

Bibliotherapy:

Adolescents with Chronic Illness

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Resources for Adolescents

Apel, M. A. (2006). *Cystic fibrosis: The ultimate teen guide*. Lanham, Maryland: Scarecrow Press, Inc.

This resource comes from a series of interviews with young people with Cystic Fibrosis (CF) and their family members. It provides an introduction to the disease and covers topics such as diagnosis, daily therapies, associated challenges, and the future. Stories from optimistic adolescents and adults living successfully with the disease can be found throughout the text. These stories of successful coping into adulthood provide teen readers with a positive outlook on the future. Boxes with interesting facts throughout the text, and quotes or poems written by CF patients give the book a unique format. Also, at the end of the text, there is additional information about CF, including a glossary, book lists, websites, and organizations. At 280 pages, this is a great resource for adolescents, grade nine and up, to use in the home or classroom. Families, friends, and teachers of adolescents with CF can also benefit from the information in this book. A volunteer experience in a teen counseling position at a CF summer camp sparked the author's interest in this disease. Since then, her interest in the disease has grown, and she briefly worked as a pediatric respiratory therapist in a children's hospital.

Canfield, J., Hansen, M. V., & Newmark, A. (2009). *Chicken soup for the soul: Teens talk tough times*. Cos Cob, Connecticut: Chicken Soup for the Soul Publishing.

Teens Talk Tough Times is a collection of stories about difficult times during adolescence written by teenagers, for teenagers. Topics vary, but those related to illness include diagnosis, treatment, school, friends, depression, emotional support, and death. The stories included are meant to both inspire and support teens that are going through difficult times. At 380 pages, the intended reading level is ages 14 and older. The *Chicken Soup for the Soul* series is well known for providing real life stories, with inspirational and positive messages.

Hautman, P. (2003). *Sweet-blood*. New York, NY: Simon & Schuster Books for Young Readers.

This is a fictional vampire novel intended for adolescents ages 12 and up. Author Pete Hautman creates a character named Lucy, who is an intelligent 16-year old female with diabetes who embraces the gothic/vampire subculture. It follows Lucy's experience with this chronic illness, and explores the theory she creates intertwining diabetes and vampire culture. The book includes information on how diabetics must care for themselves, including

monitoring blood sugar and taking insulin. It highlights her anger related to having diabetes, as well as the cost of her eventual mismanagement of the disease. After a near death experience, Lucy reinvents herself and appreciates the world around her, as well as those who love her. While stressing its fictitious nature, this is a great resource for teens with diabetes, as well as peers in school. Author Pete Hautman's interest in vampires, along with his late stage diagnosis of diabetes contributed to his creation of this novel.

Huegel, K., & Verdick, E. (1998). *Young people and chronic illness: True stories, help, and hope*. Minneapolis, MN: Free Spirit Publishing, Inc.

This work is a self-help book for teens, ages 16 and up, with chronic illness. The purpose is to help teens understand and cope with their chronic conditions. Part 1 of the book, features the stories from real adolescents with chronic illness. These stories highlight the struggles they face, along with their families, friends, interests, and dreams. A question and answer section at the end of each story tells the reader more about the featured illness. Part 2 includes information on learning to cope including managing your illness, communicating with family and friends, coping at school, and overcoming fears. Diagnosed with Chron's disease at age 12, Author Kelly Huegel

experienced the struggles and confusion of chronic illness during adolescence. This, coupled with consultation with medical professionals, allows this book to be a practical, yet comforting resource for teens and their families. Teens who have a friend or peer with a chronic illness can also find comfort and hope in this book.

Kaufman, M. (2005). *Easy for you to say: Q & As for teens living with chronic illness and disability*. Buffalo, NY: Firefly Books.

Easy for You to Say addresses the challenges faced by adolescents with chronic illness or disability. Its format is entirely question and answer style, with questions from real teens with chronic illness answered by a medical professional. The intended audience is teens, ages 12 and up, yet families, educators, and peers can also benefit. Topics covered in this book include family relationships, friends, dating, and medical issues. Author Dr. Miriam Kaufman's knowledge and experience related to this topic come from working directly with teenagers in a hospital clinic. The end of this book also includes a medical glossary, a resource section, and an appendix with charts on drugs and medications. Parents and educators using this resource with younger teens may want to use caution in exploring the appendix due to its nature.

Levert, S. (1993). *Teens face to face with chronic illness*. New York, NY: Julian Messner.

This book discusses chronic illnesses, and how they can affect an adolescent's life, including personal relationships and self-esteem. Integrated throughout the text, comments from young people with chronic conditions describe information about symptoms and treatment, medication, and self-care. These adolescents describe how they cope with a chronic illness. At 129 pages, this book is appropriate for adolescent children, grades seven through 12. It concludes with a glossary and resource list.

Maurer, S. (2010). *Change of heart*. Lodi, New Jersey: WestSide Books.

Change of Heart is a young adult novel intended for adolescents ages 12 and up. This fictitious novel features Emmi, an athletic 16-year old whose life is suddenly changed when she discovers she needs a heart transplant.

Everything that is familiar to her suddenly changes. Not only is she unable to attend school, social interactions with her peers change, and she can no longer play soccer. Without a transplant, Emmi will only have a few months to live.

This novel documents her experience waiting for a transplant, and the feelings of fear, sadness, and anxiety associated with it. In addition to the typical

struggles associated with adolescence, Emmi must face the stressors of her heart condition. While waiting for a transplant, she makes an unexpected friend in a teenage boy at the cardiac clinic. This friendship is the only thing that seems to push Emmi through the boredom and feelings of hopelessness. *Change of Heart* is a beneficial resource for adolescents across the contexts of home and school. A teen diagnosed with a medical condition or in need of a transplant can relate to and find comfort in Emmi's journey. It can also serve as a tool for educators who want to help other teens understand a peer's experience.

NOTE: In order to make Emmi's experience more realistic, author Shari Maurer spoke with several post-transplant patients before writing this novel. Also contributing to her knowledge about this topic is the fact that her youngest daughter was born with a heart defect, and her husband is a cardiologist.

Starlight Children's Foundation. Coping with chemo [Episodes 1-6]. Retrieved from <http://chemo.starlight.org/index.html#> on November 17, 2011. [online webisodes].

The Starlight Children's Foundation (SCF) partnered with The Leukemia & Lymphoma Society to create a series of six webisodes entitled *Coping with Chemo*. They created these short, animated videos to help teens with cancer cope with their disease and treatment. Documenting the experience of two teenagers with cancer, the videos speak to teens in their own language. Topics covered include diagnosis, side effects of chemotherapy, talking to your friends, and celebrating your last treatment session. Input from teen cancer survivors across the nation, as well as medical experts, contributed to the development of these videos. Because of this, the message in each webisode is realistic, yet positive. A resource such as this can help answer questions, as well as provide adolescents with a sense of control. *Coping with Chemo* also has a resource section with additional links to provide general information about a diagnosis, as well as support. This webisode resource is relevant across different contexts, including home and school. At home, teens can use the videos to learn more about their diagnosis and treatment. In the classroom, educators can use these videos as a tool with teenage students to help them understand a peer's diagnosis. The Starlight Children's Foundation is a non-profit organization dedicated to improving the quality of life for chronically ill children. They provide entertainment, education and family activities to help children cope with illness and its associated stressors.

Wolf, P. B. (2009). *I still dream big: Stories of teens living with chronic illness*. Bloomington, IN: AuthorHouse.

This book profiles the voices of 17 adolescents who have experienced chronic illness. It shares their personal experiences and stories related to the shift from normal teenage years to the uncertainty associated with chronic illness. The teens featured describe how they have overcome obstacles and remained optimistic. Despite unexpected diagnoses, they still have high hopes and big dreams for the future. Their positive attitudes suggest that life can go on after diagnosis. The intended audience is adolescent's with chronic illness, yet the stories included are also important for families, friends, and peers of a chronically ill teen. It serves as a source of motivation for teens, as well as a means for their loved ones to understand the physical and emotional challenges they face. Since her diagnosis of lupus in early adulthood, author Penny Wolf now educates and counsels individuals and families living with chronic illness. She also developed a support group for teens with lupus, which was her inspiration for this book.

Starbright World (2011). *Starbright World*. Retrieved from http://www.starbrightworld.org/default_login.aspx?ReturnURL=%2fhome.aspx.

Starbright World (SBW) is an online social network for teenagers, ages 13 to 20, with serious, chronic, or life-threatening medical conditions. Teenagers with a chronically ill sibling, ages 3 to 20, can also be a part of this community. Starbright World allows these teenagers to come together to chat, play games, and post photos, videos, and blogs. Here they can share their experiences and make friends with teens who understand what they are going through. Chat rooms are open 24-7 and monitored by trained, adult staff. A bulletin board features contests and upcoming events, including chats with a mental health specialist and learning stress related coping skills. Medical conditions that require frequent hospitalization, ongoing procedures, or long-term treatments and serious chronic conditions qualify for membership. These include, but are not limited to severe asthma, Chron's disease, cancer, diabetes, migraine headaches, cardiac problems, and transplants. Starlight Children's Foundation cautions against children with developmental, emotional, or behavioral conditions using the site, due to fast-paced nature of an online community. However, with a primary medical condition present, an exception may be made under the guidance of a parent or medical professional.

Starlight Children's Foundation (SCF), an organization dedicated to improving the quality of life for chronically ill children, developed this website. They provide entertainment, education and family activities to help children cope with illness and its associated stressors. As peer support is vital for the developing teenager, SCF created an online network for chronically ill teens to find this support. They strive to keep the community safe by not allowing adults to join, requiring parental consent, and moderating the chat rooms. Research has proven that teens using SBW experience significantly less anxiety and withdrawn behavior, as well as improved self-esteem and communication skills. These teens also show an increased willingness to return for treatment. Vivendi, a French international entertainment company, also sponsors this website.

Resources for Parents/Caregivers

Cline, F. W., & Greene, L. C. (2007). *Parenting children with health issues*. Golden, CO:

Love & Logic Institute, Inc.

This is a resource for parents or caregivers facing the challenges of raising a child with a chronic illness or medical condition. It provides parents with insight and guidance that enables them to provide more appropriate support. Topics range from providing self-care to providing emotional and behavioral support to psychological issues. Sibling relationships, discussing death, health management by the child, and parenting tips across development are also areas of interest. A list of helpful resources concludes the book. In this book, the authors aim to inform, teach, and support families as they cope with challenges. Their use of scenarios and examples makes that material more readable. Author Foster W. Cline, MD, provides insight through his work with families and children for over 35 years as a child psychiatrist. In addition, author Lisa C. Greene has firsthand experience with this topic, as she is the mother of two children with Cystic Fibrosis.

Dempsey, S. (2008). *Extreme parenting: Parenting your child with a chronic illness*.

Philadelphia, PA: Jessica Kingsley Publishers.

Parenting a child with a chronic illness is often a challenging and stressful experience. Author Sharon Dempsey can attest to this, as her young son passed away from a brain tumor. In this 206-page book, she aims to provide support for parents of children with chronic or life-threatening illness. She stresses the importance of parents coping with their child's illness appropriately, in addition to supporting their child. By providing parents with practical strategies, advice, and knowledge about how to cope, she hopes to promote healthy coping and functioning. This book both validates parents' experiences and encourages them to advocate for their child throughout his or her illness.

Resources for Educators

Castle, S. (Producer). (2003) *In the mix: Living with...serious illness* [Television series].

New York, NY: Public Broadcasting Service.

In the Mix is a unique television series aired on PBS, which is a national, non-profit public broadcasting company. PBS is known for its educational media and materials. This half-hour segment of *In the Mix* called *Living with...Serious Illness* features real teens coping with serious and/or chronic medical conditions. These teens discuss the issues they face including school, friends, and family, while sharing their concerns and advice for other teens. Diseases featured in the segment are Asthma, Diabetes, Crohn's Disease, Sickle Cell Disease, Hodgkin's Disease, Leukemia, and Ewing Sarcoma. This resource is ideal for the classroom setting, in which educators can help students understand chronic illness as related to peers. It can help promote critical thinking, discussion, and positive choices in students. In addition to the video, an education guide is available online for educators. Resources for chronic illness, as well as a Q & A section with teens from the show are accessible online for parents and adolescents. The intended audience is grades six through 12.

Castle, S. (Producer). (2008) *In the mix: Depression: What you can do* [Television series].

New York, NY: Public Broadcasting Service.

In this 22-minute episode about depression, PBS aims to help young teens recognize depression in themselves and others. It features a group of middle school students discussing depression, as well as a 15-year-old girl discussing her experience with depression. They discuss how to recognize the signs of depression, how one can help a friend, and who to ask for help. A middle school counselor and an adolescent psychiatrist also join the discussion about why depression occurs. It concludes with tips on what to do/not do if a peer is experiencing depression. The intended audience is adolescents, with a primary focus on middle school students. This resource can be beneficial to use in the classroom setting with teens who experience depression and their peers.

Gootman, M. E. (2005). *When a friend dies: A book for teens about grieving and healing*.

Minneapolis, MN: Free Spirit Publishing.

Death is a sensitive topic of discussion, especially among young people. The death of a chronically ill adolescent is often unexpected and extremely traumatic for friends and peers in the school setting. This resource is a self-help book that provides support for teenagers to help them accept the

emotions associated with loss and move forward. Questions, suggestions, and thoughts from other teens who have experienced the loss of a friend offer help and reassurance. The book does not have many words, but those included can help a grieving teen to reflect on his or her feelings. Author Marilyn E. Gootman wrote this book with empathy, as her own children suffered the death of a friend as a teen. Additional resources and recommended readings conclude the book. While this is a great resource for educators to provide for grieving students, parents and educators with a grieving teen can benefit from it as well.