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Understanding palliative care

The aim of this factsheet is to explain what palliative care offers and how it can support you when living with Multiple System Atrophy (MSA).

How can palliative care help you?

Palliative care is there to support you and your family. It aims to find ways to make the things that are troubling you more manageable and help you improve your quality of life whilst living with MSA. It focusses on your **total** wellbeing, not just physical symptoms.

The sort of things you might need support with could range from specific symptoms relating to MSA such as muscle spasm; worries about how your partner can cope in caring for you; fears about the future; or needing to consider practical changes to your living arrangements.

Palliative care provides support not just for you, but for your family, carers and all those that are important to you.

Who provides palliative care?

Many of the professionals already involved in your care are experienced in palliative care and by working together with you they can help you find ways to manage your life to fit your needs. They can also call on other professionals, such as the local palliative care consultant at the hospital or medical, nursing or therapy staff who work in hospices, if they need extra advice to manage a problem you are having.

You may already know many of the professionals who can provide palliative care support to you:

- GP
- District nurse or Community Matron
- Physiotherapist
- Speech and Language Therapist
- Occupational Therapist
- Continence Advisor
- Social Worker
- Dietician
- Specialist Nurse
- Consultant
- Day Hospice Staff

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- Psychologist
- Counsellor

These professionals have a wealth of knowledge and experience. If you are struggling to cope with a situation related to your MSA or, for example have a new symptom or treatment that is not working, then do ask one of the professionals involved for advice. If they are not able to help they should be able to refer you to another professional who may be more expert for the issue you have.

Much of the work done by GPs, District Nurses and Community Matrons is related to palliative care. However, MSA is a complex and rare condition so they may not initially appreciate that giving you palliative care support will best address the concerns and symptoms caused by your MSA. Be honest about your needs and use the MSA Trust resources and MSA Nurse Specialists support if you feel more information is needed.

Help from Occupational Therapists, Physiotherapists and Speech and Language Therapists can make a real difference in supporting you to manage your personal care and to maintain social interactions. These professionals can support you to set and achieve goals that are personal to you, in order to maximise your enjoyment and quality of life within your abilities.

Many people incorrectly think that Hospices only provide support at the end of life but their main focus is on quality of life. They provide many services which may include inpatient beds, outpatient clinics, and day services as well as visiting teams that will support you at home or in a care home (often called Hospice at Home). Hospices also support carers, family members and close friends, both during a person's illness and following bereavement.

How is palliative care provided?

Most often palliative care is provided through a team approach involving the range of professionals already mentioned. These professionals can help you identify the things that you enjoy doing and are important to you. For example, you might have previously enjoyed meeting friends for a meal, but may have become reluctant to do this since being diagnosed with MSA.

The team of professionals around you will help you to join in with your friends. They can show you different ways of doing things that will not draw attention to yourself and can provide simple aids and equipment that will make things easier. They can also help you find practical ways to explain to friends the difficulties you experience, so allowing them to help you.

Allowing other people, such as your partner or carer, to assist you with things that are difficult can help you preserve your energy to do things that make you feel good and are enjoyable. In simple terms you may want to reflect on the fact that if the situation was reversed you would want to help them and seeing you more able to cope and enjoying yourself is rewarding for them too.

If your symptoms are making life more difficult, such as fatigue, pain or muscle spasm, then your GP or Consultant can offer options to improve these. This might include medications or working with Physiotherapists or Occupational Therapists to see if different postural support, chairs or pressure relieving aids may help.

As part of MSA it is common to experience low mood or anxiety. If you feel your mood is low it is important you talk to your Specialist Nurse, GP or Consultant. They may access support for you from a counsellor or psychologist to help you address negative thoughts and to help you talk with your family about how you are feeling. In addition, there are often medications that can make a real difference in improving general mood.

Within palliative care services there are usually specialist Social Workers, Counsellors and volunteer befrienders, all of whom can be very helpful as a 'listening ear' where you can offload pent up feelings and emotions which you and your carer may not want to 'burden' each other with.

Where is palliative provided?

Palliative care can be provided to you wherever you prefer, for example:

- At home – From your local team of professionals as described above; plus hospices and palliative care teams support people at home with a range of services including pain and symptom management advice, hands-on care, practical advice and financial information. Hospices may also offer practical support and respite services.
- Day Hospices – A Day Hospice provides you with extra care and the support you need. The care and support offered may include the following: medical and nursing care; rehabilitation; creative therapies, such as art therapy and music therapy and various complementary therapies. The Day Hospice also offers you the chance to meet other people going through similar experiences. These services may be available as part of a planned day visit, or as appointments on a drop-in basis.
- Hospitals – Specialist palliative care teams are often located in hospitals and hospice inpatient units. You may be admitted to a hospice or hospital palliative care inpatient unit at an early stage of your illness for a short period of specific focussed care, to control symptoms such as pain or muscle spasm; or for rehabilitation after treatment. You may also have the option to be admitted to a hospice during the final stages of your illness.

What other support is available?

- The MSA Trust run regional Support Groups which meet a few times a year, providing a place to speak with other people affected by MSA
- Our MSA Health Care Specialists can provide you with information and support about palliative care
- The Local Advisor for Parkinson's Disease in your area is also an invaluable contact for knowledge about other resources you could access
- Your local social services, Age UK, Citizens Advice and library are useful contacts to provide information about local support
- These services are also very helpful for checking you are aware of the financial benefits you may be entitled to and you can seek confidential personalised advice from Turn2us (www.turn2us.org.uk) or the Department of Work and Pensions (www.gov.uk/government/organisations/department-for-work-pensions) directly
- If you live in Eire please visit www.citizensinformation.ie for further information and advice on benefits and how to claim the green medical and long term illness cards
- We have a Social Welfare Specialist who may also be able to advise you about benefits and care options.

It is important to access all the practical and financial support you are entitled to – these are there to maintain your independence and wellbeing.

Claiming entitlements through eligible benefits like Attendance Allowance or Personal Independence Payment (depending on your age) can for example, help you pay for wheelchair accessible taxis and meet some of the additional costs of living with MSA.

Other aspects of personal care you may need help with could be everyday tasks, like getting up, and washing and dressing which can sometimes become a struggle. When you feel that more help is needed you should contact your local authority social services adult disability team. As well as considering your needs as somebody with MSA, Social Workers should also include the needs of your main carer (if you have one) and what help and support would be useful to them. For example, it may be possible to receive support whilst your carer has some time out, say to go to the hairdressers, attend a health appointment, go shopping or just have a day out.

Sometimes, when partners and family are providing a lot of care, social services will advise how you can get respite care to give carers a total break.

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In certain circumstances your GP, Social Worker or District Nurse may call on other services, such as a local Marie Curie service or Hospice at Home team to give help overnight, allowing your carer to get a full night's sleep.

Next Steps

It is important to speak to your GP, District Nurse or Community Matron (if you have one), or Public Health Nurse in you live in Eire, about your palliative care options and wishes as they will know the range of support that is available and will help co-ordinate this.

Many GP practices have a case management register. This register ensures that GPs and the community therapy and nursing teams keep up to date with each other about your care and any decisions and wishes you have. A member of the team may be identified as your 'keyworker' and take responsibility to keep everyone involved in your care up to date.

They will also include a review of your care needs. The review process provides opportunities:

- to consider any changes that are occurring
- to address any new concerns that are arising
- to share ideas as to how these may be best managed
- to address any continuing concerns that have not been resolved despite interventions to try to address them.

Within a review thought should be given to potential care needs that are likely to occur in the foreseeable future. This will allow you to make the right decisions and to know who is best placed to help with the choices you have and how they can best be managed.

Helpful Contacts

Hospice UK

Find out information on local hospices in your area and the services they offer.

Tel: 020 7520 8200

www.hospiceuk.org

The National Council for Palliative Care

34-44 Britannia Street, London WC1X 9JGT: 020 7697 1520

<http://www.ncpc.org.uk/>

Scottish Partnership for Palliative Care - www.palliativecarescotland.org.uk

Irish Association for Palliative Care - www.iapc.ie

The Trust's contact details

If you have any questions on the information contained in this factsheet then please contact the Trust's 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/>.

MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB

T: 0333 323 4591

E: support@msatrust.org.uk

W: www.msatrust.org.uk

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

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Patient Information Forum