



INTERNATIONAL ALLIANCE OF  
ALS/MND ASSOCIATIONS

# Allied Professionals Forum

5 December 2013

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## ALLIED PROFESSIONALS FORUM

Mizar Room, Atahotel Quark, Milan, Italy

5 December 2013

### PROGRAMME

8.30	Welcome and introductions	Steve and Rod	
8.40	Withdrawal of NIV at the patient's request in ALS/MND: exploration of the issues related to communication	Christina Faull	UK
9.00	Bulbar ALS/MND: A retrospective analysis of patients treated with NIV	Elisa Falcier	Italy
9.20	Optimizing NIV in patients with ALS/MND through serial monitoring of nocturnal oximetry	Deborah Gelinias	USA
9.40	Practical and cost effective solutions for enabling independence in ALS/MND patients requiring NIV	Melanie Holmes	Aust
10.00	The 'traffic light' approach to assessing respiratory risk and guiding decision-making for enteral nutrition in ALS/MND	Melanie Lord	UK
10.20	Morning Tea		
10.50	Multidisciplinary teams: How do we care for ourselves while caring for those with ALS/MND?	Rebecca Axline	USA
11.10	Can mindfulness practices improve compassionate care to our PALS and prevent burnout of the health-care provider?	Renee Bricker	USA
11.30	Nurse coaching experience in an ALS/MND clinical centre	Elena Gotti	Italy
11.50	Medical coaching in support of ALS/MND patients and family members	Shiri Ben Arzi	Israel
12.10	Young carers in ALS/MND families	Laurie Fieldman	USA
12.30	Lunch and Networking		
13.50	Developing best practice guidelines for physical therapy evaluation of individuals with ALS/MND	Sara Feldman	USA
14.10	Multidisciplinary allied health practice guidelines for physical, speech and occupational therapy in ALS/MND	Jessica ten Broek-Pastoor	Neth
14.50	Recognising the role of occupational therapy in making sense of decision making in ALS/MND	Malabika Ghosh	UK
15.10	Afternoon Tea		
15.40	Using a Database for Clinical Management	Meraida Polak	USA
16.00	Pain of Isolation	Sarah Lavender	UK
16.20	ComuniCARE project: AAC apps for people with ALS/MND	Marco Caligari	Italy
16.40	Gadgets and gizmos II: Continuing to think outside the box	Amber Ward	USA
17.00	Close		

Co-Chairs: Steve Bell, MND; Rodney Harris, MND Victoria

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**SPEAKER:** Dr Christina Faull, BmedSci, MB BS, FRCP.,M.D. Dip Clin Hyp, PGCert Med Ed.

**BIOGRAPHY:**

Since 2003 Dr Faull has been a Consultant in Palliative Medicine at LOROS, the Leicestershire and Rutland Hospice and the University Hospitals of Leicester. She previously worked as a Consultant in Birmingham. In addition to being the medical lead for education and research at LOROS, Dr Faull also Co-chairs the Centre for Promotion of Excellence in Palliative Care (CPEP), a partnership between LOROS and De Montfort University, in Leicester. She has research interests decision making in end of life care and is undertaking a programme of work looking at the issues related to withdrawal of NIV at the request of a patient with MND.

Dr Faull is the senior editor of *Handbook of Palliative Care* which was awarded the BMA “medical book of the year” in 1999. *Palliative Care: an oxford core text* written with Dr Woof, repeated the success as BMA Medical book of the year in 2003. The third edition of *Handbook of Palliative Care* was published in December 2012.

Dr Faull can be contacted at the following address:

LOROS Hospice  
Groby Road  
Leicester  
England  
LE3 9QE

Via telephone: 0116 231 8498, or by email at: [christinafaull@loros.co.uk](mailto:christinafaull@loros.co.uk)

## ABSTRACT

**AUTHOR/s:** Kay Phelps (email: kp14@leicester.ac.uk), Emma Regen, Idaliza Garner, Chris McDermott, David Oliver and Christina Faull (email: christinafaull@loros.co.uk)

**TITLE OF PRESENTATION:** Withdrawal of NIV at the patient's request in MND: exploration of the issues related to communication.

**Key Theme:** Respiratory support and other (end of life care)

**Background:** Very little is known about the withdrawal of NIV at the request of a patient who has become dependent on it. The NICE guidance in England and Wales on the use of NIV in MND (2010) identifies the lack of any clarity in how this process should be facilitated and managed. NICE specifically suggests interviewing the professionals involved in such events as a focus of research.

**Objective:** To identify and explore with doctors issues related to communication in decision making about the withdrawal of NIV.

**Programme description:** A retrospective qualitative interview study of the experiences of NIV withdrawal of 20 Doctors including specialists in palliative care, respiratory, neurology and family practice.

**Clinical outcomes:** The loss of the ability to communicate was reported as a trigger for many patients to request withdrawal of their NIV. Other patients vacillated in making a decision or were more reticent about discussions on continuance of ventilation and doctors' narratives suggested increasing desperation to try and establish their wishes before communication was lost. In the context of profound difficulty in communication and high levels of fatigability for the patient, this was often extremely time consuming. Doctors required sophisticated communication strategies to ensure capacity was established and their impression of the patient's view was accurate and consistently expressed.

As patients' ability to communicate deteriorated doctors became increasingly dependent on family members to assist with interpretation of patient responses. Family were often in the position of identifying that patients wanted to request that NIV was withdrawn and providing the evidence for the doctor of the patients understanding of the consequences.

The loss of the ability of patients to communicate meant that doctors needed to make judgments about the patients' level of distress and the efficacy of symptom management.

**Recommendations to the field:** Loss of communication is often a key trigger for requesting withdrawal of NIV. However many patients' wishes are not known before developing profound communication difficulties. Establishing the wishes and comfort of patients with communication difficulties is complex, time consuming and worrying for doctors who need high-level skills to undertake this work.



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**SPEAKER:** Elisa Falcier

**BIOGRAPHY:**

Actual position: 2nd year resident in Respiratory Medicine at the University of Milan, currently working at Centro Clinico NEMO in Milan in the Respiratory Area. Dr Falcier is in charge of in-patients and out-patients seen in the out-clinic and Day-Hospital service for Pneumology under the supervision of Dr Rao who is the Pneumologist in charge of the Pneumology Area. Dr Falcier takes care of patients with neuromuscular disorders having respiratory problems in whom symptoms are evident or in the pre-clinic phase performing diagnostic and laboratory investigations in the Pneumology area. These include supervision of gas analysis, spirometry, cough evaluations, nocturnal O<sub>2</sub> saturation and nocturnal polygraphy with the ability of identifying patients requiring non-invasive ventilation on the basis of international guidelines. Dr Falcier's experience in the Neuromuscular field includes patients with amyotrophic lateral sclerosis, muscular dystrophies, congenital myopathies, spinal muscular atrophy, polyneuropathies and myasthenia.

Academic and Professional experience: Degree in Medicine in 2008. From 2009 to 2011 on call experience in the Nursing Homes and in Orthopedics, Neuropsychiatric and Neurology Rehabilitation Units, taking care of medical issues in general. From November 2010 to July 2012 fellowship in Pneumology at Centro Clinico NEMO.

## ABSTRACT

**AUTHOR/s:** Falcier E. - resident in Respiratory Medicine, De Mattia E. – respiratory physiotherapist, Garabelli B.- respiratory physiotherapist, Iatomasi M. - respiratory physiotherapist, Roma E. - pneumologist, Rao F. - pneumologist, Lunetta C. - neurologist, Sansone V. – neurologist. “Centro Clinico Nemo”, Milan, Italy

[elisa.falcier@centrocliconemo.it](mailto:elisa.falcier@centrocliconemo.it), [elisa.demattia@centrocliconemo.it](mailto:elisa.demattia@centrocliconemo.it),  
[barbara.garabelli87@gmail.com](mailto:barbara.garabelli87@gmail.com), [pelo884@yahoo.it](mailto:pelo884@yahoo.it), [elisabetta.roma@centrocliconemo.it](mailto:elisabetta.roma@centrocliconemo.it),  
[fabrizio.rao@centrocliconemo.it](mailto:fabrizio.rao@centrocliconemo.it), [christian.lunetta@centrocliconemo.it](mailto:christian.lunetta@centrocliconemo.it),  
[valeria.sansone@centrocliconemo.it](mailto:valeria.sansone@centrocliconemo.it).

**TITLE OF PRESENTATION: Bulbar ALS: a retrospective analysis of patients treated with niv**

**Key Theme:** Respiratory Support and Nutrition

**Background:** In literature, bulbar ALS patients (pts) have always been related to worse NIV tolerance and survival. Furthermore, there is no clear agreement on NIV parameters to be used to maximise tolerance and ventilation efficacy in ALS patients.

**Objective:** In a 4 year retrospective study we investigated the Management of Chronic Respiratory Failure (CRF) with non invasive ventilation (NIV) in ALS patients attending in the “NeMo Centre”, from disease onset to exitus/tracheostomy.

Our primary aim was to describe the NIV path in ALS patients to compare survival differences between onsets, to outline the relationship between respiratory and NIV parameters.

The secondary aim was to outline a possible relationship between the evolution of the degree of disability (measured by ALSFRS-R scale), respiratory parameters and NIV features.

**Programme description:** Our database includes 535 ALS pts, 147 attained our centre between 2008 and 2011 and had their respiratory function been tested from baseline to NIV adaptation and use, until exitus or tracheostomy. From this group, we enrolled 78 pts in a randomized way. 20 patients (25,64%) presented bulbar onset. Parametric tests were used to compare groups.

**Clinical outcomes:** Bulbar pts have the higher diaphragmatic impairment and the worst orthostatic/clinostatic FVC ratio ( $p=0,038$ ), nevertheless with EPAP titration higher than 4 cmH<sub>2</sub>O ( $5,73 \pm 1,53$ ) and a proper care of bulbar impairment they can have good tolerance and survive as long as general population. In these pts clinostatic FVC relates directly to ALS FRS bulbar and respiratory scores ( $p<0,01$ ).

**Recommendations to the field:** EPAP set higher than 4 cm H<sub>2</sub>O to reduce ODI, normalize V<sub>T</sub> and increase SpO<sub>2</sub> in NIV permits better tolerance and adherence in all pts. This allows bulbar pts to have a duration of illness from NIV adaptation comparable to other onsets. ALSFRS-R is an accurate measure of respiratory impairment.



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**SPEAKER:** Deborah F. Gelinas, M.D.  
**E-mail:** [gelinasd@trinity-health.org](mailto:gelinasd@trinity-health.org)  
**Phone:** 011-(616)-685-5242/5114  
**Address:** Hauenstein Neuroscience Center, 220 Cherry Street, Grand Rapids, MI 49503

**BIOGRAPHY:**

(2008-present) Director, MDA/ ALS Clinic Hauenstein Neuroscience Center, Grand Rapids, MI 49503; Associate Professor, Department of Neurology and Ophthalmology, Michigan State University AAN Board Certified Neurology (1989) and Neuromuscular Medicine (2011)

**SPONSORED RESEARCH:**

Study NOG112264, a Phase II Study of Ozanezumab (GSK1223249) versus Placebo in the Treatment of Amyotrophic Lateral Sclerosis

Cytokinetics CY-4026 (BENEFIT-ALS) - A Phase IIb, Multi-National, Double-Blind, Randomized, Placebo-Controlled Study to Evaluate the Safety, Tolerability and Efficacy of CK-2017357 in Patients with ALS

Protocol 12-AVR-401 - Avanir- Prism II - A Study to Assess the Safety, Tolerability and Effectiveness of NUEDEXTA (Dextromethorphan 20mg/Quinidine 10mg) in the Treatment of Pseudobulbar Affect (PBA)

EMPOWER: A Phase III Multicenter double-blind placebo-controlled trial of Dexrampipexole in patients with Amyotrophic Lateral Sclerosis 2011 (Biogen-Idec and Knopp Neurosciences)

Clinical Trial of Ceftriaxone in Patients with Amyotrophic Lateral Sclerosis 2010, Phase III Multi-center, Double-Blind, Placebo-Controlled

High Fat High Calorie Diet in Amyotrophic Lateral Sclerosis

Phase II Multi-center, Double-Blind, Placebo-Controlled

**PUBLICATIONS:**

1. Rosenfeld J, King RM, Gelinas D et al. "Creatine monohydrate in ALS: effects on strength, fatigue, respiratory status and ALSFRS. *Amyotrophic Lateral Sclerosis*. 2008;9(5); 266-272.
2. Lange D, Lechtzin N, Gelinas D et al and the HFCWO study group. Performance of an Instrument to measure change in dyspnea in patients with ALS, *Neurology*. 2006;67(6); 991-997.
3. Mendoza M, Gelinas D et al, Inspiratory pressure and forced vital capacity as potential criteria for initiating non-invasive ventilation in amyotrophic lateral sclerosis, *Amyotrophic Lateral Sclerosis and other Motor Neuron Diseases, Amyotrophic Lateral Sclerosis* Jan 2007, Vol. 8, No. 2: 106-111

**BOOKS/CHAPTERS:**

1. Miller RG, Gelinas D, O'Connor P. Amyotrophic Lateral Sclerosis. AAN Press (2005)  
Quality of Life Guide. Demos Medical Publishing.
2. Lyall RF, Gelinas DF, The control of symptoms arising from respiratory muscle weakness. Palliative Care in Amyotrophic Lateral Sclerosis, Editor David Oliver, Oxford University Press, Oxford UK 2006, 2013
3. Gelinas DF, Miller RG. Quality of Life and Psychosocial Aspects of Care of Patients with Amyotrophic Lateral Sclerosis. *Blue Books of Practical Neurology. Motor Neuron Disorders*. Edited by Pamela Shaw and Michael Strong. Chapter 19:465-484. 2003.
4. Gelinas DF. Treating the symptoms of ALS. H.R. Mitsumoto, T.L. Munsat (eds) *Amyotrophic Lateral Sclerosis. A Guide for Patients and Families*. Chapter 4:47-62. 2001.

## ABSTRACT

**AUTHOR/s:** Deborah F. Gelinas, M.D.  
Bradley M. Norg, LRT

**TITLE OF PRESENTATION:** Optimizing Non-Invasive Ventilation in Patients with ALS through Serial Monitoring of Nocturnal Oximetry in Correlation with NIV data.

**Key Theme:** Non-Invasive Ventilation

**Background:** ALS is a progressive motor neuron disease which results in death from respiratory failure. Patients who successfully use Non-Invasive Ventilation (NIV) have significantly prolonged survival and quality of life compared to non-users. Optimal timing for the institution of NIV is still undetermined but nocturnal oximetry may prove to be a more useful indicator of need for NIV than forced vital capacity. Even when NIV is utilized in ALS, correct ventilation parameters are achieved in less than 50% of users. Effective ventilation, not only adherence to NIV, is an independent prognostic factor in patient survival. Effective ventilation can be achieved, even in the face of bulbar symptoms by early recognition of nocturnal hypoventilation, serial monitoring of nocturnal oximetry, ongoing evaluation of NIV data (downloads) and (both) additional medical and equipment interventions to optimize nocturnal oxygen saturation and patient NIV compliance.

**Objective:** To educate members of ALS multi-disciplinary teams with common problems in ventilator use and to demonstrate how these difficulties may be successfully managed to optimize quality of ventilation and patient adherence to NIV treatment.

**Programme description:** Six real-life patient vignettes will be presented with clinical indications for ventilation, spirometry, nocturnal sleep studies, daytime capnometry and oximetry and serial nocturnal oximetries in order to demonstrate specific problems encountered with NIV and trouble-shooting strategies. Follow-up data on clinical symptoms and quality of life will be presented. Ventilatory challenges discussed include claustrophobia, sialorrhea, patient-ventilator asynchrony, aerophagia, laryngospasm and optimization of (pressure-guaranteed Tidal Volume). Or – “Volume assured pressure support and ideal EPAP.” Because this is what AVAPS, Trilogy with AVAPS, or IVAPS are promoting.

**Clinical outcomes:** The vast majority of patients with ALS can experience improved energy and prolonged survival with the aid of NIV. Careful attention to specific problems with ventilation, and correction of recognizable problems results in improved nocturnal ventilation as demonstrated by nocturnal oximetry and amelioration of patient symptoms.

**Recommendations to the field:** Early recognition of the need for NIV, specific challenges to the use of NIV, serial monitoring of the quality of ventilation and a systematic approach to trouble-shooting difficulties in order to achieve effective nocturnal oxygen saturation results in greater patient satisfaction, quality of life, survival and adherence to recommended therapies.





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**SPEAKER:** Mel Holmes

**BIOGRAPHY:**

After a brief dalliance with biochemistry and microbiology Mel decided that people were even more interesting than the dance of biochemicals in the cell.

Mel trained as an Occupational Therapist at Dorset House in Oxford and began her work in a rotation post at Hemel Hempstead General Hospital. She then discovered the joy of working in the community and has not looked back. After three years in a mixed town and rural area, she moved to Cambridgeshire and worked for a charity in a vocational rehabilitation setting.

Mel moved back into the NHS fold and worked in the community in and around Huntingdon and St Neots. Before leaving England, she worked for three years in a community neurology rehabilitation team, as the OT responsible for all of the people living with MND in the area.

Mel and her family decided that they needed an adventure and came to Australia five years ago.

For the period of this sojourn Mel has worked for the Victorian Respiratory Support Service (VRSS) This is based at the Austin Hospital and provides a state wide service for clients who require mechanical ventilation in the community.

Mel is also the OT at The Kevin Heinze Garden Centre in Melbourne and takes great delight in promoting Horticultural Therapy and gardening to anyone who will listen.

The talk has developed from Mel's practical skills and the research and writing skills of her colleague Amanda McLaughlin. She has gathered the information for this presentation, but opted out of the delivery, so the mantle has fallen to Mel.

## ABSTRACT

**AUTHOR/s:** Mel Holmes and Amanda McLaughlin

**TITLE OF PRESENTATION:** “Practical and cost effective solutions for enabling independence in MND patients requiring non-invasive ventilation”

**Key Theme:**

Simple, practical solutions to functional problems encountered by people with MND who require non-invasive ventilation (NIV)

**Background:**

Amanda and Mel work for The Victorian Respiratory Support Service, providing support for people using non-invasive ventilation, allowing them to remain as independent as possible.

**Objective:**

To make these solutions for the independence of the NIV users as widely available as possible.  
To encourage innovative thinking in the solution of these problems.  
To encourage the sharing of these ideas and solutions.

**Programme description:**

The programme is designed to support people with NIV and offer alternatives and solutions to the practical problems they encounter.

**Clinical outcomes:**

Extended independence for people with MND who require NIV use.  
Offer reassurance for people with MND and their carers in key areas of functioning.

**Recommendations to the field:**

Listen to the people with the disease and their concerns and fears and see if there is anything you can do about it. The solutions are likely to be applicable to others.



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**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. 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. She has also recently increased her involvement in teaching on undergraduate and postgraduate SLT courses at the University of Reading.

**AUTHOR/s:** Melanie Lord<sup>1,2</sup>, Rachael Marsden<sup>1</sup>, Kevin Talbot<sup>1</sup>, James East<sup>1</sup>, Annabel Nickol<sup>1</sup>, Martin R. Turner<sup>1</sup>.

Authors' roles: all above are essential members of the Multidisciplinary team, involved in developing and reviewing the 'traffic light' tool and abstract. Contact details:

Rachael.marsden@ouh.nhs.uk (Clinic Coordinator and Specialist Nurse)

Kevin.talbot@ndcn.ox.ac.uk (Consultant Neurologist and Care Centre Director)

James.East@ouh.nhs.uk (Consultant Gastroenterologist and Endoscopist)

Annabel.nickol@ndm.ox.ac.uk (Consultant in Respiratory Medicine)

Martin.Turner@ndcn.ox.ac.uk (Consultant Neurologist and Care Centre Co-director)

## ABSTRACT

**AUTHOR/s:** Melanie Lord<sup>1,2</sup>, Rachael Marsden<sup>1</sup>, Kevin Talbot<sup>1</sup>, James East<sup>1</sup>, Annabel Nickol<sup>1</sup>, Martin R. Turner<sup>1</sup>.

Oxford MND Care and Research Centre, John Radcliffe Hospital, Oxford, UK.

<sup>1</sup>Oxford University Hospitals NHS Trust, <sup>2</sup>University of Reading Department of Clinical Language Sciences

E-mail: [melanielord7@gmail.com](mailto:melanielord7@gmail.com), Tel: 0044 7790 649478

**TITLE OF PRESENTATION:** The ‘traffic light’ approach to assessing respiratory risk and guiding decision-making for enteral nutrition in ALS

**Key Theme:** Respiratory support and nutrition

**Background:** Clinicians and patients can face uncertainty regarding optimal timing and method of gastrostomy, as well as how to reliably quantify risk using respiratory assessment. Whilst guidelines indicate that PEG should be performed prior to significant respiratory symptoms, this is often not possible in practice. For patients with respiratory compromise, radiologically inserted gastrostomy (RIG) has been proposed as a preferred method, but there are no randomised studies and great variation in practice, depending partly on local expertise. A retrospective review of difficult cases at our centre suggested PEG may in fact be the preferred option, provided certain precautions are put into place.

**Objectives:** To improve outcome of gastrostomy through the implementation of a ‘traffic light’ system to:

- aid assessment of respiratory compromise and identify high risk cases
- guide decision-making about appropriate method, with PEG as the default choice
- put in place relevant precautions to minimise risk

**Programme description:** The traffic light system is applied at a dedicated MDT nutrition clinic, to grade risk as ‘green’ (low) ‘amber’ (medium) or ‘red’ (high). Risk is determined according to a range of respiratory assessments, prompting early referral to the respiratory team for overnight oximetry and NIV if required, including to be used during the procedure.

**Clinical outcomes:** Of all patients considered for gastrostomy in an 8 month period (n = 20), 12 successfully had PEGs inserted (6 ‘amber’, 3 ‘green’, 3 ‘red’), 2 a RIG (1 ‘red’ requiring NIV via full facemask and 1 ‘amber’ following failed PEG due to insufficient transillumination). PEG has therefore been successful in high risk cases with improved management of risk.

The traffic light assessment enabled clear identification of patients with respiratory compromise, which in turn helped evaluate risk of gastrostomy and inform patients, including for 2 ‘red’ high risk patients who declined gastrostomy. A PEG procedure was arranged but subsequently cancelled following deterioration in 4 cases (3 ‘red’ and 1 ‘green’), demonstrating repeated evaluation of patients’ risk if delay between referral and gastrostomy insertion.

### **Recommendations to the field:**

- Consider using the traffic light system to assess respiratory risk and guide decision-making for gastrostomy in people with ALS.
- Work collaboratively with range of local experts to ensure best possible nutritional management of high-risk patients.



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**SPEAKER:** Rebecca Axline, LCSW

**BIOGRAPHY:**

Rebecca Axline, LCSW is Supervisory Clinical Social Worker at the Methodist Neurological Institute.

Rebecca completed her undergraduate degree in 1976 at Oklahoma State University and her graduate degree in 1982 at University of Wisconsin-Madison.

Rebecca has over 30 years of clinical social work experience working in a variety of settings including medical centers, active duty military bases, Veteran Administration Medical Centers, employee assistance, hospice care, and school districts. She has management experience in the areas of psychiatric care, employee assistance and customer service.

Her current role starting in 2006 has been the development of an outpatient Social Work program at Methodist Neurological Institute. She continues to provide program development and clinical intervention with a primary focus of helping patients and family members cope with the stress of diagnosis and treatment of neurological disorders and illnesses.

Additionally, Rebecca provides teaching and mentorship to graduate Social Work students and clinical supervision guidance to LMSW social workers. She has been a speaker at informal and formal presentations to community groups, support groups, and continuing education attendees.

**CO-AUTHOR:** Peggy Aldred, PT DPT

**BIOGRAPHY:**

Peggy Allred, PT DPT is currently the Research Administrator and ALS Program Manager at Cedars-Sinai Medical Center in Los Angeles. She develops and implements clinical research programming for the Neuromuscular Division and facilitates the multidisciplinary ALS clinic.

She received her Bachelors of Science in Physical Therapy from Texas Woman's University and her Doctor of Physical Therapy from Simmons College in Boston.

Dr. Allred has worked in the ALS field for over 25 years and was previously with Washington University in St. Louis and Methodist Neurological Institute/Baylor College of Medicine in Houston, Texas.

## ABSTRACT

**AUTHORS:** Rebecca Axline, LCSW, Peggy Aldred, PT DPT

**TITLE OF PRESENTATION:** Multidisciplinary teams: how do we care for ourselves while caring for those with ALS?

**Key Theme:** Support for Staff

**Background:** Caring for patient with life threatening diseases can elicit grief symptoms in health care professionals. Limited descriptions exist of how individually and collectively, MND/ALS teams can safely express grief and model effective coping strategies.

**Objective:** To explore mechanisms for managing patient loss and describe beneficial components of supportive models of intervention.

**Programme description:** Individual interviews were conducted with healthcare team members to identify challenges of work-related bereavement; current management of grief and loss; and ways of supporting interpersonal functioning and resiliency. Data collection involved a nine open ended question instrument to elicit responses regarding emotions, experiences, perceptions, and grief resolution strategies.

**Clinical outcomes:** Over 28 months at our center, 176 new ALS patients were diagnosed; 124 deaths reported.

Interviews were conducted with 22/33 team members. Results indicated the following:

1. Group and individual strategies are used with positive feedback. These strategies included: sending email out to team; reminiscing among team; cards and emails; attending funeral; private tears, exercise, prayer, and journaling.
2. Grief response often corresponded to depth of relationship with patient; similarity of patient to themselves in age/gender; and unexpected versus expected death.
3. Grief response increased with frustration of late diagnosis, non-compliance with recommendations, and/or inappropriate treatment recommendations before patient arrived at our center.
4. Unique aspects of ALS diagnosed population increased grief simultaneously motivating professions to “do more” and “find a cure.”
5. Strategies provided closure and validation of their role and grief responses.
6. Grieving recognized as bonding experience, enhancing ability to re-invest energy in patients.
7. Dysfunction or burnout does not appear prevalent.

**Recommendations to the field:** While this descriptive exploration indicates one team formally and informally provides a safe environment for grief responses, further studies are needed to develop an outline of essential grief and coping components. With a grief and coping algorithm, teams can enhance their system for providing expression of normal grief responses. Recognizing the need for group and individual grief management will enable us to care for this challenging patient population. As health carers, developing some level of comfort with issues of life and death and learning to live with our own grief increases our ability to administer life-enhancing care, even to patients with a life threatening disease.



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**SPEAKER:** Renee S. Bricker, M.S., CCC-SLP, Leslie Addington, M.A., CCC-SLP

**BIOGRAPHY:**

Renee is a Speech-Language Pathologist (SLP) at the University of Virginia's Health System in Charlottesville, VA. She works as an in-patient SLP for adults and as the primary SLP for the Richard R. Dart ALS clinic. During her time at U.Va she has established a FEES program within the health system, lectures to graduate students on dysphagia, and has participated in research in her field. Renee graduated from Clarion University of PA in 2003 with a M.S. in Communication Sciences and Disorders. She completed her clinical fellowship year at Palomar Medical Center in San Diego County, CA.

Email: [rsb7d@virginia.edu](mailto:rsb7d@virginia.edu)

Phone: 1-434-760-4729

Leslie Addington graduated from Indiana University in 2009 with a M.A. in Communication Sciences and Disorders. After graduation she worked in a rehabilitation setting before transferring to adult in-patient acute care at the University of Virginia Health System in 2011. She attends the Richard R. Dart ALS clinic as an SLP.

Email: [leslie.addington@virginia.edu](mailto:leslie.addington@virginia.edu)

Phone: 1-434-760-5250

## ABSTRACT

**AUTHOR/s:** Renee S. Bricker, Leslie Addington

**TITLE OF PRESENTATION:** Can mindfulness practices improve compassionate care to our PALS and prevent burnout of the health-care provider?

**Key Theme:** Support for Staff

**Background:** We are all aware that ALS is a devastating diagnosis, both for the patient and for the health-care provider. Since there is no cure for this disease many of us who care for these patients are left with feelings of helplessness, stress, and empathy fatigue. It is widely published that health-care providers have high rates of burnout in their professions. Health-care providers who work with challenging patient populations, like ALS, report higher levels of burnout and difficulty coping. Research has shown that individuals who incorporate mindfulness practices into their lives are more successful in coping with stress and reducing feelings of burnout. Kabat-Zinn defines mindfulness as “The awareness that emerges through paying attention, on purpose, in the present moment, and non-judgmentally to the unfolding of the experience moment by moment”. It is believed that mindfulness can facilitate compassion and compassion lays the foundation for healing and connecting with our patients with ALS (PALS). Others report that compassion may foster a healing relationship between the health-care provider and the patient. If health-care providers practice mindfulness could it improve compassionate care to our PALS and reduce burn-out rates in our profession?

**Objective:** This presentation hopes to increase education and awareness of signs of burnout in our professions and how basic mindfulness practices can improve health-care providers’ job satisfaction, along with improving compassionate care to our PALS.

**Programme description:** The following topics will be discussed:

- Background research findings on burnout in health-care providers
- Information on mindfulness practices and research findings
- Summary of how mindfulness practices impact our ALS clinics

**Clinical outcomes:** The goal of this session is to 1) provide education in detecting burn-out 2) provide information on basic mindfulness practices 3) how mindfulness practices can be incorporated in our clinics to prevent burn-out and empathy fatigue and 4) can mindfulness practices not only help the health-care provider, but also improve our relationship with our PALS?

**Recommendations to the field:** More research is needed to investigate the positive effects mindfulness practices can have both in patient satisfaction rates and health-care provider burnout and retention. Could teaching mindfulness practices to staff of our clinics provide the opportunity for our staff to improve compassionate care and increase their job satisfaction?





International Alliance of  
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**ALLIED PROFESSIONALS FORUM**  
**Atahotel Quark, Milan**  
**5 December 2013**

**SPEAKER:** Elena Gotti, [elena.gotti@centrocliconemo.it](mailto:elena.gotti@centrocliconemo.it) [elenagotti2000@yahoo.it](mailto:elenagotti2000@yahoo.it)  
Phone 00393482878139 or 00393384178440

**BIOGRAPHY:**

I am a registered nurse and professional counselor.

I graduated in nursing at the University of Milan in 1999, I have a Master's degree in Palliative Care and Post Graduate Course of End of Life. I have recently obtained the title of professional counselor. At the beginning of my professional activity I have worked at San Raffaele Hospital in the immunology ward and after that in the dialysis ward. When I finished my course about palliative care and end of life I started working in palliative home care with various foundations.

I now work at NEMO, an ALS clinical centre, as nurse coach and my main occupation is training with caregivers and management of home care.

## ABSTRACT

**AUTHOR/s:** Elena Gotti - nurse coach, Celestina Corti - nurse, Elisa De Mattia - respiratory physiotherapist, Giordana Donvito – occupational therapist, Pietro Perego – nurse, Christian Lunetta – neurologist, Valeria Sansone - neurologist  
[elena.gotti@centrocliniconemo.it](mailto:elena.gotti@centrocliniconemo.it); [celestina.corti@centrocliniconemo.it](mailto:celestina.corti@centrocliniconemo.it);  
[elisa.demattia@centrocliniconemo.it](mailto:elisa.demattia@centrocliniconemo.it); [pegvox@gmail.com](mailto:pegvox@gmail.com); [giordana.donvito@hotmail.it](mailto:giordana.donvito@hotmail.it);  
[christian.lunetta@centrocliniconemo.it](mailto:christian.lunetta@centrocliniconemo.it); [valeria.sansone@centrocliniconemo.it](mailto:valeria.sansone@centrocliniconemo.it)

**TITLE OF PRESENTATION:** Nurse coaching experience in an ALS clinical centre

**Key Theme:** Changing Practice

**Background:** The Professional Nurse Coach (PNC) is a registered nurse who integrates coaching competencies into his/her professional practice, grounded in a holistic perspective. With professional nurse coaching the patient is considered the expert of his/her own condition. The PNC works with individuals or with groups and demonstrates an unconditional positive regard for patients, and personalizes the approach for each individual. The holistic perspective is based on human caring and establishing a coaching relationship is very important for the success of care management. To date, this professional figure is not a part of the team engaged in the management and care of Italian ALS patients (PALS). Moreover, in the international scientific literature there is lack of information regarding the role of the PNC in the care of PALS.

NEMO (NeuroMuscular Omnicentre) is a multidisciplinary centre dedicated to neuromuscular patients, including PALS, established in 2008 and based on an holistic approach of care for patients and their families. NEMO staff includes a PNC dedicated to neuromuscular patients.

**Objective:** To describe the first two years of activity of PNC at NEMO center and to define a new training method for coaching PALS and their caregivers.

**Programme description:** Retrospective analysis of clinical charts to describe the PNC activity and review of the scientific literature to define an interactive method of training for patients and caregivers.

**Clinical outcomes:** Since January 2013, we analyzed clinical charts of 179 PALS (89 men and 80 women) mean age of 66. Forty-four PALS had a bulbar onset of disease, 80 patients were in non invasive ventilatory (NIV) support, 73 patients in invasive ventilation (IV) and 124 patients required artificial enteral nutrition (AEN). The coaching activity included NIV training, management of AEN, caring of Percutaneous Enteral Gastrostomy and use of devices for patients and their caregivers.

**Recommendations to the field:** ALS is a severely disabling disease and its neurodegenerative progression constitutes the main problem for patients and their family. Caregivers have the burden of caring for PALS and it is important for them to learn how to help the patients also with technical skills. In our experience, PALS and their caregivers report an improvement of the well-being related to the presence of PNC in their care management.

PNC should be included as permanent staff in an ALS team.



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**Atahotel Quark, Milan**  
**5 December 2013**

**SPEAKER:** Shiri Ben-Arzi

**BIOGRAPHY:**

In 1999 I was diagnosed with a rare illness. Doctors predicted a low chance of survival and prepared me for the possibility that I would not be able to have a “normal life”.

My personal and professional achievements are not only proof these doctors were wrong; they are proof that there is always a choice – for the patient, the medical team and everyone surrounding them.

In my professional life today I work as a Medical coach as well as training more medical coaches to help people with chronic illness, terminal illness and medical trauma survivors. I offer support, counseling and guidance to help improve the practical and emotional ability to cope with the given situation, encourage the healing process and facilitate an empowering Medical alliance between everyone involved

**Professional background and training:**

- Founder and CEO of M.C.I – Medical Coaching Institute.
- Medical Coach
- Medical Coach Master Trainer
- Certified Professional Co-Active Coach
- Certified ADD/ADHD Coach
- Member of the International Coaching Federation (ICF) and the Israeli Coaching Association
- NLP Master Practitioner
- Specialization in Trauma focused NLP
- Time Line Therapy™ Master Practitioner
- META Medicine™ Practitioner
- Founder and Former Chairperson of the Israeli Pulmonary Hypertension Association
- Former Board member of the European Hypertension Association

## ABSTRACT

**AUTHOR/s:** Shiri Ben-Arzi – Medical Coaching Institute; Efrat Carmi – IsrALS

**TITLE OF PRESENTATION:** Medical coaching in support of ALS patients and family members

**Key Theme:** Blue sky thinking

**Background:** Medical Coaching is a unique model based on Life Coaching; life coaching is an interaction aimed at helping people clarify goals and helping achieve them.

Medical Coaching is aimed for people living/coping with a medical crisis and/or chronic illness.

**Objective:** To implement the Medical Coaching model with ALS patients and their family members, and measure the added value to their quality of life and general ability to cope mentally and emotionally with the challenges of ALS.

**Programme description:** During 2012-2013 we have cooperated with the Israeli ALS association – IsrALS, and offered 12 free Medical Coaching sessions to a group of 21 ALS patients and family members. Sessions were held at the coach's office, except for when the client was bed ridden. In those cases, sessions were held at the client's house. Questionnaires were filled before the first coaching meeting and after the 12<sup>th</sup> meeting.

**Clinical outcomes:** The feedback, confirmed our premise that this a valid and significant tool to help patients and family members cope mentally and emotionally with the enormous challenges of ALS. The participants choose a variety of goals to be coached on.

Example of topics chosen by patients:

- Communication with family members
- Advocating and raising awareness to the needs of ALS patients
- Coping with difficult emotions and stress
- Coping with issues of self worth
- Finding ways to deal with daily challenges and loss of physical abilities.
- Breaking of the cycle of loneliness

We received feedback from patients and family members saying they felt they had an ally “walking along side” with them, supporting and helping them create a sense of clarity within the chaos.

**Recommendations to the field:** We wish to present the results of this work and the Medical Coaching model as an additional tool for emotional and mental support for both ALS patients and their care givers.



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**ALLIED PROFESSIONALS FORUM**  
**Atahotel Quark, Milan**  
**5 December 2013**

**SPEAKER:** Laurie B Fieldman, LCSW

**BIOGRAPHY:** Laurie B. Fieldman is the Director of Social Services for the Les Turner ALS Foundation in Skokie, IL and has been with the Foundation for seventeen years. She provides in-home counseling to patients and family members, as well as facilitates monthly support groups. Ms. Fieldman completed her graduate work at the University of Chicago School of Social Service Administration and she also holds a Masters of Management degree from National Louis University.

**Credentials:**

1999–Present Director of Social Services, Les Turner ALS Foundation, Skokie, IL

1993–2003 Founder and Director, Marcie’s Place Camp for Grieving Children, Chicago, IL

**Other Lectures:**

2013 FALS Summit at the National ALS Advocacy Day and Public Conference, “Communicating with Children and Young Adults”

2012 International ALS/MND Symposium, “Helping Children in ALS Families”

The 2012 Les Turner ALS Foundation Annual Education Meeting, “Coping Strategies for the ALS Couple” Managing the Emotional Impact and Improving the Quality of Life for ALS

2012 ALS/MND Nursing Symposium, “The ALS Couple”

2011 ALS/MND Nursing Symposium, “Coping with ALS”

2009 ALS/MND Nursing Symposium, “Helping Children Cope



## ABSTRACT

**AUTHOR:** Laurie B. Fieldman, LCSW

**TITLE OF PRESENTATION:** Young Carers in ALS Families

**ABSTRACT TITLE:** Young Carers in ALS Families

**Key Theme:** Young Carers

**Background:** When a child's parent is diagnosed with ALS, her/his life changes forever. The children in ALS families sense that their lives are different than the lives of their peers, as they are needed to help their family and their loved one in ways that their friends would not comprehend.

**Objective:** This presentation will provide therapeutic interventions that can be utilized by professionals working with ALS families in order to help the young carers understand what is happening so they can better cope with their feelings.

**Program description:** This lecture will provide information about the impact of a parent with ALS on children and how to minimize the ramifications of this experience. Interventions for counseling will be described to assist allied professionals in helping the young carers of ALS families manage their feelings.

**Clinical outcomes:** Case examples will be provided to help teach the utilization of the therapeutic interventions. The goal of this session is to provide allied health professionals with tools to help the young carers of ALS patients cope with their unique role.

**Recommendations to the field:** The impact of ALS upon the children in a family is profound. It is imperative that ALS professionals learn how to guide the parents and how to help the young carers cope, in order to minimize the detrimental effects of the ALS experience as they grow up.



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**ALLIED PROFESSIONALS FORUM**  
**Atahotel Quark, Milan**  
**5 December 2013**

**SPEAKER:** Sara M Feldman, PT, DPT, Peggy Allred, PT, DPT

**BIOGRAPHY:**

Sara Feldman, PT, DPT has been the physical therapist for the MDA/ALS Center of Hope at Drexel University College of Medicine since 1994. She received her BS from Temple University in Physical Therapy in 1987, her Masters from the University of Pennsylvania in Environmental Science in 1997 and her Doctorate in Physical Therapy from Drexel University in 2012. In addition to her role as the physical therapist at the multidisciplinary team clinic she is the Clinical Evaluator for outcome measures of clinical trials and is an Assistive Technology Professional.

Sara.Feldman@DrexelMed.edu

Peggy Allred, PT, DPT is currently the Research Administrator and ALS Program Manager at Cedars-Sinai Medical Center in Los Angeles. She develops and implements clinical research programming for the Neuromuscular Division and facilitates the multidisciplinary ALS clinic. She received her Bachelor's of Science in Physical Therapy from Texas Woman's University and her Doctor of Physical Therapy from Simmons College in Boston. She has worked in the ALS field for 25 and was previously with Washington University In St. Louis and Methodist Neurological Institute/Baylor College of Medicine in Houston, Texas.

Peggy.Allred@cshs.org

## ABSTRACT

**AUTHOR/s:** Sara Feldman, PT, MA, DPT, ATP; Peggy Allred, PT, DPT

**TITLE OF PRESENTATION:** Developing Best Practice Guidelines for Physical Therapy Evaluation of Individuals with ALS/MND

**Key Theme:** Changing Practice

**Background:** Physical therapists have many evaluation and assessment methods available to them; however a review of the literature reveals a lack of standardization in choosing which assessments to use during the evaluation process for motor neuron disease. This limited evidence results in physical therapists at multidisciplinary clinics making their own assessment and treatment decisions without the benefit of experience or guidance. While we did not want to remove the ability to be flexible in the clinic or downplay the importance of knowledge and skill, we recognize that physical therapists who are new to ALS/MND might benefit from the guidance of experienced clinicians in this process.

**Objective:** The objective of our work is to investigate what evaluation tools and assessments are being used by physical therapists in the clinic and move toward standardization of the evaluation process.

**Programme description:** An initial meeting of physical therapists who were part of a research consortium revealed a strong desire to develop standards for evaluation and treatment of individuals with ALS/MND. At that meeting and at a smaller follow-up meeting, the establishment of measures of physical assessment and appropriate clinical evaluation tools was determined to be a priority. A survey was developed to produce best practice guidelines for evaluations/assessments by first surveying this initial group, and then expanding the survey to a larger group of therapists. The next step will be to validate the guidelines we propose through expert consensus. Finally, the recommendations will be made readily available to any therapist in the field.

**Clinical outcomes:** The guidelines related to the physical therapy assessment will be evaluated and integrated into a user-friendly template. The final outcome of the consensus will be provided in the presentation.

**Recommendations to the field:** The results so far indicate that there are some consistencies in the evaluation tools used by physical therapists who work with people with ALS/MND; however, there are also some variations. This leads to the question of what is the best practice? It is important to note that evaluations can be adaptable documents that can change with time and with new information. The standardization of physical therapy evaluations does not take out the needs of each individual center, but ensures that much of the same information is being captured. This is important when it comes to looking at evidenced based practice or if looking to do research across centers.





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**SPEAKER:** Jessica ten Broek-Pastoor and Sandra Offeringa

**BIOGRAPHY:**

**Jessica ten Broek-Pastoor** is physical therapist affiliated to Radboud University Nijmegen Medical Centre, Nijmegen Centre for Evidence Based Practice, Department of Rehabilitation, The Netherlands since 1998. In 2001 she graduated her Master of Science in Physical therapy (Leuven, Belgium). She is specialized in the physical therapy treatment of neuromuscular patients, in particular patients with ALS. She is a member of the ALS team Nijmegen which treats approximately 40 patients yearly with ALS/PLS and PSMA. She is the first author of the guideline for physical therapy in ALS (Dutch) which was developed as part of the project “Multidisciplinary allied health practice guidelines for physical, speech and occupational therapy in ALS”.

**Sandra Offeringa** is speech therapist and speech language pathologist (M.A.) working for the Rehabilitation Department of the Academic Medical Center, University of Amsterdam in Amsterdam, the Netherlands, since 2001.

As a member of the MND/ALS-team, she’s an expert in speech therapy for patients with ALS/PLS and PSMA and supports an interdisciplinary treatment policy. She is involved in the treatment of patients with ALS in clinical settings and outpatient services and is doing home visits regularly. She’s also a member of the speech therapy working group of the Netherlands ALS Center, where she in cooperation with expert colleagues facilitates the improvement of quality of speech therapy for patients with ALS in the Netherlands. She is the first author of the guideline for speech therapy in ALS (Dutch) which was developed as part of the project “Multidisciplinary allied health practice guidelines for physical, speech and occupational therapy in ALS”.

**Jorinde Oudenaarden** is occupational therapist affiliated to Reade centre for rehabilitation and rheumatology, Amsterdam, the Netherlands (since 2000). In 2009 she graduated her Master of Science in Evidence Based Practice at the University of Amsterdam). She is specialized in the occupational therapy treatment of spinal cord injury patients and patients with ALS and is member of the ALS team Amsterdam Reade, which treats approximately 20 patients yearly with ALS/PLS and PSMA. She is the first author of the guideline for occupational therapy in ALS (Dutch) which was developed as part of the project “Multidisciplinary allied health practice guidelines for physical, speech and occupational therapy in ALS”.

**Dr. Marike van der Schaaf** is physiotherapist and epidemiologist. She works as senior researcher in the field of allied health care at the department of rehabilitation of the Academic Medical Center, University of Amsterdam in Amsterdam, the Netherlands. She was coordinating supervisor for the project “Multidisciplinary allied health practice guidelines for physical, speech and occupational therapy in ALS”.

## ABSTRACT

**AUTHOR/s:** Broek-Pastoor Ten J, Offeringa S, Oudenaarden J and Schaaf Van der M.

**TITLE OF PRESENTATION:** Multidisciplinary allied health practice guidelines for physical, speech and occupational therapy in ALS.

**Key Theme:** Multidisciplinary, Guidelines, Quality of Life, Physical Therapy, Occupational Therapy, Speech Therapy.

**Background:** Evidence-based clinical practice guidelines improve quality and effectiveness of patient care. For ALS, such guidelines are not available for the different allied health care professions.

**Objective:** To develop recommendations to support physiotherapists, occupational therapists and speech therapists in clinical decision making with respect to the assessment and interventions of relevant impairments and restrictions in functioning of patients with ALS.

**Programme description:** A multidisciplinary taskforce carried out the entire project. The guideline was developed according to the model from the Dutch Institute for Healthcare Improvement (CBO) 'Evidence based guideline development'. This model contains the following steps: identify relevant questions, systematic literature search, quality assessment and summary of the evidence, formulation of concept recommendations, feedback from experts, rephrase of recommendations, final approval and authorisation by relevant stakeholders.

**Clinical outcomes:** The project resulted in a practice guideline with recommendations on the assessment and therapeutic interventions for occupational, speech and physical therapists within the relevant domains of the International Classification of Functioning, Disability and Health. The recommendations cover all rehabilitation stages integrating evidence from research and clinical expertise of expert health care professionals, patients and their carer's preferences, the national association of physical, occupational and speech therapy and of the Netherlands ALS Center. In addition to the practice guideline and the recommendations, a summary of the clinical reasoning process in algorithms is provided. The guidelines are e-published in Dutch and available at [www.als-centrum.nl/als-richtlijn/](http://www.als-centrum.nl/als-richtlijn/) with free downloads.

**Recommendations to the field:** The development of the multidisciplinary guidelines has allowed recommendations on the assessment and therapeutic interventions for occupational, speech and physical therapists working with patients with ALS. Use of the guideline will improve standardization and transparency of the therapeutic assessment and interventions. As the guidelines were developed simultaneously for these three allied health care professions, interdisciplinary aspects of treatment are covered which will improve care and quality of life for patients with ALS.



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**ALLIED PROFESSIONALS FORUM**  
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**5 December 2013**

**SPEAKER:** Malabika Ghosh

**BIOGRAPHY:**

Malabika Ghosh works as a Clinical Lead Occupational Therapist at the Lancashire Teaching Hospitals, NHS Foundation Trust, Preston, U.K.

This paper is based on a multidisciplinary team research led by the presenter at the Motor Neurone Disease Association at Preston.

Over the years Malabika has been involved in several areas of research in stroke, acquired brain injury, and motor neurone disease. Cognition in Motor Neurone Disease is an interest area for Malabika and it is hoped this journey would continue with further research, which adds to the evidence base for Occupational therapy and all other specialities that are involved in the care of patients with Motor Neurone Disease.

## ABSTRACT

**AUTHOR/s:** M. Ghosh, H. Noble, P. Callagher, M. O'Brien, P. Murphy.

**TITLE OF PRESENTATION:** Recognising the role of Occupational Therapy in making sense of decision making in Motor Neurone Disease

**Key Theme:** Cognition; Carer burden; Decision making; Behavioral changes.

**Background:** Cognitive impairment in Motor Neurone Disease (MND) can have a major impact on social functioning, language, and decision making ability (1). Research suggests that some form of cognitive impairment can be identified in up to 50% of patients diagnosed with Motor Neurone Disease (2). Recent research also suggests that cognitive and behavioural changes have a greater impact on carer burden in Motor Neurone Disease, even more than physical changes (3).

### **Objective:**

- 1) To explore the nature of cognitive difficulties in MND.
- 2) To explore links between cognitive impairment and difficulties with decision making after MND.
- 3) To provide advice on best practice guidelines as regards management of cognitive executive difficulties in a timely manner, in MND.

**Programme description:** A study was undertaken in order to understand patient and caregiver perspectives on decision making in MND. 20 patients diagnosed with MND, referred to Occupational Therapy, were identified for this study. Patients with severe speech impairment due to bulbar palsy, or those too medically unwell to participate were excluded from the study. Each patient was tested on their Cognitive ability using Woolley's ALS Cognitive Behaviour Scale. Patients and their carers' views regarding their presentation, and its impact on their functioning in day to day life were also documented.

**Clinical outcomes:** In day to day clinical practice, MND patients with cognitive limitations can be less compliant with interventions (4). Patients who exhibit such behaviour may not be able to provide a sound rationale for their decision making (5). The impact this can have on patients, their carers' and overall on the economic effect of commissioning of care and other services can be immense. Increased awareness and early identification of cognitive limitations is paramount to design better care programmes for patients diagnosed with Motor Neurone Disease and their families.

**Recommendations to the field:** Timely identification and strategies for management of cognitive decline is crucial in Motor Neurone Disease, to help patients and their families take important decisions regarding uptake of professional advice and end of life care in an appropriate manner. Occupational Therapists can play a significant role in 'making sense of decision making' in patients with MND.

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**ALLIED PROFESSIONALS FORUM**  
**Atahotel Quark, Milan**  
**5 December 2013**

**SPEAKER:** Meraida Polak, RN, BSN

**BIOGRAPHY:** Meraida is a graduate of the University of Florida College of Nursing. She was the nurse manager for the Neuroscience unit at Emory University Hospital from 1976-1988. In 1988 she became the neuromuscular research nurse in the department of Neurology in the Emory University School of medicine. She has practiced exclusively with ALS patients since 1992. Since that time she has started and managed a multidisciplinary clinic and coordinated more than 15 clinical trials in ALS. She has co-authored chapters on ALS in neuroscience nursing textbooks, the Core Curriculum for Neuroscience Nurses, and Amyotrophic Lateral Sclerosis, A Patient Care Guide for Clinicians.

In 2009 started the Neuralstem Inc. Phase I, Open-label, First-in-human, Feasibility and Safety Study of Human Spinal cord derived Neural Stem Cell Transplantation for the Treatment of ALS as lead study coordinator at Emory University.

## ABSTRACT

**AUTHOR/s:** Meraida Polak, RN BSN

**TITLE OF PRESENTATION:** Using a Database for Clinical Management

**Key Theme:** Changing Practice

**Background:** The Emory ALS Center's multidisciplinary clinic started in 1998 with no administrative staff support. Clinical staff created a database using Microsoft Access<sup>®</sup> to facilitate sending appointment reminder letters to patients. Over time, milestone fields and on-going clinical measurements were added to allow for tracking disease progression and tailoring support. It allows the provider to get a complete snapshot of how the patient is doing without having to cull information from notes.

**Objective:**

- The participant will see how an electronic database can be used as a clinic management tool and a clinical management tool.
- The participant will identify two methods of obtaining the skills needed to create their own.

**Programme description:** This paper describes The Emory ALS Center's Microsoft Access<sup>®</sup> database and how it is used. Documents are presented for initial data collection and procedures for efficient data entry are shown. Simple queries and reports are displayed that show values for critical measurements from their first visit to their most recent and the last visit is revealed in detail. In clinic the provider can see the slope of progression at a glance. The status of milestone conversations (feeding tube placement, advanced directives) is clear.

Besides the clinical value, the database is a rich resource for data mining. The care and outcomes for the population are documented. Questions can be asked such as the correlation between timing of feeding tube placement and survival. This in turn allows an inference about when it might be too late to proceed with PEG.

**Clinical outcomes:** The clinical team can easily see the patient's slope of progression and approach of intervention thresholds. Important aspects of care, such as initiation of NIPPV or advanced directive discussion are less likely to be delayed. The effectiveness of various interventions is visually illustrated.

**Recommendations to the field:** Obtaining database skills or hiring someone with these skills to manage a clinical database is a valuable investment. Within the ALS academic and nonprofit community, interest in sharing this data is growing. Obtaining skills in this area will allow centers to more easily join this process.



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**ALLIED PROFESSIONALS FORUM**  
**Atahotel Quark, Milan**  
**5 December 2013**

**SPEAKER:** Sarah Lavender

**BIOGRAPHY:**

I qualified as an Occupational Therapist in 1983 and subsequently worked in acute physical hospitals facilitating discharges, social services adapting property for the disabled before becoming the wheelchair therapist in North Kent in 1990.

I returned to work after having a family in 2000, and continue to work at the Wisdom Hospice, Rochester, Kent where I have specialised in Palliative Care especially with MND/ALS patients.

I have run training courses for AHPs on MND/ALS and recently been involved with Dr David Oliver updating the OT chapter in the book Palliative Care in Amyotrophic Lateral Sclerosis. I have made a DVD to show the benefits of a two seater riser recliner armchair.

I am a committee member of the South East MND Network Steering Group.

## ABSTRACT

**AUTHOR:** Sarah Lavender

**TITLE OF PRESENTATION:** Pain of Isolation

**Key Theme:** Changing Practice - People living with MND/ALS can become isolated will be considered especially when using wheelchairs, riser recliner armchairs, and hospital beds. It is important to consider how they maintain their physical contact with family and friends ie cuddle loved ones and read stories to children/ grand-children.

**Background:** It is apparent that often the provision of equipment by the statutory services is the cheapest equipment possible to assist in Activities of Daily Living. There is consideration of the physical need but the psychological, social or spiritual aspects are often ignored. Whilst carrying out holistic assessments of people living with MND/ALS there is a greater awareness of these wider aspects of care - particularly when looking at double electric beds and two seater riser recliner armchairs.

**Objectives:** All professionals should consider the pain of isolation and with equipment, strategies and “thinking outside of the box” enable the person with MND/ALS to live a fulfilled life.

**Programme description:** The results of not considering the reduced role in Activities of Daily Living will be discussed – showing how this can affect a person with MND when they are unable to carry out an activity. Examples will include:

- Hobbies – a lady living with MND struggling to come to terms with her lack of function.
- Days out and Holidays – will there be enough rails, level access to property or is it easier to stay at home?
- Family – used to always cook for the family, but now watch as she is fed through a Peg tube.

Fatigue management will be considered, showing how equipment ie a mobility scooter can prevent isolation and enable a person living with MND to continue walking their dog.

**Clinical outcomes:** A 3 minute DVD will be shown to emphasise the benefits of a two seater riser recliner armchair which has been developed at the Wisdom Hospice, Kent with an MND/ALS patient. The advantages of a double electric bed to assist with transfers will be discussed – with the aim of maintaining physical contact and quality of life.

**Recommendations to the field:** Every human being deserves a cuddle and physical contact from their loved ones, so why should a person living with MND/ALS be any different? It is important to carry out an holistic assessment where the psychological/ social / spiritual needs are as important as their physical needs and appropriate equipment provided to facilitate physical contact.

### Acknowledgements

MND patient in DVD – Pauline Pearson

Sarah Lavender, Senior Occupational Therapist, Wisdom Hospice, Rochester, Kent, ME1 2NU,  
England [sarahlavender@nhs.net](mailto:sarahlavender@nhs.net)

+441634 823589





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## ALLIED PROFESSIONALS FORUM Atahotel Quark, Milan 5 December 2013

**SPEAKER:** Marco Caligari

**BIOGRAPHY:** Dr. Marco Caligari is a Physiotherapist at the Physical Medicine And Rehabilitation Department of the “Salvatore Maugeri” Foundation, I.R.C.C.S., Rehabilitation Institute of Veruno (NO) – Italy, since 1996. He is graduated with distinction in “Therapist of Rehabilitation” at the University of Medicine in Pavia on 1996 and also graduated with distinction in Physiotherapy at the University of Insubria in Varese on 2004. Since 10 years he is developing many devices of Augmentative and Alternative Communication (AAC) and domotic devices for patients with severe motor impairments.

From 2003, Dr. Caligari collaborates with the Italian Association of ALS (AISLA) as consultant for patients with communication impairments. In 2007 he has been member of the Government Commission for the Amyotrophic Lateral Sclerosis and participates to various Technical and Scientific Committees.

He is teacher in several courses in the field of AAC and environmental control. He authored and co-authored several scientific papers published in medical and technical specialized magazines. Since 2009 he is contracted Professor at the Amedeo Avogadro University of Novara. From 2012 he leads a project of research and development for communication devices for patients with ALS supported by a grant from AriSLA – Fondazione Italiana di ricerca per la SLA, Sclerosi Laterale Amiotrofica (“Progetto ComuniCare”, 2012-13)

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## ABSTRACT

**AUTHOR/s:** Marco Caligari

**TITLE OF PRESENTATION:** ComuniCARE project: AAC Apps for people with ALS.

**Key Theme:** E-solution to improve outcomes for people living with ALS/MND

**Background:** Amyotrophic Lateral Sclerosis (ALS) produces progressive loss of voluntary muscle strength. People with ALS (PwALS) often have – in addition to motor, respiratory, and swallowing problems – phonatory impairments, and many of them become unable to speak. This condition hinders their communication and interpersonal relationships.

**Objective:** To try to solve, at least in part, this problem, we have set up, at the “Laboratory of Communication and Automation” of the Salvatore Maugeri Foundation, with the support of ARISLA (Italian Foundation for Research in ALS), the “**ComuniCARE project**”, that is implementing various solutions for communication and environmental control, suitable for PwALS who still have some voluntary movement.

**Programme description:** The ComuniCARE project has produced numerous software programs that are available for the most common platforms (Windows and Android). Our applications allow PwALS to write and communicate with a special predictive keyboard endowed with vocal synthesis through various access methods, e.g. touchscreen or scanning interface controlled by an adapted switch. Our applications also allow PwALS to surf the Internet, manage e-mails and attend social networks, or control the home environment (turning on/off lights, controlling TV, DVD player, regulating the air conditioner, etc.). The implementation of our applications is based on a close contact with the PwALS who use them daily (up to 8-10 hours per day), suggesting changes and new features.

**Clinical outcomes:** Preliminary data, collected with clinical scales that investigate Quality of Life and the effect of applications on communication impairments, are very positive and encouraging. Our next goal is to extend the availability of our applications to PwALS throughout the world through a translation into various languages.

**Recommendations to the field:** Considered the importance of the functions that our APPs recover (interpersonal communication, social relationship and environment control capabilities) and considered the wide user satisfaction we suggest to provide it in all appropriate cases.

### **Contact Information:**

Marco Caligari, Physiotherapy; Chief of “Communication and Home Automation Laboratory”, Division of Physical Medicine and Rehabilitation, Scientific Institute of Veruno, Fondazione Salvatore Maugeri, I.R.C.C.S, Veruno (Novara), Italy.

email: [marco.caligari@fsm.it](mailto:marco.caligari@fsm.it) [marco.caligari@alice.it](mailto:marco.caligari@alice.it)

Website: [http://www.fsm.it/fsm/lab\\_ric\\_sperimentale\\_linea05-6\\_07.html](http://www.fsm.it/fsm/lab_ric_sperimentale_linea05-6_07.html)



International Alliance of  
ALS/MND Associations

**ALLIED PROFESSIONALS FORUM**  
**Atahotel Quark, Milan**  
**5 December 2013**

**SPEAKER:** Amber L. Ward, MS, OTR/L, BCPR, ATP  
Occupational Therapy Coordinator  
Carolinas Neuromuscular ALS/MDA Center, Charlotte, NC USA

**BIOGRAPHY:** Amber Ward has been a treating occupational therapist for 19 years; 10 years in inpatient rehabilitation, and 9 years as full time Occupational Therapy Coordinator with persons with ALS and muscular dystrophies. She has treated a wide variety of patients, of all ages and functional levels. She currently is an adjunct professor at the OTA program at Cabarrus College of Health Sciences in addition to working in the clinic. She received the RESNA Assistive Technology Professional certification in 2004, and became AOTA board certified in physical rehabilitation in 2010. She is the author of an article about power wheelchairs with persons with ALS published in Archives of Physical Medicine and Rehabilitation in 2010. She is currently the President of the North Carolina Occupational Therapy Association.

**Contact Information:**

1010 Edgehill Road North  
Charlotte, NC 28207

704-355-0787- direct line at work  
704-825-7356- home  
704-301-7282- cell

Email: [amber.ward@carolinashealthcare.org](mailto:amber.ward@carolinashealthcare.org)

## ABSTRACT

**AUTHOR/s:** Amber L. Ward, MS, OTR/L, BCPR, ATP  
Amy Wright, SLP-CCC, ATP

**TITLE OF PRESENTATION:** Gadgets and Gizmos II; Continuing to Think Outside the Box

**Key Theme:** Blue Sky Thinking

**Background:** Every day therapists and caregivers develop creative solutions to tackle problems faced by people with ALS/MND. We inspire each other to invent and create using pre-existing adaptive equipment and/or homegrown materials. Our clinic is staffed by a team of full time therapists who devote much of their time to creative troubleshooting and developing new gadgets to address some of the challenges that PALS encounter. There is no literature on inventive solutions for the ALS/MND client. Gadgets and Gizmos was well received last year at the forum, so we wanted to build on and expand this topic.

**Objective:** To educate allied health staff from around the world in creative problem solving with existing and newly designed equipment.

**Programme description:** The OT and SLP on our team have extensive experience with assistive technology options, and use this experience to create low-tech ideas for equipment and assistive devices. Our creativity inspires PALS and their caregivers and they inspire us. We all work together to think outside the box and identify new uses for old equipment and/or household items, make custom modifications to meet specific requests or needs and design adaptive equipment from scratch.

**Clinical outcomes:** The clinical outcomes are seen in the clinical and home environments where clients have access to adaptive equipment which is functional and appropriate. This equipment provides individuals with weakness or atrophy with the ability to take on daily challenges they might not be able to manage otherwise. We would like to share some of the newest solutions developed by staff, clients and caregivers within the ALS/MND allied health community.

**Recommendations to the field:** Since many clients with ALS/MND have physical and financial constraints which do not allow them to purchase numerous pieces of equipment, the therapists who work with them must think creatively to develop low-cost solutions. We hope to inspire our colleagues to think outside the box.