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NAVIGATING EMOTIONS: A GUIDE FOR TEENAGERS WITH RARE DISEASES



Introduction

No one will tell you that being a teenager is easy. Under the best of circumstances, teens struggle with trying to fit in, peer pressure, battles with parents, dating, academics, anxiety over the future and more. As a teen living with a chronic medical condition, you face all of the challenges of being a teenager, as well as, added physical, psychological and emotional challenges that your peers cannot even begin to imagine.

This toolkit is designed to help you navigate the emotional hurdles of being a teenager with a rare disease. More specifically, it seeks to provide individual tools that you can use at school, at home and in social situations.

Introduction

What is Adolescence?

The years between puberty and adulthood are known as adolescence. It is a time of intense intellectual, emotional and social development and moving from childhood to adulthood. It is a time of forging your own identity independent of your parents.

For most, thirteen is a big birthday. “I’m a teenager!” The years between 13 and 19 may hold some of the best moments of your life. They will likely also be the most difficult. Middle school is filled with landmines—raging hormones, kids experimenting with drugs, alcohol and sex. High school is notorious for its cliques. There are the cool kids, the jocks, the nerds and more. And the simple fact that everyone is at various stages of physical and emotional maturity further muddies the waters. Add the simple biological fact teenagers’ brains are not fully developed and that everyone is developing on a different timetable and you are in for one long socially awkward ride on an emotional rollercoaster.

The good news is every single teen is along for the same ride. You probably know someone who seems to have it all, good looks, popularity, athletic ability and more. Despite appearances, trust that they too have issues with self-esteem and self-confidence. The truth is no one escapes being a teen without a few battle scars and bruises.

As a teen living with a rare disease, you have likely already survived more than your fair share of battle scars and bruises, which may provide you with distinct advantages. On the other hand, what every teenager wants most is to fit in and be accepted. The very nature of living with a rare disease sets you apart from your peers.



SECTION 1: UNIQUE CHALLENGES TEENS FACE

Original Sick Chick Poem

Different
 We spend our whole lives trying to be different
 Finding the quirks that set us apart, make us special
 We've all been told, "Colleges look for people who stand out. Who are "different."
 See different is a good thing
 Until you are a man who loves another man
 Or a woman who loves another woman
 Or a person who just can't decide who to love
 Until you are a religious minority
 Until you are the "weird kid"
 Until you are the only one still obsessed with Harry Potter
 Until you are judged for your tattoos, piercings, or hair dye
 Until you have to look for a ramp
 Or drag an oxygen tank around
 Or deal with a PICC line, a port
 Until you are in a wheel chair
 Different is great, until you are Different

—Shira Strongin
Reprinted with permission

Unique Challenges of Living with Rare Disease

Your condition and its severity undoubtedly impacts your daily life in very real ways. You may need to take medication or receive therapies or you may have to live with the fact that there is no treatment for your disease. You may live in chronic pain, or with physical deformities that draw attention every time you leave your house. You may suffer from an invisible illness that is nonetheless very real. In fact, you have daily reminders and realities of living with a chronic condition that cannot be ignored, or forgotten or cured.

What is My New Normal?

You may be well enough to attend a traditional school or your illness may require you to be homeschooled. You may meet others your age through school, church, your neighborhood and other social situations. If your condition has physical manifestations there is no place to hide. If you have an invisible illness, you may choose to keep it quiet or share with only a small group of friends. You may miss more school than the average student and have to play catch up after a hospitalization or extended time at home.

As previously shared, being a teenager comes with its own set of challenges. If you are experiencing any of the following, consider yourself a perfectly normal teenager:

- Withdrawing from family and/or parents
- Arguing with your parents
- Emotional mood swings
- Challenging authority
- Self-doubt, angst
- Experimenting with new hairstyles, clothes, music
- Rebellion against authority
- Hormonal/body changes: issues with body image

SECTION 1: UNIQUE CHALLENGES TEENS FACE

As much as the list above represents very normal behaviors and emotions, the following list may be an indication of a serious problem:

- Depression
- Loss of interest in activities and/or people
- Extreme changes in weight
- Insomnia
- Thoughts of self-mutilation or suicide
- Excessive fatigue
- Inability to concentrate

It is possible that you may have experienced some of these thoughts or emotions in living with your disease. Most people experience depression at some point. Short-term depression or sadness is normal due to stress or an unpleasant life event. Long-term depression is characterized by the inability to find any pleasure in life. If you routinely experience three or more of these symptoms you are likely experiencing serious depression and should talk to your parents, health care provider or other trusted adult.

“It is common for teens to be traumatized by their illness—treatment, frequent hospitalization, feelings of isolation—that may require professional help. Counseling is not for everyone, but if needed psychiatrists, psychologists, social workers and family counselors each provide a distinct type of help that may prove beneficial.” —Maya Doyle, Ph.D., CSW

Your condition may also make you a target for bullying. As pervasive as bullying has become, it is neither normal nor acceptable. If you go to school, you have likely been victimized by bullying or witnessed it. Educators and communities throughout the country are working to address this issue. In recent years, cyber-bullying has become an equally disturbing problem, targeting kids via texting and social media. There are numerous efforts by parents, students and educators to put an end to these destructive practices.

The leading anti-bullying organization in the U.S. is **Stomp Out Bullying** (<http://stompoutbullying.org/>). If you have been an object of curiosity or ridicule, Stomp Out Bullying offers live chat with trained volunteers who can help you. Their website has a wealth of resources, and you can even become a Teen Ambassador. It is also important to make your parents and teachers aware of any issues you may be experiencing.

SECTION 2: SUCCESS STORIES



The key to navigating adolescence is developing both self-esteem and self-confidence. Self-esteem is your own sense of self-worth. Self-confidence is how assured you feel that you can handle any situation. If you are not familiar with the photography of **Rick Guidotti**, take time to check it out at (www.postiveexposure.org). An award winning fashion photographer, Rick was inspired by a random encounter with a girl with albinism. He created Positive Exposure to transform perceptions of people living with genetic, physical and behavioral differences through photography and video. His work will help you to realize that each of us is beautiful in our own unique way.

“How do you get people to see those with differences not as victims, but kids and people first and foremost? The pity has to disappear. The fear has to disappear. Behavior has to change. These kids need to be seen as their parents see them, as their friends see them, as valuable and positive parts of society, as beautiful.”—Rick Guidotti, Positive Exposure

In addition to developing positive self-esteem, you will need coping strategies to help you deal with the pitfalls of being a teenager and the realities of living with a chronic illness. There may be as many solutions as there are problems. Because each individual is unique; there is no one size fits all solution. Try different tactics until you find what works best for you.

This list is by no means comprehensive, but provides some proven strategies:

Talking About It

You may be very open about your illness or share it with only close friends. If you have an invisible illness, it may be easy to guard your privacy. For others, there may be no place to hide. It may be helpful to write and memorize a brief description of your illness that you can share as needed. **Let's Feel Better**, a rare disease patient blog, offers tips for explaining a disease quickly and easily. (<http://letsfeelbetter.com/?s=elevator+speech>)

“The most important thing you can do is to know everything about your condition and fully understand it, so you can be your own advocate, communicate clearly to others and help them to understand.” —Julie Fain, 20

Journaling

Keeping a journal is an excellent way of expressing your feelings while maintaining your privacy. In addition to providing an emotional outlet, it creates a personal history that will be available for future reference.

Meditation

The emotional and physical benefits of mediation are undeniable. Starting with just 5 or 10 minutes a day has been shown to deliver benefits. It has been proven to improve concentration and blood pressure and reverse stress. See the **Resource Guide** at the end for meditation tools for teens.

SECTION 2: SUCCESS STORIES

Exercise

Your illness may limit what you are able to do physically, but if there is any kind of exercise or physical activity that you can safely do, it is well worth the effort and will yield both physical and emotional benefits. Talk to your health care provider about what activities would be safe for you. If exercise seems boring you may want to try participating in a sport. There are dozens of sports which have been modified to allow for people with physical disabilities, many of which offer competitive opportunities. (<http://www.disabled-world.com/sports/>)

Self-advocacy

Part of growing up is becoming more self-sufficient and responsible. Self-advocacy involves taking control of your life and managing your illness. It can mean taking your medication, talking to your doctor and speaking up for yourself. It can be empowering and also demonstrate to your parents that you are maturing.

Laughter

Research has shown that laughter can decrease stress, relieve pain, increase immunity and improve your overall health and well-being. Lindsey Hayes started **Laugh Out Lyme and all Chronic Illnesses** (<http://www.laughoutlyme.com/>) to provide a forum for people with chronic diseases to share and find laughter. Her website, blog and Facebook page provide a healthy dose of laughter. You may also watch a funny movie, listen to comedy on YouTube, and even learn to laugh at yourself.

“Humor is good for ANY illness. It truly is the best medicine. A good laugh has great short-term effects. When you start to laugh, it doesn’t just lighten your mood mentally, it actually induces physical changes in your body” —Lindsey Hayes, Founder, Laugh Out Lyme and all Chronic Illnesses

Volunteer

One of the best ways to take the focus off you and your illness is to help others. Becoming a peer mentor, volunteering at a soup kitchen, or participating in a charitable event are just a few of the many things you can do. Helping others helps you to feel good about yourself and strengthens your compassion for others who experience hardships. It may have the added benefit of having others think of you beyond your illness.

Find Your Passion

At times it may feel like your entire life centers around your illness. Pursuing an interest that inspires and heals provides a much needed escape. Take up photography or any form of art, sing or learn to play an instrument, or find a sport that you are able to do and that is fun. Although your condition may not allow you to do everything you would like to do, it is worth the effort to find something that brings you joy.

Peer Support

Both experts and teens with rare diseases unequivocally agree that the most important thing you can do for yourself is to build relationships and a support network with other teens living with a rare disease. They can offer a degree of understanding and empathy that no one else can.

“The most important thing you can do is reach out to the chronic illness and disability communities. It helps you to understand and be understood.” —Garrett Thomas, 19

SECTION 2: SUCCESS STORIES

If there is a disease specific advocacy or support organization, this is the best place to start. Most offer support groups, peer mentoring and other services that may prove beneficial. If one does not exist, Global Genes may be able to help with a handshake or introduction to another teen facing the same or similar illness.

In addition, social media has created a wonderful forum for making connections and building community. Almost all organizations and government agencies have a social media presence. These channels can be a source of news, information, laws, patient advocacy, insurance issues and more. They also provide a forum for engaging and sharing your experience with others. But perhaps the most interesting and useful are those efforts mounted by other teens living with rare diseases.

Consider, Shira Strongin, recipient of the 2015 RARE Champion of Hope—Teen Advocate Award. Shira created the **Sick Chick Blog** (<http://www.thesickchicks.com/#the-sick-chicks>) and was instrumental in creating We are More, a group of chronically ill and disabled young adults whose goal is to change the way society views them through videos, interviews and social media and to demonstrate that they are more than their illnesses. If you would like to learn more or be involved, email: contact.sickchick@gmail.com.

“My hope is that we are able to build a support network of strong, positive thinking, young chronically ill people who do not define themselves by their illness or limitations and choose to make a difference in the world we live in.” —Shira Strongin

Another great way to connect with others and have some serious fun is to attend a camp for kids with serious illnesses. Two that are highly recommended are **Hole in the Wall Gang** (<http://www.holeinthewallgang.org/>) in Connecticut and **Victory Junction** (<http://victoryjunction.org/>) in North Carolina. Both are offered free of charge and allow you to interact with others experiencing chronic illness while enjoying a range of activities and adventures. Hole in the Wall Gang also offers programs for parents and siblings, as well as a Leaders in Training program for teens aged 17 to 18.

You may also wish to participate in **World Rare Disease Day** (www.rarediseaseday.org), an international awareness campaign with worldwide events on the last day of February each year. The campaign targets the general public, policy makers, researchers and health professionals. You can upload a photo, video and share your personal experience on the Global Genes and WRDD website. Your firsthand account of living with a rare disease is invaluable to increasing understanding. Visit the **Global Genes** website to learn more about how to get involved (<https://globalgenes.org/world-rare-disease-day/>).

SECTION 2: SUCCESS STORIES

If you are just not ready to share or engage with others, **Difference Diaries** (<http://www.differencediaries.org>) may be the next best thing. "Giving voice to young adults, with defining difference," the diaries are short, documentary-style films by young people talking about living with a difference. Although you may not find someone who shares your illness, the stories of living with a chronic condition and their challenges and victories, will likely inspire you.



(<http://www.differencediaries.org/difference-diaries/carolina/>)

SECTION 3: THE PARENT TRAP



Most teens are engaged in battle with their parents in a quest for greater independence. You don't want to be treated like a child. It will be hard for them to think of you as anything else.

Know that most parents have a difficult time letting go. They have loved you and cared for you since the day you were born. You are staking your claim for independence and they are desperately holding on. Your parents may be even more protective because of your illness and understandably so.

Quite simply, opposites clash. So how do you negotiate a truce that maintains the peace and respects each other's needs?

Manage Your Illness

The first step is to learn to take responsibility for managing your illness. Make certain that you understand everything about it, in general and with regard to your specific patient history, risks and prognosis. Demonstrate that you can adhere to medication and treatment protocols. You can do this by having discussions and asking questions of both your parents and your doctors. Keeping a log of symptoms between doctor visits may prove useful. Demonstrate that you will take care of yourself as well as your parents have taken care of you. This will undoubtedly be their greatest fear and you alone have the power to alleviate it. Global Genes has created a guide to developing a medical care notebook that may provide guidance to help you create your own system. Go to globalgenes.org/Toolkits to download a copy.

Problem-Solving

During childhood your parents fixed things, told you what to do, and made decisions for you. As you grow older, it is important to learn how to problem solve. Another great way to demonstrate your independence and maturity is to begin to think through and develop your own solutions. Learning effective problem-solving skills is an essential life skill. See the **Resource Guide** for additional information.

Peer Pressure

Sooner or later you will be faced with friends or acquaintances who want you to join them in a behavior or activity that is questionable or forbidden. Don't be misguided by a desire for approval or to fit in. Having personal values and holding steadfast to them is a hallmark of maturity. Finding and associating with friends who share your values is important.

Honesty

You may think the best way to get around your parents rules is to ignore them and do as you wish behind their back. Testing boundaries is common for teenagers. You may get away with some things, but you will also eventually get caught. Losing your parents trust is a mistake you can't afford to make.

Respect

Your parents have devoted their lives to you since the day you were born. At the very least, they deserve your respect. Screaming, name calling and tantrums do nothing to support your claim that you are growing up. Find positive ways to disagree and state your case.

SECTION 3: THE PARENT TRAP

Some Thoughts for Your Parents

Your teenager will likely challenge you in ways that you never imagined. You may wonder, “Who are you and what have you done with my child?” You will have understandable concerns about your child’s health. And yet, preparing them for self-sufficiency and adulthood is one of your most important jobs. If your child’s illness makes self-sufficiency unrealistic, search for small ways that you can help them feel more self-confident and responsible.

As your teen pushes for independence, you can either push back or help them navigate these challenging years. Your parenting skills need to adapt and adjust to the emerging adult in your home. You will need to learn to strike a balance between maintaining the rules and bending them; lending a helping hand and letting them learn from their mistakes; listening and allowing them the freedom to grow.

- Pick and choose your battles. Blue hair is a means of personal expression or maybe even a deliberate attempt to annoy you. Ignore it or find something nice to say, “What a great color!”
- On the other hand alcohol, drugs and sexuality are serious topics. Make your expectations explicitly clear and do not tolerate or excuse defiance or disobedience.
- Listen and watch for cues and be open to or look for opportunities for conversation. Talking to your teen openly and honestly and respecting his or her opinion will work better than lecturing.
- Trust your teen, unless they give you a reason not to trust them.

- Tell them you love them and that you’re proud of them. With all of the insecurities teens face, they need constant reminders of your unconditional love. They may roll their eyes and duck a hug, but that doesn’t mean they don’t want or need you.

“It’s our instinct as parents to protect. We make concessions to illness, but ultimately that does not serve our children well. I’ve learned to STOP, BREATHE, THINK, before I act or respond. Kids with differences have the same experiences and emotions as other kids; they are just magnified. It’s important to provide love and support when a behavior is an appropriate outcome of the condition; but equally important not to allow your child to use illness as an excuse.”—Lisa Hedley, Holistic Health Practitioner.

CONCLUSION:

THE LAST WORD

Countless variables will define your teen years. There will be many questions and few answers. As a teen living with a rare disease, you have unique challenges that are infinitely more serious than your average teen drama. This Toolkit is designed to help you navigate your teen years. It is impossible to address all that you might encounter. This guide attempts to shine a light on some of the more common issues teenagers face and provide suggestions for approaches you may use. Most importantly, cultivate your self-esteem and self-confidence and develop a trusted support network. Bottom line, have as much fun as you can. You will find that everything that seems so very important in high school has actually very little importance once you graduate. It's a period in time. Make the best of it.

RESOURCE GUIDE



On Becoming an Adult

Depending on your prognosis, you may face all of the usual anxieties regarding your pending adulthood and then some. Will I get into a college? Can I live independently? Will I be able to get a job and support myself? Will I be able to find love, get married, and have a family?

See these Toolkits for additional information.

Taking Control: Optimizing Your Potential as a Young Adult with a Rare Disease

<https://globalgenes.org/toolkits/takingcontrol/intro/>

Taking Control: Gaining Independence as a Young Adult with a Rare Disease

<https://globalgenes.org/toolkits/transitioning/young-adult/>

Engaging in Sports

Resource list of camps and activities <http://phdinspecialeducation.com/groups-activities/>

How to advocate and adapt sports for inclusion <http://www.disabledsportsusa.org/>

Camp resource <http://www.dreamstreetfoundation.org/>

General Information on Children and Teens with Chronic Illness

AboutKidsHealth.org, Self-management Skills: Teens Thriving with Chronic Conditions
<http://www.aboutkidshealth.ca/en/news/newsandfeatures/pages/self-management-skills-teens-thriving-with-chronic-conditions.aspx>

Healthy Children.org, Living with Chronic Illness or Disability
<https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Coping-With-Chronic-Illness.aspx>

Article: Helping Children with Chronic Illness

http://www.aacap.org/aacap/medical_students_and_residents/mentorship_matters/developmentor/Helping_Children_Cope_with_Chronic_Illness.aspx

TeensHealth: <http://teenshealth.org/teen/>

Depression

Teen Depression, Mayo Clinic

<http://www.mayoclinic.org/diseases-conditions/teen-depression/home/ovc-20164553>

Dealing with Depression

<http://www.helpguide.org/articles/depression/dealing-with-depression.htm>

Empowerment for Chronically Ill Teens

Chronic Illness and Education, Helping Teens Soar:

http://www.igliving.com/magazine/articles/IGL_2006-08_AR_Chronic-Illness-and-Education-Helping-Teens-Soar.pdf

Foundations that Differ Education and Resources for Teens, Youth and Chronically Ill

Jonah & the Whale Foundation, Helping families of disabled and chronically ill children

<http://www.jtwf.org/index.html>

KASA, Kids As Self Advocates <http://fvkasa.org/index.php>

Utah Parent Center: Special Needs, Extraordinary Potential

<http://www.utahparentcenter.org/publications/infosheets/transadultinfosheets/tips-for-teens/>

Center for Parent Information Resources, Self-advocacy and Resources for Teens

<http://www.parentcenterhub.org/repository/priority-selfadvocacy/>

Meditation

Meditation Techniques for Teens

<http://everydaylife.globalpost.com/meditation-techniques-teens-14782.html>

Mindful Warriors: Meditations for Teenagers

<http://www.rootsofaction.com/meditation-children-teens-mindful-warriors/>

Drugs, Peers and Relationships

National Institute on Drug Abuse <https://www.drugabuse.gov/children-and-teens>

Planned Parenthood <https://www.plannedparenthood.org/teens>

Safe Teens www.safeteens.org

Sex, etc. <http://sexetc.org/>

Skills you Need: Problem-solving <http://www.skillsyouneed.com/ips/problem-solving.html>

Stomp Out Bullying <http://stompoutbullying.org/>

WebMD Teen Health <http://teens.webmd.com/teens-and-alcohol>

Global Genes Would Like to Thank All of This Toolkit's Contributors and Participants

Maya Doyle, Ph.D., CSW
*LCSW, PhD, Senior Social Worker,
Pediatric Nephrology, Children's Hospital
at Montefiore, Bronx, NY*
www.montekids.org

Lisa Hedley
Holistic Health Practitioner, Co-founder, Difference Diaries
www.differencediaries.org

Michele Kupfer
Co-founder, Difference Diaries
www.differencediaries.org

Lindsey Hayes
Founder, Laugh Out Lyme and all Chronic Illnesses

Julie Fain
Teen Advocate

Shira Strongin
Teen Advocate

Garrett Thomas,
Teen Advocate



<http://globalgenes.org/toolkits>