

# Real Lives: Real Choices Ethics & Decision – Making In Palliative Care

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# What's the point and what's the difference?

- PWLD are living longer, have much poorer physical health and are consequently likely to experience conditions which require palliation, or to have elderly family/carers who do so.
- Long stay hospitals which previously filled the EOLC gap no longer exist and therefore these needs will need to be met in the community.

# What's the difference?

- PWLD experience much higher levels of mental ill health in addition to their cognitive impairments ( research suggests 40%+)
- PWLD also experience much higher rates of dementia ( 4 x<sub>+</sub>) and people with Down's syndrome experience the onset much earlier (80% will now live in excess of 40yrs but 50-70% of these will have Alzheimer's disease)
- Some pwld do not use verbal speech to communicate

# When does someone become a competent adult?

- The act includes anyone of age 16+
- Is it before and if so when and on what basis is competence assumed and assessed? If not how is the process of meaningful consultation begun?
- What is the culture of your organisation in terms of consulting with service users and their family members? When there is conflict who do you advocate for?
- What might need to change for your organisation to be compliant with the spirit of the act?

# Competent decisions or competent adults?

- Whilst the MCA makes this distinction clear many pwld have never been ‘considered’ competent in **practice**. Therefore the fact that there is a legally binding process to be followed could be a benefit for many pwld – making life ‘safer’ for them than it is for them currently.
- But will practitioners be skilled enough to enable pwld to demonstrate their competence?

# Competent Decisions or Competent Adults

- Given that many of the tools with which we assess 'clarity' ( and which are therefore likely to be used in decisions about capacity) don't work for people with learning disabilities e.g. MMSE
- ? On what basis will you assess capacity in a person with a learning disability
- ? How will you be sure that you are assessing 'lack of capacity' as opposed to 'lack of the requisite skills to communicate effectively'

# Involving families

- Whilst the act makes it clear that in the case of lack of capacity that families should be consulted to try to help determine what are the 'best interests' of the patient- there are some things to consider:
- We need to remember that if capacity is on a case by case, decision by decision basis that a patient with a Id, mental health or autistic spectrum disorder may not have capacity to consent to or refuse treatment but may still have capacity to refuse to have family members involved in the decision making processes

# Families

- We need to remember that some families are motivated by
- Over protectiveness/ fearfulness
- Exhaustion
- Exploitation

And that some family members themselves do not have the ability to judge what is in the patients' 'best interests'

# Are we clear about what constitutes 'best interests' for PWLD?

- Greater difficulties in the acute setting due to shortage of time and less highly trained staff
- 59 yr old woman with a primary breast cancer refused surgery on the basis that she was 'scared of operations'
- But later asked 'This lump in my breast is growing it wont kill me will it?'

# Are we clear about what constitutes 'best interests' for pwld

- A 50 yr old man with Id and mental health problems had surgery for a primary brain tumour but no follow up treatment as doctors felt it inadvisable because of his 'pre-morbid condition'-
- He of course died of the recurrence (under the care of the pal care team but never having seen an oncologist)
- This is not completely unusual

# Best interests?

- A 35 yr old autistic man who had a rare form of MND had both a 'nippy' machine inserted directly into his windpipe and a peg feeding tube inserted. The consent in both cases was given by his mum. As he became increasingly incapacitated by his disease he requested that he be allowed to die – but from what?

# Best interests?

- A young man with Downs syndrome developed a treatable testicular cancer. Initially the treatment team decided that as he
- could not 'consent' to treatment he could not be treated.
- An oncology social worker and the man's key worker enabled the man to demonstrate his understanding and consent.
- The team leader was heard to remark 'What a shame to put him through this'

# Not in a vacuum

- Decisions are not made in a vacuum but neither will people with learning disabilities understand the Mental Capacity Act in isolation.

# Telling it like it is!

- *‘People with learning difficulties are different to other people. We get picked on- others make fun of us. People shout in the street sometimes. Black people with learning difficulties get picked on even more. People with learning difficulties should be treated fairly and not discriminated against. Scientists should find the gene that makes people pick on those who are different. Then our lives would be better.’*
- *Howarth et al (2001) in Blackman (2003)*

# Pros and cons

- [Human Rights Database 1990 reported on DRC website that since 1990, 682 British disabled people have died as a result of 'disability prejudice']
- DRC reports that pwld are 4x more likely to die of a treatable illness
- BBC News reports a recent research study which found that pwld are 58x more likely to die before age 50yrs
- Will the world feel less or more scary for pwld as a result of the MCA?- the jury is out!
- The role of well trained and supported advocates will therefore be crucial

# Bridging the Gaps: But what are they?

- *Sue says 'I'm one of only a handful of people that can understand what J says'*
- *'I know what I want'*
- *'What do you want?'*
- *'I want you to get a pen?'*
- *'What do you want me to get a pen for?'*
- *'To write it down'*
- *'To write what down?'*
- *'What I want at my funeral'.*