The use of augmentative and alternative communication aids for people with amyotrophic lateral sclerosis

Professor David Oliver, Honorary Professor, University of Kent, Canterbury, UK
Dr Steven Bloch, Senior Lecturer, University of London, UK

ABSTRACT

People with amyotrophic lateral sclerosis / motor neurone disease often present or develop bulbar symptoms, with implications for their speech. This may increasingly become difficult to understand and other methods of communication become necessary. This may be combined with cognitive change during the development of the National Institute for Health and Care Excellence Guideline of Motor Neurone Disease in the UK there was a review of the evidence for looking at communication issues, and in particular the use of augmentative and alternative communication.

METHODS

Reviews of the literature were undertaken looking for the clinical and cost-effective augmentative and assistive communication systems for supporting communication in people with MND. No relevant clinical studies were found looking for randomised controlled trials or larger cohort studies. The recommendations were made by consensus of the Guideline Development Group.

RESULTS

The discussions of the GDG agreed:

• Communication is multifaceted and encompasses many different forms and means
• Communication should include email / internet / social networking
• Communication systems may include both high and low technology systems – for instance a laminated card may be needed in a shower to allow a patient to indicate the best temperature, even if they use a computer system for other communication
• The ability to communicate is a high priority for patients
• Speech and language therapy assessment and support is very important
• Effective communication would enable the individual to maintain their role in society, workforce and family
• High and low tech devices may be helpful – often in combination – and any device should be adaptable to cope with disease progression
• Timely provision of devices is essential – as the disease progresses rapidly
• Collaborative working with the person and their family is important to ensure equipment is relevant and acceptable
• Cognitive change should be considered in making assessments – as cognitive change could make a device unsuitable
• Health and social care professionals and carers should understand how to use the equipment and enable the best communication for patients
• Patients and families need to be trained in the use of the equipment and ongoing support and reassessment is essential

CONCLUSIONS

The Guidelines have included recommendations:

• That there is a need to assess regularly the most effective mode(s) of communication on an individualised basis
• Considering face-to-face and remote communication, including email, Internet and social media
• Provide equipment without delay to maximise participation in activities of daily living and maintain quality of life maintain quality of life.
• Involve all in the Multidisciplinary team, especially occupational therapist, to ensure AAC is integrated with other assistive systems
• Ensure regular monitoring of the communication needs
• The person and their family / carers may need training in the use of the equipment.

REFERENCE


Acknowledgements:
The authors acknowledge the work of the Guideline Development Group and the Technical team for all their work on this Guideline

The work was undertaken by the Royal College of Physicians which received funding from the National Institute for Health and Care Excellence. The views expressed in this publication are those of the authors and not necessarily those of NICE

Contact: Professor David Oliver D.J.Oliver@kent.ac.uk