Negotiating Dementia Care

Aged Care & Palliative Care working together

Kirsten James & Julie Paul
Aim for today's session:

To provide practical suggestions on how to negotiate the best possible palliative care outcomes for people with dementia
Our premise:
To negotiate successfully and appropriately, as health care professionals carers we need to be:

✓ Advocates for the people we care for
✓ Person-centred
✓ Holistic
✓ Communicative
✓ Flexible
✓ Accommodating
Who are we and what do we do?

DBMAS Vic

• A 24-hr phone based service for people with dementia and their carers and / or care workers where behavioural and psychological symptoms of dementia are impacting on the care relationship

• Advice, referral, assessment, intervention, education and specialised services to

• Enhance, support and collaborate with existing services

Freecall™ 1800 699 799

DBMAS Vic can also be contacted via dbmas@svhm.org.au
Who do we help? Everybody!

- Home based carers, RACF staff, management, ACAS, care package providers, volunteers, people seeking advice or information, day respite staff, hospital staff, GPs, geriatricians, psychiatry, aged persons mental health, transition care, allied health.....
Tier 1: No dementia
Management: Universal prevention, although specific strategies to prevent dementia remain unproven

Tier 2: Dementia with no BPSD
Prevalence: 40%†
Management: By selected prevention, through preventive or delaying interventions (not widely researched)

Tier 3: Dementia with mild BPSD
(eg, night-time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing)
Prevalence: 30%‡
Management: By primary care workers

Tier 4: Dementia with moderate BPSD
(eg, major depression, verbal aggression, psychosis, sexual disinhibition, wandering)
Prevalence: 20%†
Management: By specialist consultation in primary care

Tier 5: Dementia with severe BPSD
(eg, severe depression, psychosis, screaming, severe agitation)
Prevalence: 10%†
Management: In dementia-specific nursing homes, or by case management under a specialist team

Tier 6: Dementia with very severe BPSD
(eg, physical aggression, severe depression, suicidal tendencies)
Prevalence: <1%†
Management: In psychogeriatric or neurobehavioural units

Tier 7: Dementia with extreme BPSD
(eg, physical violence)
Prevalence: * Rare†
Management: In intensive specialist care unit

* Prevalence is expressed as estimated percentage of people with dementia who currently fall into this category.
† Estimate based on clinical observations.
‡ Estimate based on Lyketsos et al.²
Banksia Palliative Care Services Inc

- Community based palliative care service
- North east suburbs of Melbourne
- Covers 3 local council areas of Nillumbik, Whittlesea and Banyule
- 330,000 population
- 1000 square kilometres
- Average 520 clients per year
People with Dementia

Can we do better?
Who should receive palliative care?

✓ Chronic condition +
✓ Progressive in nature +
✓ Has a terminal phase some time in illness +
✓ Person with Dementia and their family want to focus on quality of life
The Conventional Model of Care Versus an Improved Model

Rand Health (2006); Redefining and Reforming Health Care for the Last Years of Life, Rand Health Research Highlights, At: http://www.rand.org/pubs/research_briefs/2006/RAND_RB9178.pdf
Trajectories of chronic progressive, eventually fatal illness in the elderly

Who provides palliative care to people with dementia?

<table>
<thead>
<tr>
<th>Patient #</th>
<th>Time with a life limiting illness</th>
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Episode of care scenarios to meet palliative care needs.

(Palliative Care, Quality Resource Guide, Palliative Care Australia, 2005)
What are your challenges in caring for palliative care people with Dementia?
Some of the challenges to practice:

1. Clients
2. Families
3. Organisational
   • Time constraints
   • Lack of process
   • Lack of policy and procedure / clinical practice guidelines
   • Lack of dementia specific tools
   • Lack of education
4. US!!
   • Inconsistency within health professionals
   • Assessment processes
   • Poor communicators
   • Subjective perspectives
   • Lack of education
“If it was me...”

Mrs AB, a 90 year old resident in an aged care facility, was suffering dementia and was approaching her death. After family members had contacted their mother’s doctor, he wrote in the nursing notes:

“Family requests comfort care only at this stage. Antibiotics ceased. May have morphine 5 – 10 mg 4 times in 24 hours prn”

Mr AB was suffering from quite severe bedsores and was constantly calling out “Help me, help me” – as she had done for protracted periods during her three years in the facility

According to the nursing records only 6 doses of morphine were given in the last 6 days of this woman’s life – only 25% of the permitted dose. On some of those days she had received two or three doses of morphine, but on other days she had received none at all. Neither the RN who chose to give the morphine, nor those who did not, gave clear reasons in the nursing notes for their decision.

Nursing notes read:

“Very quite evening, no medication given”
“In distress, calling out needs attention 2 hourly”
“Accepting small amounts of thickened fluids. IM morphine 10mgs at 1220”
Do People With Dementia Experience Pain?

• Normal reasons for pain in the elderly

• Dementia itself eg. muscular distress caused by prolonged periods of muscular tensing or the person may simply be putting themselves in positions for protracted periods of time that are not corrected

• People with dementia are much less likely to receive treatment for pain and when they do it is often prn (H Merl, April 2005)
Is PRN analgesic alone appropriate for palliative care people with Dementia?

Ask yourself “Am I confident 100% that the person with Dementia is pain free?”

PRN Medication is based on two assumptions
1. That the person with dementia will recognise they are in pain and they will ask for analgesic
2. That staff will recognise the person is in pain and will consistently give the analgesic
Nine Domains of Pain Assessment

1. Physical assessment (top to toe physical assessment, PQRST, PH, current history)
2. Psychological assessment
3. Social assessment
4. Cultural assessment
5. Spiritual assessment
6. Sexuality
7. Medication review
8. Investigations
9. Care Plan (ask client/resident/family re short and long term goals)
Do you know who your Specialist Palliative Care Service is?

http://www.pallcarevic.asn.au/

A Palliative Care Service near you

Enter your post code ______________

This post code service is provided by the: Department of Human Services.

Not sure of your Postcode? Click Here

List of Palliative Care Services in Victoria
Why would you refer to a specialist palliative care service?
How would you refer a person to a specialist palliative care service?
How can your local palliative care service assist?

• Family meetings
• Case conferencing with health professionals
• Advance care planning
• Symptom assessment
• Medication advice
• Client / Resident / Family support
• Staff education
• Bereavement support
• Access to interdisciplinary team pending your need
• Volunteers
• Staff debriefing
• Policy development and review
• Establishment of palliative care committee
Free Resources in Palliative Care ...
Commonwealth Palliative Care Publications


Phone: (02) 6269 1000
Program of Experience in the Palliative Approach (PEPA)

What is PEPA? PEPA aims to improve the quality and accessibility of palliative care to people with life-limiting conditions, and their families.

PEPA provides a broad range of health care professionals the opportunity to increase their experience, knowledge and skills in the delivery of the palliative approach. In Victoria this is achieved through clinical placements, workshops, post placement support, and supporting Indigenous health workers to participate in PEPA. Clinical placements will be offered to general practitioners, nurses and Indigenous health workers. Workshops will be offered to all health professionals.

Supervised clinical placements

Applications are now being sought for PEPA supervised clinical placements in 2009. Applications will be accepted from the following health care providers:

Medical/general practitioners Nurses (general health care, residential aged care and specialist palliative care) Aboriginal health workers

Due to funding restrictions the number of supervised clinical placements available is limited. If your application is unsuccessful this year, we will try to accommodation your application in future years. Participation in the program is limited to once only for all individuals.
Palliative Care Australia
http://www.pallcare.org.au/

Publications

Palliative Care Australia produces a range of publications. For copies of our publications please send an inquiry through our Contact tab. The following items can be opened and downloaded on your computer.

Please click on the publication title to download the document. All documents are in PDF format.

- Standards for Providing Quality Palliative Care for all Australians
- Standards brochure
- Standards: Rights and responsibilities
- Asking Questions Can Help - an aid for people seeing the palliative care team
- A Journey Lived
- Facts about morphine and other opioid medicines in palliative care
- Annual Report 2005-06
- Annual Report 2004-05
- Palliative Care Service Provision in Australia: A Planning Guide 2003 (2nd Edition)
- A Guide to Palliative Care Service Development: A population based approach - 2005
- Palliative Care National Directory 2004
- "The hardest thing we have ever done" - The social impact of caring for terminally ill people in Australia, 2004
- State of the Nation - Report on National Census of Palliative Care Services 1998
- Multicultural Palliative Care Guidelines 1999
- SASA - Self Assessment Service Audit 2001

Multicultural Brochures

Click on the publication title to download the document.

All documents are in pdf format.

Relief, Comfort and Support - Caring for a loved one who has a terminal illness.

- Arabic
- Bosnian
- Chinese
- Croatian
- English
- Greek
- Hindi
- Italian
- Japanese
- Khmer
- Korean
- Macedonian
- Maltese
- Persian
- Polish
- Portuguese
- Russian
- Serbian
- Spanish
- Turkish
- Vietnamese
Welcome to CareSearch. CareSearch is an online resource of palliative care information and evidence. All materials included in this website are reviewed for quality and relevance.

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<th>For Health Care Providers</th>
<th>For Researchers and Palliative Specialists</th>
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<td><strong>Palliative care will affect all of us at some stage in our lives as a patient, carer, family member, neighbour or friend. The following resources may help.</strong></td>
<td><strong>There are different disciplines and individuals involved in providing palliative care. These resources provide information and resources for health care professionals.</strong></td>
<td><strong>Palliative care researchers and palliative care specialists may benefit from a range of specific resources and tools including:</strong></td>
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What's new on the site... Knowledge Network Project pages... Indigenous Resources... click for more

What's new in the Palliative Care Community... Communicating prognosis guidelines... Respecting Patient Choices Literature Review...click for more

Have you heard... CareSearch visitor numbers and community feedback
http://www.respectingpatientchoices.org.au

If we know your choices for future health care we are able to respect them.
Palliative Care and Dementia Discussion Paper No. 7

This paper sets out why palliative care can be important as death approaches; describes how a person with dementia can be assisted to die in comfort and with dignity; emphasises that flexibility is needed to respond to the unique needs of the individual and emphasises the importance of involving the family and carers and attending to their separate needs throughout this critical time.

Palliative Care and Dementia - Discussion Paper
PDF file, 2332 KB, February 2006
Useful Website:
www.palliativedrugs.com

Developed in 2000 by Robert Twycross and Andrew Wilcock in order to promote and disseminate information about the use of drugs in palliative care.
Network and Seek Opportunities....

• Join the palliative care consortium regional advisory committee
• Subscribe peak palliative care bodies for example Palliative Care Victoria and Palliative Care Australia
• Consider joining Banksia’s:
  – Aged care palliative care journal club
  – Aged care palliative care benchmarking group
• Review your current palliative care policies and procedures
• Set up a palliative care committee
• Survey past clients
• Survey staff
• Consider introducing a process for death reviews
• Review tools being used for clients/residents with Dementia
• Apply for PEPA
• Plan an activity for palliative care week next year
• Network with your local GP Division to improve care
• Present your work at the next ANF conference!!
Person Centred Care Approach

• Attention to the whole person

• Life story as a key to care

• Enhancing, utilising and validating remaining capabilities and senses

• Acknowledging and appropriately responding to the feelings underlying any confused speech and behaviour
How do we get to truly know the people we care for?

• Comprehensive, collateral assessment
• Spending time with them
• Use of Life Story
Where is this information kept & how is it disseminated?

- Assessments
- Care plans
- Family & Team meetings
- Handovers
- Life stories
YOU SHOW ME YOUR INDIVIDUAL CARE PLAN... AND I’LL SHOW YOU MINE...
Kirsten’s philosophy:

• Don’t wait until the person’s funeral to learn new things about them!

• Look at the light, and not the lampshade!

(Remember Gladys Wilson?)
Life Story

• Supports identity
• Useful for reminiscence & life review
• Can help loved ones with the grieving process
Life Story provides greater understanding of the person & can:

• Explain patterns of behaviour & why past experience can affect person in the present
• Promote communication & interaction
• Remind caregivers that the non-verbal person still has something to say & contribute
Other ways of supporting the person on their journey:

- Volunteers
  - Palliative Care Victoria training
  - In-house training incl. Life Story

- The “Favourites” activity
Endorphins

• Boost immune system
• Reduce pain experience
• Alter mood
• Improve sense of well being!
Unfortunately Grandpa has lost bowel control so we're allowing him to die with dignity.
BPSD that will not respond to medication:

• Wandering
• Socially inappropriate urination/defecation
• Socially inappropriate dressing/undressing
• Annoying repetitive activities (perseveration) or vocalisation
• Hiding/hoarding
• Eating inedibles
• Tugging at/removing restraints
BPSD that may respond to medication

- Anxiety
- Depressive symptoms
- Sleep Disturbance
- Manic-like symptoms
- Persistent and distressing hallucinations/delusions
- Persistent verbal and physical aggression
- Sexually Inappropriate Behaviour

Helping Australians with dementia, and their carers
Advantages of Non-Pharmacological Interventions in BPSD

- Address the psychological, environmental and underlying reasons for the behaviour
- Recognises rather than masks the underlying needs being communicated by the behaviour
- Less limitations than pharmacological management, i.e. side effects, drug interactions
- Practical and relatively in-expensive
- Predominantly psychosocial approach ↑ carer attitudes towards care recipients with BPSD compared to pharmacological approach
What can activities do for the person?

- Encourage independence
- Help maintain skills
- Encourage self expression
- Maintain and improve self-esteem
- Compensate for lost abilities
- Provide a sense of purpose and pleasure
- Provide an avenue for social contact
- Provide a structure for the person’s day
- Provide a continuation of the person’s life story
- Help reduce behaviours
- Maintain and improve quality of life
- Prevent boredom and sense of isolation
Additional Resources:

• Sheet provided
• Alzheimer’s Australia Victoria workshop
Living with dementia
How the environment, technology and you can help

This website provides information about how changes to the environment and use of assistive technology may support the independence, safety and leisure of people living with dementia. You will also find quick links to product information.
• In summary

“Death is not the ultimate tragedy of life. The ultimate tragedy is depersonalisation – dying (or living) in an alien and sterile area, separated from the spiritual nourishment that comes from being able to reach out to a loving hand, separated from a desire to experience the things that make life worth living, separated from hope”

- Dr Norman Cousins, Anatomy of an Illness
Thank you for listening to our presentation
For further information please contact:

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Kirsten James  
Kirsten.JAMES@svhm.org.au