

With you

Let's navigate ATTRv amyloidosis together

A quick guide to understanding ATTRv amyloidosis

You have been given this guide because someone you know has been diagnosed with a health condition called 'hereditary transthyretin amyloidosis (ATTRv)'. The information is designed to help you understand what ATTRv amyloidosis is and how it can affect someone living with it. Taking the time to learn more may help make the person you know feel supported and understood.

What is ATTRv amyloidosis?

ATTRv amyloidosis is a **rare condition** that can affect:

- The nerves – this is known as 'polyneuropathy'
- The heart – this is known as 'cardiomyopathy'

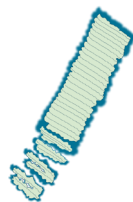
ATTRv amyloidosis is a progressive condition, which means it gets worse over time, so it should be diagnosed and treated as early as possible.

What causes ATTRv amyloidosis?

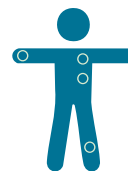
ATTRv amyloidosis happens when a protein (essential building block of the body) called transthyretin (TTR) becomes unstable.



TTR proteins become unstable, break apart and change shape (misfold)



Misfolded TTR proteins clump together to form something called 'amyloid deposits'



Amyloid deposits build up in different parts of the body. This can affect how well some organs work

Adapted from the Cleveland Clinic.

The protein can become unstable for two reasons:

1. A faulty gene that cause the protein to become unstable can be passed down through families – this is the **hereditary type known as ATTRv amyloidosis. The person you know has been diagnosed with this type**
2. The protein can become unstable over time – this is known as **wild-type**

If you are related to a person who has been diagnosed with ATTRv amyloidosis, you may have some questions or worries. A doctor can advise you on what steps to take and speak to you about genetic testing to find out if you are affected.

What are the symptoms of ATTRv amyloidosis?

ATTRv amyloidosis mainly affects the nerves and/or the heart. But it can also affect other parts of the body. On this page, you can read more about the wide range of symptoms the condition can cause.

Symptoms can differ from person to person. Even members of the same family with the condition can have different symptoms. It is unlikely that one person will experience all the symptoms listed.

Nerve symptoms:

- Numbness, tingling or pain in the feet or hands
- Burning pain in the legs or arms
- Weakness in the legs
- Problems with balance
- Carpal tunnel syndrome (in one or both hands)



Stomach and digestion symptoms:

- Diarrhoea
- Constipation
- Nausea (feeling sick)
- Vomiting (being sick)
- Feeling full after eating a small amount
- Difficulty swallowing



Heart symptoms:

- Feeling dizzy when standing up
- Fast or irregular heartbeat
- Shortness of breath
- Chest pain
- Leg or ankle swelling



Other symptoms:

- Difficulty fully emptying the bladder when going to the toilet
- Erectile dysfunction (men)
- Feeling very tired all the time
- Unexplained weight loss
- Increased sweating
- Urinary tract infections that recur
- Disrupted sleep



The person you know who is living with ATTRv amyloidosis may have other symptoms. If they feel comfortable doing so, you may want to ask them what symptoms affect them and note those down here. That way, you can offer support personal to them and their needs.

Other symptoms:

No matter how big or small, your support and understanding can make a real difference for someone living with ATTRv amyloidosis.