Multiple System Atrophy Trust

Living with MSA:

The Emotional Impact

Contents

Introduction

Living with Multiple System Atrophy (MSA) brings many challenges. Along with your physical health, there may be times when you also need support for your emotional and mental wellbeing. However, this support need can be overlooked. Partly because everyday practicalities can take up a lot of time and energy, and partly because it can feel uncomfortable talking about illness and loss. If you are reading this because you are close to someone with MSA you may also have questions about the emotional impact on both of you.

The aims of this resource are:
- To help you understand the emotional impact of MSA
- To give information on the type of help available and how to access this.
- To suggest ways of looking after your emotional wellbeing

Whether you are living with MSA, or are providing support to someone with the condition, we hope this will help you find the words to ask for support from family, friends and healthcare professionals when you need to.

As some of the sections are quite lengthy, you may choose to read them over time or to revisit some pages when you need to. You may also wish to share this resource with friends or family to help them understand how it can feel to live with MSA.

Thank you to all those people affected by MSA whose words we have included in this resource.

1. The Emotional Impact of MSA

This section describes some of the ways that MSA may affect your thoughts, feelings and emotions from the point of diagnosis onwards.

The Impact of Diagnosis

> “It took over 6 years for my husband to get a diagnosis, we were fobbed off so many times.”

For many people the moment of diagnosis is a devastating experience, for others it brings some strange relief after months, or even years, of uncertainty. Whatever your reaction, it is likely that you will never forget the day you, or someone close to you, was given a diagnosis of MSA.

As the news sinks in or as MSA progresses, you may at times be filled with dread, feel angry or frustrated at changes to your body, or upset at the impact on yourself and those you love. You may doubt the diagnosis as you struggle to believe it can be true. Or perhaps you are filled with energy and want to learn all you can about MSA as you try to take back some sense of control. You may sometimes worry about coping, yet there may be other times when you discover a resilience that you didn’t know you had.

Whatever your situation and however MSA is affecting you, a range of intense emotions is understandable, normal and human. Being open about how you are feeling with people close to you, as well as with your GP and other healthcare professionals, can really help you to manage the impact of MSA.

Feelings of Grief

> “I can cope with what is happening to me but find it difficult to cope with the worry and burden I am putting on my loved ones.”

Each person is an individual, and everyone reacts to and copes with MSA in different ways and at a different pace. Even so, there are some thoughts and feelings that many people with MSA have described and that you may recognise, including:

- A sense of disbelief that comes and goes
- Worrying about coping financially or practically, fear of being a ‘burden’
- Questioning ‘why me’ perhaps feeling angry or frustrated when previously simple tasks take longer or become difficult
- Being worried or fearful of pain or of dying itself, perhaps not talking about it for fear of upsetting others
- Sadness or frustration at changes in relationships with partners, family, friends, and colleagues
- Appreciating small everyday pleasures far more than in the past and a desire to make as much as possible of the time available
- Wanting to plan ahead, as a way of taking back some sense of control.

Many of these thoughts and feelings can be described as ‘anticipatory grief’ as you slowly recognise and grieve for the losses that you face in the present and the future. Grief can take many forms, including tears of sadness or frustration, feeling short tempered and irritable, being withdrawn or lethargic, forgetful or distracted. There may be periods when life feels fairly stable, as well as days of uncertainty and unpredictability as symptoms change, or become more pronounced.

Throughout life with MSA there will be trigger points that may increase your personal emotional fragility. For example, having to stop paid work, stopping driving, changes to sexual relationships, changes to your role within the family, needing to use a wheelchair or having to accept care from outside agencies.

But this is not the whole story. There may also be moments of closeness and humour with family or friends as you overcome challenges. You may share feelings and thoughts that you have not expressed before or may think about how you want the remainder of your life to be and what is important to attend to. Despite the sadness of anticipated losses, many people find meaning in new ways, perhaps over time arriving at some kind of acceptance or of feeling as prepared as possible for the unknown.

Facing Uncertainty

> “It’s tough - it’s exhausting - it’s the unknown.”

So much about MSA is uncertain and many people find this one of the most difficult things to cope with. Not knowing which symptoms will emerge or when; how quickly they may progress or even how many years of life are left, are just a few of many questions that are unanswerable. It is possible to spend so much time fearing the future, that worry and dread can take valuable time and enjoyment away from each day.

It is not possible to predict exactly how your future will be or how you will respond to it. You may discover that the reality, however difficult, is not quite how you expected it to be as you learn to adapt and change over time.

Trying to find ways of living now, yet taking steps to prepare for a changing future is a delicate balancing act and you may find that you move back and forth between the two. Being able to share your worries and to know that support is available while you prepare for the future can greatly help to ease the worry of uncertainty.

For further support please see the Wellbeing Hub from our partner organisation, Rareminds. This provides information on managing uncertainty, change and loss -
https://www.rareminds.org/wellbeing-hub/uncertainty-change-loss/change-and-loss/

MSA and Mental Health

People living with MSA may experience periods of low mood, depression and/or anxiety, yet mental health is often overlooked at routine appointments with health and care professionals. Being able to recognise how MSA is affecting your mental health can help you to seek professional support when needed.

Anxiety

> “MSA makes me feel very low. I miss going out and doing activities I used to enjoy, such as gardening and socialising with friends and family. I feel anxious a lot of the time as well.”

You may be familiar with a gnawing feeling when you are anxious, perhaps your chest tightens or your heart beats faster. This is because when your mind perceives ‘danger’, hormones such as adrenaline and cortisol are released into your bloodstream. This temporarily increases your heart rate, and your muscles tense up to prepare your body to either ‘fight’ or run away.

Other body functions such as digestion, speech, sexual function, bladder control and thinking can be temporarily affected as the body puts all its energy into ‘fight or flight’. When you feel safer, because the ‘danger’ has passed or because you no longer fear it, your body returns to a more relaxed state. This explains why some symptoms of MSA such as a tremor or speech difficulty can seem temporarily worse in stressful situations.

When affected by MSA, feeling anxious and worried can be a familiar feeling and it can easily become an unhelpful cycle. Perhaps you find yourself constantly scanning your body to check sensations out of fear of ‘what is coming next’. You may be avoiding places and people that are important to you because you are worried what someone might think or how they may react. These are examples of anxious thoughts interfering with your daily living.

Some people feel anxiety in the form of panic attacks, which seem to come from nowhere without warning. A panic attack is where anxiety levels rocket very quickly resulting in strong physical feelings such as shaking, tearfulness, fast breathing (known as hyperventilation) and a faster heart rate. Some people feel scared that something really bad is about to happen, which can feel very frightening.

Being in a constant cycle of anxiety or panic attacks can also cause problems with sleep and appetite. Given how much anxiety living with a life-limiting illness can cause, learning ways of helping your body to ‘self-calm’ is key to taking care of your emotional wellbeing. There are ways to help reduce anxiety including breathing and relaxation techniques, self-help, therapy and medication.

If anxiety is affecting your daily living, please consult your GP and see:

- Section 3: Looking After Your Emotional Health and Well-Being/Relaxation
- Section 5: Professional Support for Your Emotional Wellbeing

Fatigue, Low Mood and Depression

The feelings of fatigue that are common with MSA can contribute to feeling low in mood. Low mood, depression and anxiety can also contribute to feelings of lethargy or tiredness. It is important to recognise that carers may also feel very tired or low at times, due to the ongoing physical, practical and emotional support they are providing.

Life is of course not only about MSA, and there may be other family and life events that can affect your energy levels. It may feel as though you have no energy left to spend time on activities that can help your emotional wellbeing. However, it can be helpful for the person with MSA and carers to know your limits, allowing enough time for rest and relaxation and asking for or accepting help with tasks that others can carry out, can help reduce feelings of exhaustion.

Depression is a word commonly used to describe feeling very low, where life has lost meaning or joy, perhaps of feeling worthless or a burden, of feeling consistently negative and hopeless about the future. Physical symptoms such as changes to appetite and sleep patterns are often affected, and it is not uncommon to spend lots of time thinking deeply, perhaps losing interest in people and in activities that have previously brought pleasure.

> “I have found myself emotionally numbed, not caring about things that I previously would have been incensed by/excited by.”

You may recognise having had some of these thoughts and feelings at times, as part of the process of grieving, for what has been or will be lost in the future. However, if these persist you may be experiencing depression and may need some additional support. There are ways that low mood and depression may be improved, including self-help strategies such as practising mindfulness or relaxation techniques, therapy and/or anti-depressant medication.

Because MSA itself can also lead to changes with appetite and sleep, or concentration, it is important to consult your GP or Specialist if you experience any these symptoms

If low mood or depression is affecting your daily living please consult your GP and see:

- Section 3: Looking After Your Emotional Health and Well-Being/Relaxation
- Section 5: Professional Support for Your Emotional Wellbeing
- MSA Trust Factsheet: Fatigue – Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/factsheets/

Suicidal Thoughts

It is not unusual for some people diagnosed with MSA to have fleeting or occasional thoughts of wishing their life was over. If you experience this, you will probably find that it is overtaken by a stronger desire to make the most of the life you have.

This is very different from feeling an overwhelming impulse to harm yourself because you are in emotional pain.

We do not know how many people with MSA have thoughts of ending their own life, but we know that some may do. The reasons behind such thoughts are very personal and individual. They may involve fears about the future, how to cope with what is happening, or grief and anger about loss. Such thoughts might happen for some people after a change in health status, or abilities too.

Talking about any such thoughts and feelings with someone you trust can help them feel more manageable and help them pass.

This could be a family member or friend. However, if you are concerned about upsetting someone close to you, a healthcare professional or listening service such as the Samaritans can be a helpful source of support.

If you are finding it hard to find reasons to keep on living and have thoughts of suicide please do reach out immediately. Crisis support is available from:

- Samaritans: Phone number - 116 123 or jo@samaritans.org
- Your GP or a health professional that you feel able to talk to.
- NHS: 111
- Emergency Services: 999

If you are worried that someone you care about is having distressing or suicidal thoughts, you might feel concerned about how best to talk to them about these.

The Samaritans have useful advice on how to start a conversation, and support someone that you are worried about - https://www.samaritans.org/how-we-can-help/if-youre-worried-about-someone-else/.

Uncontrollable Laughing or Crying (Emotional Lability)

People with MSA may experience strong emotions such as laughing or crying uncontrollably, which can feel exaggerated or may not reflect inner feelings. This can be upsetting and may affect your confidence in social situations. Please speak to one of our MSA Health Care Specialists or your GP if you experience this, as effective medication may be available.

Hallucinations

People with MSA can describe seeing or hearing things that others cannot. These are hallucinations. Hallucinations are not a symptom of MSA but may occur if the person with MSA has an infection or can be a side effect of a medication you are taking.
If you experience this or if you are caring for someone with MSA and you notice these symptoms, please seek medical advice.

If you have any concerns about your mental health, please consult your GP and see:

- Section 3: Looking After Your Emotional Health and Well-Being/Relaxation
- Section 5: Professional Support for Your Emotional Wellbeing

2. MSA and Relationships

This section explores the impact of living with MSA on your relationships and on people close to you and suggests ways of letting people know how MSA is affecting you.

Coping styles

In your closest relationships, you each face the challenges of change and loss; of the life you have been used to, perhaps of imagined futures or retirement plans, of your health, and ultimately of the loss of each other. It can be painful to think or talk about the losses that you may face, and each person will respond in their own way.

Different ways of coping can sometimes lead to tension in relationships with partners and family members. A common example is where one person wants to look ahead and start making plans for practical adaptations as it will help to be better prepared, whilst the other refuses to discuss it and seems to be ‘in denial’.

Denial is a way of coping, a need for time to absorb the shock and news, and some people can feel stuck there for some time. Feelings of failure or shame may feel too painful to face, or a family culture of not talking about illness may make it harder for someone to talk openly.

If you and someone close to you have very different ways of coping it may help to start by telling them what you think your coping style is and asking them to tell you about theirs. Listening carefully can help you to understand each other better and can begin a conversation that will continue over time.

If it feels awkward or you are not sure how to begin to discuss your concerns, you may find it helpful to ask a professional to start the conversation for you, with family members present. For example, your speech and language therapist might be able to explain to family members or your partner that speech may become harder over time, so it is helpful to begin conversations about what is important to you as early as possible.

Personal Care

Many people find that one of the hardest things to cope with is the loss of physical independence and the need for help with personal care. If you are mainly being cared for by someone close to you this may feel awkward at first as the balance of your relationship may change. Feelings of guilt or frustration about needing increasing care are very common - even though MSA is not something you could have prevented or had any choice in. The person caring for you may also have feelings of guilt, for being well when you are not, or for getting tired or frustrated when they know how many challenges you face.

> “Unfortunately, your relationship with your husband becomes more as a carer than a wife. However we remained very close despite the challenges.”

If your partner is caring for you it may not always feel easy to move between the roles of partners, carer and patient. You may find that intimacy and sexual intimacy may be affected, partly due to MSA symptoms but also as a result of the shifts in your relationship or feeling anxious, low or physically tired. Being able to communicate with each other can help avoid feelings of rejection and can help you both adapt to changes in your relationship.

> “My sex drive is diminished and I have anxiety over my qualities as a husband/provider.”

Whether support is being provided by a partner, family or friends, there may be some aspects of your personal care that you would prefer to be given by someone outside of your family or close circle. Try to be open about this and explore your options together.

Despite the pressures, your close relationships can strengthen and deepen as a result of facing the demands of MSA. You may find that making memories together becomes even more important and that you can experience many moments of humour as well as of affection, compassion and tenderness.

Being open and able to share your concerns or worries can be a relief and can help you support each other. However great the impact of MSA, the condition does not define who you are, and it may help to remind yourself of the qualities you value in each other as you work out a way forward.

At different times you may each benefit from support for your emotional wellbeing, perhaps from a counsellor, or from someone you trust.

It is recognised that MSA impacts on the person with MSA and all who know and care about them, and therefore on all different types of intimate relationships. Same-sex or trans couples might find additional support available from organisations listed by - https://www.chelwest.nhs.uk/about-us/organisation/our-way-of-working/equality-diversity/lgbt-support-organisations.

Also see:
- Section 4: Building Your Support Network: Paid for Support
- Care Support – Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/planning-for-the-future/care-support/
- Relationships and Sex – Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/living-with-msa/relationships-and-sex/
- Rareminds Wellbeing Hub provides further information on thinking about relationships https://www.rareminds.org/wellbeing-hub/relationships/.

Letting People Know

You may have been putting off telling some people about your diagnosis, perhaps worried that you or they might get upset, or that they will treat you differently. If you are still at work, you may be worried about how your employer or colleagues will react. You will probably feel great relief once you have had those difficult conversations and can then be more open.

It is of course your decision who to tell and when, and what to say. Some people find it easier to write down some notes for themselves on how they wish to begin a conversation, or to give the news in an email or letter. It may help to ask yourself if roles were reversed would you want to know? Would you prefer to be kept in the dark? How would you like to be told?

If you are willing to talk about how MSA is affecting you, it can help to let friends and family know that it is ok to ask questions. You may want to suggest they take a look at the MSA Trust website. If you have a large family or circle of friends, you may find over time that repeated questions about your health are tiring to deal with. Some people have found that posting a regular 'update' on social media can help.

Some ideas about how to start difficult conversations can be found at:

- Talking about your illness – Marie Curie
  https://www.mariecurie.org.uk/help/support/diagnosed/family-friends/difficult-conversations
- Let's talk about dying – Dying Matters
  https://www.hospiceuk.org/our-campaigns/dying-matters

Talking to Children and Young People

Talking to your children or grandchildren about illness and dying can feel especially difficult as your natural instinct will be to protect them from pain and sadness. However difficult it is, they will cope better if they have some information about how MSA is affecting you.

Letting children know that it is ok to feel sad or angry and that there is no right or wrong way to react, will help them to cope with their feelings. If you are asked direct questions about your health, it is better to be gently honest in an age-appropriate way. It is also fine to say ‘I don’t know’ if you do not know the answers.

Reactions may vary, from becoming very protective or worried, to seeming angry or avoiding you for a while. Just as your feelings may come and go, it is the same for children and teenagers, who may need time to believe or understand what is happening.

Having a box or jar for questions or worries that anyone in the family can put messages, drawings or questions into can make it easier for conversations to get started. Over time you may find that it becomes easier to talk, laugh or be sad together. Children and grandchildren may in the future wish they had asked you things about your family or history, so you may want to record or share memories that can be passed on through the generations, and to share time together that will help build lasting memories.

Children, whatever their age, and whether or not they ask questions, may also benefit from some additional emotional support or counselling. This is so that they can talk about their own thoughts and feelings without worrying that it will upset you or your family members.

The MSA Trust has developed a Children's Activity Book for children aged 4-11 which can help you to have conversations about MSA - https://www.msatrust.org.uk/support-for-you/my-special-activity-book-for-children/. There is also a web hub for 11-17 year olds, which aims to answer some of the questions people in this age group may be asking. It can be found here - https://www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/young-people/.

Also see:

- Get support – Hope Support Services
  https://hopesupport.org.uk/support/
- Talking about dying with children – Dying Matters
  https://www.hospiceuk.org/our-campaigns/dying-matters/dying-matters-resources

Supporting Someone with MSA – The Impact on You

If you are supporting someone who is living with MSA it is likely that you will share many strong emotions as you both face uncertainty and loss, even if in different ways.

Witnessing the impact of MSA on the person you care about, coping with the effect on your relationship and on your own life and future, can at times bring a rollercoaster of feelings. These may range from worry, frustration, sadness and despair, to joy, pleasure or relief.

As well as the emotional impact on you, caring for another person can be very tiring, and you may at times question whether you are 'cut out' for it. If you are working, studying, looking after other family members or have a health condition yourself, the pressures can feel especially overwhelming. The person you care for may also be struggling with feelings of guilt and worry for you, yet may at times seem unaware of your needs, perhaps preoccupied by their own challenges.

> "We had a carer to help me every morning – this really took the pressure off. I knew if I had ever been ill someone else knew how to care for Geoff. It was such a relief."

It can be easy to overlook your own emotional health and wellbeing, to believe that there are no ways you can be helped, or to feel guilty for feeling low or for wanting time for yourself. However, it is very important to consider your own needs both for yourself and for the person you are supporting

Caring for your emotional health and wellbeing can help you to enjoy and make the most of the time that you have with the person you care about. Being able to talk openly and share your grief rather than ignore or overlook it can come as a relief to both of you. There may also be times when counselling or emotional support can help and there are organisations that provide support to carers as well as local support groups in some areas.

You may not see yourself as a carer or be aware of the support available to anyone who looks after a partner, family member, friend or someone else who couldn't manage without their help. If children under 18 help to look after a relative with MSA, such as doing some tasks around the home, they may also be entitled to receive help and support, including emotional support.

Our Social Welfare Specialist can give you information about help and support for carers, and also see:

- For Carers – Multiple System Atrophy Trust
  https://www.msatrust.org.uk/support-for-you/for-carers/
- Carers UK https://www.carersuk.org/
- Being a Young Carer – NHS
  https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/being-a-young-carer-your-rights/
- Social care helplines and forums - NHS
  https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/helplines-and-forums/

Navigating Healthcare

It can take time to get an accurate diagnosis of MSA, an experience which can impact on the quality of relationships formed with healthcare professionals. More generally it is recognised how waiting for results and support can have an impact as well.

Over time the amount of involvement from health care professionals in your care and management as the person with MSA, or as a carer, will vary. It is likely that more support will be needed from a variety of healthcare professionals as your MSA condition changes.

If previous experiences with healthcare professionals have been difficult this can influence and undermine future relationships. Thinking and talking about this may help you to manage these feelings.

Co-ordinating your own or someone else’s care can be complex and exhausting. Ask your GP if there is a nurse or other health care professional who can support and assist with co-ordinating care.
For further information please see:

- Rareminds Wellbeing Hub
  https://www.rareminds.org/wellbeing-hub/navigating-healthcare/

3. Looking after your Emotional Health and Wellbeing

Taking your emotional wellbeing as seriously as your physical health can bring great benefits as well as a sense of taking back some control. This section offers some ideas that might help. You may want to try several out so you can find what works best for you.

If you are supporting someone with MSA it is equally important to pay attention to your own general health, and you may wish to discuss your own health or wellbeing concerns with your GP.

Care for Your General Wellbeing

There is a close connection between emotional and physical wellbeing which is often underestimated or overlooked. Paying attention to your overall wellbeing is important for both emotional and physical health. Fatigue, insomnia, appetite and speech difficulties, as well as pain and discomfort, can all be directly affected by your emotions, especially at times of high anxiety. Paying attention to nutrition, getting adequate rest and gentle exercise are all beneficial. The symptoms of MSA can make this more challenging, so do refer to the relevant factsheets on the MSA website - https://www.msatrust.org.uk/support-for-you/factsheets/.

Maintaining Routine

A sudden or unexpected change in routine can feel stressful, whilst a regular routine can help you to manage anxiety levels. However, provided you plan ahead, it can also boost your wellbeing to try something new from time to time, so try and find a balance between the structure and support of a routine and taking opportunities to do things that you enjoy

Doing What You Can, When You Can

> “I try hard not to put things off one day, hoping I will feel better on another.”

Doing what you enjoy, and planning things to look forward to, however large or small, can boost your mood. It is not easy to predict when some pastimes or activities may become harder to enjoy over time. Making the most of what is possible now, rather than putting them off can bring enjoyment as well as new and lasting memories.

Maintaining Friendships

> “It has made me feel isolated, inadequate and embarrassed because people feel sorry for me.”

It can take energy to maintain friendships, as fatigue or worry may make you reluctant to meet with wider circles of friends or family, which in turn can lead to feelings of isolation or loneliness. Many people with MSA find that eating or drinking with others feels stressful and they avoid seeing friends as a result. If you find that embarrassment about changes to your body, such as problems with movement or swallowing, is putting you off being around friends, consider what is manageable for you and let friends know. Friends who care about you will not wish to be excluded from your life and will be willing to adapt to your needs so that you can maintain your friendship, just as you would if roles were reversed. Staying connected to those whose company you enjoy can make a big difference to your mood and will benefit your friend’s emotional wellbeing as well as your own.

This is a good website for searching for accessible places including restaurants, hotels, cinemas, toilets etc. - https://www.accessable.co.uk/.

> “Nowadays I still use my (IceTrike) bike to get out into the countryside with friends and family walking beside me.”

Noticing Small Pleasures

It is easy to be so busy that small moments of enjoyment get rushed or overlooked. Perhaps take a few moments every day to notice what you have enjoyed. It may be feeling the sun on your face, looking at nature or listening to a favourite piece of music. Whatever your small pleasures are, try to take time to really notice the detail and to enjoy them.

Distraction

While bottling up or completely ignoring painful or difficult feelings is unhelpful, so is spending every minute worrying or thinking about MSA. If you are feeling down or worried it can help to be distracted for a while, to give your mind a break. Whether it is watching a light-hearted film, reading or listening to a book or spending time with people you like, it is important to take regular ‘time out’.

Breathing and Relaxation Techniques

Finding ways to relax and release tension in your mind and body is key to emotional health. You will find that doing so can reduce worrying or fearful thoughts and bring improvements to sleep, appetite and mood.

Most of us have been told at some time or another to ’take a deep breath’ for good reason, as regular breathing helps regulate the nervous system. Practising a simple breathing technique every day can help to reduce feelings of anxiety and relax tension in your chest and throat. This may also help with voice control and can also be useful as a way of self-calming if you find yourself in a stressful situation. If you are unsure about how or whether to practice breathing techniques do ask your Speech and Language Therapist for advice.

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Meditation and Mindfulness

Meditation has been used for centuries as a way to still and clear the mind and gain perspective. If you have practised meditation or perhaps tried it as part of yoga or relaxation classes, you may already know they can help. Or perhaps you worried that you were not ‘doing it right’ because your mind did not switch off, or you fell asleep. There is no ‘right way’ to meditate, however there is evidence that regular practice can help manage pain levels, reduce stress and improve mental health.

Mindfulness is a form of meditation that helps you to stay in the present moment rather than get caught up in worrying thoughts about the future or the past. This is by focussing on your breath and by helping you notice your thoughts and instead of getting caught up in them, bringing your attention gently back to the ‘now’.

It is possible to be mindful in your everyday life, even without practising a full meditation. It may seem odd to start with but if you practice regularly, you will hopefully begin to notice the benefits of slowing down and focussing on the present. Your Occupational Therapist or Physiotherapist may also be able to suggest some mindfulness or meditation techniques for you to try.

Here is one example of a very simple mindful practice:

Mindful practice

When you wake up in the morning before doing anything else, just take a moment to fully focus on the present moment. Take a gentle breath and without rushing, take a few moments to notice what you can see from your bed, and see the detail, such as the pattern on your bedding or the colours on the walls, or if you can see out of your window notice the colours and shapes outside.

Now notice what you can hear, maybe a clock is ticking, or the hum of your boiler or birds singing, really focus on what sounds are around you. Smell the air, gently breathing it in and out.

Notice your body sensations, the feel of the bedding or pyjamas on your skin, the sense of your pillow, or mattress and where it touches your body. Some sensations may feel more pleasant than others, try to notice them all.

If you notice your mind wandering, perhaps worrying about a sensation of pain or discomfort, or about the day ahead, just observe how that is affecting you (e.g. making you anxious) and gently guide your attention back to your senses away from your thoughts.

Giving yourself just a few moments to focus on and really notice the present moment using all your senses can give your mind a rest and help you live more in the present than the past or future.

Wellbeing Apps

There are a number of Apps that you can download to your mobile phone, computer, tablet or other device. These include guided mindfulness meditations, visualisation exercises, muscle relaxation and breathing techniques, all of which can bring a sense of calm especially if you practice regularly.

If you have tried or dismissed these before, it may be worthwhile taking some time to see if a new or different one will work for you. More and more people are using these so you may find that friends or family can suggest Apps they find helpful. Some are free of charge and some you must pay for, often after a free trial period. Examples include:

- **Buddhify:** offers a wide range of mindfulness meditations from four to 30 minutes. There is a small one-off payment for the App, or you can subscribe if you want additional features. https://buddhify.com/
- **Calm:** offers a range of mindfulness meditations and visualisations, bedtime stories and soundscapes, The App can be downloaded for free which includes a selection to try out. If you decide you would like a wider selection there is an annual subscription. https://www.calm.com/
- For further support please see Rareminds Wellbeing Hub, which provides information on thinking about your wellbeing. https://www.rareminds.org/wellbeing-hub/

Expressing Yourself

Expressing your feelings, rather than bottling them up, from the joyful to the painful can help to reduce physical tension and stress. This does not mean that you are expected to dwell endlessly on how you feel, or to share thoughts that you wish to keep private.

There are many ways to express yourself. What works for you will depend partly on your personality and partly on how MSA is currently affecting you. Some examples include:

- Talking or communicating regularly with someone you trust
- Creative outlets such as drawing, painting, clay work etc. Some hospices run creative workshops for people living with a life-limiting illness
- Keeping some form of diary or journal, using words or music
- Prayer
- Spending a few moments each day 'scanning' how you feel and keeping a simple record
- Drumming, making or listening to music
- Counselling or psychological therapy sessions

If it is becoming more difficult to communicate in the ways you have been used to, you might try sharing ideas and solutions with others on the HealthUnlocked forum or at MSA Support Groups.

- HealthUnlocked - https://healthunlocked.com/msa-trust
- Support Groups - Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/local-support/

Maintaining Communication

> “I get very frustrated because I cannot communicate with other people because of my speech issues.”

As it is possible that speaking may become more difficult over time, finding creative and new ways of communicating is going to become very important to you. Feeling confident that you have prepared for this possibility will not take away your grief or frustration at such a change, however it will help you to bear and manage it.

People connect in many ways including body language, sign language, the written word, on apps and communication devices, emoji's, drawing, art and music. Exploring various methods of communication will ease your path if or when speech becomes too difficult or tiring. These may range from communication devices to simple cards with messages or emojis. If you enjoy being creative, you may wish to prepare drawings or select different pieces of music or objects that will express your emotions or needs best.

Asking younger friends or members of your family to help you try out various tech solutions can bring humour and companionship as you learn together. If you can, ask someone else to learn alongside you and use the same App or device to communicate regularly so that you are on a level playing field. Your Speech and Language Therapist can help you to explore different communication techniques and devices.

The MSA Trust offers a voice banking service, as well as information about communication devices.

Voice banking allows someone to record a list of phrases with their own voice while their speech is still reasonably good. A laptop or PC will be needed to do this as the service is accessed online. The recording is then converted digitally to create a personal voice.

The voice will be similar to your own, but not a true copy. You will then be able to download your voice and use it to communicate with friends and family via a laptop, tablet or similar digital device. Your Speech and Language Therapist can assist you with the voice banking process and work with you to record your voice.

Find out more at:

- Communication – Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/living-with-msa/communication/
- Voice Banking - Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/voicebanking/

Considering your Future Needs

Preparing for a changing future can be daunting and it is tempting to keep putting off conversations or decisions that may feel uncomfortable. Whilst it can cause anxiety to spend too much time dwelling on the future, making some preparation is likely to bring a sense of control and relief. Although the future may feel uncertain there are some ways that you can plan ahead for example:

- Learning about practical adaptations that may help you in the future including voice banking and communication equipment, as early as possible
- Exploring your options for additional care and support, including financial help that may be available
- If you live alone, planning for a time when this may no longer be feasible and making your wishes known

- Working out what you want to say to the people you care about, perhaps writing or recording messages or letters or dealing with any ‘unfinished business’ that may be on your mind
- Putting financial and practical matters in order such as making a Will
- Making decisions about the kind of care you would like to receive at the end of your life and making sure these are known and recorded.

Our Social Welfare Specialists and MSA Health Care Specialists are available to answer any questions you may have.

- Planning for the Future – Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/planning-for-the-future/

4. Building Your Support Network

Staying connected to the people around you and building a network of support as early on as possible is important for your mental health and wellbeing. It can help you to get the most out of each day. It can also mean that help is more easily available for you and anyone who is supporting you, if difficulties arise suddenly. This section suggests ways you can build a network of support to help you and the people close to you.

Friends and Family

“Let me know if there is anything I can do” may be something you often hear. Some friends and family may feel awkward at first, not quite knowing how to help or what to say and it can sometimes feel as though MSA is ‘an elephant in the room’. One way of getting over this is to be straightforward in saying what you need and accepting help when it is offered. If the situation were reversed, you would most likely wish to help out, so try to remember this if you feel unsure about accepting help.

Friends and family will find it easier if they are given a specific task or chore as they may not otherwise know how best to help, so make a list of ideas and have it ready. This might include fortnightly or monthly visits (online or in your home). If talking is tiring you might like to ask two friends to visit together so you can sit and listen to their news, there is then less pressure on you to contribute on a one-to-one basis. Or maybe watch a favourite TV programme together or ask for a book or newspaper to be read to you. Regular help with shopping, preparing and delivering a meal, cutting the grass or helping you get to social events are other examples of ways that friends and family can help.

> “It is about finding ways of explaining the things you need. You are the expert because you see the difficulties throughout the day.”

Being involved in your support network can help the people who care about you feel useful and show their care, as well as making it easier for them to understand the impact of MSA and to stay connected with you over time.

Peer Support

Being able to connect with others who are going through similar experiences can bring a feeling of connection, of being understood and opportunities for mutual support. Support Groups run by the MSA Trust are available to people with MSA, carers, friends, family members or healthcare professionals. Support Groups are available online and in-person.

> “We really get a lot from the group meetings, is it so helpful to meet others who have this ridiculous condition, support each other and learn more about the condition and how we might manage things.”

There may be other types of support groups in your region or some run by your local Hospice, that provide an opportunity to meet with others who are affected by a life-limiting illness. Your local GP Surgery, community hubs or library often have information about local groups.

- HealthUnlocked offers a forum for peer support online where you can ask questions, get ideas and share mutual support. https://healthunlocked.com/msa-trust
- Support Groups – Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/local-support/

Befriending

You may also wish to consider befriending as part of your support network. Befriending is a service that provides reliable and supportive contact with a trained volunteer, and this can really help to reduce feelings of isolation or loneliness. Befriending volunteers offer a listening ear and regular contact, usually on a weekly basis. Information about befriending support can be found at:

- Befriending Networks http://www.befriending.co.uk/
- Marie Curie Befriending https://www.mariecurie.org.uk/help/support/check-in-and-chat

Paid for Care and Support

You, or those who are caring for you, may understandably feel reluctant about paying for personal care as this brings another change to your lives that may feel unwelcome. However, over time you are likely to require increasing levels of help, and if one person is providing most of your care this may affect their own health and wellbeing. Building ‘paid for’ care into your routine and support network is likely to be far less stressful than having to find it at a time of crisis and also means that there are other people who get to know your care needs and how you like things done. This will also free up some regular 'downtime' for your main carer and will make it far easier for you both to manage if they are unwell or unable to look after you at times.

> “Respite was so important. We had a carer every Thursday afternoon for a few hours. We also had an old friend who was very specific in what help he wanted to offer – he offered to read to Geoff once a week for 2 hours.”

If you live alone or family or friends live at some distance and are unable to help with your personal care, it is important to know what support is available and to begin planning ahead so that your health and wellbeing is not neglected.

Whatever your circumstances, and whether you live alone or with a partner or main carer, if feelings of loyalty, financial worries, or discomfort at accepting care from someone you don't know is stopping you from arranging paid for personal care, do try and explore your options. Talking to our Social Welfare Specialist or connecting with others at MSA Support Groups or on HealthUnlocked to share concerns about accepting 'paid for' personal care may help you to adapt to this change.

- Social Welfare Specialist Service – Multiple System Atrophy Trust
  https://www.msatrust.org.uk/support-for-you/our-advocacy-service/
- HealthUnlocked
  https://healthunlocked.com/msa-trust
- Support Groups – Multiple System Atrophy Trust
  https://www.msatrust.org.uk/support-for-you/local-support/
- Care Support – Multiple System Atrophy Trust
  https://www.msatrust.org.uk/support-for-you/planning-for-the-future/care-support/

Faith and Spirituality

Living with a life-limiting illness is a profound experience. You may at times question life's purpose and meaning or have questions about death or whether there is something beyond it. You may spend time thinking about the life you have lived and may wish to pass on stories, memories or life lessons to those you leave behind.

Some people turn to or find that religious faith gives them strength, while others may find themselves questioning their faith or spiritual beliefs. If you follow a specific faith or religion, your faith leader will be experienced in supporting and talking to people who have been through similar experiences to yours. Your faith community may also be a good source of practical and emotional support.

Whether or not you follow a faith or religion, talking to someone you trust, to a counsellor, a faith leader or a hospital or hospice chaplain may help you to explore some of these questions and thoughts.

Support from The MSA Trust

> “I can definitely say, from my experience, that your help has eased the feelings of sheer helplessness and depression, just by knowing there is an organisation that understands and actually cares.”

The MSA Trust is here to support anyone affected by MSA and we have included information in this resource about some of the support we provide. When you have questions or concerns or wish to find out more about how we can be part of your wider support network, please contact us and we will do our best to help you.

5. Professional Support for Your Emotional Wellbeing

Given the close link between physical and mental health, there will be times when you may benefit from professional support for your mental and emotional health and wellbeing. This section gives information about the kinds of professional support available and how to access it.

Asking for support may not come as easily as asking for medical treatment, and not all health professionals will routinely ask about your emotional wellbeing, but don't let this put you off. If you are unsure, embarrassed or worried, you are welcome to talk through your concerns with one of our MSA Health Care Specialists.

> “Emotional support was given by family members but I think professional help for the everyone should have been readily available.”

Your GP

Including a discussion about your emotional and mental health at your GP appointments can help to get the most from the support being offered. If this feels awkward or you are not sure how to start the conversation you may want to plan what you want to say. Doc Ready is a website that helps you to put together a checklist of how thoughts or feelings are affecting you, that you can print out or take with you on your phone or tablet. https://www.docready.org/#/home

Your GP can discuss with you what kinds of mental health support may benefit you. Depending on where you live, your GP may be able to refer you for free counselling or therapy or to online self-help and support services.

> “…Just knowing people such as the MSA Specialist Nurse, our GP surgery and our OT were out there and willing to help was support in itself.”

Medication

Your GP may suggest medication to help reduce the impact of anxiety or depression, or you may wish to ask about it yourself. Your GP can explain how different medications may help and any possible side effects and should regularly check how well it is working. If you are unsure or have more questions you may find it helpful to talk to your MSA Health care Specialist about which medications may work most effectively for people with MSA. Our MSA Health Care Specialists can also speak to your GP with your permission.

Self-Help Resources

Although not specifically designed for people with life limiting illness, the NHS has some self-help guides online. These are based on Cognitive Behavioural Therapy principles to help to recognise and manage anxiety and low mood. Some are available as audio resources as well as printed and online resources.

- Self Help Leaflets - NHS
  https://web.ntw.nhs.uk/selfhelp/
- Glasgow Wellbeing Services - NHS
  https://www.wellbeing-glasgow.org.uk/
- Every Mind Matters – NHS
  https://www.nhs.uk/oneyou/every-mind-matters/
- Rareminds Wellbeing Hub
  https://www.rareminds.org/wellbeing-hub/.

Depending on where you live, your GP may be able to refer you for guided self-help for stress, anxiety or low mood, with support from a mental health practitioner online or over the phone.

Health and Care Professionals

Talking about how your physical and mental health affect each other can also help you to get the most from appointments with other health and care professionals that you see, for example: Parkinson’s Nurse, Neurology Nurse, Health and Social Care Services, Occupational Therapist, Physiotherapist, Neurologist and Speech and Language Therapist. Our MSA Health Care Specialists can speak to you about how to make the most of these services. They can also offer input to professionals about MSA with your permission, so that they understand more about the disease and how it may be affecting you.

Hospice Care Providers

Many hospice care providers offer a range of free or low-cost services that can help you to look after your emotional wellbeing. It does not matter whether the condition is in the early stages or is more advanced. Services such as emotional support, counselling therapies, as well as complementary therapies such as reflexology and massage may be available. Partners or close friends or family who are providing care to you may also be able to access these services to support their own wellbeing.

> “Alongside the physical care, the emotional support has also proved vital to us. My husband and I have both received professional counselling.”

Many people believe that hospices only provide care for people who are approaching the end of their life. However, hospices are increasingly involved in supporting people at different stages of a life-limiting illness

Because hospices are experienced in providing support to people with life limiting illnesses, they will have experience of adapting sessions to take account of your needs.

Your GP, nurse or a member of your healthcare team can give you information about any local hospices and can make a referral for you.

- What is hospice care? - Hospice UK
  https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care
- Ireland Palliative Care Programmes - Irish Hospice Foundation
  https://hospicefoundation.ie/our-supports-services/healthcare-hub/palliative-care-programmes/

Complementary Therapies

A complementary therapy is a treatment that uses a ‘holistic’ approach, aiming to treat the whole person, including mind, body and spirit, rather than treating symptoms alone. Complementary therapies can be used alongside conventional medicine and can be used for symptom management and to enhance a sense of physical, mental and spiritual wellbeing.

Examples of complementary therapies are massage, reflexology and acupuncture. All of these can help to relax muscle tension and help promote a sense of wellbeing. You may wish to discuss which therapies might work best for you with your doctor or nurse. It’s also important to tell the complementary therapist about your medical condition and any treatments (including medicines) that you’ve had or are having.

In some areas you may be able to find local organisations such as hospices that offer complementary therapy at low or no cost, otherwise it is available privately.

- Complementary Therapies – Multiple System Atrophy Trust https://www.msatrust.org.uk/support-for-you/living-with-msa/complementary-therapies/

Counselling and Talking Therapies

> “In depth counselling would, I think, have helped deal with accepting the inevitability of it all.”

Being able to explore your thoughts and feelings with a trained therapist such as a counsellor, psychotherapist, or psychologist can be very helpful when living with a life-limiting illness or when supporting someone with the condition. Therapy is confidential, meaning that you can speak openly without worrying about upsetting people close to you.

Regular sessions can help you to explore how MSA is impacting on your life and about the changes and losses that you are facing. Your therapist will support you as you explore whatever concerns you have and can help you to find ways to manage or overcome feelings of anxiety or depression.

More therapists now offer sessions online rather than you having to travel which may make it more accessible if you have a quiet and private space at home where your sessions can take place.

There may come a time however when talking becomes too tiring or challenging for ‘talking therapy’ to be accessible, and therefore you may wish to seek therapy early on or to consider options such as art or music therapy (see below)

Finding a Counsellor or Therapist

> “A local charity…provided counselling for both of us separately and together every 3-4 weeks which was invaluable.”

Therapy may be available free of charge via your GP or at your local hospice (also see section on Hospice Care Providers). In some areas free or low-cost counselling may be available from a local counselling organisation. If you live in England, you can also refer yourself (or ask your GP to refer you) to the NHS Talking Therapies programme.

Some employers also provide free counselling to employees and their families, and it may also be available on some private health insurance policies. Therapy is also available privately in most areas, although this can be expensive.

Where you live and whether you are accessing therapy via the NHS (UK) or HSE (Ireland), a hospice or local organisation, or are paying privately, will all affect which psychological therapies are available to you, as well as waiting times.

Whilst there are many different types of talking therapy, research into which therapies work best for people living with a life limiting illness is at an early stage. Most important is that you feel comfortable with the therapist, that they are open to adapting their approach to take account of the impact of MSA on sessions, and that they are an accredited member of a professional body and work to a code of ethics.

Your first meeting with a therapist, whether online or in person, is to explore what you would like to get from counselling or therapy. There will also be an opportunity for you to ask the counsellor any questions you may have, including how sessions might be adapted if needed.

More detailed information about kinds of therapy and finding a therapist can be found at:

- BACP
  https://www.bacp.co.uk/media/8274/bacp-introduction-counselling-psychotherapy-client-information-sheet-april-2020.pdf
- How to choose a psychotherapist - UKCP
  https://www.psychotherapy.org.uk/seeking-therapy/how-to-choose-a-psychotherapist/
- Types of talking therapies - NHS
  https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/types-of-talking-therapies/

Adapting Sessions

It is unlikely that therapists will know about MSA and you may wish to give the counsellor details of the MSA Trust before your initial appointment, so that they can learn a little about the condition. You may also wish to ask your Speech and Language Therapist or one of our Health Care Specialists to help you explore with a counsellor how sessions might be adapted to help you get the most from them. Examples might be shorter sessions to account for fatigue or using prompts or symbols to help prepare or start a discussion. This is especially important if you are finding speech tiring or are using a communication device.

Paying for Therapy

If you are able to pay for private therapy, you can find a therapist via the websites listed below. These are the main professional therapy organisations in the UK and in the Republic of Ireland. Fees vary considerably but expect to pay between £40 and £70 per session. The MSA Trust has a small welfare budget and in some circumstances may be able to contribute to private therapy costs for people affected by MSA, including main carers. Please contact us for further information about this or if you need help finding a therapist.

Many therapists do not charge for the first session as this is an introductory appointment, and some therapists may offer reduced rates. Each website has a directory of therapists and a search facility. You may wish to narrow down your search by entering keywords such as chronic health condition, terminal illness or disability, as this should help you to find details of therapists with experience of health-related issues. If you wish to have therapy online you can broaden your search area as geographic location will not matter. A search will show you a list of therapists who meet the search terms you have entered, along with some information about their therapeutic approach and qualifications, fees and contact details.

Main Professional Bodies:

British Association for Counselling and Psychotherapy
https://www.bacp.co.uk/search/Therapists
United Kingdom Council for Psychotherapy
www.psychotherapy.org.uk
British Psychological Society
https://www.bps.org.uk/find-psychologist
Counselling and Psychotherapy in Scotland
http://finder.cosca.org.uk/searchregistrant.aspx
Irish Association for Counselling and Psychotherapy

https://iacp.ie/g
Irish Association of Humanistic and Integrative Psychotherapy
https://iahip.org/
The Psychological Society of Ireland
https://www.psychologicalsociety.ie/footer/PSI-Chartered-Psychologist-Online-Directory
The Black African and Asian Therapy Network
https://www.baatn.org.uk/about/

Counselling for Partners or Family

There may be other people in your family, such as partners or children, who would find therapy helpful. Even if this is not something you want for yourself, being aware that it might be helpful may make it easier for them to seek or accept this kind of support for themselves.

Children can benefit greatly from counselling where someone in their family is living with a life-limiting illness. Some schools, colleges and universities provide counselling to students, or may be able to make a referral to a local counselling organisation or a hospice providing counselling and other kinds of emotional support.

Creative Art Therapies

Creative art therapies offer an alternative to talking therapies by utilising art media, or through music rather than words or speech, to express and explore thoughts and feelings and to help maintain emotional wellbeing.

> “For Les, music therapy was an opportunity to express himself through improvisation and choice of music, and the sessions were filled with joy and laughter.”

Creative Arts Therapists are often experienced in working with people with illness or disability and will offer varied ways of exploring thoughts and feelings in the sessions. You do not need to have any particular skills or any experience in the arts, and many people find the process of creating and making can feel energising and help to maintain a sense of wellbeing. Art therapy uses media such as paint, clay, collage and other materials as the main way of communicating thoughts and emotions. Music Therapy utilises sounds, rhythm, tone and instruments to create and express, which can invoke powerful memories and associations.

Sessions are confidential and non-judgemental, and as with talking therapies it is important that the therapist is a member of a professional body.

Some hospices offer creative art therapies to people who are living with life- limiting illness either free or at low cost and your GP may be able to refer you.

If you are able to pay for private therapy you can find a therapist using the websites listed below, and it may also be available on some private health insurance policies.

The main professional bodies including how to find a therapist can be found at:

British Association for Music Therapy
https://www.bamt.org/music-therapy/music-therapy-in-the-uk
British Association of Arts Therapists
https://www.baat.org/About-Art-Therapy
Irish Association of Creative Arts Therapists
https://iacat.ie

> “We gradually learn to adjust if we can maximise what we can still do, minimise the impact of what we cannot, and avail ourselves of as much information, practical help and social support as we can.”

The MSA Trust is here to support anyone affected by MSA. If you have any questions about the information in this resource, please contact us and we will do our best to help you.

We have taken every care to ensure the accuracy of the information contained in this publication. However, the information should not be used as a substitute for the advice from appropriately qualified professionals. Speak to your doctor, qualified health care professional or legal professional before taking any action. Please note that personal views and opinions expressed are not necessarily endorsed by the Trust

The resource is produced independently, is not influenced by sponsors and is free from endorsement.

References for this resource are available by contacting support@msatrust.org.uk.

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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Patient Information Forum

Created date: 07/24 | Review date: 07/27 | Version: 2

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Information, support, education and research
Services for people with MSA, carers, family,
health and social care professionals.

Telephone **0333 323 4591**

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Registered Charity No 1137652 England and Wales) and SC044535 (Scotland)

Registered Company in England No. 7302036

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