

Palliative and end-of-life (EOL) care in ALS

A practical workshop

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Disclosure

- Consultant to Novartis (JH)
- An honorarium was offered for this presentation

Who we are

- Neuro-supportive Care Service at the Montreal Neurological Hospital
- Consultation service for all inpatients and outpatients
- Team dyad: Physician and Nurse

Learning Objectives

Through case studies, the participant will:

1. Identify pharmacological and non-pharmacological strategies to manage end-of-life symptoms
2. Recognize situations requiring the use major of distress protocols
3. Identify signs of distress in patients with decreased communication skills (dysarthria, decreased level of consciousness and/or cognitive deficits)
4. Adapt assessment to a dying patient
5. Reflect upon ethical considerations at end-of-life

Mr. A.

Mr. A. was hospitalized from the ER, suffering from respiratory distress in the context of end-stage ALS. BiPap was initiated in the ER. He responded well to regular Morphine and Midazolam PRN. He initiated an official request for MAiD.

Mr. A.

His respiratory state deteriorated during the evaluation period despite the use of BiPap.

He was concerned that opioids would make him drowsy and affect his capacity to consent to MAiD.

Mr. A.

- How would you intervene with Mr. A.?

Mrs. L.

Mrs. L., 46, has been admitted to your unit for several months. She has end-stage ALS. She is ventilator dependent, has a tracheostomy and is fed via PEJ. She is unable to move her limbs and communicates with an eye-tracking device.

She has been deteriorating over the last weeks, with multi-system failure. A level of intervention C, with goals of comfort over prolonging life, has been decided with her family.

Mrs. L.

When you round, you find Mrs. L. looking uncomfortable. Her eyes are wide open. Her stomach is extremely distended. When you ask the health care team for an update, they say: « She is palliative. »

You notice there has been no bowel movement recorded in the last week, and no laxatives were administered.

Dilaudid s/c PRN was given with minimal relief.

Mrs. L.

- What do you suspect is happening with Mrs. L.?
- How do you assess the situation?
- How can you relieve Mrs. L.?

Mrs. S.

Mrs. S. has end-stage ALS. She is hospitalized for aspiration pneumonia. She has a tracheostomy (not ventilated), a PEG, and is bedbound. She communicates by writing. She has difficulty managing her secretions, sialorrhea, and occasional panic attacks.

Her level of intervention is B (No CPR, no artificial ventilation).

Mrs. S.

You are called to Mrs. S.' bedside because she is found to be desaturating, is using her accessory muscles to breathe and is cyanotic. Her respiratory rate is 32/min. The RT is at bedside attempting to suction without improvement.

She is conscious and trying to write but is severely agitated.

Mrs. S.

- What is happening to Mrs. S.?
- What can you do, along with the interdisciplinary team, to alleviate her suffering?
- Do you think this is a terminal event?

Practical tips to remember

Do:

- Allow enough time for patients to formulate answers – it can take long but don't get discouraged!
- Make sure patients have hearing aids and glasses on

Practical tips to remember

- Monitor non-verbal signs of anxiety/distress
 - Rapid, shallow breathing
 - Grimacing
 - Brow furrowing

Positioning and Comfort

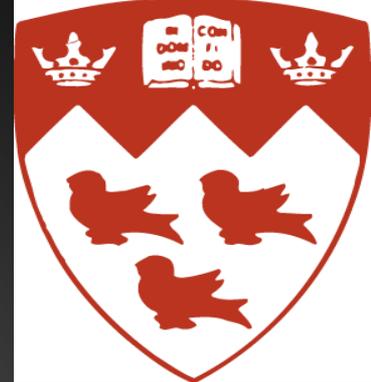
- To decrease abnormal tone
- Reduce effort to maintain sitting position
- Optimize respiratory function
- Facilitate access to communication devices
- PT/OT for head, neck and trunk support
- Treat pain

Environmental Considerations

- Turn off TV/radio
- Avoid background noises
- Shut door
- Adequate lighting to allow reading of facial expressions
- Sit where they can see you!

Augmentative and Alternative Communication

- Pen & paper
- Magnifiers
- Alphabet board
- Eraseable whiteboard
- Voice amplifiers
- More complex electronic tools: eye-tracking device



Thank you