mnda
motor neurone disease association

international symposium on ALS/MND

International Alliance of
ALS/MND Associations

Allied Professionals' Forum

10 December 2010

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PROGRAMME

8.30	Welcome & Introduction		
8.40	**Palliative Care in an ALS Clinic? Absolutely!**	**B Segal**	**USA**
9.00	**The Impact of Equipment on Relationships ~ Lessons for Practice.**	**B Taylor**	**UK**
9.20	**The Emerging American Style of Incorporating Palliative Care into ALS/MND**	**K Cross**	**USA**
9.40	**Working in Partnership to Maintain Quality of Life in a Rural Community – Mobility and Environmental Controls**	**K Thomas**	**UK**
10.00	**Resolving Pain, Contracture and Dizziness: A Prescription for Good Quality of Life for People Diagnosed with ALS**	**L Cates**	**USA**
10.20 – 10.50	Refreshment Break		
10.50	**Yoga and ALS: It's All in the Breathing**	**R Rhodes**	**USA**
11.10	**Patients with Cognitive Change – the Challenge for Families and Professionals**	**D Oliver**	**UK**
11.30	**When Someone Close has MND**	**S Schillerstrom**	**UK**
11.50	**A Study Comparing 3 Low Tech Communication Methods for People with Only Eye Movement**	**A Roman**	**USA**
12.10 – 13.30	Lunch		
13.30	**Two Heads Are Better Than One – A Team Approach**	**L Boyle**	**USA**
13.50	**To Sleep, Perchance to Dream…… Should Sleep Studies be Included in Clinical Management of ALS?**	**L Guion**	**USA**
14.10	**Improving Communication Between the ALS Center and Caregivers in the Community.**	**S Feldman**	**USA**
14.30	**Withdrawal of Non-invasive Ventilation – How Can We Help All Involved?**	**D Oliver**	**UK**

14.50	**Living Better for Longer: Facilitating a Coordinated Multidisciplinary approach to MND through ‘one stop shop’ online resources**	**C Birks**	**Australia**
15.10 – 15.40	Refreshment Break		
15.40	**The Motor Neurone Disease Year of Care**	**J Connell**	**UK**
16.00	**The Oxford ALS Nutrition Clinic: Improving the enteral nutrition pathway for patients and carers**	**M Lord**	**UK**
16.20	**Take a Break from ALS/MND**	**R Harris**	**Australia**
16.40	Summary and Close		

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ALLIED PROFESSIONALS' FORUM
JW Marriot Grande Lakes, Orlando
10 December 2010

SPEAKER: BARBARA SEGAL MS, RN

BIOGRAPHY:

-1971 graduate of the University of PA School of Nursing
.
-Earned Bachelors' degree from Boston University in 1978

-Earned Masters' degree from Boston University in 1982-
graduated as a Clinical Nurse Specialist in Oncology/Rehabilitation

-Director of several hospice programs in Boston area until our move to Vermont in 1987..

(1987- 1998) Director of the Hospice of the Champlain Valley. Was instrumental in merging the Vermont Respite House with the VNA's Hospice program in 1995.

(1998- present) Clinical Nurse Specialist in Palliative Care at Fletcher Allen Health Care. Started Palliative Care Service with Dr. Zail Berry.

Adjunct Professor at the University of Vermont School of Nursing

Received the FAHC Paul Horton Award for Nursing Excellence in 2000, the FAHC Physician's Choice Award in 2002, The FAHC Spirit Award in 2006.

Received National Palliative Care and Hospice Certification in 2001, 2006.

Has given hundreds of lectures/workshops throughout New England
.

AUTHOR: BARBARA SEGAL MS, RN

TITLE OF PRESENTATION: PALLIATIVE CARE IN AN ALS CLINIC? ABSOLUTELY!

ABSTRACT:

Background:

The diagnosis of ALS can be devastating because it is progressive, relentlessly disabling and ultimately terminal. Having a palliative care clinician as part of the ALS multidisciplinary care team can make a significant difference for patients and their families. The gentle introduction of the palliative care philosophy could and should begin at the initial clinic visit as patients and their families are struggling with the new reality of their illness. The beginning of establishing goals of care and treatment preferences as well as identifying concerns about fearful symptoms and potential frightening scenarios can be explored before a crisis occurs. Serving as a bridge between the clinic and important community services can be facilitated. The introduction of palliative care services in the early stages of the disease can influence the quality of the end of life experience.

Objective:

To describe the evolving role of the palliative care clinician in an ALS multidisciplinary clinic setting and to explore the effect of the role on the team as well as on patient/family interaction.

Programme description:

This program will describe the evolving role and its effects (both the positive aspects and the pitfalls) on patient interactions. Case studies will be presented that illustrate these aspects and how the role is developing with each new experience. It will also explore the paradigm shift that has occurred with the inclusion of a new role on an established multidisciplinary team, a role which more directly emphasizes end of life issues.

Clinical outcomes

1) **The participant will be able to describe the concept of palliative care and its tenets.**
2) **The participant will understand the evolving role of the palliative care nurse in the ALS multidisciplinary clinic and how to apply that knowledge to his/her respective settings.**
3) **The participant will be able to describe the significance of introducing palliative care early in the diagnosis of ALS.**

Recommendations to the field

The introduction of the concept of palliative care early after a diagnosis of ALS can affect the quality of the end of life experience. Although palliative care is generally a topic that is not initially welcomed by patients and their families, it can be a positive intervention if done in a gentle manner, with a focus on the hope that palliative care can bring to a difficult situation. Including a palliative care clinician in the clinic setting is something to contemplate in order to help patients and team members deal more effectively with the terminal nature of the disease.

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SPEAKER: BRIDGET TAYLOR

BIOGRAPHY:

Having completed her Master's degree in Medical Anthropology, Bridget is currently undertaking her PhD. This research combines her two areas of specialty; sexuality and life-limiting illness. She has conducted interviews with both patients and partners of patients living with MND, and is also interviewing patients and partners of patients with terminal cancer

Bridget has a background in community nursing and is currently working as a palliative care nurse at Sir Michael Sobell House, Hospice, Oxford. She is also a senior lecturer in both end of life care and sexuality at Oxford Brookes University.

AUTHOR: BRIDGET TAYLOR

TITLE OF PRESENTATION: THE IMPACT OF EQUIPMENT ON RELATIONSHIPS ~ LESSONS FOR PRACTICE.

ABSTRACT:

Background:

There are a number of studies that consider the impact of equipment on quality of life, though the experiences of people living with MND / ALS or the impact upon relationships is not considered (1,2). This doctoral research study explores the lived experiences of patients and partners of patients living with a life-limiting illness, focussing upon their experiences of sexuality and intimacy. This paper presents one of the findings, the impact of equipment on the expression of sexuality and intimacy for those living with MND.

Objective

There are a number of studies that consider the impact of equipment on quality of life, though the experiences of people living with MND / ALS or the impact upon relationships is not considered (1,2). This doctoral research study explores the lived experiences of patients and partners of patients living with a life-limiting illness, focussing upon their experiences of sexuality and intimacy. This paper presents one of the findings, the impact of equipment on the expression of sexuality and intimacy for those living with MND.

Programme description

One-to-one conversational interviews were conducted with 13 patients and 10 partners of patients at different stages along the MND disease trajectory. Each person was interviewed twice and couples were interviewed separately.

Clinical outcomes

Whilst the equipment that allied healthcare professionals provide has a positive impact on many aspects of quality of life, many types of equipment impede communication and connection between people with MND / ALS and their partners. Participants have described the ways that different equipment restricts verbal and physical intimacy and impacts upon peoples' expression of sexuality within their relationships. MND robs people of movement, and the equipment we provide robs people of intimacy and touch. Some people are able to adapt and change, whilst others describe significant loss.

Recommendations to the field

Allied health professionals who support holistic care and promote quality of life have a role in discussing these issues when introducing equipment. The Ex-PLISSIT model (3) is used to describe a range of ways that practitioners can broach these issues with clients and their partners in their day-to-day practice. Practical suggestions are given for ways to address this important aspect of peoples' relationships and to minimise their loss.

References

1. **Sainty M, Lambkin C and Maile L (2009) 'I feel so much safer': unravelling community equipment outcomes, *British Journal of Occupational Therapy,* 72(11), 499-506.**
2. **Social Policy Research Unit, University of York (2000) Surveying outcomes of equipment and adaptations. Available at: http://www.york.ac.uk/inst/spru/pubs/rworks/nov2000outc6.pdf Accessed on 21st March 2010.**
3. **Davis S and Taylor B (2006) From PLISSIT to Ex-PLISSIT, In: Davis S (Ed.), *Rehabilitation: the use of Theories and Models in Practice,* Edinburgh: Churchill Livingstone, Ch.6.**

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SPEAKER: DR KAREN CROSS

BIOGRAPHY:

Dr. Karen Cross is a specialist in Hospice and Palliative Medicine. After serving as the medical director of a small hospice in Oregon, she moved to Las Vegas and worked as the VP of Medical Services for Nathan Adelson Hospice, the largest hospice in the state of Nevada. While in Las Vegas, she was the first physician to be board certified by the American Board of Hospice and Palliative Medicine in the state of Nevada and worked with the Nevada Cancer Institute to develop their Palliative Care service department. Four years ago she moved to North Carolina and is an Associate Medical Director with the Hospice and Palliative Carecenter in Winston-Salem where she works with the Baptist Medical Center ALS Clinic.

Dr. Cross served as a member of the Board of Directors of the American Academy of Hospice & Palliative Medicine for 8 years. She is active with her organization’s Community Partnership Program working to improve the quality of life of patients and their families with serious illness She teaches students, residents, and fellows with the Wake Forest Medical School and lectures to community groups regarding hospice and palliative medicine. She has lectured nationally on a variety of end-of-life topics.

AUTHOR: DR KAREN CROSS

TITLE OF PRESENTATION: THE EMERGING AMERICAN STYLE OF INCORPORATING PALLIATIVE CARE INTO ALS/MND

ABSTRACT:

Background:

ALS/MND is a disease with high symptom burden and limited treatment options, which leads to severe physical, psychological, and social suffering for patients, their families, and caregivers. The United States been slow to accept the partnership of palliative medicine and traditional curative therapy, but ALS/MND has been one arena where progress has been made.

The Wake Forest Baptist Medical Center ALS/MND program sought support for palliative approaches to care, and found it in hospice and palliative medicine. The program has included a palliative medicine physician with a hospice background on the team for the past 2 years. This position has help the ALS/NMD team have a better understanding of the palliative philosophy and sensitivity to patients and families as human beings rather than diagnoses as well as access to sophisticated symptom control now standard in the palliative care field. This partnership has also allowed the greater continuity of care and for the ALS/NMD clinic team to remain connected to the patient and family throughout the final phase of their life with the transition to hospice services.

Objective

At the completion of this session, the attendee will understand the palliative treatment of common ALS/MND symptoms, be able to identify both the challenges and benefit of incorporating palliative medicine into the interdisciplinary team, and be able to determine when hospice services are appropriate for the patient and the services that will be provided

Programme description

This session will describe how a U.S. ALS/MND center has incorporated palliative medicine into its program of care. We will discuss responses to specific patient and family needs and some of the regulatory, financial, and psychological/social challenges. We will discuss control of common symptoms for improved quality of life. We will also discuss patient and family goals of care and Advance Directives. We will discuss a variety of case studies to elaborate on these topics. Reports from home visits provide extra depth for ALS/MND team decisions making

Clinical outcomes

Attendees will learn the steps involved in incorporating palliative medicine into the ALS/MND interdisciplinary team in order to improve patient's and their families' quality of life.

Recommendations to the field

Incorporating a palliative component into the ALS/MND interdisciplinary team will improve the quality of life of the patients, their families and caregivers by linking ALS/MND patients to expertise and resources of palliative care now available from hospice and palliative care physicians.

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SPEAKER: KEVIN THOMAS, REGIONAL CARE DEVELOPMENT ADVISOR (NORTH WALES), MOTOR NEURONE DISEASE ASSOCIATION

BIOGRAPHY:

Kevin Thomas is a Qualified Social Worker with several years experience of working in the statutory sector as a social worker, team leader and operational manager of a joint health and social services learning disability and physical disability service.

Joined the MND Association four years ago. Specialises in the devolved legislative powers in health and social care in Wales and is the Chairperson of The Wales Neurological Alliance representing over 20 Neurological organisations.

AUTHOR: KEVIN THOMAS

TITLE OF PRESENTATION: FAST TRACK ASSESSMENT AND PARTNERSHIP WORKING TO IMPROVE MOBILITY SERVICES FOR PEOPLE LIVING WITH MND IN A RURAL AREA.

ABSTRACT:

Background:

North Wales is a large, mainly rural geographic area with a dispersed population of people living with MND. The statutory Wheelchair Service in North Wales is provided through the NHS Artificial Limb and Appliances Centre (ALAC) linked to the Wrexham Maelor Hospital. Historically, people living with MND in North Wales have often experienced unacceptable delays when seeking access to wheelchairs from the National Health Service (NHS). This was the situation in North Wales until a unique partnership evolved between the statutory services, the Association and a private mobility aids supplier.

Objective

To establish a fast track assessment service which could meet current service needs, anticipate and plan future need through a range of statutory and non –statutory services, and allow the person with MND to benefit from mobility solutions in a seamless manner..

Programme description

A fast track posture and mobility referral and assessment system which identifies current need and provision from statutory sources if appropriate. Assessments that identified non-statutory solutions are referred to the MND Association for provision of non-specialist scooters within a partnership scheme managed on behalf of the MND Association by a private mobility company. The person with MND is actively and continually monitored by the statutory wheelchair service and service adjustments made accordingly.

Clinical outcomes

- **Enables person to access equipment to meet current mobility needs to be able to get on with living**
- **Timely and progressive provision of equipment as disease progresses**
- **Allows person with MND to adjust to the idea of using a powered chair through use of scooter initially**
- **Provides timely information for future practical preparations for an NHS powered chair to be used**
- **Partnership between statutory, voluntary and private sector ensures that service provision is seamless**
- **Early information enables informed choices regarding vehicle considerations for transport of powered chair**
- **Same Occupational Therapist involved from ALAC for both wheelchair and environmental controls systems**
- **Experience of cases by ALAC OT can aid other professionals in community on planning for future needs.**

Recommendations to the field

Anticipatory service planning needs to be based around early referral ahead of need. This enables professional to work at the pace of the person with MND by planning ahead. Multidisciplinary working ensures that deterioration in mobility is monitored and enables referral to other disciplines in a timely manner. Holistic solutions require partnerships across sectors.

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SPEAKER: **RUTH ANN RHODES RN**

BIOGRAPHY: UNAVAILABLE

AUTHOR: RUTH ANN RHODES RN

TITLE OF PRESENTATION: YOGA AND ALS: IT’S ALL IN THE BREATHING.

ABSTRACT:

Background: **Respiratory failure is the most common cause of death in ALS.Most ALS patients experience a decline of respiratory function over the course of their illness. Some patients initially present in clinic with full vital capacities well over 120% of predicted. These patients are trombone players, swimmers, runners, and singers who have developed increased lung capacity through their hobbies. Some of these patients use yoga breathing techniques to maintain exceptional lung function.**

Objective: **To promote yoga breathing techniques in the clinic setting by teaching patients yoga breathing to reduce stress, promote relaxation and to maximize lung function.**

Programme description: **This will be an interactive workshop promoting yoga breathing in a clinic setting. Working with a therapeutic yoga instructor, we will develop a teaching plan, focusing on 4 different breathing patterns which can be adapted to individual patient needs. The instructor will work with clinic providers to develop the lesson plan and teaching skills required to instruct patients and caregivers in the breathing techniques. The instructor will supervise the trainees and be available for consultation to develop adaptations for individual patients.**
We will use the McGill Quality of Life Questionnaire to measure stress levels and quality of life (QOL).
We will measure O2 saturations, FVCs, Blood Pressure, Pulse and Respirations with each session and follow patients over the next year.

Outcomes:

1. **Both patients and caregivers will be able to demonstrate 4 yoga breathing techniques.**
2. **Stress and QOL levels will be measured by the McGill Quality of life Questionnaire**
3. **FVCs and O2 saturations will be measured, observing for length of time at optimal respiratory function.**

Recommendations to the field: **Promoting yoga breathing in clinic can be an easy, low tech approach to improve or at least maintain respiratory function at optimal levels for a longer period of time. Yoga breathing may reduce stress and promote relaxation for both patient and caregiver, thereby improving quality of life. This may ultimately improve longevity.**
A teaching guide and lesson plan will be provided as a hand out.

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SPEAKER: DR DAVID OLIVER

BIOGRAPHY:

Dr David Oliver is a Medical Director and Consultant Physician in Palliative Medicine at the Wisdom Hospice in Rochester, Kent and Honorary Senior Lecturer in Palliative Medicine at the centre for Professional Practice at the University of Kent, where he is Director of Studies for the MSc in Supportive and Palliative care. He is a visiting Professor at the Scholl of Medicine at the University of Zagreb in Croatia.

He qualified at University College Hospital, London and then trained as a General Practitioner. He was Registrar and Senior Registrar at Christopher's Hospice London and he was appointed to this present post in 1984.

He has lectured widely in the UK and in other countries, including Croatia, Poland, USA, Australia, South Africa, Japan, Netherlands, Portugal, Italy and New Zealand. He was awarded the Humanitarian Award of the International Alliance of ALS/MND Associations in 2003, in recognition of his work.

He has written widely on the palliative care and symptom control of patients with motor neurone disease, including "Motor Neurone Disease – a family affair" and as principal editor of Palliative Care of Amyotrophic Lateral Sclerosis – from diagnosis to bereavement 2nd edition, published in 2006. He is a co-editor of Palliative Care in Neurology published in 2004.

AUTHOR: DR DAVID OLIVER

TITLE OF PRESENTATION: PATIENTS WITH COGNITIVE CHANGE – THE CHALLENGE FOR FAMILIES AND PROFESSIONALS

ABSTRACT:

Background:

There is increasing awareness of cognitive change in patients with MND/ALS. The results from research suggest that over 65% of people with MND develop evidence of frontal lobe dysfunction, although the clinical importance of these changes is not clearly known. When patients show evidence of cognitive change this presents a challenge for all involved, as decision making becomes more difficult and there can be increasing challenges in care.

Objective

A retrospective review of patients under the care of the Medway and Swale MND Clinical team has looked at the incidence and issues involved in the care of patients with significant frontal lobe dysfunction and cognitive change.

Programme description

The Medway and Swale MND Clinical team are involve in the majority of people with MND/ ALS in the area – with a population of 360,000 and at any one time up to 22 patients with MND/ALS are involved. The Team are closely involved in care at home, in hospital and the hospice.

Clinical outcomes

The care of this group of patients presents challenges to families and the health and social care professionals:

- **In helping patients make decisions about interventions and care management, when there is evidence that these decisions are difficult for them**
- **In helping families and carers – both family and professionals – to appreciate the issues involved with cognitive change and to adjust the care provided for them**
- **In caring for someone who lacks capacity as they deteriorate and may require close observation and care**
- **In instituting restriction of the person – either physically or with medication – when they become more impaired and are a risk to themselves and / or others**

Recommendations to the field

There is a need for close multidisciplinary team working to ensure that all involved in care are able to appreciate the issues involved in the care of a patient with cognitive change. Decision making becomes more complex and understanding of the issues is essential. The support of all involved – patient, family and carers and professionals - is important so that all can cope with these difficult ethical and personal issues

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SPEAKER: SHARON SCHILLERSTROM, CARE INFORMATION DEVELOPMENT MANAGER, MOTOR NEURONE DISEASE (MND) ASSOCIATION ENGLAND, WALES AND NORTHERN IRELAND.

BIOGRAPHY:

Sharon reviews and develops MND Association care literature for people affected by MND, their carers and families. Sharon is regularly in touch with people living with MND, their families and carers as their expertise is crucial to the successful development of care literature.

Sharon currently sits on the Board of Trustees for Northamptonshire Carers (this is a voluntary position) which is affiliated to the Princess Royal Trust for Carers.

AUTHOR: SHARON SCHILLERSTROM, CARE INFORMATION DEVELOPMENT MANAGER, MOTOR NEURONE DISEASE (MND) ASSOCIATION ENGLAND, WALES AND NORTHERN IRELAND

TITLE OF PRESENTATION: WHEN SOMEONE CLOSE HAS MND

ABSTRACT:

Background: MND is a distressing disease for children to grasp. They may feel inquisitive, but fearful of asking questions that might upset anyone. When reviewing MND Association literature for children, we wanted to make sure new literature reflected the needs of the child.

Objective: To create a resource to support children from 4 -10 years affected by MND in their family. Acknowledging that 'one size doesn't fit all', we wanted a resource that could be adapted and personalised to meet individual needs. We also recognised the importance of developing information for adults about how they can best support a child when an adult is seriously ill.

Programme description: A powerpoint presentation demonstrating the importance of informing and involving children in discussions when someone close to them has MND, drawing on evidence based research and best practice. We also include the benefits of working in partnership with other organisations.

Clinical outcomes: The scale and quality of positive feedback received via evaluation forms since the launch of the workbook from adults and children affected by MND provides anecdotal evidence of how valuable the resource is, including in families where denial is present. A national neurological Charity in the UK and a member organisation of the International Alliance has also expressed interest in developing something similar for their service users.

Recommendations to the field: Presenting information about MND for children in this format creates opportunities for children to ask questions and take part in important family discussions about things that really matter, one step at a time. Thus enabling children to identify and develop their own coping strategies.

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SPEAKER: AMY ROMAN, M.S., CCC-SLP, AUGMENTATIVE COMMUNICATION SPECIALIST

BIOGRAPHY:

Amy Roman is the Speech Language Pathologist and Augmentative Alternative Communication (AAC) Specialist at the Forbes Norris ALS Research Center in San Francisco. During her eleven years at the Center, she has provided solutions to patients seeking help with swallowing, communication, and computer access. This year the Center was awarded "Program of the Year" by the California Speech Language & Hearing Association.

Ms. Roman also runs an over 1,000 piece communication and computer access equipment Evaluation Center/Lending Library which provides assessments, training, trials and loans.

Ms. Roman created *AlphaCore*$^{\copyright}$*;* a page-set available on DynaVox speech generating devices, to meet the specific communication and telecommunication needs of patients with ALS.

Her publications include the book chapter "Speech, Communication and Computer Access" in *Amyotrophic Lateral Sclerosis* published by the American Academy of Neurology & Demos Publishing (2005), an article entitled "Cognitive and Behavioural Impairments in People with ALS and Their Implications for Communication & AAC Use" in *Perspectives on AAC,* December 2006 (Co-Authored with Neurophysiologist Susan Woolley). Ms. Roman was also a contributing author to *MDA/ALS Caregiver's Guide,* MDA ALS Division Publishing, 2008 and *Communication and ALS,* a publication by the National ALS Association (2004).

Ms. Roman presents ongoing workshops around the United States for speech pathologists and other care providers entitled, "AAC & ALS" and has lectured at a variety of conference and universities on topics regarding technology for people with disabilities.

Ms. Roman's "AAC" blog for patients with ALS, their caregivers, SLPs and health professionals is available at VoiceForLiving.Com

AUTHOR: AMY ROMAN, M.S., CCC-SLP, AUGMENTATIVE COMMUNICATION SPECIALIST

TITLE OF PRESENTATION: A STUDY COMPARING 3 LOW TECH COMMUNICATION METHODS FOR PEOPLE WITH ONLY EYE MOVEMENTS

ABSTRACT:

Background

This presentation will review the results of a study comparing three eye movement accessible, low-tech augmentative alternative communication (AAC) methods (E-tran, partner-assisted scanning and EyeLink) used by people with ALS. These methods allow PALS to generate a spontaneous and novel message since they allow the PALS to spell. Spelling as opposed to responding to a partner's yes/no questions or choosing from a list of pre-determined phrases or requests permits a PALS to communicate unlimited information. Eyeball accessible methods are very important since frequently volitional eye movement is preserved in end stage PALS who are often paralyzed and unable to speak.

There is a lack of evidence guiding the determination of low tech AAC methods to be utilized for literate individuals who are limited to eye movement access. Many SLPs are unaware of the variety of options for this population, lack knowledge of how to implement the methods or are implementing a method without evidence backed rationale for the method selected.

Objectives

1: Review the results of a national survey monkey describing SLP's familiarity with and frequency of selection of each of three eye movement accessible, low-tech AAC methods.

2: Compare the three eye movement accessible AAC methods in terms of average seconds per selection, patient and caregiver perception, length of time required to learn each method and relationship to patient performance on the ALS Cognitive Behavior Screen.

3. Provide a set of instructions to teach these three eye movement accessible, low-tech AAC methods.

Programme Descriptions

This presentation will review the results of a cross-over study to compare three low-tech, eye movement accessible AAC methods. The first part of the study focused on an internet survey assessing current practice of SLPs. The second part of the study consisted of five, one hour training sessions where PALS and their partners learned all three methods.

Clinical Outcomes

This study is ongoing, but will be completed by December of 2010. So far, it appears that E-tran and Eye-Link are faster communication methods than partner-assisted scanning. E-tran appears to be the hardest method to learn, but the most efficient in the end.

Recommendations To The Field

The results of this study will provide an evidence base to guide clinical implementation of low tech eyeball movement communication methods.

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SPEAKER: LAKSHMI JOSHI BOYLE, MS, CCC-SLP

BIOGRAPHY:

Lakshmi has a strong, dedicated background in the field of Speech-Language Pathology services, providing care since 1986 to adults and children, with a strength in servicing the neurogenic population and swallowing disorders. Lakshmi has provided supervision to students, speech-language pathologists and audiologists for over 15 years, while maintaining a consistent caseload that has exceeded the requirements of Lakshmi's position. Responsibilities include strong service delivery model, customer service, mentorship, teaching competencies, performance reviews, quality assurance and maintaining budgets and productivity for two departments. Lakshmi is a strong proponent of continuing education and has received the ACE award through the American Speech-Language and Hearing Association.

AUTHOR: LAKSHMI JOSHI BOYLE, MS, CCC-SLP

TITLE OF PRESENTATION: TWO HEADS ARE BETTER THAN ONE

ABSTRACT:

Background: ALS, as a disease has symptoms of significant muscle fatigue. Patients also have emotional fatigue and worry that accompanies this disease process. Often as providers of care and particularly as ALS Provider practitioners, we frequently advise people to rest, to save their energy on a daily basis for what they deem important, and overall, to participate in strategies of energy conservation. Quite ironically, we storm ahead to face of our own contradiction. We schedule multiple providers to evaluate/treat the patient, presenting a grueling schedule from which many require several days of recuperation.

Objective: To demonstrate the benefit of a Dietitian-Speech-Language Pathology team when evaluating swallowing dysfunction as malnutrition and dehydration have a direct link to dysphagia.

Programme description: Our traditional ALS clinic comprised of many providers, being scheduled with the patient, in half-hour increments. We discovered that we would ask similar questions. We also found that depending upon the order of the schedule, one could not provide specific recommendations or strategies without knowing what the other had determined. As we reviewed patients at rounds, we would find that, depending upon how the question was asked, we might get contradictory answers or that the patient would interpret the question differently. Thus, we piloted a joint schedule, whereby the Dietitian and the SLP would see the patient in tandem. The program will provide strategies for increasing effectiveness and efficiency of the patient encounter with the Dietitian and SLP. We will present case studies whereby symbiosis will be emphasized. In addition, cases will be presented where the traditional model could have been enhanced with the teamed partnership.

Clinical outcomes:
1. The participant will be able to list benefits of Speech-Language Pathologist-Dietitian team approach.
2. The participant will be able to identify when a traditional approach may be necessary.
3. The participant will learn what to do when the team model is not available.

Recommendations to the field:
There are patient and team advantages to provision of a dual approach. Both disciplines have an investment in knowing the responses to a set of similar questions. Especially when stakes are high and recommendations re: tube feeds, swallowing safety and the recommendations of one of life's basic pleasures are

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SPEAKER: LEE GUION, MA, RRT

BIOGRAPHY:

Lee Guion is a respiratory care practitioner in the Forbes Norris MDA/ALS Research and Treatment Center in San Francisco, California. In addition to her degree in respiratory therapy she holds a BA in sociology from the University of North Carolina at Chapel Hill and a MA in gerontology from San Francisco State University.
She is the author of the textbook Respiratory Management of ALS (2009, Jones & Bartlett, Philadelphia, PA). She chairs the American Association for Respiratory Care’s Neurorespiratory Roundtable, an international on-line community of allied health professionals. She lectures nationally on the respiratory implications of MND/ALS, sleep and neuromuscular disease, and decision-making at end of life.

AUTHOR: LEE GUION, MA, RRT

TITLE OF PRESENTATION:
TO SLEEP, PERCHANCE TO DREAM…
SHOULD SLEEP STUDIES BE INCLUDED IN CLINICAL MANAGEMENT OF ALS?

ABSTRACT:

Background:

Restorative sleep is essential to physical, psychological and emotional wellbeing. Patient-reported symptoms of poor sleep quality are often the first signs of diaphragm weakness in MND/ALS and may occur prior to significant changes in pulmonary function tests.

The benefit of polysomnography (PSG) in assessing and treating early sleep disordered breathing (SDB) in the MND/ALS patient population is unclear. There appears to be a high degree of variability in response to nocturnal diaphragm weakness among MND/ALS patients with similar demographics, disease onset and progression [1]. As a result, some clinicians recommend performing PSG in response to the presence of symptoms of SDB [2,3,4,5,6]. No international consensus exists regarding the use of PSG in MND/ALS, and research has provided conflicting results due to technique inconsistencies and variable patient populations [7].

P.M. Andersen and members of the European Federation of Neurological Societies (EFNS) did not include PSG in their good practice points following an evidence-based review of the management of MND/ALS [8]. R.G. Miller and colleagues found insufficient data to recommend the use of PSG as one of the optimal tests to detect respiratory insufficiency in the updated practice parameter [9]. Although one evidence-based review of the management of respiration in MND/ALS recommended that symptoms suggestive of nocturnal hypoventilation should prompt a study of sleep, the authors recommend nocturnal pulse oximetry rather than PSG due to it's time consuming and costly nature [10]. This leaves many questions unanswered regarding the role of PSG in symptom management of MND/ALS.

Objective

We seek to increase participants' understanding of how sleep studies are performed and interpreted and the value of PSG in improving patient assessment and respiratory treatment strategies in MND/ALS. New, unpublished data on sleep and MND/ALS conducted in the Forbes Norris Center and at Stanford University by Hans D. Katzberg, MD will be included.

Programme description

The presentation will include:

- **Review of pulmonary function and sleep characteristics in MND/ALS;**
- **Description of components of PSG and the science and art of interpreting results;**
- **Comparison of PSG and nocturnal oximetry, pros and cons and the value of each;**
- **Summary of new, unpublished research on sleep and MND/ALS that correlate diurnal symptoms of SDB with PSG abnormalities;**
- **Use of PSG results to identify breathing rhythms and correct nocturnal asynchrony with NIV, improving patient adherence to treatment.**

Clinical outcomes

The value of PSG is dependent upon its components, interpretation, and recommendation for treatment of sleep disordered breathing. In order to utilize PSG as a tool in MND/ALS management, an understanding of its benefits and limitations is necessary.

Recommendations to the field

As the use of sleep technology and nocturnal oxygen testing in MND/ALS varies within and among countries, allied health practitioners should strive to understand when and if it can be of benefit to our patients with suspected sleep disordered breathing.

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ALLIED PROFESSIONALS' FORUM
JW Marriot Grande Lakes, Orlando
10 December 2010

SPEAKER: SARA FELDMAN, MA, PT, ATP

BIOGRAPHY:

Sara is the physical therapist for the MDA/ALS Center of Hope at Drexel University College of Medicine. She graduated from Temple University with a BS in Physical Therapy in 1987 and from University of Pennsylvania with a Masters in Environmental Science in 1997. She is currently enrolled in the Doctorate of Physical Therapy Program at Drexel University.
In the past, she has worked in inpatient rehabilitation, acute neuro-trauma, and has been adjunct faculty at several universities. She began her work with the ALS Center in 1993 on a rotational basis and by 1994 she became the permanent physical therapist for the clinic. She enjoys her work with the multidisciplinary team at the center where in addition to her role as the physical therapist, she is the Clinical Evaluator for ongoing clinical trials and the Assistive Technology Professional.
Please feel free to contact Sara at sfeldman@drexelmed.edu with any questions.

Mark Goren, MS, OTR/L

Mark is the senior occupational therapist at Drexel University's MDA/ALS Center of Hope located in Philadelphia, Pennsylvania. He has been part of the multidisciplinary team treating people with ALS for over 10 years. Mark received his Masters of Science degree in Occupational Therapy from Temple University in 1995.
His additional areas of interest include both hand therapy and assistive technology.

Donna Harris, MA, CCC

Donna is a licensed and certified speech language pathologist and has been involved with the MDA/ALS Center of Hope since 2000. She received her Masters from Temple University in 1991. Donna has worked in a variety of settings including special needs classrooms, acute care hospitals and rehabilitation centers. Donna is committed to the ALS cause and loves working with each and every family.

AUTHORS: SARA FELDMAN, MA, PT, ATP
MARK GOREN, MS, OTR/L
DONNA HARRIS, MA, CCC

TITLE OF PRESENTATION: IMPROVING COMMUNICATION BETWEEN THE ALS CENTER AND CAREGIVERS IN THE COMMUNITY.

ABSTRACT:

Background

The MDA/ALS Center of Hope at Drexel University College of Medicine is a multi-disciplinary team clinic where individuals with amyotrophic lateral sclerosis (ALS) are seen regularly for ongoing assessments. Physical, Occupational, and Speech Therapy evaluations are performed during these visits, however the follow-up is by professionals outside of the clinic who may not be familiar with the diagnosis. Emphasis is placed on education in the clinic, but the carryover to the next setting varies. Giving written instructions to the individuals with ALS and their caregivers appears to increase their involvement in their care, however carryover of the recommendations is inconsistent. The key issue we found needing to be addressed was how to improve the carryover of the recommendations made by the experts in the clinic to the therapists and caregivers outside of the center.

Objective

Our objective is to improve the communication between the experts in the clinic and the therapists and caregivers outside of the center.

Program Description

We achieved improved communication between our site and the outside agencies by first designing a comprehensive referral form. Next, in addition to our traditional handouts, we began taking digital photos and videos in the clinic. Third, for training sessions, we have travelled outside of the clinic to people's homes or agencies as appropriate or we have held training programs for caregivers to attend. And finally, we have started putting educational information on our website.

Clinical Outcomes

A review of 100 recent charts indicated that recommendations for follow-up were made for 100% of these individuals. The use of the referral form increased the communication between the clinic and the referral target. If the individuals themselves were proactive in their care, we found the communication between our center and the outside agency increased. All of the agencies we contacted were interested in participating in an educational program. We found anecdotally that having at least one direct contact person at an outside agency improved communication and increased carryover.

Recommendations to the Field

Improving communication between the experts at the clinic and the caregivers in the field requires time and effort. We recommend using a written communication form specific to the therapy requested; taking photos and videos; and ongoing training sessions. We anticipate that the information on the website will be an additional resource. We have found it helpful to have a direct contact person and to encourage the individual to actively participate in their care.

ALLIED PROFESSIONALS’ FORUM
JW Marriot Grande Lakes, Orland
10 December 2010

SPEAKER: DR DAVID OLIVER

BIOGRAPHY:

Dr David Oliver is a Medical Director and Consultant Physician in Palliative Medicine at the Wisdom Hospice in Rochester, Kent and Honorary Senior Lecturer in Palliative Medicine at the centre for Professional Practice at the University of Kent, where he is Director of Studies for the MSc in Supportive and Palliative care. He is a visiting Professor at the Scholl of Medicine at the University of Zagreb in Croatia.

He qualified at University College Hospital, London and then trained as a General Practitioner. He was Registrar and Senior Registrar at Christopher’s Hospice London and he was appointed to this present post in 1984.

He has lectured widely in the UK and in other countries, including Croatia, Poland, USA, Australia, South Africa, Japan, Netherlands, Portugal, Italy and New Zealand. He was awarded the Humanitarian Award of the International Alliance of ALS/MND Associations in 2003, in recognition of his work.

He has written widely on the palliative care and symptom control of patients with motor neurone disease, including “Motor Neurone Disease – a family affair” and as principal editor of Palliative Care of Amyotrophic Lateral Sclerosis – from diagnosis to bereavement 2nd edition, published in 2006. He is a co-editor of Palliative Care in Neurology published in 2004.

AUTHOR: DR DAVID OLIVER

TITLE OF PRESENTATION: WITHDRAWAL OF NON-INVASIVE VENTILATION – HOW CAN WE HELP ALL INVOLVED?

ABSTRACT:

Background:

Although non-invasive ventilation in the care of people with ALS/MND often provides excellent symptom management and improves quality of life, the disease continues to deteriorate and the person faces increased disability and symptoms. Some patients may wish to withdraw from treatment, but fear increased symptoms and distress. This can impact not only on patients and families but the health care professionals involved.

Objective

A retrospective study has looked at the experiences of health care professionals in the withdrawal of NIV, in particular looking at the management of the procedure and the impact on patients, families and carers.

Programme description

A retrospective survey of patients who have been withdrawn from NIV under the care of the hospices involved has allowed information on the procedure to be ascertained.

Clinical outcomes

Withdrawal of NIV can be undertaken with minimal risk of patient distress after withdrawal and before death. However there are profound implications for the support of the families of the patients and the professional carers, who are involved in the procedure. Although the professionals involved realise that ethically that the aim is to withdraw an inappropriate and unwanted treatment and this is ethically sound many do feel that they have hastened and assisted in the death of the person. They have required support and further discussion of the ethical issues and feelings involved

Recommendations to the field

The use of guidelines on the management of withdrawal of NIV patient is important in minimising the distress to patients and families. However there is the need to ensure that families and all carers, both lay and professional, are supported at this time and have the opportunity to express their fears and feelings. These aspects of care need to incorporated into the development of guidelines .

ALLIED PROFESSIONALS’ FORUM
JW Marriot Grande Lakes, Orlando
10 December 2010

SPEAKER: CAROL BIRKS

BIOGRAPHY:

Carol trained and worked as a registered nurse in London before emigrating to Australia in 1983.

She worked part time in a variety of specialties including oncology, aged care and research before focussing on palliative care nursing. She graduated from the Australian Catholic University with a Graduate Diploma in Nursing (Palliative care) in 1996.

Carol has been working with MND Associations and people living with MND since January 2000 when she took on the role of managing and developing the MND Association of New South Wales Family Support service. In October 2006 she was appointed as national executive director with MND Australia which is the peak body for motor neurone disease care and research in Australia.

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TITLE OF PRESENTATION: LIVING BETTER FOR LONGER: FACILITATING A COORDINATED MULTIDISCIPLINARY APPROACH TO MND THROUGH ‘ONE STOP SHOP’ ONLINE RESOURCES.

ABSTRACT:

Background:
People with ALS/MND live better for longer when they receive good symptom management from diagnosis through to end of life. Early diagnosis, timely referrals and a multidisciplinary team approach, together with good symptom management and timely interventions from providers who understand MND, can improve quality of life and survival time. However, many health and community care professionals have little knowledge or understanding of ALS/MND.

Objectives:
To assist people living with ALS/MND to live better for longer by providing:

(1) ‘one stop shop’ ALS/MND online resources for Australian health and community care professionals including comprehensive and up to date:
  - **evidence based symptom management information**
  - **best practice, needs based, support and wellbeing information**

(2) easily accessible Australian referral pathways.

(3) easily accessible ALS/MND information to health and community care professionals working in Australian regional and remote areas.

Program Descriptions
A comprehensive review of existing evidence based literature was undertaken and information collated and organised. A web developer was engaged and an expert review panel (ERP) established. Staff from each MND Association in Australia provided input to the development of state based referral pathways.
A website navigation structure was developed. Content was placed and includes a quick summary of each symptom and/or issue, practice points from evidence based reviews such as the AAN Practice Parameters (where available) and links to sources, related papers, related pages in the website and the referral pathway.

Clinical Outcomes
A website has been developed that provides easily accessible, comprehensive, up to date and evidence based or best practice information for each symptom and need related to ALS/MND, including a range of issues related to quality of life.
This information will assist health professionals to anticipate need and will facilitate advance care planning.
Feedback mechanisms and statistics related to website visitors during 2010/11 will provide information on the visitors and whether the website is facilitating a coordinated, multidisciplinary and palliative team approach from the outset of a person’s journey with MND.

Recommendations to the field

This website will assist practitioners to access relevant information quickly and easily rather than having to search the ever increasing and confusing amount of information available via the internet. This is particularly relevant for professionals practising in regional and remote geographic areas where access to a multidisciplinary team maybe difficult.

The website will be relevant to practitioners internationally and could easily be adapted to include region specific information

ALLIED PROFESSIONALS’ FORUM
JW Marriot Grande Lakes, Orlando
10 December 2010

SPEAKER: JANE CONNELL

BIOGRAPHY:

Jane qualified as an Occupational Therapist in 1978 and has since worked in hospitals and the community both in the psychiatric and general medical field.

Jane has worked for the Moro Neurone Disease Association as a Regional Care Adviser and now as Regional Care Development Adviser for over 20 years and has seen many improvements in the care for people with MND.

AUTHORS: Jane Connell, Motor Neurone Disease Association, Carol Browne, Commissioner Derbys PCT; Sue Smith & Farah Nazeer, MND Association, Carol Gent MND Care Centre Co-ordinator, Philip James, Service Improvement Manager, NHS Middlesbrough, Redcar and Cleveland

TITLE OF PRESENTATION: THE MOTOR NEURONE DISEASE YEAR OF CARE

ABSTRACT:

Background

The MND Year of Care (MND YOC):

- **Was a response to the challenges made to the National Health Service by several government strategies including the 'National service framework for long term neurological conditions in the UK'.**
- **Represents an innovative approach and describes the optimum combination of health and social care provision that a person with MND needs to achieve the best quality of life possible.**
- **satisfies the three key criteria of delivery:**
  - **is affordable to commissioners**
  - **deliverable by providers**
  - **acceptable to people living with Motor Neurone Disease.**

Objective

To use the MND YOC to deliver high quality and cost effective care for people with Motor Neurone Disease

Programme description

Three pilot sites were tasked with using MND YOC.
Each area set up a steering group to oversee the project.
Area was mapped for gaps and good practice.
From the mapping, priorities were set.

Clinical outcomes

In Leeds

- **Changed protocol for referral to Occupational therapy**
- **Initiation of continuing health assessment by MND Coordinator**
- **Equipment review**

Derbyshire developed

- **generic awareness training for Adult services**
- **a respiratory pathway**
- **equitable district nurse services and multidisciplinary teams via an education programme**
- **a predictive element of personalised budgets to incorporate the specific needs of a person with MND and a smooth transition into continuing health funding**
- **Contact directory for NHS staff**
- **Register of newly diagnosed**
- **New MND Derby clinic started**
- **Extensive education programme**

In Teesside

- **Establish current ways of working with respect to patient pathways**
- **Revisit and review current patient pathways**
- **Ensure that the person living with MND is sits at the centre of care delivery**
- **Utilise the MND YOC in developing a web-based MND pathway/referrer directory of services (Map of Medicine)**
- **Develop an evidence based, web-based national MND pathway utilising the MND YOC**

<u>Recommendations to the field</u>

- **Use the year of care as a tool to benchmark services**
- **better understanding of the needs of people with MND can be costed and planned more efficiently**
- **Good partnership working between health and social care professionals across boundaries**
- **Breaking down of boundaries by shared understanding – particularly of roles**
- **Care pathways should be developed**
- **Changes in practice with out any cost implications**
- **Education and training are vital for good practice**

MND Year of Care - a unique and simple way to deliver high quality care for people with MND

:

International Alliance of
ALS/MND Associations

ALLIED PROFESSIONALS' FORUM
JW Marriot Grande Lakes, Orlando
10 December 2010

SPEAKER: MELANIE LORD

BIOGRAPHY:

Melanie Lord received her Masters of Science in Speech and Language therapy from the University of Reading in 2005. She specialised in the area of MND working as an SLT in neurorehabilitation at the John Radcliffe Hospital and the Oxford Centre for Enablement. In 2009, she joined the Oxford MND Centre team as a Research Assistant (RA), in addition to continuing to work as an SLT part-time. As RA, her role includes assisting Dr Martin Turner with the BioMOx research project, working to identify biomarkers which have the potential to improve diagnosis and assist in monitoring progression and the efficacy of drug therapies. She also updates the patient database of up to 150 new patients each year to contribute to research aiming to improve our understanding of the different phenotypes, including 'The diagnostic pathway and prognosis in bulbar-onset amyotrophic lateral sclerosis', Journal of Neurological Sciences, May 7th 2010 (E-pub ahead of print). Melanie has been involved in the clinical care and coordination of patients who have opted for enteral nutrition and developed an interest in improving the service.

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TITLE OF PRESENTATION: THE OXFORD ALS NUTRITION CLINIC: IMPROVING THE ENTERAL NUTRITION PATHWAY FOR PATIENTS AND CARERS

ABSTRACT:

Background:

Gastrostomy is a particularly sensitive issue for patients and carers, and introducing the topic of enteral nutrition (EN) can be challenging in the environment of a busy ALS clinic. Identifying the optimal timing for insertion, obtaining informed consent for either percutaneous (PEG) or radiologically-inserted gastrostomy (RIG), coordinating hospital admission for those with often complex nursing needs, the procedure itself and aftercare, are all critical issues. In a local audit we found at least 50% of patients and carers reported that information regarding gastrostomy was incomplete or inconsistent.

Objective

To improve patient and carer experience of decision-making and EN through establishing a dedicated multidisciplinary ALS Nutrition Clinic with the objective of more effective communication of information regarding gastrostomy, improved procedure planning, delivery and aftercare.

Programme description

Following preliminary discussion at the main ALS clinic visit, patients identified with EN needs were offered a separate additional Nutrition Clinic slot within two weeks. Staff available for this dedicated clinic included a Clinic Coordinator and Specialist Nurse (RM), Enteral Nutrition Clinical Nurse Specialist (SW), Dietician (JD), and Speech and Language Therapist (ML). Changes to the local EN pathway were also agreed, including appropriate pain management following the procedure.

Clinical outcomes

Clinic slots of up to 90 minutes enabled the provision of verbal and written information about gastrostomy, with ample time for discussion of individual concerns. These included carer role in the longer term, psychological and body image impact. Frequently anxieties were reduced following discussion and the opportunity to view a sample PEG tube, which patients found to be more discrete than had been anticipated. In our preliminary audit of 6 clinics, all patients and carers who attended felt it was worth the additional journey and greatly valued the opportunity

and time to feel more prepared. Patient experience of pain management improved following the procedure and there was increased agreement regarding optimal timing of insertion between clinicians and patients and carers, who appreciated flexibility to work around personal work/holiday commitments.

Recommendations to the field

We suggest wider consideration in advance care planning of the option of a dedicated ALS Nutrition Clinic. We believer it benefits both patients and carers, allowing them to feel more in control of the decision regarding EN, with the aim of reducing procedural and aftercare complications or distress that may be associated with gastrostomy.

ALLIED PROFESSIONALS' FORUM
JW Marriot Grande Lakes, Orlando
10 December 2010

SPEAKER: RODNEY HARRIS OAM

BIOGRAPHY:

Rodney Harris is the Chief Executive Officer of the Motor Neurone Disease Association of Victoria, and has held this position for over 16 years. The Association provides a limited number of strategic services that it is best placed and equipped to deliver, and works with generic community and health services to improve access to them and support for people living with MND.

He has had an extensive engagement in community-based organisations, and has been on the Boards of a number of nfp organisations. He has been a Board Member and Chairman of the International Alliance of ALS/MND Associations.

Rodney has worked extensively to develop and enhance the role of palliative care services for people with life-threatening illnesses, particularly motor neurone disease. He has undertaken leadership training at the School of Management, Mt Eliza, and at Stanford University.

AUTHOR: **RODNEY HARRIS**

TITLE OF PRESENTATION: "TAKE A BREAK FROM ALS/MND"

ABSTRACT:

Background: The impact of ALS/MND is experienced in many ways, some of which are economic and some of which are social opportunity – economic and social opportunity come together to restrict an individual's or a family's ability to participate more broadly in their community. At the same time, workers assisting families face long waiting lists to access packages of support or access to services, which leaves them feeling impotent to effect change and address the impact of ALS/MND.

There is also a need to link Corporate Social Responsibility to direct client impact, not by having staff of a supporter work with clients but through a mechanism to ensure that the supporter organization can claim an ownership of and relate to the initiative, supply funding and promote the project and themselves to their community.

Objectives:

- To develop and fund a small grants program to address issues arising from ALS/MND and its impact on a family – to give a break on the impact of ALS/MND
- To empower workers supporting families to "make a difference" by providing a budget of financial support, and enhance their sense of success and impact on the lives of clients
- Establish and support a Corporate Social Responsibility relationship which will fund the initiative, promote the initiative through new circles and raise recognition and awareness of ALS/MND

Programme description

Regional Advisors were empowered to provide cash funding of up to $500 to address issues arising from the impact of ALS/MND. The key criterion was that the impact of ALS/MND prevented the individual or family from doing things, and that doing them would be a "break from ALS/MND". The program was not advertised – it remains an initiative of the Regional Advisor. Approval of the funding was by the Regional Advisor, and the request for funding made by email. Their decision was final. Funds were transferred within 24 hours to the client's bank account, and it was up to the client to organise the activity or expenditure. Reporting on the impact has been based on collection of stories from families, and has been provided in a deidentified form to the corporate funder.

Clinical outcomes.

Regional Advisors feel empowered to make a difference where they see a need and opportunity. This has increased their sense of self worth and esteem, and reinforced the important role they play to "make a difference". Individuals and families have been able to undertake activities or purchases which they were not able to do due to the impact of ALS/MND. This has had a strong respite factor, especially with families able to undertake joint activities.

Recommendations to the field

- Creative service and support options do not have to cost a lot of money for each client
- Consider and highlight how the support can benefit staff and funders, as well as the person with ALS/MND, and plan appropriately
- Truly empower staff – don't have someone able to "outvote" or "review" their decision
- Don't bog down low cost initiative with bureaucracy
- Keep the funder informed of the impact of their money on people through their stories