

Talking to my doctor about ATTRv amyloidosis

This guide has been developed to help you understand what hereditary transthyretin amyloidosis (ATTRv amyloidosis) is and support you in talking to your doctor about whether you may be at risk.



What is ATTRv amyloidosis?

ATTRv amyloidosis is a rare but serious condition. It happens when a protein called transthyretin (TTR) in the body becomes unstable. If you are not sure what proteins are, it can help to think of these as essential building blocks in your body.

When the TTR protein is unstable, it breaks apart and folds incorrectly. Lots of these folded TTR proteins clump together and form something called 'amyloid deposits'. Over time, these amyloid deposits build up in different parts of the body causing symptoms.

If you have **Portuguese heritage** and **recognise any of the symptoms** listed on page 2, you should **book an appointment** with your doctor.

Turn to the back page for useful tips for preparing for an appointment. Early diagnosis and specialist care are key to managing this condition before it progresses.



Why I think I'm at risk of ATTRv amyloidosis

Ahead of your appointment, please fill in the details below to help your doctor understand why you may be at risk of ATTRv amyloidosis. If you are struggling to fill out these details yourself, you may wish to ask a carer or loved one to help you. This information can help your doctor decide if you may need to be referred to a specialist.

My symptoms

Tick any of the symptoms of ATTRv amyloidosis that you have experienced. You may find that you have symptoms that sit in different groups, such as some 'nerve' symptoms and some 'stomach and digestion' symptoms.

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)

Heart symptoms:

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

Stomach and digestion symptoms:

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

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

My symptoms started

Around Years ago Months ago

My symptoms are:

- ☐ Staying the same ☐ Slowly getting worse ☐ Rapidly getting worse

My background

ATTRv amyloidosis can run in families. As it can be inherited, your family history is important information for your doctor.

Family background: (tick to confirm if you have Portuguese heritage. Around 1 in 538 people with heritage from the North of Portugal are carriers of the faulty gene that causes ATTRv amyloidosis)

- ☐ I have family from Portugal

Family health:

To your knowledge, has anyone in your family experienced any of the symptoms listed on the left?

- ☐ No
- ☐ I don't know
- ☐ Yes, my (write down family member e.g. father)

Which symptoms?

ATTRv amyloidosis is a progressive condition – this means it gets worse over time.

Early diagnosis is really important for making sure you get the care you need.

How can I prepare for an appointment?

To help get the most out of your appointment with your doctor, you may want to prepare by:

- * Planning what you want to talk about
- * Filling out the 'why I think I'm at risk' checklist in this booklet
- * Recording your symptoms in a diary
- * Asking family members if they have experienced any of these symptoms
- * Bringing a notepad and pen to the appointment to take notes

What will happen at my appointment?

During your appointment, explain to your doctor what symptoms you are experiencing and why you think you are at risk of ATTRv amyloidosis. Here are some ideas to help you start the conversation:

“

I have been having problems with [symptoms]. I have learned about a condition called ATTRv amyloidosis. Could we talk about whether I might be affected?

“

I heard about a rare condition called ATTRv amyloidosis that affects people with Portuguese heritage. I recognise a lot of the symptoms. Can we talk about that today?

If your doctor thinks you may be at risk, they might:

- * Run blood tests to rule out other causes
- * Do an ECG (a test to record your heart) if you have heart problems
- * Refer you to a nerve, gut or heart specialist (depending on your symptoms) who can perform further tests

Remember, it is okay to ask what the next steps are if you are not clear. You can also ask your doctor to repeat something if you did not hear it. Or, they can rephrase something if you did not understand it. Asking a friend or family member to come to your appointments with you can also help.



Need more support preparing for your appointment?
Visit the AstraZeneca website
www.Doenca-dos-Pezinhos.co.uk
by scanning the QR code



Feedback questionnaire

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