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## Going into hospital

### Introduction

Going into hospital can be an anxious time for anyone but people with medical conditions such as 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 information sheet 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

A successful hospital admission will depend on two things: you having a good level of understanding of your own condition; and by having plenty of information to hand.

It is likely that the medical staff you encounter may not be familiar with MSA. This is OK, they do not need to be experts they just need to know the sort of support you will need and this is where you will need to prepare in order to help them understand.

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.

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The MSA Trust has a 36-page Guide to MSA, please contact us for free copies to take with you, these can be handed to the hospital staff you encounter.

**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 (e.g. midodrine), or herbal/homeopathic remedies.

Remember to take a supply of your usual medications with you when you go into hospital, as not all wards will routinely stock all your medications.

**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.

**GP involvement:** Some emergency admissions can be arranged through your GP, who can arrange for the relevant hospital doctor to see you in the Accident and Emergency department. This will save you having to see the Accident & Emergency department doctors first and may reduce waiting time.

### 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

## Unplanned Admissions

For unplanned admissions keep a bag with a set of essentials ready, including:

Wash kit      underwear      night wear      Guide to MSA

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.

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 an A4 sheet of bullet points of essential information for all to know about you.

The planning sheet (at the end of this fact sheet: more can be obtained from the MSAT office)

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## Attending hospital

Investigations and surgery can have an effect on 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
- 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 is for a surgical procedure requiring anaesthetic ask if it is possible to see the physio before to discuss breathing exercises and safe mobilising during the recovery period.

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 6-8 hours) before an anaesthetic or procedure. Being nil-by-mouth can mean that you become dehydrated which can worsen your symptoms. To avoid dehydration you may need replacement fluids by intravenous infusion: a drip. 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 can discuss this with the anaesthetist or doctor.

**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 postural hypotension leaflet) before you attempt to get out of bed is advisable, as well as sitting up slowly.

Inform the ward staff if you have blood pressure problems.

**Mobilising:** One of the priorities of nursing staff and physiotherapists is getting people up and about after surgery. This is to reduce possible complications and 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.

If you tire easily, plan frequent short periods of exercise and activity; keep in mind a little but often. Avoid being in the same position for several hours. Try to be active whilst in bed or sitting in a chair

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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 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 can't be guided purely by your temperature.

#### Key points:

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

## Recovery & 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.

**Discharge planning -** Making 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.
- Take home a supply of any medication.

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

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**Key points:**

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

**Additional uses of this sheet**

Although written to help you plan for hospital visits this you may also find the information in this leaflet 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.

**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 Specialist Nurses.

MSA Trust, 51 St Olav's Court, City Business Centre, Lower Road, London SE16 2XB  
T: 0333 323 4591 E: [support@msatrust.org.uk](mailto:support@msatrust.org.uk) W: [www.msatrust.org.uk](http://www.msatrust.org.uk)

**The MSA Trust Nurse Specialists:**

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E: [katie.rigg@msatrust.org.uk](mailto:katie.rigg@msatrust.org.uk)

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### Disclaimer

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References for this information sheet are available by contacting [support@msatrust.org.uk](mailto:support@msatrust.org.uk).

### Feedback

Your feedback helps us ensure we are delivering information to the highest standard. If you have any comments or suggestions please complete a short survey by following the links from our website: [www.msatrust.org.uk](http://www.msatrust.org.uk) or by contacting us at [support@msatrust.org.uk](mailto:support@msatrust.org.uk).

## Helpful forms

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

## Going into hospital – Planning sheet

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

Useful telephone numbers	
Multiple System Atrophy Trust	0333 323 4591
GP	
Specialist	
Social Worker/Care Manager	
MSA Nurse Specialist	

Checklist	
Current Medication	Times taken;
Allergies	
Equipment	

