Palliative Care: How can we make a difference?

Making a difference for people with learning disabilities

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Widening Access to Palliative Care

- Complementing the Care beyond Cancer programme, (2004-2008) the focus of which was on widening access to those with a diagnosis other than cancer.
- Widening Access project has concentrated on the extent to which access is determined by broader issues of ethnicity, disability, poverty and social exclusion.
- Widening Access working group established 2004, developed a publication and statement of intent. Widening Access manager recruited 2008 – aim to develop a programme of work which will equip hospices to WA to currently under-represented groups.
What Is Learning Disability?

**Department of Health**: A reduced ability to understand new or complex information (impaired intelligence) and reduced ability to cope independently (impaired social functioning) which began before adulthood and which has a lasting effect on development.
What’s the Point and What’s the Difference?

- Because of improved paediatric healthcare there are more people with LD but often with more severe physical and intellectual disabilities (+1% per yr).
- PWLD have much poorer physical health, but are living longer, and are consequently likely to experience conditions which require palliation.
- May have elderly family/carers who require pc (1/3 of pwslsld live with carers 70+ yrs) and will require psycho-social support.
- Long stay hospitals which previously filled the EOLC gap no longer exist and therefore these needs will require to be met in the community.
Setting the context: General Healthcare PWLD

- Higher healthcare needs but less access to healthcare services.
- DRC reports that pwld are 4x more likely to die of a treatable illness.
- BBC News Site reports research study which found that pwld are 58x more likely to die before age 50yrs (Mencap ‘Death by indifference’ 2007).
- Likely, on average, to have 5 undiagnosed conditions at any given time esp. UTI’s, sight, and hearing problems.
- Higher levels of mental ill health (40% dual diagnosis 3x schizophrenia (relationship with cancer), 4x dementia-downs syndrome 50% aged 40+ will have dementia).
- 20x epilepsy, 3x respiratory deaths of ordinary population.
People with LD & Cancer

- Often don’t access screening (Mencap 1998)
- More regularly experience ‘diagnostic overshadowing’
- Tend to be diagnosed late
- Have a different cancer incidence (16%:*26%)
- Have a different cancer profile (- bronchus, prostate, breast but double gastric cancers 58%:25%)
- People with downs syndrome have a specific cancer profile (less breast cancer but 10-30 x childhood leukaemia + lymphoma’s)
- Experience inequality in terms of access and range of treatments
- Die earlier of their disease (info service figures)
Webs of complexity: BME, MH & LD

• More likely to get life threatening illnesses early and to die prematurely from them

• Less likely to receive the full range of the expected evidenced based checks and treatments

• Link with schizophrenia and cancer (more likely breast 42%, bowel 90% ‘Equal treatment: closing the gap’(2006) DRC)

• People from BME communities are 3x more likely to be admitted to psychiatric hospital 25x more likely to be admitted to secure accommodation (20-30% prisoners have a LD)

• Experience diagnostic overshadowing, problems with differential diagnosis e.g. Dementia, multiple co-morbidities and complex pre-existing drug regimes
As serious as it gets!

- 6 ‘avoidable deaths’ of PWLD
- Scottish fatal accident enquiries (e.g. James Mauchland, Roddy Donnet enquiries)
Martin’s story

• Martin was 43 when he died. He died on 21 December 2005. He was admitted to hospital after a stroke.
• The stroke meant Martin was unable to swallow, so he was tested by the speech and language team and they said he wasn’t able to eat, so alternatives should be found to give him nutrition.
• But this didn’t happen. Into Martin’s third week without food doctors decided it was necessary to put a feeding tube into his stomach to get nutrition into him. But by this time he was so weak he wouldn’t have survived the operation.
• There was a catastrophic break down of communication that allowed Martin to go without food for 26 days. Martin’s family are convinced that if he hadn’t had a learning disability he would have been given care needed to keep him alive.
Making a difference in Scotland?

• The development of the ‘Lothian model’ of dedicated LD nursing liaison in acute services & QIS education modules

• The National Network for Palliative Care for People with LD (NNPCPLD) Scottish group has been re-launched, meets quarterly and is hosting a national conference in Glasgow (10th Nov)
  Contact Josephine McCulloch,
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• Lothian group hosted by Marie Curie bringing together PC & LD professionals to work across boundaries (mapping work), develop accessible materials Contact Anne Willis
  Anne.willis@mariecurie.org.uk
What’s the difference that will make a difference?

Physical
Emotional
Personal
Social support
Information

Control
Out of hours
Late
Afterwards

PARTNERSHIPS
What can you do to make a difference?

• Map your current patient demographics against those of your local community – what are the differences?
• Engage SUs in helping you to ‘process map’ your services – where are the barriers?
• Ensure your referral literature conveys your accessibility
• Ensure your environment conveys your accessibility
• Beware the numbers game (access within access)
• Avoid assumptions
• Commit to sharing and learning in proactive partnerships
Widening Access to Palliative Care for People with Learning Disabilities: Guidance and Resources for Professionals (HtH) Due Nov 2009

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