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Communication and Eating & Drinking: Support Aids and equipment for people affected by MSA

Introduction

This factsheet is one of a series that looks at support, equipment and aids that may help people affected by MSA. Here we look at communication equipment and aids to help with communication, eating and drinking.

There is a vast range of equipment available, so the information provided here is not exhaustive. Neither is it meant as our recommendations but rather to give you an idea of what sort of aids are available. Before buying any aids or equipment you should discuss with your therapists what it is you are wanting to do and the sort of aids you are looking at. They will be able to advise if they think a particular aid will be useful to you.

Speech and Language Therapist (SLT)

SLTs (sometimes referred to as SALTs) are health professionals that specialise in treating people with speech, language and communication problems. They also work with people who have eating and swallowing problems. Through a process of observation and assessment they can determine difficulties and potential solutions or coping mechanisms.

It is vital that you discuss with a SLT any items you think might be of benefit to you. You can get a referral to an SLT through your GP or other health care professional involved in your care. Many Speech and Language Therapy services, via the NHS, now operate an open referral process where you can make your own referral.

Occupational Therapist

An Occupational Therapist (OT) is another member of your multi-disciplinary team that can help determine equipment that may benefit you. An OT is trained to assess and treat physical conditions to prevent disability and promote independence.

They can carry out an assessment of an individual's needs and determine the best possible coping strategies, making recommendations of appropriate equipment for daily living. They can also visit you in your home to look at how your home environment can be made more suitable for you living with MSA.

You can access an OT through the NHS. This means speaking to one of your medical team or to your GP for a referral. You can also gain access to an OT through your local council's social care services.

Communication equipment

The majority of people with MSA will experience speech difficulties at some point, so it is important to know about the range of aids, identify any that you think may suit you and have the opportunity to practise and gain confidence with the aid as soon as possible.

You may hear or see the term AAC - Alternative and Augmentative Communication. This term covers the range of aids and equipment that can be used to supplement speech or as an alternative when meaningful speech is very difficult. There are specialist AAC teams in all areas which can be accessed by referral from your Speech and Language Therapist.

Communication boards

These basic, but very effective, aids are simply a list of words, letters or pictures on a grid. For letters the entire alphabet can be displayed; for words and pictures the most relevant and frequently-used words can be added. They are used by simply pointing to the appropriate word, letter or picture to convey meaning. Although simple they are cheap and very effective, involve no technology and fit in a pocket or bag.

A	b	c	d	1	2
E	f	g	h	3	4
I	j	k	l	m	n
O	p	q	r	s	t
U	v	w	x	y	z
5	6	7	8	9	0

There is an example of a communication book on our website, www.msatrust.org.uk, devised by a person with MSA and their carer.

Lightwriter

A Lightwriter is a keyboard communication device where the user types out messages which are then relayed through the speakers by an automated voice. Most models have a dual screen display, one that the user can see and one that is outward facing for the person who is being communicated with to read. They are portable and very versatile as you can type anything into them. Modern versions have memories that will store often used expressions or sentences such as "can I have a cup of tea please", reducing the time it takes to communicate. They have an option of voices for both male and female. The downside of lightwriters is the cost, which can be in excess of £3,000. The MSA Trust has a number of lightwriters that are offered out on long-term loan, subject to availability.



Tablets

There are a number of hand held tablet devices available such as the iPad, produced by Apple. The devices are usually a small, lightweight, touch screen and portable that comes with a variety of accessibility options. The basic version iPad 2 costs around £300 and their effectiveness is greatly enhanced by the addition of 'apps' (software applications).

One such app is Proloquo2go which costs around £110. This app is a speech software package that will turn the iPad into something similar to a lightwriter but at a fraction of the cost.

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It uses a combination of words and pictures to build up sentences that are then spoken by the iPad. Commonly used words or phrases can be saved for quick use. The main disadvantage is that the iPad uses touch screen technology and is quite sensitive, making it easy to miss the desired key or hit it several times in rapid succession. Extra technology can be bought that can guide fingers to the right keys. Not everyone can get on with an iPad but if you can, or you currently use one, software like the Proloquo2go, Easy Speak or Predictable can make the iPad a very powerful communication tool. Many apps are also available on android devices and standard PC's. Some apps will be free and others will have free trials and then a one-off cost.

Voice Amplifier

A voice amplifier is a piece of technology that amplifies your own voice. It is supplied with a clip-on microphone to attach to your clothing and a head/neck microphone to place over your head or wear around your neck. It feeds the sounds you make into an amplifier for increased volume. They are simple to use and rely on batteries for power. It is important to note that the amplifier will help people with a quiet voice as it will make it louder, but they will not correct a speech pronunciation problem or slurred speech.

The disadvantage of voice amplifiers is that some people find the head/neckband uncomfortable to use. Also, positioning of the device can be quite sensitive and create a lot of feedback interference which some people find unacceptable. The MSA Trust have a number of Voice Amplifiers that are offered out on long-term loan, subject to availability.

Intercom / Call alarms

Community call alarm systems are available through the local council or local age UK branches. These operate with a pendant or wrist band alarm that should be worn at all times so it is accessible should you have a fall when you are alone. These systems operate through your phone line for a small monthly rental payment.

Wireless doorbell or baby alarms are available from hardware stores such as B&Q. While not a communication aid, they are useful for alerting someone in a different room meaning you don't have to shout to gain someone's attention. It is important to ensure that if using the doorbell system, it is within easy access at all times.

Voice Banking

Many people living with MSA will find that their speech gradually becomes softer or slurred. As soon as you become aware that your voice is changing it is worth asking your SLT or MSA Health Care Specialist about the possibility of voice banking. The MSA Trust funds this service to enable people to continue communicating effectively. Voice Banking uses a person's own recorded voice, so that later people can still "talk" using a communication aid, no matter how compromised speech might become. For more information, please visit our website www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/speakunique/ or contact us at support@msatrust.org.uk or call on 0333 323 4591.

Assistive Technology

Each CCG (Clinical Commissioning Group) will have a person who can advise on a range of assistive technologies. They can be accessed through your Occupational Therapist. These teams can visit you at home and identify ways to improve your independence around the home through environmental controls linked to your communication aid or as a separate device.

Eating and Drinking

The following are types of equipment that a professional might recommend for helping with eating and drinking.

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Again, the list is not exhaustive and is meant as a guide to help you understand the types of equipment available. An Occupational Therapist should be consulted and they will observe you and make recommendations specific to your own needs.

Some people find eating and drinking more difficult due to postural changes such as head-drop. If this is something you experience it is worth considering trying a neck collar. There are quite a number of these available such as soft collars made of dense foam, rigid framed collars e.g. the headmaster collar or the neoprene 'snood' talarmade collar. Your Physiotherapist can usually assess and advise as to suitability for each individual.

Foam handled cutlery

These are, as they sound, cutlery that has large foam handles. This is to help improve the grip on the cutlery.



Forks with cutting edges



These forks, such as Dyna Forks, are designed with cutting edges along one side so that people with only one working hand are able to cut and eat food. They come in both left and right handed versions.

Also available is a fork, knife and spoon combined called a 'splayed' as well as other types of one-handed cutlery. Angled cutlery may also be helpful.

If co-ordinating food to your mouth is difficult then it may be worth looking at a S'up spoon which is designed for people with shaky hands. Again, discuss with your SLT and OT to be sure this would meet your needs - www.sup-products.com.

Anti-tremor utensils are available although are not cheap to buy. It is best to try and get a trial of one as they do not work for everyone. However, if tremor is the main problem that is preventing independent eating then they may be worth considering. Liftware have a selection available - www.liftware.com.

Non-slip placemats

It is often the simple ideas that are overlooked. An example of this is a rubber, or like material, placemat which will keep items from moving around while using them. Non-slip placemats can be used to hold cups, plates, computers/ iPads and books

Plate guards and plate warmers

A plate guard is a collar like device that slips around the plate and prevents food sliding off when coordination is difficult. Plate warmers can also be used to keep food warm if eating becomes slower.



Ordered meals

Companies, such as Wiltshire Farm Foods, provide ready-made nutritionally balanced meals delivered to your home. They also have a range of soft and pureed foods for those with swallowing difficulties. A brochure of the meals available can be downloaded from:

<http://care.wiltshirefarmfoods.com/>

Hands free drinking vessels

Hands free drinking vessels enable people, usually dependent upon others to help them, to access their own drink. Many different types of vessel exist and again it would be a case of the best option that suits the individual.



The 'Drink-up' range are simple and versatile and offer solutions for different situations. These include options for attaching to wheelchairs. They are available at www.livingmadeeasy.org.uk.



Neater Solutions Ltd www.neater.co.uk provide an extensive range of specialist equipment to aid eating and drinking. The Neater Drinker is a sturdy ceramic mug with lid and a non-return valve straw. They also provide a similar product with a thermos mug to keep liquids warm (pictured below in the non-return valve straw) or a thermally insulated metallic version.



The Neater Powered Drinker enables people to drink liquids and pureed foods at their own pace.

Other drinking options exist including the Hydrant 2, which can also be attached to wheelchairs and other stable frames. The platypus range of drinking bottles are commonly used by campers and for outdoor activities but they are durable, practical and offer a range of different styles.



It is very important for people with MSA to drink plenty of liquid as it helps control blood pressure, bladder problems and bowel problems.

Non-return valve straws



This is a narrow bore straw with a one way valve so if you stop to take a breath before you are able to suck fluid all the way up the straw; it stays in position in the straw. The Pat Saunders straw is an example of a non-return valve straw but other makes are available.

Equipment Demonstrations

There are many Disabled Living Centres around the country where large items of equipment can be viewed and tried. You need to ring the centre and explain what equipment you wish to see and make an appointment for a member of staff to provide a demonstration. A list of suppliers can be found on the Disabled Living website. Communication Matters organises events where you can learn more about the equipment that might be available to you and have a chance to test it out - www.communicationmatters.org.uk

Further information

Do look on a range of sites if searching the internet as often the same equipment is available on non-disabled sites and may be much cheaper. Many aids and equipment especially larger pieces are VAT exempt; you just need to declare that it is for your personal use due to disability.

The Disabled Living Foundation – www.dlf.org.uk - DLF is a national charity that provides impartial advice, information and training on daily living aids.

The Disabled Living Equipment Centre – www.disabledliving.co.uk – DLEC provide a range of services to improve the quality of life of disabled people, their families and carers.

The sequel Trust – This organisation may be able to assist funding towards communication aids - www.thesequeltrust.org.uk

Commercial sites selling products:

Better Life Healthcare - www.betterlifehealthcare.com

Kapitex Healthcare - www.kapitex.com

Neater Solutions Ltd - www.neater.co.uk

Nottingham Rehab Supplies - www.nrs-uk.co.uk

Proloquo2Go - www.proloquo2go.com/

Steddy Disability Aids - www.disabilityaids.net

Abilia (formally Toby Churchill Ltd) - www.abilia.com/en

Second hand equipment:

Disabled Living Foundation - www.dlf.org.uk

Disability Equipment Service – www.disabilityequipmentservice.co.uk

We also advertise second-hand equipment that is for sale on our website. You can browse the products available here - www.msatrust.org.uk/support-for-you/second-hand-equipment/.

The MSA Trust does not endorse or recommend any specific product mentioned in this fact sheet. We do not receive any money from any organisation mentioned.

If you have any questions about anything you have read in this factsheet, then please contact your MSA Health Care Specialist.

The Trust's contact details

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – <https://www.msatrust.org.uk/support-for-you/hcps/>.

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

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