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Going into hospital

Going into hospital can be an anxious time for anyone but people with medical conditions such as Multiple System Atrophy (MSA) have additional considerations. Being prepared can make things much easier for you. If you are going into hospital for something unrelated to your MSA be aware that staff may be unfamiliar with your illness. This factsheet has been developed to help people with MSA plan for spending time in hospital in order to make the experience as straight forward as possible.

The need to prepare

If your admission to hospital is planned, you may have some time to get prepared first. Sometimes, however, admissions are unplanned so it is a good idea to follow the guidance here and have a 'hospital information pack' ready to hand in case an emergency should occur. The time taken to prepare will greatly increase the chance of a smooth and trouble-free experience in hospital.

Preparation

The hospital staff caring for you may not be familiar with MSA. If you can be clear about your needs and have some information about MSA to give them then it is more likely you will be better supported through your time in hospital.

Information: Take all the relevant information about your condition and current medication whenever you go to hospital, including out-patient appointments. Use a folder to store all this information in one place. We produce a Hospital Information Folder which you can take with you. It is a useful place to keep information about your condition and any individual needs you may have. Please contact us on the details at the end of this factsheet to request your copy.

Know your medication: Ask your doctor or pharmacist to give you a printed list of all your current medication and include that in your folder. This will be very helpful for the hospital doctors looking after you. Tell doctors if you are on any trial drugs, unlicensed medication or herbal/homeopathic remedies.

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Remember to take a 48-hour supply of your usual medications (complete with labels and boxes/bottle) with you when you go into hospital, as not all wards will routinely stock all your medications. Keep the rest of your medication at home in case there's a problem with the hospital giving you more when you are discharged. Also remember to take a supply of catheters and bags if you use these.

Equipment: Make it easier on yourself by deciding which equipment you need to take into hospital with you such as walking frame, wheelchair or lightwriter. Clearly label all your equipment and think about adding valuable pieces of equipment to your household insurance.

Key points:

- Have information about your condition to hand
- Get a list of your current medication
- Make a list of equipment you need in hospital and label it clearly
- Take the MSA Trust's Hospital Information folder with you.

Unplanned Admissions

In case you have an unplanned admission, it could be useful to have the following essentials prepared and ready to hand, including:

- Wash kit
- Underwear
- Night wear
- A 'Guide to MSA'
- Continence aids, pads, catheters etc.
- List of emergency contact numbers: people you may need to get in touch with and let them know you are in hospital, such as your care agency or the health professionals that visit you
- Hospital Information folder (available from the Trust) and/or a filled in copy of the planning sheet at the end of this factsheet.

Prepare a list of the things you need to take with you, which can then be used as a tick list when packing. This should include: medicines and latest prescription list, equipment, set of labels with name on ready to attach to any equipment and your Hospital Information folder.

Attending Hospital

Investigations and surgery can affect your symptoms, so a little knowledge may help you plan. Find out as much as you can about the procedure you will be having. Consider:

- What preparation is involved
- How long the procedure will be

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- What the planned aftercare is

You may be asked to attend a pre-assessment clinic as part of the preparation for surgery or investigation. This is the ideal opportunity to get the information you need and to let the staff know in more detail about your condition. If your admission requires a general anaesthetic, ensure the anaesthetist is aware that you have MSA and also let them know if you have problems with your blood pressure dropping or breathing difficulties. Also, ask if it's possible to see the physiotherapist before your operation to discuss breathing exercises and any support you may need to recover from the general anaesthetic and to maintain your mobility. See the section on anaesthetic further down in this factsheet.

The staff at the hospital may be unfamiliar with MSA as it is a rare condition, our MSA Health Care Specialists are happy to speak to them, so please do give staff their contact details. There is a space in our Hospital Information folder to write your MSA Health Care Specialists contact details.

Consider how your symptoms may be affected by what you find out about the procedure. The following may help:

Nil-by-mouth: This is the term that describes the period of fasting (usually 2-8 hours depending on the procedure) before an anaesthetic or procedure. Try to increase your fluid intake as much as possible before your surgery or procedure. To avoid dehydration, you may need replacement fluids by intravenous infusion (a drip) until you can drink safely again. Even though you may be nil-by-mouth, you may still be able to take medication that will help your mobility or blood pressure in preparation for the procedure. You, your carer or a family member can discuss this with the anaesthetist or doctor. A patch for your movement medicine is another option.

Blood pressure: People who have postural hypotension (fall in blood pressure when sitting or standing) often have higher blood pressure recordings when laid flat. If you do suffer from postural hypotension (common in MSA) then you need to make the anaesthetist aware of this. Continue to keep your bed in the same position (head up tilt) if possible, although this may not be possible for some procedures or surgery. You may feel dizzy when you try to sit up after you have been lying flat and your blood pressure control can also be affected by lack of activity or exercise. Doing leg exercises (as described in the 'Living with Postural Hypotension' leaflet) before you attempt to get out of bed is advisable, as well as sitting up slowly. Ensure you inform the ward staff if you have blood pressure problems.

Mobilising: A priority for nursing staff and physiotherapists is getting people up and about after surgery. This is to reduce possible complications and to help your recovery. However, you may find that your progress is slower than other patients because of your existing condition. Remember it is important to keep mobile as much as possible, but this must be done safely, so ensure the staff are alerted to your needs such as; help getting out of bed, having walking aids within reach, needing someone with you to mobilise and, where possible, positioning your bed near to the bathroom. Inform the staff if you get up frequently in the night to use the bathroom so that they can provide you with assistance.

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If you tire easily plan frequent short periods of exercise and activity, keep in mind 'little but often'. Avoid being in the same position for several hours. Try to be active whilst in bed or sitting in a chair by doing gentle leg exercises. Advise the physiotherapist if you have "good" and "bad" days or your best time of day to carry out your exercises.

Breathing: It is important while you are less active to keep up the breathing exercises that the physiotherapists and nurses will show you. You may have your breathing and oxygen levels monitored, especially if you have any breathing problems when laid flat or if you snore loudly. You will need to continue using any equipment such as a CPAP machine (continuous positive airway pressure) that helps you breathe at night.

Infection: Staff should be made aware that you are prone to infection (urine and/or chest) because of your condition. They will need to monitor this and may need to use preventative antibiotics. It is important to let them know that people with MSA may not experience a high temperature when they have an infection, so they are not guided purely by your temperature readings.

Key points:

- Find out about the procedure
- Consider how the procedure will affect you
- Contact the MSA Health Care Specialists if in any doubt about how your symptoms may be affected.

Anaesthetic and MSA

People with MSA are often concerned about whether it is safe for them to have an anaesthetic for a surgical procedure. Many people with MSA do undergo surgery with anaesthetic successfully and uneventfully every year. As with so many aspects of life with MSA, most things are possible with good planning, and this is the case with having an anaesthetic.

Why do you need an anaesthetic?

The following three scenarios are the most likely to justify considering having an anaesthetic:

1. Is the surgery being done due to a life-threatening emergency? You can't plan for this and the medical team will do their best with the information to hand.
2. Is the surgery needed to treat a life-threatening condition but is planned so you or family are able to discuss implications and concerns and advise the surgeon and anaesthetist that you have MSA?
3. Is the surgery to address a troublesome symptom that is undermining your quality of life?

The next consideration is whether you need a general anaesthetic or whether the procedure is possible using a spinal or epidural, local nerve block or local anaesthetic. These discussions need to be had with the surgeon and the anaesthetist to identify the safest and best way forward.

If a general anaesthetic is required, then you should have a full pre-operative respiratory assessment and support from physiotherapy to practice breathing techniques.

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To assist recovery after the anaesthetic, support from the physiotherapist to encourage good deep breathing and clearance of any secretions, is needed.

Recovery and Discharge

The planning you made for your admission to hospital should have made the experience a little smoother. The final bit of thought around planning should be about getting out of hospital. This is as important but may be overlooked if focussing too much on the 'being in hospital' part.

Recovery times - Being in hospital and having surgery are major events for anybody. If you consider the additional factors related to your condition, don't be alarmed if you need longer time to recover. Convalescence will be an important part of your recovery so try not to put pressure on yourself or judge yourself by the way you have recovered in the past. Some people find they are confused for a few days after a general anaesthetic.

Discharge planning - Preparations for going home should start before admission to ensure that everything is in place to get you home safely. Consider the following:

- Include in your folder telephone numbers of the people who help you at home
- If you rely on home care services then it is advisable to avoid discharge over a weekend
- If your care needs have changed as a result of your admission you may need to speak to the hospital social worker or ask the ward manager to contact your care agency directly to advise them of any necessary changes
- Request a week's supply of medication to take home. If you need special dressings, request that you have at least one spare to take home too.

Once discharged from the hospital admission follow-up care at home may be needed. This could include visits from community nurses and therapists, as well as a hospital appointments or out-patient check-ups. Keep your information folder up to date and to hand and take it with you to appointments. Also keep the MSA Guide to hand for any health professionals who will visit you at home.

Key points:

- Make a contact list of people who help you at home
- Keep your Hospital Information folder up to date.

Additional uses of this sheet:

Although written to help you plan for hospital visits, you may find this fact sheet helpful for:

Respite care

This is an organised admission to allow your carer time to recharge their batteries. Respite care can be available on a regular basis in a community hospital, a nursing home or even a hospice.

Day centres or day hospitals

These local centres have a range of activities and therapists that you can access during your visit.

Rehabilitation Units

This is a planned admission where a team of doctors, nurses, and therapists will work with you on specific problems presented by your condition.

Going into hospital

MSA Trust contact details:

If you would like to discuss further any of the content of this information sheet, or if you would like to talk to someone about an admission to hospital, or upcoming appointment, then please get in touch with our MSA Health Care Specialists.

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/>.

T: 0333 323 4591

E: support@msatrust.org.uk

W: www.msatrust.org.uk

The following pages contain a couple of forms that may help you plan your admission to hospital.

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Disclaimer

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 information sheet 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.



Patient Information Forum



Going into hospital – Planning sheet

	Things to think about	Describe your usual routine
Communication: Do you...	<ul style="list-style-type: none"> • Have a quiet voice? • Need a nurse bell? • Use any equipment? 	
Sleeping	<ul style="list-style-type: none"> • What time do you go to bed and get up? • How many pillows? • Head up tilt? • Do you need help turning? • How do you get to the bathroom? 	
Moving around	<ul style="list-style-type: none"> • What equipment do you use? • Do you need help? • How far can you walk? • Do you have a best time of day? • Does your blood pressure or medication affect your mobility? 	
Eating Do you...	<ul style="list-style-type: none"> • Have a special diet? • Need special cutlery? • Need help cutting food? • Need help eating? • Need to eat snacks? 	
Drinking	<ul style="list-style-type: none"> • What do you like to drink? • Do you need a special cup or straw? • Can you pour drinks? • Do you need help to drink? • Do you need your drinks thickened? 	
Bladder & Bowel and Bathrooms	<ul style="list-style-type: none"> • Do you use a catheter or other continence aid? • Where are the nearest bathrooms? • Can you get there alone? • Do you need help undressing? • How often do you go to the toilet? 	
Any other info		

Useful telephone numbers

Multiple System Atrophy Trust	0333 323 4591
GP	
Specialist	
Social Worker/Care Manager	
MSA Health Care Specialist	
Paid Carers	
My Main Carer at home	
Other family members	

Checklist

Current Medication	Times taken;
Allergies	
Equipment	