



international  
symposium  
on ALS/MND



**International Alliance of  
ALS/MND Associations**

# Allied Professionals' Forum

29 November 2011

**This event has been kindly sponsored by:**

**ALS Hope  
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## ALLIED PROFESSIONALS FORUM

### PROGRAMME

8.30	Welcome and introductions		
8.40	'You're living until the day you die – there's no place like home'	Sally Boal	Aus
9.00	The effects of withdrawal of non-invasive ventilation on the professionals involved	David Oliver	Eng
9.20	The South East Motor Neurone Disease Network – An evolving model to support professionals and improve quality of care	Catherine Knights	Eng
9.40	Model of a peer supervision group implemented between allied health staff in an acute hospital setting.	Melanie Holmes	Aus
10.00	Improving continuity of Care: A Social Work perspective	Patsy Pynn	Aus
<b>10.20</b>	<b>Morning Tea</b>		
10.50	Use of the ALS Cognitive Behavioural Screen (ALS CBS) in the Multidisciplinary Clinic Setting: Enhancing Practical Management Strategies	Susan Woolley-Levine	USA
11.10	Nutrition Throughout the Course of ALS	Meenakshi Wadhwa	USA
11.30	Advance Care Planning: Initiating 'Dying Conversations'	Monica Wilson	Aus
11.50	Using a circular process to build emotional readiness for conversations about advance care planning	Robin Ray	Aus
<b>12.10</b>	<b>Lunch and networking</b>		
13.30	E-solutions for people living with Motor Neurone Disease. What do they offer? Are they the answer	Maryanne McPhee	Aus
13.50	iPad and iPhone implementation in disabilities: Access, communication, apps and mounting	Justin Ware	Aus
14.10	In-expensive and flexible gaze tracking from bed	John Paulin Hansen	Den
14.30	MND Aware: A web-based awareness training program about Motor Neurone Disease	Gina Svolos	Aus
14.50	Improving quality of care and empowering patients through electronic communication	Nicole Yarab	USA
<b>15.10</b>	<b>Afternoon Tea</b>		
15.40	Surgical Therapies in ALS/MND - optimising Techniques to improve patient care	MaryJo Elmo	USA
16.00	A Retrospective Evaluation of High Frequency Chest Wall Oscillation (HFCWO) and Mechanical Insufflation/Exsufflation (MIE) for Airway Secretion Management in ALS Patients	Carlayne Jackson	USA
16.20	Identification of pain among patients living with MND in the clinical setting	Jan Clarke	Eng
16.40	Changing Practice. The English and Turkish Partnership	Rachael Marsden	Eng
<b>17.00</b>	<b>Summary and Close</b>		

Co-Chairs - Steve Bell, MNDA, UK; Rodney Harris, MND Victoria, Australia

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**ALLIED PROFESSIONALS' FORUM  
Hilton Hotel, Sydney  
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**SPEAKER: Sally Boal**

**BIOGRAPHY:** Sally has worked as a Regional Advisor for the Motor Neurone Disease Association Victoria for the past five years. Sally worked as a teacher from 1978 until 1984 working in both metropolitan and country Victoria. After undertaking further studies while Sally's children were young Sally commenced working in the welfare and community services field and has continued working in this area for over 20 years.

Sally's experience has included working with individuals, families and groups whilst working for ;  
The Department Of Human Services Victorian Government.

- Ballarat Child & Family Services as a case manager in the Intensive Family Service Program.
- Ballarat Community Health Centre, Victims Assistance Program.
- The Regional Parenting Centre Geelong.
- Glastonbury Child & Family Services running group programs.
- Vicdeaf as a regional case manager supporting the Deaf community across the Barwon South Western Region.

Sally's formal qualifications include a Bachelor of Education and Bachelor of Social Work. The greatest education however has been life, family, colleagues and working with the many families Sally has been given the opportunity to work alongside throughout her career.

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**AUTHOR: Sally Boal**

**TITLE OF PRESENTATION: 'You're living until the day you die – there's no place like home'.**

**ABSTRACT:**

Key Theme: Integration of palliative care and tailoring supports to family needs.

Background: A person in the later stages of MND can present as requiring such high, complex care that health professionals can sometimes feel overwhelmed and the safest option from a health professional's view can be a palliative care unit or nursing home. This may be a valid option for some families, in some situations, but should not be a one size fits all solution. The majority of people MND Victoria supports want to remain living at home for as long as possible and many wish to die at home. Over the last year 70% of individuals with MND that MND Victoria have supported have stayed at home up until four weeks before their death and approximately 30% have died at home. It is also acknowledged that in some cases this may not be possible or appropriate. The decision as to where a person lives or dies always needs to be the individual's and family's choice.

Objective:

- Health professionals will view staying at home in the later stages of MND and dying at home as options to be potentially explored and pursued.
- Health professionals will build their knowledge and courage to assist people with MND to stay at home if that is the person with MND and family's wish.
- Health professionals will reflect on what we all need as humans to feel safe, to have control and feel valued.
- To assist people with MND to stay at home health professionals will collaborate with the individual, family and care networks to devise an individual, co-ordinated, person centred, concrete care plan that is reviewed regularly and that includes medical, practical, psychological and allied health responsibilities and goals as required.
- Ways of bridging specialist knowledge into concrete community care within the home to be explored.

Programme description: MND Vic is based on a person centred, holistic, person in environment approach. The video 'You're living until the day you die - there is no place like home', explores the experience of people with MND and their families in the later stages of their illness, what is important about being home and what has assisted them to stay at home including the utilization of a variety of palliative care services and other community services.

Clinical outcomes:

- People with MND will stay at home and die at home if that is their wish and their families wish with appropriate supports.
- People with MND and their families will, where ever possible, be offered a range of services that can best meet their needs.

Recommendations to the field:

- Strong collaboration, forward planning and clear communication is required between support services, the individual with MND and the family at each stage to ensure a quality, clear and concrete support plan is in place that is tailored to each family's needs.
- It is important for health professionals to reflect on their feelings and how these may influence the services and options that are offered to families.



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**SPEAKER: Dr David Oliver**

**BIOGRAPHY:**

Dr David Oliver is 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 School 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 St Christopher's Hospice London and he was appointed to his present post in 1984.

He has lectured widely in the UK and in other countries, including Croatia, Poland, USA, Australia, South Africa, Italy, Japan and New Zealand. He was awarded the Humanitarian Award of the International Alliance of ALS/MND Associations in 2003, in recognition of this 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 has been the Clinical Lead on the UK End of Life Programme Framework on End of Life Care for Neurological Disease and he is the Chair of the Neurology Taskforce of the European Association for Palliative Care.

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**AUTHORS:** Cassy Rowe-Haynes, David Oliver, Christina Faull

**TITLE OF PRESENTATION:** The effects of withdrawal of non-invasive ventilation on the professionals involved

**ABSTRACT:**

**Key Theme:** Support for staff; Integration of palliative care

**Background:**

As more people with respiratory failure from ALS / MND receive non-invasive ventilation (NIV) there are more occasions when the withdrawal of this treatment may be requested by the patient and family. This can be a very stressful time for all involved – the person with ALS/MND, their family and the professionals who are caring for them. The stresses on the staff have not been studied, although the effects of stress on staff morale, wellbeing and effectiveness are well known.

**Objective:**

To ascertain the practical, emotional and ethical issues encountered by doctors involved in the withdrawal of NIV

**Programme description:**

All doctors in the Association for Palliative Medicine for Great Britain and Ireland were contacted and offered the opportunity to complete an online survey. 134 people completed the survey – 64% were consultants, 82% were working in hospices and 97% were involved in the care of people with ALS/MND.

**Clinical outcomes:**

60% of the doctors had been involved in the withdrawal of NIV, usually rarely and only 40% had been involved in two or more occasions.

All found the procedure challenging practically, emotionally and ethically and several themes were apparent from their comments:

- People were often poorly prepared for the deterioration on NIV and without earlier discussion the later care was very difficult, as patients and families had unrealistic expectations or had received mixed messages
- Advance care planning, including advance decisions to refuse treatment were helpful, although professionals were often unclear as to their legality and use
- Different views were often found between patients and families and within the caring teams, leading to, on occasions, profound disagreements
- Some professionals felt that withdrawal of NIV was euthanasia or assisted suicide, despite ethical advice that this was not the case

**Recommendations to the field:**

The withdrawal of NIV may lead to conflict and disagreement in caring teams, and lead to profound stress. This may be reduced by ensuring that there is clear discussion of the implications of NIV when it is initiated and this continues with ongoing discussion and advance care planning by all involved. Multidisciplinary teams should consider their views before faced with a patient asking for withdrawal so that these issues can be acknowledged, discussed and hopefully resolved, with improved care not only for the patient and family but the team members as well.



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**SPEAKER: Catherine Knights**

**BIOGRAPHY:**

Catherine has been the Coordinator for King's MND Care and Research Centre, London since September 2010. She is a physiotherapist by profession and previously worked in community settings for more than 20 years. Her roles have included being team leader for the community physiotherapy team and more recently in a more generic role providing a specialist practitioner service for people with Multiple Sclerosis.

Her interest in MND began when providing the physiotherapy service to the local hospice in the mid 1990s and she continued to chair the local MND Multidisciplinary team meetings until her move to Kings.

She has been a member of the South East MND Forum since 2001 and continues to be a member of the South East MND Network Steering Group taking on the role of Chair in April 2011.

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**AUTHOR/s:** Catherine Knights, Sara Jane Murray

**TITLE OF PRESENTATION:** The South East Motor Neurone Disease Network – An evolving model to support professionals and improve quality of care

**ABSTRACT:**

**Key Theme:** Support for Staff

**Background:**

The South East Regional MND Forum was set up in 1999 with the objective ‘to raise standards of care and equity across the South East of England for people with MND and their carers through collaborative working’. In 2009 it was realised that the UK political and economic climate was having a huge impact on NHS and social services, making it more difficult to achieve equitable services. Professionals were under pressure with increasing caseloads with lack of time and funding to attend meetings and educational events. This led to professionals feeling isolated and unsupported.

**Objective:**

To re-launch the Forum, offering a more flexible model to support professionals and improve the care of people with MND across a wider geographical area.

**Programme description:**

A stakeholder event was held in 2009 to consult with a wide range of health and social care professionals on the challenges they were facing and debate ideas for workable solutions. A steering group then developed a flexible model that was designed to offer support through networking, education and the sharing of best practice through a variety of media.

**Clinical outcomes**

- Forum re-launched as the ‘South East MND Network’, open to all professionals with an interest in MND across Kent, Surrey and Sussex.
- Electronic database of members set up – current membership 221
- Newsletter circulated electronically to all members
- Short, half day education sessions offered at minimal cost to professionals, with the support of local MND Association branches, repeated across the region to increase participation. Sessions included respiratory management and compassion fatigue in professionals.
- Mapping of respiratory services using online questionnaires (Survey Monkey)
- Annual Conference offering networking opportunities, highlighting good practice from across the region and sharing information from the respiratory mapping to promote changes in practice.

**Recommendations to the field:**

The South East MND Network demonstrates a way of successfully continuing to engage and support health and social care professionals despite the current UK climate of cuts and statutory service reorganisation. Flexible networking, information sharing, and educational opportunities allow staff to engage with the Network, supporting them through challenging times and ensuring quality of care. This is a dynamic model which will continue to evolve and could be replicated elsewhere.



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**SPEAKER: Melanie 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 three years ago.

For the period of this sojourn Mel has worked for the Victorian Respiratory Support Service. This is based at the Austin Hospital and provides a state wide service for clients who require mechanical ventilation in the community. She and her fellow OT, Amanda McLaughlin, have begun researching the prevention and treatment of nasal pressure ulcers with the support of the rest of the team and especially the director, Dr Mark Howard.

Mel is also the OT at The Kevin Heinze Garden Centre in Melbourne.

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

**TITLE OF PRESENTATION:** Investigation of the prevention and treatment of bridge of nose pressure ulcers in clients who use non-invasive ventilation.

**ABSTRACT:**

**Key Theme**

It was apparent that a significant percentage of clients who require non-invasive ventilation develop nasal pressure ulcers. This can result in pain and discomfort which can make use of a ventilator mask highly uncomfortable and affects compliance and the efficiency of ventilation, as well as impacting sleep and enjoyment of activity. In the worst cases it can result in an inability to continue mask ventilation.

**Background**

The Victorian Respiratory Support Service (VRSS) is a state wide service providing long term home based ventilation. Currently we have 46 MND patients in our service who use non invasive ventilation. Pressure ulcers mainly develop on the bridge of nose but can also occur on the forehead or sides of the nose. A protocol was developed for the prevention and management of such ulcers which involved outlining and reviewing strategies to prevent damage to the nose and harden the skin, and providing the appropriate dressing according to the grading of the ulcer. Provision of education to the team was ensured to unify the approach to treatment.

**Objective**

To trial a protocol for the prevention of nasal pressure ulcers and to outline the effective treatment of pressure ulcers that do develop, ensuring early identification, management of risk, and a consistent treatment regime.

**Programme description**

A protocol for prevention and treatment of nasal pressure ulcers was developed including the identification of the most appropriate dressings. Further investigation is planned to assess the prevalence and determining factors for the development of bridge of nose ulcers. An application for a formal research project has been submitted to the Austin Hospital Ethics Committee.

**Clinical outcomes**

- The Ethics Committee at the Austin Hospital are currently considering a formal research proposal to expand the study.
- A treatment protocol has been developed and implemented on the ward.
- Staff education has been conducted.
- Family education and a sample of the appropriate dressing is provided on patient discharge.
- Follow up is provided post discharge if required.

**Recommendations to the field**

Nasal pressure ulcers are often overlooked or tolerated, ignoring the need for prevention and management before they necessitate the disruption or cessation of non-invasive ventilation. Protocols for management and family education must be provided to ensure their optimum management.



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**SPEAKER: Patsy Pynn**

Social Worker Calvary Health Care Sydney  
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**BIOGRAPHY:**

Patsy has had many years of experience as a Social Worker, particularly in areas of health and disability.

For the past seven years Patsy has been working at Calvary Health Care Sydney, with both the Palliative Care inpatient & community teams. Patsy has developed a special interest in the challenges facing clients with Motor Neurone Disease and part of her workload includes working one day a week with MND clients referred to the Calvary MND service.

**AUTHOR: Patsy Pynn Social Worker Calvary Health Care Sydney**

**TITLE OF PRESENTATION:**

**“IMPROVING CONTINUITY OF CARE: A SOCIAL WORK PERSPECTIVE”**

**ABSTRACT:**

**Key Theme:** Changing Practice; Multi-disciplinary teams; continuity of care.

**Background:** Calvary Health Care Sydney’s MND Service was established in 2001. At that time the permanent members of the “team” included a Palliative Care Specialist, a Rehabilitation Specialist and a Clinical Nurse Consultant but no designated Social Worker. Clients were seen either in the clinic or at home, depending on need. Referrals to Social Work were made to one of the two Aged Care & Disability Assessment Teams in the area, depending on the client’s residential address. There was no consistency in which Social Worker became involved. When the client entered hospital, residential care or the final phase of the illness, care was transferred to a Palliative Care Community team Social Worker. Consequently there was no continuity of psychosocial care for MND clients and their family carers, resulting in additional distress for a client group already suffering ongoing losses.

**Objective:** To evaluate Social Work involvement with the MND service and to describe changes in the service that have improve continuity of care from a Social Work perspective.

**Programme description:** In 2004 a Social Worker attached to the Calvary Aged Care Team sought feedback from an MND client and members of the MND “team” about the Social Work involvement with MND clients. In response to this feedback a paper co authored by the Social Worker and her MND client was prepared and presented to both the organisation and at an MND National conference in 2005, advocating for a designated Social Work position to be attached to the Calvary MND service. In May 2005 a designated social work position at Calvary health Care was incorporated into the MND team, resulting in continuity of care of psychosocial and emotional issues for MND clients

**Clinical outcomes:** The significance of this model change is that the social worker now remains involved with these clients from time of referral until death, regardless of whether they are still living in the community, in respite or in residential/hospice care. In addition there has been:

- an increased awareness within Calvary Health Care of the specific needs of this small but unique client group;
- a strengthening of the social work role as advocate for MND clients
- an opportunity to provide support within the team when working in this challenging and often confronting area; and
- an identification of a training need for agency workers and residential care staff.

**Recommendations to the field:** The advantages to clients, family members and the MND Service in having a designated Social Worker on the team will be demonstrated using client feedback, feedback from MND team members and case examples.

There is still no other designated Allied Health Team members assigned specifically to MND clients, resulting in:

- fragmentation of the team;
- lost opportunities for developing professional expertise;
- additional stress on MND clients and family members as allied health workers change as clients enter the final stages of the disease.



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**SPEAKER:** Susan C. Woolley, Ph.D.

**BIOGRAPHY:**

Dr. Woolley is the clinical neuropsychologist at the Forbes Norris ALS Research Center in San Francisco, California. She has worked in the ALS Multidisciplinary Clinic for 10 years, and has presented her research at several International Symposia on MND/ALS. She has also served on the Steering Committee for the International Research Workshops on FTD in ALS.

Her research focuses on apathy, insight, and cognitive impairment in ALS patients, as well as researching neuroanatomical correlates of behavioural change. She is one of the authors of the recently updated Practice Parameters for ALS (AAN publication) and is the test developer of the ALS Cognitive Behavioural Screen (ALS-CBS). She published a manuscript about its validity and utility in 2008, and the measure is now used in multiple clinics and various research studies internationally.

In addition to her work in ALS, Dr. Woolley is the neuropsychologist at the Memory Clinic at California Pacific Medical Center (CPMC), where she completes neuropsychological assessments for patients with dementia and memory concerns.

Dr. Woolley is also the Director of the Neuropsychology Training Program for the Psychiatry Department at CPMC.

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**AUTHOR:** Susan C. Woolley, Ph.D.

**TITLE OF PRESENTATION:** Use of the ALS Cognitive Behavioural Screen (ALS CBS) in the Multidisciplinary Clinic Setting: Enhancing Practical Management Strategies

**Key Theme:** Changing Practice

**Background:**

Cognitive and behavioral abnormalities can be identified in a significant proportion of ALS patients, and a smaller percentage suffer from comorbid dementia (FTD). Cognitive impairment, behavioral impairment and dementia are typically diagnosed using neuropsychological assessment, yet many ALS clinics do not have access to this service routinely. However, identification of these impairments is important, since research suggests that patients with these types of deficits are less compliant with interventions and have significantly shorter survival. Awareness of which patients are most at risk is important to help triage valuable resources when treating ALS patients. The ALS Cognitive Behavioral Screen (ALS CBS) is a validated measure used in multiple clinics that is easy to use and helps identify patients who may need further assessment or intervention due to cognitive and/or behavioral abnormalities.

**Objectives:**

To understand the administration and interpretation of the ALS CBS; to review strengths and weaknesses of the measure and how it can be best utilized in a busy clinical setting.

**Programme description:**

This programme will review specific content and administration of the ALS CBS and discuss the validity of the measure. Strengths and weaknesses of the screening tool will be discussed, as well benefits of use in the clinic setting. The presenter will discuss how screen results can be used to inform treatment recommendations and education of patients and families. Case examples will be provided to illustrate points.

**Clinical outcomes:**

Participants will become familiarized with a validated tool that can be used directly in clinical practice with MND/ALS patients. Use of a screening measure will help clinicians address cognition and behaviour, which tends to be overlooked in neuromuscular clinics. Participants will receive a copy of the ALS CBS with instructions.

**Recommendations to the field:**

Cognitive and behavioural screening is needed in the clinic setting to best triage resources and identify patients most at risk. Clinicians need to consider how to assess for potential dementia or impairment in ALS patients. The ALS CBS is one screening tool that can be considered, and is currently the only validated, ALS-specific measure. While the ALS CBS does not replace the gold standard of neuropsychological testing, it can provide preliminary information to clinicians, patients and family members.

# ALS CBST™

## ALS Cognitive Behavioral Screen



Susan C. Woolley, Ph.D.

Patient Id: \_\_\_\_\_ DOB/Age: \_\_\_\_\_ Gender: \_\_\_\_\_  
 Onset Date: \_\_\_\_\_ FVC: \_\_\_\_\_ Education: \_\_\_\_\_  
 Onset Region: bulbar, arm, leg, trunk, respiratory (circle one)

Mark if pt responses were written, attach sheet

HAND PAGE 2 TO CAREGIVER.

### Attention

- a. Commands: *I am going to say some commands. Please listen carefully and then do what I say. (If patient is unable to indicate with finger, movement can be substituted with eyes, arm or other means).*
- |  |                |   |    |
|--|----------------|---|----|
| 1. Point/indicate (with your finger) to the ceiling and then to your left. | # errors       | 0 | 1+ |
| 2. Touch your shoulder, point to the floor, and then make a fist.          | Score (circle) | 1 | 0  |
- b. Mental Addition/Language: *I am going to say some phrases. I want you to tell me the number of syllables in each phrase. For example, "the table" has 3 syllables. (Repetition of each phrase is allowed once).*
- |   |                |   |    |
|---|----------------|---|----|
| 1. The weather is nice. (correct response: 5) answer _____    | # errors       | 0 | 1+ |
| 2. Tomorrow will be sunny. (correct response: 7) answer _____ | Score (circle) | 1 | 0  |
- (score 0 if >20 seconds on either)
- c. Eye Movements: *Saccades and Antisaccades. See reverse for instructions.*
- |   |  |   |
|---|--|---|
| # of Correct Saccades out of 8: _____/8     | Score: 8/8 = 1 points, ≤7/8 = 0 points                 | <div style="border: 1px solid black; padding: 5px; width: 40px; margin: 0 auto;">/5</div> |
| # of Correct Antisaccades out of 8: _____/8 | Score: 8/8 = 2 points, 7/8 = 1 points, ≤6/8 = 0 points |   |

### Concentration

*I am going to say some numbers. After I say them, I want you to say them to me backwards, or in reverse order. For example, if I say 3-6, you would say 6-3. (If written, do not allow pt to write forward span. Discontinue after failure on two consecutive trials).*

	Correct	Incorrect		Correct	Incorrect	
2-9 (9-2)	—	—	7-8-6-4 (4-6-8-7)	—	—	<b>Maximum Span</b> <b>Correct:</b> (Enter score)
6-4 (4-6)	—	—	5-4-1-9 (9-1-4-5)	—	—	
3-7-2 (2-7-3)	—	—	8-2-5-9-3 (3-9-5-2-8)	—	—	
5-8-1 (1-8-5)	—	—	5-7-6-3-9 (9-3-6-7-5)	—	—	

/5

### Tracking/Monitoring

- a. Months: *Please say the months of the year backwards, starting with December. (circle omissions/mark repetitions & intrusions)*
- |  |                |   |   |    |
|--|----------------|---|---|----|
| <b>Dec Nov Oct Sep Aug Jul Jun May Apr Mar Feb Jan</b> | # errors       | 0 | 1 | 2+ |
|  | Score (circle) | 2 | 1 | 0  |
- b. Alphabet: *Please say/write the alphabet for me. (mark uncorrected errors, omissions or intrusions)*
- |  |                |   |    |
|--|----------------|---|----|
| <b>A B C D E F G H I J K L M N O P Q R S T U V W X Y Z</b> | # errors       | 0 | 1+ |
|  | Score (circle) | 1 | 0  |
- c. Alternation Task: *I want you to alternate between numbers and letters, starting with 1-A, and then 2-B, 3-C, and so on. Please continue from there, alternating between number-letter, number-letter, in order, without skipping any until I tell you to stop. (Errors: Any mistake in sequencing, i.e., 7-H, or 8-9).*
- |  |                |   |   |   |
|--|----------------|---|---|---|
| <b>4-D 5-E 6-F 7-G 8-H 9-I 10-J 11-K 12-L 13-M</b> | # errors       | 0 | 1 | 2 |
|  | Score (circle) | 2 | 1 | 0 |
- /5

### Initiation and Retrieval

*Say (write) as many words as you can starting with the letter F, as quickly as you can, in 1 minute. (Show pt Fluency Rules) You cannot say/write the names of people, places or numbers. Please do not say/write the same word with just a different ending, like truck, trucks. (S words can be substituted for F words). Errors: repetitions, rule violations.*

1. _____	9. _____	17. _____	# correct words	>12	12-8	<8	≤4
2. _____	10. _____	18. _____	Score (circle):	3	2	1	0*
3. _____	11. _____	19. _____		plus			
4. _____	12. _____	20. _____	# errors	0	1	2+	
5. _____	13. _____		Score (circle):	2	1	0	
6. _____	14. _____						
7. _____	15. _____						
8. _____	16. _____						

\*if ≤4 words, total verbal fluency score = 0 regardless of # of errors

/5

**TOTAL SCORE**

/20

**ALS CBS™**  
**ALS Cognitive Behavioral Screen**



Susan C. Woolley, Ph.D.

**ALS Caregiver Behavioral Questionnaire**

These questions pertain to possible changes that you have noticed since the onset of ALS symptoms. As best you can, consider changes that are unrelated to physical weakness. For example, question #1 asks about interest in activities. If the person can no longer play tennis but still seems interested in it (i.e. talks about it, watches it on television), then you would circle 3 for no change in level of interest.

If the person has always had the trait in question, please respond No Change, since there has been no change over time.

Compared to before ALS, does he/she:

	<u>No Change</u>	<u>Small Change</u>	<u>Medium Change</u>	<u>Large Change</u>
1. Have less interest in topics/events that used to be important?	3	2	1	0
2. Show little emotion, or seem less responsive emotionally?	3	2	1	0
3. Seem more agreeable or pleasant than in the past with fewer worries?	3	2	1	0
4. Fail to think things through before acting?	3	2	1	0
5. Seem more withdrawn from others but not sad?	3	2	1	0
6. Get confused or distracted more easily?	3	2	1	0
7. Have less ability to deal with frustration or stress?	3	2	1	0
8. Seem less concerned about the feelings or concerns of others than before?	3	2	1	0
9. Get angry or irritable more easily than before?	3	2	1	0
10. Seem more sarcastic or childlike than before?	3	2	1	0
11. Eat more or has a new preference for particular foods (i.e. sweets)?	3	2	1	0
12. Have more trouble changing opinions or adapting to new situations?	3	2	1	0
13. Show less judgment or more problems making good decisions (i.e. regarding safety, finances, etc)?	3	2	1	0
14. Have less awareness of obvious problems or changes, or deny them?	3	2	1	0
15. Have new problems with language, such as saying the wrong word more often, making up new words, or declines in spelling ability?	3	2	1	0

**TOTAL SCORE:** \_\_\_\_\_/45

The following questions relate to current symptoms, not changes over time:

<b>Do you think your loved one:</b>	<b>YES</b>	<b>NO</b>
• Seems depressed on most days?	[ ]	[ ]
• Seems anxious on most days?	[ ]	[ ]
• Seems extremely fatigued on most days?	[ ]	[ ]
• Suffers from unexpected crying or laughing spells?	[ ]	[ ]



**International Alliance of  
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**ALLIED PROFESSIONALS' FORUM  
Hilton Hotel, Sydney  
29 November 2011**

**SPEAKER: Meenakshi Wadhwa, MS RD LDN**

**BIOGRAPHY:**

Meenakshi completed an undergraduate degree in Food and Nutrition from Jadavpur University in India. Then she graduated with a Masters degree in Dietetics from the University of Illinois at Chicago. She is a member of the American Dietetic Association, Chicago Dietetic Association, Vegetarian Nutrition and Dietitians in Integrative and Functional Medicine practice groups. She is also an active member of the community where she takes part in projects like teaching kids about nutrition through gardening.

Meenakshi is very passionate about the nutritional treatment of individuals impacted with ALS. She is employed at the University of Illinois Medical Center (UIC) as a Clinical Dietician for the neurology/neurosurgery unit. She is the dietician for the UIC MDA certified ALS Center and the UIC ALS Association sponsored clinic. The UIC ALS multidisciplinary team has been together over 5 years and is the recipient of the 2010 Ben Byer ALS Awareness Award.

Julie Rowin MD is Associate Professor of Neurology at the University of Illinois at Chicago (UIC). She is director of the UIC MDA ALS Center and the UIC ALS Association Clinic. She has authored/co-authored over 30 peer reviewed publications. She serves on the national MDA Clinical Advisory Committee among other national committees and is the recipient of the 2010 'Iron Horse Award' ALS Association Greater Chicago Chapter and the 'Hilda Glassman Award' from the National ALS Association for Clinical Management Research, "*Enteral nutrition in ALS patients with Ventilatory Failure: minimizing the work of breathing.*" in February 2008.

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**AUTHOR/s:** Meenakshi Wadhwa, MS. RD. LDN and Julie Rowin MD

**TITLE OF PRESENTATION:** Nutrition Throughout the Course of ALS

**ABSTRACT:**

**Key Theme:** Changing practice

**Background:**

Nutritional intervention has become one of the cornerstones of treatment for many patients with ALS. Malnutrition and under nutrition are common problems for patients with ALS. In recent years nutrition (body mass index) has been recognized as an independent prognostic factor for survival and disease complications in ALS. This has illustrated the importance of individualized rigorous nutritional management and education for patients and family members. Nutritional management of ALS patients includes caloric supplementation, management of dysphagia, education regarding PEG tube placement and the management of enteral nutrition as well as symptomatic treatment of digestive complications.

**Objectives**

Upon completion of this program, the audience will understand:

- The role of nutrition throughout the changing course of ALS
- The recommendations and guidelines for the clinical management of symptoms of ALS through nutrition strategies

**Programme description**

The following topics will be discussed:

- The role of Nutrition throughout the course of ALS
- The clinical management of symptoms of ALS through nutrition including:
  - constipation
  - early satiety
  - weight loss
  - dysphagia
- Malnutrition, high fat diet theory and energy metabolism in ALS
- PEG tube (enteral nutrition) and quality of life

**Clinical outcomes:**

Changing practice:

- The implementation of early nutritional intervention in ALS by providing a high calorie diet to ALS patients may prevent the reduction of BMI and malnutrition that occurs due to a hypermetabolic state.

**Recommendations to the field**

Recommendations include:

- Early intervention with high caloric diet
- Educating patients about nutritional interventions that may improve ALS signs, symptoms and quality of life



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**SPEAKER: Monika Wilson**

**BIOGRAPHY:**

Monika is a palliative and end of life care professional who has been involved in research, education, project management, ethics consultancy and counselling for 12 years. Monika was employed by MND Queensland to carry out the Confident Caring project in Queensland and then by MND Queensland as a Regional Advisor. This year she was successful in obtaining the first ever in Queensland palliative care funding specifically for MND equipment. Monika's doctoral thesis explored the ethical dimension of how we care for people who are dying. This research was awarded the Ian Maddocks Guest Lecture at the 2009 International Palliative Care Conference as the most outstanding research conducted in Australia by someone in Australia under the age of 40. Monika now has her own end of life care service on the Sunshine Coast where she provides counselling to people at the end of life and in bereavement and facilitates workshops with health care professionals and volunteers, covering such topics as initiating dying conversations, loss and grief, enhancing spiritual support and the ethics of end of life care.

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**AUTHOR/s: Monika Wilson**

**TITLE OF PRESENTATION: Advance Care Planning: Initiating ‘Dying Conversations’**

**ABSTRACT:**

The as yet incurable nature of Motor Neurone Disease means that people living with this disease will inevitably face a dying (terminal) process. In this process choices can be made which will enable this time to be a comfortable and peaceful one. Pre-planning for these choices and options will clearly make the dying process more in line with preferred wishes and avoid crisis driven decisions and future guilt. As the Respecting Patient Choices program states: “If your choices for future healthcare are known, they can be respected”.

This presentation is not, however, about the need for, or the benefits of, advance care planning, but rather about the process of doing so. In other words, in assisting people to carry out advance care planning we will inevitably need to talk about dying with them.

Understandably, talking about dying is never easy and most people, even those living with a potential life ending illness, tend to avoid it or consider it too hard. In a recent survey Palliative Care Australia found that approximately seventy percent of the population had not discussed their health care preferences for the end of life.

Any health care professional might be in the position to initiate a ‘dying conversation’ and assist with advance care planning. You might be the one person who has the right type of relationship, at the right time, to be the best person to initiate such a conversation. However, there are understandably numerous barriers to having these sorts of conversations: feelings of fear, it being in opposition to ‘staying positive’, or it’s too hard or just generally feeling uncomfortable.

This presentation outlines the common barriers to initiating dying conversations. These barriers come from both the real experiences of regional advisors and from research. The audience will have an opportunity to reflect on what hindrances they may be experiencing or resonating with, as well as to examine some possible strategies for navigating their way through these barriers. Mainly, this presentation will focus on providing practical strategies, in line with these common barriers, thereby assisting with the development of necessary skills to make this a regular part of our caring practices.

Finally, it will offer opportunities to reflect on what qualities or self development practices you, the professional, may seek to enhance your ability to feel confident in initiating valuable dying conversations.



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**SPEAKER: Dr Robin Ray**

**BIOGRAPHY:**

Dr Robin Ray is a senior lecturer in the School of Medicine and Dentistry at James Cook University, Townsville, Australia. Her research focuses on community palliative care in particular motor neurone disease, end of life and advance care planning, as well as social support in chronic and life-limiting illness.

Her PhD developed new insights into the socio-connective trust that underpins social support systems accessed by family caregivers of people with MND. She has also been involved in a number of other MND projects including interventions that increase survival advantage and improve quality of life; development of a carer network scale, and family caregivers responses to death in MND - a joint study with a colleague in the UK.

**AUTHOR: Dr Robin Ray**

**TITLE OF PRESENTATION: Using a circular process to build emotional readiness for conversations about advance care planning.**

**ABSTRACT:**

**Key theme:** Advance care planning and decision making

**Background:** A recent Australian study of advance care planning in community palliative care identified that emotional readiness was a significant factor for health professionals, patients and family carers engaging in conversations concerning advance care planning.

**Objectives:** To develop a method of engaging health professionals, patients and family members in conversations and decision making about advance care planning.

**Programme Descriptions:** Drawing on the initial work carried out by the Respecting Patient Choices team and in consultation with local health professionals providing services for people living with progressive neurological disorders, a staged cyclic process was developed. The process begins with conversations identifying quality of life indicators and the person's understanding of their health condition. These foundational conversations improve emotional readiness by providing a lead in to advance care planning. Outcomes from these discussions guide the need for conversations with relevant others about care needs, and the identification of a substitute decision maker. From here the person or family member/s may choose to make decisions about care informally, through a Statement of Choices or a legal Advance Directive. The circle is completed by returning to quality of life and health condition discussions.

**Clinical Outcomes:** A staged cycle provides a graduated approach to advance care planning consistently grounded in the patient's/family understanding of health status and quality of life indicators. Equally the cyclic stages serve to track the progress of advance care planning conversations. This enables anyone in the multidisciplinary team to identify the next phase of advance care planning and capitalise on emotional readiness cues as situations change. This circular process has been used in a workshop on advance care planning for patients and carers living with progressive neurological disorders including MND and in the education of health professionals.

**Recommendations to the Field:** The cyclic nature of this process enables health professionals, patients and family members to revisit and work with the process continually as the health condition and/or patient goals change.



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**SPEAKER: Maryanne McPhee**

**BIOGRAPHY:**

Maryanne McPhee is currently the manager of the dynamic Speech Pathology and Neuropsychology departments at Calvary Health Care Bethlehem. Calvary is a State wide provider of clinical services for people with Progressive Neurological Diseases. Maryanne has extensive clinical experience in the management of progressive neurological diseases and holds a Post Graduate Diploma in Palliative Care.

Maryanne has worked overseas in the United Kingdom and has been working in the area of progressive neurological diseases for nearly 20 years! (How when she looks so young!) She has worked in a number of roles at Calvary Health Care Bethlehem – including project work researching “The model of care and collaborative care for people with MND in Victoria, Australia”.

As a member of the interdisciplinary team she is passionate to ensure people with ALS/MND have a “voice for life” – a means of communicating with their family/friends and carers for life. Today she will be presenting on “E solutions for people living with MND – What do they offer? Are they the answer?”

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**AUTHOR/s:** Maryanne McPhee (Chief Speech Pathologist), Ruth Skene (Chief Occupational Therapist) Fran Williamson (Nurse Unit Manager)

**TITLE OF PRESENTATION:** E-solutions for people living with Motor Neurone Disease. What do they offer? Are they the answer?

**ABSTRACT:**

**Key Theme:** E-solutions to improve outcomes for people living with Motor Neurone Disease

**Background:**

If the 20th century was the age of the industrial revolution the 21st century will be known as the age of the technological revolution. As the world's population continues to grow, lifestyle expectations are increasing and supporting technologies are becoming more sophisticated and increasingly accessible. The internet is also providing access to knowledge about e-technologies and the "ipad/iphone revolution" is raising people's expectations. State of the art e-technology and equipment can allow people to continue to be as independent as possible as well as provide a means of maintaining connectedness through communication. These advances in technology will alter the way we support people living with conditions like MND.

**Objective**

This paper will explore the technologies used to address comfort, safety and dignity whilst reinstating communication and environmental control within the context of progressive disability. The benefits, challenges and the all important what worked (and what didn't) will be discussed.

**Programme description**

In late 2007, the multidisciplinary team at Calvary Health Care Bethlehem (CHCB) became aware that there were a number of e-technologies/specialised equipment that were currently not available for use by PLWMND at CHCB. The "*Dare to Dream working party*" formed and significant fundraising was undertaken. This paper will outline the steps involved and how this one room concept evolved – and has ultimately led to the concept of "*a room with out walls*" and an enhanced model of care.

**Clinical outcomes**

- Opportunities for the PLWMND/team to problem solve/trial solutions.
- More efficient/specialised management, particularly for those in the later stages of MND/ALS.
- Greater independence and control - less reliance on nursing staff/carers.
- 48 people were assessed and used the room/e-technologies/equipment in innovative ways. DVD footage and a photo collage will provide insights into various solutions /strategies employed.
- Opportunity to collaboratively build knowledge/experience of the application of Eye Gaze systems and e-technologies for PLWMND.

**Recommendations to the field**

- Clinicians need to work collaboratively with an extended team: Project manager, interior designer, IT staff, purchasing officer, Allied Health, Communication Technology specialists and others to ensure most cost effective and "best" outcome. Clear goals and a common language are essential.
- An extensive equipment pool offers supported patient choice.
- Equipment trials facilitate realistic expectations of the e-solutions by utilising a "try before you buy" model.
- Options need to be presented in a timely manner with due consideration given to the progressive nature of MND/ALS
- E-technologies need to be supported and monitored. Back up options must also be available.



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**SPEAKER:** Justin Ware

**BIOGRAPHY:**

Justin Ware is a consultative Occupational Therapist who is passionate about helping people get the best out of technology.

Justin graduated as an Occupational Therapist in 2004 and works at The Spastic Centre at TASC (Technology solutions for computer Access, Seating and Communication) Consultative Services, where he helps children and adults with a broad range of disabilities, across NSW and ACT to access technology for education, communication, participation, independence and leisure. TASC's services are free to clients unless air travel or overnight accommodation is required to provide a service. Justin has nine years experience in working with people with a disability in Australia and in the UK. Justin has always had a strong interest in what technology can (and can't) do and he is keen to ensure that technology solutions and people can fit together rather than trying to force people to change to adapt to technology.

**AUTHOR:** Justin Ware

**TITLE OF PRESENTATION:**

iPad and iPhone implementation in disabilities: Access, communication, apps and mounting

**ABSTRACT**

**Key Theme:** E-solutions to improve outcomes for people living with MND

**Background:** There has been a groundswell of interest in iPads, iPhones and iPod touch devices (iProducts) in the mainstream world and this has been closely followed by interest by those with Motor Neurone Disease (MND). An enormous potential for the use of such devices has been identified to help clients with MND to communicate and access other technology that is available to them, such as computers and environmental control.

**Objective:** The aim of this presentation is to educate clients, carers, therapists and support workers in the process of consideration that should be undertaken when implementing iProducts. Participants will also be provided with information resources to help them find suitable apps and ways of accessing the iPad. The information will be presented in the form of a case study.

**Programme description:** TASC (Technology solutions for computer Access, Seating and Communication) is a consultative service based in Sydney within the Cerebral Palsy Alliance, providing support to people with disabilities living within NSW and ACT. TASC has a program that enables people with MND to fast track through their waiting list. Additionally, TASC has worked closely with the MND association of NSW in support of their equipment loan service.

**Clinical outcomes:** The clinical outcome targeted from this intervention is to maintain access to communication, work, socialisation, education and leisure for people with MND.

**Recommendations to the field:** Proceed with caution and do your research: Too often, iProducts are purchased by clients with MND and their families without a functional goal in mind and without consideration of future access options. If we are equipped to provide information and support to clients and their families, then their time and financial resources will be far better used.



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**SPEAKER: John Paulin Hansen**

**BIOGRAPHY:**

John Paulin Hansen is an Associate Professor at the IT University of Copenhagen. He received a PhD in 1992 from the Institute of Psychology, University of Aarhus. He initiated and co-organised the IST EU Sixth framework programme Network of Excellence “Communication by Gaze Interaction” (COGAIN), 2004-2009, with more than 100 researchers from all over the world and he is now serving as Vice-President for the Association.

He established a research group at IT University focussing on eye tracking, gaze interaction and the use of gaze for usability studies. The group has developed an open source gaze tracking system that can be used for alternative communication systems and for basic research in gaze movements, and several new interfaces and interaction principles that support gaze.

Over 10 years, the group has published more than 60 papers that have appeared in leading journals and conferences. Currently, the group is involved in projects that explore the use of gaze interaction for large displays, gaze control of communication and videoconference systems for disabled people and mobile gaze interaction (see [www.gazegroup.org](http://www.gazegroup.org) for more information and downloads).

**AUTHOR/s:** John Paulin Hansen, T: +45 72185000, F: 72185001, paulin@itu.dk  
Javier San Augustin; Henrik Skovsgaard

**TITLE OF PRESENTATION:** In-expensive and flexible gaze tracking from bed

**ABSTRACT:**

**Key Theme:** E-solutions to improve outcomes for people living with MND

**Background:**

Gaze tracking allows people with late-stage ALS/MND to communicate with friends and family by gaze typing, to browse the Internet and play computer games. Several commercial gaze-tracking systems support these activities well. Most of the systems are fixed into a single hardware unit consisting of a monitor, one or more cameras and infrared (IR) light sources. However, there are some serious limitations to current commercial systems. First, the space requirements for this setup may seriously obstruct caretaking routines. Second, the limitation of the viewing-angle of the monitor makes it difficult for people standing around the bed to follow what this person is doing with his eyes. Third, if a single part of the unit breaks down, all of it will have to be sent off for replacement or repair, leaving the user without communication means for days. Finally, the relatively high cost of commercial gaze communication systems may prevent some people with severe disabilities from having access to one.

**Objective:**

To present a gaze tracking system that does not occupy the physical space in front of the user. The system applies a large display that can be seen by a group of people and it is composed of inexpensive hardware components (display, camera, IR lights and PC) that can be substituted immediately if they fail.

**Programme description:**

The system consists of the ITU open-source gaze tracking software that can be downloaded free-of-charge from [www.gazegroup.org](http://www.gazegroup.org). This system works with an inexpensive web-camera and Windows computer that has a video projector connected to it.

**Clinical outcomes:**

Accuracy and precision of the tracking system was tested in an experiment with 12 able-bodied subjects, obtaining a tracking quality that is sufficiently good to control applications designed for gaze interaction. The best tracking condition were achieved when people were sitting up compared to lying down. Also, gaze tracking in the bottom part of the image was found to be more precise than in the top part.

**Recommendations to the field:**

Consider using a low-cost gaze tracking system if the person with ALS/MND cannot be provided a commercial solution or if there is a need for a more flexible setup than they may offer.



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**SPEAKER: Gina Svolos, BSW, M.Ed (Ad Ed)**

**BIOGRAPHIES**

Gina Svolos is the Manager of Family Support Services for the Motor Neurone Disease Association of NSW, Australia. She has a degree in Social Work and masters in Adult Education. Gina has worked in a variety of health and community settings including disability, cancer, and palliative care. She has worked as both a social worker and educator in these areas. Gina is committed to enhancing the quality of life for people living with MND through increasing the knowledge of health and community professionals working in this area.

Penny Waterson is Information Resources Coordinator for the Motor Neurone Disease Association of NSW, Australia. She has a degree in health management and her interest in the communication of health information led to the completion of a masters of Information Studies and studies in Technical Communication. Penny was Project Officer on the MND Australia MNDcare website development and implementation project. She is a member of the Cochrane Collaboration Neuromuscular and Consumers and Communication Review Groups.

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**AUTHOR/s:** Gina Svolos, Penny Waterson

**TITLE OF PRESENTATION:** MND Aware: A web-based awareness training program about Motor Neurone Disease

## **ABSTRACT**

**Key theme:** E-solutions to improve outcomes for people living with MND

### **Background**

Health and community care professionals involved in the care of a person with motor neurone disease (MND) may have little or no knowledge about MND and the needs of people living with this disease. MND NSW delivers face-to-face education about MND but it is not always possible to deliver this immediately and/or at a convenient location.

### **Objective**

To increase health and community care professional understanding about MND and the needs of people living with MND through the development of web-based training about:

- MND awareness - MND and the impact it has on an individual's life
- MND case management - effective ways of responding to people with MND

### **Programme description**

The initial consultation identified stakeholder information needs and specialised components unique to MND case management. Learning objectives and a module structure were developed. Evidence-based content for each module was sourced. People with MND, carers and health and community care professionals were invited to contribute text, visual, audio and short video content. The MND Aware training program was developed using a low-cost commercially available e-learning authoring tool.

### **Clinical outcomes**

This web-based training program provides all members of the health and community care team with information about the management of MND in our community. It provides information about:

- MND symptom management
- wellbeing and support needs of people living with MND, their family and carers
- MND care coordination and case management
- referral pathways for ongoing MND care in the community
- support for staff involved in the care of people with MND

This training program is an e-solution that overcomes the tyranny of distance to enhance the quality of life of the person living with MND by:

- changing practice and improving how health and community professionals provide care and support throughout the person's journey with MND
- strengthening quality care at the end of life

### **Recommendations to the field**

A web-based delivery of MND awareness and case management training for health and community care professionals provides the opportunity to change practice, raise awareness of carer needs, encourages the tailoring of support for families and provides resources for staff.



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**SPEAKER: Nicole Lessard Yarab, RN, BA  
Emory ALS Center, Atlanta, GA, USA**

**BIOGRAPHY:**

Nicole received her Bachelor of Arts in Sociology from Emory University in 1994. She attended and graduated from the Dekalb College School of Nursing and received her registered nursing license in 1997. She has worked as a neuroscience staff nurse and as a clinical research nurse. She held the role of assistant clinical coordinator for the WASID Clinical Coordinating Center and as the Emory study coordinator. WASID (Warfarin-Aspirin Symptomatic Intracranial Disease) was an NIH-funded (National Institutes of Health) multicenter stroke trial, based in the Neurology department of the Emory University School of Medicine. In 2004, at the end of the trial, she joined the department's neuromuscular division as the ALS nurse clinician. She is the team leader for the Emory ALS Clinic and she manages and coordinates the clinical care for over 275 patients with ALS/MND. Nicole has participated in several ALS Public Policy and Advocacy Day events in Washington, D.C, and has served on the Patient Services and Operations Committee for the ALS Association of Georgia. She regularly speaks to local hospice organizations, ALS support groups, and has presented at ALS educational symposiums at the local, national and international levels.

**AUTHOR: Nicole Lessard Yarab, RN, BA**

**TITLE OF PRESENTATION:** Improving quality of care and empowering patients thru electronic communication

**ABSTRACT:**

**Key Theme:** E-solutions to improve outcomes for people living with MND

**Background:** ALS poses a significant challenge to daily life. Employing e-solutions can make a significant impact on those living with ALS and their caregivers. An ALS Center website, social media, email access and telehealth can all provide options and empowerment to people living with ALS. Creative solutions are a necessary part of caring for people living with ALS. Over the past decade, advanced technologies have allowed both patients and providers unique opportunities for improved quality of care.

**Objective**

- Participants will define two types of telehealth
- Participants will identify two ways to use telehealth at their centers
- Participants will describe 2 ways electronic communication improves quality of life

**Programme description**

**I. Telehealth**

- Improved access to specialists
- Evaluation of PEG and skin issues
- Text communication
- Email communication

**II. Facebook page**

- Events

**III. Website**

- Educational materials
- Links to community resources
- Research
- links to news stories/interviews
- Patient stories
- Video for newly-diagnosed ALS patients
- Meet the team

**Clinical Outcomes:**

- Increased patient satisfaction
- Increased staff satisfaction
- Improved independence and communication between people living with ALS and clinical team
- Improved access to community resources
- Reduced burden and travel to ALS Center

**Recommendations to the Field:**

The ALS team can offer added support to patients and caregivers through the use of technology and electronic communication. These tools empower patients by increasing access to reliable information about ALS, research, clinical care, community resources and special events. Providing options and finding ways to reduce stress and travel to the ALS Center positively affect quality of life.



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**SPEAKER: MaryJo Elmo**

**BIOGRAPHY:**

MaryJo Elmo is the Nurse Practitioner and Project Manager for Diaphragm Pacing at University Hospital's Case Medical Center. She received her Masters in Nursing from Case Western Reserve University in 2003 and has practiced as a Certified Nurse Practitioner since that time. Mary Jo is known for her work with ventilators for over 20 years and diaphragm pacing for 8 years. She manages the world's largest group of DP patients with various diagnoses including spinal cord injury and ALS. She holds certifications from the American Nurses Credentialing Center and is a member of the American Academy of Nurse Practitioners.

She has lectured/published on the topic of Diaphragm Pacing both nationally and internationally.

Publications titles include but are not limited to:

Amyotrophic Lateral Sclerosis: the Midwestern surgical experience with the diaphragm pacing stimulation system shows that general anesthesia can be safely performed; First reported experience with intramuscular diaphragm pacing in replacing positive pressure mechanical ventilators in children; Final analysis of pilot trial of diaphragm pacing (DP) in ALS/MND with long term follow-up: no safety concerns and DP positively affects diaphragm respiration; and Nutrition and Respiration: combining Gastrostomy with Diaphragm Pacing for Improved survival.

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**AUTHOR/s:** MaryJo Elmo ACNP; Cindy Kaplan MSM; Raymond Onders MD; Bahsar Katirji MD

**TITLE OF PRESENTATION:** **Surgical Therapies in ALS/MND: Optimising Techniques to improve patient care**

**ABSTRACT:**

**Key Theme:** Changing Practice

**Background:**

There are two surgical therapies that have been shown to either improve quality of or prolong life in ALS/MND: percutaneous endoscopic gastrostomy (PEG) and diaphragm pacing (DP). Some 25% of patients present with bulbar symptoms with approximately 80% developing bulbar dysfunction. Malnutrition is associated with poor survival. Guidelines suggest PEG placement with a 10% weight loss or, because of associated increase mortality, before FVC falls below 50%. Less than 50% of patients, recommended to have PEG, receive it. Alteration of body image is a major factor in PEG refusal. Respiratory failure is a leading cause of death in ALS/MND. Guidelines recommend tracheostomy mechanical ventilation (TMV) when non-invasive ventilation (NIV) fails yet this therapy is deemed unacceptable by most patients with less than 5% of US and European patients choosing TMV. DP is a new FDA approved therapy in ALS that aids respiration.

**Objective:**

Describe how early discussion of surgical therapies allows improved planning and decision making for patients with ALS/MND and their families. DP prolongs life, improves survival during PEG placement, delays the need for TMV and can help acceptance of PEG by offering simultaneous insertion of a low profile feeding tube.

**Programme description:**

Using case studies, illustrate our short and long term management of patients undergoing DP and low profile feeding tube therapies.

**Clinical outcomes:**

Data from DP clinical trials has been previously reported. IN summary, patients who used DP and NIV survived 16 months longer than those using NIV alone; and patients undergoing combined DP and PEG had a 0% thirty day mortality and 70% one year survival. Knowledge gained from the clinical trial has been implemented into our standard practice. Only those patients showing stimulatability of the diaphragm by fluoroscopy or phrenic nerve testing were offered DP. All patients receiving PEG requested buttons prompting a change from standard PEG to direct placement of low profile feeding gastrostomy. Pacer usage was individualised based on pre-implantation status. As their disease progressed, pacing time and power were adjusted. To date, there is a 100% 6 month survival. DP has delayed death or need for TMV in this group.

**Recommendations to the field:**

DP prolongs life, delays need for TMV and makes PEG placement safer. DP should be offered and the use of an immediate low profile button for increased patient satisfaction and acceptance of enteral feeding in ALS.



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ALS/MND Associations**

**ALLIED PROFESSIONALS' FORUM  
Hilton Hotel, Sydney  
29 November 2011**

**SPEAKER: Carlayne E. Jackson, MD, FAAN**  
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**BIOGRAPHY:**

Dr. Carlayne Jackson currently serves as Director of the South Texas ALS Clinic as well as the South Texas MDA/ALS Research Center in San Antonio, Texas. She has conducted numerous clinical trials in the field of ALS and has a special interest in the respiratory management of ALS patients.

**AUTHOR/s:** Carlayne E. Jackson, MD, Lisa M. Jackson, RRT, Donna D. Gardner, RRT, Pamela P. Kittrell, RN

**TITLE OF PRESENTATION:**

**A Retrospective Evaluation of High Frequency Chest Wall Oscillation (HFCWO) and Mechanical Insufflation/Exsufflation (MIE) for Airway Secretion Management in ALS Patients**

**ABSTRACT:**

**Key Theme:** Changing Practice: Aggressive Airway Secretion Management

**Background:**

Recent American Academy of Neurology guidelines recommend that MIE *may be considered* to clear secretions in ALS patients who have reduced peak cough flow, particularly during an acute chest infection, however found insufficient evidence to support or refute the use of HFCWO. There have been no studies evaluating the combination of these therapies.

**Objective:**

The primary aim is to compare the efficacy of clearing airway secretions, based on a reduction in upper respiratory infections and hospitalizations for pneumonia, using either HFCWO, MIE or both. The secondary aim is to compare compliance between HFCWO and MIE.

**Programme description:**

This study is a retrospective chart review of 78 patients (41 F, 37 M; median age 64) evaluated in the South Texas ALS Clinic from 12/1/2010 - 5/1/2011. Patient records were reviewed through September 2008. All patients were offered treatment with non-invasive positive pressure ventilation (NIV) when their forced vital capacity was <50% of predicted or their maximal inspiratory pressure was < -60 cm. In addition, patients were prescribed an airway clearance device when their peak cough flow was < 160 L/min or when the patient complained of difficulty clearing phlegm. A "Survey Monkey" link was emailed to each patient prior to their clinic appointment which included questions regarding the incidence of any respiratory infections or hospitalizations since their last visit and whether they were compliant (either "daily" or "as needed") with the respiratory assistive device(s) they had been prescribed.

**Clinical outcomes:**

At their most recent visit, 33 patients were receiving treatment with MIE (Cough Assist<sup>R</sup>), 33 patients were receiving treatment with HFCWO (SmartVest<sup>R</sup>), and 22 patients were receiving both interventions (HFCWO treatment for 10-20 minutes followed by 5 cycles of MIE). Compliance with MIE was: 36% "daily", 39% "as needed", and 25% non-compliant. Compliance with HFCWO was: 42% "daily", 49% "as needed", and 9% non-compliant. Individual compliance with the use of either device correlated with compliance with NIV where overall compliance was 76%. There were 3 reports of upper respiratory tract infections and 3 reports of hospitalizations – all but 1 event occurring in patients who were not using an airway clearance device.

**Recommendations to the field:**

Airway clearance devices appear to be effective in reducing the incidence of serious respiratory tract infections in ALS patients, and therefore, should be prescribed until further prospective, randomized studies can be done to compare the efficacy of MIE, either alone or in combination with HFCWO.



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**SPEAKER: Jan Clarke**

**BIOGRAPHY:**

Jan qualified in 1987 and moved to London to begin her career in neuroscience nursing. In 1990 she went to work on the neuro-medical intensive care unit at the National Hospital for Neurology and Neurosurgery, Queen Square, London where she worked for many years, holding a variety of posts including plasmapheresis nurse specialist and senior ITU sister. This post also involved caring for people being set up on non-invasive ventilation and led to Jan becoming increasingly involved with people living with MND.

In 2003 the MND Care and Research centre at the National Hospital was set up with help from the MND Association and Jan became the MND nurse specialist for this service. Since its inception this clinic has evolved and expanded over the years and Jan remains committed to continuing this development in partnership with the other team members.

Alongside neurological, ITU and management qualifications, Jan has an MSc in palliative care from Kings College, London, and has a special interest in advance care planning.

**AUTHOR: Jan Clarke**

**TITLE OF PRESENTATION:**

**ABSTRACT:** Identification of pain among patients living with Motor Neurone Disease in the clinical setting

**Key Theme:** Changing Practice

**Background:**

The purpose of this research study set out to understand if pain was a symptom of patients with motor neurone disease (MND) and if so, was there a relationship between pain and the progression of the underlying condition.

**Objective:**

The aim of this research study was to conduct a demonstration-pilot study to identify patients with MND who experience pain during their illness.

**Programme description:**

To help understand the results from the cross-sectional epidemiological survey an audit was conducted to first identify to what extent current clinical practice recorded pain in the notes of patients with MND.

**Clinical outcomes:**

The audit data suggests, within the limitations noted, that recording of pain in case notes of MND patients involved in this study is very low (14.5%).

Whilst no statistical differences were demonstrated within this study the results remain clinically significant. The presence of pain was identified in just under half the sample population, of which the same number also identified having been in pain in the week preceding the study. When compared to the data obtained from the audit it would suggest that current clinical practice at the research site fails to record the presence of pain in this group of patients in a consistent and transparent manner. Further, when pain is known, there is no robust evidence to say that patients are receiving good, clinical care in relation to the use of analgesics and the relief of this pain. As a specialist centre, if we fail to clearly record and monitor such symptoms it is equally difficult for our non-specialist colleagues in the community to understand this need and make appropriate, timely referrals to more specialist teams such as the palliative care service.

**Recommendations to the field:**

In conclusion, as a pilot study this research project has demonstrated that the sample population of patients with MND did experience pain. Whilst this research study only describes these patients and cannot be generalised to the wider population of MND patients there are local recommendations to be made from this study:

- Pain should always be enquired about at each neurological appointment and documented clearly in the medical notes and in clinic letters to other health care professionals
- Appropriate onward referral to specialist teams should be sought for those patients whose pain cannot be controlled through regular analgesics and standard practice.
- Pain in MND should be considered as an area for future research, especially to understand more fully, the patients experience of this pain, the possible causes of this and strategies to help relieve this suffering.



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**SPEAKER: Rachael Marsden**

**BIOGRAPHY:**

Rachael qualified in 1987 and shortly after moved to Oxford where she became a Primary Nurse working at Ritchie Russell House – a young disabled unit. Having worked there for almost 15 years, Rachael has gained a great deal of experience of managing people with complex disability. She has carried out many different roles and responsibilities, including Sister, Senior Nurse, and Community Support Nurse. During this time she has initiated various projects, including:

- looking in to the care of adults with disabilities received when they were admitted to an acute hospital - Nursing Standard Vol 12, No 21 Feb 7-13 2001.
- Investigating the ethical dilemma nurses find themselves in when patients use cannabis as an in-patient – BMJ “Sex, drugs and the invasion of privacy” Vol 316 21 Mar 1998; and on a BBC nurses educational programme.

She also introduced a joint Health and Social Service Project called “Shared Care Protocols for Oxfordshire”.

In 2000 Rachael became involved in a project looking at the care of people living with MND. For the past 10 years she has been the Care Centre Coordinator for the Oxford MND Care Centre.

The Oxford MND Care Centre has developed in so many ways over the past 10 years that she is keen to continue this work with the MND team. Rachael has completed her BA Hons degree in Rehabilitation at Oxford Brookes University in 2004. The team have recently published two books: “The Facts – MND” and “MND – a practical manual” (Oxford University Press). She has just passed her MSc in rehabilitation – her dissertation was about Compassion Fatigue.

**AUTHOR/s:** Rachael Marsden and Jan Clarke

**TITLE OF PRESENTATION:** Changing Practice. The English and Turkish Partnership

**ABSTRACT:**

**Key Theme:** Changing Practice

**Background:**

Since 2008 the International Alliance of ALS/MND has supported two Care Centre Coordinators from England to work with Professor Coskun Ozdemir from the Association of Neuromuscular Disorders of Turkey to form a collaborative partnership.

**Objective**

To facilitate the establishment of a care structure for patients living with MND in Turkey by enabling nurses to have a better understanding of the complexities of caring for people living with MND and how to deliver care in a timely and proactive way.

**Programme description**

With the support of the International Alliance of ALS/MND Associations we have visited Istanbul on three occasions to deliver a teaching programme to nurses. Each time we feel we have made progress. An important principle underpinning this project was to produce sustainable outcomes that would continue without our input. This presentation will discuss the positive outcomes from this close Alliance, demonstrating how over the last four years attitudes have changed and progress has been made.

Following the last visit, where we trained 15 senior nurses in an 'Educating the Educators Programme', the nurses felt sufficiently empowered to use their positions of influence to establish their own care centre in Istanbul. The driving force for this is now coming from Istanbul University, where the President of the University has accepted a proposal to work with the Director of the Florence Nightingale School of Nursing Istanbul, to take this project forward within their own care structure.

Fifteen nurses who attended the course visited Care Centres in Oxford and London in early 2011. We designed a comprehensive timetable to allow observation of the multidisciplinary approach to MND care, how each patient is reviewed regularly and how care is planned in the UK.

We have also been in close contact with the Minister of Health for Turkey who is very keen to organise a visit to England in November. His remit is to establish a care centre programme throughout Turkey.

We are very grateful to the support of the International Alliance of ALS/MND Association who have made this work possible.

**Recommendations to the field**

Look for opportunities where we can assist and influence effective and sustainable development of support for people living with ALS/MND.