A Day in the Life of a Palliative Care Nurse Specialist.

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Objectives

- What is Palliative Care?
- Who needs Palliative Care?
- Where do referrals come from?
- What does a PCN do?
- Case Study: Symptom control and management. Millie’s journey
- Self care
- Access to professional bodies.
Palliative Care

Palliative care is 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.

World Health Organization. **Definition of Palliative Care**.

4 November 2006.
Where do our referrals come from?

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Community/Hospice</th>
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<tbody>
<tr>
<td>Oncology</td>
<td>GP’s</td>
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<tr>
<td>Respiratory/Cardiology</td>
<td>Hospitals - public &amp; private</td>
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<tr>
<td>Neurology</td>
<td>RCF</td>
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<td>Gynaecology</td>
<td>District Nurses</td>
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<tr>
<td>Orthopaedics</td>
<td>Public &amp; private Consultants</td>
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<tr>
<td>Urology</td>
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<tr>
<td>General surgery and medical</td>
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<td>OPH</td>
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Why are patients referred to us?

- Symptom control.
- Support for patient and/or family
- Discharge planning (from hospital)
- Discussions around death and dying
What we do

- Meet and Greet
- Assessment
- Symptom control.
- Discharge planning
- Death and dying
- Liaison
- Education
- Not forgetting, own Professional Development
Community Case Study:
Millie, a 42 year old lady.

- Diagnosed 2004 with Ca breast, multiple bony and cerebral metastases (mastectomy 2004, chemo/radiotherapy)
- Presented 9 months ago with shoulder pain - further multiple bony mets confirmed.
- Husband & 2 teenage children.
- Referred to community palliative care by GP for symptom control of nausea & vomiting
Initial visit
Initial visit

- **Aim:** To introduce Palliative care
- Joint visit with DN
- Gain an understanding of where they are at.
- Assess their needs and wishes
- Husband John and Millie present, children Joshua (16) and Francie (13) both at school.
A positive model for Maori health & wellbeing (Mason Durie)
Holistic Assessment

• How are you feeling?
• What's going on for you?
• Existential concerns?
• Are you eating ok?
• Any nausea?
• Any pain?
• How are your bowels?
• How's your mobility?
• Support you have?
What were Millie’s issues?

- Nausea
- Constipation
- Pain - general and shoulder
- Headache
- Dry mouth with thirst
- Thought process slowed.
- Psycho social concerns
Nausea and vomiting
Taking a history for N & V

- Duration
- Frequency
- Initiating factors
- Relationship to food
- Ability to keep fluids down
- Bowels
- Clarify where disease is anatomically
- Past treatments
- Medications
- Physical exam
Management

- Identify what may be causing the nausea (e.g. constipation)
- Fix anything that can reasonably be fixed (e.g. small bowel obstruction)
- Treatment of the underlying cancer (radiotherapy for brain metastases)
- Identify and address any anxiety or fear that may be exacerbating the situation
Management - continued

- Nausea can be treated with oral drugs, but alternative routes are needed for patients with severe nausea
- Persistent nausea may decrease gastric emptying with a resultant decrease in drug absorption - Use subcutaneous
- Give anti emetics *regularly*
- Combinations are often required
- Non – drug methods also important
Pain is what the patient says hurts. It is what the patient describes and *not* what others think it ought to be.
Pain

• Pain is both a physical and a psychological experience
• It is experienced according to the person’s capacity to control it effectively and ascribe a meaning to it
• Fatigue, anxiety, insomnia, depression, isolation, fear, anger and uncertainty will ALL compound suffering

Mood   Morale   Meaning
Pain Assessment

- Accept patient’s description
- Assess pain carefully - history (onset, course, site, radiation, severity, quality, frequency, associated factors, etc), examination, investigations
- Assess each pain
- Evaluate extent of disease
- Consider other factors which influence pain
- Reassess
Bowel Management
Constipation

• Assessment
• What is your usual routine?
• What is happening now?
• When did bowels last move? (and previous to that?)
• Consistency? Form? Frequency?
Constipation

Complications if untreated

• Inadequate absorption of drugs
• Faecal impaction
• Rectal tearing, fissure, haemorrhoids
• Bowel obstruction
• Intestinal perforation
<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Separate hard lumps, like nuts (hard to pass)</td>
</tr>
<tr>
<td>2</td>
<td>Sausage-shaped but lumpy</td>
</tr>
<tr>
<td>3</td>
<td>Like a sausage but with cracks on its surface</td>
</tr>
<tr>
<td>4</td>
<td>Like a sausage or snake, smooth and soft</td>
</tr>
<tr>
<td>5</td>
<td>Soft blobs with clear-cut edges (passed easily)</td>
</tr>
<tr>
<td>6</td>
<td>Fluffy pieces with ragged edges, a mushy stool</td>
</tr>
<tr>
<td>7</td>
<td>Watery, no solid pieces. Entirely Liquid</td>
</tr>
</tbody>
</table>
Multiple laxatives

- **Softeners**
  - Docusate Sodium (Coloxyl™)
- **Stimulants**
  - Bisacodyl (Dulcolax™)
  - Sennosides A and B (Senokot™)
- **Osmotic laxatives**
  - Lactulose or Movicol™
- **Combination laxatives**
  - Coloxyl & Senna (Laxsol™)
  - Pinorax™ / Pinorax Forte™ (poloxamer and danthron)
- **Suppositories**
  - Glycerol (Fleet glycerin™)
  - Bisacodyl (Dulcolax™)
- **Enemas**
  - Fleet phosphate (osmotic)
  - Liquid paraffin (Fleet™ mineral oil enema)
Management of Constipation Associated with Opioid Use

Day 1
- Consider establishing a baseline to evaluate changes in bowel movements.
- Chart bowel movements to assess for constipation.
- Use "Fisher's Constipation Chart" to document bowel function.
- Review medication chart.
- Identify potential causes of constipation.
- Monitor for signs of opioid-induced constipation.
- Initiate treatment with stool softeners or laxatives.
- Evaluate response to treatment and adjust as necessary.
- Repeat bowel movements chart.
- Monitor for improvement.

Day 2
- Review medication chart.
- Assess bowel movements for consistency.
- Consider adding a fiber supplement to the diet.
- Evaluate for signs of dehydration or fluid loss.
- Review patient's fluid intake and availability.
- Adjust treatment if necessary.
- Repeat bowel movements chart.
- Monitor for improvement.

Day 3
- Evaluate for improvement in bowel movements.
- Consider increasing the frequency of stool softeners or laxatives.
- Review patient's compliance with treatment regimen.
- Adjust treatment if necessary.
- Repeat bowel movements chart.
- Monitor for improvement.

Day 4
- Evaluate for improvement in bowel movements.
- Consider adding a dietary fiber supplement to the diet.
- Monitor for signs of dehydration or fluid loss.
- Review patient's fluid intake and availability.
- Adjust treatment if necessary.
- Repeat bowel movements chart.
- Monitor for improvement.

Day 5
- Evaluate for improvement in bowel movements.
- Consider increasing the frequency of stool softeners or laxatives.
- Review patient's compliance with treatment regimen.
- Adjust treatment if necessary.
- Repeat bowel movements chart.
- Monitor for improvement.
Management

*The hand that charts the opioid charts the laxative*

- Laxsol up to 3 b.d
- Add pinorax nocte or movicol b.d
- If no improvement do a PR
- If impacted cease laxsol and pinorax and use movicol
- If ongoing problems use coloxyl 120mg tabs and bisacodyl 5mg tabs
- Consider an abdominal x-ray
Rectal Exam

- Not fun for patient or clinician BUT it is impossible to assess properly without it
- Hard stool v soft, sensation, tone, reflexes
- Can identify painful lesions and strictures
- We all want to avoid unnecessary rectal interventions BUT well placed suppositories can save days of oral treatment in patients struggling with pain and nausea
Cerebral Involvement

• CT scan necessary or useful????
• Headaches – time of day? Intensity? What helps?
• Short term memory loss
• Use of steroids
• Complementary therapies e.g. aromatherapy or massage
Hypercalcaemia

- Paraneoplastic syndrome
- Boney metastases
- Increased bone metabolism
- Decreased renal clearance of calcium
- Dehydration
- Enhanced absorption from the gut
Symptoms and management

**Symptoms**
- Thirst and dehydration
- Increased urinary output
- Constipation
- Decreased appetite
- Nausea +/- vomiting
- Fatigue
- Pain – often back and abdominal
- Confusion, depression

**Management**
- Make the diagnosis
- Appropriate course of action?
- Consider stopping diuretics, vitamin D and calcium
- Symptom relief and reduce serum calcium to an acceptable level using minimal intervention
Family Support

- What issues does Millie identify?
- What issues for John?
- What to tell the children?
- What to tell mother?
- What is going to happen to them as a family?
- What can our service do to support the family?
Millie’s Journey

- Admitted to the hospice 3 times over the next 6 months for symptom control and respite
- Obvious decline in physical conditioning
- Multi-disciplinary team approach: dietician, Occupational Therapist, Family Support – Counseling, Social Work, Pastoral Care, Nursing and Medical staff including GP, Needs Assessor
Millie’s Journey continued

• Millie and John had initially said they wanted her to die at home

• During her second admission admitted struggle to manage at home but determined to continue

• Concerned about how John’s role was changing to being her nurse rather than her partner

• Concerned also that she was relying on 13 year old Francie

• Family meeting held prior to discharge with plan for LTC if home management failed
End of Life

- Admitted to the hospice for end of life care
- Clearly dying
- Fatigue++
- Limited food intake
- Decreased fluids
- Struggling with oral medications
- Commenced sub-cut infusion
Last days

- Discussion with Millie and John, prognosis poor – life was measured in days
- “Where they wanted to be?”
- Support John with discussion involving Francie and Josh
- Advised to let extended family know
- Encouraged to have family stay
- Involved family in assisting with physical cares
- Millie died at the Hospice with John, Francie and Joshua with her
- Several family members including her mother arrived shortly after
- Millie stayed in the room for the next 8 hours until the family were able to let her go
Self care

Self-care results in the empowerment of nurses to take a more assertive role and to have their voices heard regarding the practice environment. (Carla Mariano, Stress Management article, Winter 2007)
Do’s and don’ts for self care

- Do use your empathy and nurturing for yourself.
- Do care for and understand yourself with the same expertise you give your patients.
- Do say no when you want to.
- Do unwind after work before you jump into your responsibilities at home.
- Do develop outside interests,
- Do identify your feelings and accept and allow them.
- Do talk with colleagues. Take charge where you can. Avoid chronic complainers
- Do know when to say “enough”
- Do foster friendships where you can talk about feelings
- Do plan for regular breaks, days off, conferences, and vacations.
- Don't identify with patients too much.
- Don’t base all your self-worth on your profession or your nurturing abilities.
- Don't put self care in last place
Conclusion

We can all make a difference

• In the terminally ill phase it is not only quality of life that is important but the concept of a good death. (Smith R.2000)

• “You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.” (Dame Cicely Saunders)

• If there is a sacred moment in the life-cycle, other than a birth, it is a death and as with a birth, families will long remember, how a person died and how we helped or did not. (James L Hallenbeck)
Professional bodies and further resources

• Palliative Care Nurses New Zealand: pcnnz.co.nz
• Palliative Care Nurses Australia: pcna.org.au
• Hospice New Zealand: hospice.org.nz
• Palliative Care Handbook, Authors: Rod MacLeod, Jane Vella-Brincat, Sandy MacLeod, Published by Genesis Oncology Trust available through Hospice New Zealand
• cdhb.healthpathways.org.nz