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Building Communities of Care

By Andrew Malekoff

What do the following have in common? Asthma, Cancer, Crohn's Disease, Cystic Fibrosis, Degenerative Disc Disease, End Stage Renal Disease, Hepatitis C, Hypoglycemia, Idiopathic Dilated Cardiomyopathy, Irritable Bowel Syndrome, Leg-Calvé-Perthes, Marfan Syndrome, Multiple Sclerosis, Migraines, Polycystic Kidney Disease, Scoliosis and Supraventricular Tachycardia.

If you guessed that they were all physical illnesses you are correct. However, another common thread is they are illnesses that a group of young people in the radical-alternative DIY (do-it-yourself) community have been diagnosed with and have written about (along with a few young people that care about them) in a publication entitled *Sick, a compilation zine on physical illness*.

For the uninitiated, a zine (derived from magazine) is a topical publication typically intended for an alternative or underground audience. A zine tends to include written and visual work aimed at promoting and supporting a social movement. DIY represents an ideal or value for many young people who associate themselves with the punk subculture.

One contributor, Luci, speaks for her fellow contributors when she asks, "How can a disabled person find allies and support?" This book will help supporters and supportees to find some answers, insight and inspiration.

Among the moving narratives in *SICK* is a love story entitled "Scar Mates" by Rainbow, who has been diagnosed with chronic kidney disease. After being rejected by one young suitor who could not deal with the scars left behind after Rainbow's open heart surgery and kidney transplant, she fell in love with a young man that she met on-line, who has been diagnosed with Cystic Fibrosis and Diabetes.

Along with providing poignant first-hand accounts of living with physical illness and chronic disease, many of the authors offer practical advice for young people struggling with these ailments, as well as suggestions for friends and family members that care about them. For example, the authors advise patients to be kind and understanding about themselves and to ask for what they need.

There are also useful tips for friends and family members. In a piece entitled, "Illness and support," Ben Holtzman says that people with illness *do* want to talk about it. He says that saying something small is almost always better than saying nothing at all. The practical advice contained in the collection might be dubbed as uncommon common sense because, although it seems very basic, it is the kind of advice that requires gentle prodding and encouragement to carry it out.

Beyond practical tips, there is great wisdom sprinkled throughout. For example, Emily Klamer, a student, writer and activist from Missouri, who is living with degenerative disc disease, writes elegantly about the “lurking threat” of illness that we all face sooner or later.

SICK editor and essayist Ben Holtzman, who was diagnosed with cancer at age 26, introduces the collection by stating that, "Illness is considered taboo; it's seen by many as awkward, if not depressing, to bring up...The collective strength of these pieces...is meant to further... action toward building communities of care."

The stories are gritty, no-holds-barred, first-hand accounts of what it is like to live and cope with physical illness and chronic disease, including the struggle to get and then find one's way through the maze that is health insurance. By openly revealing what it feels like to be young and sick, the authors - mostly young women - go a long way towards supporting Holtzman's vision.

Hospitals and physicians would do well to have this publication, and ones like it, available as resources for young people with physical illnesses and their friends and family members. Giving voice to what it is like to suffer in silence, is a way that these young DIY authors have extended the bonds of belonging to create true communities of care.

Write to illnesszine@gmail.com if you are interested in learning more about building communities of care.