TALKING WITH FAMILY ABOUT HEREDITARY ATTR AMYLOIDOSIS

Amyloidosis Research Consortium

PREPARING TO COMMUNICATE

It's important when you prepare to tell your family that you have everything you need to explain the results, what they mean for you, and what they may mean for them. You want to differentiate carrier status vs. disease and ensure you share resources on genetic counseling and testing.

WHO: Identify who needs to be contacted within your family.

WHAT: Gather information on the results, what they mean and where a person can get tested.

WHEN: Identify a time where family may be most receptive.

HOW: Choose if you want to share in person, over the phone, via video chat or in a letter.

PREPARING YOURSELF TO NAVIGATE REACTIONS

Getting tested is a personal decision that everyone must come to on their own. Your role is to share what you know, because whether they get tested doesn't change their risk of inheriting the mutation. To protect your emotions, it's helpful to identify where your role begins and ends.

- It's important to try and be as calm and open-minded about your own risk or disease status as you can. If you are anxious, they may get anxious too.
- Some may be interested to learn more about their risk and how they can get tested, others may not be interested in getting tested.

HAVING THE CONVERSATION

If comfortable, share whether you were diagnosed with the disease and typed through genetic testing or if you are a carrier of the gene mutation.

Disease means you have developed symptoms that have been diagnosed by a medical provider.

Carrier of the gene mutation means you have the affected gene but no symptoms.
Note: a carrier may never develop the disease.

Be ready to answer any of their questions. If you don't know the answer, it's okay to say 'I don't know' and encourage them to connect with a genetic counselor.

Share where to access genetic testing & counseling. You can use ARC's Genetic Testing handout.

TAKE CARE OF YOU

Take note of the feelings that come up for you before, during and after the conversation. Remember, you were tested because it was right for you. Even if you think it is the right thing to do, your family members may not agree. It can be helpful to consult a genetic counselor to talk through these reactions and get support. You did your part; they must choose what their part is now.

Have Questions?
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