

ALLIED PROFESSIONALS' FORUM
Westin Harbour Castle
30 November 2007

SPEAKER: KATHLEEN BEGGS RD

BIOGRAPHY:

Kathleen Beggs is a Registered Dietitian who has worked at G.F. Strong Rehabilitation Centre since 1996 with clients with stroke, brain injury and musculoskeletal injuries and joined the Vancouver Coastal ALS Centre team in 2001. The team works in a transdisciplinary model and does outreach and consultation to client's with ALS in the province of British Columbia. Special areas of interest are tube feeding and dysphagia. Recent research was on tube placement outcomes in ALS patients

**TITLE OF PRESENTATION: CLINICAL AND PROGRAMME
MANAGEMENT APPLICATIONS OF THE ALS DATABASE**

ABSTRACT:

Background:

Vancouver Coastal ALS Centre manages people in the Province of B.C. with ALS, through direct intervention or support to caregivers and professionals from the time of diagnosis to end-of-life. When people with ALS are making choices regarding their care and quality of life, they often ask questions about other PALS, wanting both quantitative and qualitative information to contextualize their options. It is incumbent on the centre to objectively track information about clients to ensure the accurate dissemination of information/education to clients, families and their local community health care providers.

Objectives:

The database is a consolidation of client information including: age, sex, date of diagnosis, type of onset, residing region, local services, interventions received (i.e., PEG, BiPAP, trach-ventilation) and date of death. The clinician can easily isolate features to yield a client grouping, for example, clients on non-invasive or invasive ventilation. This information is relevant when the team attends respiratory rounds or when meeting with families to discuss options for ventilation. The primary objective of keeping the database is to better manage and track the clinical demands of the caseload and to inform clients/families and other health care professionals of the ALS population in B.C.

Clinical Outcomes:

While this database provides current, specific client information, it easily offers global snapshots of client profiles (i.e., by region, by interventions/treatment modalities like g-tube and trach/vents.) This tool provides a means of describing the

acuity of the caseload at any point in time. It optimizes collaboration with other provincial professional organizations and local healthcare providers when consulting, collaborating and video conferencing. The data and statistics are used in education with clients/families in decision-making around interventions/procedures. Additionally, it identifies needs for certain regions and follows trends in resource provision for those regions.

Programme Descriptions:

The ALS Centre has a diagnostic clinic with associated neurologists and EMG technologist, and an interdisciplinary team comprised of occupational and physical therapists, speech language pathologist, dietician, nursing, and social work. The Centre partners with psychiatrists, Provincial Respiratory Outreach Program (PROP), Technology for Independent Living, ALS Society of BC, Community Homehealth, and other clinical services.

Recommendations to the Field:

The database provides an accurate means to capture quantitative and qualitative clinical details of the caseload towards streamlining practice, educational in-services, and outreach collaboration. The data is used to inform clients/families particularly around decision-making regarding care management and interventions. Additionally, the database could readily be used for research.

SPEAKER: KAREN HALL MScOT, OT Reg. (ONT.)

BIOGRAPHY:

Karen has been an occupational therapist at the Assistive Technology Clinic for over five years and is the occupational therapist for the ALS/Neuromuscular Clinic at Sunnybrook Health Sciences Centre. She is a graduate of Memorial University of Newfoundland and received a Masters of Science in Occupational Therapy from the University of Toronto. She is an authorizer for the Ontario Ministry of Health and Long Term Care Assistive Devices Program in Seating and Mobility and Augmentative and Alternative Communication. Her research on power mobility driving training is published in the journal, Assistive Technology. Karen is a member of the Canadian Association of Occupational Therapists and College of Occupational Therapists of Ontario. She presented at the ALS: Strategies for Quality Living Education Day at Sunnybrook Health Science Centre in 2006 and was poster presenter at the ALSA Clinical Conference in California in 2007

TITLE OF PRESENTATION: MEETING THE CHALLENGES OF ALS: A ONE STOP SHOP

ABSTRACT:

Background:

ALS is a progressive disease posing enormous challenges for patients, family, caregivers, health care practitioners and service providers from diagnosis to palliation.

The challenge of meeting all needs, while minimizing stress and fatigue of on-going appointments requires a patient-centered approach in a centralized location for the provision and co-ordination of services.

Objectives:

- To meet the ever changing needs of ALS patients.
- To maximize accessibility to all services in one locale.
- To enable optimal communication among the patient, family, caregivers, health care practitioners and service providers.

Clinical Outcomes:

- An integrated, full service, patient-centered model of care.
- Access to all services at a single site from diagnosis to palliation.
- Provision of services that optimize patient autonomy and functional independence.
- An information sharing tool for the patient, clinic and community services that promotes consistent delivery of care.

Programme Description:

A Venn diagram is utilized to illustrate an integrated, full service, patient-centered model of care. The patient is at the center with four overlapping circles representing the interaction of groups of service providers. The services include:

- ALS/Neuromuscular Clinic: neurology, respirology, physiatry, nursing, occupational therapy, speech-language pathology, nutrition, pulmonary function testing, research, administrative assistance
- Assistive Technology Clinic: seating and mobility, augmentative and alternative communication, electronic aids for daily living
- Ancillary hospital services: gastroenterology, electromyography, magnetic resonance imaging, laboratory services, orthotics, pharmacy, retail health care equipment outlet
- Community: ALS Society, home care services, palliative care, hospice, funding agencies, social services

Recommendations to the Field:

- One stop shop for all services in one locale.
- Patient-centered, collaborative service provision.
- Consistent communication of recommendations and services provided via an information sharing tool.

SPEAKER: JULIA HIGGINS, RSW AND MARIFE FABROS, RN

BIOGRAPHY:

Julia Higgins is a Registered Social Worker who has practiced in Health Care for over 20 years, the most recent 3 years with the ALS CentreTeam at Vancouver Coastal Health's GF Strong Centre. The team works in a transdisciplinary model and does outreach and consultation to clients with ALS in the province of British Columbia. Special area of interest is in patient/family health care decision-making particularly around end of life issues. In addition to her clinical practice, Julia is a sessional

faculty with the School of Social Work and Human Services at the University College of the Fraser Valley.

Mirife Fabros is the nurse clinician of the ALS centre for 10 years now. She worked with Dr Andrew Eisen, now retired. She is also the study coordinator for all clinical trials.

TITLE OF PRESENTATION: MOBILE OUTREACH CLINIC PILOT PROJECT

ABSTRACT:

Background:

The Vancouver Coastal Health, ALS Centre Team is the province's transdisciplinary team providing services to people with Amyotrophic Lateral Sclerosis (ALS) from time of referral to end of life. The team is composed of clinicians in Neurology, Dietetics, Nursing, Occupational Therapy, Physiotherapy, Social Work and Speech-language Pathology offering outpatient and outreach assessment, intervention, consultation and educational services in partnership with a wide range of community agencies and health care providers throughout the province. In a 2006 survey conducted by the ALS Society of BC, patient and family indicated a desire to have more contact with the ALS Centre Team. Expressing feelings of social isolation and abandonment by the Vancouver ALS specialists, many patients and their caregivers reported not attending appointments in the Vancouver clinic due to difficulty traveling especially in the advanced stages of disease. Travel becomes impossible for patients not only due to their disease and but also due to the province's geography. To the west of Vancouver a body of water separates many island and coastal patients. Travel can take several hours involving long ferry waits and unpleasant weather conditions. To the east of Vancouver are the interior mountains making travel treacherous many months of the year.

Objectives:

To better serve people with ALS, their families and local community health care providers, the ALS team with the support of ALSS BC developed a Mobile Outreach Clinic Pilot Project. Beginning the spring of 2007, the ALS Team will travel twice yearly to the island and the interior.

Clinical Outcomes:

Patients, who otherwise would be unable to attend the clinic in Vancouver, are scheduled to attend the first clinic. To evaluate the effectiveness of the project, patients and their caregivers will be asked to complete a satisfaction survey after their appointments. Also, patients' local health care providers will be asked to give feedback.

Programme Descriptions:

Local neurologists and health care providers were consulted before the clinic dates were set. Health units and hospitals assisted in providing suitable clinic space. The mobile clinic staff will see clients for follow-up assessment and consultation. There will be a neurologist, nurse, social worker and either a dietitian or speech language

pathologist or either an occupational or physio therapist will see the patients and their families.

Recommendations to the Field:

People with ALS and their families are faced with a tremendous burden to cope and adjust to the relentless progression of the disease. The Mobile Outreach Clinic offers a real response to the need for patient and family care of an otherwise isolating disease.

SPEAKER: BEVERLEE MCINTOSH, MSW,RSW

BIOGRAPHY:

Beverlee has an Undergraduate degree in Philosophy and a masters degree in Social Work from Carlton University in Ottawa.

Over the past 20 years She has worked at the Ottawa hospital in Geriatric medicine, Acquired Brain Injury and Amputations rehab programs and neuromuscular clinical programs. She also worked for 10 years in Geriatric Psychiatry at the Royal Ottawa Hospital. She has been with the ALS clinical team for 8 years and during that time has co-authored an article for Critical Social Work Journal entitled “ Negotiating the Path of Ethical Decision Making in Health Care Social Work”.

Beverlee has been a member of the Board of Directors for the Ontario College of Social Workers and for the Canadian Caregiver Coalition. She presently sits on the Research Ethics Board of the Ottawa Hospital Rehabilitation Centre.

Beverlee herself is a caregiver for a spouse with Alzheimer’s and is particularly concerned about caregiver issues and government support for family members who are caring for loved ones with chronic illness.

TITLE OF PRESENTATION: CREATING A SAFE SPACE FOR CAREGIVERS ON THE ALS JOURNEY

ABSTRACT:

Background:

Despite universal health care in Canada and some limited hours of in-home attendant care, caregivers of ALS patients are at high risk for burn- out and consequent stress related illness. In 2003 the social worker on the multidisciplinary team at the Ottawa Hospital Rehabilitation Centre initiated a professionally facilitated open-model spousal support group. Anecdotal reports strongly suggest that burden of care is significantly decreased for caregivers who are able to participate in this group.

Objectives of Presentation

1. Describe a model which can maximize use of skills by the ALS team social worker through an innovative approach to care and support for ALS caregivers.

2. Describe parameters of a confidential and safe meeting place for caregivers
3. Relate unexpected outcomes from groups, such as monitoring risks in the home environment and identifying gaps in service between clinic visits, thereby which fostering good practice and information exchange amongst health care professionals.
4. Share anecdotal comments from participants which illustrate the value of this approach to caregiver support.

Clinical Outcomes

The ALS team noticed fewer telephone calls to the clinic between scheduled visits, thus reducing between visit calls to problem solve specific situations and manage crisis. Within the groups caregivers began to share resource information and advocate for better education of service providers. The facilitator also observed an increased adaptation to or compliance with recommendations made by the ALS clinic to individual patients when peer caregivers reinforced the advice. The clinical team are able to measure increase efficiencies in work load on ALS clinic days which directly relate to caregiver participation in support groups.

Programme Descriptions

Caregivers are provided with information about the appropriate group and agree to provide an e-mail contact for notification. Each group meets once monthly for 2 hours in a community room at a local shopping mall where parking is free and the atmosphere is not clinical. Discussion is informal and groups are evolving to meet the needs of caregivers at different stages of the ALS journey.

Recommendations to the Field

Separation of caregivers by gender and non-spousal groups has been most effective. Models for caregivers of new diagnosis and those in late stage ALS is evolving. Experienced professional leadership of each group maximizes timely interventions with appropriate professionals and ensures that caregivers have a safe place to find support.

SPEAKER: BENEDETTA ROSSI

BIOGRAPHY:

Benedetta's background is in nursing. Over the past 20 Years she has worked in Oncology, Palliative Care and Neurology and worked for 4 years as specialist nurse for people with MND.

She has recently completed a post grad certificate in Palliative Care and have a special interest in promoting good palliative care for people with diagnoses other than cancer.

She has worked for the last 18 months co-ordinating the MND pathway project in Leicestershire and Rutland.

TITLE OF PRESENTATION: THE MOTOR NEURONE DISEASE (MND) PALLIATIVE AND SUPPORTIVE CARE PATHWAY PROJECT IN LEICESTERSHIRE AND RUTLAND.

ABSTRACT:

Background:

Due to the devastating symptoms of MND each person living with the disease will require complex care from a large number of providers across Primary and Secondary Care involving Health, Social and Voluntary Sectors. The nature of symptoms and speed of progression mean that needs must be anticipated and met quickly.

In Leicestershire and Rutland we had pockets of excellent care and expertise but equally there were gaps in services and needs were not always being met.

Objectives

The project was established to co-ordinate partnership work between the Hospice, Health, Social and Voluntary services to provide a comprehensive, timely, responsive service for people with MND and their carers, guided by their needs.

Programme Description

A Mapping day was held with patients, carers, neurologists, MND clinical nurse specialists, representatives from Primary Care, Social services, Speech and Language therapy, Dietetics, and the Voluntary Sector. Areas of excellence were recognised and gaps were identified.

With a grant from the Help the Hospices “Care Beyond Cancer” Programme funded by The St James’s Place Foundation, we established task and finish groups, addressing:

- Patient and Carer needs and information;
- A pathway for telling the diagnosis;
- A patient held Communication Sheet;
- Support for the Multi Disciplinary Team;
- Timely provision of appropriate equipment;
- Timely interventions;
- Social Services referrals and interventions;
- A pre-respite Check List;
- A pathway for assisted feeding;
- End of life care – Avoiding unwanted emergency admissions;
- Commissioning services for people with MND.

Clinical Outcomes

Support for the project from all task and finish groups has been tremendous. Partnership working across boundaries has led to improved communication between all groups, thus services and interventions are being introduced in a more timely manner. Some work has slowed recently as a result of a financial recovery drive

within Health Services locally but it is hoped that in their continued drive for efficiency and productivity that the local Primary Care Trusts will recognise the benefits of a more co-ordinated service for people with MND.

Work in all areas continues with outcomes being monitored against the MND Association's Standards of Care. New objectives have been set for the next two years thanks to a Section sixty four grant from the Department of Health.

Recommendations

From our experience we recommend establishing a forum for building on informal multidisciplinary partnerships between health, social and voluntary sectors united by commitment to improving services for people with MND.

SPEAKER: DR JANICE BROWN

BIOGRAPHY:

Janice Brown holds a prestigious post doctoral fellowship from The Health Foundation allowing her to build on her work in the field of supportive care research in motor neurone disease. She qualified as a nurse at St Bartholomew's Hospital in London, UK and worked predominately in neurosciences in London and Southampton. After completing her first degree in nursing and later a post graduate teaching from the University of Surrey she completed her PhD in Education at the University of Southampton. Janice rebalanced her role from being predominantly education focused with research on the award of her Health Foundation Fellowship at the beginning of 2005. From this she has developed a novel conceptual framework (narrative types/storylines in MND) which is likely to have an impact in her field. Janice has a leadership role in the UK National Cancer Experiences Collaborative (CECo) as lead for the narrative theme and she is a member of both the National Council for Palliative Care Neurological Conditions Policy Group and UK MND Professional Network Group. As well as publishing in her field she co edited the 2007 nursing text entitled *Principles of Professional Studies in Nursing* published by Palgrave Macmillian

TITLE OF PRESENTATION: AN INTEGRATED NEUROLOGICAL CARE PATHWAY FOR LIFE-LIMITING NEUROLOGICAL ILLNESS: DEVELOPED THROUGH THE NATIONAL COUNCIL FOR PALLIATIVE CARE

ABSTRACT:

Background:

Patients with neurological illness present with complex needs which can be challenging to health and social professionals and service providers. In the UK it is known there are problems with service co-ordination, timely referrals and access to palliative care for people with life-limiting neurological diseases. Care pathways are a

means of supporting health and social care professionals to improve the delivery and quality of care to patients and families through developing indicators for referral and mapping clinical need to services. The neurological conditions policy group of the National Council for Palliative Care has a mission to promote the provision of palliative care in health and social care settings for all who need it and has developed an integrated care pathway for four life-limiting neurological conditions: motor neurone disease, multiple sclerosis, Parkinson's disease, Huntington's chorea. These four neurological conditions present complex care needs which require multi-professional and multi-agency services and support and are likely to be representative of a wide range of neurological conditions. The care pathway will serve as a resource with in-built triggers and referral indicators to guide professionals in enhancing quality of care for neurological patients from pre-diagnosis to specialist palliative and neuro-palliative rehabilitation care.

Objectives:

- to develop an integrated care pathway for people with four neurological diseases: motor neurone disease, multiple sclerosis, Parkinson's disease and Huntington's chorea.
- to present the pathway as a tool to support health and social care professionals to enhance the quality of care of neurological patients from pre-diagnosis to the palliative phase

Clinical Outcomes

The integrated care pathway is diagrammatically presented as two pathways with indicators for referral and in-built triggers for enhancing health and social carer professional decision making. Pathway 1 presents the pathway to diagnosis. Pathway 2 consists of four parts; 2i) at diagnosis and early action considerations 2ii) slow deteriorating neurological conditions 2iii) fast deteriorating neurological conditions 2iv) variable deteriorating neurological conditions.

Programme Descriptors

The integrated care pathway for life-limiting neurological illness reflects an optimal pathway to support health and social care professionals in the care of people with life-limiting neurological illness from pre-diagnosis to the palliative phase.

Recommendations to the Field: The integrated care pathway for neurological conditions is a tool to assist health and social professionals enhance the quality of care for people with life-limiting neurological conditions.

Key words: integrated care pathway, life-limiting neurological illness, quality of care

SPEAKER: ZAHIRA PAUL, OTR,MS

BIOGRAPHY:

Zahira is an Occupational Therapist who obtained her Bachelor's and Master's Degrees in Occupational Therapy from the University of Bombay in Bombay, India. She has an Advanced Master's Degree in Occupational Therapy from SUNY Buffalo.

She has worked in varied health care settings including nursing homes, home health settings, outpatient clinics and acute care. She alongwith Christine Brussock, PT are the consultants to the ALS clinic at Penn State Hershey Medical Center. In conjunction with other ALS team members, she provides her expertise to help patients achieve maximum independence in activities of daily living such as eating, dressing, and bathing through the use of adaptive equipment, exercise, energy conservation and work simplification

TITLE OF PRESENTATION: A CLINICAL PATHWAY FOR PHYSICAL & OCCUPATIONAL THERAPY INTERVENTION UTILIZING THE ALSFRS-R (FUNCTIONAL RATING SCALE-REVISED) AS A GUIDELINE

ABSTRACT:

Background:

The team approach, person-centered model of practice has been used by the ALS Clinic at Hershey Medical Center to guide interventions and care to safely maximize the patient's level of function and quality of life. The ALSFRSR is a widely used assessment tool for the evaluation of individuals with ALS. The reliability & validity of this tool are well established to determine degree of impairment, functional disability and as clinical & research outcome measures. The 12 items in the ALSFRSR evaluate bulbar, motor and respiratory with each item scored from 0(unable) to 4(normal). Six of the 12 items focus on activities of daily living & functional mobility that are most relevant to physical & occupational therapists.

While physical & occupational therapy cannot alter the eventual outcome of neurodegenerative diseases like ALS, interventions to improve the quality of life for the patient and caregivers may be enhanced.

Program Descriptors: As a result of our experiences, we developed a pathway to guide interventions, which addresses the physical deficits related to ALS and focuses on these six identified categories of the ALSFRSR. Utilizing the ALSFRSR, pathways were established to serve as an organizational model for planning interventions. The patient, caregiver, and/or professionals response to these identified items on the ALSFRSR triggers specific pathways for intervention. While the pathway focuses on interventions relevant to physical & occupational therapy, it is inter-disciplinary in nature and takes into consideration many conditions commonly present in individuals with ALS, including spasticity, pain, muscle weakness, cramping, fatigue, cognitive impairments, falls, deep vein thromboses and edema.

Objectives/Clinical Outcomes: Combining clinical knowledge with the ALSFRSR response pathway allows for more accurate timing of appropriate clinical interventions in caregiving, mobility, wheelchair evaluation, adaptive equipment, home assessment and modification. Additionally, because the pathways include the assessment & intervention of architectural, financial & social barriers, we have included a community/external liaison pathway that incorporates funding, insurance and follow-up. We describe our experiences utilizing the pathway to guide

intervention, coordination, patient/client related instruction and to evaluate the outcomes of these interventions.

Recommendations to the field: Evidence to support the need for these interventions will be highlighted as well as areas where additional research is needed.

SPEAKER: MARY JO ELMO, CNP

BIOGRAPHY:

Mary Jo Elmo RN, MSN, CNP is the Project Manager for the Diaphragm Pacing Program at University Hospitals of Cleveland Case Medical Center. Under the direction of Ray 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 nearly 20 years of nursing experience specializing in critical care and mechanical ventilation. Her current role consists of research and patient management. Mary Jo has been published in peer reviewed journals and frequently speaks at national and international level on the topic of diaphragm pacing.

TITLE OF PRESENTATION: THE ALS/MND DIAPHRAGM, ELECTRICAL STIMULATION AND RESPIRATORY FUNCTION: WHAT WE LEARNED DURING THE SAFETY AND FEASIBILITY STUDY OF THE DIAPHRAGM PACING STIMULATION (DPS) SYSTEM

ABSTRACT:

Background:

Respiratory failure is the major cause of mortality in ALS/MND with patients facing death or life on mechanical ventilators. The diaphragm is the key muscle responsible for breathing yet the most common methods of assessing respiratory function in ALS(forced vital capacity-FVC) and the most common treatment of respiratory treatment(noninvasive positive pressure ventilation-NPPV) do not directly affect diaphragm function. In an FDA trial, patients underwent outpatient laparoscopic implantation of electrodes with the Diaphragm Pacing Stimulation (DPS) system at the diaphragm motor point- the point where electrical stimulation caused maximal diaphragm contraction. The patients then used electrical stimulation to condition their diaphragm.

Objective: To describe the care and management of patients with the DPS. Analyze and discuss what we have learned about the diaphragm during this study and how patients have utilized DPS in their activities of daily living.

Clinical Outcomes: Surgical implantation of the DPS can be safely performed under general anesthesia with almost half the patients receiving simultaneous feeding tube placement. Fluoroscopic evaluation of the diaphragm with a sniff test is extremely beneficial in determining function and in assessing the long term success of DPS with

all of the patients having more visualized diaphragm movement of the diaphragm with stimulation than under maximal voluntary effort. By increasing diaphragm movement, the DPS system decreases posterior lobe atelectasis thereby increasing respiratory compliance and thereby decreasing the work of breathing. Many patients utilize this to help them when they first wake up or before leaving their house. Patients have also utilized the DPS to help with night-time ventilation because of our finding of abnormal diaphragm function during sleep in patients with ALS/MND. Overall looking at all patients that we have a minimum of 9 months follow-up the decrease in the decline of FVC would lead to a delay in the need of the ventilator by 24 months.

Program Description: Through a discussion of results and case reports the effects of DPS in the management of ALS/MND will be described. Utilization in research and future practice will be analyzed.

Recommendation to the Field: The DPS study has highlighted the need to specifically look at the diaphragm separate than the rest of the respiratory muscles. ALS/MND patients should have their diaphragms assessed with fluoroscopy as a minimum when determining respiratory dysfunction. Patients if eligible should be involved in the multi-center trial of the DPS system

SPEAKER: LEE GUION

BIOGRAPHY:

Lee Guion is a respiratory care practitioner and a member of the multidisciplinary team of the Forbes Norris MDA/ALS Research Center at the Physician Foundation of Californian Pacific Medical Center. She holds a Bachelor of Arts from the University of North Carolina at Chapel Hill and a Masters of Arts in Gerontology from San Francisco State University. She is on faculty of Skyline College and serves as chair of the community advisory committee to the Respiratory Therapy Program. She is a member of the Geriatrics and gerontology committee of the American Association for Respiratory Care (AARC) and contributes articles to the association's AART Times. She participates in the AARC's neuromuscular roundtable and is a member of the San Francisco-based Dyspnea Research Group. She is currently writing a text book "Respiratory Management of Neuromuscular Disease" to be published in 2008.

RESPIRATORY MANAGEMENT FOR ALS/MND: FROM DESIGN TO IMPLEMENTATION IN A MULTIDISCIPLINARY ALS/MND CENTER

ABSTRACT:

Background:

There are 2 evidence-based practice parameters for managing ALS patients (Miller 1999, Andersen 2005). Although these guidelines are very helpful, they do not address some important clinical issues because of insufficient evidence. In the European document (Andersen 2005), consensus recommendations were offered where evidence was insufficient.

The Forbes Norris MDA/ALS Research Center is a large (>250 ALS/MND patients) clinical and research center with a catchment area of Northern California and beyond. In our center, all health care providers claimed to adhere to the American Academy of Neurology Practice Parameters for respiratory management in ALS (Miller 1999),, but clinicians often differed in their recommendations to patients. This gave an opportunity to more precisely identify the gaps in current evidence of best practice and design an algorithm using consensus to fill the gaps of available evidence. We will identify this as an ‘evidence based / consensus algorithm’.

Objectives

1. Identify the gaps in evidence-based guidelines for managing respiratory insufficiency in ALS, and develop consensus for steps to fill the gaps.
2. Standardize the assessment (including development of new data collection tools), respiratory symptom management, and treatment recommendations of suspected respiratory dysfunction in patients who fall in the gaps with ALS/MND.
3. Examine adherence and outcomes related to the new ‘evidence based / consensus algorithm’ for respiratory management.

Program Descriptions / Methods

Three physicians, a respiratory therapist, and 2 nurses reviewed the literature (up to 4/07) on current respiratory management in ALS/MND using rigorous methods previously described (Miller 1999) and compared evidence based recommendations with current practices in our clinic. Using a Delphi method, we developed consensus on where gaps exist in the evidence and developed consensus recommendations where insufficient evidence was available to guide practice. We designed an algorithm to assess and treat respiratory dysfunction based on the evidence plus consensus.

Clinical Outcomes

A quantitative approach to evaluating symptoms of respiratory insufficiency was developed. This included new assessment tools and an algorithm for management. The gaps in the evidence included: management of patients with bulbar signs, with sleep disordered breathing, and patients with excessive secretions. Adherence to this internally derived standard of care is being monitored, and compared to adherence prior to this process. In addition, outcomes will be compared to those available in our database prior to this intervention.

This process quickly led to the formation of clinical questions that need further research. The assessment tools that were designed and implemented will assist in providing good quality data that will be both clinically useful and aid in research.

Recommendations to the Field

To our knowledge, this is the first report of the application of gap analysis to evidence based management in ALS. This exercise of literature review, development of consensus in the multidisciplinary team when no evidence exists to guide practice, and monitoring of one’s own current practice serve both to standardize care within a center and also to increase buy-in and adherence to guidelines by all team members.

We also believe this will improve the overall quality of care that we provide our patients.

SPEAKER: JANE CONNELL

BIOGRAPHY:

Jane qualified in 1978 from Oxford in Occupational Therapy. Worked in Mental Health , Rehabilitation unit and Social Services.

Have been working as a Regional Care Adviser for 21 years !

TITLE OF PRESENTATION: EMERGENCY SERVICES AND MOTOR NEURONE DISEASE

ABSTRACT:

Background:

The East Midlands Ambulance Service (EMAS) a UK regional NHS paramedic service, in conjunction with the Motor Neurone Disease Association (MND Association), identified issues of mutual concern concerning emergency support for people living with MND (plwMND).

Objective

The aim is through a strategic partnership to improve the support systems that already exist.

Programme Description

A working group from EMAS, MND Association with user and carer involvement, and two medical consultants has explored the emergency needs of plwMND.

Issues examined:

- timely admission to appropriate hospital
- support to avoid admission if unnecessary or inappropriate
- understanding of advance care plans ,
- care of patients with a DNAR (Do Not Attempt Resuscitation),
- the breathing space programme,
- the recent Mental Capacity Act including advanced decisions to refuse treatment,
- training for EMAS staff about MND.

A central premise of the group is that the autonomy of plwMND is respected especially about care preferences and treatments they don't want. The arrangements described below involved recognising within local polices there are operational difficulties for EMAS in supporting advanced care plans and using the medication of the MND Association's Breathing Space Kit.

Clinical Outcomes

The present agreed arrangements are:

- EMAS receives emergency call
- EMAS computer flags details of plwMND
- states appropriate hospital / consultant neurologist contact if needed
- any Advanced Care Plan incl. advanced decision to refuse treatment / DNAR
- paramedic arrives and carer (hopefully) can provide patient's own set of notes made by consultant, GP and other professionals

- paramedic may treat patient, or call in colleague with relevant training, or summon ambulance to take patient to hospital (and alerts the hospital neurology department to avoid delays in treatment)
- home treatment may be PEG or RIG repair (training is in progress for paramedics known as Emergency Care Practitioners)
- alleviation of breathing problems: airway care, medication for treatment or symptom control
- home treatment may be simply supportive / palliative care especially if there is an expected death

This systematic approach delivers holistic care often in the patients home, promoting privacy and dignity.

The partnership working of the group has proved invaluable. Ongoing work entails disseminating the arrangements to inform professionals, Association visitors, plwMND and their carers; further work is needed in terms of the new Mental Capacity Act of 2007.

Recommendations

Our experience leads us to strongly recommend the establishing of a working interface between emergency services and other professionals treating plwMND.

This forum allows the promotion of advanced care planning, patient care and choice.

SPEAKER: BARBARA GASCHO

BIOGRAPHY:

Education:

- Registered nurse since 1968
- Parish Nurse Certification 1991
- Clinical Pastoral Education at Penn State Heiskey Medical Center – 6 units
- Spirtaul Direction 2000 – 2001

Work Experience

- Varied hospital nursing 1963 – 1985
- Developed and directed Parish Nurse Program in a local congregation 1989-1999
- Deaconess 1993-2001
- Chaplain ALS Clinic Heiskey Medical Center (Penn State) 2001-present
- Facilitated ALS Bereavement Support Group 2003-2005

TITLE OF PRESENTATION: ALS CONGREGATIONAL CARE TEAMS

ABSTRACT:

Background:

Patients with ALS have extensive care giving needs which require multiple resources. Many faith-based communities view providing support to members as essential to their mission, are a resource for such a program, and can be mobilized to provide significant resources. Faith-based volunteer groups however often need guidance and support during the extended duration of the disease and the changing needs of the family.

Objectives: Provide education and support to faith communities who can provide non-medical care to ALS patients and their families.

Program Description: In the ALS clinic the pastoral care provider discusses the potential of a faith-based group as a resource for the family and offers to make a contact to the leader of the faith community to offer education, guidance and support to a volunteer care team. If a faith community wants to be involved in supporting a family in an organized way the pastoral care provider acts as consultant to the team. She provides education about ALS, works with the patient and family to identify activities that are needed, sets appropriate limits for activities and guides the faith community group in ways to organize a care structure. The pastoral care provider continues to maintain contact with the group, frequently meeting with the care team and the patient to reassess activities and new needs. Over time the pastoral care consultant provides support and counseling to the care team in dealing with conflict, and issues and feelings associated with ongoing care. As specific medical needs arise the pastoral care person serves as liaison between the faith community care team and the ALS clinic.

Clinical Outcome: This program has facilitated 12 faith-based care teams in three years. Activities that the groups have provided are: financial counseling, construction of handicap additions, meal delivery, door and ramp constructions, transportation, financial support and fund raising. Challenges encountered include problems in communication between family and volunteers, setting unrealistic expectations of volunteer availability, the need for advance planning of requests and volunteer feelings of distress and concern for the patient and family. These have been handled by the pastoral care provider meeting with the volunteer group, and family.

Recommendations: The program has been successful and will continue to be an option for coordinating support for our ALS families.

SPEAKER: LISA G. BARDACH, MS, CCC-SLP

BIOGRAPHY:

Lisa is a certified Speech and Language Pathologist with over 17 years of experience providing neurogenic rehabilitation to adult and paediatric clients. She is the owner of Communicating Solutions, a private practice in Ann Arbor, Michigan specializing in evaluation and treatment for individuals requiring argumentative and alternative communication (AAC). She also works for ALS of Michigan, where she has developed and implemented a regional clinic to provide AAC services to patients with

ALS. She serves as a resource in the state of Michigan for funding issues and documentation in ACC.

Lisa is an adjunct faculty member of the University at Buffalo, where she has presented workshops in the area of alternative access to SGDs. She has authored multiple professional presentations on AAC on local and national levels, in addition to several publications. She has served as a member of the American Speech-Language-Hearing Association's (ASHA) Health Care Economics Committee Ad Hoc Subcommittee on Medicare Reimbursement and is a member of the Medicare Implementation Team, a group of professionals formed under the auspices of the Rehabilitation Engineering Research Center on Communication Enhancement to acquire and facilitate Medicare of augmentative communication devices

TITLE OF PRESENTATION: REGIONAL AAC CENTERS: A MODEL FOR ALS INTERVENTION

ABSTRACT:

Background:

People with ALS gradually lose natural speech abilities, with most unable to talk for an extended period of time prior to death. Instruction in compensatory speech strategies, use of augmentative and alternative communication techniques, and acquisition of voice amplifiers and Speech Generating Devices (SGDs) are ways to ensure that all people with ALS have effective means to communicate throughout the course of the disease. A study by the Robert Wood Johnson Foundation on Promoting Excellence in End of Life Care for pALS (April 2002) identified several barriers to provision of appropriate AAC services to pALS, including lack of access to appropriately trained Speech-Language Pathologists (SLPs), lack of funding for evaluation and training services, and lack of equipment for the purpose of evaluation for SGDs.

Objectives

- **To create a regional AAC Center that would provide direct evaluation & training services to the ALS population**
- **To increase the number of Speech-Language Pathologists evaluating and training pALS on AAC equipment**
- **To increase access to AAC equipment by SLPs throughout the region**
- **To showcase a wide variety of AAC equipment**

Clinical Outcomes

Comparisons were made between the 3-year periods prior to and following inception of the regional Center. The following clinical outcomes were measured: the number of patients served/year; the number of initial evaluations/year; the number of extended speech-language evaluations/year; the number of re-evaluations/year; and the number of treatment sessions/year. Significant increases in all outcomes were noted over a 3 year period.

Program Description

An SLP with expertise in AAC was hired to perform evaluations on a per-diem basis during the first year of the Center. The SLP was then hired as a staff member, which enabled her to provide extended services, including comprehensive speech-language evaluations that extended over multiple clinic visits,, multiple training sessions, and computer access evaluations.

Recommendations to the Field

The establishment of a regional ALS center ensures that many pALS who are unable to get services due to lack of insurance funding or geographical distance from regional clinics or lack of local qualified personnel can get SGDs and to learn how to use them. Community based speech-language pathologists can rely on the Center's equipment and space to help pALS obtain state-of-the-art communication equipment. This model is cost-effective, allowing a large number of devices to be accessible without multiple facilities needing to spend the money for the equipment.

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. In September of 2003 she added to her responsibilities at the clinic by becoming the Clinical Evaluator for trials. In 2005 she began working full-time for the MDA/ALS Center of Hope, and recently added the additional role of Assistive Technology Practioner.

TITLE OF PRESENTATION: ASSISTIVE TECHNOLOGY IN THE ACUTE CARE SETTING**ABSTRACT:****Background:**

Amyotrophic lateral sclerosis (ALS) is characterized by progressive weakness resulting in a state of profound disability and great difficulty in communicating. Frequently, patients require hospitalizations at advanced stages of disease when they are limited in function and communication and it is difficult for hospital staff not familiar with their individualized signals to ascertain their needs. In this situation, people living with ALS face frustration communicating their needs and controlling their environment, along with fear that their needs will not be met.

Objectives

New technologies are available that allow people with disabilities alternate communication and control options. These are rarely integrated into the care of severely disabled patients in the acute care setting. Our objective was to establish a room at an acute care hospital that would enable individuals with ALS to have such control, thereby reducing the fear and frustration.

Clinical Outcomes

At the hospital we have created two rooms with assistive technology available to provide for simple communication and environmental control. One is on the neurology floor and the second is on the critical care floor (for the use of ventilated patients).

Program Description

The capacity for simple communication and ability to do straightforward activities such as calling the nurse, turning on or off the light, and controlling the TV is vital. One basic need is to be able to call for assistance. The standard **call bells** in hospitals have buttons that are too small and difficult for someone with limited hand function to use. To overcome this, we provide alternative switches to enable the person to contact the nursing station. The choice in switch varies depending on the needs of the individual.

The ability to manage their surroundings also gives back some of the lost control. Currently we are using an **environmental control** system which enables the person to operate the TV/DVD/VCR, phone and one other appliance. Both rooms are equipped with a computer with internet access. In addition to the standard keyboard and mouse, we have alternative means of **computer access** available to patients with limited movement. To enhance communication for someone having a hard time speaking, an **speech generating device** is available.

Recommendations to the Field

As new technologies are becoming more readily available, it is important that they actually be available in any setting where the individual needs them. This innovative model has the potential of becoming standard of care for acute care hospitals.

SPEAKER: LINDA CATES, MS, PT, NCS AND CARIN CAVES BIOGRAPHY:

Linda Cates is a Bachelor of Physical and Health Education ,University of Toronto, Toronto,1985

Master of Science in Physical Therapy, Beaver College, Pennsylvania, 1989

American Physical Therapy Association Board Certification as a Neurological

Clinical Specialist (NCS) 1998

Member of the APTA, American Physical Therapy Association

Work History:

Physical therapist at Duke University Medical Center, Durham, NC, 1989 to present

Acute Care 1989-91

Adult Inpatient Neurological Rehabilitation

- staff therapist 1991-1993
- Coordinator of physical therapy 1993-1995

Faculty member: Graduate Program in Physical Therapy

- Academic Coordinator of Clinical Education / teaching responsibilities: 1996-1999
- 60% Faculty (teaching) and 40% clinical therapist 1999- July 2000

Outpatient Adult Neurological Rehabilitation

Senior Clinical therapist – 100% July 2000- present

Treat patients with a variety of neurological presentations as well as patients using lower extremity prostheses/orthoses.

**Serve as one of two physical therapists at the Duke ALS Clinic

Performed data collection at the Duke University Medical Center site for the Columbia University's Phase III Trial of Minocycline in ALS Patients.

Carin Caves is an ABC certified orthotist. She worked for Rancho Los Amigos Medical Center in Downey California for six years as the primary orthotist for the post-polio clinic. She currently works for Triangle Orthopaedics and specializes in orthotic bracing of patients with neuromuscular disorders

TITLE OF PRESENTATION: ISSUES ADDRESSING EFFICIENT AND EFFECTIVE LOWER EXTREMITY ORTHOTIC INTERVENTIONS FOR PEOPLE WITH ALS. PROVISION OF ONE POSSIBLE MODEL THAT WILL MEET THE INDIVIDUALS CHANGING NEEDS.

ABSTRACT:

Background:

Lower extremity orthotic intervention is challenging when working with people with ALS. Individuals wish to remain ambulatory. However, they face an ongoing progression of weakness which impacts not only their ability to walk but directly affects their quality of life. Introduction to devices and fear of dependence on such devices creates anxiety and also can lead to delayed decision making regarding the acceptance and use of orthoses.

Therapists and orthotists have no clear guidelines in order to effectively and efficiently recommend and fabricate the ideal device. Considerations such as the individual's current physical status, estimating rate of change of the disease process, the individual's acceptance of the device, and insurance coverage all complicate the process.

Similar to clinics around the world who treat people with ALS, our clinic at Duke

University Medical Center provides care to people at all stages of the disease process. Several patients are recommended orthoses for the first time. Others come to clinic with devices that have never worked or are currently inadequate for their current level of function. Some individuals are wheelchair bound. In this presentation, our physical therapist and orthotist will jointly address the following issues. The current options available for orthotic intervention in the ALS population will be outlined. We will discuss how insurance coverage in the US impacts the decision making process. Video case examples will provide insight into the consideration for use of a more rigid AFO to provide long term support in the weakened limb while meeting the changing needs of the individual. Suggestion for a possible model will be made to effectively and efficiently provide orthotic intervention across the changing presentation of our patients. Finally, we hope to foster discussion from our fellow colleagues at the conference in order to optimize care and management for our patients in order to maintain functional, safe ambulation for as long as possible.

SPEAKER: MARK GOREN MS OTR/L

BIOGRAPHY:

Mark S. Goren 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.

TITLE OF PRESENTATION: CYBERLINK CONTROL SYSTEM

ABSTRACT:

Background:

Preliminary review of the need for alternative communication devices for people living with end stage ALS is evident from numerous multidisciplinary team visits at the MDA/ALS Center of Hope at Drexel University's College of Medicine in Philadelphia. New technologies are giving people with motor disabilities alternative communication and control channels above and beyond the traditional AAC and the manual letterboard . We are interested in using the Cyberlink Control System as a hands free means to assess a computer for people living with Amyotrophic Lateral Sclerosis (ALS).

Objectives

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

Clinical Outcomes

Results from the cyberlink trials will be available for presentation. The cyberlink will be compared to the manual letterboard for a) speed of use and b) ease of use.

Program Descriptions

Patients will be given a standard sentence to spell using the traditional manual letter board. The caregiver who is blinded to the sentence will assist the patient. The amount of time taken to complete the sentence will be recorded. The patient will then use the Cyberlink Control System to spell out the same sentence. The amount of time taken to spell out the sentence will be recorded. A comparison will be made determining speed of use. To determine ease of use a hatched line will be made on a scale from zero to ten where zero indicates no difficulty and 10 indicates impossible. The patient will blink their eye or grimace to determine where the hatch should be placed on the scale. Participants selected for the study will be required to meet the following additional 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's 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-R Functional Rating Scale score of 2 or less in the categories of speech and handwriting.

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.