**SOCIAL SERVICES AND WELL-BEING (WALES) ACT**

**CASE STUDY**

**Margaret**

Margaret is 94 years old and has been diagnosed with Alzheimer’s disease; she also has Polymyalgia, severe Osteoarthritis and Glaucoma. She lives in extra care housing (ECH) and has her own tenancy. She moved from her council bungalow into ECH about four years ago and was relatively independent and needed help with some activities of daily living such as washing and dressing, prompting with medication and help getting in to bed.

However, over the last year Margaret has become increasingly physically frail and her Alzheimer’s has become much more pronounced – she is also susceptible to regular urinary tract infections (UTIs). Moreover, Margaret’s needs fluctuate significantly. For example, Margaret will sleep in her chair for hours, up-to-nine hours on a bad day and at these times she will not drink fluids or wake up regardless of attempts to wake her. On other days she is awake and can communicate her basic needs by responding to simple questions for example “would you like a drink Margaret?” “did you see what Vivian just did?” (her great-granddaughter). Margaret is unable to talk but can nod or shake her head and sometimes smile. Also Margaret’s swallow reflex has rapidly deteriorated and she cannot manage solid food and has to eat soft food. She can no longer feed herself.

Given this deterioration in Margaret’s needs, Bethan has decided to be with her mother seven days a week and spend a large amount of time with her mum in the day. Bethan cooks, softens and purees the food and sits with her mum and feeds her for breakfast, lunch and supper. This can take up to an hour and sometimes longer. Bethan is currently coming to the scheme at 8am and helping her mum throughout the day and assisting the carers when they visit. Margaret now has six visits during the day. On these visits the carers assist with medication, toileting, getting up and getting ready for bed. Bethan will leave the scheme about 8pm when Margaret is settled in to bed. Sometimes Bethan will walk around the block or the scheme for a break. Anne, Bethan’s daughter also comes in the week to give her mother a break and looks after her grandmother for most of the day on Saturday.

The scheme manager recently took Bethan aside and suggested that her mum needs nursing care and that they, as a scheme, are unable to provide this level of care. She also said if they couldn’t find a nursing home she may need to move elsewhere as an interim measure. This has led to a great deal of distress for Bethan because she feels a move would be too much for her mother – in fact she thinks a move, when her mother is so physically and mentally frail, will lead to an untimely and undignified death. In particular, she is shocked that an interim measure could be considered which would cause even more disruption and uncertainty for Margaret.

The scheme manager has also said Margaret may benefit from a PEG feed. This has caused a great deal of distress for Bethan because she knows that her mother, despite swallow problems, still derives a great deal of pleasure from eating, in particular she loves melted ice cream (White Magnums) and lemon yoghurt – she attempts to smile when eating these foods and becomes more animated.

Bethan with her daughter, Mari, is Margaret’s attorney for welfare and finances. They both feel that Margaret has significant needs and that there are risks of choking but also knowing and being close to Margaret they feel that Margaret would prefer to take these risks rather than be fed via a tube. They also feel that Margaret would prefer to ‘stay-put’ with an increase in care to enable a dignified end of life. They feel that any move to a nursing home and a PEG feed would be detrimental to Margaret’s well-being. Anne, Margaret’s granddaughter feels that a social worker referral is needed urgently so they can express Margaret’s increased needs, wishes and
well-being requirements and put forward their own feelings and needs as Margaret’s carers. They are hoping a referral to a social worker may lead to other assessments that might help Margaret to remain in her own home.

Bethan insists that she wants to continue the level of care and support she is providing although Mari is concerned that this arrangement means that Bethan is living an ‘older old age’ before her time and that it might be too much of a commitment as Mari has said “I don't know how you do it – I couldn’t do that much”. Despite this, Bethan is insistent that she wants to look after her mother to enable her to have a comfortable end of life in her own home. Given this, Mari has agreed that her mother must do what she feels is right and will look after her grandmother on Saturday to give her mother a break and will also continue to pop-in during the week.

1. Given the overarching duties in the Act, how might an assessor approach this scenario? Hint: what must you have regard to?