

# **LISTENING TO PATIENT AND PROFESSIONAL VOICES IN END OF LIFE CARE**

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# LANGUAGE...

- Individual and context dependent
- Professionals should opt for simplicity and clarity
- But really listen and be 'curious'
- Metaphor neither good nor bad, but very personal
- My bugbears...



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

**Messages for all providers  
and stakeholders.**

**Hospices started a  
revolution but progress  
insufficient**

**Adaptability and flexibility**

# THE PROBLEM – WHO ARE WE NOT SEEING?

- Health inequalities (Marmot 2010), poverty and postcode lottery (NEoLCIN 2010)
- Ageing and frailty in a context of social change, resource constraints and system upheaval – huge unmet need and massive increase in demand. Ageism in services
- Dementia, cancer, multiple chronic conditions . Complexity – joining up health and social care needs. Young people in transition
- ‘A queue is a sign of failure’ – are we complacent, over engineered and overpriced? Inertia of ‘way we do things’ – language part of this?
- Need to think about populations as well as individuals



# THE CONCEPT OF END OF LIFE AND PALLIATIVE CARE?

- Diane Meier's critique (2013)... a step too far?
- The importance of death, dying and bereavement. ACP, GSF, CMC – expressing preferences means you are more likely to get what you want (Addington-Hall 2009). Bereavement £20m NHS Scotland (Birrell 2013) - trigger for psychological and social frailty. Not the concept at fault – but implementation and our behaviours and attitudes
- Significant failure in effective collaborations – 'intimacy at scale'
- Specialist/generalist – most will do some of both. An effective joint response to need



# MIXED PERCEPTIONS OF HOSPICE

- 'Access for hospice care neither sufficient nor equal for people with different illnesses, ages or ethnicity' (CSI 2013)
- Linked to public confusion
- Where do hospices sit in the wider system? 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 and whingeing partners. Insufficiently self critical, unaware of wider system in which they need to operate and which they could influence to the benefit of patients and those close to them.





# RECOMMENDATIONS

- Develop the evidence base
- Assume the responsibility to innovate – less demanding of resources
- Develop a flexible workforce fit for future purpose
- Use volunteers creatively
- Develop consortia to deliver shared validated training
- Strengthen community connections
- Strengthen strategic leadership
- Become partners of choice, part of the system
- Stay restless and disruptive
- Hold fast to the disadvantaged (Wachterman 2011)
- Achieving relevance, scale and replicability demands common platforms of care and influence



# HOW MIGHT LANGUAGE GET IN THE WAY?

- Derived from cancer – Simonton in the seventies and visualisation – Kate Granger's recent blog
- Poor crossover with frailty and ageing
- One third of GPs no proactive ACP (Dying Matters 2012)
- Policy makers shift from battle to journey
- Influence of 'hospice speak': holistic, spiritual, self-care, boundaries, carers – 'road map'
- Influence of 'commerce speak': chain of command, payment by results, contracts, tariffs, invitations to tender
- Influence of 'techno speak': QALYs, CQUINs, QOFs, networks, integrated pathways
- Gulf between professionals, patients and communities





# “THE PATHWAY TO DEATH”

- The LCP controversy and fall out
- Different in care homes...why?
- Training to confront our own fears and attitudes. QELCA – watching someone confident
- “Would you be surprised?”
- Advance care planning
- CQC inspection – simpler, in greater depth
- Personal social care and ‘kindness’
- Complaints



# LANGUAGE AS A BARRIER BETWEEN SETTINGS AND ACCESS

- Acronyms
- Culture and English not first language (Richards and Koffman 2011, Cherny 2012)
- 'Free'
- Continuing Care
- 'Discharge – fitting our criteria'
- '24 x 7'
- 'Choice offer'
- Reliability and transparency
- Care home funding



# PATERNALISM, PROTECTION AND PUBLIC ENGAGEMENT

- User engagement. 'Very resistant to negative...'
- Patients in groups
- Communities of interest – patientslikeme
- Hospice as a community hub: schools, concerts, choir, curry, quiz, death chat, quilts, exhibitions
- Coping with dying and bereavement leaflet
- Volunteers – training and jobs
- Involving local communities in the development, support and delivery of services
- Transparency about risk



INFORMATION FOR  
PATIENTS AND VISITORS

## Coping with dying



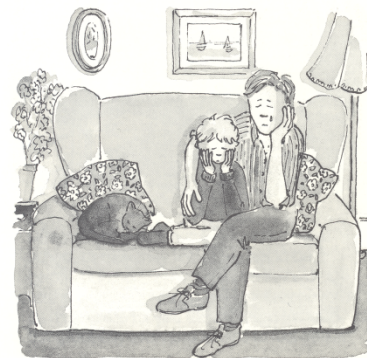
Harris HospisCare  
with St Christopher's



Often people find it hard to concentrate at school, or they may feel too upset to be helpful at home. Grown-ups feel this way too, so that it sometimes seems that they haven't as much time for you as they used to have. But gradually everyone begins to feel better.

### How do we feel...

The death of someone important to us makes us very sad. You will find that crying makes you feel better. Everyone needs to cry – men, women and children. Sometimes we feel we shall never stop crying. Both these feelings are normal and we must be patient with ourselves.



# WORDS ARE NOT THE ONLY LANGUAGE

- My daughter's delivery
- The arts
- The environment
- You can catch confidence







