the very end; the definition for “neurology” does not include the word “brain”. (Ask a lay person to define oncologist and neurologist in simple terms, and most would say “cancer doctor” and “brain doctor”.) People with lower literacy—or people whose normally robust literacy is limited by anxiety and exhaustion—may find this guide a difficult slog, especially if they are reading it in the midst of an acute health crisis. To make The Essential Hospital Handbook accessible to the broadest possible audience, the author plans to take literacy levels into consideration in a future edition of the book (P. Conlon, personal correspondence, 16 November 2009).

If you are a caregiver or anticipate being one, or if your library serves caregivers, The Essential Hospital Handbook is recommended reading. It’s a guidebook that’s best read before you anticipate needing it and kept on hand for reference at the bedside.