MSA Trust

Factsheet
Series for healthcare professionals

A guide to Multiple System Atrophy for: Care Home Staff and Home Care Workers

What is MSA?

Multiple system atrophy (MSA) is a rare neurological condition. It affects people from the age of 30 years upwards, with an average age of onset at 52 years. There are approximately 3,500 people living with MSA in the UK and Ireland. MSA is about 45 times rarer than Parkinson’s, but some symptoms are similar. It is not hereditary or contagious.

MSA is caused by an overproduction in the brain of a protein called alpha synuclein which leads to degeneration or atrophy (shrinkage) of nerve cells in three specific areas of the brain. The protein stops messages getting from the brain to the muscles and systems of the body.

There are two types of MSA; MSA-p indicates there are more Parkinson’s Disease type symptoms and MSA-c indicates there are more cerebellar symptoms. Both reduce lifespan significantly.

There is currently neither treatment or cure for MSA, but some symptoms can be managed with medications and therapies in different stages of the illness.

MSA affects the autonomic system of the body, which includes speech, swallowing, bladder, bowel, blood pressure control and movement. It varies from day to day, from hour to hour - so some days the person with MSA will be able to do things for themselves and at other times they will need your help.

Remember that people with MSA will have good days and bad days and they should have an individual care plan in place, to take into account their changing needs.

It can affect mood too. Some people will have anxiety and depression. We wouldn’t expect them to get a dementia and they can make decisions about their own care needs.

Your aim should be to help the person living with MSA maintain their quality of life and independence as best as possible.

The MSA Trust is here to help support you in your role as care giver and you can contact the MSA Health Care Specialists and Social Welfare Specialist for advice. Contact details are at the end of this factsheet.

Things to remember:

- No two people are the same and every person's experience of MSA will be different
- The person's symptoms will vary from day to day, meaning that the care you give them will need to vary too
- Listen to the person with MSA and their family about how the condition affects them - they are the experts
- People with MSA are not able to move as quickly as they want to and this can be very frustrating for them. It is important to remember they are not being difficult, particularly if they were able to do something for themself yesterday, but need more help from you today
- Allow the person with MSA time to respond to you. It can take longer for them to form a response; they will have heard you and understood you but replying can be effortful sometimes
- If the person you are caring for becomes confused or starts hallucinating, it is most likely to be caused by side effects from a medication or an infection. MSA doesn't normally cause dementia.

Symptoms and How to Manage them

People living with MSA will have a team of professionals involved in their care. These may include a Neurologist, a Parkinson's Nurse Specialist, Speech & Language Therapist, Occupational Therapist, Physiotherapist, Continence Nurse Advisor, Community Nurse or Matron, GP and home care workers.

As you are caring for someone with MSA you will notice if there are any changes and can report these to your manager or supervisor who can then discuss this with the person and their GP, Parkinson's Nurse Specialist or MSA Health Care Specialist.

Mobility

People with MSA have difficulty with balance; they may feel dizzy on standing, their blood pressure may drop suddenly, their leg muscles may not hold them up and they may fall frequently. Stiffness and rigidity of muscles can cause difficulty with movement. Movements become slower (bradykinesia) and more effortful. Difficulties include getting up from a chair, not being able to turn over in bed and losing their balance. 'Freezing' is a symptom also seen in Parkinson's and the person can stop suddenly while walking or when starting a movement. Try not to distract them by talking as this can make things worse. Ask what you can do before they stand up or wait until they are sitting safely to ask. Some people use "cues" (such as a walking stick with a laser beam) and their Physiotherapist (PT) and Parkinson's Nurse Specialist (PDNS) can advise you on ways to help using cueing strategies, which can help to restart a movement and prevent falls.

People with MSA often have upper body rigidity and stiffness (particularly head, neck and shoulders) which can be painful at times.

They may have difficulty getting out of a chair, from bed, starting to walk or turning over in bed to get into a comfortable position. They may also have difficulty with hand movements and co-ordination.

A Physiotherapist or Occupational Therapist (OT) will assess the person with MSA and suggest ways to help. They may give them regular exercises to do, which you can help with. They will provide appropriate walking aids which will change over time. You should ask the person how best to assist them, they may need you to walk alongside them or require assistance getting in and out of bed, transferring to a chair etc.

They may have advice from their Physiotherapist about how to move or may need pain relief before trying to move. The Physiotherapist may have given them daily exercises to carry out and you can help with these. They will have advised them on which aids to use. You should give people plenty of time, support and patience when they are mobilising. They may be slower than they would like to be, and this may vary each time you see them. Ask them how they are each time you visit them and what they need you to do for them today.

How you can help:

- Allow them time to do things the best way for them, offer your support and patience
- Remember that each day will be different. If they are tired or anxious their symptoms will be worse
- If they fall frequently the Physiotherapist can show you ways to help them up without causing injury to them or yourself. If they have a bad fall, they should be checked over by a doctor in case of injury
- If they are taking Parkinson's medication to help with stiffness or movement make sure these are given on time. Allow the medication to start working (30-45 minutes) before they try to mobilise.
- If they have pain, make sure they have had their pain medication 30 minutes before attempting to move them
- If they have regular falls make sure this is recorded and the Parkinson's Nurse Specialist, MSA Health Care Specialist or Physiotherapist is consulted for advice
- The majority of people with MSA will lose the ability to walk over time and will become wheelchair dependent and ultimately need to be hoisted
- If they cannot change their own position you will need to ensure they are moved regularly to prevent pressure ulcers (pressure sores) developing.

Speech

Many people with MSA will develop problems with their speech. Initially their voice may be quieter (hypophonic) then become slurred and eventually they may not be able to communicate verbally at all. They may not be able to control how fast or slow they speak, their voice may become high pitched or sound hoarse at times. Often when they are tired, for example at the end of the day, their speech may be unintelligible. Their voice may become monotone (all on one level) and they can lose the ability to express emotion.

People with MSA may have less facial expression and other people may have difficulty recognising their expressions or emotions. In a care home setting, other residents may not approach them or engage them in conversation. Body language can also be affected due to slowness of movement, stiffness or tremor.

The person with MSA may take longer to process what you have said before they respond. People with MSA may stop attempting to communicate with other people as it becomes more of an effort to speak and they may become isolated.

How you can help:

- Try to imagine how frustrating it would be if you were unable to voice your needs or concerns. Imagine how anxious it might make you feel
- Talk normally, listen carefully; you don’t need to raise your voice.
- Use short sentences and stress key words, ask one question at a time
- Be patient and allow time for the person with MSA to talk and respond. Try not to interrupt them
- Make sure they can see and hear you (do they wear glasses or a hearing aid? Do they have their dentures in place?). Offer them a drink if their mouth seems dry
- Try to be calm and reassuring and reduce any anxiety they may be feeling
- Talk to them respectfully, they do not have difficulty understanding you even if they have difficulty communicating
- Ask the local Speech & Language Therapist (SLT) to visit and assess their needs, they will give you advice on communicating with them and may suggest communication aids to help
- The MSA Trust has several Lightwriters which can be loaned to the person with MSA. If the SLT thinks this would be helpful, they can contact the MSA Trust to discuss this
- As speech worsens there may be a tendency to stop attempting to communicate with the person with MSA and speak to their family member instead -work with the SLT or Nurse Specialist and the persons family to see how to adapt so they do not feel scared, alone or not included in conversations
- If the SLT has recommended equipment to help the person with MSA communicate make sure you are taught how to use it too. If their speech is getting worse, but can still be understood, the SLT may suggest voice banking. This is where someone can record phrases and words electronically to use later. The MSA Trust can assist with the funding for this service, please contact the Speech and Language Therapist for more information.

We have factsheets on communication aids that you can download on our website or we can post to you on request.

Stridor

Stridor is an abnormal, high-pitched sound produced by turbulent airflow through a partially obstructed airway. In MSA this is usually a result of weakened or obstructed vocal cords. The sound can be variable and it may sound harsh, musical, or breathy, but you will definitely notice it is not normal breathing. This can become a medical emergency if left untreated, so if you notice abnormal breathing do report it to the GP for referral to an Ear, Nose and Throat Specialist for investigation and treatment advice.

The person with MSA may need to have an overnight admission to a Sleep Centre and require the use of a CPAP (continuous positive airway pressure) mask overnight.

Swallowing

People with MSA have weakened facial muscles which affect their ability to smile and express themselves and they may not be able to form a lip seal, making swallowing difficult.

Their mechanism to close off their airway when taking food or fluid is slower, meaning that food or fluid can go into the lungs instead of into the stomach. It doesn't take much food or fluid (or saliva) going into the lungs to set up a chest infection, which can quickly become pneumonia. Any infection in MSA can be serious and will make all of their MSA symptoms much worse. This is called aspiration pneumonia and can happen silently without any noticeable coughing or choking episodes.

An SLT can assess their swallowing capabilities as well as their speech and will advise you on any foods they should avoid such as things that make them cough (hard, dry or crumbly foods). They may need their fluids thickened with powder thickeners as thick fluids are easier to swallow than thin - a fruit smoothie will travel slower than a glass of water for example and is less likely to 'go down the wrong way' into their lungs.

How you can help:

- In order to be able to swallow safely the person with MSA needs to be sitting upright, supported with pillows if necessary. Check to see if they have their dentures if needed
- They may need adapted cutlery or cups, the SLT or Occupational Therapist (OT) can advise on these. Ask their family what things have made meal-times easier for them at home
- Make a list of food/drink likes and dislikes for the chef and staff with any instructions from the SLT or Dietitian
- Make sure that any medication required before meals has been taken on time
- If a person wants to eat on their own allow plenty of time as they are likely to be slow so food may need reheating or cutting up. Don't assume they have finished eating when everyone else has
- Offer help each mealtime as their ability to manage will vary each time. Ask them if they have any difficulty with chewing and swallowing, if they choke often it may be frightening for them
- Ensure they manage adequate fluids. When you first meet them you could keep a 24hr fluid balance chart to assess this for a few days
- After meals they may not be able to clear all the food from their mouth as their tongue will be weaker, offer mouthwashes or help with teeth cleaning if they wish. Mouth care may be required after meals to ensure no food debris is left behind
- If they develop chest infections this may be a sign of silent aspiration and the SLT should be asked to review them. They may carry out a video of their swallow to ensure it is safe for them to eat and drink normally
- Drooling of saliva can also cause problems; it can be socially embarrassing and they may request meals in their room because of this. It can make the mouth sore and it can make them cough

- If the person with MSA is losing weight ask for a dietitian to visit as they can advise on any nutritional supplements that are required. There may come a stage when they aren't able to eat and drink normally and the SLT will suggest Peg (tube) feeding.

The MSA Trust has factsheets on equipment, Peg feeding, saliva tips and other symptoms that you can download from our website or we can post to you on request.

Sleep

Sleep problems can be common in MSA. People may have difficulty getting into a comfortable position, difficulty turning in bed or have pain from muscle stiffness and rigidity.

Restless leg syndrome can also be an issue and can disturb sleep - people feel like they need to get up and move around to relieve the discomfort.

Nightmares and distressing dreams are common and people may wake feeling upset or believing that the dreams are real.

Noisy breathing while asleep and loud snoring may be an indication of stridor, which needs investigation as it can mean there is a problem with the vocal cords (see section on 'stridor' above).

Needing to pass urine several times at night (nocturia) is common and is related to low blood pressure. People are at greater risk of falling when they have an urgent need to get to the toilet and are sleepy and balance is poor.

Depression and anxiety can also disturb sleep patterns.

How you can help:

- Try to establish a routine and ask what time they like to go to bed and get up. They may wish to have an afternoon rest if they fatigue easily.
- Make sure medication is taken on time
- Ensure a call bell is within their reach so they can summon help if needed
- Ask the PT and OT how best to move the person in bed comfortably and ask if there are any aids needed to get them in and out of bed safely
- They may benefit from wearing satin pyjamas as the shiny material can help them to turn over
- People with MSA should ideally sleep with their head up at a 30 degree angle, due to low blood pressure - discuss this with the OT if the head of the bed needs to be raised
- Seek advice from their Parkinson's or MSA Health Care Specialist if you are concerned about their lack of sleep or noisy breathing/snoring
- If sleep is problematic you could keep a sleep diary to show the PDNS or Neurologist at their next appointment.

Bladder

There are several problems with the bladder in MSA. There can be urgency (where people need to rush to the toilet), frequency (where they need to go lots of times and don't empty the bladder completely), needing to go several times at night (nocturia) and the inability to pass any urine (retention). These can change over time and someone may experience all of these symptoms.

Initially the person with MSA should be seen by a Urologist or a Continence Nurse Specialist who can assess the bladder and carry out a portable ultrasound to see if the bladder has incomplete emptying. If this is the case the person is at higher risk of urinary tract infections.

There are medications that can help with each of these symptoms, but over time they will become less effective. Most people are taught how to intermittently self-catheterise (put a catheter in the bladder, empty the bladder, then remove the catheter) but over time they are less able to do this and at some point everyone will need a permanent indwelling catheter. We favour the supra-pubic type over the urethral ones as there is slightly less risk of infection. People with MSA tend to produce more urine overnight due to the postural hypotension (low blood pressure when they are upright).

How you can help:

- Be alert to changes in colour, odour and quantity of urine
- If the person is not catheterised, offer assistance to the toilet as required and assistance with clothing as needed
- Overnight it may be better to offer a urinal to men and a commode by the bed for men/women if they can’t mobilise to the toilet safely in time
- Ensure adequate fluids are taken, ideally 1.5 to 2 litres in a 24 hour period. Monitor intake and output and report any changes to the nurse in charge
- If they are catheterised ask to be shown how to care for a catheter with good hygiene and what to look out for
- Some medications can change the colour of urine, but if you notice it is darker than normal, more concentrated, the amount produced is less than normal or if the urine is malodorous (fishy smelling) do report this as it could be a sign of infection. People with MSA can have an infection without having a high temperature.

If someone with MSA has an infection, all of their symptoms will suddenly become worse. MSA doesn’t progress rapidly, it deteriorates gradually over months and years - if you notice the person you are caring for is *suddenly* worse over a 24/48 hour period, you should assume they have an infection and check their urine as they will need antibiotics as soon as possible. See information on infections later in this factsheet.

Bowel

The majority of people with MSA will have problems with constipation. This is because the whole of the gastrointestinal tract, from mouth to rectum is much slower in people with MSA. There are lots of unnecessary admissions to hospital with bowel blockages (sub-acute/acute obstructions) which can become a medical emergency. People with MSA should have a daily laxative even if they are managing a well-balanced diet. Sometimes people can vary between loose stools and constipation, but this is more likely to be medication or infection related. As the illness progresses people may need suppositories or enemas to manage the constipation.

How you can help:

- Keep a record of bowel movements (which should ideally be daily) and report if someone hasn't had a bowel movement for three days or more
- Encourage a varied diet and ensure that any laxatives are taken as prescribed
- If they are taking Parkinson's medications these will not be effective when they are constipated and their symptoms may not be as controlled
- Encourage (and assist with if needed) extra fluids
- Check that their abdomen is not distended or hard to touch if they complain of abdominal pain or discomfort
- You may notice they become more sleepy, confused, agitated or just not their normal self if they are constipated

Do contact their PDNS or the MSA Health Care Specialists for advice if there are problems.

Depression and Anxiety

Someone with MSA will have been told by their Neurologist that they have a rare condition that is going to get worse over time and there is no specific treatment or cure. There are no medications to stop the illness getting worse over time and they will become immobile, with impaired speech and swallowing. This diagnosis is devastating. All the things they had planned to do in their lifetime are now not going to happen and they are understandably scared, angry, frustrated and feeling that things are out of their control. They may be concerned about becoming a burden to their family and know that things they were looking forward to in the future may never happen. Their whole life has to be adapted and they have to come to terms with what this means to them.

When someone is given a diagnosis of MSA it completely changes their life. The news that things will deteriorate over time and that there is no cure, can be devastating for them and their family.

How you can help:

- Try to imagine how you might feel if a Neurologist had told you that you have a progressive condition that will worsen over time
- Understand that some days they will feel low in mood, they may be tearful or frustrated with the illness. If they get angry do not take this personally, they are angry at the illness, not at you
- If you feel they are low in mood a lot of the time and are taking less pleasure in things, do report this as they may need to be offered counselling or be prescribed some medication to help with their mood
- Lability of mood is common, so the person with MSA can be very high or very low in mood and not be able to find a middle balance
- There are antidepressants that can be helpful to level the mood - the MSA Trust has a leaflet on medications
- Anxiety is a common symptom and can make their MSA symptoms worse, again there are medications we can recommend to help with this
- Disturbed sleep can lead to depression and anxiety

- Ask the person with MSA what they enjoy doing and try to enable this when possible - you may need to help them adapt. For example, if they liked gardening but can no longer do this, can they have a raised bench/platform in the garden where they can help to grow herbs or flowers? Do they like listening to music or radio plays? Can you download podcasts for them? Can they take part in group activities?
- Try not to leave them with only the television for company, MSA shouldn't affect their cognition or mental abilities
- Try to be cheerful and upbeat when you see them but be mindful of them needing some time alone if they wish to cry at times.

Pain

There are several types of pain that can be experienced in MSA:

1. Upper body muscle tightness and rigidity is common and can affect the head neck & shoulders.
2. Legs can be affected by Restless Leg Syndrome (typically at night) or cramp.
3. Contractures of hands and feet are common and are caused by an increase in muscle tone (dystonia).
4. A burning sensation may be experienced anywhere in the body, often feet or legs (neuropathic pain).
5. Aching muscles may be caused by being immobile and stuck in one position for long periods.
6. Antecollis is where the neck muscles become tight on one side and weak on the other, causing the head to drop forward and onto one side - this can be very uncomfortable and permanent.

How you can help:

- For muscle stiffness, daily exercises may help. Either passive (with you helping) or active (done by the person with MSA) and the PT is the best person to advise on what exercises to do for each individual
- Physiotherapy can be helpful for muscle pain, particularly if it is related to poor posture
- Muscle relaxant medications may also be helpful - please speak to the MSA Health Care Specialists about this
- Massaging anti-inflammatory gel such as Ibugel three times a day can be good for neck and shoulder pain (providing the person with MSA is not asthmatic)
- Warmth can also be helpful, such as a warmed lavender wheat bag or electric heat blanket
- If the person has access to an aromatherapist, reflexologist or acupuncturist, these can all be beneficial – We have a factsheet on Complementary Therapies that you can request or download from our website
- Neuropathic pain may be helped by specific medication - please speak to the MSA Health Care Specialists
- Antecollis may be helped by a soft or hard collar (from PT or OT) or the travel bean bag neck cushions, Ibugel and/or warmed lavender wheat bag
- Botox can be helpful for dystonia or contractures and sometimes antecollis, via the Neurologist.

Fatigue

People with MSA will tire more easily and when they are tired their MSA symptoms will be worse. They may ask for an afternoon rest, to recharge their energy levels. They will often have a good day, followed by a bad day, so let them tell you when they feel in need of a rest.

If they have had an active day, perhaps having been out with family or at a hospital appointment, the next day they will most likely feel exhausted, so allow them more time to rest.

How you can help:

- Understand that all of their symptoms will be affected as they become more tired. Ask them to tell you when they are feeling fatigued so you can facilitate a rest period into their day
- Speech is often more difficult in the evening, so discuss other ways to communicate if their speech is problematic when they are tired. They might need to use a speech aid, a picture board or other piece of equipment. You can ask their Speech and Language Therapist how best to address this.

Blood Pressure Control

Many people living with MSA will have Postural Hypotension. This means when they change position their blood pressure drops suddenly, usually when getting out of bed or standing when they have been sitting for a while. This can make them feel lightheaded, dizzy and puts them at risk of falling. They may feel unsafe and anxious about losing their balance, especially if they have had a lot of falls.

How you can help:

- Understand that they cannot move quickly and will be looking to you for reassurance that they are not going to end up on the floor! Before attempting to help someone stand up from a chair or get out of bed, you should do the following:
    1. If they are getting out of bed, ask them to sit on the edge of the bed for 5 minutes and rotate their ankles round and round, then move their feet up and down in a stepping motion to pump their calf muscles.
    2. Give them a glass of water to drink. This helps to raise their blood pressure a little.
    3. If they have been given elastic stockings to wear, help them put these on before rising from bed.
    4. They may also have something called an abdominal binder (a bit like a stretchy corset to wear around their middle) which also helps to push the blood pressure up to their heart and lungs and brain. Assist them with putting this on.
    5. Reassure them that you are beside them and will allow them to get up when they feel ready.

- They should not sleep flat but have the head of the bed raised to 30 degrees
- People with low blood pressure should avoid large meals as this can drop their blood pressure further as it rushes to the stomach to aid the digesting process

- They should have their normal size meals but allow a break of 1 to 1 and a ½ hours after their main meal before they have dessert. They should add salt to their food as this helps to raise blood pressure too
- As their illness progresses, they will lose weight, so they may require advice from a dietitian about getting extra calories. If they become underweight, they are more likely to pick up infections, which can be serious in MSA.

There is a factsheet about postural hypotension and how to manage it on our website - https://www.msatrust.org.uk/support-for-you/factsheets/

Medications

Each person with MSA will have an individual regime of medication from their Neurologist.

As there is no specific treatment for MSA we use medications to try to improve symptoms.

Parkinson’s medications can be helpful in about a third of people with MSA and it is important that they are given them at the correct times as prescribed. Please note, if someone is constipated their Parkinson’s medications will not be effective.

Parkinson (PD) type symptoms may be treated with Levodopa - examples of these are Sinemet and Madopar and they should help with muscle stiffness and rigidity. Other PD medications may include Amantadine, which can help with balance and fatigue. Less commonly they may be prescribed dopamine agonists such as Ropinirole or Pramipexole which may help with some of the PD type symptoms.

Medications for bladder and bowel issues are common and they may also be prescribed a maintenance dose of antibiotics to try to prevent urinary tract infections.

Medications for postural hypotension are often prescribed, such as Fludrocortisone or Midodrine. Pease also see the MSA Trust factsheet on postural hypotension for non-pharmaceutical ways to help.

Desmopressin (DDAVP) may be prescribed by the Neurologist for nocturia. If this is the case regular bloods should be taken to check Sodium and Potassium levels.

Antidepressants that are helpful in MSA include Mirtazapine and Citalopram. Some antidepressants are contraindicated with PD medications.

Please speak to one of the MSA Health Care Specialists (contact details at end of this factsheet) about medication for people with MSA and any that may need to be avoided.

Infection

Due to the autonomic failure, people with MSA do not necessarily show the usual signs of infection. Their temperature regulator doesn’t work normally so they may not have a high temperature. They may be asymptomatic but still have an infection. What you will notice is their MSA symptoms have suddenly got worse over a few days; they may be less alert, drowsy, speech and swallowing or balance may be worse. If these changes happen suddenly, it isn’t the MSA causing it, the most likely cause is an infection. Check their urine and chest and get antibiotics as quickly as possible. They will take longer to recover from an infection as well.

Because their temperature regulator doesn't work, they may feel cold in warm weather and hot in cold weather. Hands and feet may feel cold all the time as the low blood pressure means the smaller capillaries (blood vessels) are not filled with blood.

You may notice changes to the colour of extremities - blue, red or mottled and they made need extra socks, gloves, blankets or heated pads to feel comfortable.

Advanced illness and End of Life Care

Because MSA is a progressive condition, symptoms will deteriorate over time. It is difficult to say over what time period as everyone is affected differently.

Advanced illness includes:

- Medication being less effective
- Increased mobility problems and more falls until they become wheelchair dependent or nursed in bed
- Swallowing difficulties increase, Peg feeding may be required depending on their personal choice
- Speech will be more impaired and may result in not being able to communicate verbally
- Pain may be more difficult to manage
- Depression and anxiety may become more marked.

Due to the range of symptoms and the increase in care needs, access to the Multidisciplinary team is important.

As MSA progresses it can lead to more recurrent infections - urinary tract or chest infections. Each infection makes the person symptoms worse and they are less likely to recover to how they were prior to that infection. They may need hospital admissions to treat the infections with intravenous antibiotics and there may come a point when they choose not to go to hospital.

Everyone should have an individualised care plan which will encompass their wishes for end of life. This should include who they want to be with them, any spiritual or religious needs and where they want to be cared for when they are dying. They should also be offered the opportunity to include legal documentation such as a Lasting Power of Attorney and an Advanced Decision (also known as an Advanced Directive or Advanced Decision to Refuse Treatment and Living Will). Their care plan should include information about palliative care.

There is more information about advance care planning here - https://www.willen-hospice.org.uk/how-we-care/in-patient-care/advance-care-planning/ and on our website here - https://www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/preparing-for-advancing-msa/.

Things to remember

- When someone is given a diagnosis of MSA it completely changes their life. The news that things will deteriorate over time and that there is no cure, can be devastating for them and their family
- No two people are the same and every person's experience of MSA will be different

- The person's symptoms will vary from day to day, meaning that the care you give them will need to vary too
- Listen to the person with MSA and their family about how the condition affects them- they are the experts
- People with MSA are not able to move as quickly as they want to and this can be very frustrating for them. It is important to remember they are not being difficult, particularly if they were able to do something for themself yesterday but need more help from you today
- Allow the person with MSA time to respond to you. It can take longer for them to form a response; they will have heard you and understood you, but replying can be effortful sometimes
- If the person you are caring for becomes confused or starts hallucinating, it is most likely to be caused by side effects from a medication or an infection. MSA doesn't normally cause dementia.

The MSA Trust

The Trust's vision is a world free of MSA. Our Mission is to find the cause and, ultimately, cure for MSA. Until that day, we will do all we can to support people affected by MSA and to strive to ensure that they are not alone on their individual journeys.

The Trust's contact details:

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – https://www.msatrust.org.uk/support-for-you/hcps/.

MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB
T: 0333 323 4591 | **E**: support@msatrust.org.uk | **W**: www.msatrust.org.uk

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Feedback:
Your feedback helps us ensure we are delivering information to the highest standard. If you have any comments or suggestions please contact us at support@msatrust.org.uk.

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