INTRODUCTION TO PALLIATIVE CARE

WORKBOOK

Name: __________________________________________________
About the Program

This program is a structured education course for nurses caring for people requiring palliative care in a variety of settings. The main goal of this program is to provide nurses and allied health with an overview of the essence of palliative care along with some resources for providing care with a palliative approach to patients in any setting. The resources within this package are assembled from many supportive websites to assist those interested in developing their knowledge about evidence based practice. This course is part of a suite of courses that build capacity within the staff of CISS to feel confident providing care with a palliative approach.

WHO IS THE COURSE FOR?

The introductory program encourages nurses and allied health to be mindful in regard to palliative care principles when providing care and symptom management for patients with a life limiting illness.

WHO DEVELOPED THE COURSE?

The program has been developed specifically for CISS Staff by the experienced Nursing, Medical and Multidisciplinary staff working in the Palliative Care Units with the Nurse Educator.

PROGRAM:

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PART 3: End of life care ..................................................................................... page 18
PART 4: Symptom Management: Breathlessness, Gastrointestinal & Delirium .......... page 22
PART 5: Grief, loss, coping and communication ............................................... page 42
PART 6: Writing reflections ............................................................................... page 50

COMPLETING THE PROGRAM

There are face to face sessions along with a workbook. When participants have completed their workbooks they can submit flagged reflections to CISS-Education@health.qld.gov.au for marking. Once marked, certificates and CPD points will be awarded. For further information contact 07 36317437. You can submit your reflections to CISS-Education@health.qld.gov.au to Cecelia Boyd Orford.
PART 1: INTRODUCTION TO PALLIATIVE CARE

OBJECTIVES

On completion of this session participants will be able to:

- Identify various illness trajectories of people needing palliative care
- Understand specific health care needs of people with various illness trajectories
- Develop an individualized care plan centered around the individual needs
- Reflect on own practice about assessment

Definition of Palliative Care

Palliative Care is a term used in a number of ways. Traditionally, palliative care was aligned with end of life care or hospice particularly for people with terminal cancer diagnosis. As the practice has grown, application of palliative care has occurred. There are a number of different definitions of palliative care that are used both within Australia and internationally. For example, ‘hospice’, ‘end-of-life care’, ‘early palliative care’, ‘palliative care for the aged’, ‘health promoting palliative care’ and ‘specialist palliative care’ have all been used interchangeably with ‘palliative care’. Hence, there are a variety of definitions are used based on the application of the term.

The World Health Organisation (WHO) defines Palliative care as:

“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care should be considered as an approach in all health care settings, including intensive care units, oncology, haematology, neonatal units, rehabilitation, cardiothoracic, transplantation, paediatric services, acute hospitals, general practices, residential aged care services, and community services.
SUBMIT REFLECTION 1: Based on your experience, what does palliative care mean to you?

The National Palliative Care Strategy

The National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life represents the combined commitments of the Australian, state and territory governments, palliative care service providers and community based organisations. It guides the development and implementation of palliative care policies, strategies and services across Australia. The Strategy has four goal areas:

Awareness and Understanding
- To significantly improve the appreciation of dying and death as a normal part of the life continuum.
- To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services.

Appropriateness and Effectiveness
- Appropriate and effective palliative care is available to all Australians based on need.

Leadership and Governance
- To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.

Capacity and Capability
- To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

Providing Palliative Care in Australia

According to the health strategy, over 130,000 people die each year in Australia. Many of these deaths will be expected as a result of serious illness, advancing chronic disease or old age. For people with progressive life limiting illness, palliative care is an appropriate framework and model of care as it is pro-active and supportive of providing patient centred care and quality of life.

Palliative care is a multidisciplinary approach, where team members communicate and coordinate care for the benefit of clinical outcomes. Not all people with a life limiting illness need specialist palliative care and many may only require consultation.
SUBMIT REFLECTION 2: What are the 4 goal areas of the National palliative care strategy for Australia? Write one application of this standard to your work area.

Example: Capacity and Capability During a ward inservice, we discussed palliative care for our patients and how we can work together to improve quality of life for people with end stage disease.

Patient Management
Assessment and management of physical symptoms is a major focus of palliative care, as poorly controlled symptoms can seriously affect a patient's quality of life. It can also reduce their ability to maintain physical functioning which then affects all aspects of their daily life.

The definitions of palliative care from the World Health Organization and Palliative Care Australia recognise that suffering may not only be physical, and that care needs to include psychological, spiritual and social care and support. Providing comprehensive care requires an understanding of the specific needs and circumstances of the individual patient.

In order to provide effective and appropriate management of symptoms, careful assessment needs to be performed. Effective symptom assessment needs to include measurement of both incidence and severity. A validated scale should be used, the symptom assessment scale used in the Palliative Care Outcomes Collaborative or Symptom Distress Scale are examples of tools to effectively measure symptoms.

REFLECTION: How has this session made me feel about my practice and how I perform assessments?
ACTIVITY: Read the case study and use both symptom measurement scales to collect the data. Discuss in the group.

Case study 1: Assessment Read the SBAR and complete a quick assessment of the patient using the symptom distress scale

<table>
<thead>
<tr>
<th>I: Jarrah Kaffay (DOB 13/1/84) has a diagnosis of non-small cell lung cancer with secondaries. He was recently discharged from the oncology ward, but been unwell over the past two days.</th>
</tr>
</thead>
<tbody>
<tr>
<td>S: Jarrah has been admitted to your unit for immediate symptom control.</td>
</tr>
<tr>
<td>B: 2 years ago Jarrah was diagnosed with NSC lung cancer and treated with chemotherapy and radiotherapy with a reasonable recovery. In the past six months, he suffered shortness of breath and was found to have secondary lung cancer and had treatment of opdivo infusions with little clinical outcome. Currently he is in palliative care and being cared for at home by his wife.</td>
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<tr>
<td>A: He states he feels nausea, pain, headaches, bloated, fatigue and insomnia. When he looks at you he avoids eye contact and seems quite uninterested in the whole discussion. He is obviously short of breath as he stops to try to catch his breath while talking (RR32).</td>
</tr>
<tr>
<td>R: Please complete his assessment using the Symptom distress scale. See attachment.</td>
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</table>

When he is asked about the following items he answers them as follows.

1. **Fatigue**, he says it is extreme, beyond scale measurements and yet he cannot sleep – he is awake most of the day and night.

2. **Pain**, he winces and holds his head. His headaches are about a 6/10 when severe, but they come and go. Medication doesn’t make a difference. He has leg pain most of the time – around 2/10.

3. **Bowels and digestion**: He can never eat a whole meal, often feels nauseated and always feels bloated. His abdomen swells out often and he sometimes has constipation.

4. **His emotions**: he says it’s all ok. His wife shakes her head and says, no its not, you don’t ever get excited about anything anymore. It’s like you have lost interest in everything. You don’t like doing anything much like you used to, not even TV or reading.

Notes:

__________________________________________________________________________________

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__________________________________________________________________________________
Assess on admission, daily, at phase change and on discharge

<table>
<thead>
<tr>
<th>Year</th>
<th>Time</th>
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<tbody>
<tr>
<td>2021</td>
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</table>

**Phase of Illness [1-4 Died or D/C] Refer to complete definition**
- **Stable** = Monitor
- **Unstable** = Urgent action required
- **Deteriorating** = Review plan of care
- **Terminal** = Provide EOL care
- **Died** = record date, no further assessment required
- **Discharge (D/C)** = assess at discharge

**Phase of Illness**

<table>
<thead>
<tr>
<th>RUG-ADL Refer to complete definition</th>
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<tbody>
<tr>
<td>4-5 = Monitor</td>
</tr>
<tr>
<td>6-10 = assist x 1</td>
</tr>
<tr>
<td>10+ = assist x 1, consider equipment, staff requirements, falls risk, referral</td>
</tr>
<tr>
<td>15+ = as above, pressure area risk, consider carer burden and MDT review</td>
</tr>
<tr>
<td>18 = as above, full care assistance x 2</td>
</tr>
</tbody>
</table>

**Bed mobility**

**Toileting**

**Transfers**

**Eating**

**Total RUG ADL (4-18):**

**Problem Severity Score Actions (0-3) Refer to complete definition and rate each domain**
- **Pain**
- **Other Symptoms**
- **Psychological /**
- **Family / Carer**

**Australia-modified Karnofsky Performance Status Scale (100-10) Refer to complete definition**
- Consider MDT review at score of 40 or below

**AKPS**

**Symptom Assessment Scale (0-10) Rate experience of symptom distress over a 24hr period**
- **Distress from difficulty sleeping**
- **Distress from Appetite**
- **Distress from Nausea**
- **Distress from Bowels**
- **Distress from**
- **Distress from Fatigue**
- **Distress from Pain**
- **Completed by Patient Fam/Carer or Clinician**

Completed by:**
- Patient
- Fam/Carer
- Clinician

Staff Initials
### Palliative Care Phase of Illness

<table>
<thead>
<tr>
<th>Clinician rated assessment</th>
<th>Abbreviated Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>Symptoms are adequately controlled by established management</td>
</tr>
<tr>
<td>Unstable</td>
<td>Development of a new problem or a rapid increase in the severity of existing problems</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>Gradual functional decline and worsening of existing symptoms or the development of new but expected problems</td>
</tr>
<tr>
<td>Terminal</td>
<td>Death likely in a matter of days</td>
</tr>
</tbody>
</table>

Complete Phase Definitions available on the PCOC website www.pcoc.org.au

### Resource Utilisation Group – Activities of Daily Living

<table>
<thead>
<tr>
<th>Clinician rated assessment of dependency over 24hr period Complete RUG-ADL definitions available on the PCOC website <a href="http://www.pcoc.org.au">www.pcoc.org.au</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>For Bed Mobility, Toileting &amp; Transfers</td>
</tr>
<tr>
<td>1. Independent or supervision only</td>
</tr>
<tr>
<td>2. Limited physical assistance</td>
</tr>
<tr>
<td>3. Other than two person physical assist</td>
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<tr>
<td>4. Two or more person physical assist</td>
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</tbody>
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### Problem Severity Score

<table>
<thead>
<tr>
<th>Complete Definition</th>
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</thead>
<tbody>
<tr>
<td>Clinician rated assessment of problems over a 24hr period</td>
</tr>
</tbody>
</table>

Global assessment of four palliative care domains to summarise palliative care needs and plan care.

The severity of problems are rated and responded to following using the scale:

- 0 = Absent; 1 = Mild; 2 = Moderate; 3 = Severe

**Pain:** overall severity of pain problems for the patient

**Other Symptoms:** overall severity of problems relating to one or more symptoms other than pain

**Psychological / Spiritual:** severity of problems relating to the patient’s psychological or spiritual wellbeing. May be one or more issues.

**Family / Carer:** problems associated with a patient’s condition or palliative care needs. Family / Carer do not need to be present to assess needs as written, verbal or observational information may be used.

### Australia-modified Karnofsky Performance Status

<table>
<thead>
<tr>
<th>Complete Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinician rated assessment of performance relating to work, activity and self-care over a 24hr period</td>
</tr>
</tbody>
</table>

100. Normal, no complaints or evidence of disease

90. Able to carry on normal activity, minor signs or symptoms of disease

80. Normal activity with effort, some signs or symptoms of disease

70. Care for self, unable to carry on normal activity or to do active work

60. Occasional assistance but is able to care for most needs

50. Requires considerable assistance and frequent medical care

40. In bed more than 50% of the time

30. Almost completely bedfast

20. Totally bedfast & requiring nursing care by professionals and/or family

10. Comatose or barely rousable

### Symptom Assessment Scale

<table>
<thead>
<tr>
<th>Complete Definition</th>
</tr>
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<tbody>
<tr>
<td>Patient Rated distress relating to symptoms over a 24hr period</td>
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</tbody>
</table>

The Symptom Assessment Scale describes the patient’s level of distress relating to individual physical symptoms. The symptoms and problems in the scale are the seven most common. **Usage:**

1. Best practice is for the patient to rate distress either independent or with the assistance of a clinician or family/carer using a visual of the scale such as the Symptom Assessment Scale Form for Patients.

2. Symptom distress may be rated by proxy. This only occurs when the patient is unable to participate in conversation relating to symptom distress i.e. Terminal phase.

**Proxy:** a family / carer or clinician who rates symptom distress on behalf of the patient though observational assessment. Use the following
codes to describe Patient = Pt, Fam/Carer = FC or Clinician = Cl

Instructions: patient to consider their experience of the individual symptom or problem over the last 24 hours and rate distress according to

A score of 0: means the symptom or problem is absent
A score of 1: means the symptom or problem is causing minimal distress.
A score of 10: means the symptom or problem is causing the worst possible distress.

Resources

Books:


National Palliative Care Project websites

Palliative Care Curriculum for Undergraduates

PC4U project aims to promote the inclusion of palliative care education in all medical and allied health care training through the provision of student and facilitator learning resources and professional development activities.

Program of Experience in the Palliative Approach

PEPA provides palliative care workplace training opportunities and workshops for a range of health care professionals.

Palliative Care Training and Information Online Portal

Australian Healthcare and Hospitals Association (AHHA) provide palliative care training, including training on the guidelines for a Palliative Approach for Aged Care in the Community Setting as well as the development of an information on-line portal.

Palliative Care Outcomes Collaboration

PCOC provides a national network for palliative care services to assist with the collection of information and reporting outcomes.

Palliative Care Australia

PCA is the peak national organisation for palliative care and end of life issues in Australia.

Respecting Patient Choices
The RPC program is a comprehensive advance care planning training program for health professionals, that aims to ensure patients' choices about their end of life care are respected.

**Carers Australia**

Carers Australia is the national peak carer organisation funded to train counsellors and other people to better support carers who are caring for someone in palliative care.

**Australian Institute of Health and Welfare**

Provides reliable, regular and relevant information and statistics on Australia's health and welfare-including Palliative Care.

**The Australian Palliative Care Knowledge Network - CareSearch**

CareSearch is a website that includes a searchable database of palliative care literature and online forums that allow groups to share research, reports and information.

**The Palliative Care Clinical Studies Collaborative**

PaCCSC is a groups of palliative care units throughout Australia which to gather the evidence required to support further Pharmaceutical Benefits Scheme (PBS) listings.

**Tasmanian Health Assistance Package** This package includes better access to community based palliative care and advance care planning.

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**Preparation for next session.**


**Reflect:** How can you use this in your practice?

**Watch:** Pick a few of the videos in the Palliative Care Bridge.

**Reflect:** Once you have watched them, identify areas you are interested in learning more about.
## Symptom Distress Scale

**Date completed:** ____/____/____

**Instructions to complete assessment:** Below are 5 different numbered statements. Think about what each statement says, then place a circle the statement that most closely indicates how you have been feeling lately. The statements are ranked from 1 to 5, where number 1 indicates no problems and number 5 indicates the maximum amount of problems. Numbers 2 through 4 indicate you feel somewhere in between these two extremes.

### Nausea (1)

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I seldom feel nauseous</td>
<td>I have nausea once in a while</td>
<td>I have nausea fairly often</td>
<td>I have nausea half the time at least</td>
<td>I have nausea continually</td>
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### Pain (1)

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<tr>
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<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I almost never have pain</td>
<td>I have pain once in a while</td>
<td>I have pain several times a week</td>
<td>I am usually in some degree of pain</td>
<td>I am in some degree of pain almost constantly</td>
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</table>

### Fatigue

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<tr>
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<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>1</td>
<td>I seldom feel tired or fatigued</td>
<td>There are periods when I am rather tired or fatigued</td>
<td>There are periods when I am quite tired and fatigued</td>
<td>I am usually very tired and fatigued</td>
<td>Most of the time, I feel exhausted</td>
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### Bowel

<table>
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<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>1</td>
<td>I have my normal bowel pattern</td>
<td>My bowel pattern occasionally causes some discomfort</td>
<td>My bowel pattern occasionally causes me considerable discomfort</td>
<td>I am usually in considerable discomfort because of my present bowel pattern</td>
<td>I am in almost constant discomfort because of my bowel pattern</td>
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### Appetite

<table>
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<tr>
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<th>1</th>
<th>2</th>
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<th>5</th>
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<tbody>
<tr>
<td>1</td>
<td>I have my normal appetite and enjoy good food</td>
<td>My appetite is usually, but not always, pretty good</td>
<td>I don’t really enjoy my food</td>
<td>I have to force myself to eat my food</td>
<td>I cannot stand the thought of food</td>
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</table>

### Concentration

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<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I have my normal ability to concentrate</td>
<td>I occasionally have trouble concentrating</td>
<td>I occasionally have considerable trouble concentrating</td>
<td>I usually have considerable difficulty concentrating</td>
<td>I just can’t seem to concentrate at all</td>
</tr>
</tbody>
</table>


**Instructions to interpret assessment:** The presence of any symptom should be discussed with your health professional (2 or above). The more intense these are (3 and above), the more it may become urgent for you to discuss these with your health professionals.
PART 2: Pain Assessment and Management

OBJECTIVES

On completion of this session participants will be able to:

- Define pain in context to palliative care settings
- Understand specific health care needs of people experiencing pain
- Develop an individualized care plan centered around the individual needs
- Reflect on own practice about caring for a person experiencing pain

**Definition:** In your own words write out a definition of pain for people in palliative care.

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**Key messages about pain** as identified from CareSearch 2016.

1. The majority of pain in palliative care patients can be effectively treated with available drugs and best practice management strategies, which includes regular assessment of pain with validated assessment tools.

2. A comprehensive approach to cancer pain begins at diagnosis, should be mechanism-based and multimodal, and must be tailored to the individual patient.


4. Oral morphine, oxycodone and hydromorphone all have similar efficacy and toxicity in opioid naïve cancer patients. According to updated recommendations from the European Association of Palliative Care, any of these opioids can be used as first line strong opioids.

5. Provision of “around the clock” coverage by long-acting strong opioids with availability of “as needed” doses of immediate release opioids continues to be recommended as best practice for moderate to severe cancer pain. The use of pre-emptive doses of immediate release opioids may also sometimes be appropriate for predictable episodes of breakthrough pain.
6. Recent evidence-based guidelines for neuropathic pain suggest that two groups of medications may be used as first line adjuvant treatment – of the antidepressants, either tricyclics, or duloxetine or venlafaxine, and of the anticonvulsants, either gabapentin or pregabalin. Of these, amitriptyline and gabapentin are the two agents recommended for neuropathic pain in recent guidelines from the European Association of Palliative Care. Opioids are also effective in neuropathic pain, and may be co-administered as first line treatments, alongside adjuvants.

These key messages are important when planning care, assessment, delivery and evaluation of care. Identify any words or concepts that you might not fully understand and make a point of exploring them further.

For patients receiving palliative care, maintaining relationships and continuing normal daily activities are just as important, if not more so, than symptom control. This premise is the cornerstone of successful palliative care.

Rod, Conjoint Professor of Palliative Care at the University of Sydney and Senior Staff Specialist in palliative care for HammondCare
Dr Rod’s Key Messages
- Adopt a systematic whole person approach to total pain assessment and management
- Administer regular analgesia in accordance with the WHO analgesic ladder
- Use appropriate adjuvant therapies as specifically indicated at any time during the illness
- Liaise with the Palliative Care team as soon as it becomes apparent that specialist advice may be needed
- Maintain involvement with the patient throughout their illness
This week’s workbook is accompanied by an information pack on pain management in palliative care by Hammond Care. Take the time to read through the pack and make notes of how this information will inform your practice.

**My notes:**

Pain assessment in palliative care

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### Painful stimuli

Heavy reliance on analgesics without the use of other appropriate interventions may produce pain relief at the cost of significant loss of quality of life.

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### Identifying the sources of painful stimuli

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### Pain perception

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### Pain interpretation

“How do you rate the severity of the pain on a scale of 0 to 10 with 10 being the worst pain you could ever imagine?”
“What does this pain mean to you?”
Impairment that accompanies ongoing pain

“What is the worst thing about the pain?”

SUBMIT Reflection 3: Syringe drivers in palliative care: what are the main ways we administer medication and the common pumps used? Why do we not use sterile water in syringe drivers for Subcutaneous infusions?

Useful resources


Cherny NI, Radbruch L; Board of the European Association for Palliative Care. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliat Med. 2009 Oct;23(7):581-93. (408kb pdf)


Preparation for next session.

PART 3: END OF LIFE

OBJECTIVES
On completion of this session participants will be able to:
- Define end of life care and its importance in palliative care settings
- Understand specific health care needs for the dying patient and their family
- Develop an individualized care plan centered around the individual’s needs
- Reflect on own practice about caring for a person at the end of their life.

Key Messages
- It is essential to identify the dying patient in order to allow them & their care givers to reorient their priorities, achieve their goals, and so that appropriate end-of-life care can be provided. [1-3]
- Best practice in end-of-life care focuses on supporting both the patient and their family. [4]
- End-of-life care attends not just to the physical but also the psychosocial and spiritual concerns of patients and their families, and extends into the bereavement period. It requires very good communication and teamwork from health care professionals. [3,5-7]
- Physical problems that must be anticipated and proactively addressed for the comfort of the dying person include pain, delirium / agitation, dyspnoea, respiratory secretions, mouth and skin care, bladder and bowel care, and nausea and vomiting. Burdensome interventions which do not improve the dying person’s comfort should also be ceased whenever possible.

Evidence:

Principles of Good End-of-Life Care

Good end-of-life care is based on the understanding that death is inevitable, and a natural part of life. As the final stage in a person’s life it is a uniquely important time for the dying person and their family and close friends.

The goals of end-of-life care are: to maintain the comfort, choices, and quality of life of a person who is recognised to be dying (in the terminal phase); to support their individuality;
and to care for the psychosocial and spiritual needs of themselves and their families. Support for families, if needed, continues after death as bereavement care. End-of-life care also aims to reduce inappropriate and burdensome healthcare interventions and to offer a choice of place of care when possible.

What is known

There is a body of good evidence (mostly from the USA) which suggests that the factors that are most important to patients and families at the end of life are:

- Pain and symptom management
- Preparation for the end of life
- Relationships between patients, family members and healthcare providers
- Achieving a sense of completion. [1-2]

Spiritual care is regarded as important by many patients and families at the end of life. [3-5] Cultural differences also need to be identified and appropriately addressed. [6]

The concept of satisfaction with end-of-life care has been studied in a recent systematic review. A number of aspects of patient and family satisfaction with care are identified in the literature; they are - accessibility, co-ordination, and competence of health care services, quality of communication and relationships with health care providers, personalisation of care, and support for decision-making. A meta-analysis of studies of end-of-life care showed that palliative care services improved satisfaction with end of life care. [7]

Shared decision-making between clinicians and patients and their families is possible when all have an awareness of the patient’s approaching death. It increases the likelihood of a good death - one in which the patient’s needs, wishes and preferences can be addressed. [8] Reluctance by either clinicians or family to disclose information about a patient’s changing condition can worsen patient distress. Supporting patients’ and families’ acceptance of the inevitability of death is acknowledged as a central part of end-of-life care. [9] Discussing changing goals of care is an important part of this process. [10] The most common goals of care identified by patients as they approach the end of life are: to be cured; to live longer; to improve or maintain functionality / quality of life / independence; to be comfortable; to achieve life goals; and support for family / caregiver. [11] These goals may shift as patients become increasingly aware that their death is imminent.

Advance care planning aims to encourage people to consider, discuss, and document their future wishes for care – well in advance if possible. The impact of advance care planning is mixed, and uptake of advance care planning processes has not been widespread. In a very large US study of the impact of advance care planning on complex hospital care at the end of life, the SUPPORT trial, it appears that advance care planning did not significantly affect outcomes. However, there is also evidence from the SUPPORT study that a substantial minority of seriously ill patients wish to discuss their treatment preferences, and may not have the opportunity to do so. [12]

What it means in practice
The most effective end-of-life care is provided when there is skilful communication with patients and families about realistic goals of care, and attention to understanding the patient’s and family’s concerns [13-14] as well as competent symptom management.

In order to achieve the goals which are important to patients and families, and to provide good end-of-life care, it is essential to identify that a patient is imminently dying. [15]

It is sometimes difficult to identify when a person is close to the terminal phase with a prognosis of days to weeks but, where this is possible, this knowledge may be of great value to patients so that they can reorient their priorities. [15]

SUBMIT REFLECTION 4: Outline the symptoms you might observe in the final hours of life and then identify the cares you may provide to the individual and their family.

Evidence


PART 4: SYMPTOM MANAGEMENT
Delirium, respiratory and gastrointestinal

OBJECTIVES
On completion of this session participants will be able to:

- Define each symptom in context to palliative care settings
- Understand specific health care needs of people experiencing symptoms
- Develop an individualized care plan centered around the individual needs
- Reflect on own practice about caring for a person experiencing distressing symptoms

DELIRIUM

DEFINITION (CareSearch)
Delirium is defined as a condition of disturbed consciousness, with reduced ability to focus, sustain or shift attention. The DSM IV - revised diagnostic criteria [1] for delirium require
- altered cognition or a perceptual disturbance (which is not better accounted for by dementia),
- symptoms develop over hours to days and tend to fluctuate during the course of the day, and
- evidence of an aetiologial cause for the delirium.

SPECIFICS of Delirium in palliative care settings (Dr James Stevenson)
Always look for more than one cause. Single cause only in <30% of cases.

Neurotransmitter Derangements (Many causes linked to this idea)

Too much dopamine, or too little acetylcholine (Ach) – the cholinergic hypothesis

ACTIVITY: Review the role of dopamine and Ach and neurotransmitters.
COMMON CAUSES

**Drug Withdrawal:** Alcohol, nicotine, corticosteroids, benzodiazepines, opioids

**Metabolic:** Fever, dehydration, uraemia, ↓O₂, ↑Ca⁺⁺, ↑Na⁺, ↓Na⁺, ↓glucose, hepatic encephalopathy

**Structural:** Brain tumour – 1° or 2°, CVA/TIA, advanced age, pre-existing dementia, postictal, previous delirium, cerebral hypoperfusion – i.e. ↓BP

**Infectious:** UTI, respiratory, cellulitis – think s/cut and IV sites, viral, CNS, embolic abscesses

**Haematological:** Anaemia, disseminated intravascular coagulation

**Physical:** Unrelieved pain and other symptoms, sleep deprivation, urinary retention, constipation/faecal impaction

**Environmental:** Change of environment, noisy ward, change of routine e.g. different sleep pattern

**Nonphysical:** Spiritual, emotional, psychological, psychiatric

**Medications cause delirium**

*Drugs often can be the underlying reason someone is experiencing delirium.* (commonest drug cause is polypharmacy, not morphine)

<table>
<thead>
<tr>
<th>Anticholinergic agent</th>
<th>atropine, hyoscine, glycopyrronium, propantheline oxybutinin, tricyclic antidepressants (amitriptyline)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticholinergic properties</td>
<td>antihistamines, benzodiazepines, barbiturates antiparkinsonian, carbemazepine, corticosteroids</td>
</tr>
<tr>
<td>Common medications</td>
<td>frusemide, digoxin, ranitidine/cimetidine, warfarin, theophylline, nifedipine, NSAIDs, antibiotics (quinolones – ciproxin), aciclovir</td>
</tr>
<tr>
<td>Opioids</td>
<td>always think of more than this, unlikely if not opioid naïve, no opioid can claim to be totally innocent (e.g. fentanyl)</td>
</tr>
</tbody>
</table>
INVESTIGATIONS

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Laboratory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Temperature, pulse, blood pressure</td>
<td>Review recent tests first the answer may already be there comparison is</td>
</tr>
<tr>
<td>Blood glucose level (what is normal for this person?)</td>
<td>more informative than single result</td>
</tr>
<tr>
<td>Pulse oximetry – dyspnoea ≠ ↓O2,</td>
<td>Haematological Hb, white cell count, Coagulation profile – for DIC</td>
</tr>
<tr>
<td>Ward test urine</td>
<td>Biochemical Electrolytes – Na⁺, K⁺ Confirm glucose, Renal function,</td>
</tr>
<tr>
<td>Rectal examination</td>
<td>Hepatic function, Minerals – Ca++, Mg++</td>
</tr>
</tbody>
</table>

Infectious

Midstream urine culture, Sputum, Blood culture Chest x-ray

Pharmacological

Digoxin Anticonvulsants – phenytoin, valproate, carbamazepine

Less common tests

Thyroid function, Vitamins – B1 (thiamine), B12, CT Brain

List some features of delirium

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Clinical diagnosis of delirium</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Onset</td>
</tr>
<tr>
<td>Delirium</td>
<td>Sudden; hours to days</td>
</tr>
<tr>
<td>Dementia</td>
<td>Insidious; usually over months to years</td>
</tr>
<tr>
<td>Depression</td>
<td>Usually over months to years</td>
</tr>
</tbody>
</table>

Queensland Health CISS Education | 25
What it means in practice

- ENVIRONMENTAL FACTORS: There is evidence for the impact of environmental factors on cognitively vulnerable patients.
- KNOW and CONSIDER clinical practices and features of the palliative care environment which may increase the risk or severity of delirium, or worsen disorientation, and to minimise these (eg, room and staff changes, day / night disruption, avoidable immobilisation and catheterisation, making sure patients have their hearing aids and glasses, and so on).
- MINIMISE MEDICATION: minimise the medication burden wherever possible, with special attention to psychoactive drugs.
- ASSESSMENT: A careful assessment of benefit and burden of any medications given to treat palliative care symptoms is necessary.
- EDUCATION: Educating and counselling caregivers is an important aspect of managing patients at risk for delirium, or when delirium is diagnosed.

The National Strategy on Delirium

Australian Commission on Safety and Quality in Health Care. Delirium Clinical Care Standard. Sydney: ACSQHC, 2016. This Clinical Care Standard describes the clinical care that a patient with delirium should be offered.
Delirium Clinical Care Standard

1. A patient presenting to hospital with one or more key risk factors for delirium receives cognitive screening using a validated test. In addition, the patient and their carer are asked about any recent changes (within hours or days) in the patient’s behaviour or thinking.

2. A patient with cognitive impairment on presentation to hospital, or who has an acute change in behaviour or cognitive function during a hospital stay, is promptly assessed for delirium by a clinician trained and competent in delirium diagnosis and in the use of a validated diagnostic tool. The patient and their carer are asked about any recent changes in the patient’s behaviour or thinking. The patient’s diagnosis is discussed with them and is documented.

3. A patient at risk of delirium is offered a set of interventions to prevent delirium and regular monitoring for changes in behaviour, cognition and physical condition.

4. A patient with delirium is offered a set of interventions to treat the causes of delirium, based on a comprehensive assessment.

5. A patient with delirium receives care based on their risk of falls and pressure injuries.

6. Treatment with an antipsychotic medicine is only considered if a patient with delirium is distressed and the cause of their distress cannot be addressed and non-drug strategies have failed to ease their symptoms.

7. Before a patient with current or resolved delirium leaves hospital, the patient and their carer are involved in the development of an individualised care plan and are provided with information about delirium. The plan is developed collaboratively with the patient’s general practitioner and describes the ongoing care that the patient will require after they leave hospital. It includes a summary of any changes in medicines, strategies to help reduce the risk of delirium and prevent complications from it, and any other ongoing treatments. This plan is provided to the patient and their carer before discharge, and to their general practitioner and other ongoing clinical providers within 48 hours of discharge.
Delirium Care Pathways

Delirium Care Pathways was developed to assist in the coordination of care and to improve how older people are managed during a delirium episode to improve care and minimise adverse outcomes. This document builds upon the Clinical Practice Guidelines for the Management of Delirium in Older People to provide a blueprint that guides clinicians in the provision of care in a range of health and aged care settings (including community care).

The three examples provided in Delirium Care Pathways demonstrate different patient journeys in acute care, community care and residential care. These journeys highlight the management of delirium in different settings and include page references to more information on assessment and management.

Delirium is an important clinical condition which is often left undiagnosed or mismanaged. Delirium Care Pathways will assist clinicians and care givers to manage delirium across a range of care settings.

Submit Reflection 5: Reflect on why it is important to assess and treat delirium in your work setting.

References


Wong CL, Holroyd-Leduc J, Simel DL, Straus SE. Does this patient have delirium?: value of bedside instruments. JAMA. 2010 Aug 18;304(7):779-86.
RESPIRATORY: DYSPNEOA (Source PCC4U)

Dyspnoea is a term used to describe a subjective experience of difficult and uncomfortable breathing. [1] The American Thoracic Society defines breathlessness as:

"...a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavioural responses.” [2]

The terms dyspnoea and breathlessness may be used interchangeably.

Dyspnoea is a prevalent symptom in advanced lung cancer, chronic obstructive pulmonary disease and other advanced diseases. It may cause severe distress and isolation for patients and their families. [3]

The pathophysiology of dyspnoea is complicated and is not fully understood. Dyspnoea results from a complex signalling process between the central nervous system, upper airways, lungs and chest wall. Signals are relayed to higher centres of the brain where they undergo further processing with an influence of behavioural, cognitive, social and environmental factors. The final result of this process is the sensation of dyspnoea. [4]

The term “total dyspnoea” characterises the multidimensional nature of the symptom and the physical, psychological, social, and spiritual impact on the person. [5] The experience of “total dyspnoea” exists as a conceptual framework much like that of “total pain”, a term coined by Dame Cicely Saunders in 1967. [6]

You might like to view the following YouTube (Respiratory System, part 1: Crash Course A&P #31) https://www.youtube.com/watch?v=bHZsvBdUC2I

Dyspnoea Causes

Dyspnoea occurs in 40-65% of people with malignant conditions and may occur as a consequence of

- Tumour involvement of lung parenchyma- primary or metastatic
- Tumour involvement of airways leading to obstruction/collapse
- Pleural effusion/haemothorax/pneumothorax
- Pericardial effusion
- Infection
- Effects of radio/chemotherapy
- Anaemia / low Hb / low iron
- Respiratory muscle weakness
- Hepatomegaly
- Cardiac failure as a consequence of chemotherapy
- Pain
Anxiety

The sudden development of dyspnoea, headache, swelling and distension of the veins of the face, chest and upper limbs suggests the development of superior vena caval obstruction = medical emergency.

**KEY POINTS: (source PCC4U)**

Dyspnoea (breathlessness) is a distressing symptom that may affect all elements of an individual’s life.

It is subjective.

A multidisciplinary, tailored approach is necessary when developing a management plan for breathlessness.

Patients at risk of developing dyspnoea should be identified, as anticipatory prescribing, education and support may be indicated.

The stage of a patient’s illness, their prognosis and their goals should be considered.

**SUBMIT REFLECTION 6:** Based on your experience, identify a number of patient experiences with breathlessness. How did it make the patient feel? How did the family feel? How did you feel?
Managing Breathlessness

There are two excellent resources for managing breathlessness. Take a look at the two websites:

**Macmillan Cancer Support UK**


**YouTube exercises for shortness of breath**

https://www.youtube.com/user/ManagingSOB

After reviewing these sites, make a plan about how to manage breathlessness.

SUBMIT 7 Plan: Ideas of how I will help my patients manage breathlessness.
Attached are a number of documents. Compare the information within these documents and identify what components you should include when performing respiratory assessment.

1. Respiratory Distress Observation Scale
2. Cancer Care Ontario Assessment and algorithm
3. Tollefson Respiratory Assessment

**REFLECTION:** Components of respiratory assessment in my practice.
REFERENCES


GASTROINTESTINAL

The Gastrointestinal System

The function of the digestive system is digestion and absorption. Digestion is the breakdown of food into small molecules, which are then absorbed into the body. The digestive system is divided into two major parts: The digestive tract also known as the alimentary canal is a continuous tube with two openings: the mouth and the anus.

There are a number of websites that offer you some interactive learning opportunities on refreshing your gastrointestinal tract A&P knowledge. Here is one that is useful, but you may prefer to find one yourself. https://www.le.ac.uk/pa/teach/va/anatomy/frmst.html

There are a number of GIT assessments that should be considered issues when a person is receiving palliative care, including: nausea and vomiting, bowel management, intestinal obstruction, oral care, taste alteration, swallowing difficulties and malignant ascites. Understanding how the GIT system works when healthy, is a key issue in understanding why certain symptoms and issues arise for people in palliative care.

NAUSEA AND VOMITING is often present and may be difficult to control. Some principles to remember:

- It is important to separate nausea from vomiting.
  - Consider how each affects the individual patient.
- A vomit a day with no nausea may be more acceptable than continuous low-level nausea.
  - For some patients nausea is more distressing than pain.
- Nausea and/or vomiting often has more than one cause.
- Choose a management strategy to fit the cause(s).
- Anti-emetics work at differing sites and receptors.
- Anti-emetics that affect multiple receptors in multiple areas
- A combination of anti-emetics is useful, particularly where there are multiple causes.

Causes and Management of N & V

- There are two distinct areas in the central nervous system (CNS), which are predominantly involved with nausea and vomiting: Chemoreceptor trigger zone (CTZ) and the vomiting centre in the medulla oblongata - can be directly stimulated or inhibited by certain agents.
<table>
<thead>
<tr>
<th>Cause</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>• higher centre stimulation - fear/anxiety</td>
<td>• counselling/explanation/listening</td>
</tr>
<tr>
<td>• direct vomiting centre stimulation - radiotherapy to the head, raised intracranial pressure</td>
<td>• cyclizine</td>
</tr>
<tr>
<td>• cyclizine</td>
<td>• dexamethasone</td>
</tr>
<tr>
<td>• vagal and sympathetic afferent stimulation - cough, bronchial secretions, hepatomegaly, gastric stasis, constipation, intestinal obstruction</td>
<td>• Cough</td>
</tr>
<tr>
<td>• Bronchial secretions</td>
<td>• Constipation</td>
</tr>
<tr>
<td>• Hepatomegaly</td>
<td>• Dexamethasone (minimal extrapyramidal effects)</td>
</tr>
<tr>
<td>• Gastric stasis</td>
<td>• domperidone (minimal extrapyramidal effects)</td>
</tr>
<tr>
<td>• Intestinal obstruction</td>
<td>• erythromycin - a strong prokinetic</td>
</tr>
<tr>
<td>• Chemoreceptor trigger zone stimulation - uraemia, hypercalcaemia, drugs e.g., opioids, cytotoxics</td>
<td>• Haloperidol</td>
</tr>
<tr>
<td>• Vestibular nerve stimulation - motion</td>
<td>• Levomepromazine (methotrimeprazine)</td>
</tr>
<tr>
<td>• cyclizine</td>
<td>• Hyoscine patch (scopolamine)</td>
</tr>
</tbody>
</table>
Bowel care

Bowel care includes alteration in bowel function is common in terminally ill people. Some common facts: Constipation is more common than diarrhoea, efficient bowel management may alleviate distress, nurses should carefully assess bowel function on a daily basis, regimens should be discussed, carried out and reported on a daily basis.

SUBMIT REFLECTION 8: Review the bowel assessment protocol for your ward. Is it sufficient to enable care of the patient receiving care with a palliative approach?

Bowel Obstruction

Intestinal obstruction is a difficult area of palliative care. There is considerable inter-individual and intra-individual variation in symptoms and optimal management.

Causes of Internal Obstruction:

- Can be mechanical or paralytic.
- Blockage of intestine by intraluminal or extraluminal tumour, inflammation or metastasis.
- Blockage can occur at multiple sites in patients with peritoneal involvement.
- May be aggravated by drugs e.g., anticholinergics, opioids.
- Radiation fibrosis.
- Autonomic nerve disruption by tumour.

Plan: Ideas of how I will identify potential bowel obstruction.
ORAL HYGIENE

Poor oral hygiene is probably the most significant factor in the development of oral disease near the end of life.

- Good mouth care is essential to the well-being of patients debilitated by advanced disease.
- Mouth problems are common - up to 90% of patients.
- Risk factors for oral problems include
  - debility, dry mouth (drugs, mouth breathing, radiotherapy), chemotherapy, dehydration, cachexia, weight loss, ill-fitting dentures, bisphosphonates (osteonecrosis of the jaw)

FIND: the oral care protocol for the ward including assessment/oral score. What aspects do you think the ward need to improve on?

Taste Alteration

Some common causes of taste alteration include local disease of mouth and tongue, systemic diseases, partial glossectomy, nerve damage, alteration to cell renewal via malnutrition, metabolic, zinc deficiency, endocrine factors, viral infections, hyposalivation, dental pathology/hygiene, diabetes, gastric reflux and medications drugs such as cyclizine, anticholinergics (leads to dry mouth), chemotherapy, lithium, ACE inhibitors and citalopram.

Common treatment includes removal and treating the cause e.g., give pilocarpine for dry mouth, stop likely drugs and administration of Zinc (but only if zinc is deficient). Taste alteration may be unresponsive to interventions
Swallowing Difficulties

Swallowing oral formulations of drugs often becomes difficult for palliative care patients.

- Drugs which are available in the capsule form may be more easily swallowed using the ‘leaning forward’ technique.
  - This involves bending the head down rather than tipping it back when swallowing capsules.
  - When leaning the head down and forward the capsule floats to the back of the throat ready to be swallowed.
  - The standard way of swallowing solid oral formulations - head is tipped back - results in the capsule floating to the front of the mouth making swallowing the capsule difficult.
  - This ‘leaning forward’ technique will not work for tablets as they do not float so use the standard tilting the head back approach.
- If swallowing remains an issue consider crushing tablets or opening capsules if appropriate, oral liquids or other routes e.g. sc, intranasal, sublingual, rectal.

Malignant Ascites

This is a common symptom in patients with breast, colon, endometrial, ovarian, pancreatic or gastric cancers.

Assessment

- Consecutive measurements of abdominal girth.
- Respiratory function - shortness of breath may occur.
- Early fullness e.g., squashed stomach.
- Portable ultrasound examination.

Causes of malignant ascites

- peritoneal fluid build-up in the abdomen due to a failure of the lymph system to adequately drain
- tumour in the peritoneal cavity
- low serum albumin
- excess fluid production
- venous compression or vena cava/hepatic vein thrombosis

Management

Symptoms usually appear at > 1 L of fluid in the abdomen.

- If the prognosis is short and the symptoms are not troublesome then no action may be needed.
- Explanation of the problem and likely outcomes may be enough to allay fears or anxieties.
If the symptoms warrant further intervention, the bowel is not distended consider paracentesis.

- Suction may be used if the fluid is viscous, e.g., of ovarian origin.
- Drain no more than 2 L in the first hour then drain slowly for 12 to 24 hours (to a maximum of 5 L in 24 hours).
- Place an ostomy bag on the site once the paracentesis needle is removed to collect any residual leaking fluid.
- Check biochemistry frequently.
- Some centres advise daily measurement of girth.
- A surgical opinion, for the insertion of a peritoneo-venous shunt, may help in recurrent ascites if the patient’s life expectancy is greater than 3 months.
- Repeated drainage may be followed by rapid reaccumulation.

**Drug treatment of symptoms**
- If the patient is fit for diuretics, give spironolactone 100 mg (or more) with or without frusemide 40 mg once daily although benefit is often extremely limited.
- For gastric stasis give a prokinetic, e.g., metoclopramide.
- If there is evidence of liver capsule stretch pain use a steroid e.g., dexamethasone.

**Cachexia**

Cachexia can be distressing for both the patient and their family and carers. It is difficult to watch a person 'waste away' and is often perceived as a sign of impending death.

- cachexia [derived from the Greek kakos (bad) and hexis (condition)]
- defined as a multifactorial system with ongoing loss of skeletal muscle mass that cannot be fully reversed leading to progressive functional impairment
- diagnosis- weight loss greater than 5%, or 2% in individuals already showing depletion
- develops progressively through various stages- precachexia, cachexia, and refractory cachexia
- refractory cachexia or cancer anorexia cachexia syndrome- very advanced cancer (preterminal), active catabolism low performance status (WHO score 3 or 4), and life expectancy less than 3 months
- may complicate many chronic or end-stage diseases in addition to cancer
- it is not starvation, which can be reversed with nutrition
- distinct from age-related loss of muscle mass, primary depression, malabsorption syndromes and hyperthyroidism

**Assessment**

Take a moment to document your ideas of GIT assessment in your practice. What documents are available in the unit to help you with this?
SUBMIT REFLECTION 9: What are the considerations health professionals should consider about eating and drinking for people during the end stage of their lives?

Notes:
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
PART 5: GRIEF, LOSS AND COPING AND COMMUNICATION

OBJECTIVES
On completion of this session participants will be able to:

- Define Grief and bereavement for individuals and families receiving palliative care
- Develop an individualized care plan centered around the individual needs
- Identify communication skills for people in palliative care
- Define and identify coping and signs of those struggling with grief
- Reflect on own practice about how you handle these situations

Overview


Bereavement refers to the event of death of a person with whom there has been an enduring relationship.

Grief is how bereavement affects us personally, with effects across several domains – emotional, cognitive, social, physical, financial and spiritual. Grief often causes disruption and disturbance of everyday life. However, grief can be expressed in very different ways: some people do not experience an intense reaction. Most people experience fluctuating reactions for a period of time while others can develop an intense and prolonged grief response. [1,2] Culture plays a major role in the expression of grief. [3]

Common expressions of grief are varied and can include: [4]

Emotional

- Depression
- Anxiety
- Guilt
- Anger
- Loneliness
- Loss of pleasure
- Shock and numbness.

Cognitive

- Thinking all the time about the person who has died
- A sense that the dead person is still about
- Denial
- Hopelessness.

Behavioural

- Over or under activity
- Social withdrawal
- Agitation.
Physical feelings

- Loss of appetite
- Sleep disturbances
- Tiredness.

Physiological

- Susceptibility to illness.

What is known

For most people, grief is accommodated over time with support of family and friends. [5] Identifying the fact that there may also be positive outcomes of bereavement, including the potential for post-traumatic growth, is a recent development within the field; [6] 'resilience' is one of the key concepts that is being used to understand and acknowledge the way that people deal with their grief and bereavement. [7]

There is no evidence that sharing and disclosure of feelings will lead to 'healthy' or less intense grieving for those people who experience normal grief reactions. [4] There is also no evidence that grief counselling improves outcomes for people who experience normal grief. [8-10]

Protective factors in the health outcomes of bereavement may include: [4]

- Responsive health care for the dying patient and reduction of patient distress before death
- Optimistic and resilient personality characteristics of bereaved individuals
- Secure relationships with family and community.

Common patterns of response to spousal bereavement have been identified. Spousal loss occurs most frequently in later life, more often affects women, and for many bereaved spouses, it interacts with and compounds other health concerns. Maintaining independence is a common challenge in this situation for older people. [11]

Bereavement is a period of increased mortality for spouses. A meta-analysis has confirmed that men who are widowed are particularly at risk, and the first six months is the highest risk period. [12] The risk is associated with both expected and unexpected deaths, but social support may reduce the risk. Patient end-of-life interventions may positively influence bereavement outcomes for spouses. [13] The increased risk is unrelated to the age of the bereaved person. Cardiovascular risk for the spouse who survives is increased, particularly in the first few weeks. [14] The vulnerability may be due to both the physiological impacts of grief, and also to altered health behaviours. There is evidence that in late-life spousal loss health behaviour changes can affect sleep, alcohol use, and nutritional intake causing involuntary weight loss. [15]

Bereavement in childhood is common. About 5% of children will lose a parent or sibling, and up to 75% will experience the loss of a relative or friend before the age of 16. [16] Most often this is associated with short term negative impact, but few longterm difficulties.

The impact of caregiving on grief and bereavement is being studied. High levels of social and emotional support can modify bereavement distress, and there is some evidence that receiving
support from palliative care services, and home deaths, may improve bereavement outcomes for caregivers. [17]

Active research areas / controversies

- There is a trend in research which is critical of stage-based models of grief that suggest bereaved people ‘move on’ from their grief and relinquish the bond or connection to the dead person. [4,18]
- Research suggests that normal grief differs from abnormal grief in a variety of ways, and that abnormal grief is distinct from other psychiatric diagnoses such as depression, anxiety and PTSD. Associated assessment tools and new treatment strategies are evolving based on improved understandings of these phenomena. [18,19]
- Research is needed into the personal profile of those at risk of abnormal grief, including psychological characteristics and interpersonal factors, such as their perception of social and community supports. [3,5] Issues of screening, referral and how to match intervention to the individual require further research.
- Research into the efficacy of bereavement interventions needs attention. While specific bereavement interventions appear to assist those people experiencing abnormal grief, more detail is needed. Cost effectiveness of bereavement services has not been well studied. [27]
- Little is known about how and to what extent bereaved people are cared for in primary care, nor the impact of that care. [28]
- The grief experiences of health care providers have not been well-studied, but these may have significant impact on health service delivery, and result in both emotional and economic costs to the system. [29]

EVIDENCE


**Key messages**

- Expressions of grief can vary widely from person to person.
- Most people who experience normal grief do not require specialist counselling, but would benefit from reassurance, acknowledgement of their losses, and access to information.
- A proportion of people who grieve may experience intense distress over a prolonged period.
- A number of options for referral for bereavement difficulties exist:
  - Specialist bereavement counsellors
  - Palliative care services usually offer bereavement follow up to their clients, often based on bereavement risk assessment, and may also sometimes accept referrals from other sources
  - Other mental health professionals with appropriate skills and expertise.

**SUBMIT Reflection 9:** How do / can staff in your unit provide bereavement for families who are experiencing grief and mourning?

**Social support: the palliative context**

- Whether the patient with cancer has support or feels supported are major factors in how they manage socially, spiritually, physically and emotionally.
- Certain points along someone’s life, including transition from active or curative care to palliative care, requires further information appraisal by both themselves and family caregivers.
- Tearfulness, fear and anger are common emotional reactions to living with a life threatening illness and professional staff may be challenged to discussing concerns with patients as they may feel out of their depth.

**Important contributing factors**

- Patients from rural and isolated communities who have travelled for treatments and services may have experienced greater disruption of family and social life.
- Past history of mental illness and substance abuse can limit social support availability.
- Family distress or dysfunction can undermine effective social support.
- Families need adequate information and support in the early phase of patient’s serious illness and treatment.
When they do not receive this, they have greater needs, less trust and confidence in the health care system.

- The kind of support required by patients can include attention to their spiritual needs as integral elements of their care.
- Health professionals, particularly physicians, are perceived as important sources of support for patients and their families in time of serious illness.
- Family caregivers can be helped to seek support for themselves from other family members and friends and health professionals.

**What is known**

Any patient who perceives that they have inadequate support are likely to experience greater psychosocial distress.

Children and partners of patients can experience equal or even higher levels of distress in relation to patients with cancer.

Men and women may require different types of support strategies.

Peer support groups are effective at increasing perception of social support for patients who feel unsupported.

Community services that support the patient and family at home must be provided early in order to enable optimum quality of life and quality of care. Timely assessment is therefore crucial.

There is an association between specific personality types, coping styles and psychological distress and HIV progression – but no relationship between social support and HIV progression.

**COPING**

(Adapted from Reachout.com http://au.reachout.com/building-better-coping-skills)

**Why positive coping strategies are useful.**

Positive coping strategies are any actions you take to manage and reduce stress in your life, in a way that isn’t going to be harmful or detrimental in the long term. People who use positive strategies are not only better able to tackle challenges and bounce back from tough times, but they are also much happier.

**Finding the right coping strategies.**

Pretty much any coping strategy which isn’t going to be harmful or ineffective in the long term is worth a try. However, you will probably find that some strategies work better for you than others in terms of how well they reduce stress and help you manage. It’s also worth noting that some strategies will work better or worse depending on the particular event/situation.

To find the best coping strategies for you, list the types of situations that you find difficult to manage. Pick a few ways to reduce stress. When the stressful situations arise, try out one of your strategies. Keep notes on how it went – things that worked, or didn’t. You’ll soon work out which
strategies work well for you, and which situations favour certain strategies over others. Keeping tabs by writing things down will also help you make using positive coping strategies a habit.

A mega list of coping strategies

- **Turn to someone you trust.** It can be a relief to share your thoughts with someone else, and it can be good to work through problems with the help of another person.
- **Write it all down.** Keeping a notebook handy for you to scribble your thoughts in whenever you feel like it can be a great way of expressing yourself. You may find it helpful to write about what is worrying you, or express yourself in a more creative way.
- **Set aside regular time for yourself.** Even if it’s just ten minutes of ‘you’ time, taking some space for yourself where you turn off your phone, spend time alone, exercise, meditate, or listen to music can really prepare you for tackling stress or challenges.
- **Walk away.** Work out which situations you are likely to get most stressed out by. If you feel like you’re getting too angry, end the conversation, take some space, and don’t resume talking until you are calm and ready.
- **Overcome negative patterns of thinking through self-talk.** Self-talk can help you see things from a more positive perspective and give a huge boost to your confidence.
- **Reduce your load.** Sometimes you just have to accept that you can’t do everything. Keep track of your schedule and how you feel each day, and working out your optimal level of activity. You should be busy, entertained, and challenged, without feeling overwhelmed.
- **Consider the big picture.** When you’re going through a stressful situation, ask yourself these two questions. ‘How important is this?’ and ‘will it matter in the long run?’ If you realise it doesn’t, it’s probably not worth getting too stressed out by.
- **Learn to forgive.** Move on from hurt, regret and anger. Whether you are angry at yourself or someone else, it doesn’t help you to hold on to negative feelings like resentment.
- **Hone your communication skills.** If you know how to communicate a problem well, it will help prevent conflict from escalating, and could help solve the cause of the stress in the first place.
- **Build your optimism.** Optimism involves learning to think positively about the future - even when things go wrong. That’s not to say you pretend that everything is fine when it isn’t. Instead, it’s about looking objectively at a situation, making a conscious decision to focus on the good. It can be hard to do, but if you practice, you’re likely to get better.
- **Learn how to set goals.**
  - **Relax.** Relaxation is a great way to refocus your thoughts, particularly when things are becoming a bit overwhelming.
  - **Build your gratitude.** Take some of your focus away from the negative things, and take 5 minutes each day to identify 3 things which you are thankful about.

**If you need something stronger**

You don’t have to work this stuff out on your own. Counsellors are great at helping to build and develop coping skills. They also can be good to talk to if you prefer not to talk to friends or family, or if your problems are making it hard to carry on with day to day life.
How are you going to identify if a patient or their family are not coping with their situation? What support can you give a colleague who is struggling at work with sadness related to work?

**Communication**

Communicating in sensitive situations can be awkward, when having those hard conversations are inevitable. It helps when we

- Build and maintain trust
- Convey positive messages both verbally and non-verbally
- Tell good stories that convey caring and empathy
- Prepare yourself for communicating in tough situations
- Craft effective responses to the most difficult questions

Communication is important in all aspects of nursing, whether with patients, health professionals or colleagues.

Good communication at the end of a patient's life involves the ability to both give and receive information at a time where strong emotions and stress can affect even the most experienced clinician.

It is important that patients have the information that they need to enable informed decision making and that clinicians clearly understand patient and family preferences in developing goals of care:

- For patients and families, the amount of information required can change with their circumstances. When someone is seriously ill, there will be many things that need to be discussed, some of which will be difficult and emotive
- For health professionals, having as much information as possible from the patient is vital to ensure any plans and decisions are inclusive and that staff are advocating appropriately for them. **Active listening** is a skill that can enhance this important process.

Communication works best when it is open and sensitive as well as appropriate to the situation and applies to both nurses and patients. [1]

Unfortunately there is no formula to direct what to say or how to say it. Working with, seeking advice from, or observing more experienced colleagues communicate (such as Social Workers, Bereavement Counsellors and Pastoral Care Workers) is one way to learn.

**EVIDENCE**

PART 6: WRITING REFLECTIONS

Reflection is:

- a form of personal response to experiences, situations, events or new information.
- a ‘processing’ phase where thinking and learning take place.

There is neither a right nor a wrong way of reflective thinking, there are just questions to explore.

Figure 1 shows that the reflective thinking process starts with you. Before you can begin to assess the words and ideas of others, you need to pause and identify and examine your own thoughts.

Doing this involves revisiting your prior experience and knowledge of the topic you are exploring. It also involves considering how and why you think the way you do. The examination of your beliefs, values, attitudes and assumptions forms the foundation of your understanding.

Reflective thinking demands that you recognise that you bring valuable knowledge to every experience. It helps you therefore to recognise and clarify the important connections between what you already know and what you are learning. It is a way of helping you to become an active, aware and critical learner.

What is reflective writing?

- your response to experiences, opinions, events or new information
- your response to thoughts and feelings
- a way of thinking to explore your learning
- an opportunity to gain self-knowledge
- a way to achieve clarity and better understanding of what you are learning
- a chance to develop and reinforce writing skills
Reflective writing is not:

- just conveying information, instruction or argument
- pure description, though there may be descriptive elements
- straightforward decision or judgement (e.g. about whether something is right or wrong, good or bad)
- simple problem-solving
- a summary of course notes

As it concerns your thoughts, reflective writing is mostly subjective. Therefore in addition to being reflective and logical, you can be personal, hypothetical, critical and creative. You can comment based on your experience, rather than limiting yourself to academic evidence.

- Reflective writing is an activity that includes description (what, when, who) and analysis (how, why, what if). It is an explorative tool often resulting in more questions than answers.
- A reflective task may allow you to use different modes of writing and language:
  - descriptive (outlining what something is or how something was done)
  - explanatory (explaining why or how it is like that)
  - expressive (I think, I feel, I believe)
- Use full sentences and complete paragraphs
- You can usually use personal pronouns like 'I', 'my' or 'we'
- Keep colloquial language to a minimum (eg, kid, bloke, stuff)

Tips to help you in your reflective writing process

- Think of an interaction, event or episode you experienced that can be connected to the topic
- Describe what happened
- What was your role?
- What feelings and perceptions surrounded the experience?
- How would you explain the situation to someone else?
- What might this experience mean in the context of your course?
- What other perspectives, theories or concepts could be applied to the situation?

AHPRA requires reflections on education and its relevance to our practice. Developing your reflective writing is important for your professional growth.

This workbook accompanies the introduction to Palliative Care workshop. If you have any feedback or suggestions please submit to CISS-Education @health.qld.gov.au

Thankyou for taking the time to attend and participate.