

Genetic Carriers – How to tell your partner

Every relationship is different, but when things get serious, it's inevitable that you'll need to have some tough conversations — whether it's money, the future, sex or some other crucial topic. And when you're affected by an ectodermal dysplasia syndrome or you're a genetic carrier, one of those conversations will be filling your partner in on what exactly that means.

When a relationship is new and you're spinning care-free in that lovey-dovey, no-you-hang-up stage, you're not going to want to bring up ectodermal dysplasias or talk about genetic carriers. But healthy relationships are built on honest communication. Those partners worth hanging on to will celebrate every part of what makes you, you, including your genetic make-up.

Timing the Conversation

It can be difficult to gauge when to tell your partner. Depending on your relationship, this conversation could come instantly or after several years. Most likely, it will fall somewhere in between those two extremes.

Share when you're are most comfortable. If you're spending a lot of time together and are invested in the relationship, then it's time to talk. However, you will need to let your partner know before the relationship becomes sexual, since even protected sex can result in a pregnancy.

Talking Points

How do I bring it up? What do I say? Talking about ectodermal dysplasias to your partner doesn't need to be scary. Practice what you'll say and anticipate your responses to both positive and negative reactions. When you're ready to start the conversation, there's no need to naturally slip it into another topic. "I'd like to talk to you about something that's a big part of my life" is as good a conversation starter as any.

Be open and honest with your partner, sharing all the details that you know and the possible effects on your future life together. To help them better understand, you could invite your partner to look at one of our Facebook groups or at the NFED website.

Providing resources, such as an overview of ectodermal dysplasia genetics, and looking at them together can take some pressure off of the conversation and make it feel less intimidating for the both of you.

"It is reasonable to anticipate rejection as a possible outcome, it is also reasonable to anticipate acceptance, compassion and questions about your disease and how to support you or what you need! Remember that we can all feel more than one feeling at once and sometimes complex situations include complex feelings and reactions. Be gentle with yourself and your partner."

— [Dawn Wiggins, a marriage and family therapist](#)

After the Talk

Your partner is going to need some time to process all of the information you've told them and what it means. Give them time and space to process. They might ask questions long after the initial conversation, once they've had some time to reflect. It's important to let them know that you're open and willing to talk about those questions, whenever they come up.

Discussing ectodermal dysplasias and what it means to be a genetic carrier with your partner can be tough. But it's a conversation that can strengthen your bond and set you up for an open and honest relationship.

Have you talked with your partner about genetic carriers or ectodermal dysplasias? How did it go? We'd love to hear your story.

Supporting a normal lifestyle