

A stylized, light blue silhouette of a human figure is centered on the page. The figure is facing forward, with arms slightly away from the body. The background is a solid, darker blue.

IDENTIFY YOUR SYMPTOMS

**and know if they
are getting worse**

Track your symptoms
and prepare for your
next conversation with
your doctor about ATTR
amyloidosis (ATTR).

UNCOVER MORE ABOUT ATTR

ATTR is an underdiagnosed disease with symptoms that can worsen over time and affect multiple parts of the body, including the **heart, nerves, and digestive system**.

There are 2 types of ATTR, wild-type ATTR (wtATTR) and hereditary ATTR (hATTR).

wtATTR

This type is not inherited and may be associated with ageing.

hATTR

This type is caused by an inherited gene variant, or change, in the TTR gene passed down through family members.

The gene variant causes the *TTR* protein to break apart and misfold, building up in the body as amyloid deposits.

Because hATTR is passed down through family members, it's important to tell your doctor about symptoms that family members may have experienced.

ATTR can affect multiple parts of your body. With heart-related symptoms, it's referred to as **ATTR with cardiomyopathy (ATTR-CM)**. With nerve-related symptoms, it's referred to as **ATTR with polyneuropathy (ATTR-PN)**.

Learn more about ATTR and how to recognize its signs and symptoms at ATTRrevealed.co.uk/about-attr/signs-symptoms.

Tracking is just the start

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This **Symptoms Checklist & Tracker** can help you take note of your symptoms, how they have been impacting your life, and whether or not they have changed over time.

Sharing this information is an important step in your journey to diagnosis and monitoring of your condition. For your doctor, these details will help them determine your next steps. For your loved ones, knowing how you're feeling gives them an opportunity to support you better.

This resource does not include a complete list of symptoms that may be experienced by people with ATTR. Each person has a different experience and you may not have all of these symptoms, or you may not have them at the same time. Talk to your doctor about all of your symptoms, even if they seem unrelated.



GABI,
living with wtATTR-CM

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Symptoms related to the heart



Which symptoms are you experiencing?

Mark all that apply.

How limiting is the symptom?

Mark the appropriate number.

1 - Minimal 2 - Mild 3 - Moderate
4 - Severe 5 - Extreme

1 2 3 4 5

How long have you had this symptom?

Note when you first experienced the symptom.

DD/MM/YYYY

How has the symptom changed over time?

Check the appropriate box.

Worse Same Better

Shortness of breath

Swelling of legs, ankles, and/or feet (oedema)

Fatigue

Fainting

Abnormal heart rhythms (arrhythmias)

Irregular heartbeat

Yes

No

Has another family member experienced any of these symptoms?

☐

Have you been diagnosed with heart failure?

☐

Notes:

Symptoms related to nerves in hands, feet, arms, and legs



Which symptoms are you experiencing?
Mark all that apply.

Burning pain, numbness, tingling, and/or pins and needles in the extremities

Loss of sensitivity to temperature

Difficulty holding on to items

Difficulty using fingers
(e.g. buttoning, writing, picking up coins)

Problems with balance and/or feeling unsteady on feet

Difficulty getting out of a chair

Difficulty walking

How limiting is the symptom?

Mark the appropriate number.
1 - Minimal 2 - Mild 3 - Moderate
4 - Severe 5 - Extreme

1

2

3

4

5

How long have you had this symptom?

Note when you first experienced the symptom.
DD/MM/YYYY

How has the symptom changed over time?

Check the appropriate box.

Worse

Same

Better

Yes

No

Has another family member experienced any of these symptoms?

Have you been diagnosed with polyneuropathy?

Notes:

6 Symptoms related to control over bodily functions



Which symptoms are you experiencing?

Mark all that apply.

How limiting is the symptom?

Mark the appropriate number.

1 - Minimal 2 - Mild 3 - Moderate
4 - Severe 5 - Extreme

1 2 3 4 5

How long have you had this symptom?

Note when you first experienced the symptom.

DD/MM/YYYY

How has the symptom changed over time?

Check the appropriate box.

Worse Same Better

Digestive issues (e.g: feeling full quickly, diarrhoea, constipation)

Nausea and/or vomiting

Unexplained weight loss

Dizziness or light-headedness upon standing

Urinary incontinence or recurrent urinary tract infections (UTI)

Increase or decrease in sweating

Sexual dysfunction

Difficulty adjusting to changes in lighting

Yes

No

Has another family member experienced any of these symptoms?

☐

Notes:

Symptoms related to muscles, joints, and tendons



Have you ever been diagnosed with these conditions, or talked about them with your doctor?

Mark all that apply.

How limiting is the symptom?

Mark the appropriate number.

1 - Minimal 2 - Mild 3 - Moderate
4 - Severe 5 - Extreme

1 2 3 4 5

How long have you experienced this symptom?

Note when you first experienced the symptom.

DD/MM/YYYY

How has the symptom changed over time?

Check the appropriate box.

Worse Same Better

Carpal tunnel syndrome



Carpal tunnel syndrome, especially in both wrists, may be one of the first symptoms of ATTR and can appear up to 10 years before ATTR is diagnosed.

Lumbar spinal stenosis*

Biceps tendon rupture

Rotator cuff injury

Osteoarthritis

Trigger finger

Yes

No

Has another family member experienced any of these symptoms?

☐

Notes:

*Narrowing of the spinal canal in the lower back that may cause pain or numbness in the legs.



General health and impact on daily activities



Which of these are you experiencing?

Mark all that apply.

Physical health interferes with normal social activities (e.g. hobbies, visiting friends or family, etc.) and/or work

Weakness and/or shakiness interferes with normal activities (e.g. shopping, housework, etc.)

Difficulty bathing/showering

Difficulty getting dressed

Anxiety or depression

Difficulty walking 100 meters on flat ground

How severe is the limitation?

Mark the appropriate number.

1 - Minimal 2 - Mild 3 - Moderate
4 - Severe 5 - Extreme

1 2 3 4 5

How long have you experienced this?

Note when you first experienced the symptom.

DD/MM/YYYY

How has this changed over time?

Check the appropriate box.

Worse Same Better

Notes:

Other symptoms



Which symptoms are you experiencing?

Mark all that apply.

How limiting is the symptom?

Mark the appropriate number.

1 - Minimal 2 - Mild 3 - Moderate
4 - Severe 5 - Extreme

1 2 3 4 5

How long have you had this symptom?

Note when you first experienced the symptom.

DD/MM/YYYY

How has the symptom changed over time?

Check the appropriate box.

Worse Same Better

Glaucoma, blurred or spotty vision

Floaters in the eye

Stroke-like episodes, causing symptoms (e.g. trouble speaking, severe headaches, or seizures)

Trouble remembering things and/or forgetfulness

Kidney dysfunction

Yes No

Has another family member experienced any of these symptoms?

Notes:

10 **Preparing for your next conversation with your doctor**

Identifying and monitoring your symptoms is an important part of being better informed when you discuss ATTR with your doctor. Because open communication with your healthcare team is crucial to figuring out what your next steps can be, here are some other things to think about before your next appointment.

List any other symptoms you may be experiencing that aren't listed in this tracker and when you started noticing them.

Which symptoms are new since your last appointment?

Since your last appointment, which symptoms have interfered with your daily activities?

Has anyone shared with you that they have noticed a change in your symptoms?

If you've been diagnosed with heart failure, which medications have you been prescribed? How have your symptoms changed since you started the treatment?

List all medications you are taking.



JEAN-CHRISTOPHE,
living with hATTR

Visit www.ATTRrevealed.co.uk to receive more educational resources and learn about ATTR.



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