What is happening at the interface between Health and Social Care in UK

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COLLIDING OR CO-OPERATING IN END OF LIFE CARE

"Death can be lonely and squalid for many people."

David Servan-Schreiber 2011

"360,000 seriously ill people every year in the UK will need caring for. How will we manage with an ageing workforce?"

- Heather Richardson National Clinical Lead. Help the Hospices (Dec 2011) talking about the crisis in the palliative care workforce which must to be able to deal with the changing needs and preferences of dying people

Key Texts in UK

- NHS , Department of Health-End of Life Care Strategy: Promoting high quality care for all adults at the end of their life. 2008
- NHS, Department of Health-End of Life Care Programme Board. Supporting People to Live and die well: A framework for social care at the end of life. 2010
- www.endoflifecareforadults/publications

The Strategy

- Aim was always to work with health and social care sectors to develop an end of life care strategy. However in the first instance was seen as just a health initiative and has led to problems of "social care not joining in"
- The concept of a "good death" as a key indicator of quality of service
- "Good death" emphasises being pain free, peaceful, dignified and not over prolonged
- Recognises more people want to die at home (YouGov poll 2010)

What contributes to the difficulties?

- This presentation will focus on some of the problems which occur because of the systemic failure of staff from Health and Social Care to work collaboratively
- To look at some of the reasons at a macro level
- To share the work being done to tackle the problem
- It will be UK focussed but will examine some European trends.
- It will make the assumption that most people will die in old age with a number of medical conditions and death will follow a period of chronic illness
- 40% of people die in hospital with conditions that cannot be treated medically (*Leadbeater&Garbier)*

Two People, different Stories

- **Isabel,** 85 years old, widowed five years ago suffering from advanced cancer, totally blind, went into hospital with a chest infection from which she recovered but was left more frail and her care needs had increased. She had lived in a sheltered housing scheme for seven years and wanted to go back there where her husband had died.. Nearest relatives were a niece and nephew who wanted her to go into a nursing home.

- Assessed for increased care but arguments between the staff from social care and health about whether she met the criteria for **continuing care and funding**. Family unsupported.

- Isabel died in hospital three weeks later still wanting go home, frightened and alone in a setting which was totally inappropriate .Ward staff and the housing warden were left feeling angry and frustrated

Continuing Health Care Funding

In the UK this funding arrangement allows for dying people to receive free care if they meet certain criteria.

Controversial because of disagreements between health and social care staff

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Two people, different stories

- Bill suffered from COPD and was 75 years old. He lived in **an extra care housing scheme**. He and his wife had carers. His condition worsened and his GP and the district nurse wanted him to go into hospital again but Bill and his wife knew his life was coming to an end and wanted him to remain in his home.
- The warden and carers had had training in EoLC arranged by the local social services and argued that with the support of the district nurses and the Macmillan Nurses they could support Bill and his wife. Bill did die at home and his main carer stayed on shift overnight to be with them both when Bill died.

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Shall we talk about Dying or Not?

- *"Dying Matters, lets talk about it"* National council for Palliative Care
- The need to get people to talk about how they want to live whilst they are dying is essential if we want to devise services that can support them. BUT I would add we need to train people to listen in a different way. Training in Advanced Communication Skills-Health orientated
- ***Leadbeater & Garbier*** quote evidence from the USA that suggests that creating a more open approach to talking about dying and the establishment of advance plans with family and friends does reduce hospital admissions at the end of life
- As a psycho dynamically trained counsellor I would suggest that this is due to more complex emotional reasons which come into play. For most people talking about things that worry us with people who are close to us and with whom we have a trusting relationship is the ideal. Hard for our nearest and dearest
- How do we encourage trust?

Containment & Trust

- Being held emotionally—what does that mean? Who can do it professionally?
- Reliability/empathy are key
- Listening skills training is not enough. We need to go back to focus training of health and social care professionals on building trusting relationships and their understanding of the meaning of them
- Health and Social Care professionals need to understand and use wisely the power that they have in the lives of the frightened, dependent, and vulnerable people
- Should have involved social care professionals in the design and roll out of the skills training


We need to more than just 'HEAR'
G.P. Surgery
We must LISTEN
What I feel I need is . . .
graham@ogilviedesign.co.uk

Demographics

- Throughout Europe those at risk of not having the care they want, when they are dying, are the **poor and isolated**
- There are huge variations in the levels of poverty from the relatively rich countries of Western Europe, where there is a greater life expectancy, to the ex Russian states and the emerging democracies in Central Europe
- These countries are tackling decentralisation on a huge scale. Many have poverty reduction strategies but are fighting against great odds
- In the UK we should be able to prevent people dying in poverty and isolation but this is not so
- Traditionally the role of social workers who are seen as the "Safety net" of society, working with the poorest and most vulnerable members of society. MUST have a more central role if things are to change. It is an issue of SAFEGUARDING

Demographics

- 500,000 people die each year in England and Wales
- 590,000 people will die each year in England & Wales by 2030 (Gomes &Higginson)
- By 2024 we will need one in four of the current population of all the universities in the UK to chose to work in either the health or social welfare sectors to meet the needs of the elderly and ill population (Hughes-Hallett 2011)

Demography in One Balkan State developing Palliative Care: Republic of Serbia

- The new census has just been completed but in the census of 2002 the following statistics showed a marked change from previous statistics;
- 22.7% were over 60 years and 37.5% of all households had a least one member of the household over 65 years.
- In the remote mountain areas there has been a huge drift of the young people to urban areas leaving whole villages with no younger people at all
- It is expected that the latest census will show the balance of low birth rates, emigration and increased life expectancy has followed the above patterns increasing numbers of older people

The Finances

- One of the major reasons for the lack of co-operation between the health and social welfare systems is funding (*Vision for Adult Care*)
- Health is funded centrally and Social Welfare is funded at a local level
- The Social Welfare budgets are never ring fenced unlike the NHS and are subject to more change due to the system of local Authority politics
- Leads to variation between LA services
- Low status of those working in the care system- mainly women who often lack qualifications and choice. Often from overseas
- Social Workers undervalued and marginalised

What is being done to improve things?

- **Social Care Framework (2010)** produced by an advisory group of senior professionals, stakeholders from social care from policy, practice, education & training
- Ten key objectives
- First follow up meeting Nov 2011
- Reports from 8 test sites etc.

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Ten Key Objectives-results

- Raising awareness-successful regional road shows +
- Embed EoLC in commissioning & inspection frameworks & standards for practice?
- Facilitating commissioning & delivery of person-centred integrated care X
- Strengthen the specialism of palliative care social work ?
- Promote best practice and understanding of holistic assessment of individuals, their carers and families at EoI -e-learning +

Ten Key Objectives-results

- Promote earlier EoLC planning (test sites)+
- Educate & train social care staff to deliver high quality EoLC + Use of Champions
- Promote supportive communities=engaging with a wide range of community services ?
- Work jointly with researchers & funders to establish robust evidence for good practice in social care ?
- Create supportive work environments to help social care professionals to maximise their contributions X

Eight Test Sites-Funded projects which reflected the ten key objectives

- EoLC skills –consultation and education for social care staff in 2 London Boroughs
- Having EoLC social care professional leads in the same boroughs
- Delivery of Integrated health and social care commissioning-problems emerged
- Integrated Discharge Planning for people with EoLC needs from a local hospital
- Hospice at Home personal budgets
- Mentoring workshop for social care assessors
- Development of key competencies for domiciliary care workers
- Implementation of an integrated palliative care service

My Conclusion of the effects of the Social Care Framework

- The pace needs to pick up
- Effects of the local authority budget cuts will not really be seen until next year
- Patchy involvement already. Problems for the poorest LAs
- Too much separation in the work streams
- Social care way behind health
- Emphasis should now be on joint national events
- One of the key education drivers will be the implementation of the Specialist Palliative Care Measures for the Manual of Cancer Services (***Cancer Action Team Draft Measures Dec. 2011***)

What is happening in Social care?

- Move to personalised budgets-gives people more choice and control
- Encouraging more independence for longer
- Encourage joint funding with health
- Already legislation to provide services for informal family carers-needs strengthening
- Social Work Reform Board and the School of Social Work . Aiming to improve the professional standing and education of Social Workers. EoLC training will be embedded into education at undergraduate level
- European Association of Palliative Care Task Force on Palliative Care Social Work

The way forward

- Serious illness is a family affair. We need more support for families to enable them to care (Carer breakdown is one of the main reasons for emergency hospital admission)
- All health and social care support systems for seriously ill people available twenty four seven
- A wider range of care facilities-joint funded home/hospices. Cottage hospital models. Extension of Hospice at Home Services. Extra care housing schemes extended
- Evidence based training work done mainly by health care professionals (backed up by e-learning) in care homes is beginning to make a difference. Rolling programmes
- Local networks and facilities encouraged to develop with proper funding
- Idea of piloting "End of Life Care Trusts" (*Leadbeater &Garbier 2010)*
- Joint financing given to health and social welfare for the provision of EoLC

An Example of EoLC Training in Social Care

- LA commissioned the author to provide EoLC training for "Flexicare" (extra care housing)
- Grant from Central government and housing
- Rolling programme of one day workshops- ten completed
- Audience-Housing officers/Scheme Managers/Carers
- Interactive Course: Skills, Difficult Conversations, EoLC tools, Loss and Bereavement and self awareness
- Evaluations=Confident/Understanding/Back their own judgement/Demystifying. Less likely to call out the ambulance. Support their clients to stay at home. Can talk about Advance Care Planning

A new UK government initiative

- "Caring for our future: Shared ambitions for care and support" published 15 th September 2011 .Three months consultation
- Aimed to engage with people who use care and support services, carers, local councils, care providers and voluntary services about improving care and support.
- Links with the Government's Commission on funding and the *Vision for Adult Social Care (2010)*

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Happy Christmas

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