THE NATIONAL Council for Palliative Care

'Duty to Care? Supporting and involving unpaid carers of people at the end of life

10th October 2013

London Marriott Hotel Regents Park, 128 King Henry's Road, London, NW3 3ST

Session 3 – 14.30 – 16.00 Capacity to Care – conflict, confidentiality, crisis

Chapter 1:

Mary was diagnosed with Motor Neurone Disease 9 months ago. She has deteriorated rapidly in this time and is now wheelchair bound and unable to communicate. While she had the capability to communicate, Mary has given her partner and carer, Nina, a Lasting Power of Attorney (for both finance & property and personal welfare) and also expressed her preferred priorities of care. Mary has indicated that, when she is at the end stages of her life, she would like to be cared for at home, by Nina, with their children around them. Mary no longer has a relationship with her parents and has made it very clear that she does not want them to interfere with her care in any way. Nina has struggled to care for Mary as her condition has worsened. She has had to become part-time at work so that she is able to care for both Mary and the children and she is concerned about how the family will cope financially in the coming months. Nina is scared about what the coming months will bring but feels trapped by Mary's wishes.

Discussion points:

- What duty of care do we owe Nina? And what duties might Mary owe to Nina?
- Is there additional support that Nina could be accessing?
- Might the care burden have a negative impact on Nina's life? How might the children cope with this?
- How might the relationship between Mary and her parents best be explored and managed? Why has the relationship between Mary and her parents broken down? And what might Mary mean when she objects to her parents' potential "interference" need this mean that they should not participate in any way?

Chapter 2:

Mary's parents are a wealthy, retired couple who have been trying to get back in contact with Mary and Nina since Mary was diagnosed. They have been calling the hospital to ask for information but due to patient confidentiality the doctors are unable to tell them anything. Nina will not answer their calls and they are becoming increasingly worried. They can see that Nina is struggling to care for their daughter and have offered numerous times to help in some way, whether this is child care, helping with care costs, or caring for Mary at their home, but Nina has refused. Despite the fact that she is struggling to cope, she feels that this would be a betrayal to Mary. However, as the weeks progress and the care costs keep mounting, Nina is forced to accept financial help from Mary's parents. This greatly troubles her and adds to her stress.

Discussion points:

• What obligations might be owed to Mary's parents? For example, should they have a right to know information about their daughter? Are the doctors right not to tell Mary's parents

about her condition, even if they are offering help? Nina is clearly struggling, could Mary's parents offer better care and support for Mary? Does acting in Mary's best interest override Nina's say?

- Is it ok for Nina to accept financial support from Mary's parents?
- How much longer can Nina cope?

Chapter 3:

Nina's health has deteriorated due to the stress and exhaustion of caring for Mary. She has developed severe migraines and panic attacks. She has become a reluctant carer and resents Mary for putting the care burden solely onto her. She resents the guilt that she feels for accepting financial help from Mary's parents and for contemplating sending Mary to a hospice. The children are starting to 'act-out' at school, clearly extremely affected by the situation and Nina has no emotional or social support to help her deal with this. She feels incredibly alone but does not see a way out. Would it be possible to override Mary's wishes and accept help from Mary's parents? Is this legal? Should she tell the doctors to include Mary's parents in decisions? She is lost and unaware of what her legal rights are and no one is offering her any support.

Discussion points:

- Carer vs. patient whose wishes take priority? Is it right for the doctors to continue to honour Mary's wishes if they can see that Nina is becoming ill from the care burden? Is it right for Mary's wishes to still take precedence?
- Do doctors have a duty to explain to Nina what her options are and who is able to decide?
- If Nina collapses, who will care for Mary and the children?
- Nina is starting to resent Mary has the care burden ruined their relationship?
- What rights and obligations, if any, are enjoyed by and owed to Mary's parents?