Is it good enough for your Mum?

*How people die remains in the memory of those who live on.* Cicely Saunders

End of life care – a political issue

- Last year
  - 2/3 over 75 years
  - 1/3 over 85 years
- Predict by huge rise by 2042
- ££ $$
- Baby boomers
  - Always ‘had it good’
  - High expectations
  - Controllers
  - Voters
How we all make decisions

Experience Memories

Feelings

Non-verbal cues
90% communication Reactions

Emotional
Total Pain
Physical

Spiritual
Social
- What we have done in Wales – strategy
- Resources for you
- Illustrate the approach
- Compassion and the law on PAS

Palliative care - fairness in Wales:
Fairness for All

- The non cancer population with End of Life Care needs
- An increasingly ageing population, living longer with co-morbidities
- Younger patients surviving treatments, whose management to improve their quality of life is complex

Overall core service

**Budget ~£2/head popn**

<table>
<thead>
<tr>
<th>Consultant</th>
<th>300,000 population or 20 hospice beds or 40 cancer centre beds or 850 DGH beds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Nurse Specialist</td>
<td>50,000 population or 7 hospice beds or 30 cancer centre beds or 300 DGH beds or Link to nursing home</td>
</tr>
<tr>
<td>AHPs and others</td>
<td>300,000 population</td>
</tr>
<tr>
<td>Beds / notional beds</td>
<td>One / 15,000</td>
</tr>
</tbody>
</table>
Children / adolescents

- Paediatric units – work links
- Transitional care – new post Musc dystrophy

Implementation Board: Oct 2010

http://wales.pallcare.info

Palliative Care in Wales

This site is part of the Palliative Care Matters network of sites. It is aimed at health-care professionals working in the palliative care field.

Are you a Patient or Carer?
If you are a patient or carer and would like to comment on the care you have received from your local palliative care team, you can do this at a website run by Paediatric Care Wales.

Palliative Care Guidelines
The full text of the Palliative Care (Adult) Network Guidelines is freely available online.

Other items of general interest (i.e. outside Wales) can be found on the main website of Palliative Care Matters.

News & Announcements

8th July How to Manage End of Life Care and Bereavement
Posted by feedback on May 10th, 9:33

08 July 2013 | WJEC, 245 Western Avenue, Cardiff, CF5 2YX

The programme for How to Manage End of Life Care and Bereavement is being delivered in partnership with Child Bereavement UK, and has been specially designed for paediatric trainees, SSAGS and consultants.

See flyer for further information
Key steps

- **7 day service**
- Prove outcomes – CaNISC
- iWGC – patient voice
- Quality standards – Peer review
- Education courses
- Non-cancer
- Keep £s

Integrated care
Phases of illness and need

- Palliative care intervention
  - Stable
  - Unstable
    - Unexpected
    - Urgent
  - Deteriorating
    - Expected
    - Non-emergency
  - Dying
  - Bereavement

Acute intervention

- Palliative Care Outcomes Collaborative Assessment tool definitions: Phase V 1.2 December 2008

Diagnosis is key

Symptom → Diagnosis

Prescribing

No relief → Relief
‘The quality of life gap’

![Graph showing the gap between hopes and aspirations and reality over time.]

K Calman

Life prolonging palliative care

- Temel JS et al NEJM 2010;363:733-42

- Early palliative care for patients with metastatic non-small-cell lung cancer

- Quality of life
- Mood
- Survival (11.6 v 8.9 months, p=0.02)
Care in last days of life

? Irreversibly dying
? Do all agree
? Family aware

All futile interventions/medication ceased
Consider fluids for comfort
Plan prn
Review review

Opioid Dose Calculator

NB Conversion values may be updated at intervals; see below for values used in the calculator.

Select Conversion Values:
- "Traditional"
- "Progressive"

Convert From:
Enter total opioid intake in last 24h:
- Oxycodone PO ▼ 160 mg/24h
- Oxycodone SC ▼ 20 mg/24h
- Fentanyl TD ▼ 75 μg/h

To:
- Morphine SC ▼ 325 mg/24h
- 4-hourly PRN: 54 mg q4h
- OR -
  - Transdermal Patch ▼ μg/h

Reset | Show Calculations

Consider reducing doses by up to 25-50% to account for incomplete cross-tolerance

All calculations must be confirmed before use. The authors make no claims of the accuracy of the information contained herein;
Measuring outcomes

- Is everyone seen in 24 hours?
- Do their global scores improve?
- How do they rate our care?
- How much are we influencing others?

iWantGreatCare

![Chart showing scores for various aspects like Trust, Respect, Recommend, Meeting, Listen, Fears, Efficiency, Delay, and Cleanliness. The scores range from 0 to 10, with Trust and Respect scoring 10, Recommend scoring 8, Meeting scoring 7, and the others scoring 5 or less.]
Add your review of the care you received
Please write below what was good and what could be improved

**Excellent - everyone was very caring**

Add your review of the care you received
Please write below what was good and what could be improved

This hospital is wonderful.
I paid privately for my healthcare for years and this is better than private care.

Add your review of the care you received
Please write below what was good and what could be improved

The care that my relative mother received was at all times exemplary. Her needs were met with respect and dignity. I was also treated with respect and I was able to ask questions and had answered with great kindness and consideration. A palliative care service such as this, which the whole is self-funded, needs to be congratulated and commended with the very that are such establishments in Wales reach this level.
The children as relatives and carers

- Children deeply affected by death
- Fragmented families
- Grandparent can provide:
  - Security
  - Unconditional love
  - Guidance, wisdom
  - Confidante

Bereaved Children 5-16yr

7,000 / m experienced death of a parent or sibling
13,000 / m bereaved of a friend

Plus children in care

Bereavement care is the most effective form of preventative medicine

Remember the children
Dignity

is having

a sense of personal worth

Dame Cicely Saunders 1992

Dignity

"Care that confers honour, recognised the deservedness of respect and esteem of every individual - despite their dependency, infirmity and fragility - could lie at the heart of care that conserves dignity"

Chochinov H et al Lancet 2002
Autonomy is relational

Our living and our dying have an effect on those around us

A common story?

- 84 years old
- Advanced cancer
- Pain on any movement
- In hospice

- I’ve had a good life – I’ve had my time

- I just want to die!
Fear the future worse than today

Pain
Loss of dignity (mind / body)
Loss of control
Loss of autonomy
Being a burden

Decisions need

1. Information
2. Capacity to make decision
3. Voluntariness
Information

Diagnosis
- Incurable illness
- Diagnostic errors – 5% at postmortem

Prognosis <6 months
- “medicine is a probabilistic art”
- Prognosis notoriously inaccurate
  - When defined as in ‘last 48 hours of life’, 3% improve again

So you really want to die?

- Listen
- Process request

Message = you are right to think that you’d be better off dead

- What is making today so terrible?
- What can we do to improve today?

Message = you are worth me working hard to improve things
Capacity to make decisions

Mental capacity
- "mental capacity, written down in law, looks simple. It sounds like something objective".
- Cognitively demanding – ‘compos mentis’
  - MND 30% cognitively impaired (HoL)
  - 1 in 8 PAS in Oregon had Motor Neuron Disease

Depression
- Oregon study 18 patients prescription for PAS
- 9 died PAS
- 3 had undiagnosed /untreated depression
- “the current practice of the Death with Dignity Act may not adequately protect all mentally ill patients”
Truly voluntary decisions

- Pressures - internal or external
- Fluctuant desire for PAS
- “Compassion”
  Not all families are loving families

- Influence of physician
- Normalisation in society becomes expectation

Trust of the doctor

- Patients have to trust doctors to give advice & treatment in best interests
- Trust makes patients particularly vulnerable
- Society ‘comforted’ by trust of doctor
No law can be 100 per cent safe

- The gravity of risk involved
- Risk - of death by error or coercion or other unintended cause
- Safeguards - a very high stringency and reliability.
- Can the law could be relaxed without putting larger numbers of more vulnerable people at risk of harm?

Oregon data
population 3.87m  >4 ½ fold increase

Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2012

*As of January 14, 2013
Washington state 6.63m

Dutch data

- 3,695 deaths in 2011
- 1,882 deaths in 2002 when law changed
- Now 1 in 37 of all deaths (all causes)
Not a medical care duty

Euthanasia

Physician assisted suicide

Assisted suicide
Ending suffering?

End life

Duty to relieve suffering?

Intervene

Capacity to experience = personhood
Is the care good enough for your Mum?