

COPING WITH HHT: FOR TEENS



IN COLLABORATION WITH
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HHT is a genetic disease. That means you inherited it from either your mother or father and you've had it since you were born. Probably you have other relatives or siblings with HHT, so you've seen how it can affect people in different ways even in the same family. Most people with HHT have frequent nosebleeds, but some don't. Other symptoms are red spots on your skin, and abnormal blood vessels in your lungs, brain, liver, or intestines.

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FS

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SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

The worst medical consequences of HHT are mostly preventable, once you know you have it.

Living with HHT can be stressful, at times, but most people can manage it.

Most people who take good care of their HHT can have pretty normal lives.

As a teenager, you can begin taking care of your HHT health needs and making decisions about your treatments.



The Cornerstone of
the HHT Community

HHT Foundation International Inc.
P.O. Box 329 / Monkton / MD 21111

HERE ARE SOME THINGS YOU CAN DO TO TAKE CHARGE OF YOUR HHT:

Learn as much as you can about HHT, your particular symptoms and problems and especially what you can do to prevent problems in the future. Your parents, the HHT Foundation website, and your doctors and nurses are good sources of information.

MANAGE YOUR NOSEBLEEDS.

- › Know the best way for you to stop the bleeding.
- › If you need help, be able to explain to others exactly what you need.
- › Tell all your friends, family, teachers and coaches about your nosebleeds, so they won't be shocked or surprised when you get one.
- › Always carry tissues, cotton, or whatever "nosebleed supplies" you need.
- › Keep hydrogen peroxide handy for getting blood stains out of clothing, sheets or carpet. Take a small bottle along when you go out with friends or stay over at grandma's.

MANAGE YOUR FATIGUE.

If you have anemia or difficulty breathing, you may get tired easily, have difficulty concentrating, playing sports or getting your schoolwork finished.

- › Ask your friends to spend time doing more laid back things with you—watch a movie, play video or board games, go out to eat. DON'T stop seeing your friends!
- › Make a list of the most important things you need to get done. Put less important things aside until you feel better.
- › If you need more time for school work, or a break from sports or gym class, discuss this with your parents and teachers. Your school should be able to change your schedule as needed.

MANAGE THE STRESS OF MEDICAL PROCEDURES.

Some people with HHT need a medical procedure or surgery to repair AVMs (abnormal blood vessels) in their lungs or brain. These treatments are usually not painful, but they can cause anxiety. Knowing ahead of time about what will happen, how long you'll need to recover, and whether you need to stay in the hospital will help you get prepared. Ask as many questions as you need to when you see the doctor. Bring along something distracting, like an iPod or book, to keep you relaxed and occupied while waiting for your appointment or recovering.

COPE WITH EMOTIONS.

Teens go through many changes physically, socially, emotionally and intellectually. All this development is amazing and leads to adulthood—but the transition is stressful. All teens have times when they feel scared, embarrassed, sad, irritable, frustrated, worried, or angry. These feelings are normal and usually get better after a while, but having HHT can make them more intense. You can learn to cope with HHT. Coping means finding ways to manage your emotions, get through rough times and generally feel good about life. Some things that you can do to cope are:

- › Talk about your feelings with people you love and trust.
- › Spend time with your friends.
- › Get involved with hobbies, games or something fun that takes your mind off your problems. Take a break from thinking about HHT!
- › Do something to relax, like yoga, meditating or listening to music.
- › Exercise, take a walk, and stay active physically if you are able.
- › If you're feeling depressed or very anxious for more than a week, talk to your school counselor, nurse or psychologist. Tell your parents or doctor. They can get you more help if you need it.

Managing your symptoms, coping with HHT and learning to take care of your physical and mental health can make you stronger. You can be proud of yourself and your ability to manage this disease. HHT does not have to define you; it's just something you have to deal with while you're busy growing up and enjoying life.



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