



Strategies for Navigating Life for Parents and Siblings of Boys with Barth Syndrome

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Author Note

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As the family of a child with Barth Syndrome, you, your spouse, and your other children face an array of stressors that have the potential to negatively affect many important domains of functioning. For example, physiological aspects of the disease, medications and other forms of treatment, frequent hospitalizations, disruptions in daily activities, and alterations in family relationships are some of the factors that may interfere with “normal” life. Not surprisingly, the impact of these disease-related stressors also has implications for your son’s social, emotional, and academic functioning. Furthermore, your son’s health status likely impacts your family’s well-being. Being the parent of a chronically ill child is often associated with caregiver burden, restrictions on social life, marital problems, and strained financial resources. Siblings, too, are frequently affected by chronic illness, and may experience feelings of guilt, anxiety, and sadness as well as restrictions on social life.

Chronic illness within the family is a psychologically and physically exhausting experience that may weigh heavily on one’s quality of life and ability to cope effectively. In the face of such difficulties, it is normal to experience fear, anger, sadness, and anxiety. Acknowledging these feelings and sharing them with others is one of the most important and healthiest ways to deal with the experience. The process of coping with chronic illness in the family can be likened to a journey, with its hills and valleys and untrodden territories. Central to this journey is the ability to adapt – to be flexible and creative in using resources and social support to approach problems actively and courageously. This pamphlet touches on ways to cope with and adapt to the stressors that you and your family may encounter along the way. Our wish is that your journey will be one of resilience and hope.

We have based the enclosed information on both our experiences in speaking with families of a boy with Barth Syndrome, as well as our research efforts within this group and other youngsters with a chronic illness. Throughout this pamphlet, we have incorporated quotes from boys with Barth Syndrome and their family members about their unique experiences with Barth Syndrome. When appropriate, we have made efforts to maintain the anonymity of the speaker. We have organized this pamphlet according to various themes that arose during our conversations with the boys and their families. These themes include:

- Medical Traumatic Stress
- Coping With Pain
- Issues of Death and Dying
- Empowering Siblings
- Family Interactions and Stress
- School Modifications and Accommodations
- Bullying and Peer Problems
- Instilling Hope and Optimism

“I wish I could fix it, but I just can’t. That’s one of the reasons I’m involved with the Barth

Syndrome Foundation – I want to do everything I can.”

-Mother of child with Barth Syndrome

Medical Traumatic Stress

Unfortunately, hospitalizations and doctor's visits can be common events in the life of a child with Barth Syndrome. Traumatic stress symptoms may occur following a hospitalization, especially if the hospitalization was unexpected or involved painful medical procedures. Being aware of possible traumatic events as well as common traumatic symptoms will help you monitor your own child's reaction to hospitalizations (see examples below). Furthermore, there are specific strategies to employ during and after the hospital visit to prevent or reduce traumatic responses.

"Having to go through all of the [medical] tests and procedures is really scary."

- Teenager with Barth Syndrome

"I worry about all of the hospitalizations, infections, and surgeries that my son will have to undergo."

- Mother of child with Barth Syndrome

"Being in the hospital with [my son] and feeling isolated from my other two children can be really difficult."

- Father of child with Barth Syndrome

"A particular time that was really tough was when I could barely breathe – I was probably 4 or 5. We stayed up all night long and I thought I was going to die."

- Boy with Barth Syndrome

Traumatic events can include:

- Being exposed to medical equipment that seems scary
- Being in pain
- Being left alone
- Being afraid of dying

Traumatic symptoms might include:

- Being irritable or upset
- Feeling anxious or confused
- Being easily startled
- Being uncooperative
- Feeling empty or numb

How to Help in the Hospital

- Be available to help your child cope. It may help to hold your child's hand or distract them with story-telling or playing a videogame during painful medical procedures. Remember to give them hugs and praise them for their bravery.
- Explain to your child what is happening in a developmentally appropriate way. Be honest and prepare your child for upcoming procedures.
- Before procedures, ask the health care professionals to describe or demonstrate to your son what he should expect to happen next.
- Talk about feelings together.
- Help your child develop positive relationship with nurses and doctors. One way to do this is to have them make pictures or gifts at home to give to their providers.
- Encourage your child to ask questions about the medical care they are receiving. As your son ages, he will have to function more independently – this is good practice for him.
- Help your child stay connected with friends and family members. Try your best to avoid letting your child become isolated from his friends and family.
- Engage in your own self-care as much as you can. This might mean taking time to read a book, take a nap, or just have a short 'break'.

How to Help After the Hospital

- Return to normal routines as soon as possible in order to enhance feelings of safety. Set normal limits and keep family rules/expectations the same.
- Speak with your child about his feelings. Encourage your child to draw, write, or tell stories about how he is feeling.
- Encourage your child to spend time with friends. Prepare your child for how to answer peers' questions (e.g., "Are you contagious?").
- Help your child to be independent. Tasks/chores that he used to complete (and is still able to perform) should be 'returned' to him.
- Follow-up with your child's doctor as appropriate.

Source: National Child Traumatic Stress Network www.NCTSNet.org

Coping With Pain

The medical problems associated with Barth Syndrome may result in significant and chronic pain. Additionally, certain medical procedures that your child must undergo to manage his illness can cause additional pain. Coping with pain on a daily basis may be a particular challenge for children who “just want to be kids.” Using some of the strategies described below may help your child to better manage his pain.

“I really hate having injections every day – they hurt. One time, I couldn’t even lift my arm because of the pain.”

- Boy with Barth Syndrome

“Tolerating the pain on a day to day basis is probably the hardest part about having Barth.”

- Teenager with Barth Syndrome

“I worry about [my son] having to go through another transplant.”

- Mother of child with Barth Syndrome

“It’s hard to deal with my muscle weakness and pain, especially because my friends are stronger than me and they don’t have to worry about pain.”

- Teenager with Barth Syndrome

Helping your child cope with painful medical procedures:

- Give honest information about painful procedures.
- Allow choice whenever possible (e.g., “Do you want the shot in your right or left arm?”)
- Model bravery for your child. Begin by expressing anxiety and uncertainty (“I’m really nervous about...”). Then help him engage in positive self-talk (“I am brave. This will only last a minute”).
- Encourage relaxation breathing. Have your child take deep breaths to reduce physiological anxiety symptoms in order to decrease the experience of pain.
- Use guided imagery. Have your child pretend that he is a brave superhero. For chronic pain, help your son imagine a special relaxing place (e.g., beach) that is somewhat incompatible with feeling pain (it won’t be totally, but may help take the edge off).
- Distract your child from focusing on the painful procedure. This can involve asking your child to name his favorite hobbies/celebrities/music or having him watch TV or listen to music.
- Reinforcement: Reward your child for cooperative behavior. Rewards may include praise, favorite treats, or small toys.

Dealing With Issues of Death and Dying

Given that the risk of death due to complications with Barth Syndrome is a painful reality, your son and your family may experience sadness and anxiety surrounding his health status. It is important to remember that people experience various stages and experiences of grief, and there is no “right” way to grieve. Below are ways to help cope with issues of death and dying that have been conveyed by families affected by Barth Syndrome, as well as our work with other youth.

“I just don’t know what will happen next.”

- Teenager with Barth Syndrome

“What worries me the most about having Barth is being dead when I wake up.”

- Boy with Barth Syndrome

“The most difficult aspect is the fear of the unknown”

- Mother of child with Barth Syndrome

“Usually, I’m not convinced that I’ll ever be better, and that’s what really worries me.”

- Teenager with Barth Syndrome

“I worry about when he’ll relapse with heart failure, and whether he’ll always be strong enough to pull out of [heart failure].”

- Mother of child with Barth Syndrome

“Getting the diagnosis and recognizing what it meant for [my son] was the most difficult time for our family.”

- Father of child with Barth Syndrome

“The grieving process has been difficult – it’s hard accepting that my child will not be like other boys.”

- Mother of child with Barth Syndrome

“Having lost one child to Barth Syndrome already, what worries me is my knowledge of what is in store.”

- Mother of child with Barth Syndrome

Helping your child cope with issues of death and dying:

- Be honest, open, and genuine with your child about his illness, but refrain from taking away all hope. Talking about issues of death and dying with your child will likely be a difficult process. However, approaching these issues with your child will open lines of communication and will allow your child to feel more comfortable discussing thoughts and feelings related to his illness. Being open and honest may prevent your child from experiencing exaggerated fears and feelings of isolation and confusion.
- Children's understanding of issues related to death and dying gradually develop over time. It is important to deliver messages of diagnosis and prognosis in a manner that the child can understand. However, we suggest avoid using euphemisms (e.g., going to sleep) to prevent confusion and possible fear associated with these natural activities (e.g., going to bed).
- Allow your child to ask questions and talk about his feelings. If he is unable to verbalize feelings, attempt to engage him in pretend play with puppets/dolls or drawing pictures.
- Depending on your background, religion can be a powerful tool to assist you in conversations with your child.

Helping siblings cope with issues of death and dying:

- Be honest, open, and genuine with your other children.
- Talk to siblings about their concerns and discuss their feelings.
- Allow your child's siblings to visit him (e.g., in the hospital) whenever possible.
- Address their own fears of dying, and reassure siblings that most people without Barth Syndrome live very long and healthy lives.

Your own coping with issues of death and dying. Although parents 'never sleep' when their child is in danger, making sure that you take care of yourself can help you cope with difficult situations:

- Empower yourself. Be involved with decision-making when possible.
- Surround yourself with social and emotional support.
- Spend positive time with your child and other family members.

Source: Innovations in Clinical Practice: A Source Book

Empowering Siblings

Siblings are often significantly affected by chronic illness. Observing their brother suffer from Barth Syndrome may cause siblings to experience feelings of guilt, anxiety, and sadness, or cause them to worry about their own health and well-being. Additionally, siblings may encounter restrictions on their social life as a result of having a brother with Barth Syndrome. It may be a difficult adjustment for them as they learn to deal with decreased involvement in peer activities or the stigma of having a brother with a chronic illness. Furthermore, siblings typically retain a strong desire for their parents' attention and resources, which are both limited by the many challenges of being a parent of a child with a chronic illness. Empowering siblings to be involved in their brother's life and health care can be instrumental in the coping process.

"We treat him just like his other brothers – there is no "bubble" around him."

- Mother of child with Barth Syndrome

"I worry about how Barth affects his brother [without Barth]"

- Mother of child with Barth Syndrome

"Doing things independently with my [non-ill] children is really important to me and helps me cope with my stress."

- Father of child with Barth Syndrome

"I can't do things and [my siblings] know it, so they'll come in and help without me asking – that has really helped me deal with my illness."

- Teenager with Barth Syndrome

"I feel really bad when [my child with Barth Syndrome] is hospitalized and [my other child] is at home - I feel like [my other child] just gets 'shuffled around.'"

- Mother of child with Barth Syndrome

Activities in which siblings can become involved:

- Draw pictures for their brother.
- Read to their brother.
- Create a scrapbook for their brother.
- Make a CD of their brother's favorite music.
- Make "get well" signs/cards for their brother.

When a sibling visits his/her brother at the hospital:

- Siblings should be permitted to visit their brother whenever possible.
- Parents should prepare siblings for what to expect at the hospital.
- Siblings should pack a bag of games to play/books to read in the case that their brother is unable to see visitors.

Source: The Children's Hospital of Philadelphia, Child Life and Education

Family Interactions and Stress

Though it seems clear that living with Barth Syndrome affects your children, it is important to remember that you and your spouse may also experience significant distress related to your child's illness. Not surprisingly, the added financial, psychological, and social stressors associated with raising a child with a chronic illness can weigh heavily on parents' abilities to effectively cope with everyday problems. Marital relationships may also be negatively affected by the increased caretaking responsibilities as well as by anxiety and guilt about the cause of the child's disease. Furthermore, social life can be restricted, family activities can be more difficult to organize, and financial resources may be more strained. Finally, as mentioned previously, siblings of children with Barth Syndrome may also be impacted by their brother's disease. Given that children with Barth Syndrome require a substantial amount of parental attention, siblings may feel isolated from their family and/or resentful of their brother's disease.

“[Barth Syndrome] affects the whole family because we revolve around trying to do what's right for [my son with Barth Syndrome], but also what's right for the family. We want to give everyone a sense of normalcy.”

- Mother of child with Barth Syndrome

“My family is always there for me when I'm in a tough time. They help me feel better when I'm starting to feel sick.”

- Boy with Barth Syndrome

“The best advice I can give is to listen to your moms – they know a lot and just want to help.”

- Teenager with Barth Syndrome

“Being a single mom, I've benefited the most from learning to balance – doing things for my son but also forcing myself to get involved socially and taking care of myself.”

- Mother of child with Barth Syndrome

“Following through as a family and keeping our routine has helped us cope.”

- Father of child with Barth Syndrome

A serious illness affects the entire family. Below are ways for everyone to cope with stress:

Physical Strategies

- *Exercise.* Engaging in physical activities, such as hiking, bike riding, swimming, or even walking the dog can help improve mood and increase energy levels. Participating in family activities such as family putt-putt or golf outings can be particularly fun for all.
- *Relaxation.* It is important to take time every day to care for yourself. Try to set aside time for a soothing bath, massage, reading, or meditation.

“Nurturing ourselves and having ‘alone time’ is really important.”

- Father of child with Barth Syndrome

- *Sleep.* Eight hours of sleep each night promotes health and reduces stress.

Emotional Strategies

- *Engage in pleasurable activities.* Doing enjoyable things, such as visiting friends, listening to music, or going to a funny movie, helps to brighten your mood.

“Playing video games with my siblings helps me feel a whole lot better.”

- Teenager with Barth Syndrome

- *Spend time together as a family.* Enjoy fun activities with family members to enhance cohesion and cooperation. Schedule “date nights” for Mom and Dad, and “special time” with kids.

“My family always cheers me up and treats me like I don’t have a disorder.”

- Teenager with Barth Syndrome

- *Laughter.* Laughing produces “feel-good” chemicals in your brain.
- *Talk or write about your feelings.* Expressing your feelings to a friend or family member or writing in a journal helps to reduce stress. It may also be helpful to seek professional help from a mental health professional if you feel overwhelmed by your feelings.

“My friends listen to me and stand up for me if I’m made fun of, and my parents help remind me about my good qualities.”

- Teenager with Barth Syndrome

“I don’t know what I’d do without the informational, emotional, and social support from other families who are dealing with Barth Syndrome.”

- Mother of child with Barth Syndrome

Mental Strategies

- *Positive thinking.* Focusing on the good things in your life helps to ease stress. Substitute a “can’t” with a “can.”

“My words of wisdom? You CAN do it!”

- Mother of child with Barth Syndrome

- *Reframe changes as challenges.* Viewing changes as surmountable challenges rather than losses or barriers can help to reduce stress.
- *Problem-solving.* Identify problems and think of possible solutions to increase a sense of control over stressful events.

“School has been a great help in working with [my son] and coming up with solutions to help him adapt. They understand what he is going through and make adjustments for him.”

- Mother of child with Barth Syndrome

- *Acceptance.* For things out of your control, try to accept and move on, and figure out ways of coping with the situation.

“Once we accepted the diagnosis, we were able to mobilize resources and begin to face the world again.”

- Father of child with Barth Syndrome

School Modifications and Accommodations

Academically, your child may have trouble keeping up with schoolwork, and may have difficulties with obtaining school accommodations. Consequently, grades and academic success may suffer and your son may not be able to maintain grade level and/or may be limited in his ability to attend post-secondary educational opportunities. Some boys with Barth Syndrome also experience specific school problems, ranging from poor attendance as a result of physical symptoms to mild visual spatial and motor learning impairments that impede learning.

Your child's illness may require school modifications and accommodations to optimize his learning environment. Given this, he may be eligible for an Individualized Education Plan (IEP) under the Individuals with Disabilities Act, or a 504 Plan under the Rehabilitation Act.

"Missing school has been the hardest part for me."

-Boy with Barth Syndrome

"Keeping on track academically has been one of the most difficult things."

- Mother of child with Barth Syndrome

"It's hard trying to get others, like the school, to understand the severity of his illness, especially because he looks healthy."

- Father of child with Barth Syndrome

"It's difficult knowing that school and career choices are limited due to Barth."

- Mother of child with Barth Syndrome

"Starting school was the time in my life that was the most difficult – you instantly know that you are different."

-Teenager with Barth Syndrome

"My teachers have been extraordinary and have become my personal friends."

-Teenager with Barth Syndrome

"Supportive teachers have made all the difference at my son's school."

- Mother of child with Barth Syndrome

Below are common school modifications and accommodations. The idea behind modifications is simply to make the playing field as level as possible. It would not be reasonable, for example, to expect a visually impaired child to read from a 'regular' textbook. Several common accommodations are listed below:

- Adjusting class schedules to minimize fatigue.
- Tutorials in particularly difficult subjects or when a child cannot attend school.
- Assistance from note-takers or permission to audiotape lectures.
- Coordination with hospital school staff to avoid extended delays in receiving educational services.
- Use of assistive technology.
- Use of peer mentor. This can be particularly helpful for creating a healthy peer relationship.
- Supplying an extra set of books and/or supplies for use in home or hospital.
- Use of alternative assignments for home or class work.
- Rest periods to prevent fatigue when doing work.
- Provision of special diet.

Bullying and Peer Problems

Your child may experience socialization difficulties and bullying that may be attributed to features of his disease (e.g., small stature, inability to participate in certain play activities that require physical exertion). Additionally, your child may have to deal with the stigma associated with being sick, and such a stigma may negatively affect peer relations. Furthermore, your child may experience difficulty participating in extracurricular and social activities. As a result of these social stressors, your child may become anxious or depressed, and may struggle with low self-esteem. Alternatively, he may engage in acting out behavior to cope with frustration in peer relationships. To help your child cope with these stressors, it is important to become educated about peer victimization and to learn ways to help your child cope with social problems.

“The hardest part about having Barth is dealing with the bullies and teasing at school. Kids aren’t nice because of my height and weak stature.”

- Boy with Barth Syndrome

“It’s tough not being able to do the fun activities, like baseball, that require a lot of energy. All the other kids are bigger and stronger than me.”

- Teenager with Barth Syndrome

“I worry about the day that he realizes that he’s not like everyone else.”

- Mother of child with Barth Syndrome

“High school is hard. People stare at me because I’m small.”

- Teenager with Barth Syndrome

“Trying to find friends who are open-minded and will accept me isn’t easy.”

- Teenager with Barth Syndrome

“Because I’m so sick, sometimes I feel like I’m ‘out of society’ and unable to spend time with my friends.”

- Teenager with Barth Syndrome

“He is unable to play with other kids sometimes, and he gets angry when we tell him he can’t do something.”

- Mother of child with Barth Syndrome

“Some of my friends will do less physical activities so that I can be included, and that makes me feel a lot better.”

- Teenager with Barth Syndrome

“Finding a happy medium with friends has been helpful – they make short visits [so I can be active and energetic while they are present] rather than hang out for the whole day.”

- Teenager with Barth Syndrome

Peer victimization is a specific form of peer maltreatment in which a child is targeted by a peer or group of peers. It takes diverse forms including overt (e.g., hitting, kicking, yelling) and relational attacks (e.g., spreading rumors, excluding others from peer interactions).

Children who victimize (i.e., bully) their peers lack empathy, have difficulty with perspective taking, are preoccupied with their own desires, and are willing to take advantage of others to get what they want.

Signs of peer victimization:

Physical: cuts, bruises, stomachaches, damaged or missing possessions.

Emotional: withdrawal, anxiety, depression, aggressive outbursts.

Behavioral/Social: sleep difficulties (including nightmares), sudden change of friends, disinterest in social activities, bullying family members.

Academic: school refusal, grade declines.

Coping with Peer Victimization

For Children:

- Walk away from the bully or try to avoid where he or she goes.
- Seek instrumental help: Tell an adult or teacher.
- Seek social support: Hang out with friends. Bullies prefer not to pick on kids who are around others.
- Use humor: Distract the bully with a joke.
- Use positive self talk: Tell yourself that you are a stronger person for not fighting back.

For Parents:

- Keep an eye open for warning signs/clues that something is wrong.
- Ask children directly about how peers treat them.
- Work with the school to address bullying. It is not acceptable for schools to ignore a climate of peer harassment – if they are not accommodating, take it to the next administrative level.
- Advocate for a bullying policy at your child's school/after-school center.
- Be a positive role model by modeling prosocial behaviors.
- Seek out positive social opportunities for your child.

Source: National Crime Prevention Council www.ncpc.org

Instilling Hope and Optimism

As a parent of a child with a chronic illness, your life may seem like a constant roller coaster of ups and downs. From time to time, the “ups” may seem to be few and far between, and the “downs” may seem insurmountable and never-ending. Sometimes, the “downs” have the potential to rob you and your family of hope and optimism. Yet, hope and optimism are essential for the coping process, as they build resilience and provide everyone with a sense of purpose for the here-and-now as well as a sense of faith for the future. As with everything else in life, what you hope for may change across the journey – at times, you may hope for a cure or advances in treatment, and at other times you may hope for improved quality of life or an end to the pain. Whatever it may be, the experience of hope and optimism will provide you and your family with the ability to face each and every day.

“The two main things that have helped me to cope with my stress and anxiety are hope and optimism.”

- Mother of child with Barth Syndrome

“In being connected with the Barth Syndrome Foundation, I’ve been able to receive support and information from other people who have been through this. Finally, someone who understands. It was an emotional day – in a good way.”

- Mother of child with Barth Syndrome

“Acceptance and being able to have a positive outlook have been essential.”

-Father of child with Barth Syndrome

“Finding a way to give [him] a sense of hope and goals has been a real struggle lately. The medical scares could be answered by doctors before, but now we have no clue where this is going to go. We need a light at the end of the tunnel – a possibility of a future.”

- Father of child with Barth Syndrome

How to encourage hope in your child

- Focus on what your child *can* do, rather than on what your child can’t do.
- Encourage your child to participate in activities that help him to communicate with family and friends (e.g., writing letters or emails, phone calls).
- Coordinate hospital or home visits with the parents of your child’s friends.
- Remember to let your child have fun – make ice cream sundaes, watch a favorite movie together.
- Ask your child, “What are you hoping for today?” and “What makes you feel best?”
- As much as possible, encourage your child to continue with school work and other activities/clubs in which he is involved.

How to encourage hope in yourself

- Keep a daily journal in which you write down good things about the present and things you hope for in the future.
- Incorporate humor and positive thinking into your day.
- Seek support from friends and family.
- If you are religious, speak with someone at your place of worship for words of encouragement and inspiration.
- Take breaks and engage in self-care rituals (e.g., taking a bubble bath).

Source: St. Jude Children’s Hospital, www.stjude.org

Family Guide

The Barth Syndrome Foundation www.barthsyndrome.org

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DISCLAIMER: This document is designed for educational purposes only and is not intended to serve as medical advice. It is not a substitute for professional care.

A final note: This goal of this pamphlet is to provide families of children with Barth Syndrome with coping strategies to facilitate the management of stressors associated with chronic illness. These strategies can help you to deal with the many obstacles and difficulties that you may encounter during your child's illness. However, at times you may feel overwhelmed by these challenges and uncertain of how to manage the tremendous stressors that you face. During these times, we strongly encourage you to seek professional help to obtain additional support and guidance.

To find a psychologist or psychiatrist in your area, call 1-800-964-2000, or research online by going to <http://locator.apahelpcenter.org/index.cfm>.

Bibliography of Helpful Resources

Websites for Parents

<http://www.cshcn.org/resources/resources.cfm>. The website for the Center for Children with Special Needs. This website provides information and tools to support families of children with chronic illness.

<http://www.ed.gov/about/offices/list/ocr/disabilityresources.html>. The website for the US Department of Education's Office for Civil Rights. This website offers information regarding Disability Discrimination Resources that may be helpful in gaining accommodations and modifications for your child at school.

<http://www.nhlbi.nih.gov/health/public/lung/asthma/guidfam.pdf>. The website for the National Institute of Health. This website provides information about the responsibilities of families and schools for students with chronic illnesses.

<http://www.apahelpcenter.org/featuredtopics/feature.php?id=39>. The website for American Psychological Association. This website offers a Resilience Guide for Parents and Teachers that addresses parenting strategies to help children cope with developmental stressors.

<http://www.compassionatefriends.org/>. The website for Compassionate Friends, Inc, an online community of people who have lost a loved one. This website offers grief support after the death of a child.

<http://www.pediatricheartnetwork.com/childdeath.asp>. The website for the Pediatric Heart Network. This website provides support and guidance for individuals coping with the loss of a child.

Websites for Children

www.kidshealthgalaxy.com. The Children's Hospital of Philadelphia's Website for Kids. This interactive website allows children to take a virtual tour of a hospital, learn about the different people they may encounter at the hospital, and watch animated movies that described some common medical procedures.

www.patchworx.org. Patchworx is a secure website for children facing illness and disability that gives children and their family members a place to share their experiences, learn from each other, and make new friends.

www.bravekids.org/kids/index.html. Club Brave Kids is an online club for children with chronic, life-threatening illness or disability.

Books for Children

The following books are published by the American Psychological Association's Magination Press, and can be purchased at <http://apamaginationpress.org>.

Imagine a Rainbow: A Child's Guide for Soothing Pain by Brenda S. Miles, Ph.D.

What About Me? When Brothers and Sisters Get Sick by Allan Peterkin, M.D.

Gentle Willow: A Story for Children About Dying, Second Edition by Joyce C. Mills, Ph.D.

Little Tree: A Story for Children with Serious Medical Problems, Second Edition, by Joyce C. Mills, Ph.D.