

Session 2 – 12.15 – 13.45

Carer vs. Cared for – collusion, capacity, confusion

Chapter 1:

James is a 40 year old musician. He is caring for his mother who has COPD. His mother, Diane, has been living independently for 10 years since the death of her husband and has very much enjoyed herself, taking up hobbies such as gardening and bowls. James' support and care has been steady over the past 3 years since her diagnosis.

He has actually moved his family to the area so he can be closer to her. Diane is an intelligent and very articulate woman. However, over the past few months James feels that his mother seems to be becoming confused at times. Her behaviour has also become somewhat unpredictable. James has asked her doctor about this but, because the episodes have been short and sporadic, the doctor has simply put it down to 'old age'. James is worried and feels that his concerns are not being addressed but he does not want to 'push' the medical team. James has managed to care for his mother for a long time and he is sure he will be able to cope . .

Discussion points:

- *Is the doctor right to dismiss James' concerns?*
- *When caring for someone with a long-term condition there are often subtle changes that you don't detect and you often do not realise that the care burden is increasingly. Therefore could Diane's behaviour change be more severe than James has noticed?*
- *What options are available to carers if they feel existing support is inadequate or unsuitable and they wish to obtain additional support, guidance or clarification?*

Chapter 2:

Sixth months later Diane has become increasingly confused and reliant on James. It is not unusual for her to call him many times a day, often to ask him the same question over again. She does not always remember to take her medication for her COPD but will often tell James that she has done so. James is now extremely worried about his mother and her ability to live independently. However, when he presents these symptoms to the doctor, the doctor ignores his concerns, probably because his mother is able to mask her cognitive impairment when around her medical team meaning that they do not witness her behaviour. As a result they believe that James is not being truthful and do not include him in decisions about his mother's care. James feels excluded and disrespected. He is angry with his mother as he feels she is making it harder for him and he resents the medical team for ignoring his concerns yet still expecting him to care for Diane. He is stressed and is arguing with his wife with whom he is spending less and less time.

Discussion points:

- *Is it right for the doctor to take the word of the patient over the carer?*
- *Could the doctors be right in thinking that James does not have his mother's interests at heart and instead is thinking of himself and his needs?*
- *Is it fair to exclude James from decisions about his mother's care yet still expect him to support her and carry the care burden?*
- *Could there be a feeling that James is only a 'musician' and therefore can afford to dedicate time to caring? Would it be different if he was a lawyer?*
- *What effect is this having on James and his family? Is it right for the doctor to only look at Diane's health and not consider how worried and stressed James is?*

Chapter 3:

James' relationship with his mother has broken down. He has grown to resent her as she will not let herself be helped. He fears that she will harm herself but while she continues to mask her dementia, the doctors insist that she has the capability to make her own decisions. James feels hurt and lost. His mother is rude to him and will not let him care for her. She is ungrateful and not the mother he knew and loved. The medical team will not listen to his worries or offer him support. He is exhausted and has spent very little time with his family. James wonders how much longer he can cope with this burden. What if it splits up his family? Can he walk away and leave her now? Why is this his responsibility and not his sisters?

Discussion points:

- *What is the doctor's role if he believes that Diane has the capacity to make her own decisions but that these decisions are unwise and have a negative impact on both the mental and physical health of her son?*
- *What would happen if James did move away? Would doctors still think that Diane could live independently?*
- *Is James being expected to sacrifice his family for his mother's needs? By whom? Is there a duty owed to James to be able to live his own life?*