

**TALKING TOGETHER:
COMMUNICATION STRATEGIES OF PEOPLE
WITH MND
AND THEIR PARTNERS**

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SUMMARY

Background: There are wider issues relating to the communication difficulties experienced by people with MND than simply the physical problems caused by diminished oral control. In addition, existing literature on MND rarely considers communication to be a joint interaction which depends on the strategies adopted by both communication partners nor does it present communication in real life settings. Joan Murphy carried out a 3 year research project which was funded by the Scottish MND Association and the Community Fund.

Aim of project: to investigate the communication of people with MND and their partners and to produce useful information for families with MND and those who work with them.

Method: 15 families with MND were visited on 7 occasions at home at 6 weekly intervals. Data were collected through video recordings, and field notes. Results were analysed using a coding grid and cognitive mapping to provide both a comprehensive list of the strategies used by different people and to also describe the interrelations between the different issues.

Results: Five main issues emerged and are discussed in detail:

- purpose of conversation – ‘small talk’ was much more in evidence than communicating needs and wants or information transfer.
- communication strategies – various techniques were used by participants which have implications for speech and language therapists
- AAC methods – high tech devices were not successful and the reasons for this are examined
- relationships with partners – participants discussed the change in roles as the illness progressed and the effect of this on their communication
- environment – simple factors like positioning of furniture, light and noise had a noticeable effect on participant’s communication

Conclusions:

Communication must be a collaborative effort and through examination of conversations in people’s own homes this study has identified the wide range of strategies and techniques that families with MND employ. New information has emerged such as, that for some people with MND, although speech may deteriorate, their communication becomes richer. The findings from this study will challenge those who work with people with MND to consider their input.

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INTRODUCTION

BACKGROUND

Motor Neurone Disease, also known as Amyotrophic Lateral Sclerosis (ALS), is the name given to a group of diseases affecting the motor neurones in the brain and spinal cord. Motor neurones are the nerve cells along which the brain sends instructions, in the form of electrical impulses, to the muscles. Degeneration of the motor neurones leads to weakness and wasting of muscles. This generally occurs in arms or legs initially, some groups of muscles being affected more than others. Some people may develop weakness and wasting in the muscles supplying the face and throat, causing problems with speech and difficulty chewing and swallowing. MND does not affect touch, taste, sight, smell or hearing, nor directly bladder, bowel, or sexual function. In the vast majority of cases, the intellect remains unaffected. MND is generally a steadily progressive disease, but the rate of progression varies greatly from one person to another.

The majority of people developing MND do so between the ages of 45-65 depending on the particular form of the disease. There is no conclusive evidence that MND is more prevalent amongst any particular class, occupation or geographical area and at present there is no known cause or cure for the illness. The incidence (the number of new cases added in a defined period, usually a year) of MND is 2 per 100,000 of total population, while prevalence (the number of cases existing at any point in time) is six per 100,000 of total population. The number of people in Scotland who will develop MND in one year is approximately 2.2 per 100,000 of the population (incidence): this means that about 100 people develop this condition in Scotland every year. Research has found that the incidence is higher in people aged over 50 years. Only 10% of cases are familial (inherited) with the remaining 90% sporadic (<http://www.alsmndalliance.org>)

The disease affects each individual differently and can have a devastating impact on family, carers and friends. The rapidly progressive nature of the disease requires constant adaptation to increasing and changing levels of disability which, in turn, require increased levels of support. Around 4 out of 5 people with MND will require some sort of assistance with communication sometime between receiving the diagnosis and their death (Saunders, Walsh & Smith 1981). MND does not usually give rise to impairment of cognition or of language ability although this has been disputed more recently and Beukelman et al (2000) report that 35.6% of people with MND have a clinically significant cognitive impairment. The disease progresses rapidly with a typical prognosis of around 4 years from the onset of symptoms.

In spite of these statistics, not all people with MND experience prolonged episodes of despair or sadness. Indeed many people with MND cope remarkably well even towards the end of their lives. McDonald (1994) reported that 37% of the 144 patients with MND in her study believed that '*something good came from their AL*'. Young and McNicoll (1998) carried out a study of 13 people with advanced MND who were coping exceptionally well and they

explored their experiences which contributed to this positive quality of life. This study also hoped to demonstrate some of the more optimistic aspects of living with MND specifically in relation to communication.

There is a considerable body of research now available on the communication strategies of people with congenital disabilities such as cerebral palsy (Parmenter 1988, Markova et al 1994). This research draws attention to the fact that the quality of life of people with severe communication difficulties is dependent on the attitudes and reactions of others, including able-bodied people and other people with disabilities. Research findings document the importance of collaborative effort between a person with communication difficulties and his or her carer resulting in shared responsibility between them for communication (Calculator 1998, Murphy et al 1996). Moreover, it has been demonstrated how augmented communication systems can enable people with congenital disabilities to develop communication skills (Zangari et al 1994, Murphy et al 1995). The situation of people with MND however presents a different picture. One is faced with at least two essential features. First, there is a gradual deterioration of communication ability of one communication partner. Second, there is a need for both communication partners to adapt to this changing situation by acquiring new communication strategies in order to move with growing speech disability of the person with MND. The person with MND may move from communication via speech which becomes gradually less intelligible as the disease progresses to communication through the use of an augmentative communication device or eventually via another person. An examination of literature shows that the preservation of effective communication is very important in allowing people to remain at home and to maintain good quality of life (Bach 1993).

Carol-Thomas (1995) suggests that effective communication is crucial for both "psychosocial and physical adaptation to changes that occur as MND progresses". Moss et al (1996) discuss the importance of early recognition of communication difficulties to allow the person with MND to make decisions before the disease becomes debilitating or life threatening. Several authors acknowledge the importance of the development of technological advances (Bocker et al 1990, Vaughan and Wolpaw 1996) but do not acknowledge the importance of the communication partner and the strategies they must employ to adapt to these new methods of communication. Most studies of communication and MND focus on the deficit model and do not suggest how the person with MND and their communication partner may compensate for their difficulties. For example, Kent et al (1990 and 1991) have studied the impairment in speech intelligibility in both men and women with MND and Mulligan and Carpenter (1994) have examined intelligibility and detailed acoustic characteristics of speech. Existing literature on MND rarely considers communication to be a joint undertaking which depends on the strategies adopted by both communication partners, nor does it consider communication in real life situations such as people's own homes.

This report presents the findings from a 3 year study carried out with 15 families in Scotland with motor neurone disease. The researcher, a practising speech and language therapist, developed the proposal and worked on the

project for one day per week for three years. The purpose of the project was to examine the communication of people with motor neurone disease and their closest communication partners in their own homes as the disease progressed.

AIMS

The project had three main objectives:

1. to examine the communication of people with MND and their communication partners as the illness progresses
2. to determine the factors which both help and hinder the communication of people with MND and their communication partners
3. to examine the interaction of people with MND and their communication partners in real life settings in people's own homes.

METHODS

Ethics

The researcher was very aware of the sensitivity of involving people with a progressive illness in such a study and made sure that there was no pressure put on the participants to take part in the study. Research participants were recruited from Forth Valley, Lothian and Tayside Health Board areas in Scotland. Ethical permission was obtained from these health boards and participants were recruited by means of the Scottish MND Register which is based at Dundee Royal Infirmary. Participants were selected after discussion with the Scottish MND Association's Clinical Specialist concerning the appropriateness of the participants' involvement with this project taking into account such factors as the stage of their illness and their home situation. The participants were initially contacted by the Scottish MND Clinical Specialist who left written information about the project with the prospective participants. It was then up to each participant to make a positive response and no one was approached personally. Those participants who responded were then visited by the researcher who carefully explained the purpose and the process of the project both in written form and orally to ensure that the participants and their partners fully understood their involvement and their right to withdraw from the project at any time. The researcher phoned each participant the day before an appointment was due to ensure that it was convenient to visit.

Initially 20 families were to be included in the study. It was anticipated that each video recording would last 5 minutes but in practice almost every participant talked for much longer. Therefore after 15 sets of data were gathered, it was agreed with the Scottish MND Association that, as there was such a volume of data, no further participants would be approached. In total fifteen families with MND were involved. The aim was to visit each family on seven occasions, including an introductory visit, in their own homes at approximately six weekly intervals. At each visit, with the exception of the first, a video recording was made of the person with MND chatting first to their chosen partner and then to the researcher. Occasionally, at the request of the participants, all three people were present at the same time. Because of the nature of the illness not all families were able to complete all visits but in total

81 visits and 124 video recordings were made. The reason for the discrepancy between visits and video recordings is that no recording was made at the introductory visit and not all subsequent visits involved 2 video recordings as some partners were not always available. Data were collected through video recordings, narratives and field notes.

Video recordings were invaluable in capturing the use and interplay of different modes of communication including speech, non verbal methods and augmentative and alternative communication (AAC) methods. Video was also the best way to note the different resources for interaction available to the person with MND and their communication partner and to consider the purpose of the interaction.

Narratives provided first hand and revealing perspectives about the communication of families with MND. Narratives have become an increasingly valued way of gathering insights and perspectives from people with illnesses and disabilities. 'Medicine has recently taken a 'narrative turn', explicitly acknowledging narrative as a legitimate method of understanding and improving clinical practice' (Greenhalgh and Hurwitz 1999). Of particular relevance to this project, the use of illness and disability narrative is now seen as a significant tool in helping people come to terms with and make sense of their disability. 'Stories have to repair the damage that illness has done to the ill person's sense of where she is in life and where she may be going. Stories are a way of redrawing maps and finding new destinations' (Frank 1995). This report is illustrated with comments from the participants and has been written, as much as possible, to reflect the experiences and views of people with motor neurone disease and their partners.

Field notes consist of 'relatively concrete descriptions of social processes and their contexts. The aim is to capture these in their integrity, noting their various features and properties' (Hammersley 1983). In this study field notes were written manually immediately after each visit. They noted any aspect of the visit which was relevant to the study including the time of the visit, the environment of the participants' home, the activity in which the participants were engaged and comments made before and after the video filming. There was no attempt at that stage to code the field notes systematically but on re-reading field notes after the initial video analysis they were extracted to provide explanation, insights and illustration to the video data.

The results from all the data were analysed using a coding grid and cognitive mapping to provide a comprehensive list of the strategies used by different people and to also describe the interrelations between the different factors. Cognitive mapping (Jones 1985) involves extrapolating comments that related specifically to the issues covered, and drawing a 'map' to represent each participant's perceptions and the connections between these perceptions. Once each participant's 'map' is drawn, individual maps are combined into more complex ones that group together comments in order to compare patterns and to highlight unique reflections.

RESULTS

Five main issues have emerged from the findings of the study and are presented in this report:

1. Purpose of Conversation
2. Communication Strategies
3. Augmentative and Alternative Communication
4. Changing Roles
5. Environment.

Papers for journal publication are being prepared from these findings.

Summary leaflets have been produced on three of the issues to make them easily accessible for people with MND, their families and staff who work with them.

Leaflet 1 - Strategies that help

Leaflet 2 - Augmentative and Alternative Communication

Leaflet 3 - Environment

A video has been made with the help of two people with MND to illustrate some of the key points.

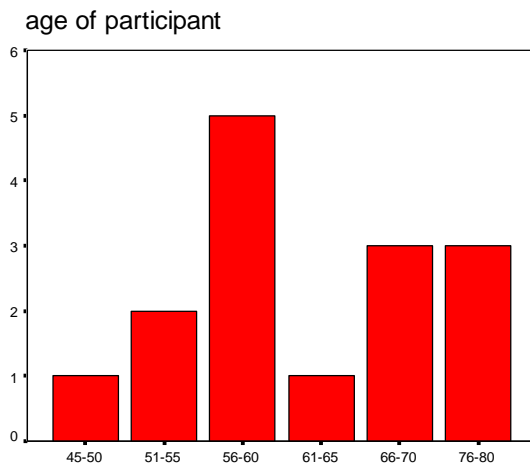
Findings have also been presented at several conferences (see Appendix 6)

FINDINGS

DEMOGRAPHIC INFORMATION

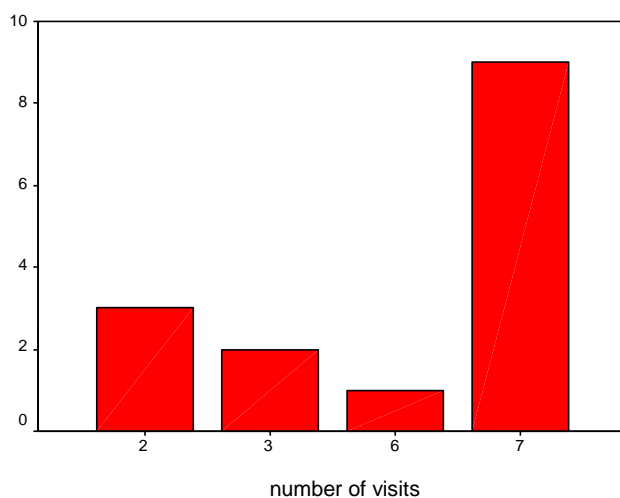
Fifteen people with MND, 8 men and 7 women, were involved in this study. All 15 lived within the Forth Valley, Tayside and Lothian Health Board areas in Scotland and were all living in their own homes. The following table shows the age range of the participants.

Table 1. Age of participants



Each participant was asked to choose someone who knew them well to be their communication partner in the study. Ten chose their spouse, 2 chose a close relative, 1 chose a friend and 2 indicated there was no one available to be involved. Although the intention was to visit each participant 7 times, including the introductory visit, not everyone was well enough for all visits and only 9 people were visited on all 7 occasions. The following table shows the number of visits made.

Table 2. Number of visits



Classification of symptoms

The symptoms experienced by people with MND are generally classified by site of involvement (that is, upper motor neuron versus lower motor neuron) and by whether spinal nerves (those supplying the arms and legs) or bulbar nerves (those supplying the muscles of speech and swallowing) are involved. Initially, either upper motor neuron or lower motor neuron involvement may predominate but as the illness progresses both usually become involved. Hence, initial symptoms may involve weakness in one or more extremities or weakness in the speech musculature. Riviere et al (1998) classified the severity of MND across the functional modalities of speech, mobility and ability to use upper limbs for activities of daily living. The classification ranged from State 1 (mild) to State 4 (terminal).

(See Appendix 1)

The researcher and a speech and language therapist observed the video data independently. They classified the participants at the first and the last visits using the Riviere classification as follows:

Table 3.

Riviere et al 1998	First visit	Last visit
1 = mild	3	4
2 = moderate	2	3
3 = severe	1	3
4 = terminal	2	Not available
	2	2
	3	4
	3	4
	2	1
	1	3
	2	3
	1	2
	2	4
	3	4
	3	Not available
	1	3

This table shows that between the first and last visits 11 participants deteriorated, 1 person did not change and 1 person improved. Two participants were only visited on 1 occasion. It is important to note that the length of time between the first and last visits varied as not all participants were well enough to be seen on all 7 occasions.

Additional symptoms

Additional symptoms, which were relevant to communication, were reported by participants and/or observed by the researcher. Table 4 describes these:

Table 4. Additional symptoms

Difficulties with cognition	4 participants had obvious cognitive problems
Difficulties with saliva	4 participants complained of problems caused by tenacious saliva (usually described as thick mucous at the back of the throat) and 2 described excessive watery saliva (usually evident as drooling due to poor control of lips and swallowing)
Dysphagia	4 participants described some problems with eating and drinking and a further participant's partner mentioned problems
Emotional lability	experienced by 7 participants (this will be discussed later)

Speech difficulties

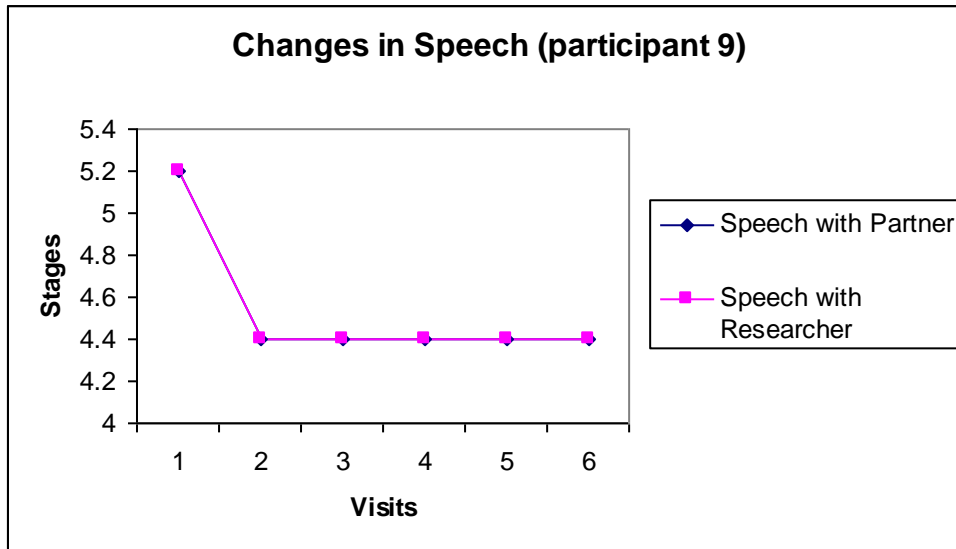
Dysarthria is the term given to the speech difficulties typically experienced by people with MND. Rosenbek and LaPointe (1985) describe the dysarthrias as 'a group of related motor speech disorders resulting from disturbed muscular control over the speech mechanism'. Swigert (1997) adds that it must be noted that the dysarthrias affect more than the ability to produce consonants and vowels (articulation). Dysarthria also includes difficulties with respiration, phonation, resonance, articulation and prosody. Mathy et al (in Beukelman et al 2000) describe the typical progression of speech in people with MND although they emphasise that the speed of progression varies widely from person to person.

It was originally planned to obtain an objective measure of intelligibility at each of the 6 sessions by the sentence intelligibility section of the Frenchay Dysarthria Assessment (Enderby 1988). However, as the data collection progressed, it became apparent that the researcher was becoming so familiar with the target and sentences that she was able to guess some as she presented them to the participants. Therefore, one minute samples of each participant's speech were taken at each visit both with the chosen partner and with the researcher. These were then scored by the researcher and another speech and language therapist using stages described by Mathy et al (2000).

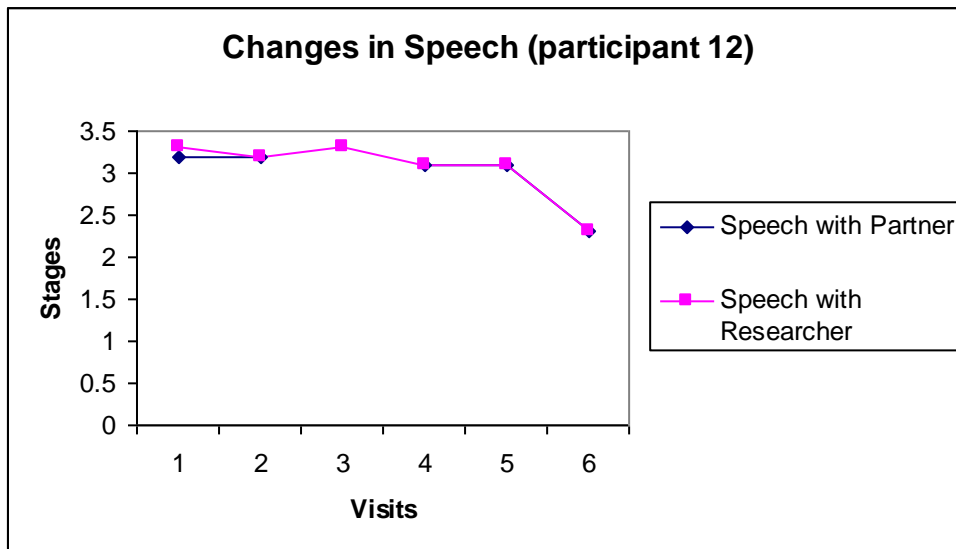
(See Appendix 2)

Several patterns of changes in speech emerged from these data. For the majority of people there was some deterioration in their speech but the speed and severity of change varied from person to person as the following graphs show. It was also possible to note if there was any variation depending on whether the communication partner was the familiar partner or the researcher.

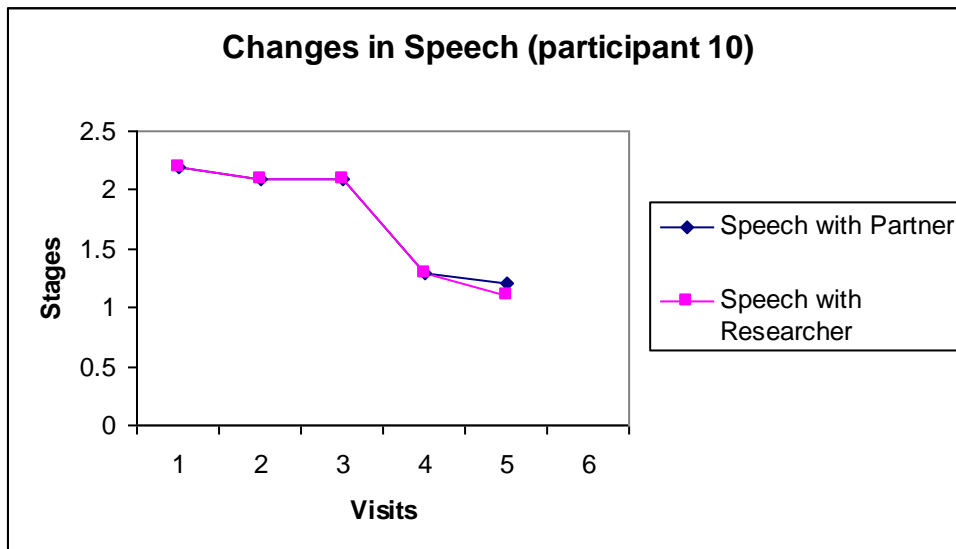
Participant 9 showed a rapid change between the first and second visits but no change thereafter. There was no perceptible difference between his speech with his chosen partner and the researcher at any of the visits.



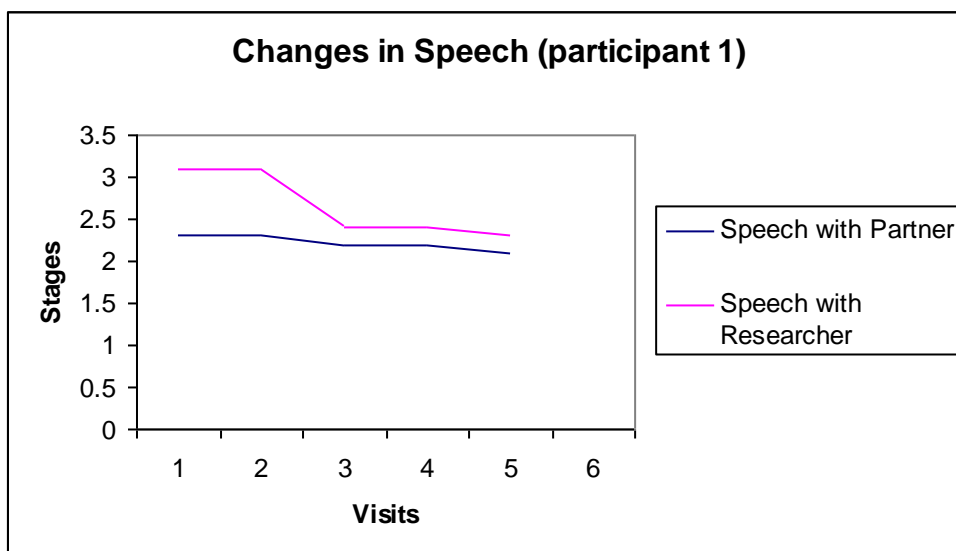
Participant 12 showed only a slight change between the first 5 visits but the chart shows that his speech deteriorated between the fifth and sixth visits.



For participant 10 there was again very little difference between his speech with his chosen partner and the researcher. However there was a sudden change in his speech between the third and fourth visits and he was too ill for any further visits.



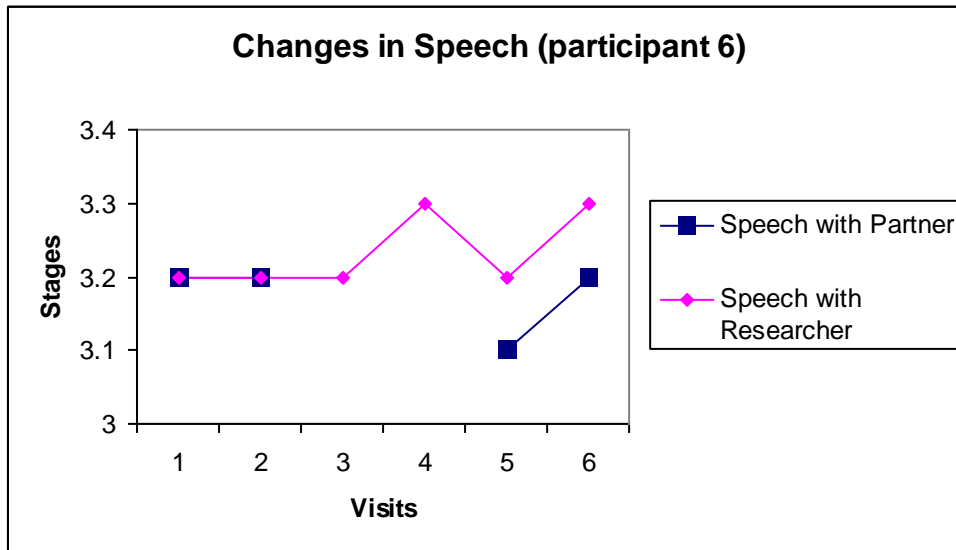
When observing the video data the intelligibility of 10 participants' speech appeared to be better when talking to the researcher than with their chosen partner. The following chart illustrates this.



It is important to note that this does not imply that their chosen partner understood them less. In fact the opposite was always the case. It simply indicates that the person with MND made more effort to be understood when talking to the researcher because they were less familiar with her and were aware that she would not understand the shared topics and non verbal clues which they shared with their chosen partner. In addition participants were more relaxed with partners and spoke to each other with strong local dialects.

One participant's speech was more intelligible at the last visit than at the first. He was the only participant who had received speech and language therapy input on his speech, the pattern of which was two blocks of six weeks therapy six months apart. He then received two weeks "booster" input when required.

The following graph illustrates this “booster” clearly. (His wife was not present at visits 3 and 4.)



PURPOSE OF COMMUNICATION

INTRODUCTION

Light (1988) in her state of the art paper defines four main purposes of human communication: needs and wants (to regulate the behaviour of another as a means to fulfil needs and wants); information transfer (to share information); social closeness (to establish, maintain and/or develop personal relationships), social etiquette (to conform to social conventions of politeness). Social closeness is clarified further by Locke (1998) who describes the two main functions of communication as 'propositional speech' and 'intimate talking'. He defines propositional speaking as the transmission of impersonal facts. This is where partner A has information which is unknown to partner B and wishes to transmit that information to partner B. In contrast he describes the purpose of intimate talking as 'the construction and enjoyment of relationships with others'. It includes casual conversation such as gossip and is 'naturally adorned by effective displays of the voice, the face and the body', i.e. non-verbal communication. Intimate talking reveals personal thoughts and feelings and elicits social reactions to those revelations. He points out that people need to know not just what others tell them but what is on their mind and therefore the main feature of intimate talking is this enjoyment and development of relationships with others. It is not a mathematical formula of phonemes and morphemes and grammar which has been the way that language has been studied mainly in the past. This supports Light's four purposes of communication.

Typically in the past, studies of communication have focused mainly on the area of needs and wants and information transfer but as Locke points out the most important purpose of communication is to develop relationships with others. This has serious implications for speech and language therapists who traditionally have worked with people in a clinic setting and who have focused mainly on the propositional type of speaking described by Locke. There needs to be a shift in the way in which we work and as Locke points out 'expressive abilities do not develop in clinics'.

In a book of personal essays on augmentative and alternative communication, Johnson (2000) explains how important her personal assistants are for her communication and how, for her, social closeness is paramount. *'It is more important for me to be involved and active in the community than to feed or dress myself.'*

Light's concept of social etiquette is further explained by King et al (1995). They emphasise the importance of 'small talk' which they describe as 'those utterances used in any environment that serve a social function but do not contain specific cognitive or communicative content'. 'Small talk' is also defined by Halliday (1973) as 'short meaningless exchanges used in socially prescribed ways for successful interactions'. King et al (1995) discuss the role of 'small talk' such as politeness and maintenance of conversation in relation to high tech communication devices. They note the importance of 'small talk' for people with a congenital communication difficulty as they become

increasingly proficient at using a Voice Output Communication Aid (VOCA) and correspondingly become aware of the need for 'small talk' as a necessary part of communication.

Traditionally, high tech devices have been limited to the production of words and phrases for transmitting needs and wants and for transfer of information. Attempts have been made, and continue to be made, to develop AAC systems that make use of prestored material and employ conversational modelling to increase communication rate and enhance the interactive aspect of the communication. Two examples of this are CHAT (Alm et al 1998) and Talk:about (Waller et al 2001). However, keeping these systems easy to use and still effective is a challenge and so far they have met with limited acceptance by providers and users.

FINDINGS

All the people in this study were living at home. The study was carried out in people's own homes because the researcher felt that it was important to observe communication in the most natural and usual situation for people with MND. The assumption is that communication within the home situation is the most typical even for people at the end stage of the illness. Preliminary data from the Scottish Motor Neurone Disease Association substantiates this. Recent statistics from MND Clinical Specialist in the East of Scotland show that more people with MND die at home than in other settings. Out of 114 patients 56 died at home, 35 died in hospital, 12 died in a hospice and 11 died in a nursing home. It is therefore vital that we look at the communication of people at home and with their immediate family and carers as these are the people with whom communication is most essential.

From an examination of the data in this study the communication of 'needs and wants' as described by Light tends to be less problematic and therefore less of an issue for people with MND than with some other client groups. This is because communication partners are usually aware of needs and wants like drinks and daily care tasks because they know each other so well. Another feature of the interaction of people with MND while living at home is that they are rarely talking to strangers and their communication is primarily with people who are familiar to them. This was often by choice. One couple described how the husband's conversation with people outside the immediate family was limited to saying "Hi" and communicating by eyes and facial expression. His wife said that he was now content with '*his own four walls and his dogs*'. Another woman described her interaction with neighbours:

Participant: When I am out and people are talking I try not to get involved cos it's so tiring – its different at home

Husband: She likes neighbours who just wave and say 'Hi' – not long tiring conversations.

Similarly, transfer of information appeared to be a less significant issue for the people in this study than with other groups, as the topics of conversation are very often shared topics whereby the communication partners are talking about some kind of activity that they are working on together. For example,

one couple were looking at a mail order catalogue to discuss the kind of headboard they were going to buy for their bed. They both already knew the kind of thing they wanted, they both knew more or less what each other's views were and they were working together at agreeing on the one they both wanted.

Another participant described how they talked to each other:

We usually speak about what's happening or what's going to happen. I usually know what I'm going to say because I'm going to have to say it to someone else. Sometimes it's a wee bit of luck. We talk a lot - always have - the rest of the family think we're telepathic!

Another participant was distressed that she was failing her grandmother as she was having difficulty understanding her deteriorating speech. She met me at the door of my second visit in tears saying 'we can't communicate any more'. In fact when we looked at the video and talked about it together it was clear that they were still 'communicating' very successfully using a range of verbal and nonverbal strategies. It is important to reassure families that they are not failing and to show them that their interaction is still successful.

In this study it appears that the most important purpose of communication between participants is the development and maintenance of social closeness. One extract from the video data shows a couple chatting when their dog wanders in and makes a series of strange noises, which causes them both to smile at each other and share the joke (non verbally) before resuming their discussion. From observing the video it is clear that the intimate exchange about the dog is the most meaningful part of this interaction. Another couple show numerous examples of social closeness even although the person with MND has severe cognitive difficulties and almost no useful speech. The nonverbal interaction between them is much stronger than any words. One man, who was still going to the pub regularly, always went to the same pub where the barman knew him and knew his order which he could indicate easily by gesture.

Discussing shared topics is also an important factor in developing social closeness. Even when talking to the researcher, the topic was often centred round a shared experience e.g. growing tomatoes, teenage children. In one video episode between the researcher and a participant the development of social closeness was clear even though they had not met before, were from different backgrounds, ages, gender and the participant had no intelligible speech. The participant initiated the conversation by pointing to a photograph of his favourite mountain and both forgot that the video camera was on once they began talking about hill walking.

Numerous extracts of conversation between couples in this study, even when largely unintelligible to anyone else, contain many aspects of 'intimate talking' such as - gossip, personal thoughts, listener reaction, communication, agreement, disagreement, continuers, confirmation, humour.

Even though the participant's speech in the following extract is largely unintelligible the three people understand each other and enjoy this conversation about where the participant met his wife.

Participant: Came back up

Researcher: Came back up (confirming)

Participant: nods

Researcher: Right and that's what you did. You came back up here with them (your parents) and that's where you met S?

Participant: More or less (laughing)

Participant: vocalisations

Researcher: And S is from B – is that right?

Participant: No (Gestures here)

Researcher: From K?

Participant: Nods

Researcher: Right. Right

Participant: Gestures and laughing

Researcher: laughing

Wife: (making a face)

All: laughing.

For the participants in this study 'small talk' was a very important feature of their communication but much of their 'small talk' was conveyed by non verbal methods. Indeed, an examination of the 'small talk' coding system given by King et al (See Appendix 3) suggests that most 'small talk' is very personal to the communication partnership and that many aspects of 'small talk' can be conveyed by vocal and/or non verbal means, especially between people who know each other. Some examples are: greetings, closings, attracting attention, affirmations, negations, comments, and continuants.

Undoubtedly electronic communication aids can give a voice to people with little or no speech but as Locke points out people need to succeed in social talk as well as in formal propositional speech. Perhaps we should be teaching our clients the importance of 'small talk' and social closeness and emphasising that much can be done by non verbal means rather by trying to use impersonal technology.

COMMUNICATION STRATEGIES

INTRODUCTION

Communication is a social phenomenon which is determined by personalities and relationships and is made up of a whole series of intangible occurrences. It requires the involvement and cooperation of at least 2 people who sometimes take it in turns to send and receive a message, but more often overlap and interrupt each other throughout the course of an interaction. Speech itself is only one of many methods of communicating and many other strategies may be employed, particularly when there is a problem in conveying and /or understanding the message. Locke (1998) emphasises that communication is much more than just the transfer of information – it is about people conveying to others what is in their minds. He refers to ‘the intimate murmurs of people who know each other well’.

It is therefore vital that any intervention to help a person with MND and his/her communication partner should focus on communication function rather than speech impairment on its own. Yorkston et al (1995) suggest that intervention that aims to stabilise speech is likely to fail and that ‘speech exercises’ may in fact ‘so fatigue the person that adequacy of speech production in natural settings may suffer’. Yorkston et al also advocate that rather than measure intelligibility when considering the speech of people with communication difficulty it is more appropriate and useful to consider ‘comprehensibility’ in the general natural setting. Comprehensibility is defined as ‘the process by which individuals share meaning using any or all information available’. Where intervention aims to maintain functional communication by helping both members of the communication dyad to make use of appropriate communication strategies the outcome can be affirmative and encouraging. There are a number of invaluable books with practical information and therapy suggestions for speech and language therapists working with people with MND such as Robertson and Thomson (1986), Beukelman et al (2000), Swigert (1997), Yorkston et al (1995), There are also an increasing number of websites that provide information about MND/ALS directing people with MND to speech and language therapy for practical help with their communication.

Robillard (1999), in his account of his own experiences as a person with MND, complained that people completed his sentences, edited his remarks, translated at the wrong spot and therefore out of context. He felt that his communication partners, including his wife, were disinclined to interpret for him and he described feelings of frustration and social isolation.

RESULTS

There were many examples of misunderstandings in the data which were caused primarily by difficulties with resonance (hypernasality) and articulation (mainly tongue movements). However, in contrast to Robillard, the enduring impression with regard to communication when visiting the fifteen families in this study was one of closeness, cooperation and understanding. There were very few real communication breakdowns as partners worked together to

resolve any misunderstandings. The cooperation and symmetry of communication between the participants in this study was striking. All the participants with MND worked with their communication partner and saw communication as a joint undertaking with many relying on their communication partner to interpret. The only negative comment was from one man:

We get there - she seems to understand what I want, or what I'm saying to her, but she doesn't always listen. I was going to say she has selective hearing but generally we communicate very well.

Paradoxically his wife said exactly the same about him!

From an examination of the video material the participants' speech was usually more intelligible with the researcher than with their close partner indicating that the participants made more effort with the researcher to articulate more carefully and speak slower. However, the close partner invariably understood the person with MND more than the researcher did for the obvious reason that close partners were more familiar with their speech and the contexts of communication:

Researcher: What is it that you do that makes it easier for you to understand than me?

Wife: Probably because we've lived together for years and we just know each other's ways - I mean some time we even think the same and then he'll be saying something and I'll say - oh - I was just about to say that.

All the participants in this study, both those with MND and their partners, were keen to discuss their own strategies and share them with others and many people said that they felt isolated and unaware of what other people did to overcome their difficulties.

Wife of man with MND: All these wee suggestions help. We don't know anybody else who has Motor Neurone Disease.

However, it is an important proviso that not all strategies will work for all people. Each person is the expert on their own communication and each family will have their own communication systems and techniques.

Communication strategies

Background

A study by Hustad and Jones (2002) clearly identifies the benefits of using strategies such as using topic cues (indicating the main idea or topic of forthcoming messages) and alphabet cues (indicating the first letter of each word while speaking). They studied listener attitudes to the use of topic cues, alphabet cues and a combination of both on listener attitude. They found that those strategies that supplement speech, particularly alphabet and topic cues combined, not only increased intelligibility but also improved listener attitudes in relation to comfort when listening to people with dysarthria and willingness to talk to individuals with dysarthria.

Speigel and Buchholz (2002) describe a multi modal approach to treatment for severe dysarthria and provide a ranked list of communication strategies:

1. total repetition
2. partial repetition/phrase
3. rephrase
4. spelling the word
5. gestures.

Findings

The people in this study made use of a number of different strategies to assist their communication. The use of gesture, facial expression and eye contact made a considerable difference in helping with intelligibility of communication and it was particularly important that partners sat in a position where they could make eye contact and notice non-verbal signals.

The following quote illustrates that people will work out their own hierarchy of strategies that they use in a sequenced way when they are not understood.

Wife: If I don't understand I'll say to him look I didn't catch that and he will maybe say it again. If I say that maybe a couple of times and I still don't catch it he will either write it down or start to write it down on a bit of paper and if I get maybe the first two or three bits of it I know exactly what he's on about. Or he'll maybe mime a bit like he did with the steering wheel.

For those people whose difficulty with speech was in the early stages, simply **repeating** what had been said or the partner asking them to repeat was usually enough to improve intelligibility. Some people used **spelling**:

I speak first – if I'm not understood I stop and think 'what's the word that's causing the problem' then I spell it if it's a long word syllable by syllable.

For some people **emphasising** or **stressing key words** was a help to their partner.

I try to get her to not repeat the whole sentence – but just repeat one word – just key words – that way you can get the rest of the sentence.

Two people found that **breathing** more deeply helped their speech and for some people having a partner who reminded them to **relax** and to take deep breaths was a helpful cue.

She has breathing exercises given by the physio - she does it before she speaks.

Several people used their partner to **interpret** for them.

Participant: T is good – he sees if I am having difficulty and he will come in and say 'my wife is having difficulty talking' then I feel better.

One woman who attended a language class where the members had to read out their work said:

If I feel I'm not speaking well enough for people to pick me up I just ask someone to read to save me having to do it.

Participants emphasised that the partner only interprets if asked or if given permission by the person with MND as this extract shows:

Researcher: So what other wee tricks have you picked up or other things that both you and H do to sort of help - thinking again about your speech and communication

Participant: Well say we're going shopping for the house or food or anything - I'll say to him before we go to the assistant - 'I'm wanting 6 pancakes and 4 rolls'

Researcher: You'll tell H

Participant: Aye - I'll tell him. If I'm all right - if I'm feeling confident I'll say to him. But if she (the shop assistant) says "how many?" right away H. will take over

Researcher: So you've worked that out between you - H. knows when to talk or when to let you take over

Participant: I'll look at him

Researcher: So you've worked that out.

One participant whose speech was unintelligible indicated that he tried to avoid people he knew when he was outside because he found it embarrassing to try to communicate. He lived alone and had no one to help him or interpret for him. The same man told me that if he needed to make a phone call he would use a neighbour. He wrote down,

I always find a way out - never stuck.

Another participant was anxious as his wife had a sore throat and was losing her voice,

I need you to speak for me on the phone and in the shops.

Therefore the findings from this study indicate that using partners to interpret in some situations is an important and successful strategy.

This role of interpreter has been developed in a more formal way in Sweden where the government has established a National Interpretation Service for people with speech disabilities. This service provides another person as the 'communication aid' by providing personal vocal support for people with speech disabilities. The trained supporter gets to know the client and takes time with the client to prepare for special situations. There are three main supports offered:

1. Accompanying the client on visits to the doctor, the bank, shopping trips and various other meetings
2. Supporting the client in 3 way communication on the telephone
3. Helping with reading / writing letters and understanding documents

(National Board of Health and Welfare 1997).

Several partners in this study described using **topic cues** and making use of the **context** as a useful strategy and it must be borne in mind that many people with MND, particularly in the later stages, are mainly with their own family and their own close friends. They may not be going out or meeting new people and their close communication partners therefore very often know the context. It was observed that when couples were communicating they were often working together at some task such as looking at a magazine or

discussing home repairs or where they were going to go for the weekend. This working together and making use of context undoubtedly helped the communication process. Some communication partners made sure that they **confirmed** that they were understanding correctly as the interaction progressed rather than waiting until the end and finding that they had gone off on the wrong conversational track.

Where **humour** was used in order to overcome misunderstandings it was noticeable that couples not only found this provided a satisfying conclusion to a misunderstanding but also contributed to the development of social closeness as described by Light (1988) and Locke (1998)

Partner: If he doesn't write he will sort of mime and if I still don't know .. well [laughs]

Researcher: What will you do?

Partner: [still laughing] no 99% of the time I must admit we are not bad together. We can sort of banter back and forth and I have a fair idea of what he's on about.

One husband in this study completely misunderstood his wife when she was talking about bingo. However once they worked together at resolving the misunderstanding and realised their confusion they both dissolved in laughter which produced a satisfying and intimate conclusion to their interaction.

One man used black humour,

I always make a joke – if someone says 'are you finished?' I say 'in more ways than one'!

In order to **conserve energy** it was important for some people to pace themselves to take rests. For example, if they knew they were going to be doing a lot of talking or meeting someone later in the day they would take rests earlier on to preserve their energy. One woman said,

If we've been out I wait till we get back into the house and C has calmed down, I make us a cup of tea and then we can talk more easily.

Where couples used very few or no strategies to compensate for communication difficulties this led to anger and frustration. This was particularly noticeable with one couple where there was increased tension with each visit. The final visit was not filmed as the spouse was so upset at her husband's unwillingness to compensate for his communication difficulties that it would have been insensitive to film them. Therefore although most of these strategies seemed fairly obvious, not everybody used them but those that did, found communication much more satisfying, effective and successful.

Control of conversation

Background

The person who controls a conversation is not necessarily the one who speaks most. More important is who directs the conversation by introducing the topic and continuing the conversation with comments and questions.

Therefore control is determined not necessarily by who contributes in terms of quantity but in terms of quality which can be determined and conveyed both verbally and nonverbally. Studies describing interactions between aided communicators and their communication partners show that AAC users tend to assume subordinate roles during conversations (Light et al 1985; Von Tetschner and Martinsen 1996 in Muller and Soto 2002). These studies which tended to involve people who use AAC because of congenital speech impairments, also indicate that aided communicators are less likely to initiate.

Findings

Unlike people with congenital speech difficulties there was no clear pattern of control of conversation in direct relation to intelligibility, even where the speech of the person with MND was severely impaired. This balance of control is undoubtedly due to the previous experience of the person with MND in having non-impaired speech and as an equal partner in conversations. The video tapes of each visit were studied by the researcher and another speech and language therapist and notes taken of who initiated new topics and who continued the conversations both by verbal and nonverbal methods. This notion of 'control' was examined with the chosen communication partner, the researcher and in a 3-way conversation where this occurred. People with MND are not a homogenous group and the contribution each person made varied according to personality rather than intelligibility or comprehensibility. Even those people whose speech was extremely effortful to them, initiated new topics and were often the one to keep the conversation going.

The following three examples from researcher's field notes illustrate this sharing of control:

1: There was generally equal control but it was noticeable at the fifth visit that participant initiated more and took more control of the conversation as her partner was obviously distressed at the participant's difficulty with speech. It appeared that the participant was trying to make her communication partner feel more at ease.

2: The participant maintained control even at the last visit before she died and despite her speech being unintelligible. She was keen for her partner to be present with the researcher and at times in these 3 way conversations she indicated that her partner should take control as she found it so effortful. Even then the topic of conversation was determined largely by the person with MND who indicated non verbally what she thought about what was being said.

3: Although the partner spoke more, the participant always responded and attempted to comment. He initiated more than his wife especially when there were silences between them. The participant initiated more novel topics when talking to the researcher than when talking to his wife.

Where there was already a topic available for discussion such as a continuation from a previous conversation or visit the interaction flowed more easily and control was more equal. Also several people made use of props such as magazines, letters, catalogues etc as the focus of their conversations.

With this in mind, the use of communication passports (Miller 1997) containing personal information about a person's interests could be a valuable tool in assisting conversation with unknown people.

Therefore in this study, control of conversation was not necessarily taken by the communication partner. On the contrary, the person with MND appeared to either control or have equal control of the conversation in most cases.

Emotional lability

Background

Yorkston et al (1995) describes emotional lability as unsteadiness of emotions where individuals may experience bouts of laughter and crying that are not in proportion to the stimuli. Lability is not typically considered of psychologic or cognitive impairment. Rather, it is consistent with bilateral corticobulbar lesions that result in loss of pyramidal tract inhibitory control over the behavioral-expressive responses of an emotion (Montgomery and Erickson 1987).

Findings

For seven people with MND in this study emotional lability, where they either laughed or cried inappropriately, was a significant problem. The following is an excerpt from field notes where one woman describes

"Researcher hands 10 cards to participant and asks her to read them to check her intelligibility. Whilst reading one of the cards, participant has a fit of the giggles. She feels that her emotions are not in control. She then explained how, when she was telling her sons of the death of a neighbour of theirs for last 18 years, she started to laugh. She says that she feels her emotions are 'completely out of sync'. She goes on to describe how her two sons get embarrassed when she cries. They watch her face and the younger one says, "I'm out of here" and leaves the room. The boys' reactions make her feel embarrassed and worse about the situation. She gets angry with herself and says "Control yourself". She also explains that her husband uses quite harsh tones if he thinks she is going to cry and that this helps her. She clenches her mouth and thinks of mundane matters to prevent herself from crying."

Another person explained that she cried over apparently trivial events and this distressed her. The researcher observed one participant who talked about his extreme frustration when he was not understood - 'its hellish' - and his feelings of hopelessness but the same man giggled inappropriately at all visits when his speech was not understood. His wife described her annoyance with her husband:

Wife: There's some nights I'm just beat and I can't get my head round it (what he's saying) at all and then he starts laughing and that makes it worse.

The strategies that participants described to overcome this included trying to **think positively** or change the subject when they felt inappropriate emotion. For one woman her it was helpful if her partner simply nudged her or

changed the subject to help her get over this feeling. One participant had been prescribed **medication** by her GP which had made a noticeable difference

I am now able to meet my friends and tell them about my illness without crying.

Speech and language therapy input

Background

Yorkston et al (1995) describes the importance of early intervention 'Attempts to manage the communication (and swallowing) needs of individuals with end stage ALS are often frustrating. Although these people's needs are urgent and profound intervention is often inadequate because of factors such as untreated secondary complications, patients and families who are unable to make informed decisions during times of crisis, lack of time or energy to implement intervention, and increasing emotional lability'. Yorkston et al found early intervention to be beneficial in a number of ways:

- to develop a relationship with the patient and family
- to provide information regarding the disorder and how to deal with it at a pace at which the family can assimilate it and at the times when it is needed
- to help educate the patient and family become informed consumers of medical and technological services. This task can be accomplished only through education.

Findings

From discussion with and observation of the participants in this study it appears that there may be critical points when people with MND and their communication partners may benefit from speech and language therapy intervention. These points occur typically when there is a change in the person's communication situation:

1. At or soon after diagnosis in order to provide information and to reassure that help will be available if and when needed. Even at this early stage it may be helpful to discuss the importance of social closeness and non verbal methods of communication which can be used by both communication partners
2. When some deterioration in speech is evident in order to explain the speech mechanism and suggest ways for both partners to maintain/preserve interaction.
3. When speech is more effortful and less intelligible in order to suggest possible strategies to assist interaction and resolve misunderstandings.
4. When speech is largely unintelligible in order to suggest alternative methods. Depending on the individual person, it may be valuable to suggest AAC methods early in order for the person to receive adequate training before fatigue makes new learning too onerous.

Only one participant mentioned receiving speech and language therapy input on communication strategies. He had been given specific work both to improve his articulation and also to help him think about strategies to alter the

way in which he communicated. Significantly he was the one person whose rating on the Riviere classification improved from 'moderate' to 'mild' by the final visit. This longer extract from the data describes clearly the benefit this participant felt:

Participant: A year ago, if you had come a year ago, you would never have made out a word I said.

Researcher: Really? So why is there a difference then do you think?

Participant: Because I think going to the speech therapist does help. She taught me how to use breathing and also getting to grips with knowing how to tackle this problem. It does help an awful lot.

However, most participants in this study had not received speech and language therapy to help their communication as this extract between the researcher and man with moderate dysarthria illustrates:

Researcher: What does your speech and language therapist do?

Participant: Nothing really – its more the dietitian – she weighs me – they (speech and language therapists) talk about how you swallow

Researcher: Is that where the speech and language therapist comes in?

Participant: Yes

Researcher: Is she not doing anything about your speech?

Participant: No – well she knows what I say anyway so....(shrugs)

Researcher: Have they suggested any communication aid?

Participant: Aye – but I'm not that bad yet.

Only 4 people in this study described problems with eating and/or drinking whereas 14 reported some problems with their speech. There should be concern amongst speech and language therapists that helping people to either maintain or improve their communication ability is being overlooked because of the emphasis on dysphagia. This is also reported in relation to dysphasia therapy by Enderby and Petheram (2002). In a study carried out across 11 health boards between 1985 and 1995 they describe the dramatic increase in referrals to speech and language therapy for dysphagia and note that the amount of treatment and treatment duration for patients with dysphasia has reduced. They comment that speech and language therapists receive more training in the assessment and treatment of speech and language disorders than in dysphagia and emphasise the importance of their skills being used appropriately. This concern that therapy to help speech and language disorders is being overlooked appears to apply equally, if not more, to people with MND.

Despite the amount of useful material available on dysarthria and communication strategies it is dismaying to read this remark from one participant who had moderate dysarthria:

The speech and language therapist says there is nothing she can do except monitor my swallow.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

INTRODUCTION

Augmentative/alternative communication refers to methods of communicating which supplement or replace speech and handwriting. The term refers to a function, not to any specific communication systems or methods. (RCSLT 1996).

AAC can be subdivided into

- a) High tech AAC which includes any piece of equipment that requires a power source such as a voice output communication aid (VOCA).
- b) Low/light tech AAC which does not require a power source – e.g. an alphabet board or communication book

There has been great enthusiasm for the potential benefits that technology can bring to people with little or no useful speech – and indeed there are many examples of AAC users, particularly people with cerebral palsy who describe how high tech communication aids have changed their lives.

Technology has changed my life in many ways. It has enabled me to talk and socialise with other people (Seals 2002).

However technology is not without its problems and this study suggests that AAC may be less successful with people with acquired and progressive communication difficulties.

Before any form of AAC is introduced it is important that the person with MND be allowed to consider and discuss what they want their goals to be. There is a danger that goals are set by professionals without truly appreciating the views and factors in a person's life that might affect their ability to accept and make use of any AAC equipment. Talbot (1991) questions if it is fair to expect people who have received an enormous emotional blow on being given the diagnosis of MND to have the same goals as professionals who are enthusiastic about giving their clients devices which they think could help them communicate better. He suggests that we need to consider the functional aspects of communication rather than the means by which we send messages to others.

The AAC Performance Report (Hill and Romich 2000) is a summary of measures of communication performance that are being used in the USA both clinically and in research. It focuses on measuring quantitative information such as: number of utterances, length of utterances in words and morphemes, communication rate, total number of words etc. There is no mention of communication strategies, quality of interaction, satisfaction of interaction or partner involvement.

Thomson and Thomson (2000) comment '*For most of our social interaction the device is actually not very useful*' and give some of the reasons – '*you can't lip read a machine, you have the worry of food spills, there is no room for it on tables, machines can do so many things it gets confusing*'. Ironically one

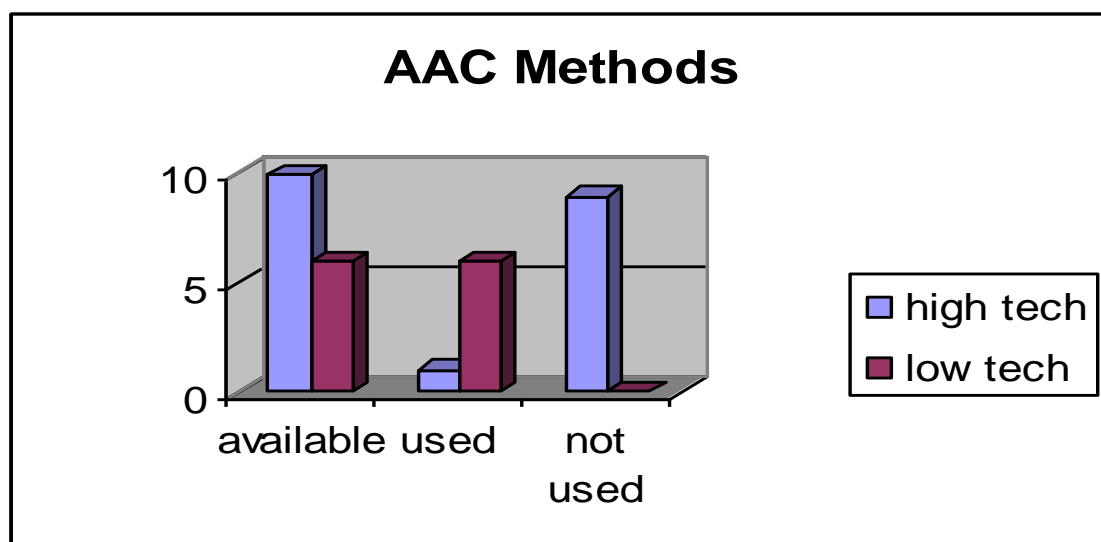
of the limitations of technology is its very sophistication and lack of simplicity. Technology can do so many things that the human beings who are expected to teach and those who are expected to learn to use devices may feel overwhelmed. As Albert Einstein said '*It has become appallingly obvious that our technology has exceeded our humanity*'

RESULTS

It could be expected that people with motor neurone disease are ideal candidates for **high tech** augmentative and alternative communication devices.

For most people with MND there is no cognitive impairment, their language and spelling remain intact, they understand the nuances of communication and they are motivated to communicate.

In this study 10 participants had been offered high tech devices but out of the 15 people that were involved only one of them was using a high tech device functionally – and that was only rarely.



For most people in the UK with motor neurone disease the device that is usually supplied is the Lightwriter™. However, all but one participant in this study had abandoned or had never even started to use their Lightwriter™ for a variety of reasons.

The following comments and observations may give some clues as to why high tech devices are not being used:

Slowness

No matter how sophisticated the device or how skilled the user, no alternative communication device can replicate the ease or speed of natural speech. One spouse remarked to her husband,

If you're in a strange place and you want to ask to go somewhere will people all wait in a queue till you spell it out?

Obtrusiveness of devices

One participant found the Lightwriter™ intrusive and awkward despite its small size and during one visit threw it on the floor in frustration.

In a paper expressing her views on AAC, a woman who has tried using both low and high tech comments,

Some high tech communication aids can be big and clumsy ...they can bring undue attention to one' Brown and Murphy (2002).

Devices break down

Although the reliability of high tech devices is improving, there are still technical problems which leave people frustrated and disenchanted with technology.

Partner: She's got a Lightwriter™ but its broken just now.

Desire to use own speech

People with MND have experienced normal speech and find it hard to accept an alternative voice. Everyone in this study, even those whose speech was unintelligible, attempted to use their own speech first and many commented that no device could ever replace the human voice.

Churchill (2000) comments *'The human voice can give my words intonation, spontaneity, humour and wit. Machines can't do that yet.'*

Researcher: Is that (Lightwriter™) what she uses?

Partner: No, I try to talk to her cos she'd rather say it rather than write it down or use the Lightwriter™ – with me that is...as I've done for many years.

Seen as a toy

Some people find it hard to see an electronic device as a serious and beneficial aid to their communication. When first given a communication aid, one man said:

I like it very much. As I said to my speech and language therapist it's a nice toy but it's like admitting defeat.

Timing

Several people had to wait for weeks, and in some cases months, to obtain a high tech device with the result that by the time they received it it was too late for them to be able learn to use it confidently or effectively. Guidelines for the management of MND (1999) state that *'when a communication aid is needed it is essential that it is provided promptly'*. There is some debate about AAC devices being provided for people early on in the illness. On the one hand it is helpful if the device is provided at a time when the person is physically able to learn to use it. The opposing argument is if an AAC device is suggested before the person's speech is affected, this may cause anxiety and distress by indicating to the person that they will lose their speech.

Model of device provided

Another issue evident in this project was that seven participants had been provided with a model of Lightwriter™ that had either no voice at all or had poor quality voice. The wife of one man commented that the voice of the machine was actually worse and less intelligible than the dysarthric voice of her husband.

Lack of training

Lack of training was noted in a previous study carried out in Scotland which looked at the obstacles to effective use of AAC systems used by people with cerebral palsy (Murphy et al 1996). It was estimated that people with cerebral palsy received approximately only 40 hours of therapy per year. It would appear from the present study that the situation for people with acquired communication difficulties is much worse. A crucial factor in the current study seems to be the lack of training provided to ensure that the person with MND and their family understand the device and its functions such as storing phrases, altering the voice, using prediction etc. It was noticeable that the participants in this study had received very little input in terms of how to use their devices.

One couple described the help they had been given:

Researcher: How much time did the therapist spend going over and explaining it?

Participant: Not much time spent with me

Wife: He had a demo one then he got his own. She (the speech and language therapist) sat down with it and sort of took him through it and gave him a book of instructions she had done herself. Just left to puddle along ourselves

Participant: I tried to use it – going by instructions – nobody helped me very much.

Another participant said:

Learning something new like this is too hard – but don't tell my speech and language therapist!

Furthermore, training should not be just a one off visit but should involve sufficient input for the user to learn how to use the device successfully and also to receive regular reviews. One man had been given a device with 6 phrases that had been stored in it for him by the professional. They included 'Happy Christmas' and 'Good New Year' but when he was visited in March they had not been changed and he did not know how to change them himself.

One study which attempted to address this problem is described by MacDonald (1997). She ran an eight-month group therapy programme designed to help four adults each using a Lightwriter™. She initially observed several of the same problems as those identified in this study such as lack of knowledge of the operational features of the machines and lack of awareness of social considerations. MacDonald describes the contents of the two blocks of group therapy which mirrored these main problems. The first focused on teaching the mechanics of the devices such as using pre-stored messages,

speech exceptions and altering volume control for different situations. The second block was aimed at improving social interaction including awareness of turn taking, appropriate eye contact and non verbal signals. All clients made observable progress and MacDonald concluded that the amount of support needed to help people use communication devices should not be underestimated.

Lack of knowledge of professionals

There is also an issue about the knowledge and skills of those providing AAC devices. Wendt (2002) in a study evaluating AAC intervention for people with MND in a German rehabilitation clinic states that most of the problems experienced in AAC service delivery were due to lack of knowledge and information about AAC. It is essential that professionals receive adequate training, time and funding if they are to be expected to provide the input and backup that is required for people with motor neurone disease and their families to use technology successfully. Many speech and language therapists have a lack of knowledge of the potential of AAC devices due the pressure of a large general caseload and lack of training. Thomson and Thomson (2000) comment *'The traditional speech and language therapists don't really know about these machines and many of them don't really trust machines'*.

Instruction manuals

Some of the people in this study had been given the instruction manual to learn from but realistically this was never going to be successful as many of the manuals are technical, complicated and difficult to follow.

Researcher: I wanted to ask you what you feel about the Lightwriter™.

Participant: Well I don't use it as often as daily. The other night I didnae feel too hot and I went to my bed. The boys were there and they said if you cannae shout use your Lightwriter™ with the buzzer.

And then – eh - I've preprogrammed some of the letters too - like "give me a drink of juice".

I am using it but not on a daily basis and in between I practice. I've looked at the manual (makes a face) but I don't need to use it as comprehensively as that but so long as I know how to do it for what I want to use it for.

The buttons are fine and they're not heavy to press.

I've got the gist of it.

I don't need to use it much 'cos there's 4 of us in the house – different if I was on my own.

One company is addressing this by producing a manual on CD Rom with clear step by step tutorials for therapists and clients (Toby Churchill 2003).

Vocabulary

The advice given to people in terms of the possible vocabulary they could store in the device is crucial in introducing an AAC device. Time must be taken to talk through the kind of messages the person might want. This will depend on many factors, not least the stage of the illness.

Stuart et al (2000) describe four stages of the illness – vigilance, relinquishing care to others, enduring self and new sense of self - and discusses the type of vocabulary needed at each stage. For example if the person is at the **vigilance** stage they may need vocabulary to help them deal with their grief such as ‘Can I have time alone please’. At the stage of **relinquishing care to others** they may need phrases to explain how they want things done ‘put my collar outside, not inside my jumper’. **Enduring self** may require vocabulary to express how they feel ‘I used to do ... but now ... ’At the stage of the **new sense of self** they may want short narratives about themselves to explain ‘events or situations to others’.

At all stages people may want vocabulary to maintain ‘small talk’ - to help maintain and nurture their personal relationships, to gossip, to minimise conflict, to tell and respond to jokes. They may or may not want to ask questions about their medical condition. Some people may want to discuss wishes for their medical treatment as they become more ill. The Adults with Incapacity Act (Scotland) 2000 states in order for medical treatment to be carried out it is a requirement that the previous wishes of a person who is no longer capable of making these decisions must be taken into account. For example if a person with MND does not wish Gastrostomy feeding or ventilation or certain medication at the end stage of their life this information should be noted and it should be suggested that it be made available in the person’s AAC device if wished.

It is crucial that these issues are considered if an AAC system is being suggested. None of the people involved in this study had been given advice about specific vocabulary they might need or want to use in the future.

Dynamic communication

Several participants emphasised the importance to them of close personal interaction and the worry that using a device would remove that.

Husband: I mean I prefer contact this close (using an alphabet chart) rather than trying to type something with the Lightwriter™ ... to lose that personal contact I think is detrimental really.

Participant: A lot of our communication is non verbal ... it could be important not to let these non verbal communication stop ... to become oblivious to it.

In two extracts of video data there is a stark contrast between the closeness of one pair of participants when trying to resolve a misunderstanding using vocalisations, gesture and eye contact in comparison to the lack of interaction when another participant is trying to use a high tech device and her partner is left sitting in silence waiting for the message. Thomson (2002) offers numerous insights from the perspective of a person with MND who uses a Lightwriter™ effectively. She describes the difficulty of preserving her personality via a machine and discusses how each word had to be chosen carefully to express not only meaning but also emotion. She became aware of people’s expectations that anything she produced on the Lightwriter™ should be profound and memorable whereas she might just want to ask for a tissue! She later stresses that communication is a dialogue, not a monologue and

that she was in danger of forgetting that '*I am always a piece in a dynamic jigsaw*'.

Robillard (1999) described why he abandoned the several high tech devices which he was given. The main reason was that he had to concentrate and work so hard at operating the devices that he could not maintain social closeness with his communication partners.

Hand control

Another difficulty for people in this study was the decrease in their hand control as the illness progressed and therefore many people were unable to use the standard Lightwriter™ because they were unable to operate the keys and access the device accurately.

Wife: He has a Lightwriter™ but he has never used it. I think he finds it is too slow by the time he has sort of punched in ... typed in his answer. He is not quick by any manner of means and with his tightening up a bit, he hasn't got the same movement. With that, I think he feels it is too slow for his reply to come through you know before he can sort of keep going. So I think maybe that's it. Maybe that's a good thing in a way that he doesn't use it because it has maybe made me a wee bit better at trying to listen and to try to pick up what he's saying.

Another couple had the following discussion:

Wife: So what do you feel about the Lightwriter™ yourself?

Participant: facial expression (not much)

Wife: It's no very good because if your fingers are stiff because of the keys I think you feel by the time you've punched in an answer to somebody the communication's gone half a mile down the road

Laughter between them both

Wife: It's too small and fiddly for you

Participant: gestures problem with his hands

Wife: If it was a bigger keyboard and if it had bigger keys you might manage it better. It's too small for your hands and when you can't use your hands any more its no good to you anyway

Participant: gestures and vocalises a bigger one

Wife: A bigger one with bigger keys – that would make it too clumsy for carrying about with you - I don't think it's altogether right for you. You haven't got the patience anyway

Participant: gestures thumping it

Both laugh.

Only two people in this project had been given information about the possibility of using the Lightwriter™ as a scanning device using a switch. However when scanning is involved the device becomes more conspicuous and for some people machines with cables and switches may be too obtrusive.

Although the Lightwriter™ is undoubtedly a useful and accessible machine for people with motor neurone disease there are other high tech devices which could be considered. No one in this study had been offered any other

dedicated high tech AAC device. Three participants made use of personal computers in their own home but these were used mainly for writing and sending emails rather than to supplement spoken communication.

High tech AAC was not successful for the people in this study and although there were many reasons for this, the main ones appear to be lack of knowledge of professionals and consequent lack of training for users.

Low tech AAC

Many of the above issues apply also to low tech AAC but in general low tech appears to be seen as more personal and less obtrusive. Six people in this study were using low tech communication successfully. One woman, who had been given a Lightwriter™ used an alphabet board with key words and phrases on the reverse side. Both she and her husband were keen to point out that they preferred using low tech as the following short conversation between them and the researcher illustrates:

Husband: I much prefer to go through here (pointing to alphabet board) and it's quicker – its definitely quicker (than high tech)

Researcher: You were saying earlier that after one or two letters you usually get the word

Husband: Yes you do – if you can't pronounce something.

Wife: It all depends what we're talking about

Husband: Yes it all depends. Yes some letters I can't understand and I've got to guess and it takes a long time obviously but most of the time we get it within seconds.

One man's wife had made him a book with key words and phrases. Another participant's grandson made a chart with key words and pictures on it. Three people preferred to use paper and pen. One man was using writing as his main means of communication but had a number of logistic difficulties which could have been overcome. For example, he was using a biro pen which was difficult for him to hold and it had a thin point which kept breaking through the paper. He used sheet after sheet of loose paper which became confused and muddled and he had nothing to lean on when writing. Perhaps if he had had something like a dry wipe board or even a firm surface to lean on with a more suitable pen and a pad of paper clipped together, communication would have been a lot easier. No one in this project reported having been offered a communication passport (Millar 1997) or any kind of symbol, picture communication book or memory book. No one had been offered the idea of optical pointing or using some kind of topic cue card to assist their communication.

As with high tech there is a serious issue about the amount of input and the amount of training people are receiving in terms of low tech AAC.

Although many people have written about their experiences using high tech, little has been written about the user's perspective of low tech. A short paper written by Brown and Murphy (2002) gives further insights into the use of AAC from the perspective of someone who has chosen to use an alphabet chart rather than high tech.

With my chart I know I have somebody's attention. Some people are better than others but most people pick it up very quick. To others that use a communication aid it probably looks slow and difficult ... sometimes it only takes a few letters for people to guess what I am saying and sometimes I have to spell out the whole sentence or word

I also feel my board gives me the more personal touch with whomever I am communicating, as they have to look at my facial expression and follow my eyes

Another definite with my board is that I can express my words in exactly the way I want and it also lets me have control of my conversation.

RELATIONSHIPS WITH PARTNERS

CHANGING ROLES

Introduction

Communication and relationships are inextricably interlinked and any change in one's role in life will have an effect on communication even when a person does not have a communication difficulty. Therefore when someone's physical and communication abilities are altered because of MND there will inevitably be an alteration in relationships. In a study carried out by Young and McNicoll (1998) of 13 people with MND most of their participants reported a dramatic shift in the focus of their lives from work to relationships with family and friends. Some continued to feel the loss of work, whereas others concluded that too much of their time and energy had been directed towards it. One of their participant's said 'Work life ... doesn't own me like it did before'. Crist-Houran (1996) argues that where people have a number of different roles such as home maker, gardener, worker etc they have a higher self esteem than someone who invests most of their commitment to one main role. This may well have implications for people with MND who may need to find and develop new roles.

Findings

Several people in the project described the pain experienced by the change in their roles in relation to their partners. Beukelman et al (2000) describes the journey that people have to go through once they have been diagnosed with motor neurone disease as a series of shifts from being an able bodied person to becoming a 'victim', to becoming a 'patient', and then working through this to become a 'recovering individual'. He describes at each stage the necessary adaptations that people have to make such as at first having to maintain a vigilance to try and hold on to their feeling of themselves as an able bodied person. When they then become a 'victim' they find they have to relinquish a lot of their independence to carers; then as they become a 'patient' they have to come to terms with the change in their own self; when they move to the next stage as a 'recovering individual', coming to terms with their illness, they then have to strive to regain their own self.

Some of the participants were finding it extremely difficult to be able to relinquish care to others. One man described very movingly his feelings when he had to allow his wife to do things for him.

Participant: I suppose I was always quite much in control, or I thought I was. Maybe that's a male thing, I don't know. I always thought I was in control with things, my driving, my ability to do things and I do get very anxious when either I can't do something or it doesn't work out for me and that even has a knock on effect when A. tries to do something for me and although she's trying her best to do it, she's actually doing it not wrongly, but not as easy as I would have done it. A simple thing is that I have to wear elastic support stockings because of the irritation on my feet and A. tries to put them on the way a lady would put on stockings. I mean they're quite stretchy and what not, so she ends up

digging her knuckles into my feet and I'm lying on my back going aaggh..

Other participants moved on to the stage where they allowed people to help them while still striving to maintain their own independence.

Participant: One of the problems that I had was trying to give directions. You're sitting (in a wheelchair) from one angle looking at something and you say it's on your left, just turn to your left, but inevitably the person turns to the right and I say no your left, not my left.

One of the big frustrations was when I was trying to give directions and I got annoyed because you were doing things completely opposite to what I wanted and the problem is that I don't know it all, I certainly don't, but I'm not one of those people who would have stood and talked about something, I'd have got right in there and found out oh gosh, I can't pull it this way, it's got to be that way and only by doing that could it work. Trying to get that through to A. and J. they were getting fed up with me trying to give directions.

Wife: No, well we couldn't have done it without you.

Participant: I found that very, very frustrating. I said to myself, what the hell am I doing here, you're not interested in what I'm telling you so I might as well be sitting at home reading a book.

Researcher: But you're laughing about it now.

Different people at these different stages need different types of support to be able to deal with each stage, particularly when someone has failing speech and may need some kind of alternative way of communicating.

The use of narratives can help people with MND and their partners make sense of what is happening to them and enables them to establish their identity and make sense of their situation (Pound et al 2002) and many of the participants in this study wanted to talk about their experiences and feelings about having MND. The participant whose views are expressed in Appendix 4. describes how he had to give up some of his previous roles and take on new ones.

STRESS

Introduction

Hogg et al (1994) comment on the stress felt by carers and suggest that carers' anxiety levels are higher the shorter the time since diagnosis.

Findings

It was noticeable that for several of the families involved in this study the partner was more distressed and needed more support than the person with MND. From comments from the participants as well as examination of the videos and field notes the following observations were made regarding relative stress between participants.

Partner most stressed	8
Person with MND most stressed	4
Neither stressed	3

It should be noted that the majority of the participants talked about '*just getting on with life*' and '*taking each day as it comes*'.

One woman with MND was keen to talk about her illness and to know as much about it as possible whereas her husband found this distressing and did not want to know what would happen in the future. At his wife's request they attended an MND conference to meet others and find out more but the husband was very unsettled by it and was clear he would not attend again.

Husband: I felt like an outsider. I would not go again

Participant: I would go- but it was a bit like 'new kids on the block' – everyone knew one another – even nodding would have helped – but their eyes just glazed over the top of us. It needed an MC to say where the coffee was and to include us more. If you've a problem with your speech you don't go forward – you want them to come to you. What I was hoping for more was just to talk to other people that have MND

Husband: You've read quite a bit – you don't want to be talking about it all the time.

Several other families were similar in that the person with MND was accepting of their situation and eager to find out more while their partner, whether it was spouse, sister, daughter, or grandchild, was much more fearful about the future. One woman was angry about the medical and social work support given to her sister whereas the woman with MND was more philosophical about her situation. One man with MND was keen to go on holiday and make the most of the time he had left but his partner was very anxious about it and reluctant to agree.

ATTITUDE

Introduction

Attitude and mood have a distinct influence on communication. Murphy (1999) carried out a study on quality of life of five people with MND and found the following:

- Some participants realised that despite their illness, there were a number of positive factors in their lives.
- Some participants had come to accept many of the changes and limitations in their life as a result of the illness.
- Relationships and support from family are crucial for people's quality of life.
- Having an interest or hobby that can be continued, even in a limited way, is important in maintaining quality of life.
- Factors relating to the issue of health do not necessarily overwhelm someone with MND.

Findings

For those people who were able to maintain a positive outlook, despite the obvious anxiety caused by their diagnosis, communication was much easier between them and their partner. Several people talked about how once they had got over the initial blow of having the diagnosis of motor neurone disease, they had in fact changed their lifestyle and had developed much more positive outlooks.

It's a very frustrating illness this – full of ups and downs but I'm determined that my fighting spirit will come back.

One participant in particular described this new outlook on life in a written account of his views (see Appendix 4).

Many of the participants in this study had made conscious positive changes to their lifestyle as a result of their illness. One family had moved to Scotland from another country in order to be closer to their daughter and grandchildren with the result that the person with MND had more stimulation, more to talk about and more reason to communicate. One woman who lived alone had organised a live-in carer which meant she had someone to talk to and to understand her needs as the illness progressed. One man taught his wife how to propagate and care for the plants in their garden. Other changes included attending a language class, producing a video of family history, learning to use a computer and going back to college. For another couple the wife had changed jobs in order that she would be with her husband more during the day. Many patients acknowledged the support from their partners with comments like "He is one in a million". These conscious choices corroborate the observations of Young and McNicoll (1998) that many people with MND have a positive attitude.

ENVIRONMENT

A number of striking factors emerged from observation of the video data relating to people's home environment.

Firstly, the simple fact of **where people sat** was extremely important in terms of the ability of people to communicate with each other. For example, some people's chairs were positioned side by side so that they could not face each other, with the result that the person with MND had to twist and strain in order to see their partner and be seen. It was noticeable that the interaction between people was less effortful and more satisfactory when they could see each other's faces more easily. Another problem for some of the communication partners was the fact that they had hearing difficulties and yet they continued to sit in a position where their deaf ear was closest to the person with MND.

Where there were 3 people involved in the conversation the positioning of chairs became even more crucial as the researcher found that she sometimes had difficulty seeing the face of the person with MND because of the layout of chairs. This invariably meant that the communication partner directed the conversation to the researcher and that the person with MND was excluded. So the simple fact of altering the position of furniture in a room could make a huge difference to communication.

One woman's chair had been positioned so that she could see into her garden and she indicated that she enjoyed watching the flowers grow and her garden was something she liked people to comment on. Also in relation to furniture, for those people who were using some form of writing to communicate or those people who were attempting to use a Lightwriter™ it was very important that they had **something to lean on**. One woman who was trying to use a Lightwriter™ got very frustrated because she was trying to balance it on her knee and as she only had the use of one hand it kept tipping over and falling on to the sofa. Had she had a firm surface on which to lean, her communication would have been easier.

Another noticeable feature was the amount of **space** in people's houses. Some houses had a lot of furniture and paraphernalia that the person with MND had to contend with. If they were ambulant there was a danger that they would fall and trip over things. However, in contrast to this, especially for people who were not ambulant, having plenty of **mementos** around their room was a valuable support to their communication. Photographs of family members, pictures of favourite holidays etc allowed people to give topic clues about what they were talking about.

Some families had given thought to **making things accessible** for the person with MND. For example, one woman's room was organised so that she could see out of her window to see people passing by, reach her telephone, cup and magazine and also pull the cord of the window blinds to keep the sun out of her eyes – all from her chair.

The amount of **light** in different people's homes was significant for communication. One house was very dark, the curtains were always partially shut, there was nothing to see out of the window and the room was generally gloomy. In contrast another family had a bright, light room with a window looking out on to the street with lots of things for the person to watch and comment on. It was also important that there was sufficient light so that both people could see each other's facial expression.

Noise was a noticeable contributing factor for people with communication difficulties, e.g. competing against a television which was constantly on or constant sound of traffic outside a window made communication more difficult.

Simple changes in the surroundings could make a huge difference to a person's ability to communicate. Several of the participants in this study had only been seen by their speech and language therapists in the clinic or hospital setting rather than in their own homes and no one reported the speech and language therapist and the occupational therapist working together to create a better communication environment.

CONCLUSIONS

This study has succeeded in fulfilling the three main aims outlined in the proposal. It has examined the communication of people with MND and their communication partners as the illness progresses. In particular it has examined their communication in the natural setting of their own homes and has determined a whole range of factors which both help and hinder communication. A video and leaflets are being produced to make these findings accessible for families, carers and professionals.

Historically, much of professional intervention with people with MND has focussed on managing medical problems which because of the nature of the illness become more and more obvious. The assumption is invariably made that quality of life for people with MND deteriorates but the findings of this study show that this does not necessarily have to be the case and that there are also positive factors and strategies available to people with MND and their families.

One of the main issues underlying this research relates to the ways in which **everyday conversation** actually works between two people. It is important that speech and language therapists understand how each couple manage their own conversation rather than assuming that there is a professional answer which will 'solve' the problem. People with motor neurone disease and their families are developing their own solutions and their own **strategies** to overcome their communication difficulty and it is very important that those working with people with MND observe and learn from these strategies and solutions which people have worked out for themselves. Communication is a **collaborative** effort and therapy needs to be provided with that in mind, not concentrating solely on the person with motor neurone disease. Any therapy must always involve the person's communication partner or partners.

From this study it appears at the moment that speech and language therapy is not always targeting the right spots. There is concern that for people with MND, speech and language therapy in some cases focuses not on speech but on swallowing difficulties. For those who are receiving therapy on communication it seems that input is often directed at assessing for dysarthria and perhaps prescribing a communication aid.

Augmentative and Alternative Communication is not working well for many people with motor neurone disease and there needs to be a much more concentrated look at what is available, how different devices work, what training can be provided for people and what support can be given.

Altering the **environment** can improve communication noticeably and there is scope for occupational therapists and speech and language therapists to work in conjunction with each other.

Finally and probably the most important point to bring to the attention of families with MND is that although speech may get worse, communication does not necessarily deteriorate. In fact for some people, because of the

nature of communication and interaction and because many people with MND work together with their communication partners more and more as the disease progresses, communication may grow stronger and social closeness become deeper as the illness progresses.

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APPENDIX 1

Classification of motor neurone disease (Riviere et al 1998)

State 1 (mild)

- Recently diagnosed
- Mild deficit in only 1 of 3 regions (speech, arm, leg)
- Functionally independent in speech, upper extremities of daily living, and ambulation

State 2 (moderate)

- Mild deficit in all 3 regions OR
- Moderate to severe deficit in 1 region, while the other 2 regions are normal or mildly affected

State 3 (severe)

- Needs assistance in 2 or 3 regions
- Speech is dysarthric and/or patient needs assistance to walk and / needs assistance with upper extremity activities of daily living

State 4 (terminal)

- Non-functional use of at least 2 regions and moderate or non-functional use of the third region

APPENDIX 2

Staging of Dysarthria (Mathy, Yorkston and Gutmann, 2000)

(To correspond with the layout of the graphs on pages 9, 10 and 11, the order of these stages has been reversed from the original)

Stage 5: No Detectable Speech Disorder

- Speech of individuals with a spinal presentation of ALS sounds normal.
- Speaker notices no change in function.
- Listeners note no changes in speaking rate, precision, or loudness.

Stage 4: Obvious Speech Disorder with Intelligible Speech

- Changes in speech are apparent.
- Changes may be more pronounced with stress or fatigue.
- Most speakers compensate unconsciously for articulatory or respiratory impairment by decreasing their speaking rate and the length of their breath groups.
- Speech at this stage remains easy to understand, although voice quality may be harsh or breathy and mild articulatory problems may be present.

Stage 3: Reduction in Speech Intelligibility

- Speaking rate, articulation, and resonance are impaired and may make speech difficult to understand, depending on the communication environment.
- Individuals can do modify their speech production (Kennedy, Strand and Yorkston, 1994).
- Helpful strategies include maintaining a slow speaking rate, conserving energy, increasing the precision of speech production, and developing strategies to resolve communication breakdowns.
- Some speakers may begin to use AAC techniques to resolve breakdowns. When speaking rate is 50% or less, AAC assessment and intervention should be initiated.

Stage 2: Natural Speech Supplemented with Augmentative Communication

- Speech must be combined with AAC approaches (Kazandjian, 1997).
- Natural speech may be limited to highly predictable messages, such as responses to questions or greetings.
- The speaker may supplement natural speech by writing key words or by pointing to the first letter of each word as he or she speaks.
- Intervention for speakers at this stage may include alphabet supplementation, changing communication modes for different situations, an alerting signal for gaining attention, augmented telephone communication, and portable writing systems (Hustad, 1999).

Stage 1: No Useful Speech

- Speakers with advanced bulbar ALS lose speech function.
- Some individuals at this stage may vocalize for emotional expression or with extreme effort but do not produce understandable speech.
- Intervention for speakers at this stage may include establishing a reliable yes-or-no system, eye-gaze systems, communication systems for speakers dependent on ventilators, and integrated, multipurpose AAC systems.

APPENDIX 3

Small Talk Coding System (King et al 1995)

1. Organisational devices

- Greetings (e.g. hi, hello, what's up)
- Closing (e.g. bye, see ya later, chow)
- Calls to attention (e.g. hey, you over there)
- Politeness markers (e.g. thanks, you're welcome, please)

2. Affirmations

- Responses that affirm or confirm the speakers' comments (e.g. correct, right, yeah, yes)

3. Negations

- Responses that deny or negate the speakers comments (e.g. no, I don't know, no way)

4. Comments

- Responses or comments about the topic at hand (e.g. geez, that must be rough, wow, no kidding, that is cute)

5. Continuants/Interjections

- Comments that keep a conversation moving (e.g. uh-huh, really, did she really, no kidding)

6. Weather Comments

- Comments about the weather (e.g. it is hot out, boy it is cold, is it sunny out)

7. Personal/Social

- Questions (e.g. how are you, what are you doing)
- Positive evaluations (e.g. I am fine)
- Negative evaluation (e.g. I don't feel good)
- Feeling/Emotions (e.g. I am sorry, Do you care)

8. Repetition Requests

- Requests from the listener to repeat the utterance (e.g. huh, what)

APPENDIX 4

Never do today what can be done tomorrow By Jim Grant

At 9.30 am on Monday 23rd of January 2000. I was called in to the consultant's office. I was there to be told the results of some tests that had been carried out in December the previous year. I sat quite calmly while the consultant looked through his notes. He looked up at me and told me that I had "Primary lateral Sclerosis" "Don't worry about the long name" he said, "What the hell is that" I asked, "It's an early form of Motor Neuron Disease" he said. I had heard of MND, but what it actually was, I wasn't quite sure. He explained how everyone is different, and that it affects different people in different ways. That was to make me feel better I thought.

Once I had broken the news to my wife and family, there was nothing else to do but accept it, because within myself I felt fine, a wee bit slower than normal but still able to walk about, I could eat, drink, talk, although I had noticed that my speech was starting to go slower. I was sent to speech therapy, that really helped me a lot.

I had to give up work, but the thing that hurt me most was that I had to sell my BMW 1000 cc RS motorbike, however it had to be done. So what on earth was I going to do with myself? My wife works full time, so I decided that I had to become a cook and bottle washer. It was quite easy for me to become domesticated, as I had spent twenty-eight and a half years of my life working in a fire station.

So I made out a daily/weekly timetable of things that had to be done around the house. We live in a three bedroom, livingroom, kitchen, and bathroom semi-detached house. I Hoover the livingroom and clean the kitchen daily, and one of the other rooms are done on different days, then the main meal of the day is prepared and on the table for the wife coming home from work. The most important things to remember is that if you feel a wee bit wabit is to sit down take five or make yourself a cuppa. I feel that it is just as important to get daily exercise, so after a plate of soup at about lunch time, I'll go for a wee walk maybe I'll sneak in for a quick pint, have a look in the local shops, then walk back home, taking my own time.

After a while, you get used to your new routine and you wonder how everyone else in the outside world is so stressed out, the answer is that everything has to be done yesterday. Well writing this has put me behind in my housework, what the heck does it matter **I'll do it tomorrow.**

APPENDIX 5



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TALKING TOGETHER: Communication Strategies of People with Motor Neurone Disease and their Partners

Information Sheet

I am inviting you to participate in a research project that I believe to be of potential importance. However, before you decide whether or not you wish to participate, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the following information. Please read it carefully and be sure to ask any questions you have, and, if you want, discuss it with outsiders. I will do my best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

My name is Joan Murphy and I am a Speech and Language Therapist in Stirling. I have received funding from the Scottish MND Association and the National Lottery Charities Board to carry out the above study.

The main aims of this project will be:

1. to identify factors that help and hindering effective communication
2. to examine the changing patterns of communication as MND progresses
3. to develop and produce materials on the basis of knowledge obtained through aims one and two in order to enable people with MND and their communication partners to communicate more effectively.

The ultimate purpose of the project is to contribute to the improvement of quality of life for people with motor neurone disease and their families by studying their communication strategies. I view communication as a

collaborative effort between a person with a communication difficulty and his or her communication partner. As people with motor neurone disease may be faced with a gradual deterioration of communication, it is essential that both communication partners adapt to this changing situation effectively by acquiring new communication strategies.

Twenty people with MND are being invited to participate.

I will visit each person on 6 or 7 occasions for approximately one and a half hours each time. On each occasion I would make 2 short videos of you chatting a) with your husband/ wife/ partner and b) with myself. I would also talk to you both about your views about your communication and how it affects your lives.

The data collected will enable me to see the problems of communication from different perspectives and to utilise this knowledge to improve the quality of life of people with motor neurone disease and their families.

My previous work emphasised that an essential part of research is feedback to the participants and I believe that, as well as producing training materials and reports, the actual process of research should provide direct benefits to participants. Throughout the study immediate feedback would be available to you and you will receive a copy of the final report.

All data obtained will be treated as confidential and stored in a locked filing cabinet. Only the researchers will have access to the data. Your GP and Speech and Language Therapist (if you have one) will be informed that you are taking part and will receive a copy of the final report should they wish. Please feel free to discuss the study with friends, relatives, your GP or Speech and Language Therapist before deciding whether to take part.

Participation in this study is entirely voluntary and you are free to refuse to take part or withdraw at any time without having to give a reason and without this affecting your future medical care or the relationship with medical staff looking after you.

The Medical Research Ethics Committee that has responsibility for scrutinising all proposals for medical research on humans in xxxxx has examined the proposal and has raised no objections on Medical Research Ethics.

If you are interested in being involved, please return the attached sheet in the SAE and I will then visit you at home to explain the study to you in more detail and answer any questions.

Joan Murphy
Research Speech and Language Therapist
Psychology Department
University of Stirling
Tel: 01786 467645

APPENDIX 6

Conference Presentations

Growing Older with a Severe Communication Impairment, Communication Matters Regional AAC Study Day, London, 2 February 2001

Growing Older with a Severe Communication Impairment, Communication Matters Regional AAC Study Day, Perth, Scotland, 8 February 2001

MND: AAC and Everyday Conversation, Communication Matters Symposium, Lancaster, September 2001

Communication Issues in MND, Scottish MND Study Day, Dundee, 11 June 2002

Communication Issues in MND, Lothian Speech and Language Therapy In-service, Edinburgh, 5 September 2002

Communication Strategies of families with MND, poster presentation at 13th International Symposium on ALS/MND, Melbourne, Australia 17-19 November 2002

MND: Current research, Disability Services Colac, Victoria, Australia, 28 March 2003

MND: Current research, Disability Services Wodonga, Victoria, Australia, 1 April 2003

Real Life Communication of Families with Motor Neurone Disease: a Challenge to Speech and Language Therapists, presentation accepted for CPLOL 5th European Congress, Edinburgh 5,6,7 September 2003

Communication Issues for Families with Motor Neurone Disease, abstract submitted to Communication Matters National Symposium, University of Lancaster 14-16 September 2003

Communication Issues for Families with Motor Neurone Disease, abstract submitted to the 14th International Symposium on ALS/MND in Milan, Italy, 17-19 November 2003

APPENDIX 7

ABOUT THE AUTHOR

Joan Murphy is a Specialist Speech and Language Therapist who works as lead researcher with the AAC Research Unit at the University of Stirling. (AAC stands for Augmentative and Alternative Communication). Since 1989 she has worked on a number of research projects studying the communication of people with impaired speech and their communication partners.

Joan is also employed by Forth Valley Primary Care Trust and works part time with adults with acquired neurological conditions as Speech and Language Therapist with a multidisciplinary rehabilitation team.

She has developed a series of training packages with accompanying videos resulting from the findings of her research. The training packages are all based on the philosophy that people with communication difficulties should play an active part in training others how to communicate with them and should have a determining role in their communication intervention.

Joan has presented papers at national and international level and has published a number of research papers.

Further information about the work of the AAC Research Unit is available on the website:

www.aacscotland.com