

Submission

Inquiry into the performance of the Health Ombudsman's functions pursuant to section 179 of the *Health Ombudsman Act 2013*.

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Submission

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Performance of the Office of the Health Ombudsman

Following my experience with the OHO, it is impossible for me to have any faith in the quality of work carried out by the OHO.

My experience was that the OHO complaint process was long, drawn out, stressful, never managed to accurately understand the issues involved, and never resulted in a resolution.

I sent a complaint to the OHO regarding a palliative care referral process which involved sending a referral and private information to another facility for in-home palliative care without the knowledge or consent of the patient.

The referral took place in anticipation that the cancer would return at some stage. This happened 3 months prior to a diagnosis that the cancer had returned. The person was then pressured for 3 months to accept a service that they did not need or want. The patient then changed care to the private system and continued to manage as an outpatient while receiving good care. The person never got to a stage where they required in-home palliative care, and the public health service had created much extra unnecessary stress for 3 months. The public health service had ignored the normal health practice of asking for consent. The health service had denied the patient his right to be informed and engaged in his care.

When I sent my complaint to the OHO, the front page asked what I wanted as an outcome.

I asked for -

An explanation,

An apology,

I also ticked "other" and I wrote one simple sentence -

I am asking for an assurance that no future patients be referred to [REDACTED]
[REDACTED] without their knowledge.

That sentence was too difficult for the OHO officer to understand. He left off the words "without their knowledge" (which was the critical point of my complaint), and stated that I had requested that "no future patients be referred to [REDACTED]". He then did the entire assessment based on an incorrect understanding. He sent a letter to the health service stating that I was asking that no future patients be referred to [REDACTED]. This would have been a senseless and impractical request, and it made me look unreasonable and ridiculous.

It is difficult to believe that an OHO Officer would mistakenly read a request for an assurance that no future patients be referred to [REDACTED] [REDACTED] without their knowledge, and replace it with a nonsensical request - "an assurance that no future patients be referred to [REDACTED]."
After the health service received this wrong information, the health service naturally formed an opinion that I was making an unreasonable request and no one could expect them to turn up to the conciliation meeting with an open mind. If the OHO Assessment Officer thought that I was making such a silly request, he should have phoned me to discuss it.

After this unbelievably bad mistake, I expected care to be taken to get the facts correct in the review of the decision but again they misread the facts and sent information to the health service that made my complaint look much less serious than it was. The OHO Review Officer claimed that a discussion that occurred in April 2014 was evidence that a discussion had taken place before a referral took place in February 2014. I do not know how anyone could have got it so wrong on two occasions. It was no wonder that the health service arrived at the conciliation meeting thinking the whole thing was a waste of their time. They were given wrong information that lead them to wrongly assume that I lacked understanding and that my problem was that I had trouble accepting death. This could not have been further from the truth.

My family member had his normal rights to be informed and engaged in his care denied by the hospital and the OHO failed to take this matter seriously and encouraged the health service not to take it seriously. I am sure that if the issue of informed consent had involved any other area of medicine other than Palliative Care, then it would have been taken much more seriously.

I find it hard to believe just how unprofessional my case was handled by the OHO. Any professional organisation that makes mistakes should be willing to discuss those mistakes. The OHO repeatedly refused to discuss these mistakes with me and just said repeatedly that I could talk to the Queensland Ombudsman. It was wrong of the OHO not to discuss these mistakes with me. To say I can discuss it with the Queensland Ombudsman is wrong as the Queensland Ombudsman explained to me that they do not normally look at the details of cases, they just look to see if the normal process has been followed (that is the decision has been followed by a review of the decision), and they do not actually look at the quality of the work. If there has been a conciliation meeting, they don't tend to get involved.

I believe that my complaint was not taken seriously because it involved a palliative care issue. This is wrong. Palliative care patients are more vulnerable than most patients so, if anything, their concerns should be taken more seriously. The failure of a palliative care patient to be allowed to be informed and engaged in their care, and the failure of the health service to get consent before sending a referral and private information to another facility should have been taken seriously by the OHO.

The overall standard of the assessment was of an extremely poor quality. The assessment contained many mistakes and much material that was irrelevant to my complaint. I have listed 8 examples in appendix 1.

The review of the assessment also contained mistakes. It also misrepresented my complaint to the health service and again the same irrelevant information was considered important to the review outcome.

This irrelevant information included much discussion about the appropriateness of the referral. This demonstrated that the OHO officers were incapable of carrying out a logical assessment. There was nothing in my complaint to indicate that my complaint was about the appropriateness or otherwise of [REDACTED]. My complaint was clearly about a referral process, failure to inform and engage the patient in his care decisions, and failure to obtain consent. The fact that the health service said that [REDACTED] was the only service in our area that provided in-home palliative care was irrelevant and did not in any way provide an excuse for not informing the patient prior to referral. (In fact it was not the only service in our community, I actually found a private specialist who provided a full in-home palliative care service if such a service ever became necessary, but it never became necessary).

The health service had twice been given wrong and misleading information by the OHO. It was no surprise that representatives from the health

service turned up to the conciliation meeting but were not prepared to listen. I believe that the health service representatives knew that the OHO had no power to do anything so they turned up with a very arrogant attitude and without a willingness to really listen and understand the concerns.

The Role of the Office of the Health Ombudsman

The OHO website uses the Charter of Patient Rights to inform consumers of what they should expect from health service providers. The website encourages people to make a complaint if these rights have not been experienced. My complaint was about a failure of the health service to keep the patient informed and engaged in their care and a failure to get consent. This is clearly denying the patient rights as set out in the Charter of Patient Rights. However the OHO has informed me that denying a patient their rights as set out in the Charter of Patient Rights is not something that they look at.

The Health Ombudsman, Mr Leon Atkinson-MacEwen wrote to me stating that "In relation to your query about the Australian Charter of Patient Rights, the charter sets out guiding principles only; the charter is not a regulatory instrument against which I can take action. "

This leaves a health consumer very confused. Why does the OHO use the charter as an example on it's website, if it has no power to enforce the charter?.

Why do we have a charter if health services know they are free to ignore the charter whenever convenient and there are no consequences?

Why is there no regulatory instrument to ensure that patients are kept informed and engaged in their care and that consent is obtained before sending referrals and private information to other facilities?

The Role of the Office of the Health Ombudsman concerning Palliative Care Complaints

Following my extensive discussions with the OHO, it seems to me that the OHO views anything that involves palliative care to be unimportant.

It is also clear that the OHO is not a suitable organisation to look into complaints involving Palliative Care Patients.

It took two years for me to attempt to get a response from the health service and then from the OHO. Most palliative care patients would be dead before getting any sort of response.

Many complaints revolve issues of lack of information, poor communication and failure to get consent. These issues need to be resolved while the patient is being treated, not after the patient is dead.

There needs to be a way of efficiently dealing with these issues as they arise. The more quickly an issue is dealt with, the easier it can be dealt with and less resources are used up in the process. If these issues are not dealt with quickly, communication issues escalate, the complaint becomes a long drawn out issue that uses up lots of resources and is often left unresolved. My experience was that the OHO complaint process was long, drawn out, stressful, never managed to accurately understand the issues involved, and never resulted in a resolution.

Having issues being dealt with by a long inefficient process is not a good use of resources.

An efficient process would be designed to quickly and efficiently respond to complaints before they become long drawn out issues. The OHO should be more proactive in facilitating resolution during a patient's treatment.

Recommendations for Improved Performance

(1) Where possible the OHO should become more proactive and less reactive.

For example, if an issue involves the complete breakdown of communication between a patient and a health service, the OHO should be able to contact the health service and help de-escalate the conflict so that it does not escalate into a long drawn out issue that uses up lots of resources and is unlikely to reach a resolution.

(2) The quality of the work carried out by the OHO should be assessed. Random cases should be looked at by an outside independent organisation to ensure that assessments are carried out in a professional, objective and logical manner. In my experience, the work seemed to be of a very low quality. Currently the Queensland Ombudsman looks at complaints but usually only checks to see if the basic process has been followed.

(3) The OHO should be transparent and accountable. Where possible, complaints (after removal of all identifying factors) should be made public so that the public can see how complaints are dealt with, view the quality of assessments and see how effective outcomes are. The quality of the OHO assessments is currently kept hidden and is not being monitored. Allowing the public to monitor quality would encourage a high standard of assessments and investigation. Making cases public would help consumers to have some confidence in the complaints system and help them to know what questions to ask of health service providers. It would also help health services to understand more about why people make complaints. Consumers should have the right to opt out if they don't want their complaint made public.

(4) The quality of assessments could easily be improved. Prior to the commencement of an assessment, the OHO should produce a statement of the basic facts involved in a complaint to demonstrate their understanding of a situation. This would give the person making the complaint a chance

to clear up any misunderstandings and provide more information if required. This would potentially improve the quality of assessments and result in fewer reviews of assessments being requested and fewer complaints going to the Queensland Ombudsman. This statement needs to be written. In my experience, OHO seemed to understand during phone conversations but written communication demonstrated lack of understanding. As OHO officers are looking at a number of cases at the same time, phone conversations can easily be forgotten by the time they look at the case again. I understand OHO officers currently take notes of phone conversations, but my experience is evidence that this is not sufficient.

(5) The OHO should play a greater role in helping consumers communicate their complaint to the health service. Currently the OHO sees their role as including the organising of conciliation meetings where appropriate. The health consumer is then told that it is up to them to communicate their concerns effectively. Consumers often do not have the skills to negotiate equally with a number of professional health service representatives. In my experience, it was difficult to face a long conciliation process by myself with two health service representatives who I perceived as being very arrogant and uninterested in my concerns. I also perceived the OHO facilitator to be biased toward the health service. This is a very uncomfortable experience for a consumer to have to face. Consumers usually have no access to impartial information and guidance while health services have access to advice and assistance from professional organisations and legal firms. Conciliation is an unequal process and steps should be taken to help consumers to have an equal say in conciliation processes.

(6) The role of the OHO should be improved so that it has some power to ensure health services provide services that are consistent with the Australian Charter of Patient Rights. If necessary these rights should be put into a regulatory instrument against which the OHO can take action.

Currently health services know that there are no consequences when they choose to ignore patient rights.

(7) An outside independent organisation should be contracted to do assessments of client satisfaction. This could be done every few years to help assess the effectiveness of the OHO. When initially contacting the OHO clients could be asked if they give their permission to be contacted for client satisfaction surveys.

An independent organisation is required as knowledge of current health related surveys and inquiries usually does not reach the clients who are being impacted by the service. Even though I have in recent months had extensive contact with the Office of the Minister for Health and with various health stakeholders, I did not find out about this inquiry until a few days before it closed. Relying on health stakeholders is a very unreliable means of reaching consumers. In my experience health stakeholders seem to be really only interested in insuring their own future existence. They rely on funding from government and service providers. They are very interested in hearing from consumers who have good experiences. They request positive stories to post on their websites. However I have not been able to find any health stakeholder willing to listen to the negative experiences that my family has endured through contact with health service providers. All just referred me to the OHO. Despite an extensive search, I have not found any stakeholder that represents consumers like myself. The State and Federal Health Ministers, Palliative Care Queensland, Palliative Care Australia, The Cancer Council, Carer's Queensland, Health Consumers Queensland, health service liaison officers, health service executives, the health service board, and the Australian Commission on Safety and Quality in Healthcare are among those that I have contacted, and none have been able to refer me to any suitable organisation that I could contact.

Appendix 1

Examples of poor work in the OHO assessment

1. The assessment officer did not consider my complaint in a professional manner.

This is evident in the assertion that "I requested that future patients not be referred to [REDACTED]". This is totally incorrect - and impractical - in fact the whole basis of my complaint was 'for an assurance that no future patients would be referred to [REDACTED] without their knowledge'. The assessment officer left off the words "without their knowledge" and sent this incorrect information to the health service making my complaint look unreasonable and ridiculous. One would not expect the health service to take my complaint seriously after they got this wrong information from the assessment officer.

2. The assessment officer did not take the issue regarding consent seriously.

The issue of informed consent should not have been considered unimportant just because my family member had a life limiting illness. He still had a right to be informed and a right to have input into his health care. Because it involves the Palliative Care Department, it seems that the OHO considers it not necessary for this public hospital to follow the Qld Health's policy and normal health processes re informed consent. Qld Health actually gives the transfer of care to another facility as an example of when informed consent is required. I had explained the issue of informed consent to the assessment officer a number of times on the phone as I feared that, given his comments to me, he was not taking the issue seriously. However he still ignored the seriousness of the issue. My family member's right to be informed and engaged in his health care decisions was ignored.

3. An unprofessional decision process is indicated by irrelevant information in the decision process, such as much referral to information regarding the appropriateness of [REDACTED]

The complaint had nothing to do with the appropriateness or otherwise of [REDACTED]. My complaint was clearly about a lack of explanation and a denial of the right to be informed and engaged in health decisions. A professional assessment would have recognised the nature of my complaint. No matter how appropriate one might believe a treatment or service might be, this does not give the health service the right to ignore my family member's right to be informed and engaged in his health care decisions. A patient's right to refuse should always be respected, unless the person lacks capacity which was certainly not my family member's case.

4 The assessment officer wrongly stated that the health service doctor had apologised.

The Submission by the Health Service provider did not provide evidence that the doctor had apologised and reflected on his practice. He apologised for my lack of understanding as he acknowledged that my family member and myself may not have understood the process. He effectively blamed us for not understanding the process. The doctor had failed to inform us and we had no way of knowing that the doctor had made a decision about my family member's health without consulting him. There is nothing in the submission by the doctor that indicates that he is aware of the seriousness of not gaining informed consent. The doctor did not even see a need to inform patients before referral.

5. The assessment officer wrongly quoted the medical notes.

Point 1 (of the Decision statement):

1c. The decision statement states that "it is not clear from the notes, as to if the Practitioner was aware that the consumer was awaiting biopsy results" and this if correct would have been irrelevant. The Practitioner had a duty to be informed about the patient's health status before discussing resuscitation. If the Practitioner had been acting in a professional manner, before talking to a post surgery patient in a surgical ward, he would have found out some basic knowledge about the patient including which procedure had been carried out. He should have checked the patient's chart in order to see if a diagnosis had been made. He should have also communicated with the patient to get an understanding of the patient's perception of his illness and diagnosis before bringing up the subject of resuscitation.

The assessment officer was wrong to say "it is not clear from the notes, as to if the Practitioner was aware that the consumer was awaiting biopsy results". The (entry by intern xxxxx xxxxxx, 12/05/2014) clearly indicates that my family member was seen by Dr xxxx, in the presence of xxxxx and xxxx. It documents that "patient aware that awaiting histology results." and "Plan: Will R/Vx again, await histo results". This entry by the intern is short and very easy to read, there is no excuse for the assessment officer to misread it. His comments regarding the notes are completely inaccurate. Dr xxxx clearly raised the issue while aware that my family member was awaiting biopsy results prior to diagnosis.

6. The assessment officer again misquoted the medical notes.

While the decision statement said that the notes say that resuscitation was subsequently discussed on 14 May, this is wrong. Again, the Assessment Officer did not read the notes accurately. The Palliative Care notes on 14/05/2014 say that I brought up a concern re the subject of

resuscitation having been raised on 12/05/2014. Subsequent discussion never happened and even if it did, this would have been irrelevant to the complaint. I was there on 14 May and I asked the Practitioner to leave as my family member was too tired to have a discussion with him. On the 14 May, Dr xxxxx had failed to see that my family member was feeling stressed after just receiving his diagnosis from the surgical team. Dr xxxxx acted in an unprofessional manner and the assessment officer has made an inaccurate assessment of the situation.

7. The assessment officer stated that there was nothing wrong with my family member being treated by a junior doctor, wrongly inferring that my complaint was about my family member being treated by a junior doctor.

This was incorrect, it was about my family member suffering more stress as the result of being misled and not being given a choice as to whether or not he wished Palliative Care to manage his pain.

When you are told that you should have Palliative Care manage your pain while in hospital because they are "experts in pain management", you are being deliberately given the impression that your pain would be treated by an experienced doctor. (Point 2, a of the Decision statement).

My complaint was not regarding my family member being treated by a junior doctor as stated by the assessment officer. My complaint is regarding being misled and being unnecessarily referred for Palliative Care to manage the pain when any junior ward doctor could have managed the pain just as well without subjecting my family member to the added stress that he felt from being referred to Palliative Care to manage pain. He should have been given a choice re whether or not he wanted Palliative Care to manage his pain while he was in hospital. The only doctor he saw during his last admission to xxxx Hospital (which was for a for a surgical procedure), regarding ongoing pain was Dr xxxxx xxxxx who commenced work as an intern at xxxx Hospital in 2014. She had

completed her first placement of some weeks as a surgical intern and Palliative Care was her second placement. I perceived her presentation as very immature and she seemed to do nothing to inspire confidence in her ability to function as a doctor. While I am aware that in theory there must have been someone supervising her, this did not happen in practice, for anyone to effectively supervise her practice, they would have also had to walk in and ask my family member how his pain was. Dr xxxx xxxx seemed to be constantly emotionally elevated with her excitement regarding having been let loose from medical school. She was not an expert in pain management.

8. The assessment officer wrongly stated that there was "no adverse outcome". Remaining in pain is an adverse outcome. It is the role of Palliative Care doctors to effectively manage pain.

My complaint indicated that my family member's pain was not addressed because the intern (xxxx xxxx) just changed the dose on the chart instead of carrying out the pain consult which, if done in a professional manner, would have included walking in and asking my family member how his pain was, and then discussing any change in dose with him - all patients have a right to be informed and involved in their care (per The Australian Charter of Patient Rights, which hangs on the walls at xxxxx Hospital). While I can't say the accurate date that this occurred, the notes indicate that Dr xxxx saw my family member on [REDACTED] and documented that I had raised concerns with her that the Palliative Care Team did review my family member regarding his pain. She said that they do Chart Reviews if the patient is not in bed and stable. Reading the notes gives a clear indication that my family member's pain was not stable and he was almost always in bed so there was no excuse for Chart reviews to be carried out in his absence. While Dr xxx saw my family member for a couple of minutes on this day, the intern was clearly the one managing his pain. (Dr xxxx also seemed to be a very inexperienced junior registrar). Most discussion

re pain was actually with Palliative Care nurses whose presence and communication style clearly made my family member feel uncomfortable and he did not like discussing his pain with these nurses. He was much more comfortable talking to the ward nurses who he trusted. Palliative Care input made his pain management more awkward, and he would have been more relaxed with the normal ward staff managing his pain. He should have had a choice.

- i. The complaint refers to my family member having issues with pain which were not being addressed. He remained in pain because the intern failed to see him. This is not managing pain appropriately.
- ii. There was unsatisfactory treatment because my family member remained in pain.
- iii. It is not true that there was no adverse outcome, as stated by the assessment officer.