



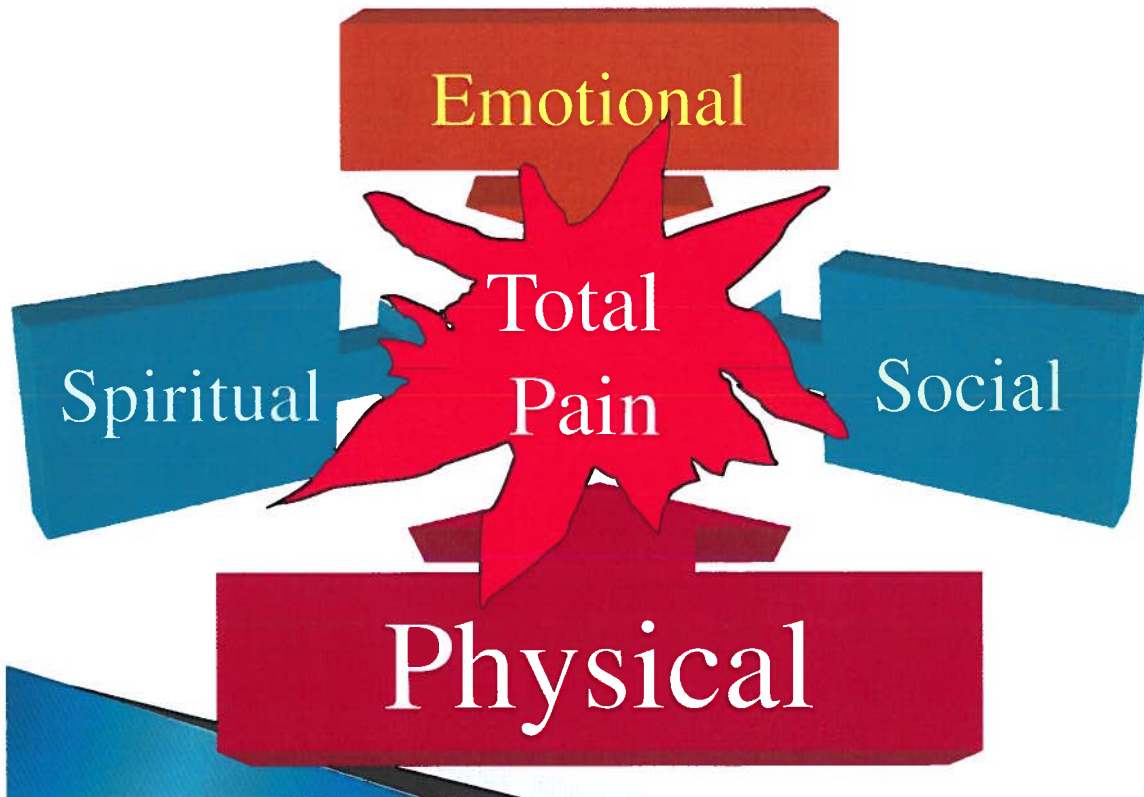
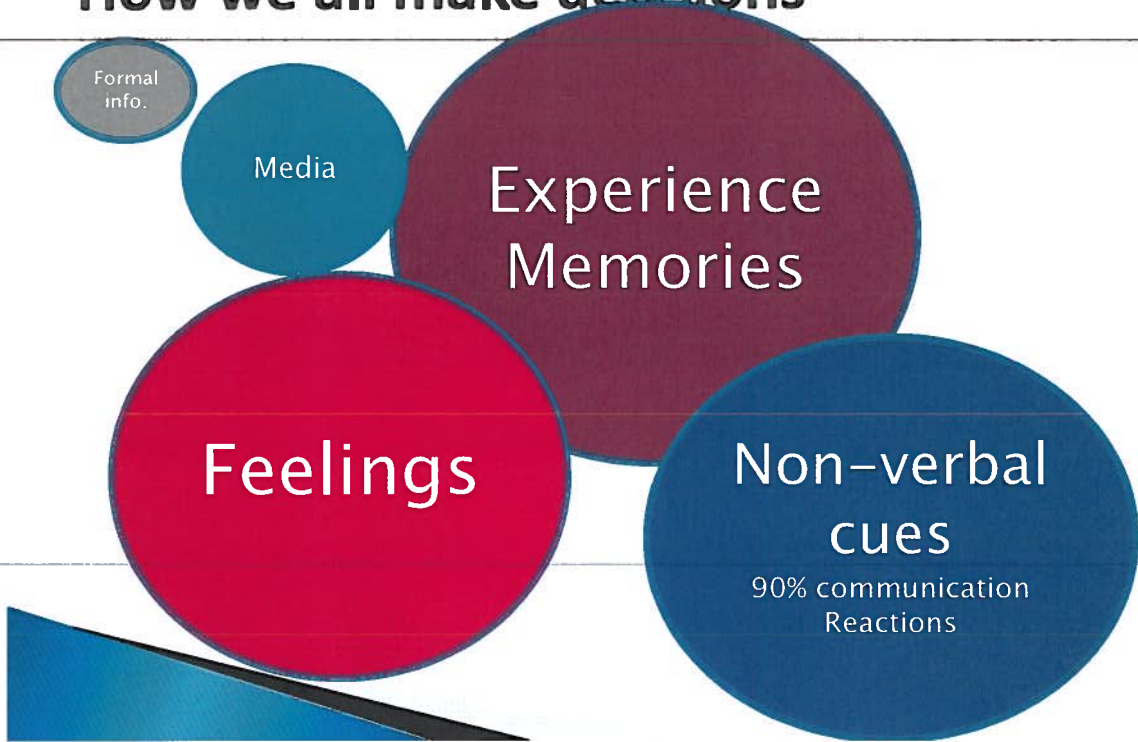
Is it good enough for your Mum?

*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

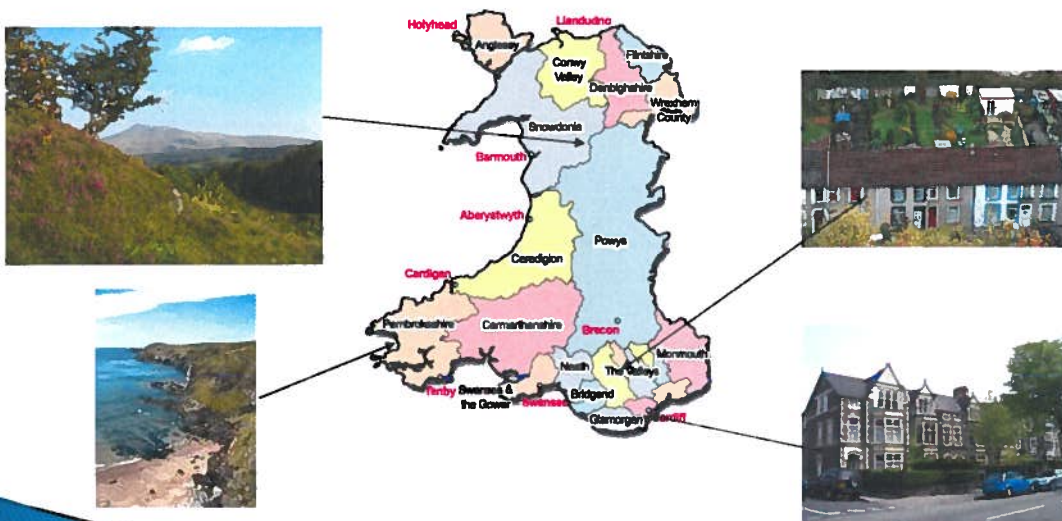
How we all make decisions



-
- ▶ 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
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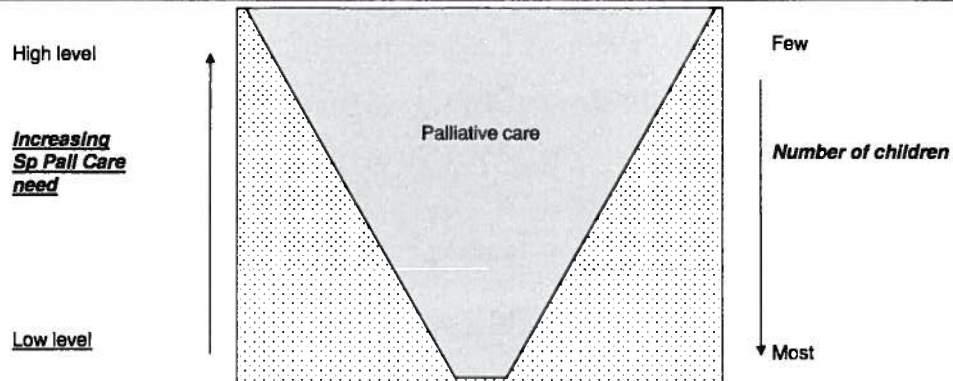


Overall core service

Budget ~£2/head popn

Consultant	300,000 population or 20 hospice beds or 40 cancer centre beds or 850 DGH beds
Clinical Nurse Specialist	50,000 population or 7 hospice beds or 30 cancer centre beds or 300 DGH beds or Link to nursing home
AHPs and others	300,000 population
Beds / notional beds	One / 15,000

Children / adolescents



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



Implementation Board: Oct 2010

http://wales.pallcare.info

Palliative Care in Wales

Projects & Groups
 Implementation Board
 Dying Well Matters
 CaNISC
 Paediatric and Transitional
 Children's Bereavement
 Research

Clinical
 Advance Care Planning
 (wIPADS)
 Anticipatory Prescribing
 Last Days of Life (ICP)
 DNACPR in Community

What's New in Wales?
 Events
 Jobs

Postgraduate Education
 Annual Conference
 Medical

Other
 Are you a Patient or Carer?
 Document library
 Service Directory
 Map of Palliative Care

External Links
 Palliative Care Guidelines

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 iWantGreatCare.

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 lanBack 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, SSASGs and consultants.

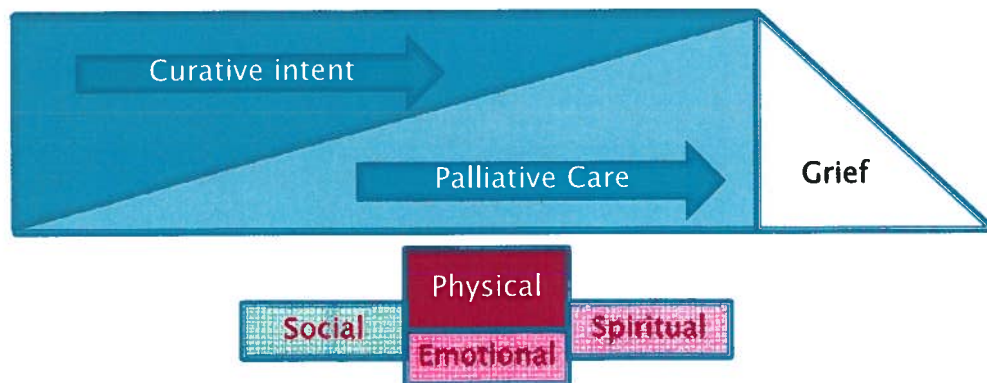
See [Flyer](#) for further information

Key steps

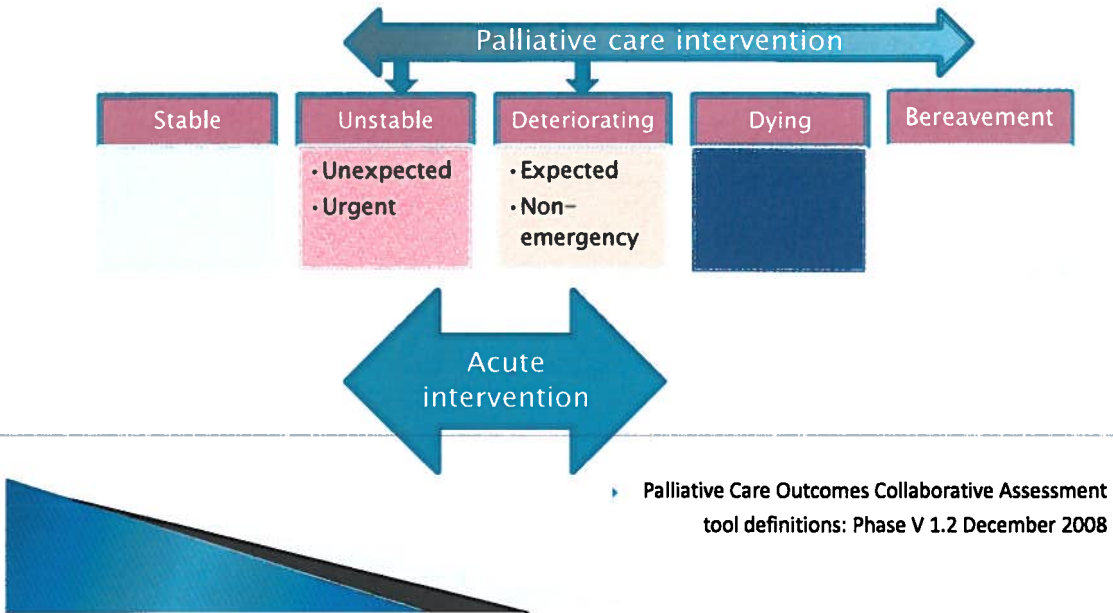
- ▶ **7 day service**
 - ▶ Prove outcomes – CaNISC
 - ▶ iWGC – patient voice
 - ▶ Quality standards – Peer review
 - ▶ Education courses
 - ▶ Non-cancer
 - ▶ Keep £s
-



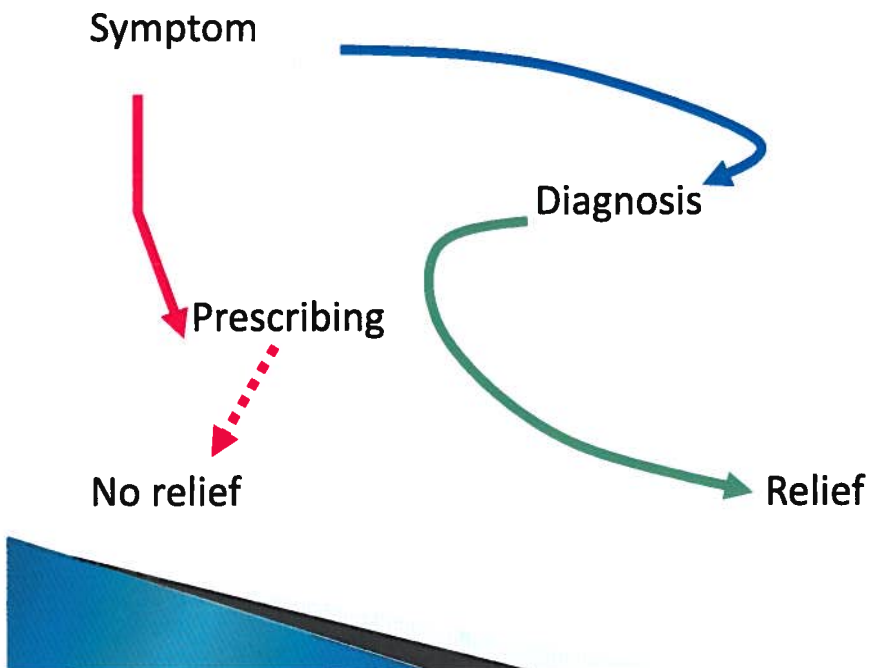
Integrated care



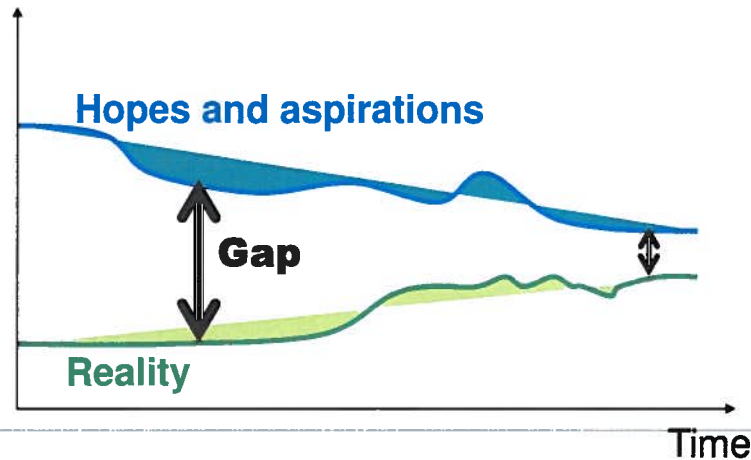
Phases of illness and need



Diagnosis is key



'The quality of life gap'



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



013 1 1031

search

Opioid Dose Calculator

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

Select Conversion Values:

"Traditional"
 "Progressive"

Convert From:
Enter total opioid intake in last 24hr:

Oxycodone PO	160	mg/24h
Oxycodone SC	20	mg/24h
Fentanyl TD	75	µg/h

To:

Morphine SC	325	mg/24h
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4-hourly PRN: 54.17 mg q4h

- OR -

- Transdermal Patch -		µg/h
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Consider reducing doses by up to 25-50% to account for incomplete cross-tolerance

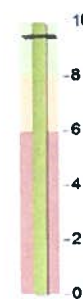
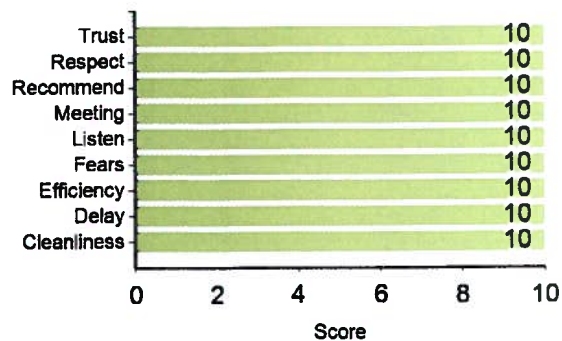
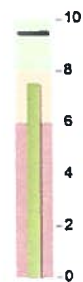
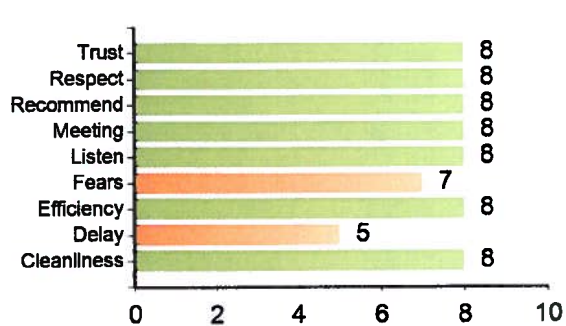
All calculations must be confirmed before use. The authors make no claims of the accuracy of the information contained herein;

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?

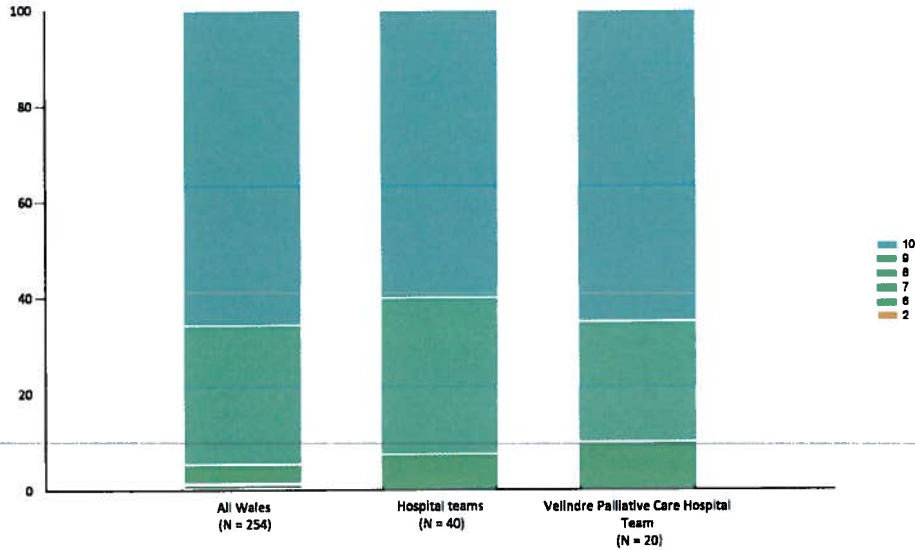


iWantGreatCare



Review monthly

Percentage of reviews by review score



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 [redacted] 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 SISTER 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 WERE ANSWERED WITH GREAT KINDNESS AND CONSIDERATION. A PALLIATIVE CARE SERVICE SUCH AS THIS, WHICH ON THE WHOLE IS SELF-FUNDING, NEEDS TO BE CONGRATULATED AND COMMENDED WITH THE HOPE THAT ALL 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".*

▶ Hotopf M 25 May 2011

▶ 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

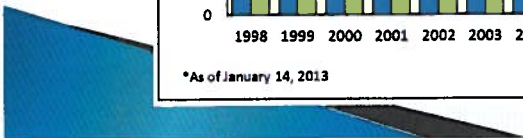
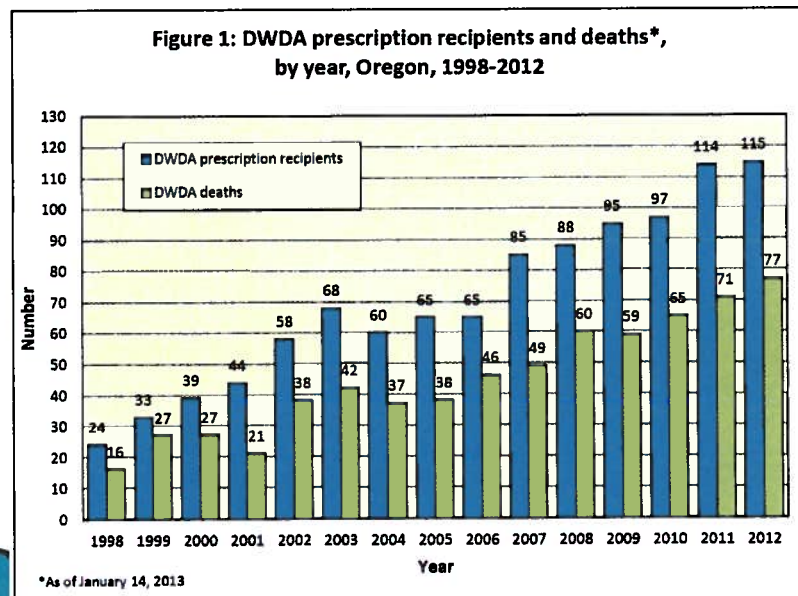
- ▶ The gravity of risk involved
- ▶ Risk - of death by error or coercion or other unintended cause
- ▶ Safeguards - a very high stringency and reliability.
- ▶ Can the law could be relaxed without putting larger numbers of more vulnerable people at risk of harm?



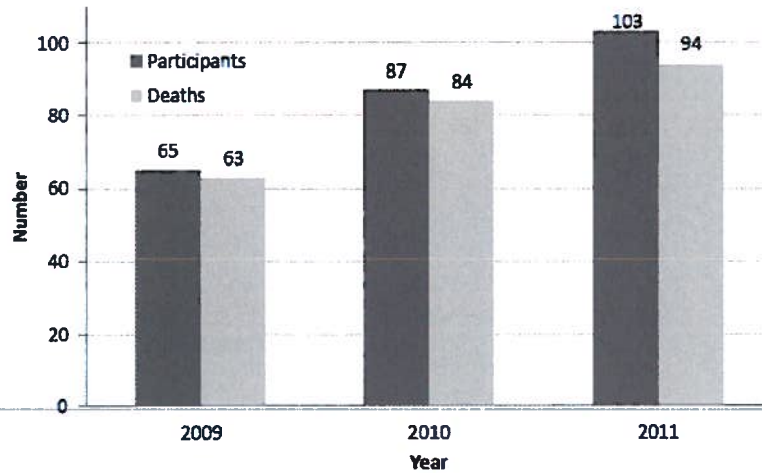
Oregon data

population 3.87m

>4 ½ fold increase



Washington state 6.63m



39

Dutch data

- ▶ 3,695 deaths in 2011
- ▶ 1,882 deaths in 2002 when law changed
- ▶ Now 1 in 37 of all deaths (all causes)



Living and Dying Well

www.livinganddyingwell.org.uk

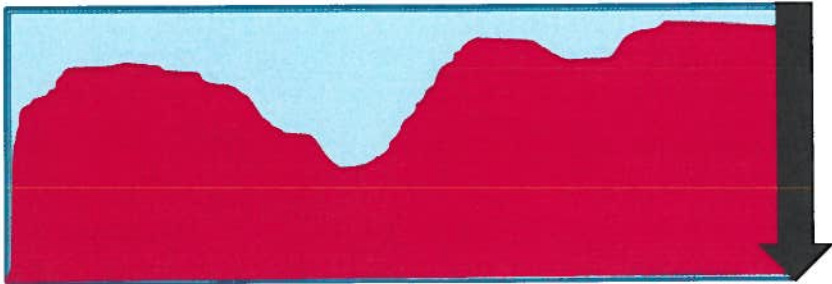


Not a medical care duty



Ending suffering?

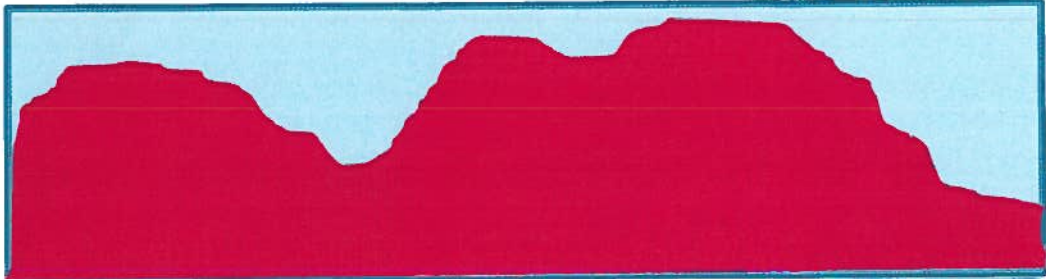
End life



Duty to relieve suffering?

Intervene

time



Capacity to experience = personhood



Is the care good enough for your Mum?
