Palliative Care in Neurosurgery: Focus on Neuro-Oncology

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Disclosure

• Consultant to Novartis
• Susan Cameron Cook Program in Neuropalliative Care
• Rossy Family Foundation for Neuropalliative Education
Learning Objectives

1. Describe a “palliative approach” to patients with neurologic illnesses (Neurosupportive Care)
2. Identify the major subtypes of neurologic illnesses to benefit from a palliative approach
3. Focus on supportive care for neuro-oncology
What is Palliative Care?
Neurosurgical procedures for intractable pain;
- Spinal Cord Stimulation
- Intrathecal Pumps
- Motor Cortex Stimulation
- Deep Brain Stimulation
- Cordotomy
- Mesencephalotomy
WHO definition of Palliative Care?

• An approach which attempts to prevent or alleviate physical, social, psychological and spiritual suffering without hastening death or prolonging life.
Practical definition of Palliative Care (Supportive Care)

• Symptom control and practical support to patients and their caregivers with a primacy on quality of life from first contact, through terminal care, death and bereavement.
Some day, we will all die, Snoopy!

True, but on all the other days, we will not.
PC/SC Skill Sets

- Symptom assessment and management
- Advanced care planning (LOC)
- Communication of bad news (SIC)
- Caregiver assessment (family and team)
Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

<table>
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<tr>
<th>Symptom</th>
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<td>Possible Nausea</td>
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<td>Possible Lack of Appetite</td>
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<td>Possible Shortness of Breath</td>
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<td>Possible Anxiety</td>
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<td>Possible Other Problem (for example constipation)</td>
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Patient’s Name ____________________________
Date _______________ Time ________________

Completed by (check one):
□ Patient
□ Family caregiver
□ Health care professional caregiver
□ Caregiver-assisted
Advanced care planning

• Current literature reveals that most patients want to know (even if the news is bad) and that they can be given this news without distress or lack of hope.

• Moreover, discussions of EOL are associated with earlier referral to hospice/PC and less aggressive medical care near death. Aggressive care near death is associated with worse patient QOL and worse caregiver bereavement.
**LEVELS OF CARE AND CARDIOPULMONARY RESUSCITATION**

The goals of care below are indicative and are intended to alert medically appropriate care.

Institution name:  

Revise using a new form following any change in health status or at the request of the user or his/her representative.

### Capacity to discuss levels of care

<table>
<thead>
<tr>
<th>Choice</th>
<th>Description</th>
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<tbody>
<tr>
<td>☐ Competent</td>
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<tr>
<td>☐ Incompetent</td>
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<tr>
<td>☐ Hemoligated mandate</td>
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<td>☐ Public/private curator</td>
<td>Name:</td>
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<tr>
<td>☐ Minor under 14 years old</td>
<td>Name of tutor, relationship with user:</td>
</tr>
</tbody>
</table>

### Previous advance wishes:

- ☐ None available
- ☐ Prior level of care form
- ☐ Advance medical directive
- ☐ Living will or other

### Levels of care: check and provide details in the box below (Explanatory notes on the reverse side)

- ☐ Goal A: Prolong life with all necessary care
- ☐ Goal B: Prolong life with some limitations to care
- ☐ Goal C: Ensure comfort as a priority over prolonging life
- ☐ Goal D: Ensure comfort without prolonging life

Give details on specific interventions in the box below, as needed.  
E.g., hemodialysis, blood transfusion, nutritional support (enteral or parenteral), preventative care, etc.

### Cardiopulmonary resuscitation (CPR): check and provide details in the box below (Explanatory notes on the reverse side)

**Cardiac (circulatory) arrest**

- ☐ Attempt CPR
- ☐ Do NOT attempt CPR

Check if NOT desired, to guide prehospital care for goals B and C (see reverse side).

- ☐ NO emergency intubation (goals B and C only)
- ☐ NO assisted ventilation if unconscious (goal C only)

### Explanatory notes on the discussion and instructions concerning specific interventions

- Discussed with:  
  - ☐ User
  - ☐ Representative

Name: ____________________  Relationship: ____________________

Contact information: ________________

Record the names of the participants as well as the words used during the discussion and all information that helps clarify the user’s wishes.

Name of physician: ____________________  Signature: ____________________  Date: (year, month, day)

Contact information: ________________

If a copy of this form is given to the user or his/her representative, it is signed by him/her so that paramedic ambulance technicians can follow the instructions on the form.

Name of user or representative: ____________________  Signature: ____________________  Date: (year, month, day)
Explanatory notes

• This form is not a substitute for consent to treatment, which must always be obtained (except in certain emergency situations).
• This form must be signed by a physician.

Description of levels of care

The discussion about levels of care is carried out with the user or, in the case of Incapacity, with his/her representative, in the spirit of shared decision-making about medically appropriate care. The explanations and examples provided in the following descriptions do not assume capacity on the part of the user, nor do they necessarily reflect his/her usual care setting.

Goal A
Prolong life with all necessary care

• Care includes all interventions that are medically appropriate and transfer 1 if the intervention is not available in the current setting.
• All invasive interventions can be considered, including, for example, intubation and intensive care.

In the prehospital setting, unless otherwise advised by the user or his/her representative, all protocols apply; intubation, assisted ventilation 2 and assisted respiration 3 are included when appropriate.

Goal B
Prolong life with some limitations to care

• Care incorporates interventions with the aim of prolonging life, which offer the possibility of correcting deterioration in health status while preserving quality of life.
• Interventions may lead to discomfort that is judged to be acceptable by the user or his/her representative acting in the sole interests of the user, given the circumstances and the expected outcomes.
• Certain interventions are excluded since they are judged to be disproportionate 4 or unacceptable 5 by the user or his/her representative acting in the sole interests of the user, given the potential for recovery and undesired consequences (e.g., short-term or long-term intubation, major surgery, transfer).

In the prehospital setting, unless otherwise advised by the user or his/her representative, all protocols apply; assisted ventilation 2 and assisted respiration 3 are included; intubation is included unless indicated as not desired on the form (checked in the prehospital care box).

Goal C
Ensure comfort as a priority over prolonging life

• The user’s comfort is prioritized through the management of symptoms.
• Interventions which may prolong life are used as needed in order to correct certain reversible health problems, by means judged acceptable by the user or his/her representative acting in the sole interests of the user (e.g., oral or intravenous antibiotics to treat pneumonia).
• Tranfer to an appropriate care setting is considered only if care available locally is insufficient to ensure comfort (e.g., for a hip fracture with significant discomfort or for respiratory distress at home).

In the prehospital setting, unless otherwise advised by the user or his/her representative, all protocols apply; assisted respiration 3 is included; intubation and assisted ventilation 2 are included unless indicated as not desired on the form (checked in the prehospital care box).

Goal D
Ensure comfort without prolonging life

• Care is exclusively aimed at maintaining comfort through the management of symptoms (e.g., pain; trouble breathing; constipation, anxiety).
• Interventions do not aim to prolong life; illness is left to its natural course.
• A treatment that is usually given with curative intent may be used, but only because it represents the best option to relieve discomfort (e.g., oral antibiotics for a lower urinary tract or C. difficile infection).
• Transfer to an appropriate care setting is considered only if care available locally is insufficient to ensure comfort (e.g., for a hip fracture with significant discomfort or for respiratory distress at home).

In the prehospital setting, unless otherwise advised by the user or his/her representative, the following protocols apply: oxygenation, salbutamol, nitroglycerine (chest pain) and glucagon. For respiratory distress in a conscious user, assisted respiration 3 (CPAP) can be used unless refused. Intubation and assisted ventilation 2 are excluded. Manoeuvres to clear an obstructed airway in a living user can be carried out.

Cardiopulmonary resuscitation (CPR)

CPR is part of the same discussion as levels of care. The decision is specified in a distinct manner to allow rapid decisions in the case of cardiorespiratory arrest. A CPR decision is only applicable in the case of a cardiac arrest with arrest in circulation. In the case that a CPR attempt is desired, measures available on site will be deployed while awaiting the arrival of emergency medical services, according to the situation.

1 The term “transfer” implies moving the user to a setting that is different from his/her current environment (leaving his/her home, inter-institutional or intra-institutional transfer, etc.). If a transfer is not being considered, a care goal other than A must be selected.
2 Assisted ventilation is carried out via non-invasive techniques (nasal-mask, Oxygenator) in an unconscious user.
3 Assisted respiration is carried out via non-invasive techniques (CPAP) in a conscious user.
4 The sense of the term “disproportionate” or “unacceptable” is based on subjective perceptions and uses that vary from person to person and across time.
5 The words used by the user or his/her representative are important to record in the box provided for this purpose.

LEVELS OF CARE AND CARDIOPULMONARY RESUSCITATION
Serious Illness Conversation

Sometimes, even if I stand in the middle of the room, no one acknowledges me.
Serious Illness Conversation Guide

Understanding
• What is your understanding now of where you are with your illness?

Goals
• If your health situation worsens, what are your most important goals?

Fears/Worries
• What are your biggest fears and worries about the future with your health?
Serious Illness Conversation Guide

Function
• What abilities are so critical to your life that you can’t imagine living without them?

Trade-offs
• If you become sicker, how much are you willing to go through for the possibility of gaining more time?

Family
• How much does your family know about your priorities and wishes?
Practical strategies

• Consider care transitions as opportunities for conversations about goals of care
  • Recent hospitalisation
  • Admission to a nursing home
  • If you realize you would not be surprised if your patient died within the next year
  • If your patient had a recent functional decline
  • If your patient is receiving third-line chemotherapy
Is there evidence in favour of Supportive Care?

- 2010 study in NEJM which randomized 151 newly diagnosed metastatic non-small-cell lung cancer into a group receiving standard oncologic treatment and into one receiving standard treatment with Palliative Care from the time of diagnosis.
Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Temel Study (2010)

• Is QOL and mood affected over 12 weeks by early introduction of Palliative Care?
• Those still alive at 12 weeks (86%) indicated better QOL and lower depression scores (Palliative Care Doctors don’t make patients depressed!)
• Fewer patients in the PC group received aggressive measures at the EOL and median survival was over 2 months longer (Palliative Care extended their lives by >20%)
Palliative Care in addition to standard therapy - is a more effective intervention than standard therapy alone!
Neuro Palliative / Supportive Care

- The applied principles of Palliative Care to patients with neurologic diseases:
  - Brain cancer
  - Stroke
  - Dementia
  - Traumatic brain injury (TBI)
  - Chronic pain
  - Neuromuscular diseases (ALS)
  - Inflammatory disorders (MS)
  - Movement disorders (Parkinson’s Disease-PD)
Unique needs of Neuro patients

• Neurologic diseases are largely incurable and reduce life expectancy.
• Neurologic diseases have a vastly more varied trajectory than cancer patients and are characterized by cognitive impairment, behavioural issues and communication problems.
Supportive Care Training?

• In the USA there is a separate board certification process for Hospice and Palliative Medicine recognized by the American Board of Psychiatry and Neurology (ABPN)

• In Canada, starting July 2017, the Royal College has introduced a two-year speciality in Palliative Medicine following Internal Medicine, Anesthesia or Neurology Certification

• In Europe there is a two year training program following Internal Medicine Certification
Oxford Textbook of Palliative Medicine

FIFTH EDITION

Edited by
Nathan I. Cherny
Marie T. Fallon
Stein Kaasa
Russell K. Portenoy
David C. Currow
Neurology & PC/SC

• Less than 1% of Neurologists are board certified in Palliative Medicine and fewer than 2% of Palliative Care Clinicians are Neurologists.
Neurosurgery & PC/SC

- No training requirements.
- Uncertainty about when to involve PC/SC in the disease trajectory of a patient.
Essence of Supportive Care Service

- Patient and family centred care delivered by a team
- Whole-person care
  - Dedicated Nursing (*Justine Gauthier*)
  - Administrator
  - Psychology
  - Social work/Physiotherapy/Occupational therapy
  - Rehabilitation services / Geriatrics
  - Spiritual Care
  - Volunteers
  - Complimentary therapy (Art, Music, Massage, Pets)
  - Legacy projects
  - Ambulatory clinics
  - Home care program
  - Teaching
  - Research
Who consults NPC?

• We are in the process of conducting a review of the inpatient consultations from our hospital. The vast majority involve patients with cerebrovascular, oncologic and neuromuscular diagnoses.

• This review will be presented at the 22^nd^ International Congress on Palliative Care, October 2-5^th^, 2018, Montreal
Demographics of “Neuro” patients

- Neuro-oncology (Malignant Glioma)
- Cerebrovascular (Stroke)
- Neuro-inflammatory (Multiple Sclerosis)
- Movement disorder (Parkinson’s Disease)
- Neuromuscular (Amyotrophic Lateral Sclerosis)
- Neurodegenerative (Dementia)
- Traumatic Brain Injury (TBI)
Malignant Glioma

• Incidence: 4-5/100,000
• Prevalence: 10/100,000
• Average age at diagnosis: 64
• Life expectancy: 14, 5 months
Neuro-Oncology

- Non-malignant pathology can benefit from a “palliative” approach
- The management and treatment of patients with malignant brain tumours is evolving but a palliative approach can be adopted early in the disease trajectory
- Palliative neurosurgical procedures can be life-saving and/or life-prolonging but should be considered in the context of patients informed by serious illness conversations and consistent with discussions of levels of care
Neuro-Oncology

• Non-malignant pathology can still carry a significant perioperative risk of morbidity and mortality

• Non-malignant pathology may be associated with life-long neurologic sequelae and/or the need for continuous follow-up by a team of health-care professionals
Malignant Brain Tumours

- Recent molecular characterization of tumour pathobiology allows some degree of prognostication given specific treatments
  - MGMT methylation
  - IDH mutation
  - LOH 1p19Q

- Advances in surgery, radio-therapy, chemotherapy and targeted immunotherapy are changing the toxicity and trajectory of these diseases
2008 Glioma
Metastatic melanoma BRAF+
pre-Rx
post-Rx
Metastatic breast cancer

2013

2013
Metastatic breast cancer
2017
Metastatic breast cancer
(palliative shunt)
Thank you
References


