

17/07/2016. *Thoughts on the Liverpool Care Pathway*

Anton has asked me to do a quick thought on care of the dying specifically touching on the now defunct Liverpool Care Pathway. Since half a million of us die every year in the UK this seems like a topic we shouldn't really avoid. I want to preface this thought by pointing out that in 2010 a review by *The Economist* ranked the UK as the global leader in end of life care. I'll start with a short "Case study":

Tom had recently retired from work and lived with his wife Wendy in rural Market Town. Wendy's mother had recently died and this had prompted Tom and Wendy think about the type of care they would want to receive if they were seriously ill. After hearing a programme on the radio about '**advance decisions to refuse treatment**', they felt that this was something they would like to know more about. They realised that these used to be called '**living wills**'.

Tom and Wendy felt unsure about completing such a document as neither of them felt strongly about refusing treatment. However for them, their faith that mattered a great deal. They knew they would want to receive spiritual support if either of them was seriously ill. However both of them were concerned about some rumours they had heard about something called the Liverpool Care pathway.

What was the Liverpool Care Pathway?

Well this was a system developed during the late 1990s intended to provide the best possible quality of care for dying patients, and was seen as a way of spreading best practice from hospices into other care settings such as home and hospitals.

Its aim was to ensure that everyone expected to die "within hours or days" received the same high standard of care, regardless of where they were being cared for.

The LCP came under substantial criticism in the media in 2012. What caused alarm was that Hospitals were provided cash incentives to achieve targets for the number of patients dying on the LCP and there were concerns that patients were being casually assessed as terminal, heavily sedated, and denied food and water. There were also reports that people had been placed on the LCP without their consent or their family's knowledge. Histrionic video's were posted on You tube containing the words "Murder" "Holocaust" and "Genocide".

The Government ordered an independent review ..the Neuberger review ..in 2012 which found that, when used properly, the LCP helped patients to have a comfortable, dignified and pain-free death. However, the panel also heard of failings in its use especially concerning lapses of communication and the difficulty of diagnosing when someone was actually going to die.

It also concluded that using the term 'pathway' in relation to people who were dying was inappropriate, and recommended the term be dropped. The review recommended that the use of the LCP should be phased out by July 2014 and replaced with "**personalised end-of-life care plans for individuals.**"

It also called for a regulatory body to be formed to oversee care of the dying and deliver the education, training and skills needed. In response to this, the '**Leadership Alliance for the Care of Dying People**' (LACDP) was formed to oversee and train care givers.

Five priorities for care have been identified as necessary:

1. The **possibility** that a person may die within the next few days or hours is **recognised and communicated clearly**, and decisions made in accordance with the person's wishes. The label '**dying**' is avoided because some patients recover.

2. **Sensitive communication is maintained between staff and the patient and their family.**
What is said should be documented, and staff encouraged to check that what has been said has been understood, and to listen to and respond to any concerns from the patient and family.
3. The dying person and family are **involved in decisions** about treatment and care. Professionals must respect any valid and applicable **Advance Decisions**.
4. **The needs of families and other individuals important to the dying person are actively explored, respected and met as far as possible**, and they are given support and information when needed
5. **An individual Care plan** which includes **food and drink, symptom control and psychological, social and spiritual support, is agreed**. The care plans should be regularly reviewed and available to all involved in their care.

So let's go back to Tom and Wendy. What advice have I got for them? Well reassure them that the LCP ceased to exist two years ago and has been updated with a more sensitive care regime. Also...

- 1) If they did wish to refuse a specific treatment, they should write it down in an “**advanced decision**” as these wishes must be in writing, signed and witnessed
- 2) They should think about appointing someone to speak for them or have a “Lasting Power of Attorney”
- 3) They should discuss their wishes with their carers, and relatives bearing in mind that some of them may find it difficult or even distressing to discuss the implications of their condition... for instance:
- Make it clear that for them for them death is not a clinical event to be managed with standard procedures ..the spiritual dimension of their life is important... give people permission to ask them about their spirituality
- They may need privacy to pray and talk deeply with their friends and family
- They may like to see a Minister or take communion
- They should plan where they would ideally want to die..
- When they would want treatment to be withheld
- If they would object to assisted nutrition and fluids
- If they would object to sedation or strong pain killers, even if there was a risk that the side effect could shorten their lives?
- Finally – what a great opportunity to write down for their carers what death means to them from a Christian perspective?

These thoughts on the Liverpool Care Pathway are by Jamie Muir