Palliative Care
The science behind the art of care

Brian Le
Director, Palliative Care – The Royal Melbourne Hospital and Peter MacCallum Cancer Centre
Disclosures

- 2014 speaker payment Roche
- 2017 advisory board Mundipharma (unpaid/unsponsored)
- No other disclosures
A case study...

- Mary, an 82 year old woman
  - Retired school teacher, previously well
  - Metastatic breast cancer diagnosed 18 months prior
  - Initially treated with hormonal therapy

- Disease progression 2 months prior
  - Increasing liver metastases and small volume lung metastases
  - Increasing frailty
- Lived with husband of 45 years in their own home
- Supportive children, closest lives 30 minutes away

- Supports from community palliative care

- Decision made for best supportive care, systemic chemotherapy discussed but not commenced
- Presents to Emergency with:
  - 24 hours of being increasingly disorientated
  - Restless and confused at times
  - Seemingly not knowing where she is
  - Speaking about people from the distant past
- **On examination**
  - Evident delirium: not orientated time, place or person
  - Fluctuating consciousness from drowsy to agitation
  - Uncooperative with examination at times
  - Not able to follow 1 step commands
- Low grade fevers
- Deranged biochemistry, but no clear reversible factors

- Presumptive diagnosis:
  - Advancing metastatic breast cancer
  - Delirium – possible respiratory infection
- Discussion:
  - Multiple prognostic factors suggest high likelihood of poor outcome
    - Admission to hospital
    - Goals of care discussion / treatment limitation
    - Time limited trial of antibiotics
    - Support for patient and family
- How do we manage her delirium?
An initial haloperidol dose for a patient with delirium is:
haloperidol 0.5 mg orally or subcutaneously, in the early evening, and 0.5 to 1 mg 4-hourly as required. Usual maximum dose 5 mg in 24 hours.
But there is uncertainty...

Effect of intravenous haloperidol on the duration of delirium and coma in critically ill patients (Hope-ICU): a randomised, double-blind, placebo-controlled trial

Valerie J Page, E Wesley Ely, Simon Gates, Xiao Bei Zhao, Timothy Alce, Ayumi Shintani, Jim Jackson, Gavin D Perkins, Daniel F McAuley

Summary

Background Delirium is frequently diagnosed in critically ill patients and is associated with poor clinical outcomes. Haloperidol is the most commonly used drug for delirium despite little evidence of its effectiveness. The aim of this study was to establish whether early treatment with haloperidol would decrease the time that survivors of critical illness spent in delirium or coma.
Clinical trials in unwell patients...

- No big deal...
  - Heart disease
  - Cancer
  - Stroke
  - Renal disease
But what about when the patient has a terminal illness?

WHO definition palliative care

Palliative Care improves the quality of life of patients and their families facing the problems associated with life-threatening illness:

- Through the prevention and relief of suffering
- Treatment of pain and other problems:
  - Physical
  - Psychosocial and Spiritual
- We are usually about being:
  - Calm
  - Clear with communication
  - Focussed on physical, psycho-spiritual and carer needs

- We provide certainty in an uncertain time (or try to)
THE ROYAL MELBOURNE HOSPITAL
THIRD PARTY (PERSON RESPONSIBLE)
PARTICIPANT INFORMATION AND CONSENT FORM

VERSION 2, 12 May 2011

Full Project Title: Randomised control trial of oral risperidone versus oral haloperidol versus oral placebo with rescue subcutaneous midazolam in the management of delirium in palliative care inpatients.

Short Title: Risperidone and haloperidol for delirium

Principal Researcher: Dr Brian Le

Please make sure that you have all 12 pages of this document.

1. Introduction

As the "person responsible" for the patient, you are invited to consider the patient's participation in this research project. Victorian law allows the person responsible for a patient to consent to the patient taking part in medical research where the patient is unable to provide consent for themselves.

The "person responsible" is defined under the Guardianship and Administration Act 1986, Version No. 070: Part 4A Medical and other treatment, in order, as

1. An agent, appointed by the patient under enduring power of attorney (medical treatment)
2. A person appointed by VCAT to make decisions about the proposed treatment
3. A guardian appointed by VCAT with health powers
4. An enduring guardian appointed by the patient with health care powers
5. A person appointed by the patient in writing to make decisions about medical and dental treatment, including the proposed treatment
6. The patient spouse or partner
7. The patient's primary carer, including those in receipt of carers payment, excluding paid carers
8. Patient nearest relative (in order - son/daughter [oldest], father/mother, brother/sister [including adopted, or step], grandparent, grandchild, uncle/aunt, nephew/niece)

You have been approached because you match one of these and are therefore legally able to give permission for the patient to participate in this study.

This study involves people who have developed delirium. A simple definition of delirium is a medical condition that occurs when someone is unwell, and it can manifest with many symptoms of varying severity. Some of these can be confusion, restlessness, agitation, disorders of perception (such as hallucinations and illusions) and disturbance in sleep.
Trials in palliative care?

- Questions abound...

  - Ethical and moral appropriateness in vulnerable populations
  - Reluctance of Ethics committees to approve
  - Importance of evidence based practice
  - Altruistic intentions
  - ?trial effect
Getting back to delirium in palliative care...

JAMA Internal Medicine | Original Investigation
Efficacy of Oral Risperidone, Haloperidol, or Placebo for Symptoms of Delirium Among Patients in Palliative Care
A Randomized Clinical Trial

Meera R. Agar, PhD; Peter G. Lawlor, MB; Stephen Quinlan, PhD; Brian Draper, MD; Gideon A. Caplan, MBBS; Debra Rowett, BPharm; Christine Sanderson, MPH; Janet Hardy, MD; Brian Le, MBBS; Simon Eckermann, PhD; Nicola McCaffrey, PhD; Linda Devilee, MBus; Belinda Fazekas, BN; Mark Hill, PhD; David C Currow, PhD

Our cancer care services are provided through a partnership between The Royal Women’s Hospital, The Royal Melbourne Hospital and Peter MacCallum Cancer Centre as members of the Victorian Comprehensive Cancer Centre Alliance.
- Delirium is prevalent in palliative care
  - (up to 40% on admission, ↑ as closer to death)

- RCT – 2008 to 2014, 11 centres
  - N=247
  - Participants:
    - MDAS > 6, DSM 4 delirium
    - Target symptom with distress
      - NuDESC score >= 1
        (inappropriate behaviour / communication, illusions or hallucinations)
      - Able to swallow medications orally
      - English speaking
      - Survival > 7 days
- \( \leq 65 \text{ years}: \)
  - Haloperidol/Risperidone/Placebo
    - 0.5mg loading dose plus 0.5mg first dose
    - then 0.5mg BD
    - Titrated by 0.25mg day 1, or 0.5mg thereafter
    - maximum 4mg/day

- \( >65 \text{ years}: \)
  - 0.25mg loading dose plus 0.25mg first dose
  - then 0.25mg BD
  - maximum 2mg/day
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<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Risperidone (n = 82)</th>
<th>Haloperidol (n = 81)</th>
<th>Placebo (n = 84)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delirium symptom score, mean (SD)a</td>
<td>2.54 (1.23)</td>
<td>2.60 (1.48)</td>
<td>2.54 (1.43)</td>
</tr>
<tr>
<td>Female sex, No. (%)</td>
<td>25 (31)</td>
<td>33 (41)</td>
<td>27 (32)</td>
</tr>
<tr>
<td>Age, mean, (SD), y</td>
<td>74.5 (10.6)</td>
<td>76.5 (8.2)</td>
<td>73.8 (10.7)</td>
</tr>
<tr>
<td>Age &lt;65 y, No. (%)</td>
<td>18 (22)</td>
<td>8 (10)</td>
<td>17 (20)</td>
</tr>
<tr>
<td>Cancer diagnosis, No. (%)</td>
<td>76 (93)</td>
<td>67 (83)</td>
<td>75 (89)</td>
</tr>
<tr>
<td>Performance status (AKPS) score, median (IQR)</td>
<td>40 (30-50)</td>
<td>50 (40-50)</td>
<td>40 (30-50)</td>
</tr>
<tr>
<td>CIRS score, median (IQR)</td>
<td>24 (21-28)</td>
<td>23 (20-26)</td>
<td>25 (21-29)</td>
</tr>
<tr>
<td>Cognitive impairment, No. (%)</td>
<td>18 (22)</td>
<td>17 (21)</td>
<td>14 (17)</td>
</tr>
<tr>
<td>ESRS score, median (IQR)</td>
<td>5.0 (1.0-8.5)</td>
<td>4.0 (1.0-8.0)</td>
<td>4.5 (2.0-9.0)</td>
</tr>
<tr>
<td>MDAS score, median (IQR)</td>
<td>15.1 (5.8)</td>
<td>14.6 (5.0)</td>
<td>13.7 (4.8)</td>
</tr>
<tr>
<td>Opioid dose, median (IQR)b</td>
<td>6.9 (0-88.2)</td>
<td>33.0 (0-153.5)</td>
<td>15.0 (0-86.4)</td>
</tr>
<tr>
<td>Patients receiving opioids, No. (%)</td>
<td>39 (48)</td>
<td>31 (38)</td>
<td>35 (42)</td>
</tr>
<tr>
<td>Benzodiazepine dose, median (IQR)c</td>
<td>0 (0-0.63)</td>
<td>0 (0-0)</td>
<td>0 (0-0)</td>
</tr>
<tr>
<td>IQCODE score, median (IQR)</td>
<td>4.1 (3.0-4.9)</td>
<td>4 (3.2-4.6)</td>
<td>4.2 (3.5-4.7)</td>
</tr>
</tbody>
</table>
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Delirium management

- When a finding goes against prevailing wisdom:
  - Result = complicated grief
  → Denial, anger, bargaining, depression, anger...

- Study needs to be confirmed but:
  - Look more closely at non-pharmacological management strategies and harm-minimisation
  - Preventative options (melatonin)
Cancer Pain
Cancer pain

- Remains a common consequence of cancer and its treatment
  - ~50% with cancer of any stage – moderate/severe pain
  - ~65-70% with advanced disease – moderate/severe pain

Breivik Ann Oncol 2009 (20)
Teunissen J Pain Sympt Manage 2007(34)
Opioids

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1986
www.who.int/cancer/palliative/painladder/en/
```
Opioids

- 70-100% will achieve adequate analgesia for cancer pain when ladder used appropriately

- Unclear factors for treatment failure
  - Pain subtype
  - Intensity of pain at rest
  - genetic mutations (OPRM1) (OPRK1)

Jadad AR, JAMA 1995;274, Quigley C, BMJ 2005 8;331
Oosten AW, Pharmacogenomics 2016 Aug;17(13)
Opioids

- Use of opioids in cancer palliative care
  - 6080 patients in UK over 7 years
  - 48% prescribed strong opioid within the last 12 months
  - Median 9 weeks before death (IQR 3-23 weeks)
  - No difference cancer type, gender
  - Less in older age group, less in hospital death vs hospice death

- **Opioids**
  - Morphine: MS Contin / Ordine / Kapanol
  - Tramadol: Tramal / Zydol
  - Oxycodone: OxyContin / OxyNorm / Endone
  - Fentanyl patches: Durogesic / Dutran / Denpax / ...
  - Fentanyl oral tablets: Abstral / Fentora
  - Buprenorphine: Norspan
  - Tapentadol: Palexia
  - Methadone: Physeptone
Refractory pain

- Diagnose the problem
- Treat underlying pathology
  - This may no longer be feasible
- Optimise opioid (dose, route, opioid rotate)
- Consider adjuvants
- **Ketamine**
  - Widely used following positive open-label case series from local and European studies in the early 2000s
  - Dissociative anaesthetic with NMDA receptor antagonist effect
  - Promoted for use in refractory pain states
Randomized, Double-Blind, Placebo-Controlled Study to Assess the Efficacy and Toxicity of Subcutaneous Ketamine in the Management of Cancer Pain

Janet Hardy, Stephen Quinn, Belinda Fazekas, John Plummer, Simon Eckermann, Meera Agar, Odette Spruyt, Debra Rowett, and David C. Currow

ABSTRACT

Purpose
The anesthetic ketamine is widely used for pain related to cancer, but the evidence to support its use in this setting is weak. This study aimed to determine whether ketamine is more effective than placebo when used in conjunction with opioids and standard adjuvant therapy in the management of chronic uncontrolled cancer pain. Ketamine would be considered of net benefit if it provided clinically relevant improvement in pain with limited breakthrough analgesia and acceptable toxicity.

Patients and Methods
In this multisite, dose-escalation, double-blind, randomized, placebo-controlled phase III trial, ketamine or placebo was delivered subcutaneously over 3 to 5 days.

Results
In all, 115 participants were included in the primary analysis. There was no significant difference between
Ketamine

- Phase III Randomised Placebo-controlled trial
  - 10 participating sites across Australia
  - 3 years to accrue 185 patients
- No difference placebo: ketamine
- 27%:31% response rate
- More adverse events
- NNT 25
- NNH 6
The response...

- More grief!
- Reduction but not elimination of use of Ketamine
- Exploration of other therapeutic strategies
- Increased attention to monitoring side effects
Cannabis

- Cannabis plant contains >60 cannabinoids
- Primary psychoactive cannabinoid is D9-Tetrahydrocannabinol (THC)
- THC interacts with endo-cannabinoids with multiple receptors in peripheral and central nervous system
Medicinal Cannabis

- Published RCTs have explored the role of cannabinoids for:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea/vomiting with chemo</td>
<td>Appetite stimulation in HIV/AIDS</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>Spasticity due to MS or paraplegia</td>
</tr>
<tr>
<td>Depression</td>
<td>Anxiety disorder</td>
</tr>
<tr>
<td>Sleep disorder</td>
<td>Seizures</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>Tourette’s syndrome</td>
</tr>
</tbody>
</table>
Cannabis – chronic pain

Whiting *JAMA* 2015;313
Nabiximols (Sativex)

- Oromucosal spray
- D9-Tetrahydrocannabinol (THC) 27mg/mL:
  Cannabidiol (CBD) 25mg/mL

- Two main published phase 2 studies in cancer pain
Nabiximols

- N=177 cancer pain
- Placebo-controlled, THC:CBD vs THC extract
- Mean pain score reduction
  THC:CBD -1.37 vs -0.69 Placebo (p=0.014)

Johnson JR, *J Pain Symptom Manage* 2010;39(2)
Nabiximols

- N=360 cancer pain
- Placebo controlled, low/medium/high dose Sativex
- Primary end-point (30% responder rate) – not reached
- Secondary analysis: low/medium dose improvement in pain reporting (p=0.035)

Portenoy RK. J Pain 2012;13(5)
Nabiximols

- Series of Phase 3 studies 2012-2015
- Closed to accrual early at predetermined preliminary analysis
- No improvement over placebo for primary end-point
- Subgroup analyses of US based sites showed improvement in pain scores (p=0.024)
- Unpublished to current date

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A brief history...

**UK**
- 1950s Dr Cicely Saunders
  - Multidisciplinary care of the dying
- 1967 St Christopher’s Hospice

**Australia**
- 1992 Pall Medicine Society
- 1999 Board Certification
- 2009 174 Pall Care Physicians
- 2010 123 hospital palliative care units (1:6 hospitals)

**North America**
- 1960s Kubler-Ross
  - “On death and dying”
- 1974 Balfour Mount
  - ‘Palliative Care’ → Montreal → world
- 1988 Academy of Hospice Physicians
- 1997 IoM Report
- 2006 board certification in Hospice / Palliative Medicine
- 2009 >1500 PC teams in US
Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial

Camilla Zimmermann, Nadia Swami, Monika Krzyzanowska, Breffni Hannon, Natasha Leighl, Amit Oza, Malcolm Moore, Anne Rydall, Gary Rodin, Ian Tannock, Allan Donner, Christopher Lo

Summary

Background Patients with advanced cancer have reduced quality of life, which tends to worsen towards the end of life. We assessed the effect of early palliative care in patients with advanced cancer on several aspects of quality of life.

Methods The study took place at the Princess Margaret Cancer Centre (Toronto, ON, Canada), between Dec 2 and Feb 28, 2011. 24 medical oncology clinics were cluster-randomised (in a 1:1 ratio, using a computer-generated stratified block size) by clinic size and tumour site (four lung, eight gastrointestinal, four genitourinary, six gynaecological), to consultation and follow-up (at least monthly) by a palliative care team or to standard care. Completion of the interventions was assessed with the PC-SQ 28.

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial


Abstract

Purpose We evaluated the impact of early integrated palliative care (PC) in patients with newly diagnosed lung and GI cancer.

Patients and Methods We randomly assigned patients with newly diagnosed incurable lung or colorectal GI cancer to receive either early integrated PC and oncology care (n = 175) or usual care (n = 175) between May 2011 and July 2015. Patients who were assigned to the intervention met with a PC clinician at least...
An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial

Irene J Higginson, Claudia Bausewein, Charles C Reilly, Wei Gao, Marjolein Gysels, Mendzas Dzingina, Paul McCrone, Sara Booth, Caroline J Jolley, John Moxham

Summary

Background Breathlessness is a common and distressing symptom, which increases in many diseases as they progress and is difficult to manage. We assessed the effectiveness of early palliative care integrated with respiratory services for patients with advanced disease and refractory breathlessness.

Methods In this single-blind randomised trial, we enrolled consecutive adults with refractory breathlessness and...
Our cancer care services are provided through a partnership between The Royal Women’s Hospital, The Royal Melbourne Hospital and Peter MacCallum Cancer Centre as members of the Victorian Comprehensive Cancer Centre Alliance.

Temel J Clin Onc 2017;35
- Advanced cancer patients and those with advanced organ failure and their carers
  - Should receive dedicated Palliative Care Services
  - Early in disease course
  - Concurrent with disease directed treatments
So how are we doing in Australia?
Our cancer care services are provided through a partnership between The Royal Women's Hospital, The Royal Melbourne Hospital and Peter MacCallum Cancer Centre as members of the Victorian Comprehensive Cancer Centre Alliance.

**Figure 1.1**

2015 Quality of Death Index—Overall scores

The 2015 Quality of Death Index
Ranking palliative care across the world

A report by The Economist Intelligence Unit
- **Quality of death index:**
  - Palliative and healthcare environment (20%)
  - Human resources (20%)
  - Affordability of care (20%)
  - Quality of Care (20%)
  - Community engagement (10%)
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### Figure 1.2

2015 Quality of Death Index—Overall scores

<table>
<thead>
<tr>
<th>Rank</th>
<th>Country</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>UK</td>
<td>93.9</td>
</tr>
<tr>
<td>2</td>
<td>Australia</td>
<td>91.6</td>
</tr>
<tr>
<td>3</td>
<td>New Zealand</td>
<td>87.6</td>
</tr>
<tr>
<td>4</td>
<td>Ireland</td>
<td>85.8</td>
</tr>
<tr>
<td>5</td>
<td>Belgium</td>
<td>84.5</td>
</tr>
<tr>
<td>6</td>
<td>Taiwan</td>
<td>83.1</td>
</tr>
<tr>
<td>7</td>
<td>Germany</td>
<td>82.0</td>
</tr>
<tr>
<td>8</td>
<td>Netherlands</td>
<td>80.9</td>
</tr>
<tr>
<td>9</td>
<td>US</td>
<td>80.8</td>
</tr>
<tr>
<td>10</td>
<td>France</td>
<td>79.4</td>
</tr>
</tbody>
</table>
Victoria – deaths from advanced cancer 2000-2010

<table>
<thead>
<tr>
<th></th>
<th>Whole group</th>
<th>NSCLC</th>
<th>SCLC</th>
<th>Prostate</th>
<th>Breast</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>N = 29,680</td>
<td>N = 11,939</td>
<td>N = 2,693</td>
<td>N = 7,708</td>
<td>N = 7,340</td>
</tr>
</tbody>
</table>

### Access to palliative care

<table>
<thead>
<tr>
<th>No palliative care referral, n (%)</th>
<th>Whole group</th>
<th>NSCLC</th>
<th>SCLC</th>
<th>Prostate</th>
<th>Breast</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>12,287 (41)</td>
<td>4632 (39)</td>
<td>1014 (38)</td>
<td>3209 (42)</td>
<td>3432 (47)</td>
</tr>
</tbody>
</table>

### Timing of palliative care

<table>
<thead>
<tr>
<th>First initiation of palliative approach to care to death, median days (IQR)</th>
<th>Whole group</th>
<th>NSCLC</th>
<th>SCLC</th>
<th>Prostate</th>
<th>Breast</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>27 (10, 64)</td>
<td>25 (10, 54)</td>
<td>23 (9, 56)</td>
<td>31 (11, 77)</td>
<td>28 (10, 74)</td>
</tr>
<tr>
<td>Site of death</td>
<td>Whole group</td>
<td>NSCLC</td>
<td>SCLC</td>
<td>Prostate</td>
<td>Breast</td>
</tr>
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<td>--------</td>
</tr>
<tr>
<td>In hospital</td>
<td>N = 29,680</td>
<td>N = 11,939</td>
<td>N = 2,693</td>
<td>N = 7,708</td>
<td>N = 7,340</td>
</tr>
<tr>
<td>In hospital, acute bed</td>
<td>23,855 (80)</td>
<td>9886 (83)</td>
<td>2211 (82)</td>
<td>6046 (78)</td>
<td>5712 (78)</td>
</tr>
<tr>
<td>In hospital, palliative care bed</td>
<td>17,085 (57)</td>
<td>7039 (59)</td>
<td>1552 (58)</td>
<td>4326 (56)</td>
<td>4168 (57)</td>
</tr>
<tr>
<td>In hospital, palliative care bed</td>
<td>6770 (23)</td>
<td>2847 (24)</td>
<td>659 (25)</td>
<td>1720 (22)</td>
<td>1544 (21)</td>
</tr>
</tbody>
</table>

Collins J Pain Sympt Manage 2016;52
Issues

- Outpatient delivery
  - Stand-alone vs embedded
  - Patient-centredness

- Interdisciplinary care seems important
  - Seems logical, but RCT evidence lacking
- **When and who should be referred?**
  - studies based on diagnosis/prognosis vs needs
  - Automatic referral vs clinician-driven?
  - Consensus criteria?

- **Generalist palliative care vs Specialist palliative care**
  - Role of GPs
Patient and carer needs

- Symptom management
- Information needs
- Communication
- Service Provision and coordination
- Psychological and social care

Moore *Pat Edu Coun* 2013
The Future?

- Standardised palliative care intervention
- Replication of findings across different settings and patient groups
- Enhanced therapeutics
- Increasing clinical research and clinical trials
Palliative care in residential aged care

Dr Alex Clinch
Deputy Director Palliative Care,
The Royal Melbourne Hospital and Peter MacCallum Cancer Centre
- Palliative care in RACFs
- Identifying the terminal phase
- Symptom management
- Communication
Our cancer care services are provided through a partnership between The Royal Women’s Hospital, The Royal Melbourne Hospital and Peter MacCallum Cancer Centre as members of the Victorian Comprehensive Cancer Centre Alliance.

Deaths by sex and age group, AIHW 2017

1/3 of all deaths in Australia occur in RACFs
RACF population

- increasingly frail

- projected 70% increase in profound disability from 2006 to 2031

Giles MJA 2003;179
Different needs at end of life

- multiple clinical diagnoses that require a variety of treatments
- require terminal care for a shorter period of time (av 2 days of intense care prior to death)
- confusion, dementia +/- or communication difficulties may be present
- some lack family support

Blackburn Palliative Medicine 1989;3
Which form of palliative care?

- Palliative approach
- Specialised palliative service provision
- End-of-life (terminal) care
Palliative approach

- The condition is not amenable to cure but providing active treatment may still be important eg. titrating diuretics, treating infective exacerbation of COPD.

- Primary goal = improve level of comfort and function and address psycho-social-spiritual needs
Specialist palliative care

- Augments the palliative approach with focused, intermittent, specific input

- Goals = assessment and treatment of complex symptoms; provide information and advice on complex issues (eg. ethical dilemmas, family issues or psychological or existential distress)
End-of-life (terminal) care

- Final days or weeks of life when care decisions need to be reviewed more frequently; death is imminent

- Goals = more acutely focused on the resident’s physical, emotional and spiritual comfort, and support for family
Figure 5. Trajectories of eventually fatal chronic illnesses. Source: Lynn and Adamson 2003.
Identifying the terminal phase

- Assists team in providing appropriate care and communication
- Difficult with a number of comorbidities and different to cancer population
- Clinician predictions of survival are inaccurate and tend to overestimate
Signs of approaching terminal phase

- requiring frequent intervention
- being bed-bound
- loss of appetite
- profound weakness
- trouble swallowing
- dry mouth
- weight loss
- becoming semi-conscious, with lapses into unconsciousness
- day-to-day deterioration that is not reversible

Addington-Hall British J Cancer 1990;62
- ‘trip wire’ questions:
  
  - Does resident/family choose goals of comfort rather than curing underlying disease?
  - Has there been a new diagnosis? (eg. cancer, dementia, MS, MND, stroke, heart failure)
  - Has there been a recent decline in function?
- Needs of residents dying in RACFs

- Most common physical problems:
  - pain
  - personal cleanliness
  - dyspnoea
  - incontinence
  - fatigue

Reynolds J Pall Med 2002;5
- Palliative care in reach program at RMH/PMCC

- 120 episodes over 12 months

- Symptoms:
  - 35% fatigue/drowsiness
  - 24% pain
  - 16% restlessness/distress
  - 11% dyspnoea
  - 14% other: nausea, anorexia, anxiety
EOLC in RACF - practical considerations

- venue of care
- staffing
- route and choice of medication
- anticipating symptoms
- identifying needs
- in one study a third of RACFs had transferred or discharged a resident requiring a palliative approach: 76% to an acute hospital, 14% to hospice, 8% to home

- Main reason for transfer was need for expert or acute care or extra resources (57%)
Venue of care

- Transfer home requires:
  - available carer(s)
  - referral to community palliative care
  - equipment
  - medications
  - involvement of GP
Medications and EOLC

- Rationalise regular medications
- Continue: analgesia, antiemetics, anxiolytics, anticonvulsants
- Route: transdermal, sublingual, subcutaneous
- Regular dosing
- Use of syringe drivers
Pain

- Assessment
- Options:
  - Transdermal: fentanyl, buprenorphine
  - Subcutaneous: morphine 4/24 sc strict or infused via syringe driver

- Always chart prn sc analgesia
Dyspnoea

- General measures: air movement, fan
- Oxygen for comfort (not SaO2)
- Prescribe opioid for dyspnoea as per pain
- Consider sedation if distress/anxiety present
Respiratory secretions

- Positioning
- Avoid suctioning
- Hyoscine hydrobromide, atropine 0.4mg SC q4h
- Family care
Agitation/distress

- Consider reversible causes: pain, urinary retention, faecal impaction
- Clonazepam oral liquid - 5 drops SL pen, can be charted as regular bd/tds dose
Communication issues

- Family conference
- Emphasise “doing everything” for dying person
- Address requests for transfer to acute
- Address emotions
- Anticipate questions:
  - prognosis and what to expect
  - nutrition and hydration
  - hearing and touch
  - arrangements after death
Nutrition and hydration

- Frequently requested by family
- Offer oral intake as able
- Education and addressing emotions

- Placebo-controlled RCT in cancer patients at end of life: no change in symptoms or survival

Bruera J Clin Oncol 2013;31
Resources

- Guidelines for a palliative approach in residential aged care

- Therapeutic guidelines: Palliative Care