Scottish
Partnership
for Palliative Care

# Palliative Care:
# How can we make a difference?

## Annual Conference 2009

# REAL LIFE CHALLENGES OF IMPLEMENTING A NATIONAL END OF LIFE CARE STRATEGY

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# STARTING A REVOLUTION

"You matter because you are you and you matter to the last moment of your life."

Support for family and friends during illness and into bereavement

Care, Research and Education

Dame Cicely Saunders, OM, (1918 – 2005)

1967 St Christopher's opened

1968 First home care team at St Christopher's

1972 First hospital support team at St Thomas'

## 2008

- 220 hospice and palliative care units
- 310 home care teams
- 307 hospital support teams
- 282 day care services
- Services established in 115 countries

# CURRENT APPROACHES INSUFFICIENT

- 2005 BBC survey – only 34% discussed wishes on dying
- 2007 – 54% complaints relate to care of dying (HCC)
- 500,000 die each year in England, nearly 60% in hospital, but 70% say they would prefer home

**'SOLUTIONS NOT PROBLEMS'**

# END OF LIFE CARE STRATEGY (JULY 2008)

(www.endoflifecareforadults.nhs.uk)

- Comprehensive – emphasis on disparities: all conditions, all care settings – community focus
- Whole system and care pathways approach – emphasis on generalists and tools
- Any new money linked to new services and local commissioning

# CHALLENGES REMAIN

- Poor care in the last days/weeks of life
- Poor support after death
- Lack of dignity and respect for some people
- Clinicians have difficulty identifying people who are approaching the end of life
- Clinicians have difficulty in initiating discussions
- Poor coordination of assessment and care
- Inadequate training and education
- Lack of rapid response, integrated 24 x 7
- Inadequate information for and involvement of carers and family
- Lack of robust measures of quality and effectiveness
- Inequalities in care

# THE EXCLUDED

- Black and minority ethnic groups
- Those living in deprived areas (urban or rural)
- Those with mental health problems
- Disabilities; learning, sensory, physical
- Refugees and asylum seekers
- Travellers, prisoners, the homeless
- Drug and alcohol misusers

- Carers and families
- Wrong disease……
- Living too long……
- OLDER PEOPLE

# NEED, DEMAND AND RESOURCE

- Rising expectations of healthcare
- Changes in demographics and disease
- Split and dispersed families
- Single person households
- Constrained financial and professional resources
- A recession!

# DEMENTIA

- 700,000 suffer from dementia in the UK = 1.1% of population
- Estimated 1.8 million by 2050
- Currently £17 billion a year = 15 - 20% of NHS budget
- Estimated to rise to £51 billion in 30 years.

# FAILURE TO TACKLE HEALTH INEQUALITIES

- Social disparities in healthcare outcomes widening (BMJ August 2005)
- Improve conditions of daily living
- Determined advocacy and political voice and action
- Emphasis on choice – what is the reality?
- "Deluxe dying for the privileged few". (Douglas 1991)
- Need not diagnosis?

# AUDIT OF WELFARE BENEFITS ADVOCACY SERVICES IN HOSPICE

(European Journal 2006. 13(1) : 5-7 Levy & Payne)

St Christopher's Welfare Officers — One third of patients in top quartile for socio economic deprivation

- 3 months, 244 cases
- £52 per week extra, per case
- 29 complex cases generated :

1585 telephone calls
724 letters written
626 letters received
1000 faxes
3191 application form pages

20 cases generated 61 appeals – 82.8% success rate

**FSA seminars**

# BME & SPC

- Poor access, poor data, poor outreach, dominant script, poor understanding

St Christopher's

- Third from top quartile for socio-economic deprivation
- 20% of patients non-white
- 15% of staff and volunteers
- 26 different languages interpreted
- Training
- CNS GP linked
- Church links
- Large spaces

Not so much about improving access to specialist palliative care as improving wider systems of health and social care

# DYING AT HOME?

- Challenge assumptions
  (Hinton. Pall Med. 1990s, Gott, Seymour et al. Pall Med 2004, Catt, Blanchard, Addington-Hall. Pall Med 2004)
- 24 hour district nursing
- Spc as hub and resource
- Move money

- 40% of patients in one PCT in Oct 2007 who died in hospital did not have medical needs. Quarter been there more than a month.

(National Audit Office – End of Life Care 2008)

- One year study of all deaths in a hospital in one year
- 20% clearly, and 13% probably, could have been looked after at home if……
- 13% admitted from nursing home (69% of these could have died there)

(Abel et al. Pall Med. 2009)

- Redistribute money
- Manage turf warfare
- Mergers
- Improve commissioning
- Improve transitions and integration
- Improve monitoring (reverse auctions)
- Improve horizon scanning (Personal health budgets) A way to spend less…….?

- Efforts to improve individual welfare cannot alone meet our aspirations for good end of life care.
- Death, dying and bereavement are primarily social experiences in which good physical care and symptom control are very important.
- Further the integration of health and social care – Continuing Care debacle

Social Care blog (www.blogs.stchristophers.org.uk)

**GOOD CARE IN THE BED YOU DIE IN**
**GOOD CARE BEFORE YOU DIE**

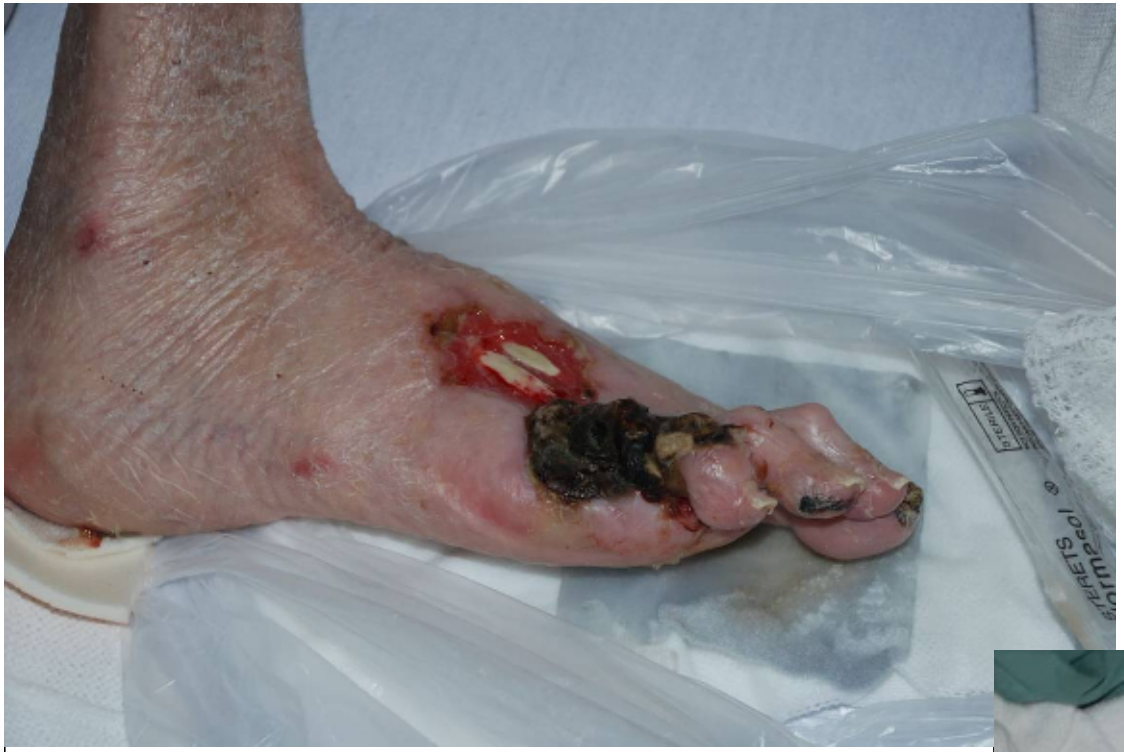
**COMPETENT AND CONFIDENT GENERALISTS**

# Responses : SETTINGS – CARE HOMES

- 1 in 5, proportion will increase
- Inappropriate admissions to hospital
- Clinics, named nurse, OOH advice
- Regional training centre GSF
- Sustainability study
- Sharing creative resources
- Thank you for your export – Jo Hockley!

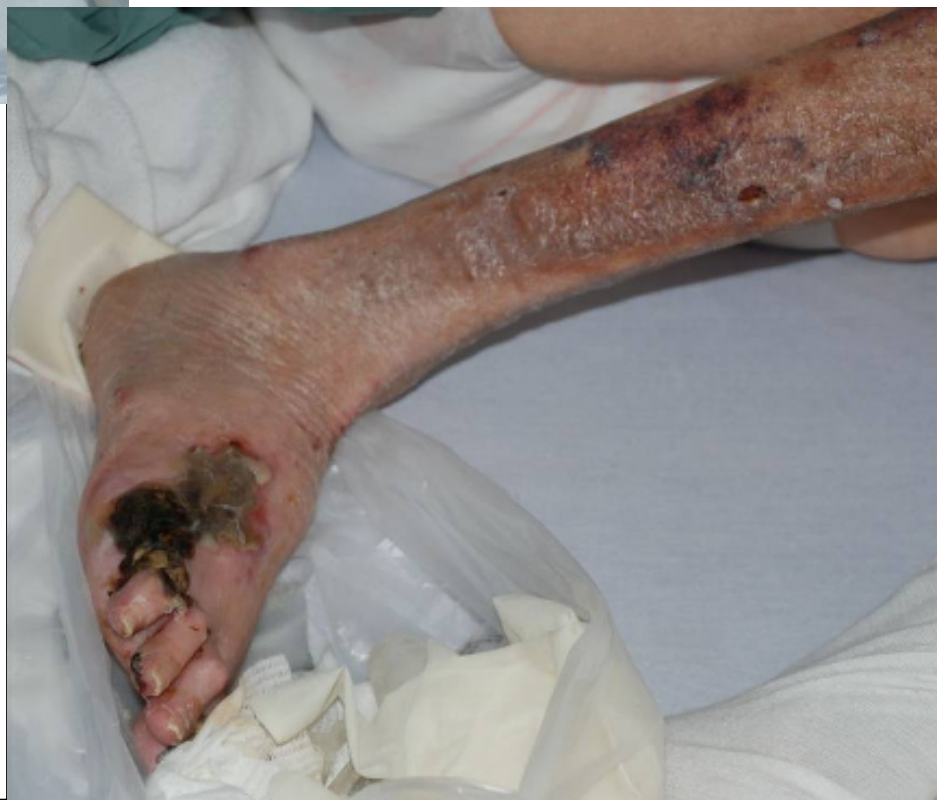
# Responses : ACTION RESEARCH – DEMENTIA – King's Fund

- It is possible to diagnose dying
- Symptom control generally should be within generalist competence – but poorly managed
- Carers' needs neglected
- Role modelling, coaching, mentoring can change practice
- 98% home or care home deaths
- Roll out 7 PCTs – wider applicability and bigger dataset



this patient was only prescribed paracetamol as required

**With a small dose of morphine regularly and before changes in dressing or position, she became communicative, happy, and started to eat again.**



# Responses : TRAINING AND EDUCATION

- Too internal.  Shift to generalist
- Contracting mechanisms and funding – resource allocation skewed? Advanced communications?
- Health and social care assistants (3 day validated course)
- Advance care planning and train the trainers
- Cheap and relevant – but e-learning or face to face?
- Teams and organisations – not just individuals
- Competencies (End of Life Care 2009)
- Get nursing back on track!

# Advance Care Plan

Personal preferences
and choices for
end of life care

For nurses who want to deliver the best care to dying people, at home, in care homes or in hospital

# End of Life Care

February 2008 Vol 2 Issue 1

In association with St Christopher's Hospice

End of Life Care, Volume 2, Number 1, February 2008

# Responses : DATA, EVIDENCE, QUALITY, COST EFFECTIVENESS

- Balance rigour and pragmatism
- "Give us four quality measures"
- Better links, over time, between academic institutions and service delivery organisations
- Simple patient generated outcome measure
- Anniversary Project
- Learn more about meeting needs of carers, families, the bereaved – lose it at our peril!

# Responses : PUBLIC ENGAGEMENT

- Community groups
- Wider professional education
- Employer support
- New forms of volunteering
- Resilience approach
- Schools Project

# SOME COMMENTS FROM CHILDREN

….I felt happy doing the art – it took my mind off death and put my mind on understanding that we all have to die some day…

….at the start I felt a bit scared and shakey 'cos I thought it would smell and be full of sick people, but they were just normal…

# SOME COMMENTS FROM PATIENTS

….I loved the kids coming here – it makes it all feel so normal and OK….

….Watching the staff and others talk to the children – it showed me a way to talk to my own grandchildren…

….I'm glad you take this seriously – I feel I've got something that the children can learn from….

"Right at the very end of her life she was treated with dignity and compassion, which meant so much to us."

Daughter of a patient

**SHOULD BE AVAILABLE EVERYWHERE**

**LACK OF MONEY OR LACK OF WILL AND VISION?**

**FUZZY EDGES**

# SCOTLAND HAS SUCH A LOT OF ADVANTAGES –

# HURRY - THEY MAY NOT LAST FOREVER!

# Mohammed

I am old and wrinkly.
I wonder if I could have had kids.
I hear voices of an owl.
I want another life.
I am old and wrinkly.
I pretend to be in heaven.
I feel cold inside.
I touch the fur from my cat.
I worry about the time I die.
I cry when things die.
I am old and wrinkly
I understand that people have to die sometimes.
I say that I care for animals.
I dream that I will get to do different things.
I try to keep my cat healthy
I hope my plants will grow
I am old and wrinkly
I want to thank everyone who helped me.
I am old and wrinkly.

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