Whether you have been recently told that you have NF1 or have known about it for a long time, it is natural to feel stressed, worried, or upset at times. The challenges of living with NF1 can be difficult; however, there are things that you can do to feel more in control and to live a fulfilling life.
STEP #1: OBTAIN THE MOST ACCURATE INFORMATION ABOUT NF1.

Why is this helpful?

Getting accurate information about NF1 is an important first step in coping with its challenges. Knowledge can help you feel more in control. It can also help you figure out what you should be concerned about and what you do not need to worry about.

What is NF1?

Neurofibromatosis type 1 (NF1) is a common condition in which affected people are prone to develop benign and malignant (cancer) tumors. Typically, the diagnosis of NF1 is first made in children who have birthmarks (café-au-lait macules) and skinfold freckling (freckles in their armpit or groin areas). The skin tumors (neurofibromas) usually begin to appear in teenagers and increase in number throughout adulthood. Some of these neurofibromas can be more extensive and appear earlier in childhood (plexiform neurofibromas). When you see the eye doctor (ophthalmologist), nearly all adults will have small pigmented bumps on the colored portion of their eyes (iris), called Lisch nodules, which do not cause any medical problems.

In addition to the above medical problems, people with NF1 frequently have learning disabilities, attention deficit, or challenges in social situations. Less commonly, individuals with NF1 may develop a cancer, such as a malignant brain tumor, malignant peripheral nerve sheath tumor, pheochromocytoma, or breast cancer.

NF1 is a genetic condition, meaning that it runs in families. In this regard, half of all people seen with NF1 have an affected mother or father with NF1. However, the other half will represent the first person in their family with NF1.

Are there treatments for NF1?

There is no cure for NF1, and currently no proven medical therapies. However, laboratory scientists and clinicians, like those at the Washington University NF Center (http://nfcenter.wustl.edu), are working hard to discover and evaluate promising treatments for many of the medical problems that arise in people with NF1.

There has been enormous progress over the past ten years, and several new treatments are now being used to treat NF1-associated learning disabilities, plexiform neurofibromas, brain tumors, and malignant peripheral nerve sheath tumors.

What is the prognosis?

NF1 is a lifelong medical condition that requires regular surveillance by healthcare professionals expert in the care of individuals with NF1. With annual check-ups, prompt recognition of new medical problems, and timely treatment, people affected with NF1 can lead fulfilling lives.

STEP #2: COMMUNICATE WITH YOUR DOCTOR.

Why is this important?

You likely have general questions and concerns about NF1 as well as those specific to how NF1 affects your own personal health. Asking these questions can clear up misunderstandings, and help you feel less worried and confused. You have the right to ask your doctor any questions. It is your body and your health.

There is also important information that you should tell your doctor to help him or her take care of your health. Your doctor may be an expert on NF1, but you are the expert about you. By working together as a team, you and your healthcare professionals can best manage your health.

What questions can I ask my doctor?

You should ask any questions that allow you to feel more in control of your NF1. Your NF1 team will be happy to tell you more about how NF1 typically affects people, what treatments are currently available, and how ongoing research will lead to improved therapies. You may also
wish to visit the Washington University NF Center website (http://nfcenter.wustl.edu) to learn more about NF1, so that you can ask more specific questions when you visit your doctor.

**What is important to tell my doctor?**

You should tell your NF1 team about any new changes in your health. They will work with you to determine whether this new problem is related to NF1, and how best to manage it. If you notice new weakness, changes in thinking, weight loss, sweating at night, or increased growth in a plexiform neurofibroma, it is important to call your medical team promptly.

**STEP #3: CONNECT WITH OTHERS WHO HAVE NF1.**

**Why is this helpful?**

Connecting with other people who also have NF1 can help you learn from their experiences, recognize that you are not alone, and receive
support for your own struggles. You can also work together to advocate for NF1 services and research.

**How can I connect with others with NF1?**

You can stay connected through the Washington University NF Center website (http://nfcenter.wustl.edu) and social media sites (Facebook, YouTube).

In addition, the two national organizations, The Neurofibromatosis Network (www.NFnetwork.org) and the Children’s Tumor Foundation (www.ctf.org), also provide information about how to join local chapters and support groups. These websites also allow you to search for doctors in your area who specialize in NF1. You can ask your NF specialist for information about other ways you can get connected with and support the local NF community.

**STEP #4: TAKE ACTION ON WHAT YOU CAN CONTROL.**

**Why is this important?**

Coping with NF1 can be overwhelming at times. When you feel this way, it is important to distinguish between what you can control and what you cannot control. This helps you to focus your energy on the things that you actually have control over.

**What can I control?**

There are many things that are within your control. Here are just a few:

- Learning about NF1
- Maintaining healthy habits
- Reaching out to your support network
- Advocating for yourself
- Getting involved in confidence-building activities
- Raising awareness about NF1
How can I take action?

Learning about NF1

If you are reading this brochure, you have already started to learn more about NF1. You may also know quite a bit about what NF1 is and what it is not. You can also learn more about NF1 by asking your doctor questions, talking to others with NF1, and reading the educational materials on NF1 posted on the Washington University NF Center website (http://nfcenter.wustl.edu).

Maintaining healthy habits

NF1 is only one aspect of your health. As you have learned, you can live a very healthy life, even though you have NF1. Important health habits include: exercising regularly, maintaining a balanced diet, and going to your regular medical check-ups.

Reaching out to your support network

When dealing with a stressful situation, one of the most important things you can do is to maintain a sense of normalcy, so that it does not feel like everything is changing at once. A great way to keep a normal routine is to continue your usual activities with family, friends, classmates, coworkers, and neighbors. Stress can make some people want to spend more time by themselves. While this is a natural reaction, spending too much time by yourself and creating isolation from others tends to make stress worse. Spending fun time with family and friends, even when you don’t feel up to it, can help to relieve stress.

We have already talked about the benefits of connecting with other people who have NF1 and how you can do this. Talking to people in your support network can also help you think of different ways to handle stressful situations, whether they are related to NF1 or not.

Some people find it helpful to tell their close friends and family about their NF1. This may allow you to clear up misconceptions and gain useful insights from others. The decision to tell others about your NF1 is a personal choice. It is useful to consider who will likely be understanding and supportive of you. As you get older, it will be important to be able to talk with your significant other about NF1,
particularly if you are considering having children. For more information about disclosure, you should read the brochure, entitled “Telling People You Have NF1”, available on the Washington University NF Center website (http://nfcenter.wustl.edu).

**Advocating for yourself**

When you were young, your parents were likely the ones who functioned as your best advocates when you had problems or needed help. Now that you are becoming more independent, it will be necessary for you to advocate for yourself. No matter how old you are, it is necessary to practice self-advocacy. Advocating for yourself means speaking up for yourself, asking questions, and telling others what you want or need. You can advocate for yourself with your medical providers, teachers, employers, family, friends, and others. Speaking up for yourself has many benefits: it helps you to build confidence, gain independence, demonstrate responsibility, and get the things that you require.

**Getting involved in confidence-building activities**

It is common to experience self-confidence issues as a teen or young adult, and sometimes having NF1 can make it even harder. It is important to realize that NF1 does not change who you are; however, it may affect how you feel about yourself. The good news is that confidence is something that can be developed and maintained. There are many different types of activities that you can do to build your self-confidence. It is important for you to find those activities that work best for you.

First, consider the things that you are already good at. They could be anything, such as playing music, bicycling, cooking, building things, helping others, gardening, playing basketball, writing, creating art, taking care of animals, playing soccer, singing, talking with friends, running, learning new things, decorating, rock climbing, reading, making crafts, taking photos, acting in a play, fishing, dancing, playing board games, bowling, giving advice, giving compliments, talking about current events, horseback riding, swimming, planning a party, and many more. Then, brainstorm all the ways that you could get involved in these types of activities. Talk with people in your support system, and make plans to participate in a few of these activities. Doing things that you are good at builds confidence.
Next, consider those things that you aren’t sure you are good at, but you think might be fun to try. Pick a few of these rewarding activities, and give them a whirl, even if you don’t feel confident. While most people would like to have confidence before they do something, confidence is often something that is gained after trying something new.

To become more confident, it helps to think positively. This can be easier said than done. Here is a daily exercise that you can use to help you get into the habit of seeing the positive aspects of your life: At the end of each day, reflect upon and write down your successes, positive feelings you have about yourself, or the things that went well for you today. This will help you discover the reasons you already have to feel good about yourself. When you are feeling down, you can also go back and review your list to help you feel more positive.

It also helps to show confidence, even when you don’t feel that way. By acting confident, you will actually start to feel confident. Some small things that you can do every day to show confidence include standing tall, making eye contact, and smiling at the people you meet.
STEP #5: ACCEPT WHAT YOU CANNOT CONTROL.
BE WILLING TO LIVE WITH IMPERFECTION AND UNCERTAINTY.

Why is this helpful?

With every stressful situation you face, there will be things that you can control and things that you cannot control (but really wish you could). Living with NF1 is one of these types of situations. It is important to accept the things that you cannot control, because the longer you spend trying to change them, the less time and energy you will have for those things in your life that you actually have control over. Acceptance can free you to focus on more fulfilling activities.

What can I not control? What do I need to accept?

**Imperfections:** NF1 can cause changes in your appearance, owing to the presence of neurofibromas. It is usually unrealistic to “fix” all of these imperfections.

**Uncertainty:** No one can be sure whether your NF1 will get worse or not, or whether your children will be affected or not.

How can I accept the imperfections that come with NF1?

Most people are dissatisfied with their appearance in some way. You cannot control if you get more neurofibromas, but you can control how you choose to live your life. You are much more than just your appearance. You can live a full and successful life, regardless of how you look or think you look. You cannot know what others are thinking about you. They may not even notice or really care about the imperfections and differences that you notice. Even if someone does not like you or how you look, people have different opinions, and your worth is not determined by the opinions of others. The goal is not to look perfect, be perfect, or feel perfect, but rather to live your life with imperfections. One of the best ways to achieve this goal is to keep doing your normal activities and get busy with the things you enjoy.
If you really want to overcome your worries about how you look, you can make a plan to gradually face your fears. By facing your fears, you will have a chance to get accustomed to situations that right now make you feel self-conscious. To establish your plan, list the situations that you currently avoid because you are worried about how you look. Put them in order from those that make you feel the least self-conscious to those that make you feel the most self-conscious. For example, a person who always wears long-sleeved shirts or blouses, even during the summer to hide their café-au-lait spots or neurofibromas, might make a “situations list” like this (from least uncomfortable to most uncomfortable): wearing short-sleeves at home around my family, wearing short-sleeves when I am out with my close friends, wearing short-sleeves at school or work, wearing short-sleeves to a party where I don’t know everyone there, and wearing short-sleeves when I go out on a date. To gradually face your fears, start with the situation from your list that bothers you the least, and practice it several times until it doesn’t bother you as much. Do this again with each situation, one at a time, working your way up from the easiest situations to the hardest. The more practice you get, the more comfortable you will feel about your imperfections and the more confident you will be as a person.
How can I cope with the uncertainty that comes with NF1?

No one can know the future before it happens. Not knowing what will happen is difficult, but NF1 is not completely within your control. No matter how much worrying you do, you still cannot predict what will happen in the future. You have to accept that difficulties are a part of life, and like everyone else, you have to cope with the challenges that you have been given.

The goal is not to convince yourself that nothing bad will happen, but rather to live your life anyway. You don’t know what will happen in the future, but you have an opportunity each day to live your life more fully and to pursue your life goals. To do this, it is often useful to reflect on what is important to you and what goals you have. It is good to dream and set big goals, but, in order to achieve them, you should break them down into smaller, more manageable steps. Take one step at a time and don’t forget to reach out to those around you to help you in this process.
STEP #6: SEEK PROFESSIONAL HELP.

Why is this important?

While talking to your family and friends can be a great source of support, there may be times when you feel like you could use more help than they know how to provide. Similarly, you may want to speak with someone who is not a member of your family or friendship group. Professional therapists or counselors are trained to help people cope with adversity and stressful emotions. They also maintain your privacy, so that you can feel comfortable sharing how you feel without having to worry about what other people might think.

When should I seek professional help?

Counseling can be helpful for many people. Here are a few signs that should prompt you to consider seeking professional help:

- If you frequently feel sad, worried, or angry
- If you are less interested in the things that you used to enjoy
- If your stress is affecting your sleep or appetite
- If your stress is affecting your performance at school or work
- If your stress is affecting your relationships with family, friends, or others

How can I find a therapist?

You can contact your doctor to find a suitable therapist or counselor. You can also call your insurance company, the local mental health association, or 314.454.TEEN (8336) for a list of mental health providers in your area.
INFORMATION FOR THERAPISTS AND COUNSELORS

What psychological difficulties are more common in people with NF1?

Some people with NF1 struggle with psychological difficulties. Instead, it is important to be aware that some difficulties are more common among people with NF1 than in people without NF1. These difficulties include learning disabilities, attention deficit/hyperactivity disorder, and autism spectrum disorder. NF1 has also been linked to increased problems with recognizing social cues as well as with motor coordination and organizational skills. In addition, individuals with NF1 may be more likely to experience periods of anxiety and depression as they try to cope with NF1 and other life struggles.

What therapeutic techniques might help someone cope with having NF1?

Cognitive-Behavioral Therapy (CBT) and Acceptance and Commitment Therapy (ACT) are evidence-based psychotherapies that are effective for helping individuals manage stress, anxiety, depression, and anger. CBT involves developing coping thoughts that are more helpful and accurate than one’s negative thoughts as well as establishing coping behaviors, such as practicing problem-solving skills, gradually facing one’s fears, and participating in pleasurable and productive activities. ACT involves noticing and accepting one’s thoughts and feelings, committing to core values, and taking action in accordance with one’s values.

Living with NF1 can be difficult at times, but there are many things you can do to overcome these challenges. We hope that you will use this guide to learn more about NF1, talk with your doctor, connect with others, take control of your life, accept imperfection and uncertainty, and seek help if you need it. NF1 is a condition you have, but it does not define who you are. You define yourself and how you live your life. Don’t let NF1 stop you from pursuing your goals and living your life to its fullest.
BOOKS TO HELP TEENS BUILD CONFIDENCE

The Self-Esteem Workbook for Teens: Activities to Help You Build Confidence and Achieve Your Goals
By Lisa M. Schab, LCSW

The Shyness and Social Anxiety Workbook for Teens: CBT and ACT Skills to Help You Build Social Confidence
By Jennifer Shannon, LMFT

What Do You Really Want?: How to Set a Goal and Go for It: A Guide for Teens
By Beverly K. Bachel

WEBSITES ABOUT NF

Washington University Neurofibromatosis Center
http://nfcenter.wustl.edu

Neurofibromatosis Network
www.NFnetwork.org

Children’s Tumor Foundation
www.ctf.org

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