

Navigating Relationships with FSH: Resources

Books

Burroughs, A. (2012). *This is How: Help for the Self*. New York: St. Martin's Press.

******Totally unexpected "self help" book, written by a hilarious autobiographical writer. Sharp, hilarious, completely honest. Like "Chicken Soup for the Soul" for cynical, sarcastic people ☺*

Davis, H. (1993). *Counseling Parents of Children with Chronic Illness or Disability*. Leicester, UK: BPS.

****Useful if you are a parent or thinking about going to individual, family, or group therapy.*

Edwards, L. (2008). *Life Disrupted: Getting Real About Chronic Illness in your Twenties and Thirties*. New York: Walker & Co.

*****Autobiography of a 30-something woman with a genetic respiratory disease & an autoimmune disorder. Quick read, nice writing style. Honest and upbeat without being syrupy-sweet.*

Fennell, P. A. (2012). *The Chronic Illness Workbook: Strategies and Solutions for Taking Back Your Life*. Latham, NY: Albany Health Management.

***Workbook. Kind of cheesy but has some good guides for planning your week, staying balanced.*

hooks, b. (2002). *Communion: The Female Search for Love*. New York: Perennial.

*****bell hooks is a noted cultural critic, feminist theorist, and scholar. Her books discuss oppression and politics. If you are interested in theory, she is a wonderful place to start.*

Joannides, P. (2011). *Guide to Getting It On! (6th Ed.)*. Oregon: Goofy Foot Press.

******Awesome book. Chapter on Sex & Disability is great. Fun, super easy to read, solid advice. Definite must have if you have or will have a teenager.*

Kaufman, M., Silverberg, C., & Odette, F. (2003). *The Ultimate Guide to Sex and Disability*. San Francisco, CA: Cleis Press.

******Really good resource. Covers a wide range of topics, language is accessible, sex-positive. Highly recommend!*

Livneh, H., & Antonak, R. F. (1997). *Psychosocial Adaptation to Chronic Illness and Disability*. Gaithersburg, MD: Aspen.

****Good. Chapter on MD focuses too much on Duchenne's (but what else is new). The first few chapters are the most helpful. See if you can snag a PDF copy of chapters 1-3 online.*

Lyons, R. F., Sullivan, M. J., Ritvo, P. G., & Coyne, J. C. (1995). *Relationships in Chronic Illness and Disability*. Thousand Oaks, CA: Sage.

*****This is meant to be an academic text but it is actually a quick read and very informative. Chapters include narratives from couples, which can be really helpful.*

Mcruer, R. & Mollow, A (Eds.). (2012). *Sex and Disability*. Durham, NC: Duke University.

****Super dense, difficult to get through. This is a good intro on Disability Studies/critical theory. If you're not into that, don't both with this one.*

Murphy, R. F. (1990). *The Body Silent: The Different World of the Disabled*. New York, NY: Norton & Co.

******Riveting autobiography of a well-respected anthropologist who became a paraplegic and then a quadriplegic in his late 40s/early 50s due to a tumor that had grown around his spine. Really well written, explores the topic of disability throughout history and in different cultures as the author struggles to make sense of his own identity. Highly recommend.*

Myers, K., & Ferlin, F. (Eds.). (2006). *My Body of Knowledge*. San Francisco, CA: Cracked Bell Publishing.

*****Cracked Bell Publishing was started by FSH'er Karen Myers. Her short story in this anthology will resonate with anyone who has FSH.. All of the authors in this collection have various disabilities.*

Ritter, R. (2006). *Coping with Physical Loss and Disability: A Workbook*. Ann Arbor, MI: Loving Healing Press.

*****Don't be fooled by the ridiculous looking cover, this workbook is actually one of the most straightforward and helpful resources I have reviewed. The author is a clinical social worker and was disabled in the military. This is something you can do on your own, in a group, or with a therapist. Worth the \$\$.*

Smith, B. G., & Hutchinson, B. (2004). *Gendering Disability*. New Brunswick, NJ: Rutgers.

****Another theory-heavy book. Great into to disability studies, interesting chapters on Helen Keller, Frida Kahlo, & Tennessee Williams.*

Wendell, S. (1996). *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York, NY: Routledge.

**** Critical theory focusing on feminism and disability. It is well-respected in the academic world but honestly, it's a little whiny. Again, if you are into theory, go for it – you might love it. If not, save your pennies.**

Journal Articles

****I accessed most of these through my university. If you don't have university access, search on Google Scholar. Full text results will have a link on the very right. If you can't get the full-text for free, many journals offer reasonable fees for access to particular articles or volumes. You might also check your local library to see if they have any subscriptions to peer-reviewed journals.**

Arthritis Research Campaign (2006). Growing up ready for emerging adulthood: An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities. Chesterfield, UK: McDonagh, J. E.

Brueggemann, B. J., Garland-Thomson, R., & Kleege, G. (2005). What her body taught (or, teaching about and with a disability): A conversation. *Feminist Studies*, 31(1), 13-33.

Chen, R. K., & Crewe, N. M. (2009). Life satisfaction among people with progressive disabilities. *Journal of Rehabilitation*, 75(2), 50-58.

King, G. A., Shulz, I. Z., Steel, K., Gilpin, M., & Cathers, T. (1993). Self-evaluation and self-concept of adolescents with physical disabilities. *The American Journal of Occupational Therapy*, 47(2), 132-140.

Mossman, M. (2002). Visible disability in the college classroom. *College English*, 64(6), 645-659.

Murphy, N., & Young, P. C. (2005). Sexuality in children and adolescents with disabilities. *Developmental Medicine & Child Neurology*, 47, 640-644.

National Institute of Child Health and Human Development (NIH). (1997). *Reducing the Risk: Connections that make a difference in the lives of youth*. Bethesda, MD: Blum, R. W., & Rinehart, P. M.

Piotrowski, K., & Snell, L. (2007). Health needs of women with disabilities across the lifespan. *JOGNN*, 36(1), 79-87.

Raghavan, R., Bogart, L. M., Elliott, M. N., Vestal, K. D., & Schuster, M. A. (2004). Sexual victimization among a national probability sample of adolescent women. *Perspectives on Sexual and Reproductive Health*, 36(6), 225-232..

- Sawin, K. J., Bellin, M. H., Roux, G., Buran, C. F., & Brei, T. J. (2009). The experience of self-management in adolescent women with spina bifida. *Rehabilitation Nursing, 34*(1), 26-38.
- Swain, K. J., Bellin, M. H., Builta, E., Vassel, L., Buran, C. F., & Brei, T. J. (2006). Cross-informant agreement between adolescents with myelomeningocele and their parents. *Developmental Medicine & Child Neurology, 48*, 188-194.
- Yeo, M., & Sawyer, S. (2005). ABC of adolescence: Chronic illness and disability. *BMJ, 330*, 721-723.

Websites

Resources for emerging adults and parents

Bad Cripple (Blog)

<http://badcripple.blogspot.com/>

Diary of a Goldfish (Blog)

<http://blobolobolob.blogspot.com/2014/05/blogging-against-disablism-day-2014.html>

IZadaptive (Retail: Designer clothing, created for sitting)

<http://www.izadaptive.com/>

Mitchell Tepper – Sexologist (Blog)

<http://mitchelltepper.com/>

Rolling Around in My Head (Blog)

<http://davehingsburger.blogspot.com/>

Rolling with the Punches (Blog)

<http://loopys-rollingwiththepunches.blogspot.co.uk/>

SexualityandDisability.org (Blog)

<http://www.sexualityanddisability.org/default.aspx>

She's a Bibliophile (Blog)

<http://shesabibliophile.wordpress.com/>