Palliative care for people with learning disabilities: an overview

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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.*

Palliative Care Is:

'...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO 2004)

Setting the Context: Healthcare of PWLD Generally

- Higher healthcare needs but less access to healthcare services.
- Pwld are 4x more likely to die of a treatable illness (DRC)
- Pwld are 58x more likely to die before age 50yrs (BBC news) Mencap 'Death by indifference' 2007
- Likely, on average, to have 5 undiagnosed conditions at any given time esp. uti's, sight, and hearing
- 20x epilepsy, 3x respiratory deaths of ordinary population
- Higher levels of mental ill health (40%+ dual diagnosis 25% have risk factors for mental illness, 4x dementia 3x schizophrenia (relationship with cancer 'Mind the Gap DRC 2006)

The Difference That Makes the Difference

- Higher levels of cardiac, respiratory disease, lower levels of cancer
- Lower incidence of cancer
- Different cancer profile (including double the incidence of gastric cancers) Helibactor P and GORD
- People with Down's syndrome have particular cancer profile (-breast, +childhood leukaemia)
- Multiple co-morbidities and complex pre-existing drug regimes

What's happening in Palliative Care?

- Increasing emphasis on widening access to patients both in terms of diagnosis i.e. Non-cancer and social circumstance e.g. prisoners & asylum seekers
- EOLC strategy + ring fenced funding (2011)Consultation on EOLC for PLD due to begin
- Alongside an increased emphasis on Advance Care Planning + tools to support this
- Pathways approach to standardise care in acute and hospice and home settings e.g. GSF & LCP

The end: where to begin?

Physical
Emotional
Personal
Social support
Information

Control
Out of hours
Late
Afterwards

But where are we really?

'...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO 2004)

Some recent thoughts/learning

- Access improved but still patchy and uneven (access within access)
- Care settings and related funding arrangements complicate practice
- Emphasis of spc on intervention and being outcomes driven ('evidence based' practice) may ignore process and story (echoes of **'total pain'**)

It's not a 'new' story

- '*Crucially total pain was tied to a sense of narrative and biography, emphasising the importance of listening to the patient's story and of understanding the experience in a multi-faceted way'*(Clark D. 2000)
- Earnshaw-Smith described TP as 'emotional pain' which is inextricably interwoven with physical pain and which is experienced in the present but is closely interwoven with the pain of the past (holocaust survivors/bereaved)
- Though unacceptable it is often appropriate '*Unlike physical pain, it often cannot and should not be cured, but it must be understood and acknowledged. Because emotional pain is to do with the intensity, the triumph and the tragedy of life itself it must not be denied or suppressed'*Earnshaw-Smith E. (1982)

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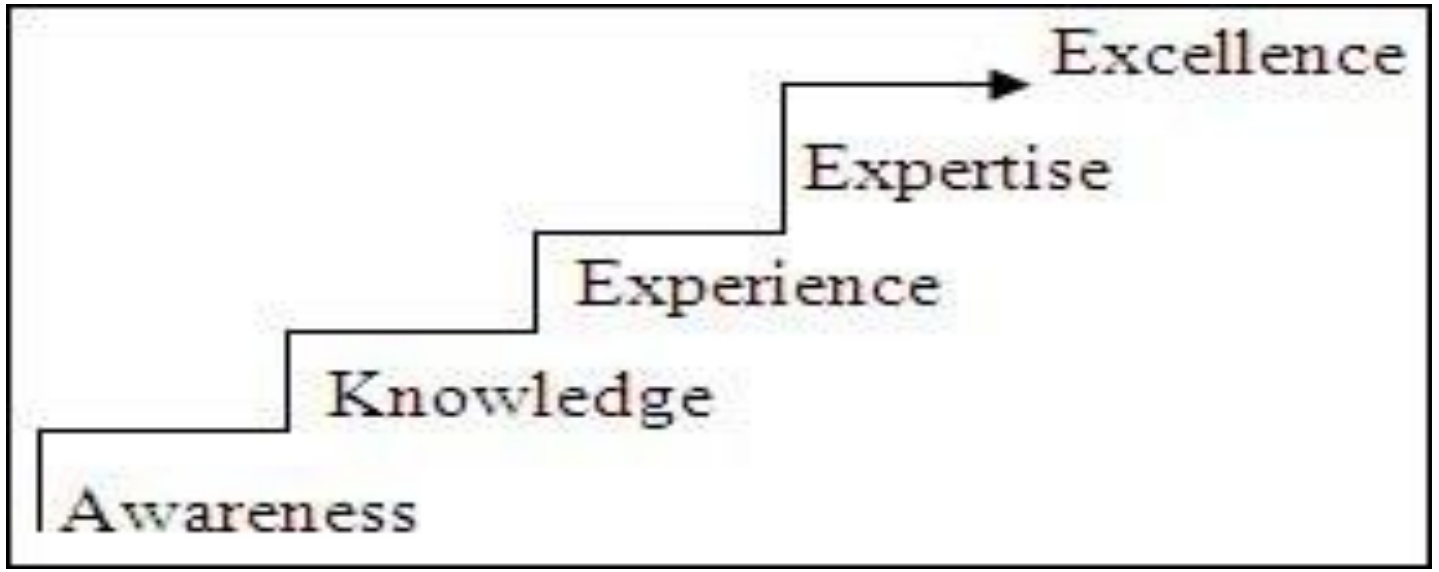
How is *Total Pain* diagnosed in people with learning disabilities?

- ? Nothing written specifically about this- though implicit in some works
- Swinton extends Regnard's work on 'diagnostic overshadowing' and DisDAT to include spiritual distress

'…*when this happens, the severity of the person's suffering is underestimated or overlooked completely; they are often left to face their suffering alone. Within a palliative care context, this can lead to forms of care that are strong on [physical] pain control and functional care, but significantly lacking in emotional and spiritual dimensions*' (Swinton 2006)

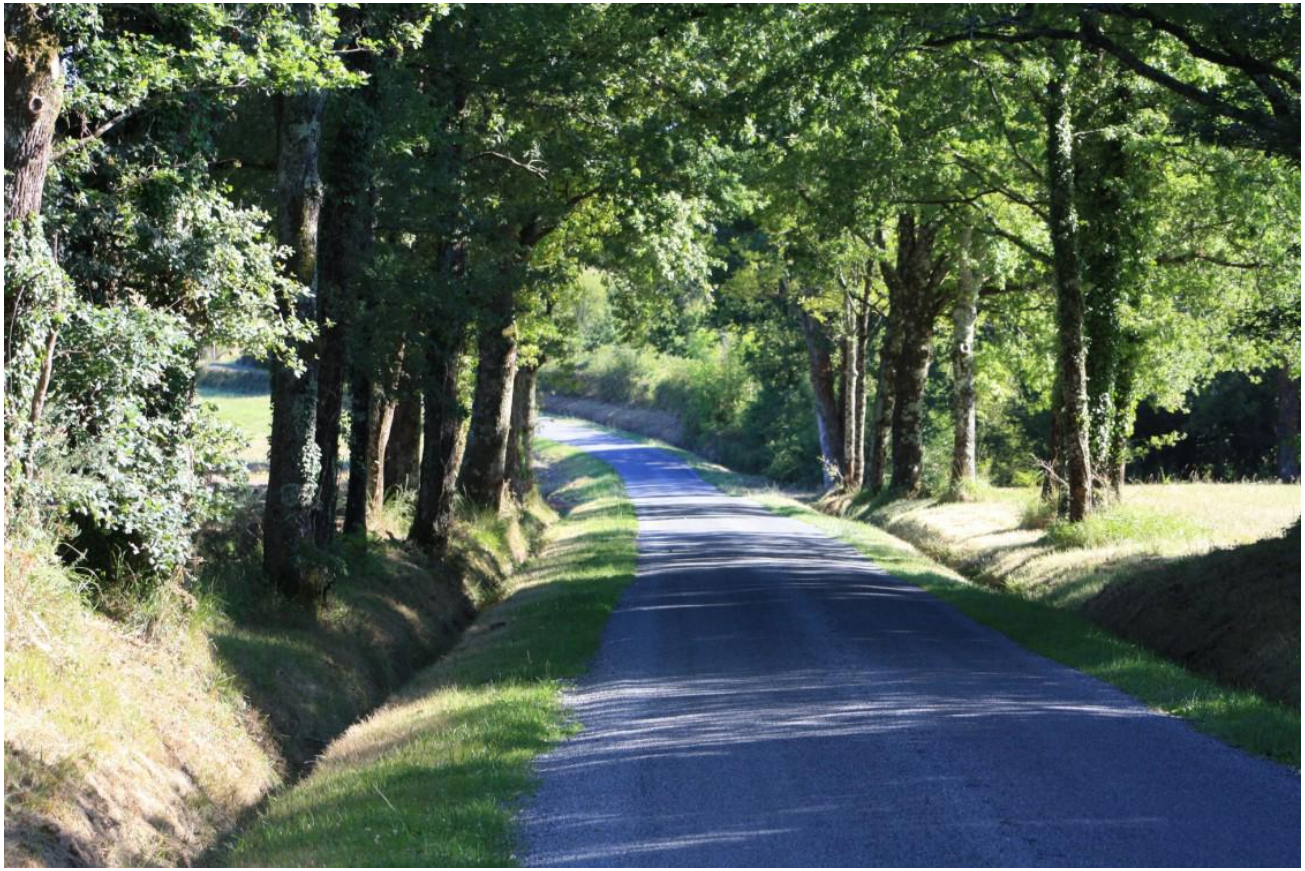
Hierarchies of need vs. Pinnacles of excellence

Steps to excellence



Note: none of these can be gained in isolation!

Excellence is a journey not a destination



Things you will need for the journey

- A healthy curiosity
- Informed by the ability to listen (and learn)
- The ability to 'travel light' = let go of preconceptions and limiting beliefs whilst holding onto good practice
- But **don't forget** a respect for the resilience of people with ld
- **Or that** – there is always more around the next bend!