

Youth Living with Chronic Illness

The Myalgic Encephalomyelitis Association of Ontario published a Brochure entitled '**Youth Living with Chronic Illness**' in 1995. The preparation and printing of this brochure was made possible through grants provided by the Ontario Ministry of Citizenship's Community Action Fund, and The Myalgic Encephalomyelitis Association of Ontario's Fundraising Committee.

The following Brochure may be reprinted if acknowledgement is given to The Myalgic Encephalomyelitis Association of Ontario.

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Introduction

This brochure presents issues that affect youth living with a chronic illness. The intention of the brochure is to confirm the experiences of youth and to provide insights to teachers, family members, health care professionals and others who are in a position to make a difference in the lives of these young people.

Chronic Illness

There are several commonly misunderstood facts about chronic illness. Chronic illnesses do affect children and teens, they do not always get worse over time, symptoms often fluctuate from day to day, and they are frequently an invisible form of disability. Although each person's experience of illness is unique, there are similarities in the issues that these people face.

The Diagnosis

People living with a chronic illness are people first. They work to cope with symptoms that may interfere with daily living, while they also deal with other people's attitude towards them. Although a diagnosis may be reassuring, this process may take a long time. Sometimes the diagnosis is not socially acceptable or medically well understood. A diagnosis should not be considered a prerequisite for providing the compassion, understanding, and support that is needed.

People react differently to a diagnosis. Some people feel relief about having an explanation for their symptoms. Others feel empowered when they know what to expect and can plan to work around potential barriers in their everyday activities. Living with an uncertain future can be stressful. Most people feel grief over lost time, abilities, and social contacts. These factors can lead to social isolation and depression.

Adolescents with Chronic Illness

Adolescence is a critical stage in life because it is when young people are trying to develop a sense of their own identity. They are refining their interests, searching for a focus for future employment, learning ways of interacting with others, and gaining experiences that will influence them throughout their lives. For many, it is a time of dreaming about the future and living life to the fullest. It is also a time when the pressure to conform to peer standards is strong. For these reasons, adolescence can be a particularly difficult time to be coping with a chronic illness.

A strong self-esteem is critical for these individuals to maintain their own dignity and pride. Some people undergo a distinct identity shift from able-bodied to disabled, while others do not. Young people must figure out their own way to do typical teenage things, while also acknowledging and accepting their health-related limitations.

Reacting to a Youth with Chronic Illness

Parents, teachers, friends and others react to youth living with a chronic illness in different ways. It is important to recognize that some reactions can cause as much suffering for the youth as their symptoms. Some people act as if the illness does not exist, perhaps because they believe that the symptoms are "all in their mind" or because they are too uncomfortable to talk about it. Others become fearful that a particular condition is contagious when it is not. There are also people who try to help by providing constant advice, which may leave the youth with the unintended message that they have not been working enough to help themselves or that they have not been making the right choices.

It can be very difficult to know just how to help a youth with a chronic illness. What is most important is to take your cues from the person living with a chronic illness. An adolescent should be able to tell you the type of assistance that would be helpful and respectful. People should assume that personal information disclosed by the adolescent is confidential and that their permission should be granted before it is shared with others.

Support versus Independence

People with chronic illnesses often feel a loss of control and independence. For example, people may not be able to predict the symptoms that interfere with planned activities, and they may need to receive support from others to do activities that they once could do independently. For adolescents who are going through a natural period of struggling for autonomy, independence is a significant issue. It is important to recognize that the chronically ill youth may need help one day but desperately want to be independent the next. Holding a young person back from exploring the limits to their abilities may leave them feeling resentful and rebellious.

The Impact of Society's Values and Myths

Youth living with chronic illness have found that there are a number of common beliefs in society that make life difficult for them. Everyone can help by working to confront the following **myths**:

- if you cannot see a disability, it is not real
- if you are sick, it is your fault
- if you have an illness, you should behave as if you are sick all the time
- young people are not trustworthy or capable of making their own decisions
- people should never talk about their problems or symptoms
- it is best for people to do things totally independently
- one set of standards can and should be applied to all people

Creating Your Own New Reality

Youth living with a chronic illness often find that they need to create their own reality. Not only does this help the individual locate their own limits and accept the need for creative problem-solving, but it can help to avoid getting caught up in society's myths and unrealistic expectations. Dealing with the attitudes of others can be particularly difficult when the condition is invisible, not well understood or stigmatizing.

"Creating your own new reality" emphasizes the need for youth to be confident in themselves. This approach is important for young people who frequently find that, because of their age, their perspectives are not acknowledged. This concept is also important in terms of helping youth to keep their voice, strength, control, dreams and hope. Suicide may become an issue for those who find the challenges to be too great, and so lose hope.

When youth create their own reality, they can identify their own issues and help others to understand their world. This approach, combined with effective

communication, can help youth learn to take care of themselves and play a role in directing the care that they receive from others.

Clear Communication

Youth with chronic illness and those in a position to support them can benefit from clear communication skills, they may find that a supportive counsellor, friend, or parent can help them to practice communication and to deal with issues.

Here Are a Few Tips For Youth

1. Clearly state what type of support you expect and deserve. You can say, "I would like you to support me by doing,," or "thank you for offering your help, but I would like to do this on my own today."
2. Sometimes people are afraid to ask questions. You can take the initiative by asking them, "Do you have questions about my illness or how it will affect my ability to do.....?"
3. Sometimes people may wrongfully assume that you are not able to do something because of your illness. You can take control by clearly stating, "I may have a chronic illness and I may need to do some things in different ways, but I am capable of doing....."

Advocacy

Young people's experiences living with a chronic illness deserve to be acknowledged and not sensationalized or trivialized. These youth are also entitled to reasonable accommodations within society. Advocating for rights and educating others can consume a lot of time and energy. Youth with a chronic illness should be encouraged to use their limited energy on things that are important to them, including social activities, academic studies, and health care. For these reasons, a young person should have at least one advocate who can assist them in dealing with information, policies, and people's attitudes. An advocate might be a parent, teacher, social worker, or a representative from a disability organization. This person can work with the youth to change programs or attitudes so that the young person with a chronic illness can participate in similar activities to their peers. The advocate can help the young person review options and make the decision that best matches their goals and needs. Other people can be supportive by recognizing the youth's abilities, skills, and strengths, and by providing suggestions for overcoming health-imposed limitations.

How to Help

Many people wonder what they can do to help a youth living with a chronic illness. As you review the following suggestions, remember that each individual and circumstance is unique.

A Message for...

...YOUTH LIVING WITH A CHRONIC ILLNESS

- Believe in yourself
- Believe in your dreams, rights and abilities
- Make sure you are considered a person first. You are not your illness. You are a person with interests, feelings, strengths, and weaknesses, who also has a chronic illness.
- Keep or develop interests and hobbies such as music, movies, books, school, computers
- Find a way to tell your friends that you still want to be invited out to social events even if you can't always accept the invitation
- Try to find new ways to maintain or develop relationships. For example, join an interest group or a computer network using a modem from home
- Talk to others with similar symptoms or dilemmas. They may have found ways of coping with daily symptoms, discriminating attitudes, and policies
- You are allowed to have bad days. Remember that bad days will eventually be followed by better days
- You are allowed to talk about having bad days and good days
- Try to find a couple of people who will listen supportively on a regular basis
- Try to be realistic about your abilities
- Judging where your limits are can be difficult, especially if they are always changing. Remember to learn from your mistakes.
- Set up an emergency plan to get the help you need on difficult days
- Have a backup plan when your symptoms might require you to do things differently
- Do something nice for yourself when you are having a hard day
- Try to think of life as a challenge and not as impossible * Never lose hope
- Reward yourself or celebrate with others when something good happens
- You can use humour to break the ice when other people are uncomfortable
- Don't forget to have fun and laugh
- Telling some people, such as teachers, about your illness can help them to accommodate your health issues. You may choose not to tell other people
- Learn to receive help from others without feeling guilty or inadequate
- Be clear with people when you want to make your own decisions

- Explain your situation with confidence. Let people know that you can support them in understanding your situation

...FRIENDS

- Having a chronic illness is just one part of life. Everyone has other interests, like friends, music, movies, books. Talk about all these things
- Offer to give updates by phone when your friend misses a social event
- Do not act like the illness is contagious when it is not
- Fight the myths about chronic illness. Educate your friends and teachers
- If you want to help but you're not sure how, just ask the person who is ill
- If you have an idea about how to help, you can ask first to make sure it is okay
- Think of ways you can support your friend with school activities. For example, drop by with notes or discuss a lesson by phone
- Think of creative ways to include your friend in social activities. For example, go to your friend's house with a video when your friend can't go to the movie theatre
- Don't be afraid to invite your friend to a social event or activity even if you think that for health reasons, she or he may not be able to join you
- Try to be understanding when your friend has to cancel a plan at the last moment, and invite them again next time

...PARENTS

- Believe what your teenage is telling you
- Be a supportive listener
- Be encouraging by focusing on abilities and strengths
- Encourage your adolescent to be clear about when they want help and when they would like to do something independently
- If you have a idea about how to help them, you can discuss it ahead of time
- Support your teenager in learning how to make their own informed decisions
- Your child will make mistakes. Gently support them in learning from their mistakes
- Advocate within the school and health care systems or find someone who can
- Document conversations and meetings regarding your child and the requests made for special accommodations within the school and health care systems
- Join groups for parents of disabled children/adolescents, to learn about effective coping strategies and sources of support

...TEACHERS

- Become informed about the condition and how it affects learning and school participation

- Remember that many chronic illnesses have neurological or cognitive impacts affecting, for example, short-term memory and concentration. This may mean that the student needs special support
- Chronic illness affects the student's energy level, which in turn can interfere with the speed with which work is completed
- Chronic illness affects the general health of the student and can affect the ability of the student to attend classes on a regular basis. Home schooling may be appropriate
- The student with a chronic illness frequently needs to be provided with alternative ways to achieve their academic goals
- Teachers need to be supported within the school system by administrators who understand the need for flexibility
- If you have questions or need information, ask the youth or the youth and parent
- Consider working with the young person in educating school personnel and students about chronic illness
- Set up supports within the school system so future students can receive help too

...AN ADVOCATE

- Discuss issues with the young person and help them to clarify their issues
- Advocate with, not for, the youth. Find a way to include them in the decision-making
- Write letters and arrange meetings where the youth's issues can be addressed
- Keep a detailed, dated record of all conversations and meetings
- Help in obtaining more information about the illness, other cases, health and school policies, and legislation regarding accommodation
- Help in distributing information and increasing general awareness of the illness and the way it impacts upon a person's life
- Be persistent