HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion - Case 98HDC21016

Complaint

The complainant complained about the care his daughter received from a public hospital. In particular, his complaint was that:

- *There was no review of the consumer for discharge planning, or home support organised when she was discharged from the public hospital in late June 1998.*
- *There was a delay in performing the surgery for a cervical lymph node biopsy until mid-July 1998, when the need for this procedure was identified in early July 1998.*
- *There was a lack of acknowledgement of the consumer's deteriorating condition and her father's requests for intervention.*
- *The consumer's family were not fully informed of the consumer's medical condition, and not included in the plans for her treatment.*
- *The medical staff displayed a lack of empathy towards the consumer's family, frequently avoiding contact with them as the consumer's condition deteriorated.*
- *The public hospital's complaints process was inadequate in responding in a timely manner to the consumer's father's concerns, and requests for information relating to the treatment and death of his daughter.*

Investigation Process

The complaint was received on 19 November 1998 and an investigation was commenced on 12 April 1999. Information was obtained from:

Complainant/Consumer's father
Chief Executive Officer/Hospital and Health Service (HHS)
Provider, Clinical Head of Internal Medicine/Cardiology, HHS
Provider, Medical Specialist, Public Hospital

Copies of the consumer's clinical records were obtained from the public hospital and viewed. A copy of the post mortem pathology report was obtained and viewed. The Commissioner sought advice from an independent intensivist and emergency medical specialist.

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation

The consumer was a 21 year old woman who presented at an accident and emergency clinic in early June 1998 with diarrhoea, vomiting and fever. In mid-June 1998 she was diagnosed as having gastric 'flu' and given gastrolyte and metaclopramide (pain relief/anti nausea medication). These symptoms resolved over three days, however, because of continuing fatigue and weight loss, the consumer consulted her general practitioner (GP) eight days later with rash all over her trunk, enlarged lymph glands, weight loss and a low grade cough. The consumer's GP referred her to the provider hospital for another opinion.

In late June 1998 the consumer was admitted to the hospital's Admission and Discharge Unit (ADU) under the medical specialist's medical team. The consumer was found on admission by the medical registrar, to have a raised temperature, papular (small raised spots) rash, and tender, rubbery supraclavicular (above the collarbone) lymph nodes. The admission notes record that she denied having chest pain, cough or sputum. The impression at that time was that the consumer had a viral infection. Laboratory blood examination showed haemolytic anaemia (resulting from the destruction of red blood cells). A number of blood tests were sent to the laboratory for examination to exclude viral infection. There was no plan recorded to define the extent of the consumer's lympadenopathy (enlarged lymph glands) or plan for the investigation of her symptoms.

Nursing staff recorded in the progress notes daily from the day after admission until her discharge that the consumer had a dry cough. This cough was not recorded by the medical staff in their notes. The nursing notes also recorded at 11.00pm on the day of the consumer's admission that her APTT (activated partial thromboplastin time) was elevated at 68 seconds, and that the doctor requested another blood test. APTT is a blood test to assess clotting; the normal range is 25 to 37 seconds. The repeat test also returned as 'abnormal'. The nursing staff noted in the progress notes that the medical registrar was informed and would review in the morning. There is no record that this result was followed up by the medical staff.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

A dermatologist reviewed the consumer the day after her admission and indicated in her review that the consumer had a thrombocyopaenia (low platelet count), and abnormal liver function tests. She noted that although the rash lesions suggested '*hand, foot and mouth disease*' the distribution was wrong. The dermatologist noted that a viral causation for the rash was more likely, but that the rash was not typical of infectious mononucleosis (glandular fever). She noted that if the rash persisted following the weekend (i.e. in 48 hours), "*it may be helpful to perform a biopsy*".

The next day the consumer was reviewed by the infectious diseases consultant, who also concurred that the cause of her problem was likely to be viral. Additionally, he speculated about other causes, including cat-scratch disease, an infectious disease of humans, transmitted by the scratch or bite from a cat, and recommended further serology. There is no record in the notes that the consultant examined the consumer and concurred with the findings of lymphadenopathy (disease of the lymph nodes).

An abdominal ultrasound examination six days after the consumer was admitted indicated enlargement of the consumer's liver and spleen and also confirmed enlarged retroperitoneal (behind the membrane of the abdominal cavity) lymph nodes. The radiologist recorded this examination in the progress notes, along with a potential differential diagnosis of lymphoma (malignant tumour of the lymph nodes) and also included an offer for an ultrasound-guided biopsy examination. The medical team did not record any impression of the relevance of the ultrasound examination report, and did not refer the consumer for an ultrasound-guided biopsy examination.

Between the day of admission and the day of discharge (a period of six days), there was a continuing drop in the consumer's haemoglobin: 127 recorded by her GP, 124 on admission to ADU and 116 four days after admission. Normal haemoglobin levels for females are 115 to 165. There was a drop in her red cell count and her mean cell volume. Her platelet count dropped to 84. Normal platelet levels are 150 to 400. The consumer's blood test results were significantly abnormal.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

All of these test results had been initialled as having been seen by the doctors, but were not noted as having any significance in relation to the consumer's disease.

A chest x-ray taken the day the consumer was admitted showed pleural effusions. The consumer also had organomegaly (abnormally enlarged organs) and enlarged intra and retro-peritoneal (inside or behind the membrane lining the abdominal cavity) lymph nodes. Throughout this period she was spiking high temperatures, had a dry cough and was eating and drinking poorly. The nursing staff indicated in the progress notes that she was finding it difficult to perform normal daily living tasks.

The medical specialist informed the Commissioner that:

> "*My assessment at that time was of a febrile illness with diffuse painful adenopathy*, [swollen lymph glands] *probably viral. My conclusion was supported at that time by similar opinions from dermatology and infectious diseases. Therefore my plan was of a weekly ward review to assess the course of her disease expecting this to be self limiting. I did not identify mobility or nursing concerns at that time.*"

There is no mention in the consumer's clinical records of concern regarding her low platelet count and dropping haemoglobin.

The consumer was anxious not to stay longer in hospital and in late June 1998, six days after her admission, she was discharged home with a fever chart and instructions to present to the hospital ward for review in early July 1998 and a week later, in mid-July 1998. The consumer's family were offered no support to care for her, and there is no record in the notes suggesting that home support was required. The family were distressed by her continuing high temperatures, thirst and weight loss.

The discharge summary sent to her GP recorded some aspects of the consumer's history and examination. The virology is mentioned, with notes that the urine showed no abnormalities, and that she had a normal haemoglobin (blood iron). The impression recorded is one of a viral illness, although mention is made of the ultrasound report. The consumer was to return in early July 1998 for review. There is no mention of the significance of her blood test results.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

The consumer returned to the hospital for her first ward review in early July 1998. She was seen by the medical specialist, who noted that the consumer was continuing to have spiking fevers and that her lymph nodes were enlarged. A fine needle aspirate of one of the lymph nodes was taken and sent to the laboratory for testing. The consumer was asked to return one week later for the results of the needle aspiration and for further investigation if needed. When the consumer returned for her review a week later, the fine needle aspiration test results raised the possibility of unusual infection. Arrangements were made for the consumer to have a formal lymph node biopsy and she was admitted to a ward of the public hospital for this procedure.

On this day the consumer's family sat in the ward with her for four hours, waiting for a lymph node biopsy to be performed. She was then informed that the surgeon was unavailable to perform the biopsy. The consumer was advised to go home and that she would be notified of an alternative appointment.

The medical specialist, in his response to the Commissioner, stated:

> "*At the first ward review* [in early July 1998] *a cervical node aspirate was arranged. At the next ward review* [the following week] *a cervical node biopsy was suggested. I had requested the surgical referral made that day and asked the* [consumer's] *family to stay in the ward until they were seen. Regrettably the surgical registrar did not appear that day and I recall* [the consumer] *was very reluctant to stay in hospital. She was to be contacted by the surgical team for the biopsy to be done on their elective surgical list later that week. As this was only a matter of a few days I accepted this delay. Unfortunately there were further delays.* [The consumer] *was deteriorating and I felt the answer lay in the lymph node biopsy.*"

The consumer's father contacted the medical specialist the next day about an alternative date for a biopsy for his daughter. The medical specialist informed him that he would make an appointment for the consumer to be seen as a surgical outpatient at a clinic two days later. This appointment was transferred to the public hospital for late July 1998 due to heavy booking lists and other clinical demands on staff time.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

Meanwhile, the consumer's general condition deteriorated, she continued to lose significant weight, and was unable to care for herself. She had a consultation with a haematologist, who noted that "*The node biopsy is essential in order to obtain a diagnosis*". The anaesthetist who reviewed the consumer on this day in mid-July 1998 thought her general condition was too poor to proceed with general anaesthetic and asked for intensive care review by a specialist the next day.

The consumer's father stated that the family were informed that the biopsy was to be performed and that it was a minor procedure. He said that they left the hospital that morning under the impression that the biopsy was a routine procedure and that there was no cause for concern.

When the consumer's family returned to the hospital on that afternoon, they were informed that the consumer was in Intensive Care. The consumer's father was told that his daughter had been transferred to the Intensive Care Unit as a routine precaution and that she was being given intravenous fluids and antibiotics before going to theatre. The consumer's father stated that when he saw his daughter in intensive care, she was distressed, and calling for oral fluids, which were being withheld due to the pending surgical procedure.

A lymph node biopsy was performed that afternoon. The consumer developed respiratory failure on her return from theatre. She was intubated and required aggressive treatment with intravenous fluids overnight. A chest x-ray showed increasing opacity of her right lung, thought to be due to the consumer inhaling fluid into her lungs during surgery. The biopsy failed to provide a definite diagnosis.

A specialist in intensive care was asked to review the consumer, and noted in her clinical records:

> "*I have discussed her* [the consumer] *with* [a specialist] *and* [the medical specialist] *and just now spoken with* [the haematologist].
>
> *In short she had developed R sided CXR* [chest x-ray] *changes post-operatively and respiratory failure.*

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

In the meantime we will repeat cultures, carry on with Primarin, transfuse her (Hb 60 after dilution) and given her supportive Rx [treatment].

I have spoken to her family and they understand our concerns."

The day after the intensive care review, the haematologist took a bone marrow biopsy from the consumer. The plan was to start treating her aggressively when the results of this bone marrow examination were confirmed. The medical staff considered it unlikely that the consumer would survive her illness and informed her family of the seriousness of her condition at this point.

The consumer's father stated to the Commissioner that he told a member of the nursing staff that he wanted clarification of the issues relating to his daughter's illness and treatment. He was informed that the doctors were drawing up a treatment plan. He stated that he did not see this plan. The clinical records showed that the doctors had written the results of their investigations and their plans for further investigation of the consumer in order to reach a diagnosis.

The consumer's father was concerned that the doctors appeared to be avoiding talking to him and members of his family as his daughter's condition deteriorated.

The medical specialist stated to the Commissioner that:

> "*In the initial weeks of her illness I think I tried to communicate my diagnostic uncertainty in that the impression was of some sort of viral illness that couldn't be specified further. In the latter stages of her illness with such a rampant and overwhelming physical deterioration a number of other doctors had now become involved, particularly with her move to first the surgical and then the intensive care ward, and I now had much less contact with the* [consumer's] *family.*

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

> *My lack of contact with the* [consumer's] *family resulted as I became part of the larger number of staff involved in her care. I am sorry if they did not perceive empathy on my part, it may be they misread the frustration as I tried to arrange the cervical node biopsy.*"

A specialist in intensive care noted in the consumer's file at 12.30pm on the day of the haemotologist's review:

> "*Spoke to* [the consumer's parents] *I told them that although the diagnosis is not yet known* [the consumer] *is gravely ill and may not survive this illness.*"

The nursing notes for this day recorded:

> "*Parents in most of day, aware of condition.*"

The haematologist noted in the consumer's file at 7.00pm on that day:

> "*Many cases of aggressive haemophagocytosis* [cancer of the blood cells] *like this are associated with an underlying lymphoma – often T cell – and can be difficult to diagnose despite multiple bone marrow and other organ biopsies.*
>
> *Given* [the consumer's] *prior clinical state there seems to be nothing to lose by giving some chemotherapy. I have discussed* [the consumer's] *treatment with* [two haematologists].
>
> [The consumer's] *low Hb* [haemoglobin] *and pH contin* [continue] *and the pressure of coagulopathy clearly put her in a poor prognostic group and I would have grave concerns about whether she will survive regardless of therapy.*
>
> *I have discussed her bone marrow results in general terms with her parents.*"

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

The nursing notes for the same day recorded:

> "*Family have seen doctors today.*"

Three days later, in late July 1998, the haematologist that did the biopsy noted:

> "*The large nucleated cells in the bone marrow have not stained with B or T cell markers and to date there is no definite evidence of malignancy on the sample obtained.*"

The haematologist then went on to outline the options available for treatment, and finished the notes with:

> "*I have discussed the above with her parents.*"

The consumer died on that day.

The consumer's father informed the Commissioner that he telephoned the hospital's Chief Executive Officer, seeking answers to his concerns regarding his daughter's illness and death. The consumer's father stated that his daughter's clinical notes were only made available to him following letters of enquiry from his lawyer and a Member of Parliament.

An appointment was made for the consumer's father to meet with the Clinical Director of Medicine in mid-October 1998. At that meeting the Clinical Director undertook to respond in writing in seven days to a series of questions put to him by the consumer's father. These questions included whether a plan should have been put in place to manage his daughter's illness and to ensure her condition was monitored, and why her surgery was not carried out at the time originally scheduled in mid-July. The Clinical Director informed the consumer's father that there were problems with the systems at the hospital. The consumer's father (the complainant) stated that the Clinical Director committed himself to come back within seven days with answers to his questions.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

One week later the Clinical Director left a message on the complainant's mobile phone apologising for not having got back to him, and inviting the complainant to ring him. The Clinical Director assured him that a letter would be in the post, which the complainant would receive in four days time.

The complainant stated that in early November he telephoned the hospital and spoke to the Clinical Director's secretary, requesting a copy of the Clinical Director's letter by facsimile. The complainant did not receive a faxed copy of the letter, or further communication from the Clinical Director's office.

The complainant stated that in mid-November 1998 he faxed the Clinical Director's office requesting that the letter to be forwarded, and informed the Clinical Director that a complaint had been made to the Health and Disability Commissioner.

Four days later the Clinical Director left a message for the complainant that he could expect the letter in three days (late November 1998). The letter arrived in early December 1998.

In relation to the complainant statement that the hospital's complaint process was inadequate in responding in a timely manner, the Clinical Director informed the Commissioner that:

> "*This statement is unfortunately correct and was contributed to both by internal process issues and my inability to respond in a timely manner. We have been in the process of improving the complaints process and this is undergoing continued audit.*"

The complainant stated that he also had difficulty in obtaining a copy of the post mortem report, which was eventually located at the general practitioner's office.

The Clinical Director informed the Commissioner that a clinicopathological conference was held specifically so that the consumer's case could be discussed among all the physicians at the Hospital and Health Service, so that the learning points could be discussed and passed on.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Information Gathered During Investigation *continued*

The Clinical Director of Internal Medicine and Cardiology at the HHS has spoken to groups of junior and senior doctors regarding the consumer's family's feelings of exclusion and incomplete provision of information. The Clinical Director acknowledged to the Commissioner that it is important to include the family and patient in any and all communications.

Independent Advice to Commissioner

An independent intensivist and emergency medical specialist advised the Commissioner that:

> "[The complainant], *in his comments, has indicated a frustration over the often-used term 'in hindsight'. It should be pointed out at this stage, that clinical diagnosis, particularly in a presentation such as* [the consumer's], *is extremely difficult and requires a great deal of 'consideration and thinking' through of the many probabilities involved.*
>
> *Appropriate testing strategies and consultation options are also required in order to narrow down the possibilities.*
>
> *...*
>
> *The standard for a clinical assessment by a doctor pursuing an explanation for patients presenting with lymphadenopathy includes a careful medical history and physical examination.*
>
> *...*
>
> *The physical examination in a patient with lymphadenopathy can provide further useful clues such as the extent of the lymphadenopathy (localised versus generalised), the size of the nodes, the texture of the nodes, the presence or absence of nodal tenderness, signs of inflammation over the node ... The texture of the lymph nodes may be described as soft, firm, rubbery, hard, discrete, matted, tender, movable or fixed. ... Nodes involved with lymphoma tend to be large, discrete, symmetric, rubbery, firm, mobile and non tender.*

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Independent Advice to Commissioner *continued*

…

In [the consumer's] *case, it must be stressed that there was no definitive diagnosis even after an autopsy that included gross and microscopic pathological analysis. It was not until further experts were consulted along with a review of* [the consumer's] *history of presentation, her clinical course and her autopsy findings that a definitive diagnosis was reached. This difficulty is representative of the rare and variant presentation of post-thymic T cell Lymphoma occurring in young adults and one having such a rapid and fulminant course.*

It is only in 'hindsight' that certain of her findings can be explained – for example, the significant rise in her serum Beta Human Chorionic Gonadotropin (HCG) level tested [late] *July 98 equalling 1548 Units/Litre. The finding of this positive 'Blood Pregnancy Test' led to a repeat pelvic ultrasound that was negative for a gestational sac and, to the autopsy review of her uterus, also negative for a pregnancy. However, the pathologist, on microscopic examination of her ovaries during the autopsy of July* [late] *1998, noted, '… each show(ed) scanty collections of atypical cells with features similar to those described in the lymph nodes'. As* [the Clinical Director] *indicated in his review, the lymphoma involved her ovaries and most likely was responsible for the false positive pregnancy test.*

…

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Independent Advice to Commissioner *continued*

[The consumer's] *case should be considered, not for its rarity, but for the lessons that can be learned with regard to the system's design weaknesses. The aim is not to place fault or blame but to indicate where important issues were not given 'due care' and thus contributed to the adverse outcomes experienced by the patient and her family. These adverse outcomes included suffering: patient and family; frustration: patient, family and clinical staff; and, discomfort: patient, family and clinical staff. According to the biopsy findings and experts in this disease,* [the consumer's] *death could not have been avoided. What might have been avoided however, was her and her family's suffering, discomfort and frustration.*

…

Summary

From the information … it can be deduced that [the consumer] *presented with a very rare, diagnostically very difficult and exceedingly rapid and aggressive haematological malignancy. To have had the clinical team from* [the HHS], *in late June 1998, uncover the precise diagnosis would have been a coup of sorts.*

However, it is apparent that basic medical decision-making and diagnostic logic was not performed to the standard required or expected. … [T]*here were communication gaps in the information provided by* [the consumer's] *GP (admittedly, there is no note to indicate any verbal exchange of information) and in the full history initially outlined by the admitting registrar. As well, the performance of the initial physical examination and the consideration of the blood tests provided by* [the consumer's GP] *were below the standard to be expected.*

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Independent Advice to Commissioner *continued*

At no time during her first admission, was there any evidence of more information being sought from [the consumer] *or* [of] *any of the blood test results being thoroughly examined. In contrast to her admission of* [mid] *July, there was no written review of findings or diagnostic probabilities outlined and no written comments on the concerns and queries of the doctors caring for* [the consumer]. *The consultants reviewing* [the consumer], *failed also to ensure that* [the medical specialist] *and his clinical team understood their own diagnostic uncertainty. Every doctor reviewing a patient should be able to provide a more general as well as specific overview of the patient.*

It is difficult to understand the logic behind her discharge from hospital given the diagnostic uncertainty with regard to her condition. It was noted throughout the nursing notes that [the consumer] *frequently expressed a desire to go home. Given the fact that the clinical staff had diagnostically felt that what she was suffering from had a viral causation for which there was no specific treatment other than time, it is likely this influenced their decision to discharge her. This is despite the fact that she was increasingly unwell, noted to be exhausted and was not able to eat or drink. In the notes there was an underlying thread that this may have been related to anorexia nervosa – although the only clinician to state this was the dietician who saw her on the day of her discharge from hospital.*

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Independent Advice to Commissioner *continued*

What is notable is that there was significant evidence of an aggressive underlying pathology from the very first day of her hospital admission. She had abnormalities on her urinalysis, her chemistry profile, her chest x-ray and had evidence of a coagulopathy as well as of a haemolytic process. Her viral studies failed to shed any specific light on the diagnosis. The dermatologist, although conceding [the] *probably viral origin of her disease noted the lack of conformity of the rash with any common viral disease. The infectious disease consultant, who also conceded that this was most likely viral, also raised the possibility of other infectious causes to be considered. No haematology opinion was sought which certainly confirms the fact that her haematological abnormalities were not really considered by the clinical staff. The knowledge that she had enlarged supraclavicular lymph nodes should immediately have raised concern re: intra-abdominal and retroperitoneal pathology. When an abdominal ultrasound was sought, the findings appear to have been largely dismissed as indicative of any major concern despite the differential of lymphoma being raised by the reporter.*

When [the consumer] *returned* [in early July] *for review, no notes were recorded. There was no evidence that she was weighed despite the fact that her father reports that she had been eating and drinking very little over the preceding week.* [The medical specialist] *outlined in his letter the need for a fine needle biopsy of a node. However, in this report, I have indicated that medical opinion is that this is not an appropriate test to do in order to determine a diagnosis in patients presenting with lymphadenopathy. I could find no documentation of the procedure, the consent for the procedure or the advice provided to* [the consumer].

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Independent Advice to Commissioner *continued*

[In mid-July], *on reviewing* [the consumer] *once again, some urgency as to the need for a lymph node biopsy was indicated.* [The consumer's] *father again notes that none of the doctors caring for her had sourced the report on the fine needle aspirate, expressing his discomfort with this. Once again, tests were ordered, results were available, but none of the clinical staff appeared to have been concerned enough to evaluate the meaning of these results in the context of* [the consumer's] *presentation and ongoing symptoms.*

This is an important issue to raise with regard to standards of due care. The purpose of performing blood and other tests is to enable accuracy of diagnosis and therefore clarify potential therapeutic options and to develop a reasonable management plan for the patient's condition. Blood tests are painful and invasive as are fine needle node aspirates. In order for clinical people to be able to justify obtaining these tests, the information should be important and hopefully add to the diagnostic decision-making required – that is they should either exclude or indicate a direction toward a possible diagnosis. Throughout the first month of her care by [the HHS], *there is no definitive effort made to utilise all of the information provided by the tests that were performed other than to pick out those tests that appeared to support the clinical diagnosis that she was suffering from a viral disease.* [The medical specialist] *in his December 1999 letter indicated that he had tried to communicate his diagnostic uncertainty however, he very much appeared to be supporting a viral causation over this early course of care.*

On her admission of [mid-] *July, very good care was provided. This care was significantly improved over her earlier course. It is obvious from reading through the early notes of this admission, that the severity of her illness was very apparent to all clinical staff. Nonetheless, a very thorough review was performed of all of the available clinical information and appropriate further testing, consultation and care provided.*

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Independent Advice to Commissioner *continued*

It is also very obvious that on her admission, she was already in a systemically decompensated state – her pulse rate, her shortness of breath, her peripheral oedema and her peripheral cyanosis were cardinal symptoms and signs of a deteriorating clinical condition. She was in the early stages of clinical shock and it is not too surprising that she progressed rapidly into full blown multiple organ system failure. It is also not surprising, given her severely run down and stressed physical state that this was the final event prior to her demise. There is no doubt, however, in reviewing all of the information from this admission, that she received a very good standard of care from all of the clinical staff involved.

Conclusion

The major conclusions from perusal of [the consumer's] *clinical file and disease course at* [the HHS] *are:*

1. *That she had a very rare, rapidly progressive and fatal disease for which no current therapeutic strategy has been shown to be significantly effective.*
2. *That she did not receive a reasonable standard of 'due care' from the clinical staff attending her from her admission* [mid-June], *1998 through to her final admission* [mid-July], *1998.*
3. *That she did receive a good standard of 'due care' during her admission of* [mid-July], *1998. The fact that this admission ended in her demise is no reflection on the excellence of the clinical care provided over this time.*
4. *That during her final admission, gleaned from reading through the clinical notes of* [late July], *frequent reference is made of information and communication with the family.*"

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Independent Advice to Commissioner *continued*

The HHS's Chief Executive Officer informed the Commissioner that:

"…

In accordance with your findings I enclose a letter of apology to [the complainant] *and a memo to all junior registered medical officers to ensure that all communication, examinations and investigations are well documented on the patient records.*

I also enclose a copy of the new Complaints and Incidents Policy which was ratified at [a] *Clinical Board meeting last night.*

A new computerised complaints and incidents programme has been introduced at [the HHS] *with appropriate training being given to all staff to ensure that incidents and complaints are followed up within the timeframe set down by the Health & Disability Commissioner's Code of Rights.*

…"

The medical specialist informed the Commissioner that:

"…

I have been found in breach of [the consumer's] *rights by failing to treat her with the appropriate skill, knowledge and understanding expected of me. In particular I failed to assess her physical and laboratory findings with due care. I will be more attentive and diligent to the laboratory tests in future and wish never to repeat this error. I know that this will not bring* [the consumer] *back but hope that I have learnt from this for my future patients.*

…"

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Code of Health and Disability Services Consumers' Rights

The following Rights in the Code of Health and Disability Services Consumers' Rights are applicable to this complaint:

RIGHT 4
Right to Services of an Appropriate Standard

1) Every consumer has the right to have services provided with reasonable care and skill.
2) Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.
5) Every consumer has the right to co-operation among providers to ensure quality and continuity of services.

RIGHT 10
Right to Complain

3) Every provider must facilitate the fair, simple, speedy, and efficient resolution of complaints.
4) Every provider must inform a consumer about progress on the consumer's complaint at intervals of not more than 1 month.
6) Every provider, unless an employee of a provider, must have a complaints procedure that ensures that –
    a) The complaint is acknowledged in writing within 5 working days of receipt, unless it has been resolved to the satisfaction of the consumer within that period.
7) Within 10 working days of giving written acknowledgement of a complaint, the provider must, -
    a) Decide whether the provider –
        i. Accepts that the complaint is justified; or
        ii. Does not accept that the complaint is justified; or
    b) If it decides that more time is needed to investigate the complaint, -
        i. Determine how much additional time is needed; and
        ii. If that additional time is more than 20 working days, inform the consumer of that determination and of the reasons for it.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Code of Health and Disability Services Consumers' Rights *continued*

8) As soon as practicable after a provider decides whether or not it accepts that a complaint is justified, the provider must inform the consumer of –

i. The reasons for the decision; and

ii. Any actions the provider proposes to take; and

ii. Any appeal procedure the provider has in place.

Opinion: No Breach Clinical Director of Internal Medicine and Cardiology

In my opinion the Clinical Director of Internal Medicine and Cardiology did not breach Rights 10(3), 10(4) or 10(7).

Rights 10(3), 10(4) and 10(7)

The consumer's father made a complaint to the HHS Chief Executive Officer at the end of September 1998, regarding the treatment and care his daughter received at the public hospital.

The Clinical Director contacted the complainant to arrange a meeting to discuss his concerns, within a month of being informed of the complainant's complaint by the Chief Executive Officer. The meeting was held in mid-October 1998.

The Clinical Director agreed at that meeting to provide the complainant with a written response to his concerns. When it appeared that there was going to be a delay in providing this written response, the Clinical Director contacted the complainant by telephone four days later, and assured him that he would receive the agreed documentation. The complainant received the Clinical Director's letter in early December 1998.

Every provider has a responsibility under the Code to facilitate the fair, simple, speedy, and efficient resolution of complaints, and inform a consumer about progress on the consumer's complaint at intervals of not more than one month. The Clinical Director was acting as the representative of the HHS in this matter, and was not provided with policies to guide him in the resolution of the complainant's complaint. In my opinion it would be unreasonable to find the Clinical Director in breach of Rights 10(3), 10(4) and 10(7).

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Opinion: Breach Medical Specialist

In my opinion the medical specialist breached Rights 4(1) and 4(2) of the Code of Health and Disability Services Consumers' Rights.

Rights 4(1) and 4(2)

Initial examination at the hospital in late June 1998
The consumer was admitted to the public hospital in late June 1998, under the medical specialist's medical team. The registrar who admitted the consumer considered that her symptoms were due to a virus and ordered a number of diagnostic tests including viral serology and chest x-ray to obtain a diagnosis. The records showed that no other possible diagnosis was considered at this time.

I am advised by my expert that the recording of probabilities that need to be considered is important in a case such as the consumer's because of the number of conditions presenting with these symptoms. The standard for a clinical assessment by a doctor pursuing an explanation for patients presenting with lymphadenopathy (disease of the lymph glands) includes a careful medical history and physical examination, carefully selected laboratory tests and occasionally an excisional lymph node biopsy.

I am advised that the medical team's assessment of the consumer's condition on her admission was not of a professional standard, as it failed to indicate the size of the nodes described, whether they were discrete, whether they were tender and whether they involved more than a single region. The significance of the finding of supraclavicular (above the collar bone) node enlargement was also not appreciated. The registrar also noted in his initial examination of the consumer that she did not have a cough, although the general practitioner and the nursing staff each recorded the consumer's cough. The medical team did not provide a written plan that indicated a need for an examination to define the extent of the lymphadenopathy.

I am advised that clinical notes, as a standard, should include the issues being considered by the clinical staff with regard to a plan for investigation noting their concerns regarding the potential diagnosis as well as the main findings contributing to the diagnosis. There were no notes in the consumer's records that outline any of these considerations or probabilities.

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HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Opinion: Breach Medical Specialist *continued*

The medical team also failed to note any organ abnormality, however the abdominal ultrasound examination performed on the day the consumer was discharged, indicated enlargement of her liver and spleen, and also that her retroperitoneal lymph nodes were very enlarged. The radiologist recorded this examination in the progress notes and made a differential diagnosis of lymphoma and offered a further examination of an ultrasound-guided biopsy, but this was not followed up by the medical specialist.

Blood tests taken in late June 1998 showed markedly abnormal liver function tests, with a series of other blood tests for platelets and haemoglobin indicating abnormalities. All of these test results had been initialled as having been seen by the doctors, but were not noted as having any significant in relation to the consumer's disease.

The consumer's discharge from the hospital in late June 1998 and outpatient reviews of early July and mid-July 1998
The consumer was discharged home in late June 1998 with a temperature chart and weekly reviews. There was no rationale described for this action in either the consumer's clinical records or the discharge letter by the medical registrar to the consumer's general practitioner.

There was no mention in the discharge letter of the consumer's abnormal blood test results, the reasons for her haemolytic anaemia or the significance of her extensive intraperitoneal and retroperitoneal lymphadenopathy. The discharge summary records some aspects of the consumer's history and examination.

The impression recorded is still one of a viral illness although the ultrasound report is mentioned. It was noted that the consumer was to return in early July 1998 for review. The medical specialist planned to see the consumer weekly at ward reviews, as he expected her disease to be self-limiting.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Opinion: Breach Medical specialist *continued*

On the ward review of early July 1998, the medical specialist arranged for the consumer to have a cervical node aspirate. The result of this test did not assist the medical staff to establish a diagnosis. I am advised that the fine needle biopsy was an inappropriate test to perform in order to determine a diagnosis in patients such as the consumer, who present with lymphadenopathy.

There is no written record of the review in the consumer's notes, documentation of the aspiration procedure, consent for the procedure or the advice provided to the consumer. The medical specialist did not repeat the consumer's blood tests at this visit.

The consumer was next reviewed in mid-July 1998, when the medical specialist arranged for her to be admitted for an excisional lymph node biopsy. This biopsy did not take place due to the lack of an available surgeon to perform the procedure. The medical specialist did not comment on the consumer's blood test results, order further blood tests or request a haematological opinion. The consumer was again discharged with a plan for her to have a lymph node biopsy if her symptoms persisted.

A doctor must treat his or her patient with the skill, knowledge and understanding that can be reasonably expected of a doctor with similar experience and training in such circumstances. As the medical specialist in charge of the consumer's case, the medical specialist had the responsibility to direct the team in the investigation of the consumer's symptoms, and the analysis of the results of those tests. In my opinion, the medical specialist's diagnosis and decision making in relation to the consumer from late June 1998 to late July 1998, was not performed with reasonable care and skill and failed to comply with professional standards. The medical specialist therefore breached Right 4(2).

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Opinion: Breach Hospital and Health Service

In my opinion the Hospital and Health Service breached Rights 4(1) and 4(5), and Rights 10(3), 10(4), 10(6), 10(7) and 10(8).

Right 4(1)

Management of the consumer's treatment and care, and interaction with her family by hospital staff

The consumer presented with a very rare type of lymphoma with the predominant pathology represented by haemophagocytosis (cancer of the blood cells). I accept that it is improbable that any therapeutic attempts could have been made to prevent the consumer's death, even if she had undergone lymph node biopsy at an earlier stage in her illness.

However, at no time during the consumer's first admission was there any evidence of more information being sought from her, or of her blood test results being thoroughly examined. There was no written review of findings or diagnostic probability outlines and no written comments on the concerns and queries of the doctors caring for the consumer. The consultants reviewing the consumer also failed to ensure that the medical specialist and his clinical team understood their own diagnostic uncertainty.

In my opinion the consumer did not receive services of an appropriate standard from the HHS from her admission in late June 1998 through to her final admission in mid-July 1998. The consumer and her family experienced discomfort and frustration as a result of unnecessary delays and omissions by the hospital.

I accept that the consumer did receive services of an appropriate standard from her admission to the hospital in mid-July 1998 until her death six days later, and that her death was no reflection on the excellence of the clinical care provided over that time.

Health care delivery in a hospital setting encompasses complex and often overlapping processes. At or between any of these points in the delivery of care, delayed or neglected actions, technical or judgmental errors or communication failures may result in potential or actual adverse consequences for the patient.

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HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Opinion: Breach Hospital and Health Service ***continued***

Failure to provide well co-ordinated services, with reasonable care and skill, may be the result of poor system design or care management decisions such as unrealistic workloads, over scheduling, inadequate training or resource policies that may contribute to jeopardising a patient's interests.

I am aware that the HHS is engaged in a range of continuous quality improvement processes to improve the services provided to its patients. However, the care that the consumer received from the hospital, and the communication between staff and the consumer and her family, highlights the fact that 'quality care' is an empty phrase if it does not translate into well co-ordinated services, performed with reasonable care and skill on the part of all clinical staff. It is currently accepted that most adverse events in hospitals result from poorly designed systems and processes. The HHS must accept responsibility for the systems that let down the consumer and her family. I accept my independent advice that although "[The consumer's] *death could not have been avoided*, [w]*hat might have been avoided ... was her family's suffering, discomfort and frustration*".

In my opinion the HHS did not have systems in place to ensure that the consumer was provided with services with reasonable care and skill. In these circumstances, the HHS breached Right 4(1).

Right 4(5)

The consumer's care from her admission in late June 1998 through to her final admission in late July 1998 were not well co-ordinated. The recommendation from radiology for further examination was not followed up, discharge instructions and support were not well planned, and arrangements for the surgical procedure of biopsy were deferred twice, due to staff shortages.

While the consumer was treated with reasonable care and skill during her final admission from late July 1998 until her death six days later, her family found the overall treatment of the consumer at the hospital, and lack of communication, frustrating and distressing.

Continued on next page

HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Opinion: Breach Hospital and Health Service ***continued***

In my opinion, the HHS failed to have systems to ensure co-operation and co-ordination between the staff involved in the consumer's care so as to promote her right to quality and continuity of service. The HHS therefore breached Right 4(5).

Right 10(3)

The consumer's father telephoned the HHS's Chief Executive Officer in late September 1998, seeking answers to his questions relating to the illness and death of his daughter. An appointment was made for the complainant to meet with representatives of the hospital in mid-October 1998.

On this day the complainant met with the Clinical Director of Internal Medicine and Cardiology, who apologised for being on his own. The Clinical Director advised the complainant that the medical specialist had moved on from the hospital. The Clinical Director and the complainant discussed the lack of discharge planning and delay in surgery for the consumer. The Clinical Director informed the complainant at the meeting that he would respond to his questions in seven days.

In late October 1998, the Clinical Director left a message for the complainant, apologising for the delay, and assuring him that he would receive the letter of response in four days.

In early November 1998, when he had still not received any documentation from the Clinical Director, the complainant contacted the Clinical Director's secretary and requested a faxed copy of the letter. The complainant did not receive the letter or an explanation from the Clinical Director's Office about the missing letter.

In mid-November 1998, the complainant faxed a further request for the letter to the Clinical Director's Office.

Four days later the Clinical Director left a message for the complainant informing him that he could expect the letter in four days' time. The letter arrived in early December 1998.

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HHS/Public Hospital / Medical Specialist / Clinical Director of Internal Medicine and Cardiology

Report on Opinion – Case 98HDC21016, continued

Opinion: Breach Hospital and Health Service ***continued***

The complainant approached the hospital and its representative, the Clinical Director, four times over four months, attempting to have his concerns about his daughter's illness and death answered. The manner in which the HHS responded to the complainant's justified concerns about the care his daughter received at the hospital was lax and insensitive, and added to the complainant's sense of grievance. In my opinion the HHS did not facilitate the fair, simple, speedy and efficient resolution of the complainant's complaint, and therefore breached Right 10(3).

The HHS also failed to meet the time frames set out in the Code for responding to the complainant's complaint. In my opinion the HHS therefore breached Rights 10(4), 10(6), 10(7) and 10(8).

Actions

I recommend that the following actions are taken:

- The medical specialist is to apologise in writing to the complainant. This apology is to be sent to the Commissioner who will forward it to the complainant.
- On behalf of the HHS, the Chief Executive Officer is to apologise in writing to the complainant for the breach of the Code. This apology is to be sent to the Commissioner who will forward it to the complainant.
- The Chief Executive Officer is to review the HHS's current complaint policy and procedures and report the results of that review to the Commissioner.
- All staff at the HHS must receive training on the Code, including details on how to action complaints within the HHS's policy.

Other Actions

A copy of this report will be sent to the Medical Council of New Zealand, the Minister of Health, the Ministry of Health, the Health Funding Authority, and the Crown Company Monitoring Advisory Unit.