

NOSM Palliative Care Clinical Rounds

ALS Cases

Thursday, February 3rd, 2022

Dr. Karen Booth

Disclosure Slide

- **Speaker: Dr. Karen Booth**
- **Relationships with commercial interests: NONE**
- **Potential for conflict(s) of interest: NONE**

Session Evaluation and Outcome Assessment

These short forms serve important functions!

- For **speakers**: Your responses help them understand their strengths and weaknesses, participant learning needs, and teaching outcomes
- For **the CEPD office**:
 - To plan future programs
 - For quality assurance and improvement
 - To demonstrate compliance with national accreditation requirements
- For **YOU**: Reflecting on what you've learned and how you plan to apply it can help you enact change as you return to your professional duties

Please take 3-5 minutes to fill the evaluation form out. Thank you!

Learning Objectives

At the end of this presentation, participants will be able to:

1. Apply a palliative lens to ALS patients nearing end of life.
 - Brief ALS Overview from a Palliative Lens.
2. Review Community Focused Symptom Management Pearls
 - Case based
1. Discuss Interprofessional Supports for ALS Patients
 - Algoma Perspective
2. Regional Successes/Challenges supporting care for ALS patients



Rationale

1. 2500-3000 Canadians currently living with ALS
2. Terminal, Incurable Illness
3. Life expectancy: 2-5y from diagnosis
4. Algoma Perspective/ALS Referrals to PC Team:
 - **6 patients 2020**
 - **7 patients 2021**
 - *Trend: We are learning/caring for more patients with ALS*

Resources for Providers

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Guideline

Canadian best practice recommendations for the management of amyotrophic lateral sclerosis

Christen Shoesmith, Agessandro Abrahao, Tim Benstead, Marvin Chum, Nicolas Dupre, Aaron Izenberg, Wendy Johnston, Sanjay Kalra, Desmond Leddin, Colleen O'Connell, Kerri Schellenberg, Anu Tandon and Lorne Zinman

CMAJ November 16, 2020 192 (46) E1453-E1468; DOI: <https://doi.org/10.1503/cmaj.191721>

Resources for Providers

KEY POINTS

- Management of patients living with amyotrophic lateral sclerosis (ALS) requires specialized multidisciplinary holistic care.
- Disease-modifying pharmacologic therapies to treat ALS include riluzole and edaravone.
- Close attention to nutritional support and respiratory care is required for optimal care in ALS.
- Multiple treatments are available to ease the symptoms of ALS.
- Palliative care and caregiver support are important components of assisting patients along their journey with ALS.



Case 1: Mr. Lovely

- 70yM
- Rapidly progressive symptoms:
 - Generalized limb weakness, reduced motility
 - Swallowing and speech difficulties
 - Progressive breathlessness, cough
- Diagnosis – *out of town*
 - Disease Modifying Therapy: Riluzole
 - Referral local HCC

Disease Modifying Therapies

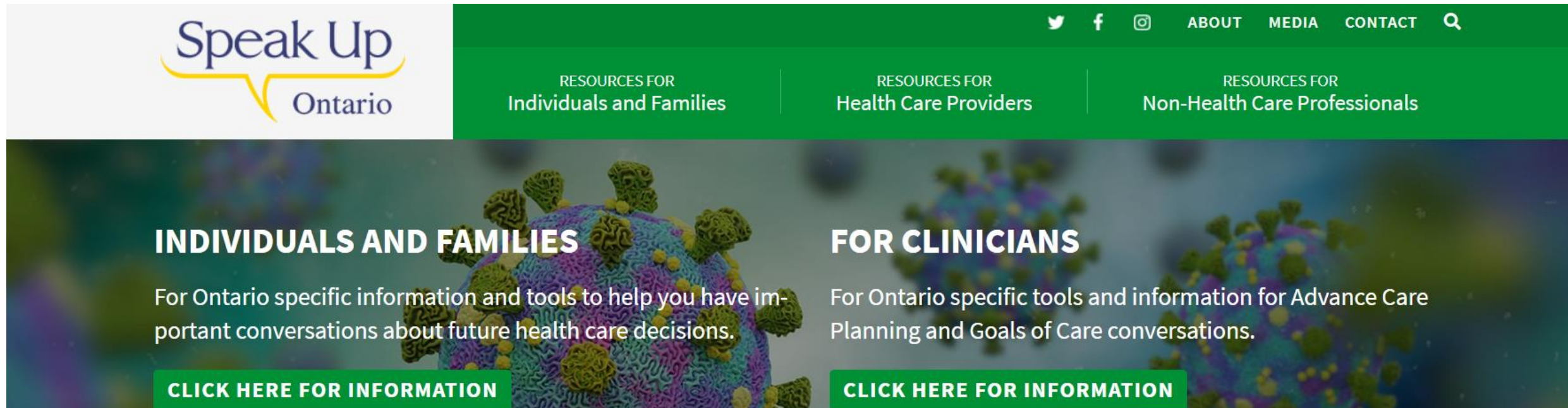
- Riluzole
 - Coverage – YES
 - Modest benefit on survival, *meta-analysis
 - Increase median survival from 11.8-14.8m **(3m)**
 - Limited evidence if extends across specific/all stages of ALS
 - Recommended to be started soon after diagnosis
 - Insufficient evidence that it loses clinical efficacy with progression
 - Generally well tolerated
 - Oral route
- Edaravone
 - Coverage – EAP coverage/specialist
 - IV therapy
 - Select group (earlier stage/severity) slower decline x6m
 - Benefit at other stages not demonstrated

Mr. Lovely

- Ultimately referred to PC Team
 - *Minor weekend crisis, aka very late referral*
 - PPS 30%
 - Confirmed ACP – avoid life prolonging therapies
 - Transferred to hospice

Mr. Lovely

- Highlighted Importance Advance Care Planning
 - Limited information/communication of diagnosis, expected course
 - Opportunity for patient to express wishes/values
 - Confirm SDM



The screenshot shows the Speak Up Ontario website. The header is green with the logo on the left and navigation links (Twitter, Facebook, Instagram, About, Media, Contact, Search) on the right. Below the header is a green bar with three columns: 'RESOURCES FOR Individuals and Families', 'RESOURCES FOR Health Care Providers', and 'RESOURCES FOR Non-Health Care Professionals'. The main content area has a background image of a virus. It is divided into two sections: 'INDIVIDUALS AND FAMILIES' and 'FOR CLINICIANS'. Each section has a description and a green button that says 'CLICK HERE FOR INFORMATION'.

Speak Up Ontario

RESOURCES FOR Individuals and Families | RESOURCES FOR Health Care Providers | RESOURCES FOR Non-Health Care Professionals

INDIVIDUALS AND FAMILIES

For Ontario specific information and tools to help you have important conversations about future health care decisions.

[CLICK HERE FOR INFORMATION](#)

FOR CLINICIANS

For Ontario specific tools and information for Advance Care Planning and Goals of Care conversations.

[CLICK HERE FOR INFORMATION](#)

Mr. Lovely

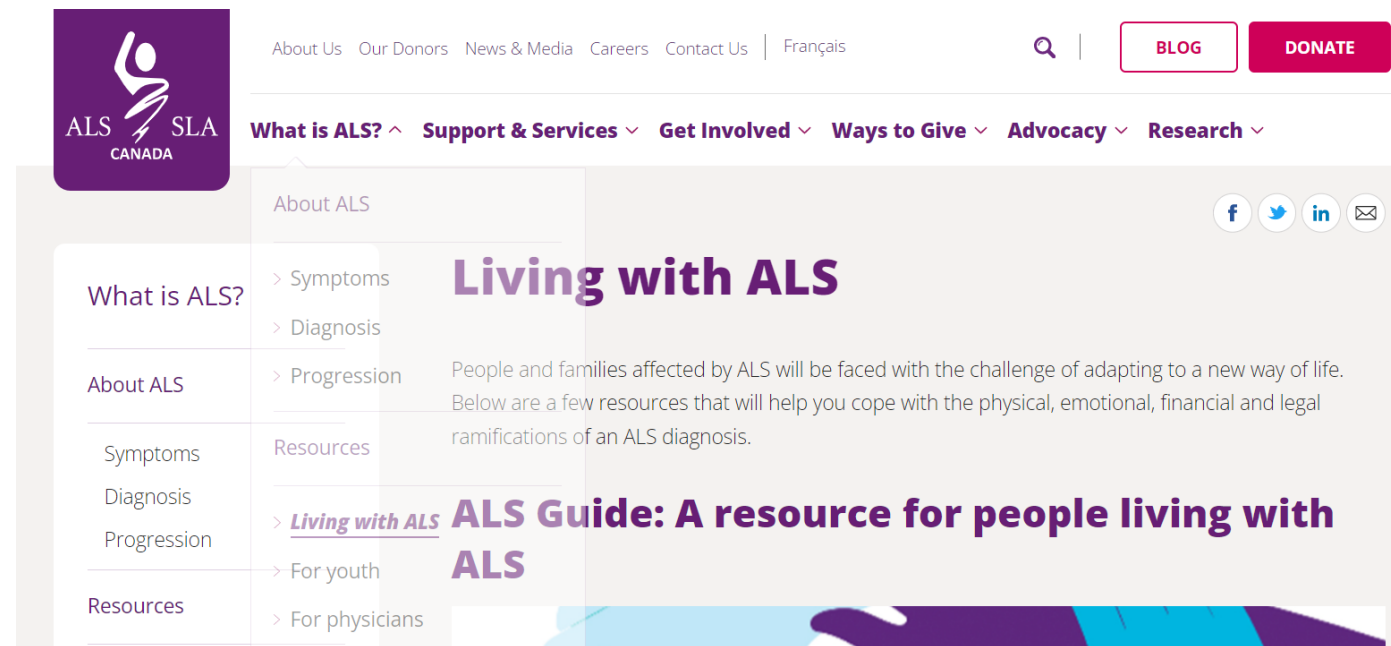
- Multidisciplinary Community Team
 - Home and Community Care (HCC)
 - Occupational Therapy (OT)
 - Physiotherapy (PT)
 - Respiratory Therapy (RT)
 - Dietician
 - Speech Language Pathology (SLP)
 - PSW/Respite for Caregiver
 - Spiritual Support
 - *Primary Care Provider - none*
 - *ALS Clinic – none locally*

ALS Clinic - Multidisciplinary Approach

- **Survival benefit** (level B).
- **Fewer and shorter hospital admissions** than patients not attending such clinics (level B).
- Increased use of **adaptive equipment** (level C).
- Increased use of **riluzole, percutaneous feeding tubes and NIV** (level B).
- **Enhanced QOL** (level C).

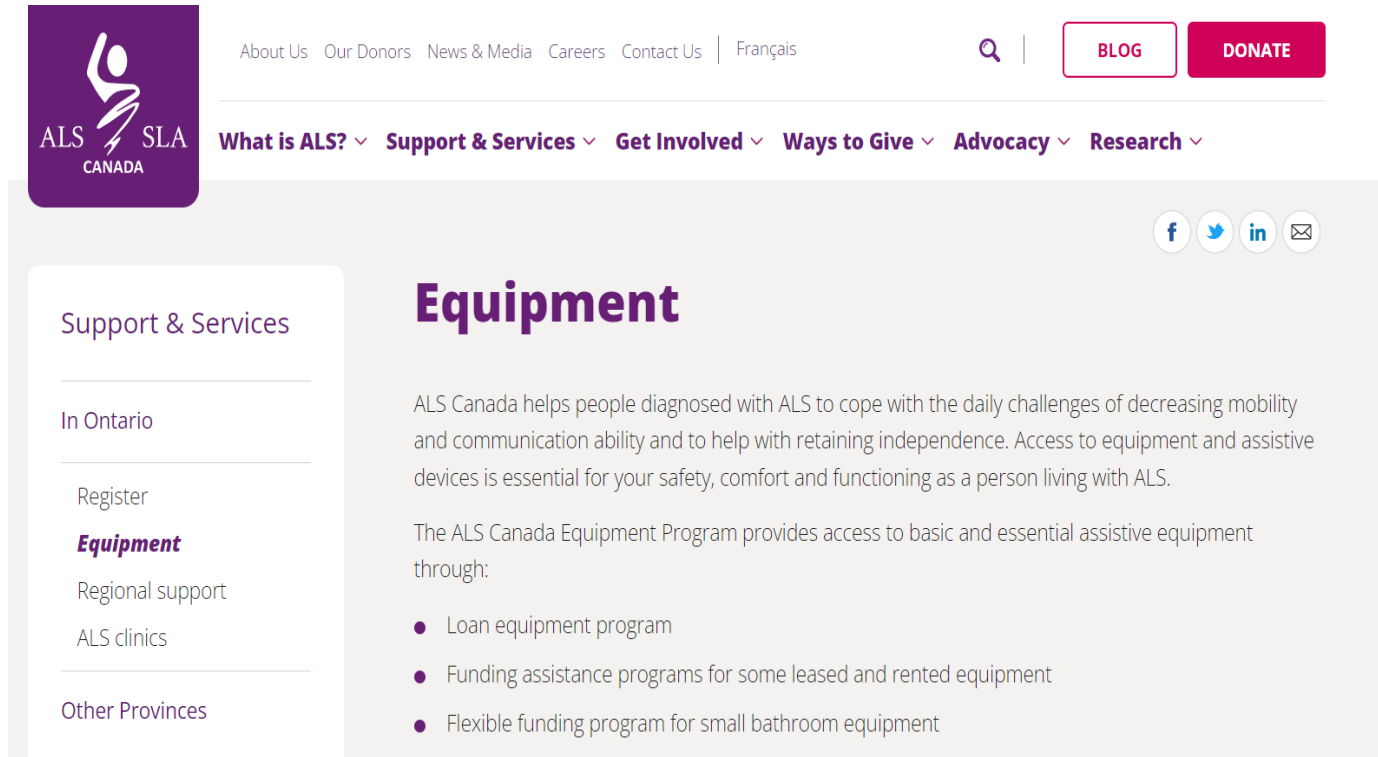
ALS Society - Resources

- Information, connection
- Education – patient and provider
- Assistive Equipment
- Funding Assistive Programs



Mr. Young

- 45yM
- Connection ALS Society
 - Manager Sudbury
- Support expensive equipment
- Communication devices
 - Eye gaze monitor
 - Supported QOL



The screenshot shows the ALS Canada website. The header includes the ALS Canada logo, navigation links (About Us, Our Donors, News & Media, Careers, Contact Us, Français), a search icon, and buttons for BLOG and DONATE. A secondary navigation bar lists: What is ALS?, Support & Services, Get Involved, Ways to Give, Advocacy, and Research. The main content area is titled "Equipment" and describes the ALS Canada Equipment Program. A sidebar on the left lists "Support & Services" with links for "In Ontario" (Register, Equipment, Regional support, ALS clinics) and "Other Provinces".

ALS Canada logo: ALS SLA CANADA

Navigation links: About Us | Our Donors | News & Media | Careers | Contact Us | Français

Buttons: BLOG, DONATE

Secondary navigation: What is ALS? | Support & Services | Get Involved | Ways to Give | Advocacy | Research

Social media icons: Facebook, Twitter, LinkedIn, Email

Equipment

ALS Canada helps people diagnosed with ALS to cope with the daily challenges of decreasing mobility and communication ability and to help with retaining independence. Access to equipment and assistive devices is essential for your safety, comfort and functioning as a person living with ALS.

The ALS Canada Equipment Program provides access to basic and essential assistive equipment through:

- Loan equipment program
- Funding assistance programs for some leased and rented equipment
- Flexible funding program for small bathroom equipment

Support & Services

In Ontario

- Register
- Equipment**
- Regional support
- ALS clinics

Other Provinces

Resources for Providers

A GUIDE TO ALS PATIENT CARE FOR PRIMARY CARE PHYSICIANS	
	 <p>A GUIDE TO ALS PATIENT CARE FOR PRIMARY CARE PHYSICIANS</p> <p>AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF CANADA</p> <p>www.als.ca</p>
PREFACE AND ACKNOWLEDGEMENTS	Pg. i-ii
INTRODUCTION TO ALS	Pg. 1-4
PSYCHOLOGICAL SUPPORT	Pg. 5
THE ALS HEALTHCARE TEAM	Pg. 6-8
DYSARTHRIA	Pg. 9
DYSPHAGIA AND NUTRITION	Pg. 10
DYSPNEA	Pg. 11-12
SIALORRHEA	Pg. 13

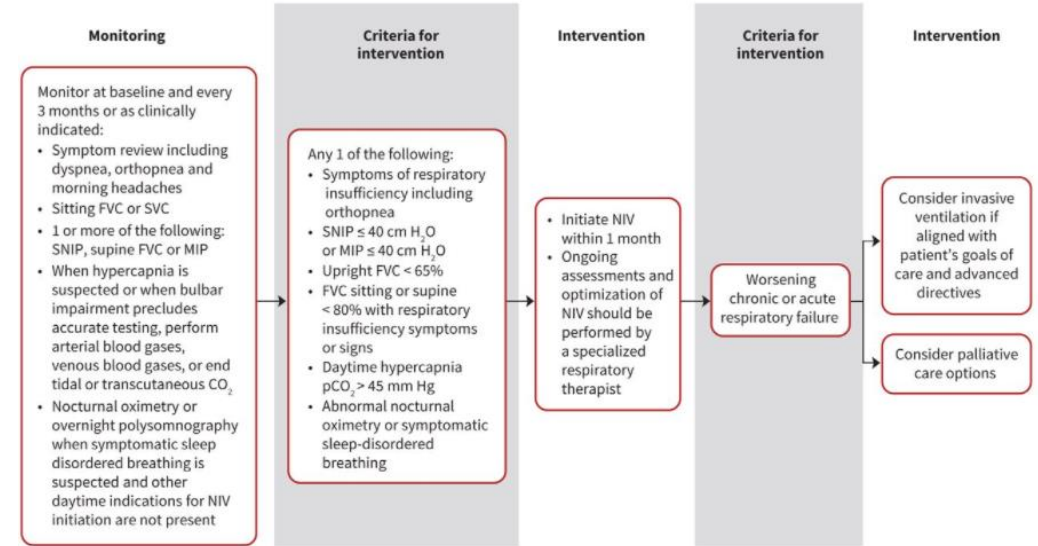
Mrs. O's Symptom Burden

- 60yF, progressive symptoms
- Dyspnea
- Headache
- Sialorrhea
- Dysphagia
- Complex Pain
- Suffering

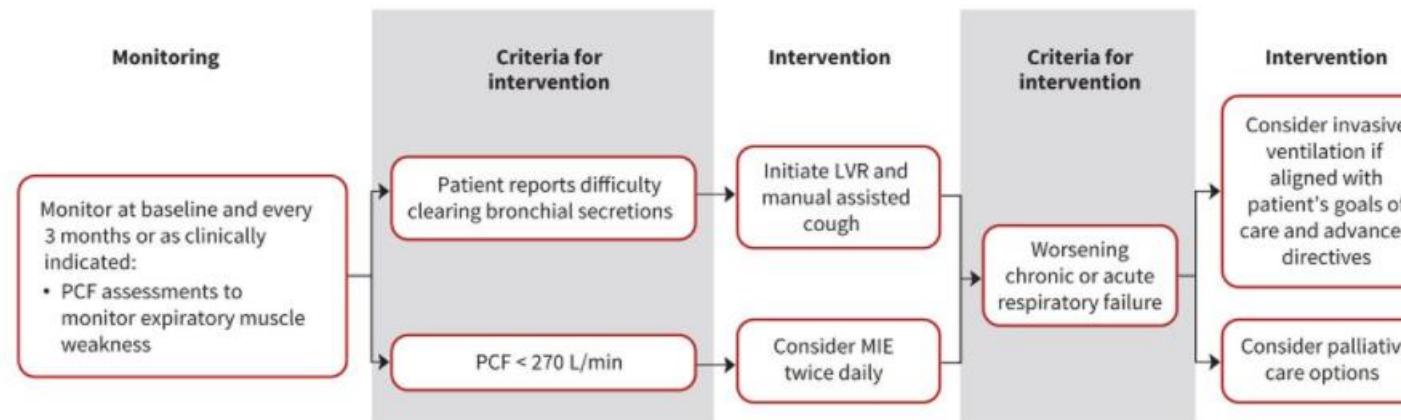
Ventilatory Support

- Not exhaustive review/entire talk
 - CMAJ resource for details→
 - Excellent Fast Facts Summary #73
- Survival + symptom benefit
 - With understanding ALS will continue to progress even w ventilatory support
- Connect with local resources
 - RT, Respiriology, ALS Society
 - PPV, nocturnal O2, cough assist

A) Ventilation



B) Airway clearance



Mrs. O's Headache

- Respirologist involvement
- Hypoxia & hypercarbia mediated
- Absolute pCO₂ ≠ clinical symptoms
- Clinical benefit with PPV/O₂ overnight
- *Headaches did improve*
 - “Brain learns to tolerate abN O₂/CO₂ levels”
 - Weaned from PPV, NO rebound headaches
 - Important to facilitate hospice transfer/COVID

Mrs. O's Sialorrhea

Secretion Management:

- Positioning, oral suction, perioral skin care
- Glycopyrolate
 - ODB coverage LU #481
 - Parenteral formulation use orally
 - No RCTs to evaluate effectiveness TCA, atropine, scopolamine, glyco
- Radiation, Botox
 - Not locally available



FAST FACTS AND CONCEPTS #299
MANAGEMENT OF SIALORRHEA IN ALS

Kristin Scott MD, Robert Shannon MD FAAHPM, Alva Roche-Green MD

Dysphagia/Nutritional Support

- Early Dietician & SLP referral
- Feeding Tubes
 - ‘Offer to ALS pts losing weight’
 - May prolong survival if implemented **early** in disease course (3-8m*)
 - Complex decision making
 - Indications
 - Risk/Benefit Discussions



Feeding Tubes: PEG (Percutaneous endoscopic gastrostomy)

FACT SHEET | WWW.ALS.CA



FAST FACTS AND CONCEPTS #411

NUTRITION FOR PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS)

Julia L. Frydman MD (1), Elizabeth Pedowitz MD (1), Elizabeth Lindenberger MD (1,2)

Mrs. O's Pain

- Complex Pain
 - MSK, rigidity/spasticity, neuropathic, total pain
- Positioning, PT, OT
- MSK – NSAIDs
- Spasms/cramps – baclofen, quinine, benzo
- Neuropathic – gabapentin, CBD
- Total pain – SNRI, benzo's, spiritual support

Mrs. O's Pain

- Complex Pain
 - MSK, rigidity/spasticity, neuropathic, total pain
- Opiates
 - Complicated loss po route, low body mass, fear respiratory depression
- Oxycodone → Fentanyl sl/TD

Mrs. O's Suffering

- MAID Request
 - Frequent
 - ACP/GOC Conversations, Discuss Early
 - Involvement of her SDMs
- Local MAID resources, support
- Support – spiritual, psychosocial, PC

Terminal Symptom Management

- Risk Rapid Decline – very rapid!
- ‘Crucial to have plan in place’
 - Education
 - Who to contact
 - SRK
 - Palliative Sedation
- Respiratory Distress/Failure
- Aspiration

'Top Ten' ALS Community Pearls

1. Earlier Palliative Approach/PC Involvement
2. Diagnosis/Illness Understanding
3. Advance Care Planning
4. Confirm SDM
5. Prepare yourself as providers
 - Provider Resources
 - Local Resources/Go-to persons
 - ALS Society

‘Top Ten’ ALS Community Pearls

6. Multidisciplinary Team + ALS Society Resources
7. Symptom management
8. Crisis Symptom Management
9. EOL planning
10. MAID Requests

Share Experiences

- Thank you!
- Please share experiences, reflections
- Questions, Chat Q/A
- Contact:
 - boothkar@gmail.com

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