Neuropalliative Care: An Emerging Subspecialty

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CME Day Geriatrics
April 19th, 2018
Disclosure

• Consultant to Novartis (JH)
• 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
2. Identify the major subtypes of neurologic illnesses and their demographics
3. Manage common clinical scenarios including; increased intracranial pressure, seizures, serious illness conversations and discussions regarding levels of care
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 (1).
Our 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.
Paradigm Shift

- Supportive care focuses on the relief of suffering and planning for decline and death as an *expected and natural outcome* and not as a failure of medical treatment (4).
What is Palliative Care is NOT

- The end of hope
- Admission of defeat
- Failure of treatment
- Who you call when “nothing more can be done”
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
• Communication of bad news (SIC)
• Advanced care planning (LOC)
• Caregiver assessment (family and team)
### Edmonton Symptom Assessment System: (ESAS-R) (revised version)

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

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Pain</td>
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<td>Pain</td>
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<tr>
<td>No Tiredness</td>
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<td>Tiredness</td>
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<td>(Tiredness = lack of energy)</td>
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<td>No Drowsiness</td>
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<td></td>
<td></td>
<td></td>
<td>Drowsiness</td>
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<tr>
<td>(Drowsiness = feeling sleepy)</td>
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<tr>
<td>No Nausea</td>
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<td>Nausea</td>
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<tr>
<td>No Lack of Appetite</td>
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<td></td>
<td>Lack of Appetite</td>
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<tr>
<td>No Shortness of Breath</td>
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<td></td>
<td>Shortness of Breath</td>
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<td>No Depression</td>
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<td>Depression</td>
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<td>(Depression = feeling sad)</td>
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<tr>
<td>No Anxiety</td>
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<td></td>
<td>Anxiety</td>
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<tr>
<td>(Anxiety = feeling nervous)</td>
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<tr>
<td>Best Wellbeing</td>
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<td></td>
<td>Wellbeing</td>
</tr>
<tr>
<td>(Wellbeing = how you feel overall)</td>
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<tr>
<td>No Other Problem (for example constipation)</td>
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<td></td>
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<td></td>
<td>Other Problem</td>
</tr>
</tbody>
</table>

**Completed by (check one):**
- [ ] Patient
- [ ] Family caregiver
- [ ] Health care professional caregiver
- [ ] Caregiver-assisted
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
Palliative Medicine
A CASE-BASED MANUAL
THIRD EDITION
EDITED BY
DOREEN ONESCHUK | NEIL HAGEN | NEIL MACDONALD
WITH A FOREWORD BY
Dr Derek Doyle

12/411p
3%
NeuroPC
Palliative Care in Amyotrophic Lateral Sclerosis
FROM DIAGNOSIS TO BEREAVEMENT
second edition
EDITED BY DAVID OLIVER | GIAN DOMENICO BORASIO | DECLAN WALSH
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.
How can we support it?

- Establish an on-site service that works in collaboration with existing services of MUHC and McGill Palliative / Supportive Care
- Training and Teaching
- Research
Essence of Supportive Care Service

- Patient and family centred care delivered by a team
- Whole-person care
  - Dedicated Nursing (*Justine Gauthier*)
  - Administrator (*Luisa Birri*)
  - 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 22nd International Congress on Palliative Care, October 2-5th, 2018, Montreal
22nd International Congress on Palliative Care

October 2 - 5, 2018
Palais des Congrès, Montréal, Canada
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
Stroke

- Incidence: 269/100,000
- Prevalence: 980/100,000
- Average age at diagnosis: 56
- Life expectancy: High risk of death in the first month especially for hemorrhagic (63.3%) or subarachnoid (58.6%) stroke compared to ischemic stroke (9%).
Multiple Sclerosis

- Incidence: 8/100,000
- Prevalence: 208/100,000
- Average age at diagnosis: 36
- Life expectancy: 5-10 years less than average population
Parkinson’s Disease

• Incidence: 13/100,000
• Prevalence: 150/100,000
  - 40-49: 40/100,000
  - 50-59: 106/100,000
  - 60-69: 428/100,000
  - 70-70: 1,086/100,000
  - >80: 1,903/100,000
• Average age at diagnosis: 66
• Live expectancy: Same as average
Amyotrophic Lateral Sclerosis

- Incidence: 2/100,000
- Prevalence: 4.4/100,000
- Average age at diagnosis: 55
- Life expectancy: 2-5 years
Traumatic Brain Injury

• Incidence: 500/100,000
• Prevalence: 1M Canadians
• At risk ages: 0-4, 15-19 and >65
• Life expectancy: Leading cause of death (and disability) in people less than 40
Dementia

• Incidence:
  – 65-74: 200/100,000
  – 75-84: 1300/100,000
  – >85: 3700/100,000

• Prevalence: in >65 year 5,234/100,000

• Average age at diagnosis: 74

• Life expectancy: Decreased (fifth leading cause of death in persons 65 and older in US)
FIGURE 4
Projected Number of People Age 65 and Older (Total and by Age Group) in the U.S. Population with Alzheimer’s Disease, 2010 to 2050

<table>
<thead>
<tr>
<th>Millions of people with Alzheimer’s</th>
<th>Ages 65–74</th>
<th>Ages 75–84</th>
<th>Ages 85+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year</td>
<td>2010</td>
<td>2020</td>
<td>2030</td>
</tr>
<tr>
<td>2010</td>
<td>4.7</td>
<td>4.7</td>
<td>4.7</td>
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<tr>
<td>2020</td>
<td>5.8</td>
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<td>2030</td>
<td>8.4</td>
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<tr>
<td>2040</td>
<td>11.6</td>
<td>11.6</td>
<td>11.6</td>
</tr>
<tr>
<td>2050</td>
<td>13.8</td>
<td>13.8</td>
<td>13.8</td>
</tr>
</tbody>
</table>

Created from data from Hebert et al.31,12
Palliative Approach

- Identify sources of suffering in patients and their families and caregivers with specific neurologic diseases
- Undergo training to develop Supportive Care skills in physicians and paramedical staff caring for Neuro patients
- Participate in training of medical students, residents, fellows, nurses and paramedical staff
Practical Management

- Increased intracranial pressure
- Seizures
- Decreased communication
- Serious illness conversations
- Discussions regarding levels of care
Intracranial Pressure (ICP)

- Monro-Kellie Doctrine: the sum of the volumes of intracranial contents (CSF, blood and brain) are constant and bounded by bone
  - an increase in volume in any component must be compensated for by a decrease in another or the ICP will increase
  - as ICP increases symptoms become more severe from headache, nausea and vomiting to decreased level of consciousness, coma, brain death and death
Monro-Kellie Doctrine

Intracranial Pressure vs. Intracranial Volume

- CSF
- Blood
- Mass
- Brain
Elevated ICP - Diagnosis

- Imaging will detect a mass lesion (tumour, blood or pus) or hydrocephalus.
Elevated ICP - Treatment

• Surgical
  • Decompression
  • CSF diversion (shunt, EVD, LP)

• Pharmacologic
  • Dexamethasone
  • Hypertonics (mannitol, 3% NS)
  • Acetazolamide
Elevated ICP - Treatment

- Non-pharmacologic
  - Positioning
    - Elevate HOB
    - No restrictions jugular venous return
Persistent Seizures

• Many patients with neurologic illnesses will have seizures and be taking a variety of anti-epileptic drugs (AEDs)
• Towards the end of life they may not be able to take AEDs orally
  • Sedation protocols for these patients should favour benzodiazepines over antipsychotics and seizure protocols using SQ medications should be available to nursing staff
Definition of Seizure

• Transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain
Epilepsy is a disease of the brain defined by any of the following conditions:

1. At least two unprovoked (or reflex) seizures occurring >24 h apart

2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years

3. Diagnosis of an epilepsy syndrome

Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.
ILAE Seizure Classification

ILAE 2017 Classification of Seizure Types Expanded Version

<table>
<thead>
<tr>
<th>Focal Onset</th>
<th>Generalized Onset</th>
<th>Unknown Onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor Onset</td>
<td>Motor</td>
<td>Motor</td>
</tr>
<tr>
<td>aware</td>
<td>tonic- clonic</td>
<td>tonic- clonic</td>
</tr>
<tr>
<td>Impaired Awareness</td>
<td>clonic</td>
<td>epileptic spasms</td>
</tr>
<tr>
<td></td>
<td>myoclonic</td>
<td>myoclonic- tonic- clonic</td>
</tr>
<tr>
<td></td>
<td>myoclonic- tonic- clonic</td>
<td>myoclonic- atonic</td>
</tr>
<tr>
<td></td>
<td>epilepsy spasms</td>
<td>epilepsy spasms</td>
</tr>
<tr>
<td></td>
<td>Nonmotor (absence)</td>
<td>Nonmotor</td>
</tr>
<tr>
<td></td>
<td>typical</td>
<td>behavior arrest</td>
</tr>
<tr>
<td></td>
<td>atypical</td>
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<tr>
<td></td>
<td>myoclonic</td>
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<tr>
<td></td>
<td>eyelid myoclonia</td>
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<tr>
<td></td>
<td>focal to bilateral tonic- clonic</td>
<td>Unclassified</td>
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</tr>
</tbody>
</table>

1. See text for details.
2. See text for details.
3. See text for details.
Terms no longer in use

- Complex partial
- Simple partial
- Partial
- Psychic
- Psychomotor
- Dyscognitive
- Secondary generalized tonic-clonic
Less common but important seizure patterns in EOL care

- Epilepsia partialis continua
- Non-convulsive status
- Prolonged post-ictal confusion
Seizure Protocol

• Lorazepam 1-2 mg PO/SL/SQ for 3 or more focal seizures or one generalized seizure repeat Q 15 minutes until seizures stop OR
• Midazolam 2,5-5mg SQ Q15 minutes until seizures stop
  • If seizures continue:
  • Phenobarbital 30-60 mg SQ
    • If seizures continue:
    • Continuous IV or SQ sedation
Decreased communication

- Practically speaking this is a hallmark of most patients with neurologic illness at some point in their disease trajectory
- Even experienced clinicians are often uncomfortable with the assessment and treatment of these patients
- FIGHT DISCRIMINATION OF THE DOMINANT HEMISPHERE!
Dominant hemisphere

- For the vast majority of patients the left hemisphere is critical to language comprehension and production.
- Neurologic illnesses which primarily affect this hemisphere pose unique challenges and we must remain vigilant to avoid deferring to family.
  - Inability to communicate verbally does not necessarily imply globally impaired cognition.
  - Memory and understanding may be intact.
Jill Bolte Taylor got a research opportunity few brain scientists would wish for: She had a massive stroke, and watched as her brain functions -- motion, speech, self-awareness -- shut down one by one. An astonishing story.
How to overcome hemispheric discrimination?

• Spend the same amount of time (or maybe even more) in the presence of patients with impaired communication to establish rapport
Serious Illness Conversation

Sometimes, even if I stand in the middle of the room, no one acknowledges me.
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 (6).
• 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 (7).
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 – For MDs

- 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

Lakin et al. (2016). Improving communication About Serious Illness in Primary Care: A Review. *JAMA Internal Medicine, 176*(9), 1380-1387.
Levels of care and cardiopulmonary resuscitation form

- To be used by all patients in the province of Quebec.
- Implemented at the MUHC in May, 2018
# Levels of Care and Cardiopulmonary Resuscitation

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

### Revision 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
- [ ] Competent
- [ ] Incompetent
- [ ] Homologated mandate
- [ ] Public/private curator

- [ ] Minor under 14 years old
- [ ] Name of tutor, relationship with user:

#### Previous Advance Wishes
- [ ] None available
- [ ] Prior Level of Care Form
- [ ] Advance Medical Directives
- [ ] Living Will or Other

### Levels of Care: Check and Provide Details in the Box Below

<table>
<thead>
<tr>
<th>Goal</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Probing life with all necessary care</td>
</tr>
<tr>
<td>B</td>
<td>Probing life with some limitations to care</td>
</tr>
<tr>
<td>C</td>
<td>Ensure comfort as a priority over prolonging life</td>
</tr>
<tr>
<td>D</td>
<td>Ensure comfort without prolonging life</td>
</tr>
</tbody>
</table>

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

### Cardiopulmonary Resuscitation (CPR): Check and Provide Details in the Box Below

#### 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

<table>
<thead>
<tr>
<th>Discussed with</th>
<th>User</th>
<th>Representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Relationship</td>
<td></td>
</tr>
</tbody>
</table>

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 (day, month, year) |

### 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 (day, month, year) |

### User’s File

### Physician’s Copy
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.

<table>
<thead>
<tr>
<th>Goal A</th>
<th>Prolong life with all necessary care</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Care includes all interventions that are medically appropriate and transfer(^1) if the intervention is not available in the current setting.</td>
<td></td>
</tr>
<tr>
<td>• All invasive interventions can be considered, including, for example, intubation and intensive care.</td>
<td></td>
</tr>
<tr>
<td>• 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 when appropriate.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Goal B</th>
<th>Prolong life with some limitations to care</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Care incorporates interventions with the aim of prolonging life, which offer the possibility of correcting deterioration in health status while preserving quality of life.</td>
<td></td>
</tr>
<tr>
<td>• 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.</td>
<td></td>
</tr>
<tr>
<td>• 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).</td>
<td></td>
</tr>
<tr>
<td>• 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).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Goal C</th>
<th>Ensure comfort as a priority over prolonging life</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The user’s comfort is prioritized through the management of symptoms.</td>
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</tr>
<tr>
<td>• Interventions which may prolong life are used as needed in order to correct certain reversible health problems, if 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 pneumonitis).</td>
<td></td>
</tr>
<tr>
<td>• 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).</td>
<td></td>
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<tr>
<td>• 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).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Goal D</th>
<th>Ensure comfort without prolonging life</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Care is exclusively aimed at maintaining comfort through the management of symptoms (e.g., pain, trouble breathing, constipation, anxiety).</td>
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<tr>
<td>• Interventions do not aim to prolong life; illness is left to its natural course.</td>
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<tr>
<td>• 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 infections).</td>
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</tr>
<tr>
<td>• 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).</td>
<td></td>
</tr>
<tr>
<td>• In the prehospital setting, unless otherwise advised by the user or his/her representative, the following protocols apply: oxygenation, salbutamol, nitroglycerin (chest pain) and glucagon. For respiratory distress in a conscious user, assisted respiration(^3) (CRIP) can be used unless refused. Intubation and assisted ventilation(^2) are excluded. Maneuvers to clear an obstructed airway in a living user can be carried out.</td>
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</tbody>
</table>

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.

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1. The term "transfer" implies moving the user to a setting that is different from his/her current environment (e.g., 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 (NIV) or CPAP in a conscious user.
3. Assisted respiration is carried out via non-invasive techniques (CRIP) in a conscious user.
4. The sense of the term "disproportionate" or "unacceptable" is based on subjective perceptions and varies from user to user and over time.
5. The words used by the user or his/her representative are important to record in the box provided for this purpose.
Pamphlet available to patients in English and French

CARE OBJECTIVES, LIFE OBJECTIVES
A discussion about levels of care aims to facilitate communication when the time comes to make decisions about the care and treatment that a seriously ill person wishes to receive, or not receive.

At the end of this conversation between the doctor and the patient, four options may be considered:

Prolong life with all necessary care
The health care team will perform all medically appropriate interventions, and may transfer the patient if the intervention cannot be done on site.

Prolong life with some limitations to care
The interventions carried out aim to reverse the deterioration of the patient’s health while preserving his or her quality of life.

Ensure comfort as a priority over prolonging life
The care provided primarily aims to ensure the patient’s comfort by relieving symptoms. Interventions aiming to correct reversible health problems may also be performed.

Ensure comfort without prolonging life
The care provided essentially aims to ensure the patient’s comfort and relieve symptoms.

Cardiopulmonary resuscitation
During the discussion about levels of care, the doctor will also raise the issue of resuscitation in the event of cardiorespiratory arrest (CRA).

Do you want someone to attempt to resuscitate you in the event of cardiorespiratory arrest?
This is an important question because in this kind of emergency situation, the medical team must make quick decisions and will not be able to consult you.

Your decision regarding resuscitation in the event of cardiorespiratory arrest is also recorded on the form that states your choice regarding levels of care.

You may obtain a copy of this form to keep on hand at your place of residence. Ambulance attendants will be able to consult it in the event of an emergency intervention.

Your decisions regarding levels of care and cardiopulmonary resuscitation are not final. You may change your mind at any time and modify your choices. After discussion with your doctor, a new form indicating your new choices will replace the old form.

This process does not replace consent. This is why the health care team must always have your consent before treating you, except in exceptional emergency situations.

Whatever decisions you make, you are always free to consent to, or refuse, treatment.

TO START THE DISCUSSION:
- If you think the time has come to discuss levels of care for yourself or for a loved one, talk to a doctor.
- If, for example, a critical situation arises or you are hospitalized, you can ask the care personnel whether it is a good time to start talking about these decisions.
- If this is the case, the doctor will explain how likely it is that your health will improve as well as treatment options and their chances of success, their drawbacks and side effects.
- This information will allow the doctor to guide you in choosing the care objectives and level of care (A to D) that suit you best.
- The doctor will then fill out a form, noting the decisions made during the discussion. He or she will also record your wishes regarding whether to attempt cardiopulmonary resuscitation (CPR), if necessary. Finally, he or she will sign the form and place it in your medical record so that the health care team can act accordingly.
- A copy of the completed form may also be taken to your place of residence so that this information will be accessible to ambulance attendants, who will then be able to make quick decisions that respect your wishes.
- A standard “Levels of Care and Cardiopulmonary Resuscitation” form is available at all Quebec health care facilities.
- In addition to getting advice from your doctor, a nurse or a social worker, you can get information on this process from the users’ committee of your health care facility.
Thank you
References


