SHARING A DIAGNOSIS

How and when to share that you or a loved one has a diagnosis of ectodermal dysplasia can be difficult to determine. First and foremost, there is no perfect way to share this information and sharing medical information may be different in every family and culture.

According to Dr. Patricia Marik, a pediatric psychologist at the Medical College of Wisconsin, consider these factors when sharing information:

- Is it your information (your diagnosis) or that of a loved one (a partner or child)?
- Who is receiving the information and why? What you share with your best friend about your diagnosis is likely different from what you share with your boss. Your child's tennis coach may need to know more details about how to keep them cool than their piano teacher needs to know.
- Do you want to provide all of the information or do you want to direct someone to resources such as the NFED, or both?

Download Ectodermal Dysplasias Fact Sheet

Sharing Your Child's Diagnosis With Others

Consider what your child may want and not want shared. Remember that information shared online never really goes away - what you share when they are a baby may still be accessible when they are a teenager. If they are old enough, involve them in the conversation about who and what others know.

If they are uncomfortable with information being shared but it's important that this information is shared (such as with a coach or teacher) help them understand why it's important to share this information. Ask if they want to be present when the information is shared or would prefer not to. This will help them feel that they have some level of control over their own personal information. Our School Advocacy Toolkit has more resources for how to talk about ectodermal dysplasias at school.

Consider the developmental level of your child and their peers. With younger children, you may want to emphasize that ectodermal dysplasia does not mean they cannot play and have a good time and be a good friend.

If you are helping your child with what to say about their condition, download our

nfed
NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

resource, “What You Can Tell Peers About Ectodermal Dysplasias” in the library at NFED.org.

Empower your child to share information by role playing. Encourage them to consider how they want their friends to support them. For example, “I like it when my friends take breaks in the shade with me.” “I like being updated on anything that happened at school the day I was out for my dentist appointment.” Plan ahead for times when they may be meeting new people, such as going to college and talking to a new roommate.

Sharing My Diagnosis With Others as an Adult

This is similar to sharing any private information with friends or co-workers. There may be some people who you feel comfortable knowing details about your medical history and others with whom you only want to share the basics. And that’s ok!

How and when you share the information will also vary. Easy times to bring up the topic may surround doctors and dentists appointments. “I saw my dentist today and it reminded me that I never told you about my ectodermal dysplasia.”

It may be helpful to let your friends know how they can help you:

”I have this diagnosis but it doesn’t impact anything I do. I don’t need anything from you,” or “Sometimes when it’s hot, I may need us to meet inside instead of outside.”

Sharing a genetic diagnosis with a romantic partner can bring up unique feelings and concerns. Check out the resource on the NFED website called, “Genetic Carriers: How to Tell Your Partner.”

What Do I Tell My Employer?

In the United States, you legally do not need to share any medical history or diagnoses with an employer, unless it will interfere with your ability to carry out essential job functions. But, it may be helpful for your employer to be aware in case you may need any accommodations.

The Americans with Disabilities Act prevents discrimination against people with disabilities. This can include chronic health conditions but not always. But, the employer has to know about the disability. They do not have any obligation to make accommodations if they don’t know.
It may be helpful to provide information from the NFED for more rare or lesser known conditions like ectodermal dysplasias. Consider what accommodations you are asking for before a meeting (for example, keeping a water bottle at your work station) or if you’re just telling them for their knowledge. Consider scheduling check-ins to see how accommodations are working.

Depending on the level of accommodations you’re asking for, you may want to consider looping human resources (HR) in the conversation. Your direct employer may not be able to make specific accommodations. You can also start with HR first.

You’re Not Alone

Telling others has its benefits as it helps others understand your needs and can reduce misunderstandings. Sharing the ectodermal dysplasia diagnosis can also help you build confidence as you learn to explain the condition. But, you get to decide who to tell, how to say it, and when to share it, or not.

And we’re here to help. You are not alone on this journey. If you need additional support, call our office. Or, you may want to connect with our community in one of our NFED Facebook groups.

- Updated May 2026