

## What are the Non-Motor Symptoms in Persons with Ataxia?

Although most people associate ataxia with walking difficulty and coordination problems, many other symptoms do not involve movement, called "non-motor symptoms." These symptoms can markedly affect the daily life of individuals with ataxia.

**There are treatment options available for many of these symptoms – talk with your healthcare team about what you're experiencing. Recognising and addressing these symptoms early can greatly improve your quality of life.**

## Common Non-Motor Symptoms

### 1. Thinking and Memory Problems (Cognitive Symptoms)

Patients with ataxia may experience difficulties with:

- Concentration and focus: Tasks that used to be automatic now require conscious effort
- Planning and organizing: Difficulty managing daily activities and multitasking
- Working memory: Trouble holding information in your brain temporarily
- Problem-solving: Challenges with thinking flexibly and finding solutions
- Language skills: Difficulty finding words or expressing thoughts clearly
- These thinking problems are part of what the doctors call "Cerebellar Cognitive Affective Syndrome."
- About 25–50% of people with ataxia experience some degree of cognitive difficulties.

### 2. Speech and Swallowing Difficulties

These problems occur because the muscles used for speaking and swallowing become poorly coordinated.

- *Speech problems (dysarthria)* are very common in ataxia. Patients might notice their speech becoming slurred or unclear, making it harder for others to understand. There may be pauses or separations of syllables, and the spoken words may seem broken, which doctors call "Scanning speech." The voice may sound harsh or tremulous, and patients might have trouble controlling the volume or rhythm of their speech.
- *Swallowing difficulties (dysphagia)* may affect nearly everyone with ataxia at some point. Patients may experience trouble chewing, food remaining in their mouth after meals, a sensation of food being stuck in their throat, or coughing and choking while eating or drinking. Some people may aspirate (food or liquid entering the lungs) without coughing, which can lead to chest infections.

### 3. Sleep Disorders

Sleep disturbances are very common among individuals with ataxia, affecting about half of those affected and include:

- *REM Sleep Behavior Disorder (RBD)*: Acting out dreams physically during sleep
- *Restless leg syndrome*: Uncomfortable sensations and urge to move legs
- *Periodic limb movements*: Involuntary twitching of limbs during sleep
- *Sleep apnea*: Disruptions in breathing during sleep
- *Insomnia*: Difficulty falling asleep or staying asleep
- *Excessive daytime sleepiness*

## 4. Autonomic Nervous System Problems

People with ataxia may face autonomic problems that can affect body functions you don't consciously control, such as blood pressure regulation, heart rate, and temperature control.

### *Blood Pressure Regulation:*

- Dizziness or lightheadedness upon standing
- Blood pressure fluctuations with body position (blood pressure drops when standing)

### *Urinary Problems:*

- Difficulty initiating urination or incomplete bladder emptying
- Urgency/ increased urination or loss of bladder control

### *Digestive Issues:*

- Constipation
- Difficulty swallowing
- Changes in appetite, nausea, vomiting

### *Temperature Regulation:*

- Excessive sweating or inability to sweat
- Difficulty maintaining body temperature

## 5. Emotional and Mood Changes

Many people with ataxia experience:

- *Depression:* Affecting 13–75% of people with ataxias
- *Anxiety:* Feeling worried or nervous more often than usual
- *Apathy:* Loss of interest in activities you once enjoyed

## 6. Fatigue and Pain

*Fatigue* is one of the most common and disabling non-motor symptoms affecting up to 70% of people with ataxia. This isn't just ordinary tiredness – it's a persistent, overwhelming exhaustion that doesn't improve with rest. Fatigue can be physical or mental, like difficulty concentrating for extended periods.

*Pain* in people with ataxia may occur even before movement problems become noticeable and doesn't always correlate with disease severity. Chronic pain is often described as musculoskeletal pain, and muscle cramps are particularly common in the legs.

## 7. Sensory Symptoms

Sensory symptoms in ataxia commonly include numbness, tingling, or pain in the hands and feet. Patients may lose their sense of touch, vibration, or position, making it difficult to know where their limbs are in space. These sensory problems can worsen balance, especially in dark environments.

## 8. Eye Movement Problems

- *Eye movement disorders are very common in ataxia, affecting approximately 90% of patients.*
- *The most frequent problem is nystagmus – involuntary eye movements that appear as rhythmic, back-and-forth motions of the eyes.*
- *Patients may also have trouble tracking moving objects with their eyes or making quick, accurate eye movements to look at different targets.*
- *These problems can cause blurred vision, dizziness, and nausea, making it harder to read, drive, or perform daily activities*