THE ALL-PARTY PARLIAMENTARY GROUP
ON MOTOR NEURONE DISEASE

CONDEMNED TO SILENCE

INQUIRY INTO ACCESS TO COMMUNICATION SUPPORT FOR PEOPLE WITH MND

EXECUTIVE SUMMARY

CHAPTER 2

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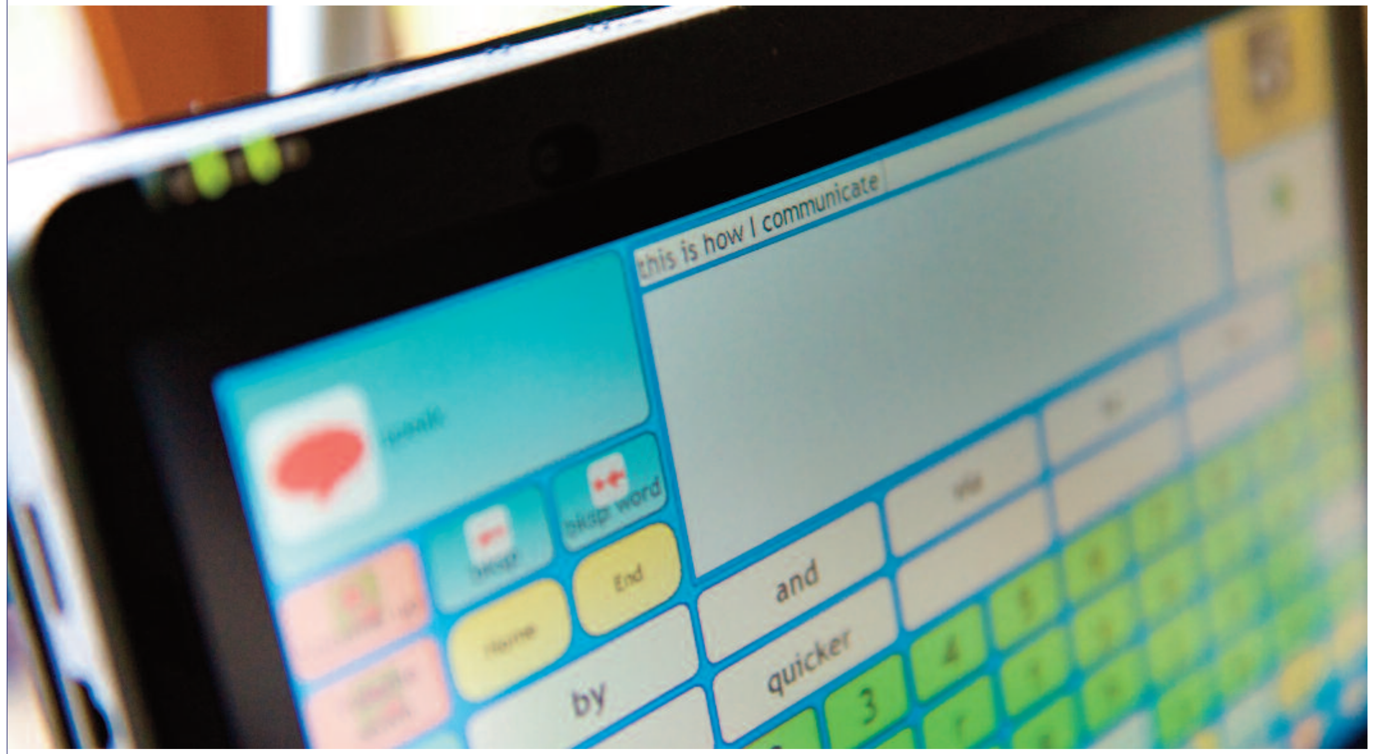
1.0 OVERVIEW

People with MND who have communication difficulties are not receiving the services that they need. Although there are pockets of excellence, there are also areas where services are letting people down. The underlying causes of this variation differ somewhat between the nations and regions of the UK.

People who are left without a voice have their wellbeing compromised. The impact of not being able to communicate is devastating for people with MND and those around them. Some people with MND are dying while waiting for equipment they need, and sometimes even dying while waiting for the initial assessment.

Despite technological change revolutionising the opportunities available to people with MND who lose their speech, many people with communication impairments are not benefiting from new technology.

This inquiry examined the current state of communication support for those affected by MND, comparing what is thought to be happening with what individuals are experiencing. 1,692 people – including healthcare professionals and people living with MND – responded to our survey and several attended sessions to give further evidence.



2.0 NATIONAL POLICY IN ENGLAND

The evidence and testimonies received from healthcare professionals and from individuals with MND indicated that NHS England has not as yet successfully implemented its plans for better communication aids.

As a result of the Coalition Government's 2012 reforms to the NHS, meeting communication needs is now clearly the responsibility of NHS England. This represents major progress from the situation beforehand, when individual communication aids had to be funded by whatever ad hoc mixture of health, social care, charitable and other funding could be found.

Evidence we received showed that in too many areas services are poor. The promise of a consistent service specification for the whole country is not being delivered. Areas particularly found to have poor services included Surrey, Sussex, Birmingham, Worcestershire and West Yorkshire.

3.0 WALES, SCOTLAND AND NORTHERN IRELAND

There is no statutory duty on the NHS to fund communication aids in Wales, Scotland or Northern Ireland. The devolved administrations may wish to consider whether or not to introduce a statutory duty.

Provision in north Wales appears to be strong, although we were also told that journey times to the Walton Centre in Liverpool are a barrier for some. In south Wales there were concerns expressed about the capacity of the specialist communication centre at Rookwood to meet the volume of referrals.

In Scotland, communication aids supplied by MND Scotland are the major source of support for people with MND. MND Scotland suggested that the 2012 report 'A Right to Speak' did not lead to any substantial improvement in augmentative and alternative communication (AAC) provision in Scotland. First Minister Nicola Sturgeon has recently announced £700,000 of funding to double the number of MND nurses in Scotland, which should be welcomed.

Survey responses indicated that AAC services in Northern Ireland seem to be effective, with a specialist centre in Belfast providing support to local speech and language therapists (SLTs). However, difficulty and slowness in securing funding for communication aids was apparent in Northern Ireland.

4.0 THE STATE OF SERVICES ACROSS THE UK OVERALL

Currently the NHS funds communication aids for fewer than half the people with MND who need them.

People with MND are sometimes prioritised for assessment and treatment, but not as consistently as many believe the disease warrants. Where prioritisation occurs, this often seems to be because of the good will of individual professionals, and not because of a clear policy within the NHS.

5.0 THE IMPORTANCE OF COMMUNICATION TO PEOPLE WITH MND

The impact of losing one's voice is devastating in many ways.

- Many people with MND describe it as the worst aspect of the disease
- For some, it can seem to undermine the individual's morale fundamentally and even appear to hasten the end of lifeIt is socially isolating: people struggle to keep up in conversations, and often eventually give up and shun social contact
- Losing the ability to speak is often described as losing part of the individual's personality; to carers, it can seem as though the person they love is not there anymore, even while they are still alive
- Communication problems can often lead to bad temper, ill feeling and permanently changed relationships within families
- Many practical tasks, including anything involving a phone call, become impossible
- It can be hard to communicate essential care needs, for instance if a person is in danger of falling while being moved between chairs
- Hospital stays often result in appalling indignity, suffering and lack of care because nursing staff do not realise that the person with MND cannot communicate
- It makes the end of life particularly hard: important choices about care cannot be communicated, and final words are left unsaid.

6.0 HOW PEOPLE WITH MND EXPERIENCE DIFFERENT TYPES OF COMMUNICATION SUPPORT

Testimony made it clear that tablet devices and smartphones were very useful for people with MND, although their usefulness declines when people begin to lose function in their hands.

Lightwriters were generally viewed by those giving evidence as heavy and outdated, although some people with MND and speech and language therapists (SLTs) felt they still have a role to play, either because older people find them easier to use, or as short-term solutions.

For some people, MND brings cognitive as well as physical change. This can drastically interfere with the ability to use a communication aid, particularly if it renders it difficult to spell, or to recognise that their speech has deteriorated.

Low-tech solutions can be highly useful, depending on the individual and their circumstances. A high-tech communication aid is not automatically right for everyone or at all times.

The training given to people on how to use aids provided appears to vary enormously, and many people are not given the support they need to make use of their equipment.

Self-funding of communication aids is very common, particularly on consumer electronics. The least well-off are more likely to be excluded from the benefit they can bring.

The limited choice of accents in modern synthetic voices can be upsetting to people who naturally spoke with regional accents.

Awareness of voice banking among people with MND is low. The technology is immature and does not always produce a synthetic voice that is either intelligible or recognisably like the person's original voice.

Some people with MND are able to use funding from the Access to Work programme to obtain communication aids to allow them to remain in work.

7.0 WORKFORCE AND TRAINING ISSUES

The majority of speech and language therapists who responded believed that their workforce is not currently adequate to meet the needs of people with MND. There are too few speech and language therapy (SLT) posts, both specialists and generalists.

There were concerns in England that the new specialised AAC hubs may not be able to recruit the specialist staff they need. One hub has advertised and failed to recruit. We were told that sufficient numbers of new therapists are being trained, but that the problem was that there are not sufficient posts being funded for them to go into.

Our survey found pessimism among SLTs about the future of their profession. Increased demand from an ageing population and a growing squeeze on SLT funding and numbers may create a crisis.

8.0 THE ROLE OF CHARITIES

Charities have traditionally played a major role in meeting the communication needs of people with MND. Despite the introduction of new obligations for NHS England to provide funding, the MND Association is planning to increase the amount of money it spends on communication support in England.

MND Scotland believes that communication is the highest area of unmet need among people with MND in Scotland.

There is widespread support among people with MND, carers and care professionals for the principle that the NHS should fund communication support for people with MND.

NHS England's policies currently do not allow it to reimburse a charity where that charity has stepped in to provide equipment that should have been NHS England's responsibility. This should be rectified.

RECOMMENDATIONS

1 NHS England should implement its service specification for AAC as an urgent priority.

2 NHS England should investigate why the implementation of the specification was delayed.

3 The Secretary of State for Health should investigate the problems with specialised AAC for people with MND in England.

4 NHS England should publish the current version of the service specification for AAC on its website.

5 The Royal College of Speech and Language Therapists should investigate whether there is the potential for a crisis in speech and language therapy.

6 Throughout the UK, specialised AAC provision should be closely integrated with environmental control, wheelchair and computer access provision. There should be no 'gaps' where health and wellbeing could be improved by aspects of technological support. A concerted effort to raise performance is needed to ensure that people with communication impairments and other disabilities benefit from advances in technology.

7 The NHS should develop clear policies so that tablet devices may be funded for use as communication aids, with other functionality intact so as to contribute to the wider wellbeing of the individual.

8 The NHS should investigate options for establishing loan banks of modern communication aids.

9 The NHS should ensure that people with communication difficulties receive appropriate care when they are admitted to hospital. Nursing staff should receive training on the implications of communication difficulties for patients. Appropriate communication aids must be available in hospitals.

10 The NHS should prioritise people with MND for anticipatory speech and language assessments, striking an appropriate balance between the requirements of individual patients and the often rapidly progressive nature of MND.

11 In order to assure the ongoing quality of provision and drive future improvements, the NHS should collate data on the provision of communication support, including:

- Number of referrals to each service
- Equipment delivered
- Times between referral and assessment, and between assessment and delivery
- Numbers of assessments and re-assessments
- Outcomes for patients and carers.

12 The NHS, the MND Association, the Royal College of Speech and Language Therapists and Communication Matters should engage in a sustained programme of communication, education and training, once the specification is implemented, to ensure that speech and language therapists understand how the programme is intended to operate for people with MND.

13 Lightwriters should be recognised as having a more limited role in the mix of available communication support than in the past. Other than for select user groups who cannot use more modern devices, and possibly short term aids, they are generally not preferable to tablets and similar devices. It should not be easier to obtain NHS funding for a Lightwriter than a tablet device

14 The National Institute for Health and Care Excellence (NICE) should ensure that all aspects of communication for people with MND are thoroughly reflected in the guideline it is currently developing.

15 Training should be given much more consistently to people who are issued with communication aids on how to use them.

16 Manufacturers of communication aids with synthetic voices should include options for regional accents.

17 Voice banking technology is not yet mature. Once it is available, it should be appropriately publicised to people with MND.

18 NHS England should develop a policy around the circumstances in which it will reimburse a charity for communication aids, and specifically approve this when the charity has provided it.

19 The Minister for Care and Support should clarify his parliamentary reply of December 15th 2014 in light of the evidence we present about the current status of specialised communication support services.

20 The voluntary sector should arrive at a common understanding of what its role should be in supporting care in this field, without impinging on any statutory duty on the NHS.

21 Research should be conducted into the link between communication, wider wellbeing and longevity in people with MND. If it is found that communication support demonstrably improves quality of life and/or longevity, this should be reflected in clinical practice and guidance.

22 Research should be conducted on how many people with MND could benefit from eye gaze technology, to inform future purchasing decisions.

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