Code A

MM/LH/YJM

22 August 2000

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Dear Code A

Further to my earlier letters I am now able to respond in detail to your complaint about the care provided for your mother, Code A on Dryad ward. We are sorry that it has taken so long to conclude our investigation - thank you for your patience. As you know, our investigating officer, Mrs. Sue Frogley, spoke with those concerned with your complaint, and reviewed medical and nursing records. Following this Mrs. Lesley Humphrey (Quality Manager) and Mrs. Fiona Cameron (General Manager for Gosport and Fareham) reviewed the investigation report, drawing conclusions and making recommendations.

Our investigation highlights the differing expectations of you and your family from the clinical staff. It also very powerfully highlights a breakdown in the relationship and trust between yourselves and the clinical team. I am very sorry for the distress caused by this and I will return later to this issue.

First, I would like to respond to your specific questions in the order that they were posed.

1. Why did Dryad ward offer different pressure sore advice to other areas?

   Code A had developed two extensive sacral sores prior to her admission to Dryad ward. A pressure sore assessment completed on the day of admission registered that she was at high risk. A score of 20 or over is considered very high risk and Code A scored 27. The best treatment for, and indeed prevention of, pressure sores is to relieve the pressure. We cannot comment on what you have been told by others, however bed rest with a pressure relieving mattress was the appropriate care at this stage - as confirmed by our wound care guidelines (a copy of two of the guide appendices is enclosed).

2. Dr. Barton's advice that morphine enhances healing, stimulates the appetite and is an efficient mood enhancer

   We have checked with our pharmacy advisory service; morphine can cause a state of euphoria and thus enhance a person's mood. There is, however, no identified link between morphine and wound healing or stimulation of appetite. We are sorry that you were given the impression that morphine had these properties.

It would be fair to say that relieving someone's pain and enhancing their mood might improve their general feeling of well-being, with a positive effect on their appetite and healing, etc. Conversely, however, morphine can cause nausea and vomiting in some people, and indeed drowsiness. I am sorry that you were left with a false impression of the potential effects of morphine and for the distress this has subsequently caused you.

3. Why did it take a week and a day for the morphine to arrive and administration begin?

It is very clear that pain was a major problem for your mother, and that managing her pain proved to be very difficult, for a number of reasons. As you state in your letter, you were originally horrified at the thought of morphine being used, as was your brother, Code A The staff were acutely aware of this and did not want to cause you any upset.

On 8th December, 1999 Dr. Reid saw your mother. He suggested to her that her pain killing medication (analgesics) could be changed (i.e. that morphine could be used) but she was reluctant for this to happen and requested that she stayed on her current medication.

That same day Dr. Reid saw your brother, Code A They agreed that it was essential to get your mother's pain under control if she were to get back on her feet. They also agreed that if other analgesics proved to be inadequate we would try to persuade your mother to have morphine.

Your mother's regular pain killing medication at this time consisted of: Tramadol (which is in the same group of medications - opiates - as morphine, but has fewer of the opiate side effects); paracetamol; and ibuprofen (a non-steroidal anti-inflammatory medication). The ibuprofen was stopped on 10th December because of concern that it might be affecting the functioning of your mother's kidneys. When the ibuprofen was stopped a TENS (Trans Electric Nerve Stimulation) machine was introduced, initially with good effect. This machine works by interrupting the pain signals to the brain.

Despite all these efforts however Code A remained in pain, particularly on moving. Oral morphine was commenced on 14th December, 1999, six days after Dr. Reid's conversation with Code A

From our investigation it seems there was no delay in the morphine arriving or being given; in fact, morphine is routinely kept on the ward. The staff were of the impression that they were following the wishes of Code A and your brother and yourself, by continuing with other analgesics before resorting to morphine.

I understand that morphine made little significant difference to Code A pain. By the 16th December, 1999 Code A condition had begun to deteriorate and it was recognised that the morphine might be contributing to this. At your request, the administration of morphine was stopped, and only subsequently given with your explicit agreement, or on request from your mother.

The whole issue of pain and pain relief seems to have created a great deal of tension between yourselves and the staff. Sometimes pain is difficult to control, and although distressed by her pain it seems that [Code A] was reluctant to accept stronger pain killers. I am very sorry that we were unable to satisfactorily control your mother's pain, and for the distress this caused her and yourselves. On reflection, it seems possible that the tension between you and your family and the clinical staff may have clouded the issue of what would clinically have been in your mother's best interests.

4. Why were you excluded from any input to your mother's well-being?

I think perhaps there are two elements to this question: your influence on and your involvement in [Code A] care. From our records it is clear that you and your brother had many meetings with the clinical staff, sometimes more than one a day, to discuss your mother's care. The staff felt that they did their best to accommodate your wishes, allowing you to influence care, whilst being mindful of what they felt was clinically in [Code A] best interests.

With regard to your involvement in your mother's care, and you being asked to leave the room whilst care was provided, it seems that the staff took an unfortunately rigid line. So long as [Code A] agreed, there was no reason why you should not have helped, or indeed provided, some care. (I understand that you did assist with washing.) There is also no reason why you should have been asked to leave the room whilst dressings were changed. I would like to apologise for the rigidity of the nursing approach, and for the distress this caused you.

Dr. Reid remembers the visit you describe. He asked you to leave so that he could talk confidentially to [Code A] about her wishes and how she was feeling. The patient's wishes are always paramount and they have a right to confidentiality which the doctor must respect. Relatives are regularly asked to leave the room so that the doctor can talk privately to the patient. Dr. Reid meant no disrespect to you, nor was he deliberately trying to exclude you. He is sorry that you felt insulted, and he denies showing any discourtesy.

You mention staff always attending in twos, giving the impression that a chaperone or witness was needed. In fact, the staff felt this to be the case. The nature of the relationship between you all was such that staff felt intimidated and, at times, threatened. This was an unfortunate situation for everyone and I will comment more in my conclusion. It would also, however, be fair to say that as many of your questions spanned both medical and nursing issues, it was an advantage to have both a doctor and a nurse present.

5. Why was there an unsympathetic approach to simple medications and to information about blood sugar medication?

There is no valid reason, other than established ward routine, as to why the Kamillosan and Bonjella that you brought into the ward were not left in your mother's locker. These are simple medications which would have caused no harm so long as the package instructions were followed.

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With regard to giving you information about blood sugar and insulin, the Patient's Charter states "if you agree, you can expect your relatives and friends to be kept up to date with the progress of your treatment", with the aim of preserving the patient's wishes. In your mother's case, given the existing level of your involvement in her care, the response you received to your questions was very unhelpful. If the staff had any doubts about whether your mother wished such information to be shared with you, they should have asked her.

I would like to apologise for this unfriendly approach and rigid routine, and the distress it caused.

6. Restriction on food from home

When Code A was admitted to Dryad ward her blood sugars were unstable, they were high. Her blood results and insulin needs were carefully monitored and her diet was strictly controlled. Initially this was best managed through keeping to hospital food, as her food intake needed to be carefully controlled and monitored. To eat food brought from home, in addition to the food provided in hospital, would have caused her blood sugars to rise.

That being said, however, once the situation settled there was no reason why agreement could not have been reached about what foods you would bring in to replace some of the hospital food. The dietitian recorded in the medical notes that she met you on 7th December, 1999 and discussed what foods it would be appropriate for you to bring in. It would, of course, have been important for you to keep this list, and to agree with the ward staff what hospital meals you would be replacing. I am very sorry that this situation was not amicably resolved.

7. Why was liquid intake not monitored to avoid possible kidney problems?

At interview the nursing staff have confirmed that Code A was regularly encouraged to drink and her fluids monitored; her care plan for catheter care regularly records that her catheter was draining well. There is, however, no record in the nursing notes of volume of fluid taken or passed. We would expect that specific volumes be recorded if monitoring of intake and output is to be effective. We would not, however, consider it necessary to monitor the fluid balance of all patients; we would only measure when there was a potential or actual problem. I can only apologise that Code A fluid intake and output was not recorded more accurately.

I would now like to turn to the more general comments made at the end of your letter before drawing some overall conclusions.

You felt that Dr. Reid and the rest of the team made no effort to rehabilitate your mother, and that an assumption was made that she was terminally ill with cancer. With regard to the latter, Dr. Reid has stressed that he always had an open mind because there was no evidence of recurrent cancer, and that no assumption was made about terminal cancer. Towards the end of her stay on Dryad ward he was, however, of the opinion that Code A condition was deteriorating, that she had little strength or reserves left, and that it was quite likely that she would die. I understand that he explained his concerns to you on 16th December, 1999.

With regard to rehabilitation, Code A had spent some three months in Queen Alexandra Hospital before moving to Dryad ward. From the notes it seems that for quite some time before she left Queen Alexandra Hospital there was concern that she was unlikely to regain much mobility. You may remember Dr. Logan visiting to give an opinion on whether she might be suitable for his rehabilitation ward. After assessing your mother's needs he concluded that there was little likelihood of any success from formal rehabilitation. He felt she was reaching the end of her life, that she had huge nursing needs, and would be likely to need long-term nursing care, possibly in a nursing home. Before she was admitted to Dryad ward Code A could not stand and bending her knees caused extreme pain, in addition to her surgical wounds and extensive pressure sores. The physiotherapist at Queen Alexandra Hospital recorded that trying to mobilise and sitting out in a chair aggravated your mother's pain, while resting alleviated the pain.

Code A pain severely limited any rehabilitation. Dr. Reid explained that if her pain could be brought under control it might be possible to try to get her back on her feet. It was not that no efforts were made, but that rehabilitation in these circumstances was not possible.

With regard to your comments that "Dryad ward practice a regime that is totally out of date", we would agree from our investigation that there are some areas of ward philosophy and practice which need updating. The service manager will be working closely with the ward manager to review and revise how some aspects of care are managed.

So, our conclusions. Understandably you, your mother and your brother had a desire for Code A to be returned to the state of health she had enjoyed before she was admitted to Queen Alexandra Hospital. The collective opinion of a number of clinicians (not just from Dryad ward) was that rehabilitation was unlikely to be successful and probably impossible. The doctors and nurses on Dryad ward spent many hours discussing this with you. Given all the circumstances, the care provided on Dryad ward was appropriate to Code A clinical needs, and indeed to her personal capabilities, at the time.

This fundamental (and seemingly unresolvable) difference in opinion and expectation between yourselves and the clinical team led to a breakdown in the relationships and trust between you all. You refer in your letter to frustration and frayed tempers on more than one occasion. I understand that the staff too felt frustrated and also felt that this conflict affected their ability to provide what in their professional opinion would be the most appropriate care for your mother. You obviously care deeply for your mother and wish the best for her. Equally the staff had a duty of care towards her. Balancing her assessed clinical needs against your wishes for her care seems to have turned into a power struggle.

Unfortunately there seems to have been no winners, only losers, in this struggle. We have to conclude that everyone concerned had some responsibility for this situation developing as it did. The service manager will be working with the ward team to explore the ways of building effective partnerships with relatives, and in handling conflict. Dr. Barton no longer works for the Trust so she will not be included in this work.

We have thought long and hard about the issues raised in your letter, which I hope is indicated in this response. I also hope that this helps to clarify the different perspectives about what happened and why. Please let me know within one month if there is any further action you would like me to take.

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I realise that you will not be completely happy with all of this reply, but do hope that you will accept our apologies for the shortfalls in nursing care.

You mentioned to Mrs. Frogley, investigating officer, that you would like to see a copy of the notes made by the nursing staff during meetings. The only records retained are the notes made on the nursing contact sheet which quite extensively detail your conversations. Mrs. Frogley has confirmed that Code A has agreed to you having access to her records in this way. Enclosed is a full copy of these contact notes.

Mrs. Frogley was very impressed with the care you provide for your mother at home, and I hope Code A remains comfortable at home.

Yours sincerely,

Max Millett
Chief Executive

Silent copy to: Dr. I. Reid
Mrs. F. Cameron