



TELLING PEOPLE YOU HAVE  
NEUROFIBROMATOSIS TYPE 1

Children's  
HOSPITAL • ST. LOUIS  
BCH HealthCare

## Introduction

Neurofibromatosis Type 1 (NF1) is a common genetic condition that can cause a wide variety of medical problems in different organs of the body. Although many people have not heard of NF1, it affects one in every 3000 individuals worldwide. Neurofibromatosis Type 2 (NF2), although similar in name, is a completely separate medical condition, and will not be discussed in this booklet.

Whether your diagnosis of NF1 is known or unknown by your peers, employer, teachers, or friends, you probably have struggled at some point with the thought of explaining NF1 to someone. You may even have worried about whether someone would treat you differently once they knew about your diagnosis of NF1. It is also likely you have questions regarding the best place or time to bring up your diagnosis. The purpose of this booklet is to provide you with suggestions about when, who, why, and how you might wish to tell others that you have NF1 ("disclosure"). In all situations, disclosure is most effective when you are knowledgeable about your diagnosis of NF1 and have a clear outcome in mind. It is important to remember that, first and foremost, you are a person with needs, wants, desires, and goals. None of this should change just because you happen to have NF1.



## Who Should You Tell?

Telling another person about something private is always a personal decision. Regardless of how obvious the features of NF1 might be, you never have to inform others that you have NF1 unless you choose to do so. The decision to disclose your diagnosis is legally defended under the Privacy Rule from the Health Insurance Portability and Accountability Act (HIPAA), which states that you have the right to keep your health information private. Healthcare professionals are an exception to this law; they need access to your medical records in order to provide you with the best medical care.

Since you are not required to disclose your diagnosis of NF1 to anyone, deciding whether to tell someone should ultimately depend on what specific outcome you desire. There are two general types of individuals you may wish to tell about your diagnosis. These include people you have a personal relationship with and those you encounter in professional settings (teachers and employers).

In personal encounters, your willingness to tell others that you have NF1 may serve to strengthen relationships and minimize misperceptions. You should gauge how comfortable you are with this person. If you know the person is judgmental and can't be trusted, you may opt not to tell them. However, someone whom you have trusted with sensitive information before may be easier to talk to about your diagnosis of NF1. You should consider: *Does this person treat you with respect and positive regard? Is he or she considerate and kind?*

In professional settings, you may wish to disclose your diagnosis of NF1 to obtain resources or accommodations necessary for your success at school or in the work place. You will not know these individuals well, but you will be approaching them in their capacities as educators, counselors, or employers.





If you are unsure whether to tell someone, talk with your parents, close friend, sibling, or partner. They may have helpful advice, since they know you well and may even know the person you wish to disclose your diagnosis of NF1. It may also be valuable for you to rehearse your approach to a disclosure discussion with someone you trust, such as your mother, father, or close friend. Ask them to play the role of the listener and then switch roles. This will give you a better idea of how the conversation might go in real life and how you can better direct the discussion.

Remember, you should be comfortable with your own diagnosis of NF1. To learn more about NF1, you may wish to talk with your NF1 doctors, nurses, or social worker and consult the websites listed at the end of this brochure.

## Why Should You Tell?

Although NF1 is a common condition and the features (café-au-lait macules or neurofibromas) may not be visible, neurofibromatosis is not a familiar word to most people. There are several reasons why people choose to disclose their diagnosis of NF1.

First, you may wish to clear up any misconceptions about your diagnosis of NF1. These types of disclosures typically involve your peers. Due to the lack of familiarity, you may find yourself in situations where others stare at you or have misperceptions about your condition. For example, a friend may ask you about your café-au-lait spots or a classmate may not understand why you struggle paying attention in class. In these circumstances, you may want to explain your diagnosis of NF1, so that others can better understand you and avoid any misunderstandings.

Second, you may also be motivated to tell others so that you can obtain extra resources or accommodations at work or at school. This is an important reason to disclose your diagnosis of NF1. Depending on the manifestations and severity of your NF1, assistance may include extra time on tests in school, time off work for doctor appointments, or wheelchair access at public events. No matter what resources you require, don't be afraid to ask for what you need to allow you to function at your best.

Third, you may wish to disclose your diagnosis of NF1 in order to educate others and raise awareness about NF1. In doing so, you not only teach others about NF1, but you also act as proof that those affected with NF1 can lead fulfilling lives. Because some of the material about NF1 on the Internet is scary, incorrect, or misleading, your disclosure provides an opportunity to give people accurate information.



## How Should You Tell?

Every encounter is different and should be approached individually. How you tell a friend about NF1 may not be the same as how you tell a co-worker. This means that you most likely will never have the same conversation about NF1 twice. Even among friends, some will be easier to open up to than others. In this regard, no matter how prepared you are to tell another person, you cannot predict how the conversation will go. Even the tone of a conversation may vary depending on the person with whom you are talking. Sometimes you may use casual conversation as an opportunity to educate someone about NF1. In another situation, it may feel like a private subject that you are hesitant to talk about. In either case, it helps to carefully consider how you will go about telling another person and what you want to say.

## Types of People You May Tell: Personal Encounters

### Friends

Telling a friend about your diagnosis of NF1 may not only strengthen your friendship, but may also provide you with additional support. Deciding whether or not to disclose your NF1 to a friend, no matter how close, may not be easy, as you never know exactly how he or she will react. If you are unsure, ask yourself: *Do I trust this friend? Have I confided in this friend before? Was he or she sensitive about what I told him or her in that previous situation? Would this friend have any reason to hold this information against me?* You should trust this friend first and know you can confide in him or her.

Once you decide that you want to share details about your diagnosis of NF1 with a friend, approach the conversation in whatever way makes you feel most confident and comfortable. This may take the form of a light impromptu conversation, or it could be a more serious discussion. If you feel anxious, it may help to plan your approach ahead of time. Here are a few suggestions to help you prepare for disclosure:

- Pick an appropriate time and place for a private, possibly lengthy, conversation. You don't want to be interrupted in mid-conversation.
- Outline what you want to say or even write down how you wish to explain your diagnosis of NF1.



- Use simple language. Don't offer too much information at once. You don't want your friend to misunderstand the dense, sometimes complicated, facts about NF1.
- After explaining, give your friend some time to react. It may not be easy hearing that someone close to you has a potentially serious condition.
- Encourage your friend to ask questions to avoid confusion or misperceptions.

These suggestions are fairly general, and could be applied to most people you decide to disclose your diagnosis of NF1.



### Boyfriend/Girlfriend

Although similar to a friendship, a boyfriend-girlfriend relationship adds an extra layer of closeness and intimacy that may make it harder to talk about your diagnosis of NF1. Some people believe that the earlier the disclosure occurs, the better. Others may decide to wait until they have established a secure relationship before disclosing their diagnosis. In reality, there is no perfect time in a relationship for this kind of discussion. Every couple reaches a point of comfort at a different time in their relationship. Sometimes it is on the first date, while, in other situations, it may take years. Most importantly, your diagnosis of NF1 should never prevent you from getting close with another person.

It is important that you provide accurate information about NF1 based on fact, rather than speculation. A great deal is known about NF1. For more information, talk to your NF specialist or consult the websites listed at the end of this brochure. When disclosing your diagnosis, you should be as honest and open as possible to foster a healthy relationship. This approach will be very reassuring for your partner, especially for difficult conversations regarding children.

### Roommates

Living in the same room with another person who is not a member of your immediate family is a new and challenging experience for most people. Close quarters make it tricky to be discrete about anything personal, including your diagnosis of NF1. Although you may choose to keep your NF1 private, talking about it with your roommate may keep him or her from guessing and making false assumptions. For example, many people are quick to assume that medical conditions are contagious. This is obviously not the case for NF1, and assuring your roommate that NF1 is a genetic, not a contagious, condition will avoid potentially awkward or hurtful situations.

### Strangers/Acquaintances

People are often brutally honest and may not be afraid to point out those "marks/bumps" on your body, or any other visible feature of NF1. This can be an uncomfortable situation, especially if you aren't prepared for the question or comment. Although you have no obligation to answer questions regarding your appearance, it may be helpful to have a ready response, as many people are just curious. Have a quick, simple response at hand such as, "It's a genetic disorder" or even more simply, "I was born with it." Simple and quick responses give you the option of either leaving the conversation as is, or allows the opportunity for you to answer questions. Other times, you may decide to be assertive by addressing the stares directly and saying, "Do you have a question I can answer?"



## Types of People You May Tell: Professional Encounters

### Teachers

Deciding whether to tell a teacher about your diagnosis of NF1 can be difficult. Often, you may be torn between wanting appropriate accommodations and not wishing to be singled out as different from your classmates. However, it is important for you to obtain the resources you deserve to succeed in school. Without knowing that a student has NF1, learning problems might either be overlooked or mislabeled as behavioral problems. It is critical that a teacher is aware of your diagnosis of NF1, since learning problems are common in young adults with NF1. Informing your teacher or school administrator will help you stay on top of your schoolwork and flourish in the classroom setting. Disclosing that you have NF1 should not mean that your teacher will label you as “slow” or draw attention to you in front of your classmates. Rather, this information should be used to provide you with the assistance and accommodations critical for your success in school.

Explaining NF1 to your teacher can be difficult, especially if he or she has never heard of NF1. If you don't feel comfortable talking about NF1, The Washington University NF Center has many helpful booklets on their website about NF1 (<http://nfcenter.wustl.edu>). Using these materials will help your teacher understand what you need, and will reduce the pressure on you to assume the role of a medical professional.

It may also be beneficial for you to talk about how or if you want your teacher to discuss your diagnosis of NF1 with your classmates. *Would you prefer that your classmates know or should this topic remain confidential?* Let your teacher know what would make you feel most comfortable.

If you don't feel confident approaching your teacher(s) by yourself, you should include your parents as a bridge between you and your teacher(s). They can talk with your teacher(s), tell them what is known about NF1, and explain how your diagnosis of NF1 interferes with your daily activities or classroom performance. To maintain your privacy, your teacher(s) and parents can meet outside of the classroom setting to discuss any support you might need to succeed academically.

Student-teacher relationships usually change once you enter college. In most situations, your parents are not available, and you will likely have



to inform your professors by yourself. To make things more challenging, professors often have busy schedules and hundreds of students to keep track of, which limits their focus on any one individual student.

Most institutions have an office for students with disabilities. It may be helpful for you to set up an appointment and bring reports of your previous accommodations. While most institutions alert faculty and staff of any special accommodations needed for students, it may also be helpful for you to directly inform your professors, as they may not know exactly what assistance you require. It is not necessary to provide a detailed account of your condition, but you should find a time to meet with your professors and clearly articulate how NF1 impacts on your ability to function in the classroom, how it affects your ability to learn, and what accommodations you may need to succeed in their course.

## College Admissions Officers

There is no requirement to disclose your diagnosis of NF1 on a college application or anytime during your college attendance. Many people do not worry about discrimination if they are certain that NF1 will not affect their ability to function and succeed in college. However, disclosure may be a good idea if it provides clarification about certain aspects of your college application. This way, the college admissions officers can better understand you as a student. Examples of this type of situation include:

- You didn't take all the high school classes that a college requires for admission. Some colleges will waive those requirements under special circumstances.
- You had consistently lower grades due to learning problems associated with NF1.
- Your grades improved when you were given appropriate accommodations or resources.
- Your diagnosis of NF1 dictated the classes you took in high school and/or the major you decided to pursue.

Disclosure on a college application is a proactive way for you to plan for your higher education. Informing your prospective institution of your diagnosis of NF1 enables you to obtain information about available support services. In addition, this early disclosure provides you an opportunity to discuss your specific needs with the support staff before school starts and to ensure that the appropriate accommodations are provided.

Regardless of whether or not you decide to disclose, the new independence afforded by college life should not be limited by your diagnosis of NF1. While it may feel frustrating to occasionally rely on others, remember that the transition to adulthood is an adjustment for everyone, and most people need others for help and/or support at some point during this time. For more information, the Washington University NF Center has a helpful booklet on their website entitled, "Transition to Adulthood" that offers useful advice on college and adult life.

## Employers/Supervisors

There can be many advantages to telling your employer about your diagnosis of NF1, including, but not limited to, receiving work-related accommodations and having a legitimate excuse for missing days at



work due to medical reasons. The more difficult question for many people regarding disclosure to an employer is: *If I decide disclose my diagnosis of NF1, when should I do it?* There are many opportunities for this discussion, including on the application, during the interview, and anytime during employment. Telling people you have NF1 at any stage has its pros and cons, and no particular time is ideal. If you tell your potential employer about your diagnosis of NF1 on the application, it could be interpreted as a work-related liability. Therefore, you may decide to disclose your diagnosis of NF1 after you have applied, completed an interview and been offered the position. Informing employers at this stage provides an opportunity to explain this condition in person, discuss any accommodations you may need, and assure them that this diagnosis will not limit your job performance.

If you decide to disclose your diagnosis of NF1, it is important that you provide clear information to your employer. You are not required to disclose any personal health information, but the information you share should focus on your ability to accomplish the tasks assigned to you and meet the job expectations.

## Conclusion

Living with the diagnosis of NF1 may lead you to explore the option of disclosure. When making a decision to disclose your diagnosis of NF1, take the time to evaluate the pros and cons of each situation carefully. You may also want to refer to the reference chart available on the Washington University NF Center website (<http://nfcenter.wustl.edu>) that addresses the questions of who, why, when and how. Working with friends and family who you trust can help you prepare and practice prior to disclosure. Once again, disclosing about your diagnosis of NF1 is most effective when you are knowledgeable and clear about the outcome and results you want.

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## Helpful Internet Sites

**Washington University Neurofibromatosis Center**  
<http://nfcenter.wustl.edu>

**St. Louis Children's Hospital**  
[StLouisChildrens.org](http://StLouisChildrens.org)

**Neurofibromatosis, Inc.**  
[www.NF1network.org](http://www.NF1network.org)

**Children's Tumor Foundation**  
[www.ctf.org](http://www.ctf.org)

**Information about NF1 for Educators**  
[http://www.NF1aa.org.au/PDFs/NF1\\_Guide\\_for\\_Educators.pdf](http://www.NF1aa.org.au/PDFs/NF1_Guide_for_Educators.pdf)

**Information on Health Information Privacy**  
<http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html>





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