Advocacy Cases Report 2014 – 2015

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

Unit 6 Wellington Fair, 40 Lord Street, EAST PERTH WA 6004
GPO Box C134, PERTH WA 6839
Telephone: (08) 9221 3422, Free call: 1800 620 780, Facsimile: (08) 9221 5435
http://www.hconc.org.au

About the HCC

The Health Consumers' Council (HCC) is an independent community based organisation representing the consumers' 'interest' in health policy, planning, research and service delivery in Western Australia.

The values and objectives underpinning the HCC's work are for consumers to:

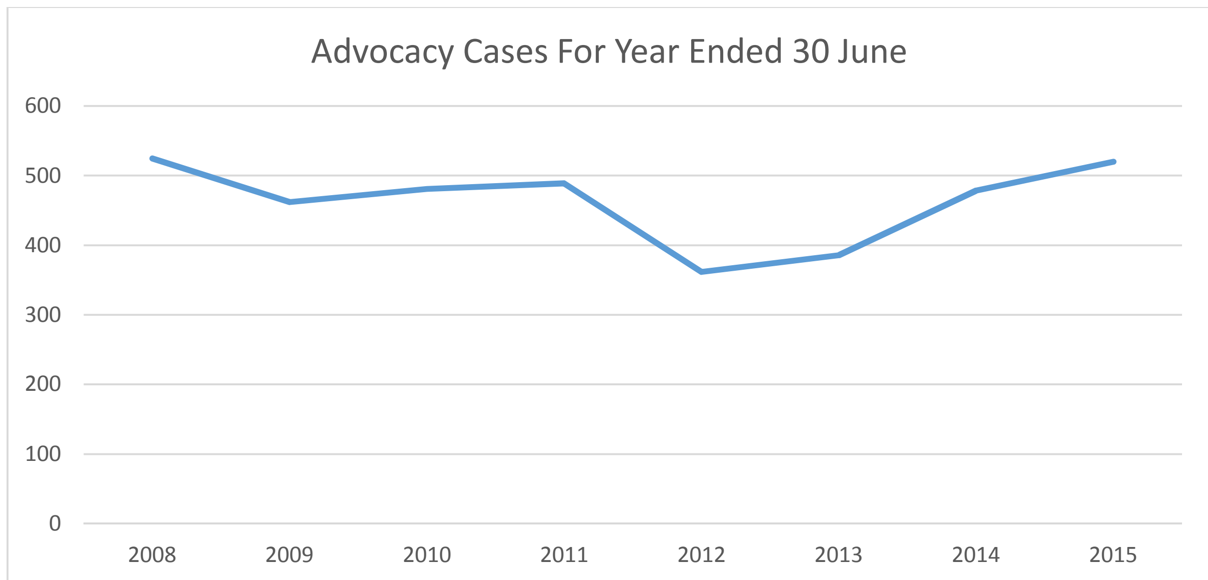
- be treated with respect, dignity and understanding;
- be informed about their rights and have those rights protected and enhanced;
- receive safe evidenced based care;
- be informed about their condition and any prosed treatment;
- have equitable access to health services and
- have access to information about themselves held by health professionals and the right to correct anomalies in this information.

One of the core activities of the HCC is to provide advocacy service for individual consumers experiencing difficulties in the WA health and mental health system. The HCC employs 2.6 advocates and are funded solely by the WA Department of Health to provide this service. Our advocates are not medically or legally trained but experienced in consumer rights, knowledge of the health system and consumer rights and responsibilities.

New Cases

In the year 1 July 2014 to 30 June 2015 the HCC received 621 requests for advocacy. However 101 of these requests were not proceeded with for a variety of reasons, including the consumer was not able to identify a specific issue or withdrew their request for assistance as the issue resolved itself. As a result HCC Advocacy Service acted for 520 new cases. This 520 includes both Aboriginal and non-Aboriginal consumers who approached the HCC for support. However it does not include individuals serviced by the HCC's Aboriginal Advocacy Service. In addition there were a number of carryover advocacy cases from 2013/2014, however this report deals exclusively with new cases.

Figure 1. This figure represents the total number of cases per year from 2007/8 to 2014/15.



Comparison with prior years

The number of new cases (520) for 2014/15 is the highest number since 2007/8 (525). Data for 2014/15 was recorded using different categories from previous years. For the first time there is the capacity to analyse separately the nature of issues related to physical and mental health. Because this data was not collected in previous years there is limited data for comparison with the 2014/15 year.

Data collection

Contact with the HCC is usually initiated by consumers or by or their family. A small proportion referrals originate from other agencies. Most contact is by phone or email, with a minority of consumers writing a letter or meeting face to face with an advocate at the office.

Data is collected on each case for five categories:

1. Public sector or private sector health consumer.
2. Metropolitan (Perth and Mandurah) or regional location of consumer.
3. Identity of person first seeking help: self, family or other.
4. (Physical) Health or Mental Health related issue.
5. The nature of the issue; Access to services, concerns about treatment or diagnosis or cost, etc.

This data is analysed below.

Location

Table 1: Residential Location of Consumers.

Location	Mental Health	Physical Health	Total
Perth/Mandurah	163	261	424
Regional	17	79	96

There were 424 new cases concerning consumers residing in Perth/Mandurah and 96 new cases from regional areas. The proportion of issues raised by consumers in regional WA (18%) was similar to proportion of the population (20%). However the proportion of issues that related to mental

health was considerably larger in the Perth/ Mandurah area (38%) than in regional WA (18%). The reasons for this are unclear.

Public or private sector consumer

Table 2: Public or Private Consumer.

Public/Private	Mental Health	Physical Health	Total
Public	158	229	387
Private	22	111	133

There were 387 of new cases regarding public health services (74% of all cases), while 133 (26%) of the cases related to private health services. Mental health cases constituted 41% of the public cases but only 20% of private cases. This may reflect the fact that many mental health consumers are relatively economically disadvantaged and disproportionately rely on free government run services.

Person initiating contact

Table 3: Person initiating contact

Method	Mental Health	Physical Health	Total
Self	140	222	362
Family	30	94	124
Other	10	24	34

There are three categories that represent the different categories (self, family and other) of people who contacted HCC advocates for assistance. The 'self' category refers to people who have contacted the HCC to seek support for their own issues. 'Family' is used when a member of the consumers' family has contacted the organisation on behalf of the consumer. 'Other' refers to non-family members including other agencies approaching the HCC on behalf of a consumer. For adult consumers HCC advocates obtain the permission of the consumer to discuss their issues with family members or other parties.

Most cases were self-initiated (70%). Mental health consumers were more likely to initiate contact on their own behalf (78%) than physical health patients (65%). Advocates reported that they experienced relatively few instances of conflict between consumer and family wishes, although this was more common for mental health patients than for physical health patients. This may account for the higher proportion of mental health consumers seeking support for their own issues.

Service Provider

The service provider category details wether the issues raised by consumers relate to a hospital, residential facility, single practitioner or other service. Those issues relating to a single practitioner are further broken down by profession (GP, dentist, chiropractor, psychiatrist etc.). Similarly issues relating to a 'clinic' are detailed by the nature of the clinic.

Nearly half (47%) of all issues related to a 'hospital' with the majority of mental health issues (54%) and 39% of physical health issues relating to hospitals. It should be noted that clinics within hospitals, like Fremantle Hospital's Alma Street Mental Health Service, were reported under the hospital category.

A total of 91 issues (17% of the total) were reported as ‘other’. These issues were very diverse and often unique. They could not easily fit into one of the defined ‘service provider’ categories as they did not relate to a specific service. Examples include consumers seeking advice on mental health law, health insurance, or on how to access information on pharmaceuticals, or freedom of information processes.

PROVIDER TYPE	Mental Health	Physical Health	Total
Hospital	**98**	**148**	**246**
Residential	**10**	**27**	**37**
Other	**37**	**54**	**91**
Single Practitioners			
GP	9	34	43
Specialist	0	25	25
Psychiatrist	8	0	8
Psychologist	2	0	2
Nurse	1	1	2
Midwife	0	0	0
Counsellor	0	0	0
Physiotherapist	0	0	0
Chiropractor	0	1	1
Pharmacist	1	2	3
Dentist	0	5	5
Other	0	1	1
Total	**21**	**69**	**90**
Clinic			
GP	2	9	11
Specialist	0	10	10
Psychiatrist	8	0	8
Psychologist	1	0	1
Nurse	0	0	0
Midwife	0	0	0
Counsellor	1	0	1
Physiotherapist	0	0	0
Chiropractor	0	0	0
Pharmacist	0	0	0
Dentist	0	10	10
Other	2	13	15
Total	**14**	**42**	**56**
TOTAL	**180**	**340**	**520**

Nature of Issue

The issues section of this report is possibly the most significant. It details the nature of issues raised by consumers. Each mental health or health issue is classified as either:

1. Access Denied
2. Disputes Diagnosis or Treatment
3. Rights or
4. Costs issue.

The categories are then broken down into sub-categories.

Access denied:

- Emergency Treatment
- Ongoing Support
- Consumer behaviour prevents access
- Unreasonable wait time
- Other

Disputes diagnosis/treatment:

- Disagrees with diagnosis
- Disagrees with treatment
- Failure to diagnose
- Poor follow up
- Other

Rights:

- Threat of involuntary detention or treatment (mental health only)
- Involuntary detention or treatment (mental health only)
- Lack of informed consent
- Unethical/unprofessional behaviour
- Communication
- Other

Note: The Rights category has a small difference between the mental and physical health sub-categories. The mental health category includes threat of involuntary detention/treatment and involuntary detention/treatment sub-categories which do not apply for health.

Costs:

- Unreasonable
- Charges not disclosed
- Insurance dispute
- Other

Some consumers could have multiple related issues. For example some mental health consumers who dispute a diagnosis, also dispute their treatment. Furthermore some consumers have related health and mental health issues. However, for reporting purposes advocates chose a single category and sub-category that best described the consumers' dominant concern. The analysis below deals with health and then mental health issues.

Nature of the Issue	Mental Health	Physical Health
Access denied		
Emergency Treatment	1	3
Ongoing Support	15	17
Consumer behaviour prevents access	4	6
Unreasonable wait time	0	20
Other	13	53
Total	**33**	**99**
Disputes diagnosis/treatment		
Disagrees with diagnosis	5	3
Disagrees with treatment	26	65
Failure to diagnose	0	18
Poor follow up	3	13
Other	14	22
Total	**48**	**121**
Rights		
Threat of involuntary detention or treatment	14	NA
Involuntary detention or treatment	32	NA
Lack of informed consent	0	7
Unethical/unprofessional behaviour	16	24
Communication	14	22
Other	20	27
Total	**96**	**80**
Costs		
Unreasonable	1	15
Charges not disclosed	1	3
Insurance dispute	0	2
Other	1	20
Total	**3**	**40**
TOTAL	**180**	**340**

Physical Health Issues

Over a third (36%) of physical health issues related to disputes about diagnosis and treatment with more than a half of these (19%) relating to disputes about treatment and 13 cases of poor follow up care (4%). There were 18 issues (5%) relating to a failure to diagnose with a small number of cases (three) where the diagnosis was disputed.

'Access denied' to service issues accounted for 29% of all physical health issues with 20 cases (6%) relating to unreasonable wait times and 17 (5%) relating to a lack of access to ongoing support. There were three complaints of denial of emergency services however, six consumers reported that they had been told their behaviour was the reason they have been excluded from services.

Rights related issues were less prominent for physical health consumers than for mental health consumers. Nonetheless there were 24 physical health consumers (7%) who identified unethical or unprofessional behaviour by a health service or professional as their primary concern.

Costs related issues were relatively more prominent amongst physical health consumers (12%) than for mental health consumers (2%) with 15 physical health consumers (4%) complaining about unreasonable charges for services.

Mental Health Issues

Over half (53%) of the mental health issues raised related to consumer rights. This was much higher than the proportion for health related consumer issues (24%). This discrepancy is at least in part due to the fact that, unlike health patients, mental health patients can be detained and treated against their express wishes.

HCC advocates handled issues for 32 consumers who had been involuntarily detained and/or treated against their will (18% of mental health issues). Another 14 consumers (8%) were primarily concerned that they were being coerced by express or implied threat of involuntary detention or treatment if they did not agree to the treatment recommended by a treating psychiatrist. This often involved consumers feeling forced to take a higher dose of psychotropic medication. While there were no cases where allegations of a lack of informed consent was raised as the major issue, it is important to note that all cases of involuntary detention and treatment (and the threat thereof) necessarily involve a lack of informed consumer consent.

Other rights related concerns were the 16 cases (9%) involving allegations of unethical or unprofessional behaviour by mental health practitioners or service staff and 14 cases where poor communication was identified as the major issue.

Disputes about diagnosis and treatment accounted for 27% of all mental health issues. The distinction between disputes diagnosis and disputes treatment is somewhat arbitrary as many consumers dispute both.

Denial of access to services accounted for 18% of mental health issues. There was only one complaint of denial of emergency services however, four consumers reported that they had been told their behaviour was the reason they have been excluded from services. While this is a small number, denial of access to services on the basis of 'poor behaviour' for mental health consumers is obviously problematic. The most common access issue, raised by 15 mental health consumers (9%), was a lack of continued support for consumers with ongoing mental health needs.

De-identified Case Studies

HCC advocates dealt with very diverse issues, some relatively simple and quickly resolved, others complex and require sustained advocacy. Although mental health cases constitute only 34.6% of total case number HCC advocates report that they are typically more complex than physical health cases. While no statistics in regard to time spent on individual cases are kept, advocates indicate at least half their workload relates to mental health cases.

The following de-identified case studies reflect the diversity of issues and highlight key themes.

Case 1 - **Inappropriate (off label, unsupervised by trained staff, and without permission of spouse) use of antipsychotic medication on elderly patient in dementia unit aged care residential facility**

Bob (named changed) is aged about 80 and is a dementia patient on a high dependency residential ward. His wife Alice (name changed) asked her pharmacist to have a look at the list of medications Bob had been prescribed by the GP who visited patients on the ward. The pharmacist told Alice he believes Bob is being over medicated (particularly with antipsychotics) and told Alice this is this particular doctor's common practice.

At Alice's request a HCC advocate attended the meeting between Alice and Bob's GP. After it was pointed out to the Doctor that there were 'premature death' warnings for prescription of antipsychotics to dementia patients the GP agreed to remove the 'use as needed' instruction for Risperidone (an antipsychotic) and halve the dose for the first week with a view to removing it all together by two weeks.

The GP stated the rationale for the 'use as fit' capacity had been that Bob gets agitated and the medically untrained staff needed the capacity to manage his behaviour as they saw fit. Alice pointed out that the reason for Bob becoming agitated was that staff (one in particular) were surprising Bob who is blind by touching him to direct him where to move without telling him they were going to touch him. After the meeting the HCC Advocate and Alice discussed the possibility of removing the use of antidepressants gradually as well.

The HCC Advocate attended a follow up meeting two weeks later. The GP had reduced the Risperidone dose by half and removed the capacity of untrained staff to dispense as fit and agreed to gradually remove it altogether. The GP also promised to review Bob's antidepressant use. The GP also undertook to consult Alice who would authorise any future medication changes.

Two weeks later the management of the residential facility, Alice and the HCC Advocate met. Management agreed with Alice's concerns about approaching Bob and promised to talk to staff in order to deliver a 'person centred' approach. Management also agreed that if Bob becomes agitated they will call Alice any time of day or night. Alice was happy and for now at least no further action.

Case 2 – **Relatively young person distressed at being inappropriately housed in an aged care facility with no independence.**

John (name changed) in his 50's who lives in regional WA contacted the HCC for assistance. John was admitted into hospital for a period of six weeks following his third stroke. At the time of discharge, John's long term carer became unable to continue in this role and so John was transferred to an aged care nursing home. John was hugely distressed to be living in the nursing home alongside elderly patients with severe mobility and mental incapacities.

The aged care facility manager made an application to the State Administrative Tribunal (SAT) for a guardianship and administration order. The application was poorly written and vague and didn't include any reference to John's wishes. The HCC advocate shared concerns around this with the SAT.

HCC advocate liaised with various agencies and John's long term friends in a bid to gather information prior to the SAT hearing. The advocate visited John to ascertain his wishes and needs and prepared a written submission to the SAT outlining John's wishes.

The advocate spent time prior to the tribunal explaining to John what to expect and encouraging him to express his views. John is diagnosed with vascular dementia which appears to affect his memory and insight. However, he retains the capacity to communicate his wishes clearly to those who listen patiently. John asked the advocate to speak on his behalf as he was concerned his slurred speech would be difficult to understand.

The HCC advocate supported John during the hearing and ensured his views were put forward specifically his desire to maintain some independence and financial control. Both a guardian and trust manager are now in place to find appropriate supported accommodation for John and to make decisions in his best interests. After the HCC advocate lobbied John's guardian (who was initially reluctant to support John's wish to move) John was moved to a supported 'all age' unit which allows him a much higher level of independence. John has told the advocate he was very happy with this outcome.

HCC advocacy was essential to ensure that these orders included some level of independence for John as opposed to him losing all control. Additionally the HCC Advocate was able to explain to John the role of the Public Trustee and Public Advocate in and helped to navigate him through a very complex process.

Case 3 – **With mental health patient permission, increased involvement of family member treatment and care decisions.**

At the request of a young adult mental health patient, Peter, (name changed) and their parent a HCC advocate attended a meeting between the patient, their public sector psychiatrist and the consumers' parent to discuss the patient's transition from public sector clinic mental health support to the care of a GP. The patient, who is blind and therefore unable to read, and the parent were both concerned about continuity of care and communication in regards to care plans and medication.

The HCC advocate suggested that the psychiatrist and the GP with the patient's permission provide the parent with all copies of documents relating to ongoing care, most notably medications, so that the patient and parent can discuss ongoing care. All agreed this would be a helpful process and the psychiatrist agreed to forward copies of all future documents to the parent.

Case 4 – **Mental health consumer concerned about being placed on a Community Treatment Order**

Kelly (name-changed) was feeling suicidal and self-admitted to a public hospital. She had been on the mental health ward for 9 days when she contacted HCC. Kelly requested that an advocate contact the hospital prior to a treatment review meeting. She feared they would place a Community Treatment Order (CTO) on her for depot injections even though she has been compliant with oral medications. The Advocate rang and spoke to the hospital ward staff and explained Kelly's concerns. The ward staff advised the advocate that there was no plan to put Kelly on a CTO. The advocate then

spoke to Kelly, who was reassured by this information. After discharge from hospital Kelly contacted the advocate and advised she had not been put on CTO and continued on oral medication.

Case 5- **Fear of being involuntarily treated with mental health medications like those that had previously made the consumer very sick.**

Fler's History

Fler (name changed) told a HCC advocate she had previously been made an involuntary patient by in a public sector mental health service, however, the Mental Health Tribunal overturned their involuntary detention order and freed her (this only happens in approximately 3% of cases). Fler said that the medications she was given while an involuntary patient (Risperidone and Abilify) had made her very unwell (Parkinsonism and feeling like a zombie).

After she 'won' the Mental Health Tribunal hearing another psychiatrist (who was not involved in the original involuntary treatment) at the same public sector service helped her off all mediations and she said she felt much better. Fler said this psychiatrist had diagnosed her with PTSD caused anxiety. She said with the help of her this psychiatrist she had developed effective non drug management strategies. This psychiatrist has subsequently left this service to work elsewhere.

HCC Involvement

At Fler's request a HCC advocate attended two meetings between her and another psychiatrist from the same public sector service. The meetings attended by the HCC advocate were follow up meetings from previous meeting between Fler and the psychiatrist.

Fler stated that at the earlier meeting the public sector psychiatrist had suggested he thought she was getting unwell (increasingly anxious). Fler said that he strongly suggested she should be put back on similar medications to those she had previously been prescribed when she was an involuntary patient. Fler said that she agreed she was becoming increasingly anxious, but said this was because she feared he was going to lock her up and drug her again.

At the meetings attended by the HCC advocate (she also took a close friend) the psychiatrist said Fler didn't need to change medications if she didn't want to. Fler expressed the view that his attitude had been far friendlier and less pushy (towards medications) when her friend and the HCC advocate attended the meetings.

Fler said she was relieved by the outcome but questioned why the same service should provide such variable treatment.

Case 6- **Fatality result of the failure to listen to family members of a very distressed (suicidal) mental health patient.**

Mr Zorich contacted HCC two years after the death of his wife. Mr Zorich's (name changed) wife had been experiencing mental distress for a number of years and had been in and out of psychiatric hospitals. She had made numerous suicide attempts one resulting in serious injury.

After a period of being well she reacted badly to a change in medication and became suicidal and was actively attempting to take her own life. The family called the Emergency Mental Health Liaison Team for assistance. 45 mins later during which time Mr Zorich had to physically restrain his wife two nurses arrived, they spent a little time talking to her and she calmed a little, they advised her to take a walk, Mr Zorich says he begged them to admit her, saying she knew how to manipulate staff. They refused and left saying they would inform the GP in the morning. Within two hours Mr Zorich's wife committed suicide.

He believes her death was avoidable and feels the mental health service failed by not listening to the family. The HCC helped Mr Zorich to obtain his wife's medical records and the root cause analysis. Liaising with HaDSCO, Coroner's Office, Risk Management, and finally a lawyer. Mr Zorich is now within the court process and hopes to get an outcome soon.

Case 7– **Fear of involuntary treatment by voluntary mental health patient.**

Teresa (name changed) a mental health consumer phoned requesting an advocate to attend a Hospital in the Home (HITH) review by a psychiatrist and mental health nurse. She was very worried that she would be forced to have depot-injection of anti-psychotic medication. She has not had injections for several years but because she was diagnosed with having had a psychotic episode and had been made an involuntary mental health patient in the past she was fearful that not only would she be forced to have injections or increased dosages of anti- psychotic medications, but also that she could be made an involuntary patient and forced to stay in a locked ward. Teresa became anxious about this and other personal issues to the point of feeling panicky and knew she can become psychotic if her panic is allowed to escalate.

Before the HITH meeting occurred Teresa was unable to get out of hours support so she presented to the emergency department of a public hospital and was admitted. She reported that some nurses and some psychiatrists seem to threaten her with involuntary admission or treatment if she does not do as they advise.

With this in mind, the consumer requested her advocate from HCC attend a case review while she was an inpatient. The advocate gently mentioned to the nurse that the consumer was very anxious about the prospect of being forced to have depot injections; so much so that her anxiety could spiral out of control due to fears about the injections. The nurse assured the patient that she was not going to be forced to have any anti-psychotic injections against her will.

However, when the psychiatrist arrived the psychiatrist did not discuss increasing the consumer's medications with the consumer; rather she just stated she was increasing the dosages so that the consumer's anxiety would be reduced. The advocate asked Teresa if she felt the increased dosages would be helpful. Teresa was hesitant in responding but stated she trusted her doctor's judgement. This was not consistent with what she had previously told the advocate and Teresa's reasons for saying this are unclear.

Nonetheless after the advocate asked the question for the remainder of the meeting the psychiatrist began to ask Teresa for her opinion on her own treatment. The consumer spent several days in the mental health observation ward before returning to her home under HITH service.

After a discussion with her advocate, Teresa was able to mention to HITH staff that the occasional abrupt manner and repeated questioning of some personal issues do cause stress and anxiety at times. Teresa advised the advocate that the staff and eased off and seemed friendlier. She also stated she felt things were better for having advocate involved and thanked HCC for their assistance.

Case 8- **Lack of informed consent for Non-English speaking family and iatrogenic harm to sight from a failed eye operation**

Hassara (name changed) was born with cataracts in both eyes. When a small child before she had a lens fitted to one eye. This gave her normal vision in the eye. Her family later moved to WA while she was still a child and she had surgery through the public system on the other eye. However, the operation was unsuccessful and had caused the nerve in the eye to die.

HCC assisted Hassara (now an adult) to obtaining her patient records. A significant concern is that the consent form for the surgery (performed when she was a child) has no interpreter's signature, despite the fact that Hassara and her mother could understand little English.

Hassara's mother was the person who had consented. Her mother says risks of the surgery were not explained to her and she was not aware of any. Hassara believes that the surgeon made her eyes much worse and failed to provide important information regarding her eye pressure and the need to use eye drops every day. A lawyer is reviewing the case.

Case 9- **Poor care at a regional hospital emergency department leading to sterility.**

Millie a teenage girl was taken by her mother to a regional public hospital with severe stomach pain. She was diagnosed gastro, with the doctor ignoring her mothers' concerns that something was seriously wrong. Millie was sent home. The same thing happened again a few days later when she again presented at the hospital.

Highly concerned her mother took Millie (three hours way) to a Perth public hospital where a cyst was discovered and a twisted fallopian tube, requiring emergency surgery. Some months later Millie again presented to the same regional hospital in terrible pain and again received inadequate treatment. Her mother took her to another regional where it was discovered her fallopian tube had twisted again and the cyst had ruptured, resulting in emergency surgery and the loss of her ovaries and fallopian tubes.

The HCC advocate is assisting the family to obtain the patient records (including a root cause analysis) from all the hospitals involved. The HCC advocate will then assist the family through the complaint/legal processes involved.

Case 10- **Security of an involuntary patient.**

Thomas (name changed) contacted the HCC because his wife who is an involuntary patient in a public hospital. She went missing and a few days later was found in Interstate. He wanted some assistance seeking reimbursement of the flight costs to bring wife back to WA.

The HCC advocate suggested to Thomas that in the first instance he raise the complaint formally with the hospital, which he did. The HCC advocate had to chase the hospital response on several occasions. When it finally materialised Thomas was not satisfied with their response as he felt it did not address the issue raised of the hospital's policies in regard to safeguarding the inpatients from absconding. After a discussion with Thomas he decided to make a complaint to HaDSCO.

Case 11- **Death from alleged failure to diagnose pulmonary embolism.**

Cheryl (name changed) husband Chris (named changed in his early 40's) without warning became sick with vomiting, breathing problems and significant behaviour changes. Chris was admitted into a public hospital. Cheryl believes the doctors didn't monitor him properly and incorrectly advised MRI's could not be carried out during the weekend. Doctor's brushed off his symptoms as being minor and sent him home. Cheryl called an ambulance soon after. Cheryl raised concerns about his breathing but these were dismissed each time by the doctors. Cheryl tried on numerous occasions to raise concerns about his despondence, again this was dismissed. Chris died within a few days of the first presentation. An interim death certificate has been issued that states the likely cause of death was a pulmonary embolism and acute encephalitis.

The HCC advocate provided information on how to obtain patient records and later spent time with Cheryl and her family reviewing the contents and an appointment with the lawyer was arranged. Research conducted revealed that Chris' death was categorised as a sentinel event classification 3. With the HCC advocates support Chris has requested an explanation as to why the death was not categorised as sentinel event classification 1 (SAC1). 'Sentinel events are defined as 'occurrences involving death or serious physical or psychological injury or risk thereof. SAC 1 includes all clinical incidents /near misses where serious harm or death is/could be specifically caused by health care rather than the patient's underlying condition or illness.'

Case 12- **Mental Health patients' wishes (when well) as to who is their guardian/trustee ignored.**

Sheila (name changed) is senior citizen who suffers from intermittent mental health issues. Sheila has no children but has an estranged sister with whom she has very little contact. Sheila has a long term close friendship (over 30 years) with Tina (name changed). Tina has helped care for Sheila for many years, particularly since her husband died. Sheila regards Tina 'like a daughter' and has made Tina a beneficiary of her will. Tina had been made her guardian a few years ago. Both Sheila and Tina understood this was to become 'active' if Sheila became physically or mentally unwell.

Sheila became unwell when she (of her own volition) ceased taking thyroid medication and was admitted as an involuntary mental health patient. A social worker at the facility applied to SAT to give Sheila a guardian and trustee excluding Tina from decision making. Sheila and Tina were not informed of this process. When her medications were stabilised she recovered, against her wishes was given a guardian from the public advocate (health decisions) and trustee from the Public Trustee (financial decisions). Sheila wanted Tina re-appointed as her guardian/trustee and carer. Tina and Sheila both acknowledged that there would have to be closer supervision of Sheila's medication administration if Tina was reappointed as guardian.

The social worker had sighted 'conflict of interest' as one of the reasons Tina should not be Irene's guardian/trustee. When Sheila was very unwell she was assessed as not being competent to make decisions, including nominating Tina as a guardian. When she got better she wanted to appeal the SAT decision.

According to Sheila the basis of the original SAT investigation (and decision) was information from people who either did not know Irene well including her estranged sister or a neighbour who had never got on with Irene.

Sheila wanted to get and pay for a second opinion from a psychiatrist. This was resisted by her guardian however she got her wish in preparation for a SAT appeal. The second opinion determined that when well she was competent to decide who should be her advocate. Sheila complained that the public advocate was not paying her bills (having cancelled standing orders) and the guardian was not listening to her treatment wishes.

The HCC advocate helped Sheila and Tina prepare an appeal against the SAT decision and prepared a detailed submission supporting Irene's appeal. Sheila won her appeal and Tina is now her carer

Case 13- **Tardy return of a patients' own medical records.**

Sarah (name changed) had obtained her patient records from a previous medical specialist (who had retired). She handed the file to a new specialist a few months ago. Sarah now wants to change specialists as she is unhappy with the new specialists' services. She had requested the return of this file on several occasions but the specialist was uncooperative and dragging his heals returning the file. A HCC advocate phoned the surgery and they were returned the next day.

Case 14- **Patient threatened with involuntary status if not put on increased dose (3 times maximum recommended dose) of antipsychotic.**

Cathy (name changed) rang concerned about the high dose of Olanzapine (20 mg a day) given to her young adult son who has one functional kidney. He was being threatened by a psychiatrist at a public hospital with being put on a dose of 50mg a day otherwise he may be made an involuntary patient. The HCC advocate researched the prescribing information and found that 15mg is maximum recommended dose and that the medication can cause or exacerbate kidney problems. The advocate informed Sally and she relayed this information to the treating psychiatrist and the threat subsided

Case 15- **Registered addict denied Xanax.**

Because he is registered as an addict Peter (name changed) has been blocked from receiving Xanax from his GP for anxiety. He has received Prozac however, he doesn't believe it helps. He stated other patients who are registered as addicts have received Xanax medications for anxiety from his GP. I asked him if he has raised that with his GP. He said no but he would. We discussed the difficulty in changing GPs and the likelihood of being identified as a doctor shopper. He decided to stay with his GP and ask about alternatives.

Case 16– **Beyond prescribed dose use of pain killers leads to the consumer "running out".**

Fiona (name changed) has been on Oxycontin for gynaecological pain for over a year. Her GP doctor put her on a dose for 30 mg. Fiona believes this was not enough and despite telling her GP she could not get her dose increased. Often she would take extra tablets to combat the pain and would on occasions end up in hospital due to the pain. She did see a pain specialist who gave her an authorisation code to take an agreed amount, but her GP has since taken her off the higher dose. She works away a lot and often gets her prescriptions early, but currently has no medication left because of having to take extra tablets and can't get additional prescriptions because she is supposed to have medication to last another 5 weeks. The HCC advocate spoke to her and they

agreed the only way she could get the medication was through her pain specialist liaising with her GP. She was going to approach her pain specialist.

Case 17 – **Released involuntary patient anxious about being readmitted.**

Tom (name changed) had been an involuntary patient who was recently discharged but was anxious about being readmitted. Tom had heard that the service that detained him had prepared a 'form 8' and he wanted to know what that meant. The HCC advocate advised him it is a 'termination of an involuntary treatment order' and he was reassured.

Case 18 – **Released involuntary patient anxious about being readmitted.**

Karen (name changed) had been an involuntary patient who was recently discharged but was anxious about being readmitted if she returned to the service to pick up her passport that they had stored for her. Tom had heard that the service that detained him had prepared a 'form 8' and he wanted to know what that meant. The HCC advocate rang staff at the service who said if she came in would be given her passport with no risk of being made an involuntary patient. The HCC advocate informed Karen who said she would go and get it.

Case 19- **Threat of exclusion of support person from meeting between hospital representatives and a young adult regarding the death of their parent.**

Veronica (name changed) said her niece (a young adult) had been told that that they could not have Veronica as a support person at a meeting in regards to her sister's death in a regional public hospital. I advised this was not the case and to insist on her right to attend. When Veronica rang the hospital she was advised a junior staffer had got it wrong and she was very welcome to attend.

Case 20- **Misleading information provided to patient and their advocate including the patient being made 'involuntary' despite assurances this was not 'in the plan'.**

Josie (name changed) who had previously been an involuntary patient phoned the HCC because she was worried about being made an involuntary patient following a visit from two staff from a local public mental health clinic. Josie believes her daughter who lives in the eastern states (with whom she has a strained relationship) may have rung the clinic. On Josie's behalf a HCC advocate phoned the clinic and spoke to her case manager who said she was meeting with Josie within the week and was see it wasn't on the plan at all. The advocate phoned Josie and told her that.

Ten days later Josie rang the advocate to inform them she had been made an involuntary patient and given an injection against her will. The HCC advocate immediately rang the Council of Official Visitors (COOV). The COOV advocate visited Josie. The HCC advocate also rang the ward and was told by a nurse on the ward who said Josie was being held on the grounds of "danger to own safety". The nurse also said that the COOV advocate had been told and agreed with Josie being an involuntary patient. The HCC advocate rang the COOV advocate who said that was not true. The COOV advocate followed up and Josie was made a voluntary patient and then discharged.

Case 21- **Involuntary treatment has life threatening side effects.**

Vince (name changed) was put on an involuntary Community Treatment Order (CTO) for the treatment with Paliperidone injections. Vince says the Paliperidone caused severe side effects most notably Neuroleptic Malignant Syndrome which is warned about (as life-threatening) in the Prescribing Information document. Vince had an upcoming Mental Health Review Board hearing. An HCC advocate took steps to ensure Vince had legal representation at the hearing. Vince 'won' his hearing and the CTO was removed. Vince decided that despite suffering significant harm he did not want to take further action.

Case 22- **Privacy breach resulting in unsolicited contact.**

Vicky (name changed) a young woman was concerned about a breach of privacy leading to unsolicited contact from a non-medical staff member of a private sector health service. A HCC advocate raised the issue with the manager of the service who apologised on behalf of the service and sacked the employee.

Case 23 - **Access to PATS funding.**

A relative of Patrick, (name changed) a young Aboriginal man from regional WA, sort help on behalf of Patrick. Patrick had been denied Patient Assisted Travel Scheme (PATS) funding for a trip to Perth for an eye operation. I rang PATS who said he needed to visit the hospital and get the Dr to say that because of his heart condition he couldn't be operated on locally. The relative accompanied Patrick to hospital and he received PATS funding.

Case 24– **Fear of a repeat of a Community Treatment Order for a medication that had made a consumer very unwell.**

Ted (name changed) has a long term diagnosis of Bipolar disorder which he accepts and believes is managed well on a low dose of injected Haloperidol. He had previously been made an involuntary patient and the treating psychiatrist in the public hospital insisted he be treated with Paliperidone. Ted said this made him very unwell until he went off it when the CTO ceased. He said he continues to suffer sexual dysfunction as an after effect of the Paliperidone. Ted was very annoyed by the unwillingness of psychiatrist to consider his opinion (including his willingness to take a higher dose of Haloperidol) at the time this CTO was imposed.

Ted contacted the HCC when he had been asked to attend a meeting with the same psychiatrist at the same hospital, fearing a repeat. With Ted's permission a HCC advocate made contact with the psychiatrist and attended the meeting. Ted was very distrustful in the meeting and did not engage with the psychiatrist. In the meeting Ted stated that the psychiatrist was going to do what he wanted to irrespective of what Ted did or said. Prior to the meeting Ted said the same thing and asked the HCC advocate to do his best for him.

Ted wanted a low dose of Haloperidol. The psychiatrist insisted on a new CTO. The advocate asked if it could be for Haloperidol at the dose Ted wanted. The psychiatrist said it would be for Haloperidol at what he described as a low dose but this dose was about twice what Ted wanted. The HCC advocate and the psychiatrist viewed the prescribing information in the meeting and the advocate confirmed to Ted that the dose the psychiatrist had identified was actually below the recommended therapeutic dose. Although Ted was not happy with the psychiatrist outside the meeting he said he

was very happy with the outcome of the meeting. He had previously said he would contest any CTO through the Mental Health Tribunal however he said he wouldn't do this now.

Case 25 – **Well involuntary patient detained for an extra week because of staff illness**.

Terri the mother of Sarah (names changed), a young adult involuntary mental health patient in a regional public hospital rang. Sarah had been an involuntary patient for several months on a locked ward (over three hours from her home, friends, family and support network). She was now well and had been told she could be discharged. However, a week later because a key staff member of the facility had been off sick, Sarah was still detained on a locked ward. A HCC advocate rang the Council of Official Visitors who in turn contacted the ward. Sarah was immediately released.