

Dame Cicely Saunders and the Hospice vision

Is Hospice fit for the 21st Century?

Dame Barbara Monroe

The questions

- What are the core values and legacy of the Hospice concept?
- How does the vision stand today and is it relevant to the future?
- What is the evidence for Hospice efficacy in meeting need?
- What role might Hospice play in meeting future challenges?

Starting a revolution



St Christopher's opened in 1967

- Home care established in 1969

Care, research and education

In the UK:

- 220 Inpatient hospices
- 360 Home Care Teams
- 300 Hospital Support Teams

Palliative care in over 120 countries - about half.

Globally 1 in 10 who need it get it¹

Dame Cicely Saunders, OM, (1918 – 2005)

“You matter because you are you.....”

Dame Cicely's Vision

- Early vision (1958)

...a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring hope and consolation to the end.

- Prospectus (1967)

The Hospice will try to fill the gap that exists in both research and teaching concerning the care of patients dying of cancer and those needing skilled relief in other long term illnesses, and their relatives.

- Wider vision (1978)

There is a need for diversity in this field... A few hospices will be needed for intractable problems, research and teaching... but most patients will continue to die in hospitals... or their own homes; the staff they find there should be learning how to meet their needs.

“Movements tend to become monuments”¹

The objectives have been clear for some time:

- Everyone, in every setting, everywhere in the world
- All diseases - in England 500,000 deaths - 170,000 receive S.P.C.
- Three quarters are expected deaths - just under half cancer²
- Only 10-15% of Hospice patients have non malignant disease

Good care is both effective and cost effective

Dependent on:

- Availability of opioid drugs
- Early identification
- Service integration, 24x7
- Good communication – earlier
- Support for patient, carers and family – culturally appropriate care
- Adequate funding
- The drive to the community
- Effective, widespread programmes of education
- Evidence

Where are hospices on care? Who is not being seen?

“We emerge deserving of little credit; we who are capable of ignoring the conditions that make muted people suffer... The dissatisfied dead cannot noise abroad the negligence they have experienced.” (*Hinton 1967 Dying*)

WHO definition in 2003 “Impeccable assessment and treatment of pain and other problems....”

Economist Intelligence Unit ranks UK top for quality of death in 2010

Followed in UK by raft of highly critical reports and documentaries – deficits in care delivery and continued exclusion – about attitude as well as resource.

Hospices rated significantly higher for quality of care (77% Excellent) but 13% report inadequate pain relief (*VOICES 2013*). Growing concern in US (*Teno 2014*)

Palliative care associated with survival and improved outcomes (*Temel 2010*), reduced hospital costs and admissions and increased likelihood of home death (*Chitnis 2013, Obermeyer 2014, Seow 2014*)

Health inequalities growing

- In England - Marmot Review (2010) looked at the social gradient in health: the wealthier you are, the healthier you are. Cuts in health and social care budgets. Changes in state benefits - hospices muted on social justice
- Few die how and where they wish – postcode lottery (*NEoLCIN 2012*)
- Rise in deaths in usual place of residence from 38% in 2008 to 44% (*NEoLCIN 2014*)
- Spending variations for Specialist Palliative Care are £193 to £7445 per death. Data variations – can't link to outcomes (*NAO 2012*)
- Access poor for BME and deprived - under represented in hospice care (*Higginson 1998, Koffman 2004, Calanzani 2013*)
- Learning disabilities - poorer access, poor pain and symptom control (*CIPOLD 2013*)
- Homeless, prisoners, travellers, young people in transition, primary mental health difficulties....
- Hospice planning has been random and unclear messaging creates public confusion

Ageism in all our services

- Ageing and frailty with multiple chronic conditions and complexity in a context of social change, resource constraints and system upheaval – huge unmet need and massive increase in demand.
- Number of oldest old with personal care needs rises by >60%, already 40% live alone (*Kings Fund 2013*). Preferences for hospice death increase with age yet oldest old under represented (*Calanzani 2013*)
- ‘A queue is a sign of failure’ – are hospices complacent, over engineered and overpriced? Inertia of ‘way we do things’
- Need to think about populations as well as individuals. This is what professional responsibility means

“Yet caring for frail elderly people is now the core business of most hospitals. Imagine a commercial enterprise that regarded its principal customers as an awkward inconvenience.”

Guardian leader 19 Nov 2014

- A home death is not necessarily a good death
- Not all hospital admissions “inappropriate” - not all experiences poor
(Gott 2014, Robinson 2014)
- St Christopher’s experience on Linden Ward in Lewisham Hospital

The concepts and language of hospice, end of life and palliative care?

- Diane Meier's critique (2013)... a step too far?
- Importance of an open culture around death, dying and bereavement
 - GSF, EPACCS – expressing preferences means you are more likely to get what you want (*Addington-Hall 2009, Smith 2012*)
 - Bereavement is a trigger for psychological and social frailty. Unmet bereavement need costs NHS Scotland £20m (*Birrell 2013*).
- Crude understanding of preferences and trade offs
(*Gomes 2011, British Social Attitudes Survey 2012*)
- Not the concept at fault – but implementation and our behaviours and attitudes
- Specialist/generalist – most will do some of both. An effective joint response to need

A case for change in Hospice

- Changes in demand and needs of users
- Increasing and unmet public expectations
- A more competitive environment in England
- Constrained and uncertain funding - 50% UK hospices report NHS funding cut or frozen (*Hospice UK 2014*)
- Increasing need for proactive rather than reactive care
(*Gill 2010, Gott 2011, Hanratty 2012, Seymour 2013*)
- A role in the much needed integration of health and social care?
- The requirement to do more for less

Mixed perceptions of Hospice

- Where do hospices sit in the wider system? Do they work to the same rules of transparency in terms of evidence, planning and how money raised and spent? Merger saves 20% in six months. Occupancy
- What principles do hospices use over resource allocation and how are decisions made between quantity of people helped and quality?
- Hospices sometimes seen as poor partners. Insufficiently self critical and unaware of wider system in which they need to operate

What about the NHS?

“We are not fit for the future.... An unprecedented shift of resources and care to GP surgeries is necessary... The sickest patients need much more time to discuss their health.”

Professor Sir Bruce Keogh Jan 2015

HELP THE HOSPICES
COMMISSION

into the future of hospice care

Future ambitions for hospice care: our mission and our opportunity

The final report of the Commission
into the Future of Hospice Care

October 2013

Messages for all providers and stakeholders.

System wide approaches - adaptability and flexibility

“Current and future needs for hospice care: an evidence-based report”
(Calanzani, Higginson, Gomes 2013)

With Hospice independence comes responsibility

- Delivering good enough, cost effective, evaluated care and service innovation, easily accessible and replicable at scale
- Supporting the development of a confident and competent health and social care workforce
- Spearheading efforts to change public attitudes and enable community participation
- Doing the difficult and holding fast to the disadvantaged

Living until you die and access to good enough care in whatever bed you die in

- Commitment to mission that everyone should get the care they deserve, brings obligation to consider how best to use hospice resources as part of system of care – an issue for all Boards
- Joint needs assessments: uncomfortable local questions for hospices
 - What care should be provided directly?
 - What should be done to support the work of others?
 - What should be done through education and advocacy?
 - Should some services be withdrawn or reconfigured, where can hospices work with others to do things better?

Where are hospices on research? What isn't known?

The legacy:

- '50s Saunders: meticulous case studies of patient experience and pain
- '60s and '70s Twycross and Walsh: pain control, morphine and more
- 70s Murray Parkes: bereavement, prognosis, outcomes; Hinton depression '80s Carter and Baines: obstruction and dysphagia
- '90s O'Brien, Booth and Hinton: MND, breathlessness, home care outcomes for patients and families
- 2000s Thorns, Sykes and Ali: survival and use of opioids and sedatives, MRSA and morbidity
- 2008, 2011-14 Maudsley: CBT, depression
- 2013-14 Hockley and Kinley: Care Homes

Developing the evidence base

Overall Hospice response has been poor

- Failure to allocate resources to evaluation - no longer sufficient to be a 'good thing'
- 80% of SPC beds in voluntary sector, inadequate data on home care
- Agree common data sets to share activity, costs and outcomes nationally and across voluntary and statutory (*Murtagh 2013*). CLAHRC and OACC. Benefits of benchmarking clear (*Currow in Australia*)
- What support is most effective for whom, at what cost?
- The need for home care can be demonstrated but not how best to deliver it (*Gomes 2013*). Most studies do not differentiate hospice supported home care. Perfect test bed – variety of home care models in hospice sector
- The notion of the effective 'dose' to empower
- Better research partnerships emerging – determined focus on gaps required
- Risks of an ageing and part time workforce

The responsibility to innovate (1 of 2)

- Short idea to action time in hospice
- Triaged home care - releases 30% resource - same outcomes
- Unbundled day care - 20 a day increases to 200. 8:00am to 9:00pm x 7
- Building as community hub - schools' programmes, choir, curry, quiz, death chat, concerts, Sunday lunch and more
- “Sweating” the physical resource - rehabilitation programme and transition initiative at weekends
- Physiotherapy in circuit groups - threefold increase in numbers supported *(Talbot Rice 2014)*



The responsibility to innovate (2 of 2)

- Extending services to the wider community e.g. bereavement and lymphoedema
- Care Homes. 25% increase in care home deaths. Sustainability, sharing creative artists, triage telephone advice. *(Hockley and Kinley 2013/14)*
- Namaste dementia programme - reduction in behavioural symptoms *(Stacpoole 2014)*
- Hospice supported care home beds
- 24x7 single point of contact care coordination. 20% home death rises to 83%, only 8% transferred to SPC. Rapid hospital discharge services
- Large scale delivery of personal social care: recruitment, training , supervision. “He is such a well mannered boy, and that is healing in itself”. 70% home deaths

“I can’t believe the way I feel at the end of a shift, even the stressful ones. When I get home even though I might feel exhausted, I am also glowing with contentment and pride. I have never experienced anything like this before.”

How are hospices doing on education and training?

Developing a flexible workforce fit for future purpose (SCH Education Centre opened in 1973)

- The legacy: specialist, international, MP week, MND, pain, bereaved children and families, CBT, social care, GSF; delivered by those who do the job. And the MSc
- Initiatives fragmented, duplicated and lacking in scale and accreditation
- Have we made a specialism out of a generalism?
- What about the role of GPs? New links with geriatricians, cardiologists, respiratory physicians, psychiatrists and rehabilitation.
- Flexible – far from it! Do producer interests dominate, role of professional bodies?
- Use training to drive change e.g. specialist doctors – what are the relevant skills: dementia, pain management and the community. Nursing and health literacy
- Work across settings, where most needed, sharing 24 x 7 - co-location

Hospices should play a strategic role in training and education

- Ring fence human resource and money
- Undergraduate syllabus of all professions - seeing good care in practice
- Recognise the huge opportunities to develop the basic health and social care workforce. (*Cavendish Review 2013*)
- Develop a nationally endorsed curriculum for vocational education courses
- Work together to create consortia large enough to compete and win the funding needed
- Develop and share common products e.g. QELCA
- Significant progress

Using volunteers creatively

- Key to resourcing change
- Volunteers reduce hospice costs by an estimated 23% *(Candy 2014)*
- Training drives diversity. SCH: 37% under 48, 40% male, 28% BME
- Need for standard accreditation of portable training
- Variety of roles: community, housework, handyman, research, continuity
- Challenge the barriers from within
- Volunteer mentoring and management support roles

Hospices can strengthen community connections

- Involving communities in service development and the support and delivery of care e.g. St Nicholas Hospice Care Hospice Neighbours scheme, Milford Hospice Compassionate Communities Programme
- Education and training can bring two needs together – volunteering as an escalator for unemployed young people and returners to work.
Summer Schools
- Avoid getting out of step with public – LCP. Clear shared narrative. Public understand rationing, want clarity and reliability

Strengthen hospice strategic leadership

- Manage the inevitable perils of individual organisational marketing and develop a collective voice
- Drop some competitive instincts and get clarity and appropriate uniformity about access and services
- Responsibility to reach out and respond to inequalities and to maintain support to vulnerable and underprivileged. Not always put into action. US evidence of cherry picking (*Wachterman 2011*)
- Think about how to value and develop all staff and volunteers, especially middle managers: action learning sets, cross sector mentoring and job exchange.
- Transparency about risk – take it as well as manage it. Support staff and engage families and the public.

We can transform care - together

Creating a health and social care system fit for the 21st Century - hospice care remains vital

- Hospices are rooted in communities - unique resources. Repositories of professional, compassionate confidence and competence, with multi professional teams accustomed to working together to support complexity
- Hospices offer the breadth and depth of services that future needs demand and the freedom to innovate
- But hospices must not wait for a fair and level playing field, for an invitation, for the respect they think they deserve. Morale and culture in parts of NHS is a risk. Tick boxes are not a substitute for thoughtful care.
- Hospices should act with urgency, responsibility, generosity and deliver evidence
- In addition to partnering well hospices should remain restless, disruptive and sceptical
- Care is not a commodity

...a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring hope and consolation to the end. *(1958)*