



Route to success: achieving quality in end of life care for people with learning disabilities

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Enfold: End of life information for people
with learning disabilities



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Arises from NNPCPLD development of the Macmillan Network
Information and Support Service 2005 -2009 which set out to:

- To map, collate and design information nationally about resources (literature, services, training, personnel).
- Develop national 'virtual' information service
- Raise awareness of the issues re pal care & Id and educate and train to meet these
- Advise developing projects and research
- Currently a 'reactive' service but undertaking specific pieces of consultancy e.g. Route to Success work 2010 - 2011



Where's death & dying at generally?

- The numbers of deaths in UK expected to rise by 17% between 2012 -2030
- Average age of death+ multiple conditions both increasing (Gomes & Higginson 2008)
- 2/3 of people want to die at home, 1/3 do (Higginson 2003)
- Complex web of reasons why & therefore policy + research has sought to address this: 3 main publications
 1. Building on the best (2003)
 2. Our health, our care, our say (2006)
 3. The End of Life Care Strategy (2008)



1) 'Building on the Best: Choice, responsiveness and equity in the NHS'

- Strategy paper published by the government in 2003 highlighted 6 priority areas of NHS care in which to increase 'choice', one of which was end of life care. Sought to:
 1. Develop more responsive services
 2. Offer patients 'real' choices
 3. Ensure best use of services to ensure 1 + 2



2) 'Our health, our care, our say'

- White paper published by DoH in 2006 which committed to:
 1. Double the funding for EOLC
 2. Establish networks to improve service co-ordination
 3. Implement national roll out of end of life care tools such as the Gold Standards Framework (GSF) and Liverpool Care Pathway (LCP)
 4. A move away from an acute care model to community based model (to enable home deaths)



3)The End of Life Care Strategy

- Published in 2008 and sought to:
 1. Provide a step change in access to high quality end of life care for: *all people, with all diseases, in all settings*
 2. Adopts a 'whole-systems approach' by outlining a 6 step end of life care pathway which seeks to guide both the **commissioning** and **delivery** of services
 3. Key themes are workforce development, communication, co-ordination
 4. Also developed a series of 'quality markers' (**pg39**) for each stage of the pathway which outline the structures and processes that enable good outcomes for people at the end of their lives. Supported by *Routes to success* guidance documents



So what about people with learning disabilities?

- People with learning disabilities account for about 2.5% of the English population with an average GP surgery likely to have 50 learning disabled people on their register
- Due to improved healthcare there is now an ageing population of people with learning disabilities, however, many of these elderly people have multiple co-morbidities and complex drug regimes related to their physical and mental health needs in addition to their cognitive and communication impairments
- As a result of improved paediatric care many children who in previous years would have died at birth or in early childhood now live into adulthood with both cognitive and physical impairments, some of which are life-threatening.
- But PLD are 58x more likely to die before the age of 50 and many times more likely to die an 'avoidable death'



So what about people with learning disabilities? (2)

- As a result of these and other factors the population of people with learning disabilities is expected to rise by 1.1.% of its total each year with older people with learning disabilities (i.e. 60yrs plus) set to increase by 36% between 2001-2021 . Many young people with learning disabilities who are currently served by children's hospices are likely to survive long enough to require adult palliative care services
- Research has demonstrated that there is a variant cancer incidence and profile within this group. In addition the Disability Rights Commission report 'Equal treatment: Closing the Gap' (2006) indicated that people with learning disabilities are likely to encounter all of the major life threatening diseases at least 5-10 years in advance of the general population and survive for much shorter periods than the general population. Dementia is a huge issue especially (but not only) for people with Down's syndrome



So what about people with learning disabilities? 3

- Access to general healthcare has been highlighted in several reports and most shockingly in the Mencap 'Death by Indifference' (2007) report and the subsequent independent enquiry 'Healthcare for all' (Sir Jonathan Michael 2008) .
- However whilst this did not include end of life care specifically there is some evidence from previous research that people with learning disabilities are disadvantaged in their access to end of life care. Norah Fry centre carrying out investigation into premature deaths of people with learning disabilities
- Research (Hogg & Turnbull) found that people with LD are likely to experience 'access within access' issues when it comes to hospice care.
- There is also evidence to suggest that achieving preferred place of care is complex for people with LD



So that's where we are but where next? Or 'that's all very nice but so what?'

- Cause to celebrate some of where we are at present:
- Legislative & policy commitment to equitable services enacted in commissioning and inspection (EqIA)
- Pathways and standardised tools (GSF, LCP, PPC) give us a ratchet standard against which to measure and challenge inequitable services



Learning Disability Observatory

- Recent report 'How people with Learning disabilities die' (2010) working with death certificates found that:
- All people with possible or definite LD died younger than people without a LD
- People with DS commonly die in their 50'/60's
- People with hydrocephalus die in their 30/40s
- Preventable causes aspiration+ epilepsy
- Hydrocephalus + pressure sores = septicimaea



Follow the path and you wont get lost!

The EOLC 6 step pathway offers us real opportunities to:

- Structure our thinking for individual clients and services
- Identify where the gaps (or is that chasms?) in services are
- Offers us a common ground for development of thinking and practice
- Route to success documents try to provide a road map for specific care settings or groups



National End of Life
Care Programme
Improving end of life care



The route to success
in end of life care - achieving
quality for people with
learning disabilities



Publication: routes to success series

Developed within a multi-agency /professional context

- Give background context to EOLC issues of either a particular client group or within a particular care setting and aim to:
- Provide a practical guide to support those who care for the specific client group in knowing about and how to link to key professionals
- Help health professionals to clarify what measures need to be taken to ensure people can access appropriate care
- Help those working in particular contexts or with particular client groups to develop an awareness and understanding of the EOLC pathway and how it relates to specific groups or care settings



The 6 steps

1. Discussions as the end of life 'approaches'
2. Assessment, care planning + review
3. Coordination of care
4. Delivery of high quality services in different settings
5. Care in the last days of life
6. Care after death

Spot the workforce development and service delivery gaps or yawning chasms!



The consultation

- Aims to: work with 2 groups of people. 1 professional group and 1 LD reference group (pge 11)
- To map the current situation regarding EOLC for PLD
- To identify resources, support and good practice models that staff can be signposted to when seeking to provide high quality end of life care in whatever settings people with learning disabilities live (Pages 22, 28, 32)
- Seeks to supplement existing pathways and tools rather than to devise completely new models
- Seeks to 'mainstream' good end of life for people with LD utilising the established End of Life Care Pathway and building upon Quality Markers and Core Competencies that are crucial to workforce development in end of life care for all people, in all settings.

Follow the path and you wont get lost! **But** beware the potholes or believing you can see round corners!



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Some potholes!

- Standardisation versus the unique
- Accessible documents are not necessarily accessible processes
- It might be clear but its not straightforward!
- Complex relationship between professional duty of care, analysis of 'risk' and giving 'real' end of life care choices alongside conflicting professional and family perspectives



Also!

Getting it right won't make it pain free

'Having a structured way to talk with her about her care and what to do with the things she loved helped us to listen and helped Belinda to tell us what was important to her. It was not a way to avoid tears; it was a way to deal with difficult issues in a way that kept us respectful and kept Belinda feeling respected'

Leah Ann Creaney Kingsbury (2009)

Intersections are vital

- Some practitioners are developing 'person-centred planning' approaches to end of life care planning
- *'As we help a person consider future health care and possibly the end of life, what is important to the person, what is important for the person and what we like and admire about the person all remain pertinent questions'* Kingsbury (2009)
- The tension between to and for is probably the most important corrective to develop 'best practice' in end of life care for people with learning disabilities



References

- People planning ahead: a guide to communicating healthcare and end of life care wishes : Leah Ann Creaney Kingsbury, American Association on Intellectual and Developmental Disability (2009)
- How people with LD die: (2010) Glover G., Muhammad A. Learning Disability Observatory
- Dignity in healthcare for PLD: (2010) RCN
- Equal Access: Creating a single equality scheme that includes improving access for pld (2009)





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