NHS Suffolk Retrospective Continuing Healthcare Panel

Agnes [redacted]

Meeting held on Wednesday 30th May 2012

Present: Howard Stanley (Chair)
John Morton (Mental Health Representative)
Dr Gareth Richards (Medical Representative)
Julia Dalziel (Local Authority Representative)
Sue [redacted] (Non-voting member of Panel)
Diane Forster (Minutes)

Peter [redacted] (Son of Agnes [redacted])

Introductions:

The Panel Chair welcomed Mr [redacted] and introduced him to the members of the Panel.

Explain Panel Membership:

The Panel consists of a Chair, a GP (Medical Representative), Registered General Nurse (PCT Nurse Representative), Social Care Manager (Local Authority Representative). In addition to this others may be co-opted onto the Panel as necessary to give advice and support in their areas of expertise e.g. Registered Mental Health Nurse (Mental Health Representative).

Remit of Panel:

The NHS Suffolk Retrospective Continuing Healthcare Panel is the body charged with examining a case in order to determine whether a person was eligible for NHS Continuing Healthcare.

Purpose of Family and/or Representative Involvement:

Attendance of the Family and/or their Representative will enable them to have the opportunity to give a brief history of the case before outlining the Patients needs in more detail. If they believe that NHS Continuing Healthcare should be retrospectively granted they may also wish to inform the Panel of why this is so. To clarify further; the Family and/or Representatives attendance should focus on the Patient's specific needs throughout the period in question. The family should not focus on the legality of NHS Continuing Healthcare which is outside of the Panel's remit.

After this the Panel Members may ask the Family/Representatives questions relating to statements made by them either in writing or at the Panel.

To reiterate; the Family and/or their Representative are invited to the early stages of the process thereby ensuring that there is involvement and that their views can be fully considered by the Panel.

The Family and/or their Representative will then be asked to leave to enable the Panel to give the matter due consideration in order that they can establish whether or

not the Patient would have been retrospectively eligible for NHS Continuing Healthcare.

Family and/or their Representative give brief history of the case:

Howard Stanley advised Mr [redacted] that Sue [redacted] was attending to assist in presenting the case and clarified that she would be a non-voting member of the Panel. It was agreed that the period being considered was from 4 September 1998 to 6 November 2002. Howard informed Mr [redacted] that the criteria that the Panel would be applying is the local criteria that was in place towards the end of that period i.e. the Norfolk, Suffolk and Cambridgeshire Strategic Health Authority and Norfolk, Suffolk, Cambridgeshire and Peterborough Social Services Departments Joint Policy and Eligibility Criteria for NHS Funded Continuing Health Care. The Panel will also apply the Primary Health Needs Test, looking at the nature, intensity, complexity and unpredictability of Ms [redacted]' health needs.

Sue [redacted] gave brief summary of the case to the Panel.

Howard Stanley asked Mr [redacted] to give the Panel an outline of his feelings of his mother's needs at this time.

Mr [redacted] told the Panel that this was the first time in their lives that either he or his wife had come across anyone with Alzheirmers. They had some support from [redacted] but felt that to a large extent they were very much on their own. Ms [redacted] required round the clock care and Mr [redacted] feels that her care needs should have been assessed by the NHS as medical rather than social, hence the reason for this claim.

Mr [redacted] went on to say that with help from himself and his wife his mother was funding her own illness and that "doesn't feel right", the NHS should be free at the point of need. Ms [redacted] was admitted to Ipswich Hospital in May 1998 - she had been found sitting on a grass verge. She was confused, but otherwise healthy and mobile. She was discharged from hospital in November 1998. Following discharge she was in a poor state and was very frail, immobile etc. Because she was now disabled and also incontinent Mr [redacted] felt that a Continuing Care Assessment should have been carried out prior to hospital discharge but there was no evidence of this being done, either at Ipswich or Hartismere Hopsital. Ms [redacted] required a high level of supervision and equipment to preserve her life on an ongoing basis. Mr [redacted] therefore felt that his mother should have been funded to some extent by the NHS. He added that the quality of nursing provided by the care home was probably equal to that his mother would have received in a long stay dementia ward.

John Morton asked Mr [redacted] to give an overview as to the progression of Ms [redacted]' dementia over the four year period. Mr [redacted] told the Panel that when his mother was admitted to hospital her short term memory was non-existent. Her longer term memory was patchy. Mr [redacted] went on to say that prior to her admission to hospital she said that people were staying with her, for example, she said there were gypsies at the bottom of garden which obviously there weren't. When she was in hospital she remembered him and his wife but probably 6 months into her time at the care home she didn't know them.

John asked if Mr [redacted] found that within the realms of her dementia she displayed any behavioural issues - was she aggressive or resistant to care? Mr [redacted] replied that she wasn't hostile, however, she was medicated so he didn't know what

effect this would have. As far as he knew she did not display any aggressive behaviour.

John asked if Mr [redacted] had noticed changes that occurred while she was still in her own home. Mr [redacted] confirmed that he had - he and his wife tried to visit as often as possible. His mother had meals on wheels and the family would go shopping for her and put it in the cupboard but she didn't know what to do with it and would eat all the food at once. Carers would go to make food and say there was nothing in the cupboards. He explained that he had asked the carers to keep a diary - they had a locked case and put medication in there together with the diary. Towards the end of Ms [redacted]' time at home the family were worried because she had a gas cooker and she would leave the gas on. There was a period when she would put her clothes on back to front or inside out. Also she didn't know how to take care of herself, she would drop food on herself. She was not aggressive, however, she was certainly challenging to deal with and disorientated.

John stated that in early stages of dementia, people often have periods of lucidity. He asked Mr [redacted] what was the presentation of his mother's overall mood? Mr [redacted] informed the Panel that when dementia started to take hold she did have periods where she knew something was wrong and she got quite upset and depressed.

John asked if Ms [redacted] appeared settled in the care home. Mr [redacted] replied that she was certainly agitated and anxious. She didn't really know where she was and had imaginary visitors. She didn't know him and his wife most of the time. He added that he thought that if his mother had presented with aggression/shouting the care home would have noted it.

Howard Stanley asked Mr [redacted] about his mother's "imaginary visitors" - were they actually hallucinations? Mr [redacted] replied that she would say that someone visited her and they knew that wasn't the case. The family didn't dwell on it and tried to move on and it was relatively easy to do so.

Howard asked about Ms [redacted]' ability to communicate. Did Mr [redacted] feel that she was able to make choices with regards to her meals etc? He replied that he didn't see any evidence of this. She would respond appropriately if asked a direct question e.g. would you like a tea/coffee, however, this did change as time went on. She could not engage in any meaningful conversation. Howard asked if she would express that she was thirsty/hungry? Mr [redacted] replied that she would not.

Mobility

Howard asked if Ms [redacted] was mobile when she went into [redacted]? Mr [redacted] said that she was not. The Home Manager had originally said that she would take Ms [redacted] as long as she could stand up however when she was discharged from Hospital she could not stand up and had to be moved in a wheelchair. Mr [redacted] stated that he did not know how the Home Manager decided to take Ms [redacted] against her own criteria. She had been in [redacted] previously for a week's respite. Howard noted that reports state that she was able to transfer with aid of two carers and a handling belt so she was taking some of the weight at that time, however, Mr [redacted] said that he had never witnessed this.

Howard asked if Ms [redacted] had any falls at [redacted]. Mr [redacted] replied that she had had several falls and that one day when the family visited she wasn't there as she had fallen and had been taken to the emergency unit at Ipswich Hospital.

John Morton asked if Ms [redacted] was able to feed herself. Mr [redacted] replied that he couldn't really say as the only occasions he had seen her eating were when he either arrived a bit early or she was late getting up and he saw her eating a piece of toast.

Skin

Howard noted that Ms [redacted]' skin was intact for most of the period in question and asked if Mr [redacted] was aware of any problems. He replied that he was not although there was some mention towards the end of her leg going blue.

Howard asked if there were any persistent problems with breathing, did Ms [redacted] seem short of breath. Mr [redacted] informed the Panel that he always saw her relaxed in a wheelchair, therefore he had no idea how she would be when being transferred for example.

Sue [redacted] noted that the involvement of the GP happened in the last couple of months - there was no specific event just a gradual decline. She asked how the communication from the Home was at this time. Mr [redacted] stated that he had received occasional phone calls from a carer but no communication from the Care Manager. He added that towards the end the family didn't have much in the way of communication.

Julia Dalziel asked if Mr [redacted] had had any concerns about the care his mother was receiving. He replied that he did in retrospect, however, not at the time.

Howard asked if there was anything else that Mr [redacted] would like the Panel to be made aware of that had not been discussed or not contained in the documents that the Panel had obtained but he replied that there were no further issues that he wished to raise.

Thanks to Family and/or their Representative for attending:

Howard Stanley thanked Mr [redacted] for attending. He advised that NHS Suffolk would provide the family with the Panel's decision in writing, together with the rationale for that decision along with the minutes of the meeting as soon as possible, usually within 4 weeks.