Communication Changes and Challenges in ALS/MND

Modifications et défis en matière de communication dans le contexte de la SLA / MMN

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Abstract

The ability to communicate effectively is a crucial factor in both psycho-social and physical adaptation to the changes which occur as ALS/MND progresses. At a time when communication might offer the most effective means to reach equilibrium it is often not readily available. As ALS/MND advances, many individuals experience progressive erosion of physical access to communication with related problems of altered communication style.

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L'aptitude à communiquer efficacement est un facteur décisif de l'adaptation psychosociale et physique aux changements qui surviennent au fil de l'évolution de la SLA / MMN. Lorsque la communication pourrait constituer le moyen le plus efficace de parvenir à un équilibre, elle est souvent difficile à établir. Au cours de l'évolution de la SLA / MMN, de nombreuses personnes subissent une érosion progressive de l'accès physique à la communication liée à des problèmes de modification du style de communication.

> "It wouldn't be so bad if my best ideas didn't invariably materialize when I'm trapped in bed. There seems to be a predictable, almost uncanny relationship between the poignancy of my thoughts and the distance to my computer. If I didn't know better, I'd swear my mind had a mind of its own. Often I struggle for hours, even days, trying to figure out the best way to make a particular point or get some critical message across. Then the second my head hits the pillow—eureka! But until I'm within pecking distance, all I can do is file the idea away with all the other eurekas and hope it's still there when I need it. As time has gone by, my idea inventory has built to a point where the only way I can remember something new is to forget something old.....
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> To make matters worse, as time goes by, the more I type, the slower and less accurate I become.... Every last letter, space, shift and return means bobbing my head up and down, or more accurately, down and up. Not surprisingly, all this bobbing brings on neck spasms which repeatedly cause me to miss the keys I'm aiming for.... Conservatively, not counting rewrites and editing, I figure I've got at least half a million bobs invested so far, and the closer I get to the end of the book, the more weak my neck becomes. (Kaye, 1993)

Among clients and families attending an ALS clinic, there is an expectation that with the provision of a communication aid, communication needs will be met. There is a further assumption that, if the system involves a computer, communication problems will be solved. Dennis Kaye's words clearly demonstrate that this is not the case.

In most of Europe, the term motor neuron disease (MND) is used to refer to a group of diseases in which motor neurons in the spinal cord and brain are progressively destroyed, resulting in weakness and wasting of muscles. Three main clinical variants are usually identified: progressive (spinal) muscular atrophy, progressive bulbar palsy and amyotrophic lateral sclerosis (ALS). In North America, the terms motor neuron disease and amyotrophic lateral sclerosis have largely become synonymous and frequently are used interchangeably. The incidence of ALS/MND is estimated at 1 - 1.8: 100,000 population with an average survival period of 2-5 years. It occurs primarily in the sixth decade of life, with more men affected than women, 1.5 to 1 (Kurtzke, 1982). Bulbar involvement results in progressive dysarthria and eventual loss of oral communication. In progressive bulbar palsy, limbs are not involved and writing is preserved. In ALS, functional quadriplegia accompanies speech loss.

Provision of communication systems and strategies to individuals with ALS/MND differs in one very important

dimension from service delivery to other AAC populations. As a group in the prime of life, often characterized as high achievers and with shortened life expectancy, they have so much to say and so little time left in which to say it.

The key management issue is frequently not device selection, access/interface or vocabulary selection but forced adaptation to altered communication style, loss of spontaneity and potential loss of control.

Communication issues too are different, with greater emphasis upon abstract, complex communication functions rather than concrete needs. The ability to communicate effectively is a crucial factor in adapting to the changes which occur as ALS/MND progresses. In its simplest form, communication is having something to say and the means to say it. The something to say, or communication use, ranges from the relatively straightforward functions of choice-making and decision-making to more complex functions where communication is the means to be an active participant in living. It is the principal mechanism for coping and adapting, the means to confirm identity and the primary learning tool to promote growth and change. Perhaps most importantly, communication is the mechanism for supporting and nurturing relationships.

In considering communication aids prescription, the means to say things tends to focus on the physical aspects of access both to the system and to the language of use. However, communication readiness is the key to successful aid use. Communication readiness requires emotional, cognitive and spiritual readiness; readiness to conclude unfinished business, to build bridges, mend fences, or perhaps break them.

At a time when communication is needed most, it is often not readily available. Access problems are very familiar to prescribers of communication aids, especially where hand function is involved. Effort required to access a system, the energy investment in altered access and the development or acquisition of secondary problems such as neck fatigue are familiar areas to many.

Less familiar and often of greater importance are problems of altered communication style. First among these problems is loss of immediacy or spontaneity, both to initiate and respond. This is frequently described by patients/clients as a "time warp". Other problems arise around lost subtleties in speaking. Voice synthesizers simply do not have the capability of expressing degrees of emotion, sarcasm and humour in a satisfactory way. The result of altered communication style is the development of an unequal communication partnership which radically changes the dynamics of personal relationships.

Solutions to these problems fall into two major categories: the technical and the psycho-social. Technical solutions include acceleration techniques and user strategies such as telegrammatic communication. Effective training is also a factor in meeting technical requirements. Energy conservation is of particular importance and may be a driving force in access mode selection. Achieving a balance/blend of high tech, light tech options also is extremely important. However, of greater importance, are the psycho-social solutions, beginning with recognition of the problems and followed by early prediction and preparation for change in the context of progressive loss.

Clients must learn to adjust priorities for both speech and other activities. They must learn adjusted rules for conversational control and language pragmatics in the context of lost spontaneity. Above all, they must learn to preserve and cherish humour.

> Through it all, I've been haunted by the thought that I might get to the last word, of the last sentence, on the very last page, and not have quite enough strength to fin
> (Kaye, 1993)

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