END OF LIFE CARE – A CONCEPT TOO CONSTRAINED TO MEET FUTURE CHALLENGES?

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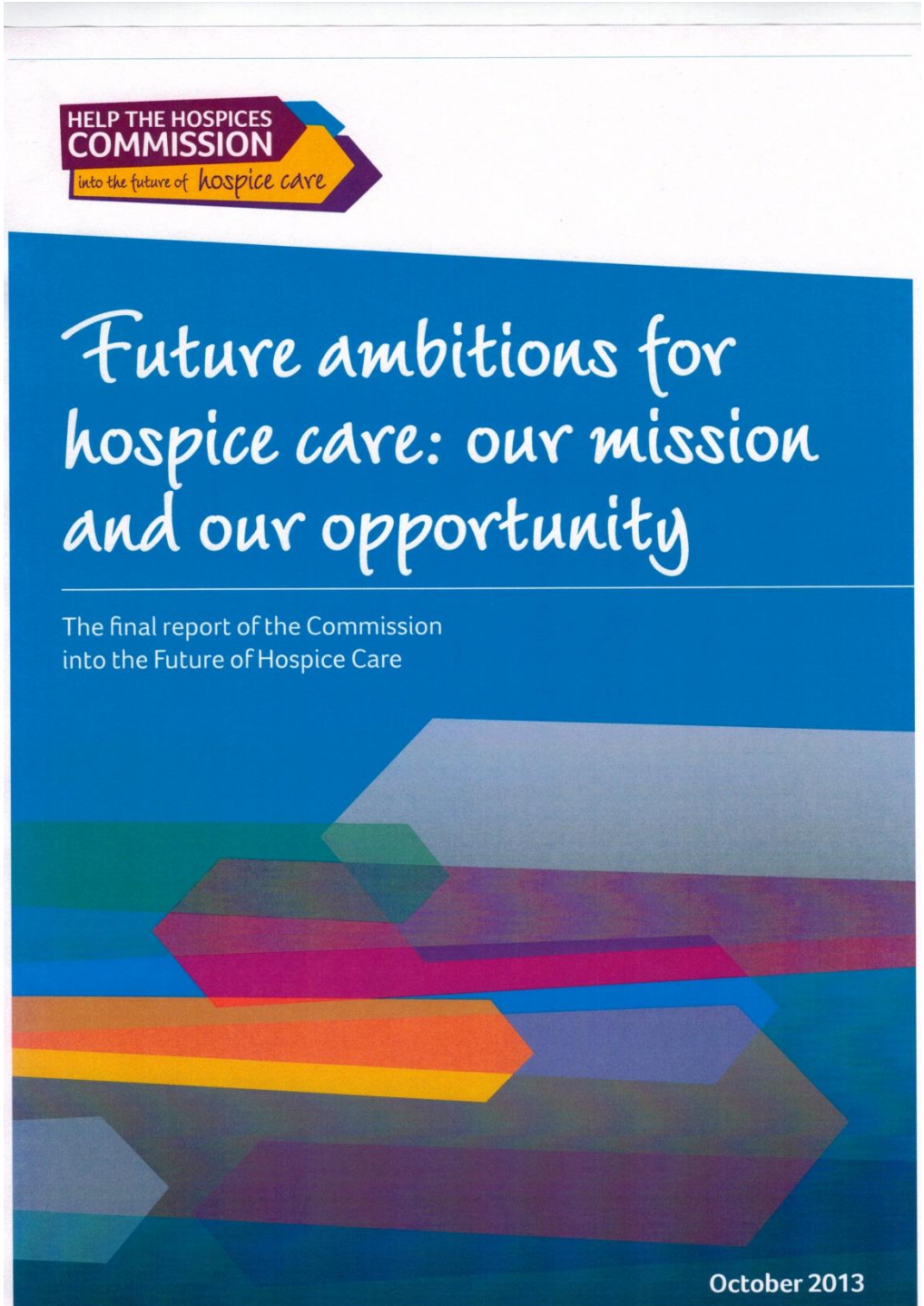

Messages for all providers and stakeholders.

Look at the full range of reports – Help the Hospices website

THE PROBLEM – WHO ARE WE NOT SEEING?

- Economist Intelligence Unit – UK top in 2010
- Followed by raft of negative reports and documentaries
- 'Deluxe dying'. (Douglas 1994) - 'Movements can become monuments' (Twycross 2006)
- 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
- Dementia, cancer, multiple chronic conditions . Complexity - 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' and producer driven interests
- Need to think about populations as well as individuals

THE CONCEPT OF END OF LIFE CARE?

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

THE COMMISSION'S CASE FOR CHANGE

- Hospice care not limited to hospices
- Changes in demand and needs of users
- Increasing and unmet public expectations
- A workforce unfit for future need
- A more competitive environment in England
- Constrained and uncertain funding
- A context of increasing accountability
- Mixed perceptions of hospice care from external stakeholders
- How do we move to proactive rather than reactive care?
  (Jayne Seymour 2013, Hanratty 2012, Gott 2011, Gill 2010)

MIXED PERCEPTIONS

- '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? Do they work to the same rules of transparency in terms of evidence, planning and how money raised and spent?
- 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

LIVING UNTIL YOU DIE AND ACCESS TO GOOD CARE IN WHATEVER BED YOU DIE IN

- How do we establish hospice care as a significant part of the answer to future challenges, not part of the problem?
- Commitment to mission that everyone should get the care they deserve, brings obligation to consider how best to use our resources as part of system of care – an issue for Boards.
- Achieving relevance, scale and replicability demands common platforms of care and influence
- Joint needs assessments: uncomfortable local questions
  - What care should we provide directly?
  - What should we do by supporting the work of others?
  - What should we do through education and advocacy?
  - Should some services be withdrawn or reconfigured, are local efficiencies possible, where can we work with others to do things better?

RECOMMENDATIONS : DEVELOP THE EVIDENCE BASE

- No longer sufficient to be a ‘good thing’
- Allocate resources to evaluation
- Agree common data sets to share activity, costs and outcomes nationally. Demonstrate value for money
- What support is most effective for whom, at what cost?
- Perfect test bed – variety of home care models
- The notion of the effective ‘dose’ to empower
- Robust UK wide mechanisms to share our project learning and mistakes
- Better research partnerships – focus on gaps eg support of families and carers. Not use ‘tyranny of RCT’ as an excuse – interrogate information
- Regulatory environment – systems for ensuring quality – accountability and transparency
- Integrating Health and Social Care as a priority
- What can we learn from the private sector and its business mechanisms?

RECOMMENDATIONS : THE RESPONSIBILITY TO INNOVATE

- Short idea to action time – responsibility to deliver and evaluate innovation, replicable at scale – ring fenced funding?
- Triaged home care
- Unbundled day care
- Supporting care homes – 21% increase in care home deaths
- Telemedicine and social media
- Care Coordination Centres, rapid discharge
- New ways of delivering social care
- ‘Sweating’ our physical resource : rehabilitation group work in physiotherapy gym – reaching out to survivors
- Linden Ward and home ward – think differently about beds

RECOMMENDATIONS : DEVELOP A FLEXIBLE WORKFORCE FIT FOR FUTURE PURPOSE

- Age of specialist workforce – number retiring in 10-15 years
- Difficulties in recruitment and retention and an increase in part time working
- Flexible – far from it!
- Work across settings, where most needed, 24 x 7
- Use most expensive resources to greatest effect – lowest grade competent to do task – good systems of consultation
- Use training to drive change eg specialist doctors – dementia, pain management and the community. CNS and health literacy
- CNSs and doctors – the elephant in the room?
- New ways of working with GPs – 1/3RD no proactive ACP (Dying Matters 2012). New links with geriatricians, cardiologists, respiratory physicians and rehabilitation.

RECOMMENDATION – THE CREATIVE USE OF VOLUNTEERS

- Key to resourcing change
- Community, housework, research, continuity
- Challenge the barriers from within
- Training drives diversity. SCH: 37% under 48, 40% male, 28% BME
- Reciprocity demands accredited training
- Volunteer mentoring and management support roles
- Hub concept – links with other volunteering organisations

RECOMMENDATION – THE STRATEGIC IMPORTANCE OF TRAINING AND EDUCATION

- Ring fence human resource and money
- Huge opportunities to develop the basic health and social care workforce. (Cavendish Review 2013)
- Work together to create consortia large enough to compete and win the funding we need
- Develop a nationally endorsed curriculum for vocational education courses
- Develop and share common products eg QELCA. Use hospice nursing as a model
- Remember to look to our own!

RECOMMENDATION : THINK DIFFERENTLY ABOUT OUR COMMUNITIES AND STRENGTHEN OUR CONNECTIONS

- Hospices have a unique resource in terms of their engagement with their local communities. Are we doing enough to involve them in service development and the support and delivery of care? Eg dementia friendly communities
- Education and training can bring two needs together – effective escalator for unemployed young people and returners to work. Kindness!
- Training and education for carers
- Avoid getting out of step with public – LCP and assisted dying! Adopt a higher profile in public debates? Remember public are customers, carers, funders and supporters
- Schools programmes, retirement courses, adult education. Our buildings as a community hub

RECOMMENDATION : STRENGTHEN STRATEGIC LEADERSHIP

- National leadership crowded and confused – how can we best work together as well as independently - HtH initiative
- Advocacy is part of our role. Become politically adept . Manage the inevitable perils of organisational marketing and develop a collective voice
- 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)
- Hospices need to stop sitting on fence – give HtH clear mandate to represent them and HtH take responsibility for leadership
- Develop trust. Drop some of our competitive instincts and get clarity and appropriate uniformity about access and services
- Develop middle managers, engage all staff and volunteers, action learning sets for CEOs
- Transparency about risk – take it as well as manage it. Support staff and tell public

FUTURE AMBITIONS FOR HOSPICE CARE : OUR MISSION AND OUR OPPORTUNITY (OUR RESPONSIBILITY) (HtH 2013)

- Modern hospice care developed in 60s as a response to appalling deficits in care
- Challenges persist and grow; hospices uniquely placed to support new revolution
  - Rooted in individual and their networks
  - Repositories of professional competence and confidence
  - Resource for training by those who do it
  - MP teams accustomed to working together to support complexity
- Need to hold on to our values – 'fried egg sandwich and pee!' But not wait for the fair and level playing field, for an invitation, for the respect we think we deserve. Go more than halfway – take some risks
- Act with urgency, responsibility, generosity and optimism – attributes already in our DNA
- In addition to partnering well we must remain restless and disruptive
- The prize is worth it and the yardstick is clear