

ALLIED PROFESSIONALS' FORUM
Hilton Birmingham Metropole
2 November 2008

SPEAKER: SUSAN GEIS, BSc (P.T)

BIOGRAPHY:

Susan holds a Bachelor's degree in Physiotherapy from McGill University, Montreal, Canada.

Susan began working at the Ottawa Hospital's Rehabilitation centre in 1983, soon after graduating. She has greatly enjoyed her position as rotating Physiotherapist on many of the Centre's services, including spinal cord injury, stroke, respiratory, psychogeriatrics, in and outpatient orthopaedics, amputees and chronic pain.

Susan has been working on the Rehabilitation Centre's ALS team since 2001 and has co authored several posters which were presented at previous International Symposiums. She is very proud to present the Integrated Care Pathway for ALS, developed by her team in conjunction with the local Community Care Access Centre.

AUTHORS: S. GEIS, E. CAWADIAS, C. ROY, M. BUTLER, N. RIDGEWAY

TITLE OF PRESENTATION: FROM DIAGNOSIS TO DEATH: ENHANCING PARTNERSHIPS AND QUALITY OF LIFE USING AN ALS INTEGRATED CARE PATHWAY

ABSTRACT:

Background:

The ALS Integrated Care Pathway (ICP) for the Champlain Region (Ottawa, Canada) was developed in response to feedback from community service providers who had few patients with ALS and were therefore unfamiliar with the disease. They needed an easy-to-use guide to ALS and its management.

Objective

The ALS ICP was designed to be a user-friendly guide to educate professional service providers in the community and to enhance their understanding of the disease process from onset to end-of-life. The goal was also to promote and support the development of multi-disciplinary care partnerships.

A survey to assess whether the ICP is fulfilling the objectives has been undertaken and the results will be presented.

Programme description

The Ottawa Hospital Rehabilitation Centre ALS Clinic interdisciplinary team and the Champlain Community Care Access Centre developed the structure and the content of the ICP. Input was also received from community groups.

The ICP is divided into seven areas: mobility, respiratory, communication, cognition, eating and swallowing, nutrition and spirituality. Each area includes background

information and describes the stages of progression of ALS with presentation, psychosocial considerations, potential risks, interventions and supportive resources. In addition, there is detailed information of key service resources for ALS management including clinic and community programmes, books and videos.

The ICP has been available since March 2007 in hard copy and as a PDF file in both English and French.

Clinical outcomes

Clinical goals of the ALS ICP are:

1. ease of use
2. education of professional care providers in the community
3. increased efficiency and effectiveness of care delivery
4. reduction of crisis situations
5. promotion of multi-disciplinary care partnerships

The ultimate goal of the ICP is improved quality of life for our patients and their families.

Recommendations to the field

This ICP provides concrete suggestions on the everyday management of the disease from diagnosis to death. The ICP enables professional service providers and non-professional caregivers to recognize problems early and suggests interventions and supportive resources to manage the problems thus averting crises.

The ICP is intended not to replace professional clinic assessment and support but rather to complement them. Its purpose is to ensure a consistent continuum of care throughout the course of the disease whether the care is provided by the clinic, community services in the patient's home or at a care facility.

SPEAKER: PAULINE CALLAGHER

BIOGRAPHY:

On completing her nurse training, Pauline worked on the acute neurology ward for a number of years. After a period of secondment as an infection control nurse she then returned to the neurology department before working as a clinical nurse practitioner in the neurosurgical department. She then returned to the acute neurology ward to take up the position of nurse manager. For the past four years, Pauline has worked as the co-ordinator of the Preston MND care and research centre. She has had a role in implementing new initiatives such as the MND fast track diagnostic service, a multi disciplinary team clinic, introduction of nurse-led clinics in hospices within the locality served by the care centre of Lancashire and South Cumbria. She has also played a pivotal role in implementing the NHS patient held document 'Preferred Priorities of Care' amongst people living with MND. Pauline is also involved in clinical trials, working as a research nurse, and is a co-applicant on a National Institute for Health Research, 'Research for Patient Benefit' project, which involves the experiences of people living with MND, their carers, and past carers.

AUTHORS: PAULINE CALLAGHER, PROF J DOUGLAS MITCHELL, ROBERT ADDISON-JONES, WENDY BENNETT, JOYCE GARDHAM

TITLE OF PRESENTATION: EVALUATION OF THE FAST-TRACK DIAGNOSIS PROCESS FOR PEOPLE SUSPECTED OF MND

ABSTRACT:

Background:

As part of an initiative to improve services for people living with MND a Fast Track Diagnostic Clinic (FT) was established at the Care Centre. This lessens any diagnostic delays resulting in an explanation of symptoms for the patient; minimising the risk of mismanagement, allowing advice on symptom control and support at an earlier stage. The service aims to undertake relevant investigations and communicate a diagnosis within a controlled setting, four weeks from first visit.

Objective

- Compare timelines for FT and non-fast track (NFT) diagnostic services
- Gain the perceptions of patients going through the FT pathway compared to the more traditional diagnostic routes.

Programme description

Comparisons relating to the patient journey were made from referral to neurological consultation and from referral to diagnosis between those in the FT process and those following NFT pathways. A patient satisfaction questionnaire based on the 'MND Association Guidelines on Diagnosis Giving' was completed by patients diagnosed with MND between April – August 2006.

Clinical outcomes

Median time from referral to diagnosis was 51 days for the FT patients and 104.5 days for the NFT patients.

Of twenty-one questionnaires issued, nineteen were returned.

Seven FT, twelve NFT patients.

All the FT patients felt that they were given enough privacy, both when discussing their condition and when being examined.

Most patients indicated they were given their diagnosis by a Consultant Neurologist, 1FT and 1NFT patients were unsure, who gave the diagnosis. All FT patients were given the opportunity to have someone with them.

86% FT patients felt that the reasons for investigations, referrals or treatments had been explained to them in a way they could understand.

All patients felt that the doctor and specialist nurse had listened to them and that they had been given enough time during consultations.

100% FT patients saw the specialist nurse when receiving the diagnosis. 33.3% NFT had the specialist nurse involved in diagnosis giving, 25% saw the MND nurse immediately after, 8.3% seen within 1 week, 33.3% seen by the specialist nurse within the next few weeks.

Recommendations to the field

A barrier to achieving an efficient diagnostic process can arise through atypical presentation, confusing co-morbidities etc. Swift access to diagnostic investigations is paramount to success in achieving diagnosis to treatment within 18 weeks. However, for those with suspected MND at referral, a fast track diagnosis is achievable and enables diagnosis giving to be managed in a more controlled environment

SPEAKER: WENDY BENNETT

BIOGRAPHY:

Wendy Bennett qualified as a registered general nurse in 1991. Her first role was in the regional Neurosurgery centre in Preston which included a period caring for ventilated patients in a neurosurgical HDU. Wendy moved into acute Neurology in 1993 where she nursed people from diagnosis through to terminal care. Whilst there, she completed her Diploma in Critical Care and ENB 148.

Since 2004, Wendy has worked as part of the specialist nursing team within the MND Care and Research Centre at Lancashire Teaching Hospitals Foundation Trust. In this role, she has supported the implementation Preferred Priorities of Care and nurse-led clinics within a hospice setting. She also has an active interest in research and has coordinated a clinical trial in conjunction with a pharmaceutical company.

AUTHORS: PAULINE CALLAGHER, ROBERT ADDISON-JONES, WENDY BENNETT, PROF J DOUGLAS MITCHELL, JOYCE GARDHAM, LIZ HASSEY, EMILY WAGGSTAFF, ANNA CONLAN

TITLE OF PRESENTATION: INTRODUCTION OF MND NURSE LED CLINICS INTO THE COMMUNITY HOSPICES IMPROVES SERVICE AND ACCESS TO PALLIATIVE CARE

ABSTRACT:

Background:

- The Care Centre covers a wide geographical area which means patients travel long distances for appointments, which become increasingly difficult during the disease trajectory.
- Hospital car parks are often full leading to patients feeling they need to arrive a great deal earlier than the appointment time which leads to unnecessary stress when attending clinics.
- Access to hospice services were patchy in some areas leading to inequalities in access to palliative care.

Objective

Moving the clinic outside the hospital environment and into the hospices has many benefits.

- Reduction in travel for patients
- Better parking facilities
- More comfortable and relaxed atmosphere in waiting areas
- Introduction to the hospice services at an early stage in the disease trajectory, thus dispelling some of the myths that surround hospice 'as places where people go to die'.

Programme description

Hospice nurse managers or directors were approached to discuss the possibility of hosting nurse led clinics. The MND nurses had an initial meeting to discuss what palliative services could be offered to the patient. MND Nurse specialists would arrange the appointments and manage the clinic, summary letters are then copied to the hospice directors so that they have the information on file should a referral for hospice services be required.

Clinical outcomes

The clinics have been very well received by patients, finding the environment more relaxed, thus aiding communication, leading to more productive and less stressful clinic appointments. The team are more aware of the services individual hospices offer and many patients take advantage of these services since attending clinics e.g. day care, respite, complimentary therapy treatments and counselling. Carers also benefit from the support the hospices offer.

In a number of the hospices, local community therapists also attend the clinics. This improves patient management, expediting the referral process and encouraging close liaison and a multi professional approach to care.

Recommendations to the field

The Care Centre has six hospices within the locality, all offering clinic space for nurse-led clinics on a two - three monthly basis. Although community therapist involvement relies on the good will of the therapist so far their involvement has been well received. Ultimately taking the nurse-led clinic to the hospices improves access to palliative care and the patient experience. This activity could be replicated in other areas.

SPEAKER: JANET MCMILLAN LRAM, CHAIR, LEICESTERSHIRE AND RUTLAND BRANCH, MND ASSOCIATION

BIOGRAPHY:

Janet became involved with the MND Association in 1986, shortly after the death of her father from the disease. Having helped establish the Leicestershire and Rutland Branch that year, she served as its first committee chairman for several years and has been closely involved with the Association ever since. In 1987 she became a member of the National Executive Committee (Board of Trustees) and was elected to serve as Chairman from 1989 to 1995. During that period the concept of an international alliance of MND/ALS organisations, health professionals and scientists emerged and Janet attended the very first International Symposium in Birmingham, England in 1990

AUTHORS: ISOBEL JENKINS AND JENNY HOLMES SHUTTLEWOOD

TITLE OF PRESENTATION: OPTIMISING VOLUNTEER INVOLVEMENT IN THE MULTI-PROFESSIONAL TEAM

ABSTRACT:

Background:

The Motor Neurone Disease (MND) Palliative and Supportive Care Pathway project has established robust systems providing a comprehensive, timely, responsive service for people with MND and their carers, guided by their needs. Partnership work between the hospice, health, social and voluntary services has been pivotal.

After a mapping day highlighting areas of good practice and gaps in service provision, task and finish groups are addressing the major issues.

Volunteers from the Leicestershire and Rutland branch of the MND association belong to the project steering group and these task and finish groups:

Patient and carer needs and information;

Timely provision of appropriate equipment;

Support for the multi disciplinary team;

Novel MDT meeting and clinic.

Objective

The multi disciplinary meetings were developed to provide a forum for professionals or volunteers caring for someone with MND to discuss issues and updates of their involvement.

The multi disciplinary clinic developed in response to a questionnaire to people with MND and their carers, who wanted to see different members of the team 'under one roof'.

Programme description

The MDT meetings are held fortnightly at the hospice, chaired by the MND Clinical nurse specialist (CNS) and attended by workers from health, social and voluntary sectors.

Patients are discussed, from recent diagnoses to deaths.

The clinic follows afterwards. Core members of the clinic are the MND CNS, a Consultant in Palliative Care, the hospice Occupational Therapist and the MNDA volunteers. Patients are greeted by the volunteers, who have an information stand and leaflets set out in a quiet part of the waiting area. They chat informally and have a separate clinic room available if needed.

Clinical outcomes

Positive outcomes of attending the MDT meetings and clinics are better appreciation of the MNDA volunteer role by others, enhanced mutual respect and more patients accessing the volunteers. Recognising not all MND patients wish to see an Association Visitor at home, the clinic provides the opportunity for volunteers to meet patients and their families in the early stages and build up a rapport.

Volunteers provide support in a less hierarchical relationship from the patients' perspective, often with first hand experience of caring for someone with the disease.

Patients discuss different types of concerns compared with other MDT members. Another advantage has been the prompt assessment of individuals' needs and targeted referrals for specific equipment or services.

Involvement in the meetings and clinics also offers support to the volunteers who might otherwise be working in isolation.

These improvements in team working mean that that people with MND are better supported by Health, Social and Voluntary care workers.

Recommendations to the field

We recommend establishing a forum for multidisciplinary problem solving and care planning, which we have found optimises the significant and meaningful role played by Association Volunteers, as well as enhancing patient care.

SPEAKER: CATHERINE MADISON

BIOGRAPHY:

Catherine Madison MD is the Manager of ALS Clinical Care at the Forbes Norris Research Center in San Francisco California. With over 20 years of experience in neurology, Dr. Madison shifted her focus 7 years ago to help provide the best in clinical care to ALS patients and their families. She has been a co-investigator in numerous ALS scientific and clinical trials and has developed an interest in caregiver quality of life. Her current project is an attempt to support health in the clinic staff; the source for optimal patient care.

AUTHOR: CATHERINE MADISON

**TITLE OF PRESENTATION: A SIMPLE INTERVENTION TO PREVENT
COMPASSION FATIGUE IN ALS CLINIC
PROVIDERS**

ABSTRACT:

Background:

32 certified ALS Association (ALSA) clinical care centers in the U.S. provide multi-disciplinary care to a diverse and complicated group of patients. The risk of compassion fatigue in this group of providers is high, as the patients being dealt with face increasing obstacles as their disease progresses.

Objective

To demonstrate how a simple intervention with the team members of a large multi-disciplinary ALS/MND regional center can improve scores on a Compassion Fatigue survey after only eight weeks.

Programme description

Members of the Forbes Norris MDA/ALS multi-disciplinary team were asked to participate. The intervention consisted of 8 weekly 15 minute sessions of mindfulness led by a specialist in this field. Mindfulness is a practice of paying attention to the given moment in a non-judgmental fashion. This allows one to remove the sense of unawareness professionals tend to develop to protect themselves from continued exposure to stress.

Clinical outcomes

Sat Kartar Khalsa-Ramey led the short group sessions aimed at reconnecting individual providers with their inspirations for work, rebalancing their needs, and diffusing grief. The sessions provided time for individual and group communication.

Recommendations to the field

Maintenance of staff well-being is critical for staff team members in the ALS/MND community. This type of an intervention is easily implemented and can be done with variations of approach to suit the unique setting of each ALS/MND team. While improving satisfaction with work, there is also a secondary improvement in patient care. This intervention allows those working in this difficult field to retain their focus and continue to provide the excellent care that the ALS/MND community is committed to.

SPEAKER: PROFESSOR MARGARET O'CONNOR AM,RN, DN, MN, B.THEOL, FRCNA

BIOGRAPHY:

Margaret has held the Vivian Bullwinkel Chair for 5 years, which formally encompasses 3 clinical partners adjacent to her University campus. She is responsible for the Palliative Care Research Team in the School and manages a number of clinical research projects. Margaret sits on many State and National Committees related to palliative care and is well published in her research areas. She received the national honour of an Order of Australia in 2005 for services to the development of palliative care in the State of Victoria.

AUTHORS: MARGARET O'CONNOR AND VIVIAN BULLWINKEL

TITLE OF PRESENTATION: USING A RETROSPECTIVE DATABASE TO PREDICT CLINICAL SUPPORT NEEDS OF PEOPLE WITH MND.

ABSTRACT:

Background:

The complete client records of people, who had received care from MND Victoria over the last 10 years, were considered a suitable resource for a longitudinal retrospective analysis of issues about care, treatment and supports required.

Objective

To undertake a retrospective analysis of patient data to map care requirements, the influence of treatment and other commonalities and differences.

Programme description

This paper discusses a joint research initiative between a research team and the State peak body for MND. The project designed and developed an Access data base capable of recording and reporting on variables pertaining to past, current and future MND client records.

All deceased MND Victoria clients were allocated an individual code and their data de-identified. Basic demographic data included gender, postcode and date, country of birth, carer / family details and the relationship of the primary carer. Disease-related information

included date of onset, diagnosis and death, symptom phenotype at time of registration, and related information such as the introduction of PEG feeding or ventilation equipment. Professional contacts and referrals were also identified in the histories and included.

Clinical outcomes

Data entry commenced with the most recent electronic data first and worked backwards through all available records. A pilot of 30 cases was imputed initially to check for completeness and viability of the process and was repeated after the first 100 client records were coded and entered resulting in slight adjustments to the fields of data collection.

The 28 fields of core data were entered on a primary table with 3 linked sub tables capturing specific information on symptom severity on registration, professional contacts and referrals. The database is cumulative and capable of producing standard reports in a variety of formats, texts and tables.

This paper reports on distinctive aspects of the data that have been analysed by formulating queries run through the co-joined database tables, allowing for a broad range of comparative statistics. We report on aspects of care like requirements for respite as the disease progresses, points of deterioration that indicate equipment requirements and the numbers and types of professional supports received over the length of the illness.

Recommendations to the field

This detailed profile of the lived experience of people with MND in Victoria, will enable the prioritising and development of service development strategies to better assist their care and support.

SPEAKER: DR MARGARET GILES

BIOGRAPHY:

Margaret was appointed Senior Lecturer in the school of Accounting, Finance and Economics at Edith Cowan University, Joondalup, Western Australia from 1 July 2008. Prior to this appointment, Margaret was Silver Chain's project co-ordinator for the Lotterywest funded collaborative project "An Investigation into the Home Support Needs of Adults Living with Multiple Sclerosis, Huntington's, Parkinson's and Motor Neurone Diseases", 2006 to 2008. Margaret was joint winner of the 2008 Nina Buscombe Award from MND Victoria. The Award is in recognition of her support and commitment to improve quality of service delivery for people living with MND.

Margaret has degrees in economics and has previously worked for State and Federal Governments in research, policy and planning positions, and in the university sector in research and teaching roles.

AUTHORS: MARGARET GILES AND GILL LEWIN

TITLE OF PRESENTATION: MIND THE GAP: THE HOME SUPPORT NEEDS OF PEOPLE WITH MND IN WESTERN AUSTRALIA

ABSTRACT:

Background:

A study investigating the home support needs of adults living with four neurodegenerative disorders (NDD), including Motor Neurone Disease (MND), was undertaken in Western Australia in 2006 - 2008. Thirteen organizations participated in the project including disorder support agencies and home care support providers. The study had six components - a postal survey, client and carer interviews, case studies, client and member database summaries, database linkage and projections of needs and gaps in home care support to 2050.

Objective

The purpose of the project was to provide home and community care providers, planners and policymakers with information that will assist them to better understand the current and future needs of individuals (and their families/carers) living with NDD in the community.

Programme description

N.A

Clinical outcomes

For those respondents with MND who received home care support (n = 34), the shortfall was found to average 0.7 hours per week (ranging from no gap to a 4 hour gap) for personal care (n = 8), 0.5 hours per week (0 to 3 extra hours) for domestic assistance (n = 15), and 0.7 hours per week (0 to 2 extra hours) for gardening and home maintenance (n = 6). There were no gaps in social support. The average gap over all categories was 0.9 hours per week (0 to 4 extra hours). When disaggregated by stage of disorder and living arrangements, people without carers and/or who were in the late stage of their disorder had wider home support gaps than people with live-in carers or who were at earlier stages of their disorder.

Recommendations to the field

The findings suggest that the funding of both packaged and unpackaged home care support for people with NDD should increase and be sufficiently flexible to allow variations between individuals and across support categories.

SPEAKER: JULIE COMPTON

BIOGRAPHY:

Julie is employed by the MND Association (UK) as Regional Influencing Co-ordinator covering central England and Wales. For the past three and a half years Julie has focused on planning, implementing and influencing activity - working with key decision makers in health and social care services.- to achieve positive outcomes for people with motor neurone disease.

Julie's twenty years experience as a social worker working with people with complex physical disabilities, including motor neurone disease, has been invaluable and has enabled her to use those insights to inform her work advising, assisting and influencing policy and strategy formulation.

AUTHOR: JULIE COMPTON

TITLE OF PRESENTATION: MND YEAR OF CARE PATHWAY

ABSTRACT:

Background:

The MND Association of England, Wales and Northern Ireland seeks to drive forward equity of access to the best quality care for all people with MND/ALS (pwMND/ALS) and their carers. Current policy changes within the National Health Service (NHS) and social care system – the emphasis on commissioning services, user and care involvement, personalisation and choice agendas, as well as partnership between health, social care and voluntary sectors - are providing new opportunities to influence the standard of care available for pwMND/ALS.

The MND Year of Care Pathway is a tool to improve the ‘intelligence’ of commissioners across health and social care, and the quality of services they commission from the range of providers within health, social care and the voluntary sector. It is a ‘road map’ covering the range of services, and support that might be required in the last year of care costed against known tariffs.

Objective:

- Enable pwMND/ALS to access best care to achieve quality of life, and die with dignity
- Ensure carers of pwMND/ALS have access to support and information enabling them to achieve quality of life
- Achieve sustainable systemic change in the longer term
- Facilitate organisational development through enhancing the Association’s influencing capability and capacity

Programme description:

The MND Year of Care Pathway was developed in partnership with a London Primary Care Trust, pwMND/ALS, carers, national and regional MND Association staff, and supported by specialist healthcare consultants, the MAC Partnership. It was subsequently validated in a larger health and social care economy in the north of England involving commissioners, providers and plwMND/ALS and their carers.

The intention was to devise a pathway which was accessible, affordable to commissioners, deliverable by providers, and was satisfactory (should we use acceptable? If that is agreed an appropriate text thats fine) to pwMND/ALS and their carers. A framework for implementation and evaluation has been developed, and launched. (is this the Year of care Framework?)

Clinical outcomes:

It is intended that this development will lead to people with MND/ALS and their carers having access to the highest standard of care and support

Recommendations to the field:

Initial recommendations will be highlighted in the presentation in light of progress in implementing the programme of work, and engaging with commissioners.

SPEAKER: ROD HARRIS

BIOGRAPHY:

Rod Harris is passionate about quality living, no matter what a person's circumstances might be. He believes that helping people live better for longer should be the goal of all services, including those provided by palliative care. MND Victoria is focused on helping people with ALS/MND access services that will improve their quality of life and address unmet needs. MND V provides information and support to service providers to ensure that every service can apply their skills and expertise to support people living with ALS/MND.

Rod has been a significant influence in shifting palliative care services in Victoria from a pain/cancer model to one that embraces people who need their services no matter what their diagnosis. The next phase of that shift is to move from palliative care being described as an “end of life” service to a “quality of life” service, and to extend services and support provided by agencies to people with unmet needs that can be addressed by the service.

Rod Harris is CEO of MND Victoria, one of Australia’s States, and was formerly a member of the Board of Directors, Palliative Care Victoria and Chairman of the International Alliance of ALS/MND Associations.

AUTHORS: G DALTON, J ARNEL, H AUSTIN, S MATHERS, J KENWRIGHT, G ANDERSON, C DUCK, J NOONAN, R HARRIS

TITLE OF PRESENTATION: PALLIATIVE CARE AND MOTOR NEURONE DISEASE: LIVING BETTER FOR LONGER.

ABSTRACT:

Background:

People with motor neurone disease (ALS/MND) may require and benefit from palliative care. Despite ALS/MND being a terminal illness, there is uncertainty about how and when to access palliative care. Referral of people with ALS/MND to palliative care services 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.

Objective and Programme description

The Motor Neurone and Palliative Care (MAP) project aimed to use the best available evidence to establish a framework that supports people with ALS/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 (DHS) and MND Victoria.

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).

Outcomes

This project makes six recommendations for the coordinated integration of palliative care into the overall management of people with MND and their carers. They are:

- Develop a document for health professionals to illustrate the range of needs and availability of providers to assist people with MND.
- development of a shared care worker model for people with ALS/MND when receiving palliative care.
- development of education to palliative care staff regarding ALS/MND and to people with ALS/MND and their carers about palliative care.
- development of guidelines for supplementary funding for inpatient and community palliative care services to meet identified high care and ongoing needs of people with ALS/MND.
- recognition of the importance of timely access to appropriate respite services.
- specific consideration given by DHS to the needs of people with ALS/MND and their families when considering future policy decisions for access to after-hours palliative care support.

The outcome has been a successful budget initiative funded by the Victoria Government with support and services to commence third quarter 2008

Recommendations to the field

- The DHS works actively MND Victoria to provide policy guidance to palliative care services for people with MND to assist with living better and longer.
- Funding initiatives need to be underpinned by effective research with both quantitative and qualitative elements
- Recommendations contained in the report be reviewed by others regarding approach and options
- That concerted work be undertaken to present palliative care and hospice as quality of life services

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

BIOGRAPHY:

Amy Roman is the Speech Language Pathologist and Augmentative Alternative Communication (AAC) Specialist at the Forbes Norris ALS Research Center in San Francisco. During her nine years at the Center, she has provided solutions to patients seeking help with swallowing, communication, and computer access.

Ms. Roman also runs an over 1,000 piece communication and computer access equipment lending library. Through this library and demonstration center she provides evaluations, training, trials, loans and to patients.

By developing a training program for volunteer speech pathology students, Ms. Roman is able to provide free supplementary services to patients who use AAC and train future clinicians.

Ms. Roman will be presenting *AlphaCore*®, a tool for speech generating devices, specifically developed to meet the communication and telecommunication needs of patients with ALS. *AlphaCore*® utilizes unique strategies to reduce the physical and cognitive challenges of using these devices. Individuals with complex communication and access needs are therefore able to express themselves with greater ease, speed and independence. *AlphaCore*® also is composed of alternative page sets that allow for transitions as physical abilities change. All of these elements, along with a self guided tutorial, provide patients support and consistency in their communication system.

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

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

AUTHOR: AMY ROMAN

**TITLE OF PRESENTATION: ALPHACORE: A COMPREHENSIVE AAC SOLUTION
DESIGNED SPECIFICALLY FOR PALS**

ABSTRACT:

Background:

Providing effective Augmentative Alternative Communication (AAC) to people with ALS (PALS) is an international challenge. Interventions must be timely as ALS is rapidly progressive. PALS have multifaceted communication demands with complex alternative access needs.

Unfortunately, clinician’s time and knowledge about AAC is often limited. As a result, PALS are not using speech generating devices adequately customized to their needs or taking advantage of telecommunication tools essential for remaining connected in today’s world.

The presenter, Amy Roman, an AAC specialist with the Forbes Norris ALS Research Center in San Francisco, has developed AlphaCore in response to these realities. AlphaCore is a tool that provides new strategies for communication enhancement that, for the first time, places modern communication and computer access at the fingertips of users. DynaVox, the largest international

distributor of Speech Generating Devices, now features AlphaCore as the centerpiece of its AAC solutions for PALS.

Objective

1. Review the complex communication needs of PALS and explain the need for a well designed, *out of the box*, AAC solution customized for PALS.
2. Demonstrate how AlphaCore provides innovated language strategies and telecommunication access designed to transition patients through multiple access methods.
3. Illustrate how the AlphaCore Tutorial serves as a guide for clinicians and PALS.

Programme description

This presentation demonstrates how AlphaCore meets the needs of PALS by providing rapid message construction, intuitive navigation and appropriate adult language. Additionally, telephone, email, instant messaging and text messaging access is built seamlessly into the system. Clinicians with limited time and funding can now provide PALS with successful communication and independent use of the vital computerized communication technologies of the 21st century.

Clinical outcomes

PALS shaped AlphaCore's 8-year-development by dictating expectations from a user's perspective. Speech therapists throughout the US began requesting AlphaCore to achieve outcomes once considered outside the realm of standard practice. AlphaCore is now available at no cost through an international AAC distributor.

By using the 6 unit Tutorial, PALS have been able to use AlphaCore effectively with limited assistance, giving them greater independence.

Recommendations to the field

All individuals participating in PALS' care must have an awareness of our clients' unique communication *needs* as well as the available *technologies* if we are to achieve optimal communication outcomes. Comprehensive *out of the box* solutions developed specifically for PALS must be utilized to efficiently meet the communication needs of PALS.

SPEAKER: MARK GOREN

BIOGRAPHY:

Mark S. Goren MS OTR/L is the senior occupational therapist at Drexel University's MDA/ALS Center of Hope located in Philadelphia Pennsylvania. He has been part of a multidisciplinary team treating people living with ALS for over 10 years. Mark received his Master of Science degree in occupational therapy from Temple University in 1995.

Additional areas of interest include both hand therapy and assistive technology.

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

AUTHORS: MARK GOREN AND DONNA HARRIS

**TITLE OF PRESENTATION: COMPARING THE ERICA EYE GAZE SYSTEM TO THE
MANUAL LETTER BOARD FOR COMMUNICATION
PURPOSES IN THE ALS PATIENT POPULATION.**

ABSTRACT:

Background:

New technologies are giving people with motor disabilities alternative communication and control channels. We are interested in using the ERICA Eye Gaze System as a hands free means to access a computer for people living with Amyotrophic Lateral Sclerosis (ALS).

Objective

- 1) Determine whether this is a practical and realistic communication device for ALS patients.
- 2) Compare to the manual letter board for efficiency, reliability and ease of use.

Programme description

ERICA Eyegaze System, is a hands-free way to operate a tablet personal computer. ERICA is a system that can determine where its user is looking. The system tracks eye movement by monitoring features on the eye that may be translated to a gaze position. The gaze position or point of regard represents the location of a user's gaze. The ERICA system empowers people with disabilities with hands-free communication and computer access. After a quick calibration, users have complete control over the system with their eye.

Up to 25 people living with ALS will be evaluated and consented. Participants selected for the study will be required to meet the following criteria: 1) cognitively intact 2) no other neurological disease 3) no unstable medical problems 4) able to travel to the MDA/ALS Center of Hope for training sessions 5) Patient must have no more than 25% speech intelligibility 6) patient's must have minimal active upper extremity movement deeming them unable to directly select a keyboard 7) an ALS Functional Rating Scale score of 2 or less in the categories of speech and writing.

Clinical outcomes

Results from the ERICA Eyegaze System will be available for presentation.

The ERICA Eyegaze system will be compared to the manual letter board for a) speed of use
b) ease of use.

Recommendations to the field

The potential benefit of acquiring a reliable, effective, hands free means of computer access for communication purposes. Due to the progressive nature of ALS which along with immobility includes loss of speech, the computer interface technology and related technologies may be of substantial value for improved quality of life for people living with ALS

SPEAKER: SARA FELDMAN, MA, PT, ATP

BIOGRAPHY:

Sara Feldman graduated from Temple University with a BS in Physical Therapy in 1987 and from University of Pennsylvania with a Masters in Environmental Science in 1997. She worked in acute rehabilitation until 1993 when she started at Hahnemann University Hospital in the neuro-trauma department. As part of this rotation, she covered the ALS clinic, and by 1994 became the permanent physical therapist for the clinic. She enjoys her work with the multidisciplinary team at the MDA/ALS Center of Hope at Drexel College of Medicine where she participates as the physical therapist for the clinic; as the Clinical Evaluator for ongoing clinical trials; and as the Assistive Technology Practitioner.

Please contact her with any questions after the program at sfeldman@drexelmed.edu.

AUTHOR: SARA FELDMAN

TITLE OF PRESENTATION: COMPUTER ACCESSIBILITY FOR INDIVIDUALS WITH ALS

ABSTRACT:

Background:

Amyotrophic lateral sclerosis (ALS) is characterized by progressive weakness resulting in a state of profound disability. The rise of new technologies allows individuals with motor disabilities alternate ways to access their computers. Previously, we determined that individuals with a higher level of disability relied on their health professionals for information about available technology. Therefore, it is essential that professionals are educated in assistive technology as it relates to computer access.

Objective

The objective of this lecture is to educate health professionals on where to begin when addressing computer access and to increase their knowledge on available devices. It is important to understand the steps that can be taken to address the needs of individuals with ALS as their ability to use a standard keyboard and mouse declines.

Programme description

Individuals are seen at our center every two to three months. During the initial evaluation, we document information on their computer use. Throughout the course of their illness, issues related to computer access are re-evaluated. Any concerns that arise are addressed beginning with discussion and the introduction of educational materials. As needed, the equipment can be brought to each individual for further demonstration and to allow for trials of the devices.

The focus of this presentation is to discuss in detail the broad spectrum of assistive technology that is available, how to determine appropriate access, ideas to establish a trial library, and information on funding sources.

Clinical outcomes

Based on the premise that people will turn to us for information on computer access, we have designed a system to address their needs for assistive technology at our multidisciplinary center. Through specific grants and donations we have developed a library of equipment that is available for demonstration, education and trial.

Recommendations to the field

Computer use is an important avenue for people with ALS to communicate and avoid isolation. However, our patients reported that they would stop using their computers as they began to have difficulty with access. While information is available on computer accessibility, piecing it all together can be difficult, and providing this information to people with ALS in an easily

understood and useable format will provide an added dimension to their care. It is hoped that by attending this seminar, the health professionals will leave with information that they can take back to their patients with ALS and begin to use immediately.

SPEAKER: DAVID OLIVER

BIOGRAPHY:

Dr David Oliver is Medical Director and Consultant Physician in Palliative Medicine at the University of Kent, where he is Director of Studies for MSc in Supportive and Palliative Care. He is a Visiting Professor at the School of Medicine at the University in 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, Japan, Nigeria, Italy 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 of 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, published in 2006. He is a co-editor of Palliative Care in Neurology.

AUTHOR: DAVID OLIVER

**TITLE OF PRESENTATION: SPECIALIST PALLIATIVE CARE AND MND /ALS CARE
– CHALLENGES FOR THE FUTURE**

ABSTRACT:

Background:

Although specialist palliative care services have often been involved in the care of people with MND/ALS the roles are changing. Due to increasing pressures there is a tendency for services to be involved later in the disease progression but as the use of interventions, such as gastrostomy and ventilatory support, increase there may be an greater need for involvement and wider discussion earlier in the disease progression. If these discussions do not occur there an increased risk of invasive ventilation, with a tracheostomy, starting in an emergency situation as patients using non-invasive ventilation develop problems. These situations lead to many problems – both practical and ethical.

Objective

There is the need for all to be involved in team discussion on the introduction of interventions such as gastrostomy or ventilatory support to people so that they and their families are aware of the issues that may arise and advanced care planning can occur.

Programme description

The Medway and Swale MND Clinical Team has been collaborating with services in hospital, hospice and community for many years, and this role appears to be increasing. This increased collaboration and co-ordination has allowed discussion and planning before the instigation of non-invasive ventilation and gastrostomy, so that there can be discussion regarding the progression of the disease process. The role of all involved with the patient and family can be clarified and advanced care planning – of the place of care and death and the interventions that may occur – can occur so that deterioration and care at the end of life can be anticipated and the most appropriate care provided, with the best quality of life for patient and family.

Clinical outcomes

The management of MND/ALS is changing with the increased use of ventilatory support and gastrostomy and the life expectancy may be increased. Moreover the expectations of the patient and family may become over optimistic, with reduced awareness of the possibility of deterioration and death.

There may be an increasing role for palliative care services to be involved alongside other neurological or rehabilitative services and to take a greater role as the end of life is approached. This would allow involvement, and support, in decision making by patients and families. This is particularly important when non-invasive ventilation is introduced to patients so that they and their families are aware of the issues that may occur as the disease progresses, and care may be planned ahead.

Recommendations to the field

A more collaborative approach in the care of people with MND/ALS may need to be considered, with increased collaboration at particular times, when decisions are made, and reduced contact when the patient is relatively more stable. There will be the need to ensure that despite all the interventions that are made the patient and family are still aware of the potential for deterioration and the need to anticipate and prepare for the end of life.

SPEAKER: MARY JO ELMO CNP

BIOGRAPHY:

Mary Jo Elmo RN, MSN, CNP is the Project Manager for the Diaphragm Pacing Program at University Hospitals Case Medical Center. Under the direction of Raymond Onders, MD, a pioneer in diaphragm pacing, Mary Jo developed the role of Diaphragm Pacing Nurse Practitioner Researcher for both Spinal Cord Injury and Amyotrophic Lateral Sclerosis (ALS). She has 20 years of nursing experience specializing in critical care and mechanical ventilation. Currently, she is co-investigator for 5 clinical trials and she provides patients management for all subjects. Mary Jo has been published in peer review journals and speaks frequently and on the national and international level on Diaphragm Pacing

AUTHORS: MJ ELMO, RP ONDERS, B KATIRJI, R SCHILZ, AR IGNAGNI

TITLE OF PRESENTATION: DIAPHRAGM PACING IN ALS: EXPERIENCE AT THE FIRST AND LARGEST IMPLANT SITE

ABSTRACT:

Background:

Respiratory failure is the major cause of mortality in patients with ALS/MND. The Diaphragm Pacing Stimulation (DPS) system provides electrical stimulation to the motor points causing diaphragm contraction. DPS requires a minimally invasive laparoscopic implantation procedure and is currently utilized world wide to maintain diaphragm breathing. DPS therapy offers a specific therapy for diaphragm dysfunction in ALS.

Objective

To describe our experience with our 47 implanted ALS patients. Analyze and discuss what we have learned about the diaphragm, affects on the ALS diaphragm and how patients have utilized DPS.

Programme description

The effects of DPS in the management of the ALS/MND patient will be discussed. Results and case reports will be described. Utilization in research and future practice will be analyzed.

Clinical outcomes

From 2005-2008, 47 patients tolerated the surgical implantation of the DPS with 18 receiving simultaneous feeding tube placement. No significant perioperative adverse events occurred even with forced vital capacity(FVC) as low as 20%. Fluoroscopic evaluation of is extremely beneficial in determining function with patients having more visualized diaphragm movement of the diaphragm with stimulation than under maximal voluntary effort. Utilization of DPS to overcome night time sleep dysfunction has been used by almost 50% of patients with or without non invasive positive pressure ventilation. DPS can also continuously assess diaphragm EMG activity and this has become a key marker to follow patients diaphragm function. Increase usage of DPS has corrected hypercarbia. With DPS, there has been maintenance of the respiratory sub-score on the ALSFRS_r scale. DPS has been shown to decrease the rate of decline of FVC from a pre-implantation rate of 2.4% per month to 0.87% per month after DPS conditioning of the diaphragm. This extrapolates to an additional 24 ventilator free months. Presently now have had patients stop DPS when they lose their ability to communicate allowing dignified death without the need and stress of mechanical ventilator choice. For 26 patients implanted greater than 12 months there is a mean survival from diagnosis of 45 months. For patients with simultaneous PEG and DPS the one year survival is 75% with no 30 day deaths which is much improved over historical reports of up to 30% 30 day mortality rate.

Recommendations to the field

DPS positively affects diaphragm function in patient with ALS. It offers another therapy to improve respiratory dysfunction and decreases the decline in respiratory failure delaying the need for mechanical ventilation

SPEAKER: NIENKE DE GOELJEN

BIOGRAPHY:

Nienke is nurse practitioner and has an academic degree in nursing science.

She has been working in the University Medical Centre in Utrecht for more than 20 years. Since 2001 she is a nurse practitioner, specialised in neuromuscular diseases and started working in the Dutch ALS center. She is involved in patient care and established multidisciplinary guidelines in ALS treatment. Nienke has special interest in the treatment of feeding difficulties in ALS .

AUTHORS: N DE GOEIJEN, J.C., PIEPERS, S., KRUITWAGEN, E.TH., VAN DEN BERG, J.P., VAN DEN BERG, L.H.

TITLE OF PRESENTATION: AN EVIDENCE BASED GUIDELINE ON PEG TUBE INSERTION IN ALS

ABSTRACT:

Background:

The mainstay of treatment for ALS patients remains symptomatic management. Enteral feeding (tube feeding) is offered to many people with ALS/motor neuron disease experiencing dysphagia and maintaining adequate nutritional intake leading to weight loss. Generally patients and families are positively regarding PEG, although the impact of PEG on quality of life in ALS has not been studied in detail. Patients and families require information appropriately to timed decision making. The safety of PEG-tube insertion is related to respiratory function and the timing of PEG tube insertion is often determined by progression of respiratory decline. The Dutch ALS Centre is a virtual centre comprising three tertiary referral centres and co-working with ALS rehabilitation teams. The major goal of the ALS centre is the improvement of ALS care.

Objective

The Dutch ALS centre aimed to establish a national, evidence based, guideline offering optimal care and safety in PEG tube insertion, by reviewing the literature on PEG tube insertion in ALS patients

Programme description

A guideline was established translating information from the literature and expert's opinions into useful and practical suggestions. The guideline includes tools to provide patients with adequate information, assessment of the risks of PEG tube insertion, proposes standardized care during the clinical period and during the period after discharge from the hospital. The multidisciplinary care that is needed for PEG tube insertion is clarified by a flow chart.

Clinical outcomes

Specialists from the Dutch ALS centre reviewed the literature on PEG tube insertion in ALS. PEG tube insertion is indicated when ALS patients have symptomatic dysphagia with accelerated weight loss. Respiratory function using the FVC must be monitored in regular intervals to assess the risk of PEG tube insertion. A forced vital capacity (FVC) of 50% is regarded as a minimum for safe tube insertion. Respiratory dysfunction and hypoventilation may however exist long before FVC falls below 50%, causing serious complications during PEG insertion. To reduce the risk of tube insertion a careful history taking of symptoms of nocturnal hypoventilation is essential. Blood gas analysis should be performed in patients with reduced FVC values or positive symptoms of (nocturnal) hypoventilation. Sedation during the procedure is limited to patients with normal respiratory function.

Recommendations to the field

PEG tube insertion in ALS is a challenge for patient, doctor and paramedics. Standardized care decreases the risk and optimizes care for ALS patients.