

National MND Conference Paper – 24 June 2008

Title	A Day is Better than a Week - Mask Ventilation the Austin Way.
Presenter	Alana Levin, Christopher Smith, David Berlowitz and Dr Mark Howard.
Affiliation	Victorian Respiratory Support Service, Austin Health.
The Issue	Non invasive ventilation (NIV) increases survival and quality of life in Motor Neurone Disease (MND) and is provided in Victoria by the Victorian Respiratory Support Service (VRSS). Since 2003, a combined neurology and respiratory multidisciplinary clinic has increased access to NIV such that approximately 70% of people with MND are reviewed by the VRSS and some 40% of these people go on to use NIV. Historically, when a person with MND commenced NIV they would be admitted to hospital for a week. This admission included multidisciplinary assessments of the individual's needs and other tests including sleep studies. As demand for NIV increased, so did waiting times because no additional inpatient beds were allocated for NIV implementation. There is a relatively short therapeutic window in which NIV should be implemented before the MND progresses "too far" and the benefits, in terms of both survival and quality of life, diminish. Therefore in September 2007 the VRSS began piloting an ambulatory care, day admission model of NIV implementation.
The Initiative	People with MND are evaluated in the combined clinic. Where a trial of NIV is deemed appropriate, the person's suitability for a day admission is assessed. The "admission" involves a 3-hour stay for allied health assessment, commencing ventilation, and basic education on the equipment. The patient then goes home with the opportunity to contact the hospital should any problems arise. A sleep study is organised within the following 2-3 weeks to formally review the impact of the ventilation whilst also allowing time for familiarisation with the equipment. The VRSS Outreach Service provides formal discharge education after the sleep study and a respiratory physician review is organised for 2-3 weeks after the sleep study. Ongoing allied health input is also provided as needed.
The Outcome	Data are presented which describe the six months prior and the three months since the new approach. Additionally, these data are for those waiting for NIV only, not PEG (gastrostomy tube) only or NIV and PEG. Before September, there were 14 people waiting for admission an average of 47 days. The average length of hospital admission (LOS) was 4.3 days. Three people died on the waiting list and another had NIV implemented at another hospital. Since September 12 people are on the waiting list for an average of 9.9 days. Ten have been admitted and implemented with an average LOS of 1.5 days; nine had a LOS of only one day. Similar improvements were observed in those people admitted for inpatient PEG insertion, although the changes were less marked.
Take Home Message	<ul style="list-style-type: none"> • Integrating the service of the neurology team at Bethlehem and the VRSS led to an exponential increase in people with MND being assessed for ventilation. • This new short stay initiative has resulted in a number of valuable improvements to the service including decreased waiting times, shorter LOS and the patients have reported positive experiences from the model. • The more timely commencement of ventilation and the resultant allied health service delivery changes have substantially increased access to NIV, a therapy that provides more improvement in survival than

	<p>Riluzole.</p> <ul style="list-style-type: none"> • No deleterious outcomes of the change in service delivery have been observed. • The pilot period has provided opportunities to identify which patients are most suitable and to develop a procedure for the continued use of this approach. • Further evaluation is required to examine the impact of this model of service delivery on client satisfaction, staff satisfaction and staff workload.
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Title	Innovations In Occupational Therapy Service Delivery At Prince Of Wales Hospital: Enabling Patients With MND To Live Better For Longer.
Presenter	Jacqueline Gregor.
Affiliation	Motor Neurone Disease Clinic, Prince of Wales Hospital, Sydney, NSW.
The Issue	Motor Neurone Disease (MND) is a rapidly progressive neurodegenerative condition. MND patients are now living longer due to advances in medication, non invasive ventilation, nutrition & the management of patients by multi disciplinary teams. This results in increased morbidity and numbers of patients living in the community in their own homes with profound disability. The subsequent high level of disability presents a challenge to Occupational Therapists (OT) providing care to patients with MND. OT has an important role in managing the impact MND places on a patient's independent function, quality of life and their family. However, due to the relatively rare incidence of the condition it is often difficult for OT's in all areas of care to develop expertise in the area of MND. As a result of this there is a need to provide more flexible methods of service delivery to meet the complex needs of MND patients and their families.
The Initiative	NSW Health priorities outline a need to provide services that maximise the quality of life for people with progressive advanced disease & terminal illness. At Prince of Wales Hospital a multidisciplinary clinic offers a comprehensive assessment service to patients with MND. The aim of the multidisciplinary clinic is to provide comprehensive assessment & referral to appropriate local community services to ensure the best quality of life for the patient & their family. The OT service within the MND Clinic has been developing & evolving a model of care that provides support & advice to OT's in the local area health services throughout metropolitan and rural NSW. This is an effort to assist in the implementation of best practice interventions and improve the quality of life for MND patients. This has been achieved through regular liaison with treating therapists, provision of an evidence based practice workshop for OT's in NSW and dissemination of up to date information regarding best practice interventions.
The Outcome	One of the initiatives, the best practice workshop was held at Prince of Wales Hospital with 33 OT's participating. The evaluation showed 96% of the OTs' learning objectives were met and 100% of participants recommended this training to other OT's. Developing knowledge & skills amongst OT's develops confidence in their ability to manage patients with MND in the community. This paired with ongoing support from the OT service at Prince of Wales Hospital aims to improve the quality of life and care provided to patients with MND and their families.
Take Home Message	<ul style="list-style-type: none"> • There is a need to deliver OT services in a more flexible manner in line with NSW Health Priorities for patients with MND. • The further evolution, development and promotion of a consultancy service at Prince of Wales Hospitals for Occupational Therapists will endeavour to improve the quality of care available for patients with MND throughout NSW.
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Title	Case Study: VRSS Outreach involvement in care of a client living with MND.
Presenter	Gavin Fahey and Tim Walsh.
Affiliation	Victorian Respiratory Support Service. Austin Health.
The Issue	The Victorian Respiratory Support Service (VRSS) is the major provider of domiciliary chronic ventilator support for the State. The VRSS Outreach Service is a small team incorporating Clinical Nurse Consultants, a part-time receptionist and a Biomedical Engineer.
The Initiative	The presentation involves a case study of a client living with MND and the involvement of VRSS Outreach in his care during the course of his illness. The study includes day-to-day issues surrounding non-invasive ventilation and the face mask. Facial changes do occur with the progression of the illness and there is an array of masks that can assist in managing this. VRSS Outreach are also trained in the management of PEG tubes.
The Outcome	Through frequent review including home visits, outpatient appointments and regular phone contact, the VRSS Outreach service can address issues as they arise and assist the client in living safely and comfortably in their home.
Take Home Message	<ul style="list-style-type: none">• Non-invasive ventilation can be an effective tool to relieve symptoms associated with muscle weakness.• Ventilation and mask requirements may change throughout the course of the disease process.
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Title	Smooth sailing: riding the waves of MND challenges in unison.
Presenter	Sarah Macneil /Bev Leith.
Affiliation	Ballarat Health Services.
The Issue	The multiple challenges faced by people with MND, their families and carers, and staff working with them can easily result in poorly coordinated, disjointed and discontinuous care, which is slow to respond or purely reactive in nature. This in turn can lead to frustration on the part of all concerned and increased fragmentation of services.
The Initiative	This presentation will describe the coordinated, client-centred, interdisciplinary approach that is taken within Ballarat Health Services. It will describe some of the outcomes and effects we have experienced and observed through the adoption of this approach.
The Outcome	Some of the changes we have noted include increased client achievement of their goals, increased client and family satisfaction with their care (reported), increased client confidence in the staff they're working with (reported), reduced likelihood of crises occurring, and greater satisfaction amongst staff.
Take Home Message	<p>The key messages of this presentation will include:</p> <ul style="list-style-type: none"> • The essential need for a team approach from initial referral, including regular formal and informal meetings to ensure that client goals are being satisfactorily addressed. • An interdisciplinary team approach ensures clients don't drop off the radar. There is always someone in touch to monitor needs and identify likely future needs. • The benefit of early involvement of case managers, allied health and palliative care trained staff. • Team members should be comfortable to be non-territorial. There should be respect for individual and professional skills, balanced with acknowledgement that the seamless interdisciplinary team approach requires role blurring at times.
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Title	From the neck up I'm fine.
Presenter	Louise Hoffman.
Affiliation	Palliative Care Service.
The Issue	Do health professionals truly understand the impact of loss which manifests within a patient who has a diagnosis of MND? If we try to understand the losses then we can help patients prepare and they will indeed live better for longer.
The Initiative	To try to understand what it is like to have such a progressive debilitating disease, an interview was conducted with a community patient (Norm). This interview was recorded on amateur video.
The Outcome	The outcome was a greater understanding for me, and those involved, and (I hope) the viewers of this recording, of the significance of the losses involved of MND. Norm has given wonderful insight and he has spoken honestly of how it has been for him to live with this disease. The incidental effects of this interview include giving Norm an opportunity to express himself – he may even use part of this interview in his eulogy. The end result is a wonderful teaching tool.
Take Home Message	<ul style="list-style-type: none">• An insight into the feelings of someone with MND.• Timely, appropriate interventions.• Supporting patient choice and independence.• Spirituality.• Carer issues.
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Title	Choking: not a laughing matter.
Presenter	Janet Mostovoy/Roxanne Maule.
Affiliation	Calvary Health Care Bethlehem.
The Issue	<p>The issues associated with dysphagia and secretion management are multifocal and the <i>challenges and dilemmas</i> involved particularly with the management of coughing and choking episodes are well known. Successful management requires <i>partnerships</i> reflecting cohesive multidisciplinary input with the patient and those caring for them.</p> <p>With the client at the heart of all decision making the structured management of coughing and choking episodes is a recognised aspect of Care Management provided at Calvary Health Care Bethlehem. Care management is grounded in a neuro-palliative rehabilitation approach, focusing on quality of life for the individual and their carers.</p>
The Initiative	To provide an insight into the unique care management strategies employed by the multi-disciplinary team to address the <i>challenges and dilemmas</i> associated with coughing and choking.
The Outcome	Quality of life for the individual and their carers.
Take Home Message	<p>A Palliative Approach to swallowing management</p> <ul style="list-style-type: none"> • allows an acceptable level of risk and incorporates choking management as a natural extension of dysphagia management • constitutes a patient centred approach and is therefore diverse and specific to a broad range of individual needs, desires and contexts. • comprises a heavy emphasis on informed decision making • has foundations in a holistic multi-disciplinary approach • necessitates the ongoing involvement of the speech pathologist irrespective of the decisions made regarding preferred course of dysphagia management.
Contact Details Presenter	<p>Janet Mostovoy/Roxanne Maule Speech Pathology Calvary Health Care Bethlehem 476 Kooyong Road Caulfield, Victoria, 3162 Telephone: (03) 9595 3343 Fax: (03) 9595 3301 Email: janet.mostovoy@easternhealth.org.au Email: RoxanneM@bethlehem.org.au</p>

National MND Conference Paper – 24 June 2008

Title	FlexiRest, a new respite initiative for people living with motor neurone disease, muscular dystrophy and multiple sclerosis.
Presenter	Jane Barrett.
Affiliation	Motor Neurone Disease Association of NSW.
The Issue	The majority of people with MND want continued care at home. Their carers are particularly at risk of burnout due to the nature of MND and the potential rapid rate of progression. People with MND require flexible respite options that take into account their particular needs, to maintain their quality of life and prevent crises which may result in a premature admission to residential care facility. Carers too need support, both physically and emotionally, to help sustain their primary caring role.
The Initiative	Initially MND NSW approached the Multiple Sclerosis Society of NSW to look at ways of working together. The issue of respite was raised and the commonality of need became apparent. With the Muscular Dystrophy Association of NSW, the three organisations advocated on behalf of their members, all with progressive neurological disorders, for funding to provide more responsive respite.
The Outcome	<p>The successful application resulted in the establishment of FlexiRest which provides funds for respite that cannot be accessed through other services in NSW. Such respite can be for the person with MND and their carer. It is short-term, time-limited, in-home or community based. It can also cover emergency respite.</p> <p>A consortium, a partnership of the three associations, was established to run the program with a Program Coordinator, auspiced by the Multiple Sclerosis Society of NSW, to administer it. FlexiRest is funded by the NSW Department of Ageing, Disability and Home Care (DADHC).</p> <p>This paper will describe the development of the FlexiRest Program and the outcomes achieved for people living with a progressive neurological disorders, specifically MND.</p>
Take Home Message	<ul style="list-style-type: none"> • Flexible, timely and choice-driven respite is essential for people with MND and their carers who have on-going and increasingly complex needs. • FlexiRest means just that: each application is considered on an individual basis after meeting certain criteria. • FlexiRest can offer that welcome break, change of scenery, time out, a rest, something special for people dealing with the huge impact of MND on a daily basis.
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Title	Calvary Health Care Bethlehem and Comtec Yooralla unite to provide a joint assessment/management clinic for people with motor neuron disease.
Presenter	Maryanne McPhee.
Affiliation	Calvary Health Care Bethlehem (CHCB).
The Issue	Motor neuron disease is a rapidly progressive disease affecting the motor neurons and resulting in weakness of voluntary muscles of the body. Approximately 90% (Shaw 2005) of those diagnosed experience bulbar involvement at some stage during the disease, with many developing severe communication impairment. Successful management requires cohesive multidisciplinary input with the patient and those caring for them. With this in mind, CHCB and Comtec Yooralla have united to provide specialist assessment /management clinic to address severe communication impairment. The Comtec Yooralla team consists of speech pathologists and occupational therapists with expertise in communication and technology for people with disabilities.
The Initiative	<p>This paper will present the results from this unique clinic. Over the last 18 months, 46 patients have attended the clinic – 34 with MND. Information regarding: the phenotype/type of presentation of MND, time from onset/diagnosis, type of communication difficulties (type of dysarthria, intelligibility ratings), and the recommended augmentative and alternative communication options will be presented.</p> <p>Discussion regarding the range, timing of communication options recommended for people with MND will be presented and particular needs of people with MND. Relevant information for community clinicians will be highlighted.</p>
The Outcome	<p>Range of communication devices: Patient may utilise multiple communication systems at one time, and various options over the course of their disease.</p> <p>Timing. For patients with MND: Global/Bulbar Patients – often need to consider AAC within 12 months of diagnosis, PLS patients have a longer disease trajectory, frequently beyond 10 years from symptom onset (1) – may be better candidates for eye gaze systems. Future research needs to map phenotypes of MND to timing and type of AAC.</p> <p>Community therapists need to consider the following when working with MND patients and their families:</p> <ul style="list-style-type: none"> • Individual coping styles. • Consider priority of communication in relation to other areas of need. • Timely introduction of AAC. • Clear understanding of expectations – the patient’s, family/friend’s. • Ongoing support and counselling. • MND patients often use a range of communication options. <p>Opportunity to explore a range of options, consider multimodal combination of high and low tech communication options over the course of their disease.</p>
Take Home Message	<p>To ensure quality communication the speech pathologist must:</p> <ul style="list-style-type: none"> • Monitor and review regularly. • Facilitate and encourage adaptation to AAC and

	<ul style="list-style-type: none">• Provide ongoing support, care & time as they face the challenge of coping with ever-<i>changing</i> communication impairment. <p>For complex communication issues clients can be referred to CHCB COMTEC clinic.</p>
Contact Details Presenter	Maryanne McPhee Chief Speech Pathologist, Calvary Health Care Bethlehem 476 Kooyong Road Caulfield, Victoria, 3162 Telephone: (03) 9595 3343 Fax: (03) 9595 3301 Email: MaryanneM@bethlehem.org.au

National MND Conference Paper – 24 June 2008	
Title	Incorporating a palliative approach to care of individuals with MND and their families: Clinical challenges.
Presenter	Prof Linda Kristjanson.
Affiliation	Curtin University of Technology.
The Issue	<p>The paper will discuss the clinical challenges of including a palliative approach into the care of a person with MND. Questions to be addressed will include: when is the right time to discuss a palliative approach; how to help the individual and family to understand a palliative approach to care, and care-related cues that may be used to help trigger the need for this approach.</p> <p>Motor neurone disease (MND) is a rapidly progressive neurological disease of unknown cause that results in a variable loss of function and progressively high levels of disability. However, there is little empirical literature that describes how individuals and families might be helped to consider a palliative approach to care in the context of a rehabilitative model.</p>
The Initiative	<p>The paper is based upon a large national study currently funded by the NHMRC to develop and evaluate an education program for health professionals to integrate best practice in management of MND with a palliative approach to care. As part of this study, a review of literature and results from preliminary work indicate that health professionals play a central role in reducing the suffering associated with the disease, with value placed on providing practical assistance. Studies also report that people with MND and their families consider emotional support to be a priority. The beginning of deterioration potentially changes the emphasis of care. Expectations and support needs may rapidly change for people with MND and their families and individual quality of life is determined by a continuous process of adjustment to increasing disability. In some instances, people with MND may grapple with the terminal nature of this disease from the time of diagnosis and it is possible that people with MND and family member may be at different stages of acceptance of the terminal nature of the illness. Individuals may also associate a palliative approach with a loss of hope. Therefore, this discussion must be managed with care.</p>
The Outcome	Appropriate and sensitive incorporation of a palliative approach may help the individual, family and health care team to prioritise needs, clarify goals of care and better anticipate the most appropriate plan for care.
Take Home Message	<ul style="list-style-type: none"> • People with MND and their families are challenged to come to terms with the terminal nature of their illness from diagnosis. • People with MND and their families may benefit from the knowledge and expertise of health professionals who can help facilitate a palliative approach to care. • Careful communication about palliative care, attention to timing of the discussion, and identification of cues that indicate that a palliative care need may be helpful will be identified.
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Title	Developing a model of collaborative care for people with MND.
Presenter	Dr Susan Mathers.
Affiliation	Calvary Health Care-Bethlehem
The Issue	How to provide specialist-supported, but locally delivered health and social services to people with MND.
The Initiative	DHS sponsored project.
The Outcome	This will be an up-date of this current project.
Take Home Message	<ul style="list-style-type: none">• People with MND and their families require timely and well-informed, multidisciplinary and social care in their communities.
Contact Details Presenter	Dr Susan Mathers Neurologist and Clinical Director of Neurology Calvary Health Care-Bethlehem 476 Kooyong Road Caulfield, Victoria, 3162 Telephone: (03) 9595 3355 Fax: (03) 9595 3301 Email: SMathers@bethlehem.org.au

National MND Conference Paper – 24 June 2008	
Title	Palliative care and motor neurone disease: Living better for longer.
Presenter	Mr Gregory Dalton.
Affiliation	Department of Human Services.
The Issue	People with motor neurone disease (MND) may require and benefit from palliative care. Despite MND being a terminal illness, there is uncertainty about how and when to access palliative care. Referral of people with MND is not systematic, access is variable and there is a lack of published evidence about frameworks that may assist in promoting timely access to palliative care.
The Initiative	<p>The Motor Neurone and Palliative Care (MAP) project aimed to use the best available evidence to establish a framework that supports people with MND accessing palliative care at appropriate times and supports palliative care services to provide specialist health care and practical support for this client group. The project was jointly undertaken by the Department of Human Services and MND Victoria.</p> <p>The project aims were met by combining information from a literature review and questionnaires and interviews with people with MND (n=9), their current or former carers (n=31), palliative care workers (n=31) and key opinion leaders in palliative care (n=5).</p>
The Outcome	<p>This project makes six recommendations for the coordinated integration of palliative care into the overall management of people with MND and their carers. The recommendations are:</p> <ul style="list-style-type: none"> • A document developed for health professionals to illustrate the range of needs and availability of providers to assist people with MND access appropriate palliative care and community services. • The development of a key worker model for people with MND when receiving palliative care in order to promote early referral, support development and delivery of education to service providers. • The development of education to palliative care staff regarding MND and education to people with MND and their carers about the specialist healthcare and practical support provided by palliative care. • The development of guidelines for supplementary funding for inpatient and community palliative care services to meet identified high care and ongoing needs of people with MND. • Recognition of the importance of timely access to appropriate respite services. • The DHS give specific consideration to the needs of people with MND and their families when considering future policy decisions for access to after-hours palliative care support.
Take Home Message	<ul style="list-style-type: none"> • The Department of Human Services is actively working with MND Victoria to provide policy guidance to palliative care services for people with MND to assist with living better and longer.
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National MND Conference Paper – 24 June 2008

Title	Talking with Young People about Motor Neurone Disease.
Presenter	Judi Kiraly.
The Issue	To identify the need and develop strategies for strengthening opportunities for parents, schools & health professionals to communicate with and support children when a parent has MND.
The Initiative	The need for the project was identified by MND Victoria and MND NSW. A joint submission was made for a Palliative Care Grant from the Australian Government Department of Health & Ageing in 2006. The project was funded as a 3 year initiative to be completed by early 2009.
The Outcome	<p>The project has produced a ‘Parents Pack’ of six booklets suggesting strategies for talking about MND for:</p> <ul style="list-style-type: none"> • Parents • 8 to 12 year olds • Teenagers • Friends • Schools • Health professionals <p>2000 Packs will be produced and distributed to families in all States by late 2008. Information in the pack will be posted on Australian MND websites.</p>
Take Home Message	<ul style="list-style-type: none"> • Communicating effectively during an illness like MND is essential to the health of all family members as well as the person with MND. • Parents appreciate help with talking with their children, particularly around the time of diagnosis. • Using the right words or actions is often a learned rather than a natural skill. • Asking questions can be as effective as making suggestions. • Teachers, health team members, counsellors and palliative care workers can help to strengthen parents’ abilities to communicate with their children and vice versa.
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