Palliative Care is Everyone’s Business

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Anglicare Australia Brisbane Sept 2013
Myth: Hospice and palliative care is just for people with cancer

Fact: All those who are diagnosed with a chronic life-limiting illness can benefit from hospice and palliative care.
MYTH

Having hospice and palliative care means you will die soon.

FACT

Hospice and palliative care is not just for the end of life. It is a holistic approach that includes caregiver support, spiritual care, bereavement and much more.
**MYTH**  
Palliative care manages pain through the use of addictive narcotics.

**FACT**  
Palliative care is whole person care that provides psychosocial and spiritual care along with pain and symptom management.
What is Palliative Care?

Palliative care is an approach that 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 by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Dying in Australia

• In 2011 there were almost 147,000 deaths in Australia

• Around 107,000 could have been enhanced by access to palliative care

• Less than half were

• Australians want to die at home but the vast majority die in hospital
Context

- Number of people dying annually in Australia will double in next 40 years.
- Over 85 year old age group will quadruple over this period.
- Implications for the provision of quality end of life care through the health system, within aged care and within the community. It also emphasises the need for all health professionals to receive education in end of life care.
- Every clinician is trained to conduct CPR but will rarely use this skill, yet few are trained to recognise when a palliative approach would be more appropriate than curative treatment.
Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all.
From this experience I have come to appreciate the fragility and value of life. I've learned to care about someone other than myself, to give freely without expecting anything in return.

Keith Barile
Advance Care Planning

• Most people have not discussed preferences with loved ones

• Most people haven’t recorded anything about what care they want at the end of their lives in an advance care plan or otherwise

• Most people haven’t asked their loved ones about their preferences

Let’s chat about dying

Don’t leave it too late
Make sure you tell those closest to you what you want for the end of your life

Find out about support and services at: www.palliativecare.org.au

Palliative Care Australia
Why do Advance Care Planning?

- 80% of deaths occur under the care of health professionals
- When it comes time to make end of life decisions 50% will be incapable
- Uncertain - default is to treat
- If there have been no conversations about end of life issues it is difficult to reliably predict people’s true wishes
Instructions for completing this workbook and Advance Care Directive

1. Get the information you need to make an informed decision
   Make use of the Asking Questions about Dementia Care Help booklet at the back of this folder.

2. Think about your values and beliefs and what quality of life means to you
   There are some questions soon that will help you to work this out.

3. Talk to your family and those closest to you

4. Decide who will be your Person Responsible
   There are some questions in the Workbook to help you here.

5. Complete this Workbook

6. Complete your Advance Care Directive
   You can use the form at the back of the Workbook or you can just write down your wishes in a letter.

7. Don’t lock these documents away anywhere!
   Give copies to your Enduring Guardian or Person Responsible, other members of your family and/or friends, tell your doctor or other health care provider and get them to keep a copy in your medical record.

8. Review your plan regularly
   If you make any changes don’t forget to replace all the copies you have left with people!

www.palliativecareensw.org.au
Nurses too busy to speak to dying patients in their final hours

Doctors and nurses are too busy to speak to dying patients on hospital wards while many of the terminally ill keep quiet because they don’t want to be a burden, a report warns.
What did we get?

Palliative and end of life care should be core business for aged care services
Living Well & Dying Well project in Aged Care
The Gold Standards Framework in Care Homes Training Programme

Aims

1. To improve **quality** of end of life care for all residents
2. To improve **collaboration** with GPs, primary care teams and specialists
3. To reduce avoidable **hospitalisation** in the last stages of life
GSF 7C’s
Communication
Collaboration
Coordination
Continuity
Control of symptoms
Care of dying
Continued learning
Care of carers
Gold Standards Framework

CARE is

- Person centred.
- Dignity promoting.
- Aligned with person’s values, priorities and preferences.
- Planned ahead, avoiding crises

- Culture change (heart)
- Training (head)
- Framework (hands)
3 triggers for the Register:

The Surprise Question

General Indicators

Specific Clinical Indicators
Ask the Surprise Question
Would you be surprised if the patient were to die in the next months, weeks or days?

Step 1

NO

Don’t Know

YES

Do they have General Indicators of Decline?

YES

Don’t Know

NO

Reassess regularly

Do they have Specific Clinical Indicators?

YES

Reassess regularly

NO

Reassess regularly

Begin GSF Process

Identify
Include the patient on the care register.
Discuss at team meeting.

Assess
Discuss this with patient and carers, assess needs and likely support and record advance care planning discussions.

Plan
Plan and provide proactive care to improve coordination and communication.
Identifying the Person’s Preferences for:

1. **Information**
   diagnoses, prognosis, if dying, pathway care options

2. **Involvement in Decisions**
   about day to day care + medical care + planning in advance

3. **Preferred Place of Care**
   now, when deteriorates, dying.
Advance care planning

Dignity, Values and priorities

Freedom... Choice... Autonomy... Comfort... Pleasure... Joy... Safety... Security... Certainty... Quality of Life preferences
What is Important to Bill

What is important to Bill

- Being healthy and alive
- To be well cared for - as I can't remember things
- To be “well fed and watered”
- Painting and craft
- Reading the paper and doing the crossword
- To have a shower every morning and be smartly dressed
- To be independent
- Looking after his budgie
- Listening to classical music and comedy shows on his radio
- Going out for meals particularly at Christmas
- Having someone to have a laugh and a joke with
- To know he has someone to listen to him when he has a problem

What others like and admire

Friendly
Helpful
Enthusiastic
Enjoys a laugh
Independent

How best to support Bill

- Qualified nurse to discuss issues with Bill when he feels the need
- Ensure Bill has clean towels for his shower each morning
- Give Bill clean bed linen so he can make his own bed
- Help Bill with his crossword when he gets stuck
- Remind Bill when the painting and craft class are on if he forgets
- If there is an outing anywhere ensure Bill is invited to go
- Be prepared to sit and talk to Bill, especially when he gets frustrated and forgets things, he needs a lot of reassurance.
- Assist Bill to go shopping for new clothes etc as needed
- When giving Bill information remind him to write it down in his book
- Accompany Bill to go to hospital appointments etc as needed.
“This project has given me a process I can use to work through end of life discussions with residents and families. It makes me more confident in this area and takes much of the stress from my work in this area.”
“We need to look at the deaths of our patients. It is not something we have done before. In the nursing home we can examine whether the dignity of the resident was maintained, whether the preference for place of care was attained and whether anticipatory planning and prescribing were in place to contribute to an overall improved experience”
My daughter knows what kind of treatment and care I want at the end of my life.

Have you told someone what you want at the end of your life?
What do we need in a nutshell ...

All Australians should be able to expect to die with their preventable pain and other symptoms well managed, with the people they wish to be present and, whenever possible, in the place of their choice.
• www.ehospice.com
• News, views and ideas from hospice and palliative care
• International directory of services
Thankyou!

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National Palliative Care Standards

Dignity
Empowerment
Compassion
Equity
Respect
Advocacy
Excellence
Accountability

Standard 1: Individualised care planning involving patient and family
Standard 2: Holistic care
Standard 3: Impeccable assessment
Standard 4: Coordinated care
Standard 5: Support for carers
Standard 6: Respect for patient’s wishes
Standard 7: Values driven service
Standard 8: Formalise access to bereavement care
Standard 9: Building community capacity
Standard 10: Equitable access
Standard 11: Commitment to quality improvement and evidence
Standard 12: Skilled workforce
Standard 13: Care for the caregivers
The Productivity Commission is the Australian Government's independent research and advisory body on a range of economic, social and environmental issues affecting the welfare of Australians.

Its role, expressed simply, is to help governments make better policies in the long term interest of the Australian community.
Palliative Care
everyone’s business
Great idea in theory
Too many varied forms
Forms complex
Can we meet their needs?
Legal?
When is the right time?
AIHW Palliative Care Services

- Hospital admissions up by 50% in 10 yrs
- <25% residents in RACFs receive pall care funding
- Pall med attendances doubled in 5 yrs
- Less scripts by GPs for pall care medications filled
The Senate Inquiry into Palliative Care in Australia

- Broad terms of reference
- PCA spoke at 2 public hearings in Canberra, and our member orgs spoke at all others
- PCA’s submission 146 pp, 138 submissions
- 38 recommendations

I particularly want to commend the work of Palliative Care Australia. They drove this inquiry. They were the ones who haunted our offices and said: 'This is what's happening in our country. We all need to understand the reality of palliative care.' It worked, because when you sit down and have these discussions you know that there is someone in your family or someone in your neighbourhood who is working through these issues and that one day it will be you too.