MSA Trust

Factsheet

Notes for Health and Social Care Professionals assessing people living with Multiple System Atrophy (MSA) for Continuing Health Care

This factsheet is designed to help health and social care professionals who are assessing an individual living with MSA for NHS Continuing Health Care (CHC) funding.

The National Framework for CHC and FNC (Funded Nursing Care) revised in 2018 referred to throughout this document can be found at https://www.events.england.nhs.uk/upload/entity/30215/national-framework-for-chc-and-fnc-october-2018-revised.pdf.

Most people living with MSA are, at some stage, likely to qualify for CHC funding. As section 50 of the National Framework states:

Whilst there is not a legal definition of a health need (in the context of NHS Continuing Healthcare), in general terms it can be said that such a need is one related to the treatment, control, management or prevention of a disease, illness, injury or disability, and the care or aftercare of a person with these needs (whether or not the tasks involved have to be carried out by a health professional).

For people whose condition is rapidly changing and who may be approaching the end of their life a fast track CHC application should be made without delay. Consideration of this should be made before completing a checklist assessment or a full DST assessment.

What is MSA?

MSA is a rare progressive neurological disorder affecting adults, usually over the age of 40. It is caused by the atrophy of nerve cells in multiple areas of the brain. Initially it may be diagnosed as Parkinson's Disease or Cerebellar Ataxia but as time goes by the differences become evident and the prognosis changes significantly. The progression of MSA is complex, variable and unpredictable. MSA is a life shortening condition.

There are three groups of symptoms which reflect the three main regions of the brain which may be involved. These are:

Parkinsonism (basal ganglia):

- Feeling slow and stiff when moving
- Difficulty in starting to move
- Writing slow and spidery
- Difficulty turning in bed
- Tremor

Cerebellar (cerebellum):

- Feeling clumsy and dropping things
- Poor fine motor skills
- Unsteadiness
- Poor balance
- Difficulty writing
- Slurred speech

Autonomic (brain stem):

- For men, difficulty with erections. In both men and women, sexual dysfunction
- Bladder problems
- Blood pressure problems (feeling dizzy or fainting)
- Pain around the neck and shoulders
- Altered bowel function
- Cold hands and feet
- Problems with sweating control and temperature regulation

In addition, there are a range of other issues including:

- Weakness and rigidity in arms and legs
- Unpredictable emotional response
- Restless sleep
- Nightmares
- Noisy breathing/snoring
- Weak and quiet voice
- Swallowing problems, choking episodes

- Eye muscle weakness which may cause blurred vision and blepharospasm
- Sleep apnoea

The 12 domains and some of the issues to consider when assessing a person living with MSA

Every individual is different and the points below are merely an aid to assessment.

Comorbidities may exist and where this is the case, specialist advice for each medical condition should be sought.

Breathing:

Physical postural changes alongside the autonomic dysfunction seen in MSA result in a range of breathing related issues.

- People with MSA may need medications to assist with the management of secretions. Devices such as airway suction machines and cough assist machines to help expectorate the secretions and maintain a viable airway may be required. Use of these requires competent carers who are trained to use these devices and who are able to recognise when they need to use them.
- Monitoring of breathing in terms of changes in rate, changes in noisiness and evidence of difficulty breathing – gasping / choking episodes – is essential. Any of these require urgent referral to a respiratory specialist and/or ENT specialist to assess and initiate appropriate management.
- Inspiratory sighing through the day, reduced daytime functionality, increased fatigue and increased snoring and changes in regularity of breathing whilst asleep are all suggestive of sleep apnoea, which may or may not be obstructive. These symptoms require respiratory review and sleep studies. Non-invasive ventilation support, for example, CPAP, may be needed. If this is used carers will need to know how to fit the mask and how to use the machine as the person with MSA ultimately will not manage to do this independently.
- Recognition of stridor and reduced respiratory effort is critical and needs urgent response as it suggests central respiratory failure or vocal cord spasm which require urgent management to prevent sudden, unexpected death and medical emergencies. Vocal cord problems due to autonomic dysfunction may require the person to have a tracheostomy. If this is the case the presence of someone 24/7 who is trained to address any acute tube blockage, assess when to apply suction and when to change the tube is essential as the person with MSA is unlikely to have the co-ordination to manage this themselves - and in an acute episode would certainly not manage this.
- There is a susceptibility to chest infections due to silent aspiration, recognising promptly that the person has an infection and starts antibiotics is crucial. Hospital admission may be required.
- People with MSA may not display the common symptoms of infection due to a lack of temperature control.

  There is a need to be vigilant to other signs of infections and to act promptly.
- A sudden deterioration in symptoms may indicate chest infection.
- Increased secretions and tenacity of secretions may require medications to dry up or thin the secretions requiring skilled monitoring and care to assist coping with them.

Inability to cough effectively and clear secretions increases risk of aspiration and chest infection.

- People with MSA commonly have significant reflux and require medication to manage this. Reflux increases the secretion production in the oesophagus compounding secretion management issues and increasing risk of aspiration. Even with gastrostomy feeding there is risk of feed regurgitation and reflux due to incompetence of gastric cardiac sphincter, and slowing of gastric emptying causing aspiration and chest infection.
- Vigilant monitoring for chest infection – risk of 'silent aspiration' and prompt treatment required. Frequency of chest infections is a strong indicator of prognosis with more frequent chest infections being seen towards the end of life for people with MSA.
- People with MSA may also have REM sleep disorder causing shouting out and hitting out and moving whilst asleep, after this they may need assistance to get back into comfortable upright position which aids breathing.
- A highly skilled MDT including a respiratory specialist, a Speech and Language Therapist (SLT) and a Physiotherapist are required as ongoing monitoring is essential as the condition progresses.

Nutrition:

People living with MSA will experience swallowing problems. Swallowing deteriorates over time and the risk of aspirating and choking will be high. Ongoing assessment/review by the SLT and dietitian is essential to avoid malnutrition, aspiration and choking. Supervision especially when feeding is required to ensure safety.

• Supervision and limitation of distractions is required during meals particularly where cognitive or behavioural challenges indicate that a person may be at increased risk of choking.

• Those with poor swallowing may need assistance following medical advice to modify consistency or thicken drinks.

- Postural changes, muscle rigidity, tremor, poor co-ordination and impaired manual dexterity along with deterioration in functional ability and fatigue will have an impact on the ability to eat and drink. The person with MSA may require support with feeding and with positioning prior to feeding. Some people have particular difficulty if their head position is chin on chest (antecollis) and they may need assistance to put a collar on if worn.
- Poor swallow co-ordination increases the risk of aspiration of fluids and food and modification of these consistencies is often required, and increasingly commonly gastrostomy feeding is needed to maintain a safe body weight and maximise hydration (critical to support a safe blood pressure and increase hydration during infections). Fatigue can also impact upon nutritional intake.
- Calorie intake can be significantly reduced. Monitoring using a Malnutrition Universal Screening Tool (MUST) score is useful.
- A person with MSA may choose an alternative method of feeding (which should be discussed early). Assistance with all aspects of managing artificial feeding may be required.

- There is still a risk of aspiration even where an artificial feeding tube is fitted.
- If artificial feeding tube is not fitted support from skilled carers will be required if patient is 'fed at risk' because of the risk of choking.
- Ability to swallow safely will vary with good days and bad days, at different times of day and when fatigued. Carers need to be able to monitor this and act accordingly. Illnesses such as infections may also have an impact on swallowing ability.
- Refer to records on choking incidents and weight loss and to SLT and dietitian reports. Request records of the time taken to eat meals.

Continence:

Bladder issues include urgency, frequency, nocturia or retention (or a combination of all).

- People with MSA are at high risk of developing bladder infections. Symptoms of urinary retention and incomplete bladder emptying can lead to urinary infections. People living with MSA may reduce their fluid intake because of issues such as urgency or incontinence and may easily become dehydrated. Dehydration leads to urinary tract infections. People living with MSA and their carers need to be alert to this and oral fluids or top up fluids via an artificial feeding tube may need increasing.
- The use of continence products is likely to be required. Sensitive assistance to manage continence is usually required.
- Infections make the symptoms of MSA deteriorate rapidly. Due to autonomic dysfunction the usual signs of infection (e.g. high temperature) may not be present. Prompt treatment is required. Maintenance dose antibiotics may be required on a daily basis and these may need to be changed every 3-6 months.
- Input from a continence nurse specialist and/or a urology specialist may be needed along with ongoing District Nurse support.
- Catheter use may be required. People may need to learn to self-catheterise or they may require an indwelling catheter.
- Body image and sexuality are affected by catheter use. Monitoring and professional support with these issues may be required.
- People with MSA are likely to need intervention for bowel management – commonly constipation is a problem but people can also experience hypermotility of the gut causing loose stools. Most people will require a daily laxative. Regularly recording and monitoring and thorough bowel assessment is required to ensure appropriate interventions. Bowel irrigation may be needed and the management of this may require carer and District Nurse support.
- Constipation makes all other symptoms of MSA worse and can affect efficacy of medications, especially Parkinson's medications.

Skin Integrity:

Because mobility is impaired, and movement is often restricted people with MSA are at risk of their skin breaking down.

- People with MSA experience many mobility issues, which can include difficulty in initiating movement, rigidity, stiffness, tremor, dyskinesia, dystonia, spasms and

contractures. Pain can limit mobility.

It can be expected that they will get progressively worse over time and may get acutely worse during periods of fatigue, infection, and other acute episodes.

- Specialist Occupational Therapy (OT) and physiotherapy input should be in place. Help with specific tasks such as turning over in bed and the use of head collars or aids to reduce complications of specific issues such as antecollis and saliva management is needed.
- People are at risk of falling and damaging their skin, so all care should be taken to reduce this risk.
- Continence issues, excessive sweating or an inability to sweat can all lead to skin breakdown.
- Help may be required with positioning. Pressure-relieving mattresses and other specialist aids are often needed to help prevent skin damage.
- Good hydration and nutrition are important to skin health, and can be difficult for someone with MSA due to difficulties with independently accessing food and drink and with fatigue.
- Regular skin assessments will be essential if spontaneous or independent movement is difficult. Regular monitoring should be done to assess the risk of them developing pressure damage.
- Tissue Viability and Dermatology services may need to be involved if tissue damage occurs.
- To reduce risk of contractures, regular massage and movement, and potentially palm protectors or splinting, use of botox and physiotherapy will reduce risk of pressure damage to areas such as hands where fingers have contracted into the palm.
- People with MSA are thought to have lower pain thresholds due to neurological damage, so skin breaks are especially painful. Conversely due to peripheral autonomic dysfunction of capillaries they may be unaware of damage so vigilant monitoring is required.
- Ongoing management is essential. Encouraging adequate drinking can be difficult in the presence of swallowing and urinary issues.
- Due to the effect of MSA on the autonomic system, people with MSA may struggle to control their temperature and find that they sweat too much. Often, they then go on to sweat too little, or not sweat at all making skin prone to being sweaty or dry, both putting them at risk of skin integrity being compromised.

Mobility:

Mobility is impaired due to problems with stiffness and slowness of movement and poor balance, wheelchair dependency is expected, and some have to be nursed in bed due to blood pressure problems.

- Difficulty initiating movement, so a person may freeze unexpectedly, or their feet feel as if they are stuck to the floor, with poor foot pick up. This results in a high risk of falls with the likelihood of injury/fracture.
- MSA causes blood pressure control problems. A change of position from lying to sitting

or sitting to standing can result in a sudden plummet in blood pressure, with significant risk of collapse / syncope.

Someone needs to be in the vicinity of the person with MSA at all times to assist with safe management of blood pressure problems – administering first aid, giving medication, calling for help.

- Myoclonic tremor may be a significant and painful problem, and this makes activities and movement difficult.
- Spatial awareness and vision can be impaired, so person is liable to veer sideways into walls, misjudge steps or not recognise how far something is from them.
- Over time postural abnormalities become fixed – with head down and to the side, trunk side tilt or forward trunk tilt all impacting on centre of gravity and being able to see where they are going to mobilise safely. Limbs or trunk may need support if a wheelchair user.
- Those people with predominantly cerebellar symptoms may feel like they are on a boat, feeling constantly unstable and experiencing movement sickness type symptoms which impair all aspects of moving around and even when sitting still the room feels like it is moving. Certain medications for this can make MSA symptoms worse.
- Cerebellar damage causes significant co-ordination problems in terms of fine movements, such as doing buttons, zips, picking up pills and cutting up food. There can be difficulty co-ordinating the safe use of mobility aids.
- Stiffness and rigidity due to Parkinsonism along with slowing and reduced movement causes pain. People can experience sudden paralysing spasm. Limb contractures and dystonia can mean limb positioning makes mobility difficult.
- If someone with MSA is in bed or falls they will need assistance to get themselves up. Turning in bed is particularly difficult.
- Support from Physiotherapist and OT throughout is essential as the needs of someone with MSA are constantly changing and need reassessing to ensure safety and maximise quality of life.
- Wheelchair dependency is expected for everyone with MSA and regular reassessment from wheelchair services is essential.
- Mobility may be affected by spasm pains in limbs, 'coat hanger' pain and other neuropathic pain
- Restless legs may be problematic, prompting needing assistance with mobility or passive exercise at any time but often in the evening/at night.
- Some people with MSA may have subtle cognitive changes resulting in them not appreciating the risks of trying to mobilise and may try to do so even if it is unsafe.

Communication:

It can be expected that communication will eventually be severely impaired for people with MSA. People with MSA can suffer from progressive dysarthric and dysphasic speech impairments and with micrographia and blurred/double vision. They may have slurred speech or have high-pitched ataxic, or 'wobbly' voice, and they experience hypophonia; presenting as a quiet voice where the volume of speech is reduced over time until eventually there is no speech.

- People with MSA should be seen by a SLT on an ongoing basis and specialist assessment of communication difficulties should be made and appropriate aids provided. Timely access to national Access to Communication and Technology (ACT) services may be needed.
- Postural changes in MSA may cause someone to lean forward and have their chin rested on their chest, which reduces the opportunity for spontaneous eye contact and face-to-face communication as well as impairing their breathing and their ability to project their voice.
- A person's ability to communicate will fluctuate on a day-to day basis depending upon levels of fatigue and whether there are any other issues such as infection, dehydration, constipation or any of the other factors that cause variability or worsening of symptoms in a person with MSA.
- Symptoms of apathy, anxiety, depression and emotional lability can also affect communication and can lead to social isolation.
- Often people with MSA need to concentrate on one thing at a time and so cannot converse in a group or find that conversation has moved on by the time they can formulate and verbalise a response. This reduction in social interaction can reduce quality of life.
- Cognitive changes can case slowness of thought, difficulty with recall and word-finding and other language difficulties. Changes to executive function can mean learning to use new things such as a communication aid, can be difficult.
- Impaired motor control and reduced dexterity due to symptoms of tremor, weakness, poor coordination, dyskinesia and bradykinesia can make using communication aids difficult.
- Although a person with MSA may lose the ability to communicate, their cognition is usually such that they know what is going on around them and what they would like to say. Carer familiarity can help with word anticipation.
- Hypomimia – muscles of the face may 'freeze' so a person's expression is much less animated. This can impact on face to face communication as they may be perceived as bored or disinterested but does not impact on their ability to understand and engage in what is being said.
- Handwriting becomes more difficult due to motor symptoms and the ability to read can be impacted due to issues with eye muscles, positioning and posture, and the loss of the ability to co-ordinate or hold a book or device.

Psychological:

Anxiety and depression are common in MSA. Having a life shortening diagnosis is overwhelming. There is often fear of an unknown future and of how death will occur.

A person with MSA faces many losses and concerns (financial and emotional stresses on their family, the effects on their children seeing their condition progress, managing a progressive and unpredictable condition). Sleep and appetite are often affected.

- As depression is common it should be assessed for and where appropriate treatment options discussed.

- There may be a lack of awareness of some risks.
- Carer skills in recognising low mood and depression and alertness to thoughts of despair or suicide are important.
- Social isolation and poor communication skills can inhibit the ability to access psychological support. Carers need to be sensitive to the overwhelming nature of the condition.
- Emotional lability is a feature of MSA meaning a person cannot maintain a stable level with their mood and may cry or laugh inappropriately which impacts negatively on social relationships. The person may be aware a reaction is inappropriate but be unable to stop or control it.

Cognition:

Some people with MSA have mild cognitive change and others more significant cognitive change. It can be a challenge to assess this as it is difficult to tell what slowness is caused by physical and communication challenges and what is due to cognition changes.

- Detailed cognitive testing may need to be used to establish the severity of any issues and cognition may need to be assessed over a number of sessions because of fatigue and communication issues.
- Executive functioning skills can be affected – slowness of thought, difficulty with recall, word finding/language difficulties may be present and may make learning new things difficult.
- Slowness of thought can affect the ability to communicate, and people with MSA should be asked only to do one thing at a time (for example do not ask questions whilst they are using all their effort and energy to concentrate on walking or eating).
- Ability to follow instructions may be significantly slowed with delayed responses.
- It can be challenging to establish mental capacity and skilled support to determine this may be needed as there may be lack of awareness of risks.
- Risk assessments where appropriate, may provide valuable insights/evidence. Carer vigilance is required.

Behaviour:

Many changes in behaviour including frustration, anxiety, apathy and emotional lability.

- Anxiety is significantly heightened in MSA and reliance on routine is important. If something unexpected happens or routine is changed people with MSA can have a high anxiety reaction which can result in an inability to function at their normal level and an increase in any tremor. Mobility and speech can be particularly impaired when anxiety is heightened. This can lead to a high risk of falls and difficulty calling for help.
- Emotional lability is a feature of MSA – with, for example, uncontrollable giggling or crying inappropriately with minimal stimulus. People with MSA remain insightful and may be acutely embarrassed by their emotional responses so tend to avoid social situations.

- Altered confidence can occur as the person with MSA can no longer be sure how they are going to cope with everyday functions from one day to the next, and sometimes across a day; they feel their body lets them down unpredictably and things they thought they could do they suddenly find they can't. This constrains their confidence to go out of the safety and controlled structure of their own living space, and they struggle to cope in an environment that is unfamiliar. They have set ways they can manage things and due to changes in executive functioning cognitively they are unable to adapt.

- Cognitive processing is reduced and people with MSA need more time to assimilate and respond to new situations and information, such as changes in care tasks and routines.

- Frustration is common for people with MSA because they have insight to their changing situation but it can take time to accept the reality and so they try to do things they can no longer really manage and then get into difficulties and feel frustrated with themselves that they did this. Usually people with MSA are well motivated and keen to maintain their independence, so at risk of accidents and falls.

- Many people with MSA have REM sleep disorder, impaired oxygenation overnight and sleep apnoea, and commonly need to be up several times to the toilet. Poor sleep quality adds to the overwhelming fatigue that is a core symptom of MSA and this too impairs functionality and increases frustration and risk of falls.

Medication and Symptom Control:

Many symptoms such as anxiety, mood, agitation, pain, constipation, movement, tremors and management of excess saliva, may require medication management on a regular or as required basis.

- Fluctuations in condition are likely. Medication needs to be managed by skilled carers able to monitor efficacy and make decisions to provide further medications on an as needed basis as prescribed, and to observe for side effects. Carers also need to be able to liaise with the medical team to titrate medications to optimum levels for symptom control.

- Carers need to be able to recognise and report any signs of chest infections/pneumonia or UTIs, which increase in frequency as the condition progresses and will require prompt treatment (as per person's individual wishes regarding treatments). Infections can cause sudden deterioration requiring fast intervention to minimise impact.

- People living with MSA may not show the common signs of infection. For example, they may not have a raised temperature, may not cough or have a change in going to the toilet. If there is a rapid deterioration over a few days then infection should be considered and tested for, usually by the GP. Carers need to be familiar with the person so they can pick up subtle changes in condition such as increased sleepiness or reduced responsiveness.

- There may be non-concordance or non-compliance with medications due to cognitive impairment.

- Ability to swallow tablets may well be impaired so carers need to monitor this and liaise with pharmacist /doctor to supply medication in liquid or other forms or to administer medication via feeding tube.
- Many of the symptoms of MSA are complex and inter-related and require multifaceted symptom management, there is no simple medication protocol, and all this is within the context of a person coming to terms with a life-limiting condition with multiple losses. They need the skilled input of the palliative care team and multi-disciplinary team. Symptoms also change over time and adjustments to care and management are needed as is regular review.

Altered States of Consciousness:

Skilled care is needed to try to avoid blood pressure drops, and emergency care accessed when they occur.

- Due to the postural hypotension (a sudden drop in blood pressure on change of position) that is a common symptom in MSA, blackouts or loss of consciousness can occur. This is especially likely to happen when transferring or changing position, for example when going from lying to sitting or sitting to standing, when opening their bowels, in hot steamy conditions such as in a bathroom, after food or sexual intercourse. People may not have any warning of this so there is a high risk of injury from falls. This symptom is worse when an infection is present.
- Regular monitoring of blood pressure is required for all people with MSA recording lying, sitting and standing blood pressure when possible and recording at times of acute collapse. The person with MSA must keep well hydrated and cool and the carer must know how to respond to blood pressure related problems that are very variable. Emergency support may be needed if breathing is laboured or person is unconscious. Carers need to know what to do in this situation. They need to be trained in anticipating and avoiding this situation where possible and know what to do if it occurs, knowing how to care for an unconscious patient. They need to know when to call for emergency help and what to do until help arrives.
- As MSA progresses blood pressure problems can increase or become more troublesome and many people experience increasing episodes of sleepiness throughout the day. It is important to check they are rousable and to ensure medications, food and fluids are maintained as well as possible through these episodes. Such episodes may be indicative of infection so this should be checked for.
- Carers need to be familiar with the person so they can pick up subtle changes in their condition such as increased sleepiness or reduced responsiveness.

Other Significant Care Needs

The multiple systems involved and their interrelation lead to complex, unpredictable needs.

- MSA requires careful and complex management of many factors and symptoms. A high level of specialist multi-disciplinary team support is essential on an ongoing basis.
- Symptoms will compound other symptoms. For example, if a person is experiencing difficulty swallowing, they may reduce their fluid intake.

This increases the risk of urine infection and lowers their blood pressure. Due to bladder issues and urgency, a person may then need to urinate quickly. They stand up quickly (as executive functioning impairment reduces their understanding of the risk of doing this) and their blood pressure drops and they are at risk of syncope (a temporary loss of consciousness due to a fall in blood pressure). Because of their mobility issues they are then at high risk of falling.

- There can be significant challenges when trying to manage fatigue and/or pain
- There can be daily fluctuations and periods of rapid, unpredictable deterioration.
- MSA is a progressive condition and palliative care needs will arise. Skilled support is required to help prepare a person and their family appropriately with, for example, advanced care planning.
- It is important to gather information from all key MDT members and, crucially, from family carers and/or staff working with a person on a regular basis.

Notes on Assessing a Person Living with MSA

It is very important that assessors have an understanding of MSA or that they seek the specialist input of someone who does. This is recognised in section 126 of the National Framework.

"*It is important that those contributing to this process have the relevant skills and knowledge. It is best practice that where the individual concerned has, for example a learning disability, or a brain injury, someone with specialist knowledge of this client group is involved in the assessment process."*

Appropriate specialists to consult for someone living with MSA may include a Parkinson's Nurse Specialist, a Community Matron, a Specialist Palliative Care Nurse, a neurological conditions nurse specialist or one of the MSA Trust's Health Care Specialists

Assessor(s) should be aware of the range of professionals involved and should engage these professionals in the assessment process. Obtaining detailed evidence from professionals is key. Professionals involved with a person with MSA are likely to include the following: GP, Neurologist/Care of the Elderly Physician, Specialist Nurse, Community Matron, Clinical Case Manager, Community Nurse/Matron, Physiotherapist, Occupational Therapist, Continence Specialist, Speech and Language Therapist, Dietitian, Hospice or palliative care team, social worker, psychologist and professional carers. Some people may also see respiratory specialists and/or pain specialists. Section 121 of the National Framework states:

"…. the MDT should usually include both health and social care professionals, who are knowledgeable about the individual's health and social care needs and, where possible, have recently been involved in the assessment, treatment or care of the individual."

and

Section 124 of the National Framework states*:*

"Establishing whether an individual has a primary health need requires a clear, reasoned decision, based on evidence of needs from a comprehensive range of assessments relating to the individual. A good-quality multidisciplinary assessment of needs that looks at all of the individual's needs 'in the round' – including the ways in which they interact with one another – is crucial both to addressing these needs and to determining eligibility for NHS Continuing

Healthcare. The individual and (where appropriate) their representative should be enabled to play a central role in the assessment process."

The assessment must include evidence from the person living with MSA and their carer(s). As the National Framework section 67 states:

"The process of assessment of eligibility and decision-making should be person-centred. This means placing the individual at the heart of the assessment and care-planning process."

Section 125 states:

"It is important that the individual's own view of their needs, including any supporting evidence, is given appropriate weight alongside professional views."

If there is disagreement about a domain level assessment the guidance says to choose the higher need level and record the differences.

Family carers often underestimate the complexity of the care they provide – especially in front of the person they are caring for. Evidence from family carers may include carers diaries, pain charts and video clips.

Not all symptoms of MSA are obvious and skilled questioning is required to fully understand the picture.

Not only the 12 domains but the Nature, Intensity, Complexity and Unpredictability of a person's needs must be fully discussed with them and, if they wish, with their family carers.

Well met needs are still needs. Section 142 states:

"*The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need, such that the active management of this need is reduced or no longer required, will this have a bearing on NHS Continuing Healthcare eligibility."*

For people whose condition is rapidly changing and who may be approaching the end of their life a fast track CHC application should be made without delay.

The MSA Trust is here to support not only people living with MSA but the professionals working with them. Please do contact us if you require further information.

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/.

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