Condition Insight Report (CIR)

Multiple System Atrophy

VERSION 1.1

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Completed in collaboration with MSA Trust

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Overview

What is the condition usually called/ any abbreviations used?

Multiple System Atrophy or MSA

Brief overview of the condition

Multiple system atrophy is a rare nervous system disorder where nerve cells in several parts of the brain deteriorate over time.

This causes problems with balance, movement and the autonomic nervous system, which controls a number of the body's automatic functions, such as breathing and bladder control.

The condition is progressive so there are no real constants, all symptoms get progressively worse. Over time people become less and less able to manage activities of daily living for themselves and so require more assistance.

What is the generally preferred term for someone with this condition?

An individual living with MSA.

Presenting Symptoms

The symptoms are wide-ranging and include muscle control problems, similar to those of Parkinson's disease. Unfortunately, the medication used to relieve them in people with Parkinson's disease (levodopa) isn't very effective for people with multiple system atrophy. Many different functions of the body can be affected, including the urinary system, blood pressure control and muscle movement. Although there are many different possible symptoms of multiple system atrophy, not everyone who's affected will have all of them.

- **Bladder problems:** constantly feeling the need to pee, peeing more frequently, loss of bladder control, being unable to empty the bladder properly, being unable to pee
- **Erectile Dysfunction**
- **Low blood pressure when standing up known as** postural hypotension
- **Problems with co-ordination, balance and speech** due to damage to the cerebellum. This can make the person clumsy and unsteady when walking, known as cerebellar ataxia and can also cause slurred speech
- **Slowness of movement and feeling stiff.** Slower movements than normal (bradykinesia). Movement is hard to initiate, and the person will often have a distinctive slow, shuffling walk with very small steps. Some may also have stiff, tense muscles. This can make it even more difficult to move around and cause painful muscle cramps (dystonia).

People with multiple system atrophy may also have:

- Shoulder pain and neck pain
- Constipation
- Cold hands and feet
- Problems controlling sweating
- Muscle weakness in the body and limbs – it may be more pronounced in one arm or leg
- Uncontrollable laughing or crying
- Sleep problems – insomnia, snoring, restless legs or nightmares
- Noisy breathing and unintentional sighing
- A weak, quiet voice
- Swallowing problems
- Blurred vision
- Depression
- Dementia (although this is uncommon)

Fluctuations

The symptoms vary considerably from day to day, week to week, and time of day. When blood pressure drops, which is a common problem, all symptoms are suddenly worsened. Urine infections and chest infections are frequent problems, which also make symptoms suddenly worse, and although treatment with antibiotics may improve things they are not likely to completely regain their pre-infection function.

Think about exploring things like:

- **How has the condition been over the past 12 months?** What changes have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previous?
- **Any recurrent infections?** How does this impact them and over the past 12 months how many times has this occurred? What treatment is given when they have the infections?
- **What level of pain/fatigue?** Can they quantify this, do they use a scale and can they describe it? Can they share what a 'typical' day might be for them? What are their triggers? Whilst exertion is a main trigger, what amount of exertion is enough to cause further limitation? How are triggers managed?
- **Cognitive function** How consistent is their presentation, how do they manage their memory deterioration, are they orientated, can they plan tasks as they used to?

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY	TIMELY	ACCEPTABLE STANDARD	REPEATEDLY
Do they have any symptoms which could cause a safety consideration?	For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?	How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?	Are they able to repeat a task as often as required? Is this the same every day?
Due to the varied nature of symptoms safety is a critical area which needs to be explored. Cover how risks are mitigated and if there is a history of incidents within activities 1, 2, 3, 4, 5, 9, 11 and 12 to ensure you have addressed the needs of the individual claimant. Safety considerations can be a result from physical and psychological symptoms.	Weakness, pain, fatigue, rigidity can all affect time frames of how long it takes an individual to complete a task. This will vary for each individual. Remember that there are no specific time frames outlined for what is reasonable. **Ensure to ask:** • How long it takes to complete tasks such as 1,4, 5,6,7 and 12. • Why they feel it takes them this long? • Where they report having any breaks in task, how long are these breaks and how frequent?	As it progresses, how they have adapted will become their 'normal'. This may mean they do not raise these during superficial questioning. Explore **HOW** they complete the task in depth to draw out any compensation strategies. E.g. using a sink to help get on/off the toilet. Remember that not everyone is comfortable talking about their restrictions. Be sensitive and explore both their physical and psychological symptom impact.	The variation between days experienced needs to be explored for all relevant activities. You should try to explore how someone may be before, during and after activities to determine fully whether the task is repeatable in the same way as often as required, especially with elements like fatigue affecting their presentation.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

- Continence issues – retention, urgency, frequency, nocturia
- Sexual/relationship issues – erectile dysfunction, speech and communication get progressively more difficult
- Mobility
- Personal hygiene issues and dressing/undressing
- Cognitive slowing
- Behavioural changes (the person with MSA is usually unaware of this)
- Psychological impact of a life limiting condition
- Palliative care - advanced care planning and end of life care

Watch **'what is MSA'** **HERE**.

Watch **James** talk about his MSA **HERE**.

Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?

In general

- Please speak to them, don't ignore them
- Give them plenty of time to reply to questions
- Do not rush an answer or attempt to finish their sentences
- Make use of open questions to allow them to bring out information they want to
- Include the claimants companion in the assessment
- **They will fatigue quickly. Offer breaks**

During face to face interactions

- Give individuals time especially where communication has become effortful, as whilst the person may well be able to understand it may be very difficult for them respond quickly due to cognitive slowing and difficulties forming their response.
- They may well not describe the full extent of their care and needs. It may be appropriate to ask their carer to speak for them and then get their agreement that this is accurate. For some people communication is eased by using specialist communication aids.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Ataxia, pain, rigidity, fatigue and changes to movement will affect their ability to stand, prepare fresh ingredients and cook.

There may also be cognitive effects.

Remember in PIP…

Are they completing this activity safely? Have they had any accidents? Could they recognise if food is cooked? Do they have physical difficulties standing, lifting and chopping/peeling? How long does it take to cook? Does completing this activity increase their fatigue or pain?

Activity 2: Taking nutrition

Nutrition, especially use of thickeners or PEG is likely for some.

Remember in PIP…

Can they chew, swallow, cut food and bring it to their mouth? Are they eating regularly? Are they at risk of choking and if so, do they require supervision? Do they need prompting throughout the duration of a meal? Do they use any aids or any supplements?

Activity 3: Managing therapy and monitoring a health condition

Due to the changes to movement that can occur physiotherapy may be a normal part of an individual's life and they may need support to complete any exercises they have been given.

Remember in PIP...

Can someone manage their medication or therapy independently. If they require therapy, is this in the home environment and how long does the support received take? Are they completing this on the majority of weeks?

Functional Impact

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Activity 4: Washing and bathing

Physical changes (poor balance, spatial awareness, coordination difficulties, ataxia) can affect safety in the bathroom getting in/out of an unadapted bath/shower. The range of movement can be reduced, or it can take longer to complete.

Psychological effects can impact motivation, orientation, sequencing.

Individuals may not be able to manage with aids due to the changes in their functional ability not being reliable.

Remember in PIP…

Do they require prompting to wash? Do they need assistance to wash or could they utilize aids to overcome physical restrictions? Are they safe? Can they manage to get in and out of the bath? Can they wash their entire body? If they report they can, how long does this actually take them? How do they feel after?

Activity 5: Managing toileting needs and incontinence

Retention, urgency, frequency, nocturia will impact their continence. Wearing incontinence pads is a usual way to manage this but as physical restrictions progress individuals may need assistance to manage their hygiene needs.

Due to rigidity, pain and changes in movement patterns, getting on and off the toilet can be difficult. Aids or assistance may be required.

Remember in PIP…

If the claimant is incontinent, how frequent is it and is this of both bladder and bowel? Can this be managed with pads independently or do they need assistance to maintain hygiene?
How do they transfer on/off the toilet? Do they use any aids? Can they use them reliably or do they require assistance?

Activity 6: Dressing and undressing

Range of movement can be reduced or affects to movement patterns mean it can take longer to complete. Dexterity may be reduced and grip strength may be diminished.

Psychological effects can impact motivation, orientation, sequencing.

Individuals may not be able to manage with aids due to the changes in their functional ability not being reliable.

Remember in PIP…

Do they require prompting to dress? If they can dress, how long does this take? Can they use aids or do they require assistance? How do they feel after dressing? Do they struggle with grip and managing things such as buttons and fastenings? How do they overcome this?

Functional Impact

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Activity 7: Communicating verbally

Speech and communication get progressively more difficult which can make it difficult to control volume and clarity of speech which can lead to others misunderstanding what they are trying to express.

Remember in PIP...

You need to consider someone's ability to both express **and** understand verbal communication. They may have cognition, but can they reliably express themselves? Do they require assistance to communicate their needs? How long does it take them to express a basic sentence?

Activity 8: Reading and understanding signs and symbols

With any cognitive changes, this can affect the ability to process and understand written information and in some cases support is required.

Remember in PIP…

This is the ability not only to read written information, but also understand it. Are they reading comics/magazines with little understanding of the context? Could they read a text message?

Within the scope of PIP, complex written information is more than one sentence.

Activity 9: Engaging with others face to face

Anxiety, agitation and apathy can also be symptoms which can affect an individual's ability to engage socially.

Remember in PIP…

If they report restrictions engaging, how does this manifest? How do they engage with familiar and unfamiliar people? Do they experience any anxiety or agitation towards others? How do they manage this? If they report difficulties engaging with unfamiliar people, who can support them? If someone specific is reported, why is this?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

As any cognitive functions are affected or an individual experiences anxiety or depression this can also result in assistance being needed for this task.

Remember in PIP…

Can they manage both basic and complex budgeting? Would they understand what change to expect in a shop? Can they plan for future budgeting? Could they manage a household bill? Do they need support with any areas of budgeting? Do they lack motivation to manage bills?

Activity 11: Planning and following a journey

Anxiety and changes in cognitive function can result in restrictions for individuals going out and result in individuals needing support when they complete journeys.

Remember in PIP…

Can they do this activity safely? How do they manage familiar and unfamiliar journeys? How would they cope with a diversion? Can they use public transport? If they report anxiety, does this meet the threshold of OPD? If so, how often are they able to go out of the home with support? Do they experience OPD on both familiar and unfamiliar journeys? Do they require support to overcome this?

Activity 12: Moving around

Mobility and history of falls/blackouts. Fatigue, dystonia, can cause falls, reduce distance that can be walked, increase timings and will affect the repeatability of ability to move around.

Remember in PIP...

Lived examples help to paint a clear picture of function to the Department. Where can they walk? How long does it take? Do they have falls? Can they repeat? Do they use aids? Have they had falls? Do they have pain? How do they feel after walking any distance? Do their symptoms worsen as the day progresses?

Additional reading or other resources

EXTERNAL

- Multiple System Atrophy, Wenning G., Fanciulli A. -Springer 2014, ISBN 978-3-7091-0686-0, www.msatrust.org.uk/
- For further information see NHS Conditions and Treatments: https://www.nhs.uk/conditions/multiple-system-atrophy/

INTERNAL

- Desktop Aid – Activity 12, Activity 6

Version control