


Your family and hereditary ATTR amyloidosis



If you have recently been diagnosed with hereditary ATTR (hATTR) amyloidosis, you may want to speak to your family about the condition. Talking about health can sometimes feel uncomfortable, so it's important to know there's no right or wrong way – every family is unique.

This leaflet is designed to help you consider what's right for you and your family. It will also help address how your loved ones may wish to support you.



 Why talking to your family about hATTR amyloidosis can help

“My family... have been the biggest support”

Catilena. Living with hATTR amyloidosis



Family can be a vital source of support and information about hereditary ATTR (hATTR) amyloidosis. The condition is caused by an inherited gene mutation, and family history can have a role in diagnosis. When one relative receives a diagnosis, this could indicate that other family members may also develop a disease risk.

This is why talking to family members can be very important for individuals living with hATTR amyloidosis.

When one parent carries the gene mutation that can lead to hATTR amyloidosis, their child has a 50% chance of inheriting it. This doesn't always mean that a person with the gene will definitely develop symptoms. Even if an individual does develop symptoms, the age of onset can vary.



“The way the news spread in my family... one uncle took the lead...he told everyone to get tested”

Philip. Living with hATTR amyloidosis

Anyone living with hATTR amyloidosis will have inherited the condition from one parent who will have inherited it from one of their parents in turn, so the condition may affect wider family members too.

That’s why telling family members can be stressful. But it’s important to do so, as telling family members with or without symptoms may help them decide whether they wish to take a genetic test to see if they are also a carrier of the gene. If they are, having that conversation enables them to consult a healthcare professional for advice, to receive a diagnosis and to potentially start any treatment sooner. As hATTR amyloidosis can be inherited, telling relatives could also help inform their plans when it comes to starting a family, regardless of whether they have symptoms or not.



When to talk to your family about hATTR amyloidosis

It is important to get an early diagnosis. How and when you choose to speak to your family members is personal to you and depends on your own situation. If you have any questions or concerns, you can always ask your doctor or healthcare professional for advice.

Here are some other questions that can help you prepare to talk to your family about hATTR amyloidosis

- Which side(s) (or arm[s]) of the family might be affected?
- What ages are my relatives?
- Could my relative be thinking about starting a family?
- Do I know enough about hATTR amyloidosis to have the conversation?
- What is their knowledge of the condition?
- Do I feel prepared to have the conversation?
- What questions might my family ask?
- Am I prepared for these questions?
- What emotions or reactions could this conversation bring up?
- Who is my relative likely to tell?

Family Health Tree

Map your family's history of hATTR

If you have decided that you would like to talk to family members or are still making your decision, you might be thinking about who in your family might be affected. You can use the Family Health Tree (see separate leaflet) to help you create your own record of your family history, identifying parents, children, uncles, aunts and cousins who may be at risk. You can use it as a tool for yourself or work through it with your family, whenever you feel the time is right.



If you're considering talking to your family, your doctor or healthcare professional can offer you advice that's personal to your situation. You can hear from others and find out more using the contacts on page 14.

Caregivers play an important role

Not everyone living with hATTR amyloidosis has the benefit of a caregiver, but for those who do, your support can be incredibly important. A caregiver is someone who helps with daily tasks like:

- Monitoring health, managing medications
- Driving to medical appointments
- Sitting in during appointments, asking questions
- Food shopping, cooking, housework
- Taking a shower, getting dressed
- Handling finances and other legal matters

Many caregivers find their role very rewarding and it is certainly appreciated by those who receive the care.



"The advice I can give to other families is not to abandon your family members. Because if the person was good before the disease, they are still good after the onset of the disease"


Margarida.
*Caregiver to her husband,
Vitor, who is living with hATTR
amyloidosis*

As a caregiver, you also need to take care of yourself

Caring for someone with hATTR isn't always easy. You may notice a change in your financial situation and there's potential for the physical and emotional stresses of caregiving to impact your personal health and wellbeing.

It is important to look after yourself, to give you the strength and energy to handle the daily demands of caregiving. Here are some of the things you can do to stay fit and healthy:

- Exercise and eat well – keep active and eat a balanced diet to provide your body with all the nutrients it needs
 - Sleep – get enough sleep to help you stay healthy, both physically and mentally
 - Do something for yourself – set aside time each day for something you enjoy, like reading, listening to music or chatting to a friend
- Connect with the hATTR community – seek help from other caregivers and organisations to give you the extra support you may need



"I can't care for myself. My wife must help me. She helps me put clothes on, close buttons, get my jacket on or off, wearing my shoes.... because I didn't have the strength anymore in my hands to do that."

Roland. *Living with hATTR amyloidosis*

If you are at risk of hATTR, look out for the signs and symptoms

As hATTR is genetically inherited, if you are a genetically related family member, you could also be at risk of the disease. If so, it's even more important that you maintain your own health.

Take time to understand the symptoms and speak to your doctor if you think you might be at risk. Early diagnosis and treatment are so important in preventing or slowing down the progression of hATTR amyloidosis.

There are lots of places to turn to for support

You don't need to do it all yourself – you can always ask other family members or friends to share the caregiving tasks. Support from others can also help you cope with the emotional impact of caregiving. There are some professional services that you can contact for further help or advice on page 14.

📖 Sources of support



<https://www.hattrbridge.eu>

The Bridge™ is a website developed and produced by Alnylam Pharmaceuticals; it is designed to help raise awareness of hereditary ATTR (hATTR) amyloidosis and promote education on the condition for patients and their families.

ATTR AMYLOIDOSIS ALL IRELAND SUPPORT GROUP

amymatrs@gmail.com

ATTR Amyloidosis All Ireland Support Group offers support to patients affected by Hereditary ATTR Amyloidosis or Wild Type ATTR Amyloidosis. We are committed to raising awareness to ensure people are diagnosed and have access to available treatments at the earliest opportunity.



Amyloidosis Alliance is an international umbrella patient advocacy organisation, aiming to raise awareness and improve the quality of care of amyloidosis patients.



info@UKATPA.org

<https://www.ukatpa.com>

UK ATTR Amyloidosis Patients' Association acts to provide extensive patient information and support.

Find your path to better health with **STAR: The Symptom Tracker** app for people with **ATTR amyloidosis**.



For more information, please refer to the sources of support listed within this leaflet.

STAR: The Symptom Tracker app does not pursue a medical purpose. It is designed to keep a record of users' symptoms, how they change over time and their impact on users' well-being and lifestyle. The app is not intended as a disease monitoring tool or as a symptoms checker. To have symptoms checked, users are advised to talk to their healthcare professional. Furthermore, **STAR: The Symptom Tracker** app does not make any medical diagnoses. Users are advised to seek the advice of a medical professional if they are concerned about their health.



**ATTR AMYLOIDOSIS
ALL IRELAND
SUPPORT GROUP**

