Communication Aids

This is a summary of a presentation by Sonya Chevis, a speech and language therapist with the Hounslow and Richmond Community Healthcare NHS Trust. The main details have been reported by Anita, the Branch Publicity Officer.

**Who makes up the Hounslow MND Team?**

The Hounslow MND Team is there to support the person with MND and their family. They provide information, practical help, care and support as MND progresses. In addition the team aims to support the person and family in adjusting to psychological changes where possible. They meet every 6 – 8 weeks to review the needs of everyone on their register.

The Hounslow MND Team is made up of the following:

- The person with MND and their carer
- The MND Association’s RCDA and AV
- Speech and Language Therapist (SLT)
- Physiotherapist (PT)
- Occupational Therapist (OT)
- Dietician
- District Nurse
- Specialist Palliative Care Team
- Neurologist
- GP
- Social Worker

**Bulbar problems**

25% of MND patients have bulbar (speech and swallowing) problems as the initial presentation of their disease and up to 80% of all MND patients may develop bulbar problems as the disease progresses.

**Swallowing**

The SLT advises on ways to protect airways to prevent chest infections, modify food and drinks textures to aid in swallowing and oral hygiene. The SLT makes referrals to the Dietician when alternate feeding methods may be required.

**Communication**

The SLT assesses the speech difficulty, advises on strategies and arranges for the provision of Alternative and Augmentative Communication (AAC) as needed. As some of you may know, there are a number of different types of AAC aids, including: speech amplifiers, ABC chart to show the first letter in a word, portable writing devices, lightwriter, Speak It App on iPad, E-tran Frame, Eye-Gaze.

**Training**
Sonya told us that within the Hounslow and Richmond NHS Trust, student and qualified nurses receive specialized training twice a year. The main aim is to provide nurses with the tools to effectively communicate with people with MND. The goal is that people with MND who are admitted to hospital feel safe and comfortable, and are able to communicate their needs. Some of the tips below are useful for us all.

**Tips on communicating with people with speech difficulties**

- Allow time for the person with MND to speak and/or use alternative means of communication
- Reduce background noise where possible
- Remember that most people do not have impaired hearing or intellect
- Look at the person’s face as well as communication aid
- Do not guess at what someone is saying
- If the person is difficult to understand, repeat back what you have understood
- Use an alphabet chart where necessary
- Use closed questions requiring a YES/NO answer
- Have a pen and paper ready to write down the message

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**AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) STRATEGIES**

*From Helen Paterson, Advanced Specialist Speech and Language Therapist*

I was very honoured to be invited to speak at a West London & Middlesex branch open meeting, to talk about all things AAC. AAC stands for Augmentative and Alternative Communication – these are methods of communication used by individuals with communication difficulties, which add to (augment) or replace spoken communication. Around 80-95% of individuals who have MND experience deterioration in their speech and may require technology or assistive devices to help them.

I talked about a range of AAC strategies and tools, from simple letter or picture boards to dedicated computer based systems. Communication aids can be accessed directly, such as by pointing on a chart or typing with fingers on an iPad or by whatever movement you have, such as using your head control or eyes to select letters on a screen using eye gaze. Eye gaze was beautifully demonstrated by eye gaze artist Sarah Ezekiel who attended my talk.

Technology has been developing and no longer do individuals need to have someone else’s digital-sounding voice on their communication aid. One new development I talked about
was voice banking. It’s important to do this in the early stages of your disease so that your banked voice can then be used on your device, ensuring you maintain your identity as much as possible.

Funding is now available to individuals with MND who require a communication aid. Your local Speech and Language Therapist will be able to help you in the initial stages and, if you are then having difficulty and require a more complex aid, for example if you are losing your hand function, you can be referred to a specialist centre, or ‘hub’. For the West London Region, Compass, based at the Royal Hospital for Neuro-disability, is the local hub, where I work. We can visit you at home to trial out different devices that might help you.

Feel free to contact me with any queries: hpaterson@rhn.org.uk
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About NHS AAC hubs and spokes: http://www.communicationmatters.org.uk/
Voice banking: https://www.modeltalker.org/