

18 December 2002

Dear Mr C

Following the release of my provisional opinion to you on 27 November 2002, I have now completed my investigation into the complaint you made on behalf of your family about the services provided by a Hospice and Ms B, Principal Nurse, to your father, Mr A. I note that you did not respond to my provisional opinion. I also note that Ms B, and other family members, did not wish to make any comments in response to my provisional opinion.

Your complaint was summarised as follows:

Complaint

The Hospice

The Hospice did not provide the appropriate standard of health care to Mr A in 2000. In particular:

- *The Hospice provided inadequate pain relief as:*
 - *Mr A was only given Panadol syrup and aspirin tablets, although he was in constant pain, experienced severe pain when moved, could not swallow and was often in a semi-coma.*
 - *Morphine was not administered until less than 24 hours before Mr A died.*
- *The Hospice provided inappropriate nursing care as:*
 - *Mr A became dehydrated and, in addition, nursing staff did not properly address this.*
 - *Mr A's mouth was in poor condition and, in addition, swabs and an oral tray for mouth care were not supplied until requested.*
 - *Although Mr A was incontinent and could not use a toilet, napkins were not supplied until October 2000. This meant his sheets needed changing regularly, which caused Mr A severe pain as he had to be moved.*

- *Mr A was not provided with:*
 - (i) liquid foods even though he could not swallow*
 - (ii) cream for skin care, such as for bed sores*
 - (iii) nursing care on a daily basis and so was not attended for periods of two to three days.*
- *A nurse from the Hospice did not check on Mr A between midnight and 6.00am in October 2000 although the family was advised that a night nurse would visit. As a result Mr A lay in a heavily soiled nappy for many hours.*
- *A night nurse was only provided for one night and this only occurred less than 36 hours before Mr A died.*
- *The Hospice did not properly liaise and coordinate their services with other health providers caring for Mr A.*

Ms B

Ms B did not provide the appropriate standard of health care to Mr A in 2000. In particular:

- *In October 2000 Ms B declined the request of Mr C (Mr A's son) for someone to visit because Mr A was lying in heavily soiled sheets and his lower body was covered with body waste. Mr C and his mother had previously been advised by Dr D not to move Mr A because of his pain, but to leave this to the professionals.*

Instead, Ms B stated that no one could come that evening and he and his mother could do more to clean Mr A themselves. Alternatively, Mr A could be left as he was and someone from the Hospice could visit the following day. Ms B and a nurse later visited after a second phone call from Mr C.

Information

During the investigation I carefully reviewed information from the Chief Executive Officer of the Hospice, Ms B, Dr D (Mr A's General Practitioner) and yourself. I sought independent expert nursing advice from Ms Ramona Clark, and independent expert medical advice from Dr Brian Ensor, general practitioner with expertise in palliative care. I enclose copies of Ms Clark's and Dr Ensor's advice.

Chronology of events

- In 3 October 2000 a home help service referred Mr A to the Hospice for an assessment.
- On 6 October 2000 the Hospice made a referral to the district nursing service.
- On 9 October a district nurse visited.
- Dr D remained responsible for Mr A's medical care. On 9 and 17 October Dr D was contacted by nursing staff about Mr A's analgesia.
- On 9 October the GP arranged an inpatient bed but this was declined by Mr A.
- On 17 October Mrs A called the Hospice with concerns about Mr A's condition. Ms B visited and provided nursing care.
- Dr D saw Mr A on 18 October 2000.
- Mr A died at home on 19 October 2000.

Decision

In my opinion, the Hospice and Ms B did not breach Right 4(1) of the Code of Health and Disability Service Consumer's Rights. Right 4(1) states that every consumer has the right to have services provided with reasonable care and skill. My decision is made on the following grounds:

The Hospice

- I acknowledge the statement made by Ms Clark that "all the health professionals and family were working very hard to provide Mr A with the very best care, while respecting his autonomy and wish to be left alone" and that "they were very aware of the problems and instituted appropriate strategies, given the circumstances". Furthermore, I acknowledge Dr Ensor's statement that both the family and the health professionals were distressed, particularly in the last days when Mr A's condition deteriorated. The health professionals could not provide what they felt was adequate care such as extra analgesia and admission to hospital, as Mr A refused it.
- I accept the advice of Dr Ensor that "prescribing is always subject to the patient's wishes" and that there was no neglect on the part of the health professionals in the administration of analgesia for pain relief.
- I accept the advice of Ms Clark that patients with advanced cancer have a small appetite and may eat or drink little or nothing. I acknowledge the practice of not rehydrating patients with intravenous or subcutaneous fluids during the last days of palliative care as there is increasing evidence to demonstrate that this can reduce suffering.
- I accept the advice of Ms Clark that mouth cares were important for Mr A's comfort and that the Hospice nursing care plan and notes indicate that nursing staff were aware of this and gave appropriate care when visiting.
- I accept the advice of Ms Clark that as Mr A became weaker, it became increasingly difficult for him to get up to the commode and he was less able to control or anticipate defaecation. Moreover, I accept that Mr A and his family declined an admission to the Hospice and that it was impossible for district nurses to be available to attend to all hygiene needs as they arose.
- I accept the advice of Ms Clark that "frequent change of position is the accepted management of preventing pressure areas" rather than the application of creams.

Ms B

In her response, Ms B stated that she received a phone call from Mr C on 17 October 2000, not 16 October 2000. Her notes indicate that she visited Mr A on 17 October and provided nursing care, including hygiene cares, arranged night care and contacted Dr D to commence a syringe driver.

I accept the advice of Ms Clark that Ms B's assessment and response to the situation on 17 October 2000 was appropriate and acknowledge Ms Clark's statement: "Convincing the family to accept nursing support was a wise course of action." I accept that Ms B responded appropriately and provided nursing services of a reasonable standard.

Comments

Communication and coordination

It is clear that the coordination of palliative care services is a difficult yet critical role. Although in my opinion the Hospice provided services with reasonable care and skill in the circumstances, I acknowledge my advisor's comments in relation to the less than satisfactory coordination of services and make the following comments:

- I accept the advice of Ms Clark that, although the nursing care provided to Mr A was generally appropriate and of a high standard, there are concerns that "the communication, liaison and provision of care between the people and organisations responsible for providing care was not smooth". In particular, there was a three-day delay in a written referral to the district nurses. If a telephone referral was made it was not documented. The district nurses did not visit Mr A until 9 October 2000 when the lack of support was questioned by the home help service.
- I acknowledge Ms Clark's reference to Standard 5 of the "Hospice New Zealand Standards for the Provision of Hospice/Palliative Care" which states: "Effective liaison and coordination ensures the patient/family/whanau timely access to relevant agencies and services." In addition, Standard 10 Continuity of Care of Quality Health New Zealand's "Accreditation Standard for Health and Disability Support Services (1999 Draft Standards)" states: "Effective liaison and coordination between the hospice/palliative care service and relevant agencies and services ensures timely access and continuity of care for patients and their families/whanau." I accept Ms Clark's advice that the delay in the provision of services was not optimal given that there were only 15 days between Mr A's referral to the Hospice and his death.
- The poor communication and liaison between the various providers is further supported by the fact that during a home visit on 5 October, Dr D was unclear which nursing service was responsible for Mr A's cares. In addition, the care plan indicated Ms B's intention to liaise immediately with Dr D about Mr A's pain especially on movement but whether this happened was not documented in the Hospice notes.
- I accept the advice of my expert advisors that the involvement of Mr A's family could have been more effective. In particular, Dr Ensor has advised that in cases where oral intake is erratic, subcutaneous medication is an option and it would have been appropriate to discuss this option, particularly when Mr A's condition deteriorated. Furthermore, Ms Clark has stated that it would be expected that the

family be instructed on how to provide mouth cares and recommended that “either the hospice nurses or the District Nurses should have left pads with the family to make hygiene easier should faecal incontinence happen”.

Actions taken

In response to my provisional opinion, the Hospice advised me that it has accepted my comments about the inadequate communication between it and the other services involved in palliative care. However, it has said that it had taken significant steps to address this since the circumstances giving rise to the complaint.

In particular, I understand that the Hospice has, as a temporary measure, negotiated a system of coordination with the District Nursing Service. Although this system has some difficulties, the Hospice and the District Nursing Service are actively reviewing it to ensure that it is effective.

I also acknowledge that the Hospice considers, as a long-term solution, it should undertake the responsibilities of the District Nursing Service. The Hospice advised me that the District Health Board commissioned an audit of the palliative care services provided by it as a prelude to facilitating such a change. The audit was completed in October 2002 and notes that there have been problems in the linkages between the Hospice and the Community Health Services of the District Health Board. These problems have included duplication of services and lack of continuity care. The audit recommended that the Board and the Hospice address these problems.

I also note a letter from the Board to the Hospice which details a timetable for review of the issues raised in the audit, and the development of options for service provision. This process is to begin in January 2003 and the changes to existing contracts are to be implemented by 1 July 2003.

In my opinion, the Hospice has responded appropriately to ensure that problems with service integration identified by my expert nursing advisor are addressed.

Recommendations

I recommend that the reference to “a 24 hour service” in the Hospice’s brochures be clarified. I accept the advice of Dr Ensor that the reference to “a 24 hour service” available to patients at home may be open to misinterpretation. Although the patient and family can call on the Hospice at any time, the main burden falls on the family and at times this can prove very difficult.

Notification of final report

I will send a copy of my final opinion to the Licensing Section of the Ministry of Health and the Nursing Council of New Zealand, and a copy, with identifying features removed, will be sent to Hospice New Zealand and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Conclusion

I offer my condolences of the death of your father and trust this independent investigation of the matter has addressed some of your concerns.

Thank you for bringing your concerns to my attention.

Yours sincerely

Ron Paterson
Health and Disability Commissioner

Ref: 00/11970

Complaint: HDC 00/11970/AM

“Was Mr [A] prescribed appropriate medication to relieve his pain? If not, what medication was appropriate?

If morphine was appropriate, at what point should this have been prescribed?

The picture that I get reading through the notes is of a man who refused medical intervention and has taken to his bed to die. The family is very concerned about his pain level particularly when he is moved. He then becomes faecally incontinent which compounds everything. The nursing notes have a pain assessment on referral that localises and grades the pain. Mr [A] however has been refusing anything more than paracetamol, and the question is asked as to whether he should have had more pain relief, specifically morphine. The distress of the family in their letters also has some parallels in the distress apparent in the notes from the nurses and GP written at the time. This reaches a peak in the last couple of days, when things are obviously deteriorating. They cannot provide what they feel is adequate care. Extra analgesia is offered but refused. Likewise admission into hospital was offered but refused.

Any prescribing should be the result of negotiation between the patient and the prescriber. [The Hospice] are explicit about this in their Informed Consent, describing ‘Consent to such medication or therapies as I and the Hospice staff jointly agree on...’ Furthermore they recognise the right of patients to ‘decline specific treatments’. This becomes difficult for family and professional staff when the patient refuses to accept medication that the doctor, or the family, feels to be appropriate. This is not an uncommon situation, though it can be a very uncomfortable one. The patient’s General Practitioner gives a good description of Mr [A’s] general feeling towards medication and medical intervention, and in my experience, such people will put up with pain rather than take medication.

Regular paracetamol is indicated for the aching bone pain which Mr [A] seemed to suffer, and antibiotics were indicated for the pain related to infection in the penis. Morphine, or other stronger painkiller, is indicated at this stage, but if the patient has expressed a wish not to have morphine, it should not be given. When the patient has become too unwell to be able to discuss these things, it is not uncommon to introduce morphine then, with the agreement of the family. It may be argued that even at this stage, the patient’s wishes should still be paramount, and morphine avoided. However unless there are specific religious or cultural reasons not to administer a particular treatment, commonly the prescriber will give what he/she thinks is in the best interests of the patient.

This, I believe, is what happened in this situation. Prescribing is always subject to the patient’s wishes. I do not see evidence of neglect on the part of the medical and nursing attendees.

Was the form in which the medication was administered appropriate in view of Mr [A's] condition?

There is some discrepancy about whether Mr [A] was able to drink liquids or not until his last day or two. Some notes say he was taking a little and managing his medications, one letter implies he was not able to take anything from about 10 days before he died.

Certainly in cases where oral intake is erratic, subcutaneous medication is more appropriate. In this case, it would have been appropriate to offer subcutaneous medication at any time over that last week, even just before doing nursing cares if these were painful and he was comfortable enough the rest of the time. Morphine, or morphine and a sedative like midazolam are commonly used. I would be hesitant to offer rectal medications, particularly so when there were incontinence problems anyway, but it is a possibility.

It would have been reassuring for me to read in the notes that there was discussion about these options. Although Mr [A] may have been very clear about his wishes previously, when things started to get tough, the offers should have been put to him again. The notes are not clear what extra analgesia was offered until the last days, when the syringe driver was put up.

Again it may have come down to what was acceptable to Mr [A] at the time.

Was the communication between Mr [A's] general practitioner and other health providers adequate?

The communication seems very reasonable, apart from [...] comments about systematic problems at a bureaucratic level which compromise the speed at which referrals can be actioned over weekends.

Further Comments

I am concerned that although hospices throughout NZ advertise '24 hour care in the home', this is very open to misinterpretation. It has to be read alongside statements such as '*hospice assists families in their care for their loved one...*' There is not adequate 24 hour nursing care in the home in New Zealand unless the family is willing to pay over \$2,000 a week. The main burden does fall on the family, and with the best will in the world, this can sometimes prove at best very difficult, and at times, impossible.

Brian Ensor
17th October 2002"

“Report to the Health and Disability Commissioner

00HDC11970

Ramona Clark

October 23, 2002

I have reviewed the following documents relating to the care received by Mr [A]:

- Response and information [a Hospice].
- Response from [Ms B] received on 7 November 2001.
- Notification letters.
- Action notes dated 29 November 2000; 30 January, 22 March, 10 April and 4 September 2001.

October 2000, the month of Mr [A’s] death, must have been difficult for family and for the health professionals caring for him. The notes from the General Practitioner and [the Hospice] both indicate that Mr [A] was an independent individual who liked to make his own decisions about what cares and treatments he would accept. This often seemed to be at odds with the advice of the professionals. This must have been very difficult for family members wishing to do the very best they could. However, people do have the right to choose for themselves what treatments to accept.

Reading the notes indicates that all the health professionals and family were working very hard to provide Mr [A] with the very best care, while respecting his autonomy and wish to be left alone. The notes indicate they were very aware of the problems and instituted appropriate strategies, given the circumstances.

In relation to his food, it is noted in the Hospice nursing notes that on 3rd of October 2000 that Mr [A’s] appetite was small. This commonly happens to people with advanced cancer and it is accepted practice to only offer small tempting servings of whatever the person wishes and to accept that little or nothing may be eaten. The same is true of fluids although people tend to wish to drink sips of preferred fluids longer and while the person is conscious fluids are offered frequently. The Hospice nursing care plan, dated 3rd of October 2002 indicates that fluid intake was to be encouraged. Mr [A] may well have been becoming increasingly dehydrated. It is not an accepted palliative care practice to rehydrate people with intravenous or subcutaneous fluids, especially when death is expected within days. There is increasing evidence to demonstrate that a degree of dehydration can make for a more comfortable death. Fluid can tend to accumulate in the lungs of well hydrated individuals making breathing more laboured. This can be difficult for the individual and for their family. Mr [A] had compromised lung function; adding extra fluid would not have been good management.

Mouth care would have been very important for Mr [A’s] comfort. Increasing dehydration, the side effects of medications (if he was taking them) and mouth breathing all contributed to his dry mouth. The Hospice nursing care plan and notes indicate that nursing staff were aware of this and gave appropriate care when visiting.

The referral form to the District Nursing Service indicated the need for continued assistance with hygiene. Mouth care is an accepted part of hygiene cares. One would also have expected the family to be instructed on how to provide these cares.

Mr [A] had a urinary catheter in place so urinary continence should not have been a problem. The need for catheter cares was documented. He did however have a long-standing problem with constipation and was prescribed aperients. When he was first assessed (3rd of October 2000) he was able to get up to the commode with help. It is likely that as he became weaker this became increasingly difficult and he was less able to control or anticipate defecation. Mr [A] and his family declined admission to the Hospice and it is impossible for District Nurses to be available to attend to all hygiene needs as they arise. I understand however how difficult it can be for family members to deal with cleaning faeces especially if the person would rather be left alone. With the wisdom of hindsight, either the Hospice nurses or the District Nurses should have left pads with the family to make hygiene easier should faecal incontinence happen.

Frequent change of position is the accepted management of preventing pressure areas. While creams are soothing (if the person accepts them) they will not prevent pressure areas.

The communication, liaison, and provision of care between the people and organisations responsible for providing care was not smooth. There was a three day delay in writing a referral to the District Nurses (6th October, 2002) although I accept a telephone referral may have been made on October 3rd when the first Hospice nursing assessment was completed. If a telephone referral was made it was not documented in the notes. It is impossible to know when the written referral arrived, but the District Nurses did not visit until the 10th or 11th of October (this is unclear from the Hospice notes) when the home help service [...] questioned that lack of District Nursing support. The general practitioner [...] on a home visit on October 5th was also unclear regarding what nursing service was responsible for Mr [A's] cares. When the Hospice team became aware of the confusion they followed this up ensuring the District Nursing Service was consulted and that admission to the Hospice was offered.

The pain assessment (undated) undertaken by [Ms B] probably on October 3rd as part of the initial home assessment indicates Mr [A] was in severe pain especially with movement. The care plan indicates the intention to liaise immediately with [the GP]; whether this happened is not documented in the Hospice notes. There is no mention of a call or written message in the GP notes. However, [the GP] was able to make his own assessment of Mr [A's] pain when he saw him on October 5th. In his letter to [the Hospice] (2 January 2002) he takes full responsibility for Mr [A's] pain management and indicates Mr [A's] continued ambivalence about taking his prescribed medications. On the 17th in response to a phone call from [Mr A's] family, [Ms B] visited and suggested a syringe driver be commenced to provide pain relief; [the GP] prescribed the medication and Mr [A] died without pain the following day.

[Ms B's] assessment of and response to the situation on the 17th of October seems most appropriate. Convincing the family to accept nursing support was a wise course

of action. It seems that although Mr [A] might not have welcomed this intrusion the family were tired and in need of a helping hand at this very stressful time.

It is of concern that the co-ordination and liaison between agencies and health professionals and [Mr A's] family was not smoother. *Hospice New Zealand Standards for the provision of Hospice/Palliative Care* addresses this issue in Standard 5 (pg 11) which states, 'Effective liaison and co-ordination ensures the patient/family/whanau timely access to relevant agencies and services'. Quality Health New Zealand *Accreditation Standard for Health & Disability Support Services* 1999 Draft Standards also addresses this issue in Standard 10 Continuity of Care (pg.18) 'Effective liaison and coordination between the hospice/palliative care service and relevant agencies and services ensures timely access and continuity of care for patients and their families/whanau'. There were only 15 days between Mr [A's] referral to the Hospice service and his death; the 7 day delay in provision of nursing services was not timely.

The lack of meeting these important standards is not the sole responsibility of [the Hospice]. The other agencies must share this responsibility. These difficulties may reflect, in part, larger funding and workloads issues. This withstanding, [Mr A's] family had a right to reliable support.

In conclusion, I believe that in general the nursing care provided to Mr [A] was appropriate and of a high standard. However, I am concerned that there is not more effective and timely liaison between the various providers, especially the Hospice and the District Nursing service.

Ramona Clark RCpN, M.A.”