HEALTH MATTERS

Health Consumers' Council (WA) Inc. Magazine
Summer 2016

(Limited) Free Medical Negligence Legal Advice available through HCC

Patient Experience Week Event Series 2016

Interview with Learne Durrington, CEO of the WA Primary Health Alliance

HCC Health Consumer Excellence Awards 2016

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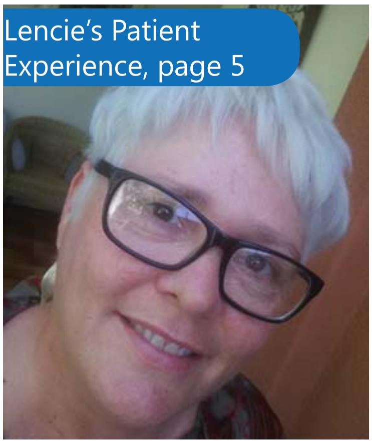
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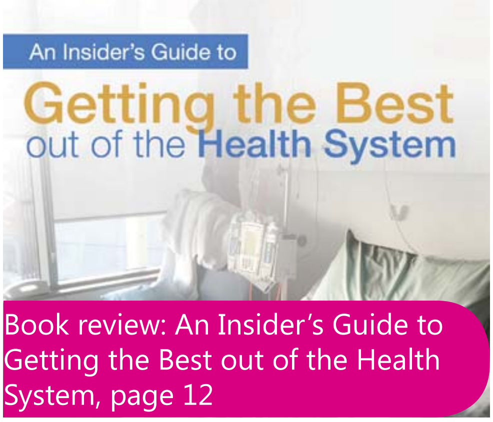

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Foreword

Happy New Year! I hope that you had a wonderful Christmas break. Welcome to the Summer Edition of Health Matters where we focus on Patient Experience.

In December 2015, Health Consumers' Council was a co-sponsor for the Patient Experience Debate. The keynote speaker was Mr Alan Lilly, Chief Executive of Eastern Health in Victoria. Alan Lilly has been an enthusiastic adopter of Patient Opinion, and inspired the audience with his "how-to" approach to implementing the required culture change to facilitate patient centred care. Health Consumers' Council presented on 'Journey to Partnership' and the opportunities that consumer centred care offers health services. Audrey Koay, from Patient Safety and Clinical Quality, WA Health highlighted what is being done in the health department to measure patient experience. Gail Milner presented the Recommendations from the Outpatient debate, representing the Director General of WA Health.

Ms Lencie Wenden presented on her own patient experience and a full version of her speech is provided in the magazine on page 5. The theme of next edition is 'Your health information'. If you would like to submit an article, please contact us on info@hconc.org.au so we can provide submission guidelines.

New Contract with WA Health

On 1st of January 2016 HCC formally commenced its new contract with WA Health. This is an outcomes based contract, which means we will be reporting on the outcomes of our advocacy and consumer and community engagement services. As you can appreciate, having secure funding in this environment is something to be celebrated.

2015-2020 HCC Strategic Plan

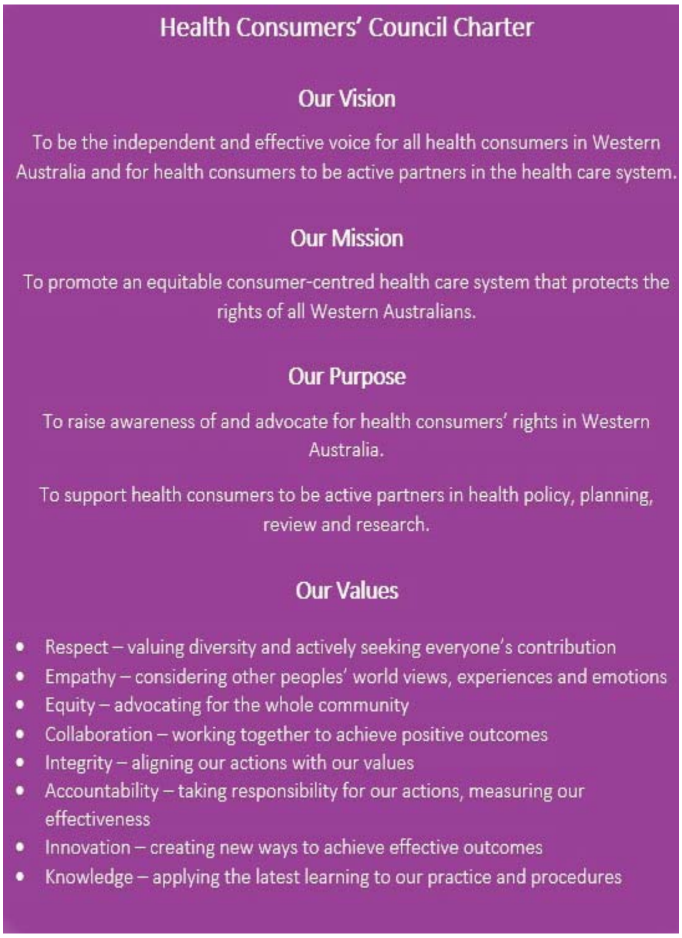
The HCC Strategic Plan has been endorsed by the HCC Board and highlights include:

Support individuals and community through advocacy and health literacy initiatives

Drive effective consumer, community, clinician and stakeholder engagement

Identify and communicate health trends and awareness to key stakeholders

Maintain an effective organisation through competent governance, strategic partnerships, consumer-centred leadership and outcomes based organisational management



Health Consumers' Council Charter

Our Vision

To be the independent and effective voice for all health consumers in Western Australia and for health consumers to be active partners in the health care system.

Our Mission

To promote an equitable consumer-centred health care system that protects the rights of all Western Australians.

Our Purpose

To raise awareness of and advocate for health consumers' rights in Western Australia.

To support health consumers to be active partners in health policy, planning, review and research.

Our Values

- Respect – valuing diversity and actively seeking everyone's contribution
- Empathy – considering other peoples' world views, experiences and emotions
- Equity – advocating for the whole community
- Collaboration – working together to achieve positive outcomes
- Integrity – aligning our actions with our values
- Accountability – taking responsibility for our actions, measuring our effectiveness
- Innovation – creating new ways to achieve effective outcomes
- Knowledge – applying the latest learning to our practice and procedures

Key Strategy Areas

A full version of the Strategic Plan is available by request via info@hconc.org.au or (08) 9221 3422.

Pip Brennan
Executive Director
Health Consumers' Council

Letters to the Editor...

Lucy Palermo Marketing & Communications Coordinator / Health Matters Editor | HCC

Letters to the Editor aims to capture your feedback. We welcome your letters & messages. You can leave messages on Twitter and Facebook using #hconcwa_editor, email info@hconc.org.au or post GPO Box C134, PERTH WA 6839, please include your name, suburb and phone number. Letters may be edited for legal issues, space or clarity.

Thank you for the knowledge

Dear Editor,

I enjoyed and have learnt much from the articles in the Spring edition of Health Matters, centring on the theme of Outpatient Care, so wanted to say well done and thank you!

Dr David Gaskell, WACHS Kimberley

Editor: Thank you for your feedback.

Message to Members

From the 1st of January the cost of posting Health Matters rose from $1.20 to $2.20 each. Due to this and other rising costs Health Consumers' Council (WA) have made the decision to only produce printed copies of Health Matters for members who have elected to recieve correspondence by post.

All other members will receive an electronic version by email.

As usual copies of all recent issues are available on the HCC website at www.hconc.org.au/resources/health-matters/

Hard copies will still be available upon request, by calling (08) 9221 3422 or info@hconc.org.au

Health Consumers' Council (WA) appreciate your support with this issue.

If you have any questions regarding this, please don't hesitate to contact Health Consumers' Council (WA) Inc. via info@hconc.org.au or (08) 9221 3422.

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

PATIENT EXPERIENCE WEEK EVENT SERIES

Perth WA | April 28-29 2016

For more information, visit www.hconc.org.au or call (08) 9221 3422
#hconcwa_PatientExpWk16

The Patient will see you now - Thinking beyond accreditation to focus on the patient experience

Pip Brennan **Executive Director |** HCC


Pictured: Alan Lilly, Chief Executive of Eastern Health Services Victoria

In December 2015 Health Consumers' Council, along with WA Health's Patient Safety and Clinical Quality Division, sponsored the Clinical Senate Debate, 'The Patient will see you now - Thinking beyond accreditation to focus on the patient experience'. It was wonderful to attend a debate focusing solely on the patient.

The keynote address was from Alan Lilly, Chief Executive of Eastern Health Services in Victoria. His talk, entitled "Getting yourself into the patient's shoes to understand the patient experience" outlined how their health services executed the change required to re-orient themselves to a whole of service patient centred approach. Alan Lilly can be frequently seen contributing to the Patient Opinion posts about health services under his management. His exceptional commitment to positive patient experience was very inspiring. At question time he addressed the necessity of culture change as including "getting the right people on the bus, and the wrong people off the bus."

WA Health's Dr Audrey Koay provided a summary of what WA Health is currently doing to measure the patient experience. The WA Patient Satisfaction Survey was covered, including results from the 2014-15 survey, and results from recent accreditation and how WA Health services are demonstrating their compliance with Standard Two.

The Health Consumers' Council presentation focused on the Journey to Partnership and the opportunities that were created through engaging consumers at all levels of the health system. The importance of culture change was emphasised as the key challenge to address. The vision for the Health Consumers' Council is that Standard Two, "Partnering with Consumers" is not a "side dish" for health services, that see it as necessary for compliance purposes, instead, partnering with consumers is what health services do, and "met with merit" is a natural consequence of the health service's culture.

The consumer presentation was by Lencie Wenden and was a powerful story to highlight the patient journey between primary health and hospital services in the two years between her diagnosis with breast cancer and her life now. Lencie's presentation was very powerful and articulate and has been included in full on the following page.

Gail Milner, Assistant Director General addressed the Senate with feedback from the Recommendations from "Outpatient Care – a look to the future" debate. Endorsement of Recommendations was made by the State Health Executive Forum bearing in mind the impending changes in governance with the Health Department, with authority being delegated to the Area Health Service Boards.

For the Patient Experience Debate afternoon session two questions that were addressed;

1. How do we capture the patient experience, measure it and feedback results to frontline clinicians to improve quality outcomes?
2. How do we innovatively meet the new accreditation standards for consumers and carers?

The Senate recommendations will be presented to the Director General of WA Health shortly and will be available on the website link below when they have been finalised. ww2.health.wa.gov.au/Improving-WA-Health/Clinical-Senate-of-Western-Australia/Clinical-Senate-debates-and-publications/2015-Clinical-Senate-debates

Lencie’s Patient Experience

Lencie **Wenden | Health Consumer**

Pictured: Lencie Wenden

The following is the speech that Lencie Wenden gave at the Clinical Senate Debate about her patient experience: I’d like to start by thanking the Clinical Senate for inviting me to speak today. I’m pleased to see today’s theme is ‘The Patient Experience’ and even more pleased the word ‘Experience’ has been chosen over ‘Journey’ - because journey is a euphemism - it implies you’re going somewhere nice.

There’s a range of sympathy cards on the market designed by a cancer survivor that I particularly like, one of which reads: “I promise never to refer to your illness as a journey - unless someone takes you on a cruise”.

The public health system is a very big, at times impersonal beast, and one in which it is often hard to feel seen and heard. So it means a lot to have this opportunity to share my personal experience of the rollercoaster ride I’ve been on for the past two years following my diagnosis with Stage III breast cancer in 2013.

I would like to stress at the start that I have often had really excellent care. The individual clinicians treating me are, more often than not, a credit to their profession.

I am acutely aware of how difficult it is to deliver high quality health care in a climate of ever-shrinking budgets. And given the constraints the people who look after me work with every day, the Health Department should, in my opinion, be proud to have them in their employ.

The bad experiences I’ve had were usually the result of systemic rather than individual failures. But knowing this only helps a bit when your file’s been lost in the system, or your treatment is spread across seven departments and four different hospitals, as mine is, and none of them seem to speak to each other.

Life as I knew it came to a screeching halt just over two years ago. As I stepped out of the shower one morning and looked in the mirror I noticed some sinister looking changes to my right breast. Being just 48 at the time I was not yet having the recommended screening mammograms that might have picked up the cancer in its early stages.

I went to my GP immediately, and subsequent imaging and a biopsy confirmed my suspicions - Invasive ductal carcinoma, and it had already visibly spread to at least four lymph nodes. This bit sounds like it happened quickly but it was nine days from looking in the mirror to getting the diagnosis - nine days of not sleeping, of feeling sick with worry, of not being able to think straight, of not knowing what the future held.

Although I lived in the Fremantle catchment my GP referred me to Charlie’s for treatment because they had the nice new integrated cancer centre where I would get more streamlined treatment. He had done this before for other patients and said it shouldn’t be a problem.

And this is where the wheels first fell off. The continuity of care failed before it even got started. Unbeknownst to my GP, a directive had come down from the health Department just two months earlier that from now on all patients would be treated strictly by postcode. Why didn’t my GP know this?

And so, the next day some faceless staffer at Charlie’s got my faxed referral, saw my postcode, and simply put the file in the internal mail to Fremantle. They didn’t phone me or my GP to inform us there was a problem.

Fortunately my GP, Sacha Saralam, is a freakin legend, and even though it was his day off the next day, and even though he would be at his girlfriend's mother's funeral (I'm not making this up), he gave me his mobile number and told me if I hadn't heard from the hospital by midday to call him and he would chase it up. If it wasn't for his subsequent enquiries I probably would have spent another unnecessary week waiting to hear anything.

This window - between finding a lump and meeting your surgeon - is the singularly most terrifying part of the journey. The questions fly around in your head. How far has the cancer spread? Am I dying? What treatments will I have to go through? What will my prognosis be at the end of treatment? How soon can they operate?

But I think I was lucky in the end to be relegated to Fremantle hospital, because it meant I got Saud Hamza as my breast surgeon - an extraordinarily caring and empathic clinician, the likes of whom I have not met before or since.

The disconnect between general practice and the hospital system next became evident a month later when, following a bilateral mastectomy and axillary clearance, and a one-night stay at Kaleeya, I was discharged with just four days supply of analgesia.

I had three surgical drains, half a metre of incisions, a lot of swelling, and severed nerves from the surgery - but the one-size-fits-all policy dictated that if I needed any more OxyContin I would have to see my GP, because it's their job to manage chronic pain conditions.

I still had bottles and tubes hanging off me, and HITH nurses coming daily. How had I gone from acute to chronic so quickly? I was in no state to be popping down to my local doctors surgery. And over the next month, after the tubes came out, I had to return to my breast surgeon four times to have seromas drained.

Feb to May 2014 was a blur of chemo and its side effects, including the sudden onset of severe menopause symptoms, which have still not abated more than 18 months later. Still - at least menopause wont kill me - I just wish it would sometimes!

I had watched my mother go through chemo nearly 20 years earlier, and although it extended her life by maybe a year, it was not a year worth living in my opinion. But don't worry, they said - chemo is much better targeted now, and side effects can be managed well with medication. Really? I don't know about you, but I never expected to wear adult diapers in my 40s. Every cycle produced explosive diarrhoea - and even with the diapers, there was at least one spectacular feacal disaster with each round.

I still can't figure out how you get poo on the toilet door when your bum's facing in the opposite direction. But I guess that's what happens when you inject drugs so toxic they can burn holes in a lino floor, into humans. My GI tract has never been the same since.

None of the anti-nausea medications I tried were terribly effective - certainly not as effective as the medical marijuana I eventually turned to. When the chemo infusion was switched to docetaxil for my final 3 rounds, the muscle and joint pain was so severe I spent the first week after each round in an opiate haze.

Radiotherapy followed, and everyone said it would be a walk in the park after chemo. I suppose it was if you imagine that park was in The Gaza Strip. Never mind having to get to Royal Perth every day for five weeks as there was no radiotherapy on offer at Fremantle. And yes, the burns became terribly painful, developing into weeping blisters before subsiding. But I had been more or less told to expect this.

What I wasn't expecting was the underlying tissue trauma that developed after the skin settled down. This point was supposed to mark the end of the active treatment phase and the beginning of my return to health. But instead, an escalating series of cock-ups meant the next three months were the most traumatic of this whole 'journey' so far.

As the swelling from radio subsided, a lump appeared on my chest wall. This was to be the first of several scares that made me think the cancer was back and I was, clearly, done for. The lump turned out to be another seroma, but since the radiotherapy had caused a lot of fibrosis, the fluid was sitting in several pockets and would need to be aspirated under ultrasound. Fremantle Hospital's radiology dept was drowning under patient demand, as many staff had already moved across to Fiona Stanley even though it was months away from opening. So I was referred to a private radiology practice, Healthcare Imaging Services (HIS), in the hopes I could be seen there more quickly.

Despite promises made to the hospital by HIS that their complex cases could be seen urgently, the soonest I could get an appointment was two weeks away, and in the meantime a staph infection developed. On the day I was to have the fluid drained I woke up bathed in pus. The seroma had burst in the night and I now had a full thickness chest wound - which the clinic's sonographer merely stuck a pressure dot on (which wouldn’t stick as the wound was still exudating) and told me I would need to see my GP to have it dressed properly.

I complained about the poor treatment from Healthcare Imaging Services, and after an initially promising response from the company’s owner, Sueanne Burford - she was very apologetic and promised to report back to both me and Fremantle Hospital following an internal investigation - this never happened. Several attempts to phone her in the following weeks were unsuccessful. She never returned my calls or reported back to the hospital. They stopped referring patients to Healthcare Imaging Services.

Although I was put on antibiotics, within a few weeks the infection took hold again, and this time, after more fruitless battling with Fremantle Hospital’s radiology dept for outpatient treatment, I was admitted. By now a surgical washout was required. Discharged a week later, I was left with a 10cm abscess in the chest wall which had to be kept open to drain, and dressed every second day for the next six weeks by Silver Chain nurses. I was on antibiotics for 3 months.

On reflection, I think that failures are not just either individual or systemic. My experiences have been defined by how an individual clinician relates to the context they work within. The best people have not been cowed by systems that were not patient centred, systems designed to satisfy other imperatives first, like saving money or making workflow easier for staff. If a policy or procedure is primarily patient centred they could action it in a fairly straightforward way. But if it wasn’t, and the clinician was motivated to make the system work for the patient and not the other way round, it took an extra level of analysis, more time and a higher care factor to see past the limitations. They were the ‘yes’ people who identify more with the patient than the health system they work in, who see a ‘no’ as just one stage in the process of caring for patients, not the end point. ‘Yes’ people do not seek refuge in the rules that govern them. They see the system they work in, and can navigate a way through it.

After a year of treatment and complications I thought I would now finally start to regain my health and get on with life. But it was not to be. In December 2014 I developed Lymphoedema in my right arm. My immune system has also been slow to recover from all the interventions. Recurring bouts of bronchitis through the first half of 2015 escalated to a secondary pneumonia, and another hospital stay in June, this time at Fiona Stanley.

My mother had died of ovarian cancer so I was referred for genetic testing when I was first diagnosed with breast cancer. After a six month wait, the results finally came through in April - I had tested positive for the BRCA-2 gene mutation.

I was then referred to the gynaecology oncology clinic at King Edward to discuss risk-reduction surgery. I was strongly advised to go ahead with the surgery as there are no reliable screening tests for detecting ovarian cancer before it metastasises.

I had a 50% lifetime risk of developing the disease, and a 10% chance I already had it - yet the first available appointment to discuss the procedure was not for another four months - more waiting and worrying. Eight weeks after that appointment I finally had a hysterectomy and oophorectomy - that was 6 weeks ago.

I hadn’t realised just how much my life has been in limbo until a couple of weeks after the latest surgery, when I recently got this tiny inkling that just maybe, I might survive this bloody thing after all.

Looking back, the active treatment phase was - surprisingly - the easiest part. You’re told what to expect - this treatment, followed by this treatment, followed by this treatment. Friends and family rally around. You’re being seen by lots of clinicians and monitored closely.

Then all of a sudden it’s over and you’re cut loose - you go from daily treatment if radiotherapy is your final protocol to......see you in three months for a check-up, then a six or twelve month review. The casseroles have stopped arriving on the doorstep and it’s time to pick yourself up and get on with life.

But nothing is the same. I’m left with what feels like a broken shell of a body sometimes - raging menopause, lymphoedema, pain from the fascia scarring and muscle contraction in the chest and arm, nerve damage, brittle nails, flaky skin, dodgy guts, and muscle and joint pain from the medication I have to stay on for another 8 years. I’ve put on 20 kilos, my mental health has suffered, and my husband and I are $60,000 further in debt because I’ve hardly worked in the last two years.

I have struggled to get back on the bike of life in the face of a seemingly endless stream of complications. And the sword of Damocles hangs overhead now - and I have to find a way of living with the uncertainty, wondering if and when the cancer will return. There’s a good chance it will. I remain a high risk patient.

This is my ‘patient experience’.

PATIENT EXPERIENCE WEEK EVENT SERIES

Lucy Palermo Marketing & Communications Coordinator / Health Matters Editor | HCC

In 2015 the Health Consumers' Council (WA) (HCC) took the decision to begin the tradition of running events during global Patient Experience Week. The inaugural Patient Experience Week Event Series will run on the final two days of Patient Experience Week, 28 and 29 April.

In the true tradition of partnership, the Institute of Health Leadership has offered to "lend" us Tony Dawson, a Patient Safety Ambassador and Senior Vice President & Chief Operating Officer, New York-Presbyterian/Milstein Hospital. Tony Dawson's current focus is on Patient Experience and his lunch time address on 'Patient Experience Friday' is not to be missed.

In addition, new author Kate Ryder talking about her book, 'An Insider's Guide to Getting the Best out of the Health System'. Kate will have signed copies of her book available for purchase. Professor Michael Greco, Patient Opinion Australia CEO; Dr Karen Luxford, Clinical Excellence Commission of New South Wales, Director of Patient Based Care; Professor Anne Williams, Murdoch University, Chair of Health Research and Helen Fernando, Consumer Advocate and 'Patients for Patient Safety' champion, will present on the latest and best patient experience tools.

We are very excited to be able to build on the momentum of the National Safety and Quality Health Service Standards, Partnering with Consumers, the current environment of change, reform and re-focus on the patient by bringing you this new Event Series.

Patient Experience Week will close with the annual Health Consumers' Council Health Consumer Excellence Awards. Since 1997 the Health Consumers' Council has been celebrating the achievements of the unsung heroes in WA Health, from the administrator to the clinician and to recognise health consumers that go out of their way to make a difference. Nominations are now open, and you can complete and return your nomination form to us any time between now and close of business April 15th, 2016.

Patient Experience Week is an initiative of the Beryl Institute. It is an annual event to celebrate healthcare staff impacting patient experience every day. Inspired by members of the Institute community, Patient Experience Week provides a focused time for organisations to celebrate accomplishments, re-energise efforts and honour the people who impact patient experience every day. From nurses and physicians, to support staff and executive professionals, to patients, families and communities served, the Institute hopes to bring together healthcare organisations across the globe to observe Patient Experience Week.

Details of Patient Experience Week and HCC Health Consumer Excellence Awards are available on www.hconc.org.au/get-involved/patient-experience-week or you can call (08) 9221 3422 or email info@hconc.org.au for more information.

Patient Experience Week Facebook & Twitter Hash tag: #hconcwa_PatientExpWk16

HCC Health Consumer Excellence Awards 2016

Nominations are now open for the HCC Health Consumer Excellence Awards. Nominations close end of business April 15th, 2016. The awards comprise of five categories, detailed as follows:

Category 1: Health Organisation Award

This category is for working effectively with consumers to improve services. The Award recognises health organisations that demonstrate an ongoing partnership with health consumers to improve health outcomes and/or the patient experience. Evidence of this in the form of feedback letters from patients and/or measures (KPIs, goals, objectives) will help support the organisation's candidacy.

Category 2: Health Professional Award

This category is for demonstrating excellence in patient care. The Award recognises health professionals who demonstrate ongoing commitment to improving health outcomes and/or the patient experience. Evidence of this in the form of feedback letters from patients and/or measures (KPIs, goals, objectives) will help support the health professional's candidacy.

Category 3: Health Consumer Award

This category is for demonstrating excellence in contributing to the improvement of the patient experience. It recognises a health consumer who demonstrates commitment to improving health outcomes and/or the patient experience. Evidence of this in the form of feedback letters from consumers/patients/health professionals will help support the health consumer's candidacy.

Category 4: Rosemary Caithness Award

This award is to acknowledge outstanding service to health consumers. This award is highly selective and typically the recipient has supported health consumers over many years. The Health Consumers' Council will only award the Rosemary Caithness Award should there be a worthy recipient in any given year.

Category 5: Aboriginal/Torres Strait Islander Health Award

This award is to acknowledge outstanding service to Aboriginal/Torres Strait Islander health consumers. The candidate(s) is an Aboriginal/Torres Strait Islander person or organisation. They can be a health professional, consumer, other individual or organisation. Evidence of this in the form of feedback letters from consumers/patients/health professionals will help support the nomination.

To apply simply go to www.hconc.org.au/get-involved/patient-experience-week to complete the forms or call (08) 9221 3422. For further information please contact Health Consumers' Council (WA) via (08) 9221 3422 or info@hconc.org.au

HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

Advocacy Program: (Limited) Free Medical Negligence Legal Advice available through HCC

Dr Martin Whitely Advocacy, Policy & Research Manager | HCC

Image source: www.soundsforsights.com

Many consumers seek help from HCC's Advocacy Service because they believe they have received poor medical treatment. Some believe their treatment has been so bad that should receive compensation for 'negligence', however, for a host of reasons, few of these situations result in compensation payments. Nonetheless, if you believe you or your friends or family have suffered significant harm from poor treatment it may be worth getting legal advice.

In cases where HCC advocates believe it is warranted, we offer consumers the opportunity (at no cost and without obligations) to meet with a lawyer with expertise in medical negligence. These meetings usually once at our 'once a month' free legal evening at the HCC office. The HCC Advocate and the consumer have usually prepared a short case summary before the half hour meeting with the lawyer. Although it is generally preferable to meet 'face to face', if it is too difficult to attend the legal night in person, the meetings can occur via telephone. The lawyers volunteer their services. If a consumer decides to pursue legal action, there is no expectation that they will choose the lawyer they met through the HCC.

Sometimes the Advocate will suggest that a consumer attends a free legal night because they believe they may have a chance of making a successful claim. On other occasions it can help consumers to understand the reasons why legal action is not likely to be worthwhile.

To be successful a medical negligence claimant needs to be able to show:

1. The treatment received was negligent, in that it failed to meet the professional standards current at that time - Just demonstrating a 'wrong diagnosis' or 'harmful treatment' is not enough. Mistakes are made and medicine is not an exact science. Different 'competent experts' will often make different diagnosis and recommend different treatments. To establish medical negligence, it needs to be shown that the diagnosis or treatment was careless or incompetent and not consistent with the range of accepted practices in the circumstances at the time.

2. Significant (usually ongoing) harm was CAUSED by the negligent treatment - Just showing careless/incompetent behaviour by a medical professional is not enough. It is quite common for HCC advocates to hear detailed stories of what on the face of it appear to be 'negligent' treatment, however very often the consumer makes a full recovery and there is little lasting 'damage'. Along with out of pocket expenses the extent of any financial compensation is correlated to the degree of lasting damage or disability with relatively high thresholds before any entitlement occurs.

There are a surprisingly high number of cases where consumers are able to demonstrate negligent treatment and significant suffering, however it is often very difficult to show that the negligence caused the suffering. This is particularly common for psychiatric conditions where it is often impossible to distinguish between problems caused by the diagnosed mental illness and the harms potentially caused by the side effects of mental health 'medications'. In summary outcomes are not always 'fair' and the burden of proof on claimants is often onerously high.

Although legal proceedings - or the threat of them – for medical negligence claims are the only mechanism for receiving financial compensation, there are other options for those who "want to make sure what happened to them doesn't happen to someone else". HCC advocates frequently assist consumers to make a complaint to bodies like the Health and Disabilities Complaint Office (HADSCO) or the Australian Health Practitioner Regulation Agency (AHPRA who control professional registration). In extreme cases AHPRA may even suspend a professional from practicing.

Measuring the Patient Experience

Louise Ford Consumer & Community Engagement Manager | HCC

Hearing, understanding and measuring the experience of patients in WA hasn't always been an easy task. Some insight can be gained by using the information available from the Australian Bureau of Statistics (ABS) and website Patient Opinion. However, The Commission on Australian Safety and Quality in Health Care (ASQHC) is currently developing a new national patient experience questionnaire, making measuring the patient experience a national focus.

ABS conduct an annual Patient Experience Survey, the statistics listed below relate to 2014-15. The survey "collects data on access and barriers to a range of health care services, including:

- general practitioners (GPs)
- medical specialists
- dental professionals
- imaging and pathology tests
- hospital admissions
- emergency department visits (ED)"

> *"COMPARISON WITH NATIONAL RESULTS*
> *Western Australians were less likely to see a GP in 2013-14 compared with all Australians (77.7% compared with 82.2%). People living in WA were less likely to receive a prescription for medication compared with all Australians (64.2% compared with 68.9%).*
>
> *A lower proportion of people in WA saw a medical specialist compared with all Australians (32.0% compared with 36.2%). However, Western Australians who saw a medical specialist were more likely to report waiting longer than they felt acceptable to get an appointment compared with all Australians (29.4% compared with 25.0%).....people living in WA were more likely to experience issues caused by a lack of communication between health professionals compared with all Australians (18.2% compared with 14.3%)."*
>
> *(Source: ABS (www.abs.gov.au/ausstats/abs@.nsf/mf/4839.0))*

In contrast with ABS, Patient Opinion uses a social media interface allowing people to provide feedback to health services in 'real-time' supplying a 'personal' view of the Patient Experience. Founded in the UK in 2005, Patient Opinion launched in Australia in 2012 as a not-for-profit organisation, offering a platform for both positive and negative comments about people's experience of health care. *"Patient Opinion is about honest and meaningful conversations between patients and health services. We believe that your story can help make health services better." (Source: Patient Opinion (www.patientopinion.org.au))* HCC also believes patient comment's need to be about providing constructive feedback in order to promote and support positive change in health care provision.

Unfortunately, information that is gained by the ABS is general, making it difficult to assess the patient experience of people from CaLD/refugee-like backgrounds. Little research has been carried out in this area. The following abstract from the article, "Importance of community engagement in primary health care: the case of Afghan refugees" written by I-Hao Cheng, Sayed Wahidi, Shiva Vasi and Sophia Samuel illustrates the difference in health care provision between Australia and Afganistan, and how refugees previously accessed health care.

> *"Refugees can experience problems accessing and utilising Australian primary health care services, resulting in suboptimal health outcomes. Little is known about the impact of their pre-migration health care experiences... It considers the implications for Australian primary health care policy, planning and delivery...Importantly, Afghanistan and Australia have different primary health care strategies. In Afghanistan, health care is predominantly provided through a community-based outreach approach, namely through community health workers residing in the local community. In contrast, the Australian health care system requires client attendance at formal health service facilities. This difference contributes to service access and utilisation problems. Community engagement is essential to bridge the gap between the Afghan community and Australian primary health care services. This can be achieved through the health sector working to strengthen partnerships between Afghan individuals, communities and health services. Enhanced community engagement has the potential to improve the delivery of primary health care to the Afghan community in Australia." (Source: www.publish.csiro.au/paper/PY13137.htm)*

In late 2015 HCC partnered with ACSQHC to conduct focus groups with consumers from WA and NT who had experienced an overnight stay in hospital or who had visited a primary health care practitioner. These focus groups were part of national research by the ACSQHC to develop the first national Patient Experience Questionnaire in Australia. To learn more about 'Measuring the Patient Experience' at the Patient Experience Event Series April 28-29, 2016, go to www.hconc.org.au/get-involved/patient-experience-week

Book Review: An Insider's Guide to Getting the Best out of the Health System

Pip Brennan Executive Director | HCC

Pictured: Author Kate Ryder

Just before Christmas I received a copy of 'An Insider's Guide to Getting the Best out of the Health System' with a covering letter from the author, Kate Ryder, MPH, BA (Hons), RN. Her background intrigued me as she is a clinical professional and had been a patient advocate and a senior investigator with the New South Wales' Office of the Health Care Complaints Commission. Her passion for influencing the culture shift towards patient centred care was immediately evident.

> *'I knew this was a book that needed to be written when a colleague remarked: "You haven't told them that, have you?", after I informed her I had written in this book that no intravenous antibiotic should be administered to a patient in less than two to three minutes because of the damage it may do to a patient's vein. As you can see, some of my professional colleagues are seemingly concerned with patients knowing what should happen to them in hospital. This book is written with you and them in mind.'*

At just under 200 pages the book is like a giant health literacy leaflet. It is well organised, in linear sequence; before hospital, in hospital, discharge, and life after discharge. Rather than reading it from cover to cover, it is an excellent resource to dip into when the situation is relevant to you.

1. Before you go to hospital
    - Time to Act (focuses on the importance of compiling a personal medical record and seeking help in a timely manner)
    - Getting the most out of your General Practitioner
    - So you need further tests or investigations
    - Choosing the right specialist and the right hospital
    - Preparing for your admission to hospital

2. A patient in hospital
    - Safety features of a thorough admissions process
    - What you need to know on admission to hospital
    - Technical information (PICC lines, PCAs etc.)
    - What to do if things go pear-shaped

3. Discharge from hospital -protecting yourself leading up to and after your discharge

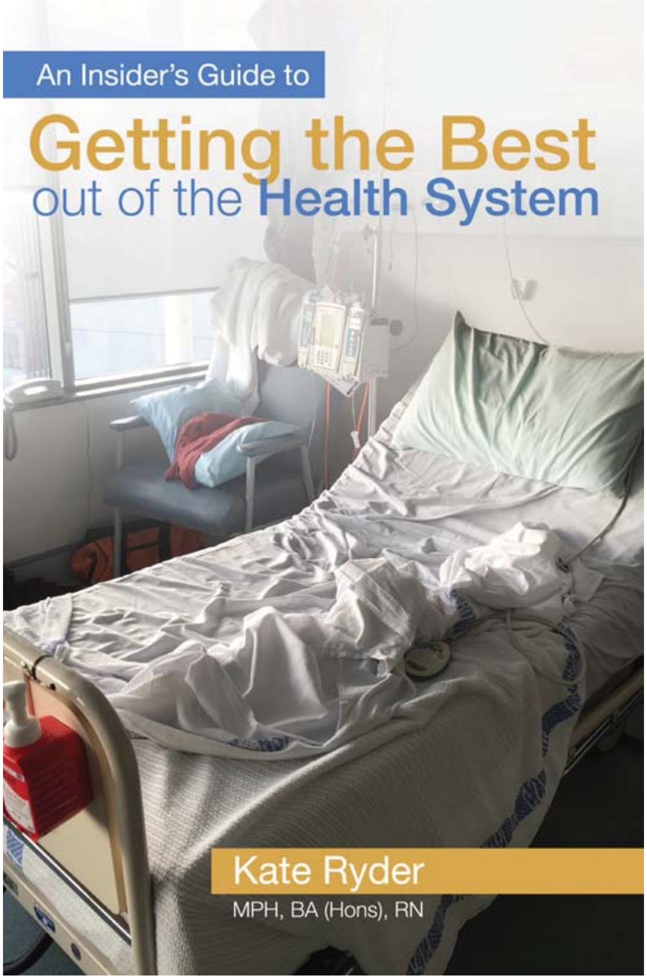
4. Protecting yourself and others into the future

   One section I particularly liked was "What to do if things go pear-shaped" and its' inclusion of the concept 'stay between the flags.'

> *'On the basis that only one person has ever died in Australia while swimming between the flags on beaches that employ life-guards, the Clinical Excellence Commission of New South Wales has adopted the image of keeping patients within the flags when conceptualising a set of safe parameters for patients.'*

The idea is you try and keep a patient's observations within a defined set of parameters or flags, and escalate their level of care should their observations fall outside these parameters.

The book is available as a paperback and an e-book. This is important as the prime audience are older Australians, who are less likely to be connected to the internet. It speaks to key issues such as the unwillingness to seek medical attention. It also addresses unwillingness to question or complain.



Pictured: Getting the Best out of the Health System Cover

> *'...if you think you are ill enough to consider calling for an ambulance, call one... the worst that will happen is that you will have a long wait in the emergency department, you will have to pay for the ambulance, and you may feel a little bit silly. This is a small price for saving one's life.'*

Kate also reflects on the experience of health care workers in providing care, as well as encouraging you to take responsibility for your own health.

PATIENT EXPERIENCE WEEK EVENT SERIES

Kate Ryder will be speaking at the Patient Experience Event Series on April 29 from 11:00am - 12:00pm. For further information or to book go to www.hconc.org.au/get-involved/patient-experience-week or call (08) 9221 3422.

The paperback version can be ordered from www.amazon.com . The ebook is available at iBooks and the Kindle version from www.amazon.com.au.

Limited signed copies of the book are available by contacting HCC on (08) 9221 3422 or info@hconc.org.au

Interview with Learne Durrington, CEO of the WA Primary Health Alliance

Pip Brennan Executive Director | HCC

Pictured: Learne Durrington, Chief Executive Officer, WA Primary Health Alliance

The WA Primary Health Alliance (WAPHA) was established by over 20 organisations in October 2014, following months of planning and stakeholder engagement, with the vision of improving health equity in Western Australia.

In 2015 WAPHA won the Commonwealth Health Department's tender to establish three Primary Health Networks (PHNs) in Western Australia which replaced the former Medicare Locals.

The PHNs were established by the Commonwealth Government to increase the efficiency and effectiveness of primary care services for patients, particularly those at risk of poor health outcomes, and to improve coordination of care to ensure patients receive the right care in the right place at the right time.

PHNs work directly with general practitioners as well as other primary health care providers, secondary care providers and hospitals to facilitate improved outcomes for patients. In Western Australia the three PHNs are Perth North, Perth South and Country WA. As noted WAPHA operates all three.

For further information, visit www.wapha.org.au and www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Background

Who is the WA Primary Health Alliance? How does it relate to Medicare Locals?

WA Primary Health Alliance or WAPHA was awarded the Commonwealth Health Departments tender to run WA's three PHNs. In the past there have been other primary care building blocks including the former Divisions of General Practice and Medicare Locals. So while PHNs are a new beginning, we have taken the relevant and important elements of those previous primary health organisations into the PHNs.

Today the Commonwealth Health's clarity about the role and purpose of PHNs is very different than in the past. Medicare Locals were both service provider and funder and this was an impediment to developing co-ordinated primary care. The main difference from Medicare Locals is that we are charged with working at a systems level whereas Medicare Locals were responding to local needs. While we are looking at local issues, we are charged with whole of primary care review and development to ensure we meet the high level outcomes of delivering a joined up primary care system.

What's your vision for the WA Primary Health Alliance this year?

From our establishment in July 2015 to now it has been a time of establishment and building of the infrastructure such as the Clinical Commissioning Committees and Community Engagement Committees because these are foundational to the future.

The next six months is building on this work and supporting the dynamic group of individuals' that make up the clinical and community committees so they understand and align with what WAPHA are hoping to achieve.

Our next key piece of work is the Comprehensive Needs Assessment of the community's primary care requirements. This will bring together a whole suite of data to clarify the priorities for the next few years. The committees will be key in undertaking these needs assessments and reviewing the data to testing that identified priorities makes sense from their perspective as clinicians and community members.

How will the health consumer be at the centre of the work you do?

At the end of the day the patient, consumer, end user is the primary beneficiary of anything we do. We need to be very clear that our contribution creates value for the health consumer and an outcome that they will be seeking however we need to do that with the engagement of clinician and health providers. So while we don't provide any services our primary focus is better outcomes for health consumers.

What are the opportunities created for Western Australians with the establishment of WAPHA?

The real opportunity here is WAPHA being a single organisation across the whole state allowing better opportunity to reduce the fragmentation of the system like never before.

For the first time WA has an entity that looks across the whole state rather than being focused on one area. WAPHA can keep the focus on patient value and patient experience across the broader geography and health system of WA.

The patient experience and the patient journey is what matters most and we know that the system is complex for both providers and service users and we seek to reduce some of that complexity.

I think the other thing that is very different today is that our focus is on engaging with GPs. We are working closely with the Royal Australian College of General Practitioners and key stakeholders and there has been an alignment across Commonwealth, State and peak bodies as to what needs to be done to reduce fragmentation.

What about rural WA?

We have an obligation to ensure that we tailor whatever we do to the regional environment. There is no point in imposing a solution that works in one community into another. From our perspective having the community and clinician perspective will ensure we tailor the solutions but at the same time have the overview required to ensure connected care pathways across the whole of country.

What are your thoughts about the current Primary Care review our Federal government is undertaking? And the Medicare Benefit Schedule Review?

Overall I think there are great opportunities for primary care that can come from these reviews. Change can be difficult, however we need to take these opportunities such as how we manage chronic disease in primary care. Bundling up care around the patient is a key opportunity that could come from both of those reviews.

How do you see WAPHA and the Area Health Service Boards working together?

Very well as there is clear alignment with the priorities of Boards and WAPHA.

A lot of good work has also occurred with WA Country Health Service (WACHS). We are not going to duplicate any consumer based forums and we will leverage the existing relationship with the District Health Advisory Council and continue to work with WA Country Health Service.

Statewide News

Pip Brennan **Executive Director |** HCC

Pictured: Pip Brennan, Executive Director, Health Consumers' Council (WA) and Andrew Jones,WA Health, Health Networks

For this edition, State News is quite significant. On 25th November 2015 the Minister for Health announced that there would be a (resource neutral) addition of an Eastern Area Health Service, and also announced the Interim Area Health Service Board Chairs. See the table below for information.

Area Health Service	Interim Board Chair	Hospitals
North Metropolitan Health Service	Professor Bryant Stokes	Sir Charles Gairdner Hospital King Edward Memorial Hospital Osborne Park Hospital Joondalup Health Campus
South Metropolitan Health Service	Mr Robert McDonald	Fiona Stanley Hospital Fremantle Hospital Rockingham Hospital Peel Health Campus
Child and Adolescent Health Service	Ms Deborah Karasinski	Princess Margaret/ New Children's Hospital
WA Country Health Service	Dr Neale Fong	Country Hospital Services
East Metropolitan Health Service	Mr Ian Smith	Royal Perth Hospital St John of God Midland Public Hospital Bentley Hospital Kalamunda Hospital Armadale Hospital

You can go to ww2.health.wa.gov.au/Improving-WA-Health/Interim-Health-Service-Board for further information or ask us if you want access to printouts of the relevant fact sheets.

Joining the Dots in Maternity Care

The Health Consumers Council and Womens and Newborns Health Network convened a maternity services sector update on 4th December 2015. Attendees at the event gave feedback on the key questions:

1. What action can service providers take to increase the implementation of continuity of midwifery care models?
2. What action can consumers take to increase the implementation of continuity of midwifery care models?

The agreed objectives from the event are as follows:

1. Women's and Newborn's Health Networks to approach WA Primary Health Alliance (healthpathways@wapha.org.au) to progress maternity care pathways as part of the Health Pathways Project by 29/2/2016.

2. Health Consumers' Council to liaise with WA Primary Health Alliance by 31/1/2016
    - to explore how consumer resources clearly outlining all maternity care choices in their area can be developed
    - Health Consumers Council to discuss with WA Health's Health System Policy and Planning/ Media and Communications re updating the Having a Baby Website page with key statistics and maternity care choices for women and families by 31/1/2016.

3. Women's and Newborns Health Networks to prioritise the update of the state Maternity Services Plan for 2016.

4. WA Health's Nursing and Midwifery Office in partnership with Womens and Newborns Health Network to undertake a Literature Review, costings, outcomes review of midwifery models of care a continuation of the Endorsed Midwives Project in 2016 focusing on existing WA continuity of care models.

5. HCC to provide a submission to the MBS Review to highlight the possibilities in maternity care by 31/1/2016

6. WA Health's Nursing and Midwifery Office and HCC to seek funding for a partnership project to co-ordinate a workforce survey and workforce training program to support implementation of continuity midwifery models of care. Application to be progressed by 29 February 2016

7. HCC to liaise with Area Health Services regarding facilitating consumers to provide feedback on their maternity services by 29 February 2016.

8. HCC to provide secretariat support for a maternity consumer and community representative group by 29 February 2016

9. HCC to liaise with Telethon Institute re the outcome of their project on women's experiences of maternity care and promote the results through their channels and networks by 31 March 2016

10. All attendees to support the Choices. Change. Continuity campaign.

11. Maternity Choices Australia/ HCC to meet by 29/2/2016 to co-ordinate to:
    - Ensure more local community input into services and challenge the postcode lottery
    - Write Letters to AMA, ANF, MCA, HCC, DG of WA Health
    - Approach multicultural community organisations to share information about maternity choices for women
    - Undertake regular surveys of women's experiences
    - Support consumer and community members to develop self-advocacy skills

WA Primary Health Alliance Survey on Community Engagement

WA Primary Health Alliance are seeking feedback on their community engagement framework to support the participation of local communities in policy development, planning and service delivery. They are seeking your opinion to assist then in understanding health and social issues specific to your community along with themes, trends and recommendations. Community Survey closes at 5pm on Monday, 29 February 2016.
www.surveymonkey.com/r/communityhaveyoursay2015

National News

Pip Brennan Executive Director | HCC

Australian Government
Department of Health

Medicare
Benefits Schedule

Medicare Benefits Schedule Review

The Medicare Benefits Schedule (MBS) Review is continuing, working through the first phase, which is eliminating redundant items from the Schedule. This is a much-needed exercise because:

- Until 1 January 2010, there was no clear process for adding new items to the MBS.
- There was also no clear, consistent system for identifying and removing items from the MBS when they were no longer considered best practice or effective.
- There was no consistent and formal process in place to test or review items already on the MBS, or new items coming onto it, to ensure they were doing what they were intended to do and were safe and cost effective.
- Only three percent of items have been assessed for safety, effectiveness and cost-effectiveness. You read that right. Only three percent.

The MBS Review team have been utilising Citizen Space to seek feedback from the community for the current round of review into specific item numbers. Moving forward they are interested in having consumers present in the clinical committees where Item numbers are discussed in detail. The Consumers Health Forum has been seeking consumer representatives for several of the committees. You can stay in touch with what's happening by going to www.health.gov.au/internet/main/publishing.nsf/content/mbsreviewtaskforce

Federal Mental Health Review

In November 2015 there were changes announced to how mental health services will be delivered in Australia. The key points of the reform include a consumer centred approach to working with people in primary care, so instead of having a set program of 10 counselling sessions for example, people will be matched with support that meets their needs. So if a person is considered to have severe and complex mental illness they can access integrated services across a range of disciplines. This could look like someone receiving a package of care including care co-ordination, psychological support, peer support, employment support, drug and alcohol counselling etc. Trial sites will be announced this year.

These services will be delivered via our Primary Health Networks (note the interview in this edition with the Chief Executive Officer of WA Primary Health Alliance, (WAPHA) which oversees all of Western Australia's Primary Health Networks). This provides the opportunity of appropriately localising services to each local community. This reform package is funded across the nation at $350 million and will include services such as Access to Allied Psychological Services (ATAPS), Headspace, Early Psychosis Prevention and Intervention Centres (EPPIC) as well as a more co-ordinated approach to suicide prevention. An additional $85 million over three years to provide greater access to mental health services for Aboriginal mental health consumers. The Health Consumers' Council has been invited to be part of the Expert Advisory Group on mental health convened by WAPHA.

www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2015-ley032.htm

Aboriginal Advocacy Program: What is Cultural Security in Health Care?

Laura Elkin Aboriginal Advocacy Manger | HCC

Painting by Brian Ocean Ward, Artist and Aboriginal Health Consumer

To improve the patient experience for Aboriginal people we need a health system that is culturally secure. But what do we mean when we talk about cultural security? The WA Department of Health Aboriginal Cultural Security background paper provides the following definition:

"Cultural Security is a commitment to the principle that the construct and provision of services offered by the health system will not compromise the legitimate cultural rights, views, values and expectations of Aboriginal people. It is a recognition, appreciation and response to the impact of cultural diversity in the utilisation and provision of effective clinical care, public health systems administration."

To better understand what this means we need to acknowledge that the national health crisis impacting too many of our people stems from legacies of colonisation. We need to understand the impacts of past government policies and practises that denied Aboriginal families and communities basic human and citizen rights, segregated Aboriginal people from mainstream Australian society, removed children systematically over generations and displaced communities and Cultural practises. To improve health outcomes and the patient experience for Aboriginal people, we need a health system that acknowledges the intergenerational trauma and legacy of grief and loss still being experienced today, and a system that responds to the alienation too many Aboriginal patients still feel.

Since the Aboriginal Advocacy Program first started in 2006 a lot of Aboriginal consumers have reported experiences of racism and discrimination and feeling powerless in mainstream health services. When people feel discriminated against it undermines their ability to feel safe and makes people feel distressed and like services don't care. This makes it highly unlikely that they will feel they would be taken seriously or treated respectfully if they lodge an official complaint. And it can even make people fear they will be treated worse if they do. It can make it difficult to trust and communicate with health practitioners. It can impact a patient's choice and even ability to follow recommended treatments, and their choice to attend health services when in need.

The WA Aboriginal Health and Wellbeing Framework 2015-2030 which was developed by the Aboriginal Health Division following extensive state-wide consultations provides leadership and specific strategic direction to develop "a culturally respectful and non-discriminatory health system. WA Health recognises racism as a key social determinant of health for Aboriginal people. Health care, whether government or community provided, is to be free of racism and discrimination."

The framework also highlights that we need a health system that recognises the "importance of culture and connection to Country, spirituality, family and community" and provides direction and guidance for all health services to embed cultural security in policy and practise across the WA health system.

Fleur's* Patient Experience

Lucy Palermo Marketing & Communications Coordinator, Health Matters Editor | HCC

Fleur* is in her 40's. She was diagnosed with bi-polar disorder in 2009 after taking antidepressants since early 2008. She was also diagnosed with Multiple Sclerosis (MS) in 2012, after suffering vision impairment. She is now considered legally blind although she still has some sight. She also shakes when she walks and has recently started using a cane.

I was diagnosed with depression in early 2008 and was prescribed antidepressants. After taking these for a year, I had my first manic episode in 2009. I had no memory of the event, I was told this is common. It resulted in my hospitalisation and I spent one month in a secured ward at Bentley Hospital, I was then transferred to the open ward where I spent several weeks.

The food was horrible. It felt like I was in jail. I remember thinking "Why am I here?". They didn't care that I had other medical issues. I was suffering from back pain. When I asked for some help I was told that they would get a physio to have a look at it, but it never happened. I also had a wound on my leg which wasn't healing, it took my mother's intervention to finally get some anti-biotics.

When I had the clinical discussion with the psychiatrist, the diagnosis of bi-polar didn't really sink in. I couldn't remember how I had behaved in my manic state. According to my mother who I was living with at the time, I had started behaving strangely. I didn't really understand what it meant to be bi-polar and how it would affect my life. I had booked a trip overseas which had to be delayed, fortunately I was able to go after I had been released.

If I had been told in that initial meeting 'it's just a disease and it's treatable', it may have softened the blow. I don't go around telling people that I suffer from bi-polar. There is a stigma attached to the term and you feel you are always being judged.

In February/March 2009 I saw even more doctors regarding depression, I asked if my medication could be reduced. My GP has been very supportive through this process and has monitored my care, he prescribes my medication when I am out of hospital. I am currently on Epilim, a medication used for people with Epilepsy. I take this morning and night.

I can't remember when I saw the psychiatrist last. Fortunately, I have also had the same nurse monitoring my out-patient care. He drops by every 1-2 weeks to check on how I am feeling. He is a very kind person, he sometimes brings fruit and vegetables grown in his garden.

Over the following years I had more than 6 treating psychiatrists, there is no continuity of care. Most of the anti-depressants I have been prescribed have resulted in a manic episode. Sometimes it might take a week or two weeks for me to become manic. It has resulted in me being in hospital in 2010, 2012, 2013 and 2014. The dosage changes all the time which can be costly.

In 2011 my vision started to become fuzzy and I went to the optometrist. After a series of tests, I was eventually diagnosed with MS in 2012. Apparently I had the least bad type of MS. My eyesight got progressively worse and eventually I was considered legally blind. By this time, I was living on my own. This has meant that I am unable to work or drive, losing some of my independence. However, I manage to walk my dog regularly and I can still go to the cinema, although I have some difficulty seeing the night scenes or reading the credits.

I am wobbly because of my MS. Sometimes when I take my dog for a walk I get funny looks. One man thought I was drunk, another stoned. I usually say "I have MS this has affected my brain and my ability to walk". But when I am particularly low I can't get past the stares or the comments and I retreat into myself.

In 2014 my nurse dropped by and noticed that I wasn't travelling well and advised that I see the psychiatrist, he told me that it was a new one. They prescribed anti-depressants, I said this wasn't a good idea, because in the past it resulted in a manic episode and within two months I became manic. This resulted in a brief stay in hospital, where they prescribed anti-psychotics.

During the week I was an inpatient at Bentley Hospital I had an MRI booked at Sir Charles Gairdner Hospital (SCGH). I was informed by a doctor at Bentley Hospital that they had rescheduled my MRI. I was quite angry that they had done this without consulting me. They had changed my appointment to 8:30pm. I called SCGH to change the appointment back, but was told that the time was no longer available.

I had to catch a cab to and from SCGH. When I returned to Bentley I was accosted by the nurse on duty and was accused of going out drinking. I said "No I have MS and I have been to SCGH for an MRI". Clearly either she hadn't read my file or been informed of my appointment or that I suffered from MS. My GP wasn't notified of my hospitalisation or my medication. He became quite angry that he wasn't kept informed regarding my care. Again my mother and I had booked a trip to overseas, but fortunately we didn't have to change our plans.

Recently I was prescribed the original drug that caused the first manic episode. I needed to voice my concerns. There had been a lack of continuity of care (many different treating psychiatrist's), the doctors weren't listening and they kept putting me on different drugs including some that had resulted in manic episodes. They weren't helping me. I contacted Helen Morton's office (Mental Health Minister) and they provided HCC's details. The Health Consumers' Council (WA) (HCC) were able to support me. An advocate came to my home and helped me to write a complaint letter so that my concerns could be put into writing.

*Name has been changed to protect her privacy.

HCC PATIENT EXPERIENCE WEEK EVENT SERIES LAUNCH

You are invited to the launch of the inaugural Health Consumers' Council (WA) Inc (HCC) Patient Experience Week Event Series. This Free event will showcase what Patient Experience Week means and how you can start helping to improve patient experiences.

To coincide with the global focus on Patient Experience Week (April 25-29, 2016) the Health Consumers' Council Patient Experience Week Event Series is about 'Connecting for Patient Experience'. HCC aligns with the growing evidence that when health consumers and health care staff, who are focused on the patients' needs, meaningfully connect the experience of patients, their family and carers, health care staff not only can improve, they can be exceptional.

The launch offers the opportunity for health consumers and health professionals to network and share their stories of success. After the launch, the 'Agents Improvocateurs' acting troupe will front the 2 day Patient Experience Event Series with 'The two sides of the Patient Experience', an interactive patient experience improvisation with audience participation.

Event series attendees can look forward to 2 days of hearing from international and national experts, with thought-provoking sessions and skills building workshops. Bringing the latest in how to provide a great patient experience as an individual, a team and as an organisation.

Date:
Thursday 28th April, 2016

Time:
9:30am – 11:30am

Location:
Boulevard Centre, 99 The Boulevard, Floreat
(lower level of Cambridge Library)

Cost: FREE

Bookings:
To book go to www.hconc.org.au/get-involved/patient-experience-week or call (08) 9221 3422

Refreshments:
Morning Tea provided

Parking:
Free parking is available

Public Transport:
Buses 81, 82, 83 & 28 stop at Floreat Forum stop number 17424

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

Maternity Services not Meeting Cultural Needs

Louise Ford Consumer & Community Engagement Manager | HCC

Photo source: http://imagesci.com/multicultural-babies-images-15254-hd-wallpapers.html

According to the results of two consecutive studies, Australian maternity services are not meeting the needs of immigrant women of non-English speaking backgrounds.

Using data collected from population based surveys in 2000 and 2008, this study reports on the views and experiences of immigrant women of non-english speaking backgrounds (NESB) giving birth in Victoria, Australia.

The findings of this study are important for two reasons:

1. Women of non-english speaking backgrounds or seeking refuge are over-represented in maternal mortality statistics.
2. Australia is currently one of the most multicultural countries in the world, with an estimated quarter of Australia's population being born overseas.

The findings from both surveys revealed that NESB women are more likely to receive care from within the public maternity care system, with over two-thirds reporting that English was not their first language.

In comparison with Australian-born women, NESB women reported less favourable experiences of antenatal, intrapartum and postnatal care in both 2000 and 2008 surveys.

In 2008, 47.1% of NESB women vs 26.8% of Australian-born women were dissatisfied with their antenatal care (adjusted OR 2.17; 95% CI 1.7-2.7), 40.5% vs 25.5% were dissatisfied with their intrapartum care (adjusted OR 1.81; 95% CI 1.4-2.3) and 53.5% vs 41.0% rated their postnatal care negatively (adjusted OR 1.52; 95% CI 1.2-1.9).

The main findings from the two populations surveyed suggest that in contrast to Australian-born women, NESB women reported that their primary caregiver did not always remember them between visits, neither did the caregiver make an effort to get to know their main concerns.

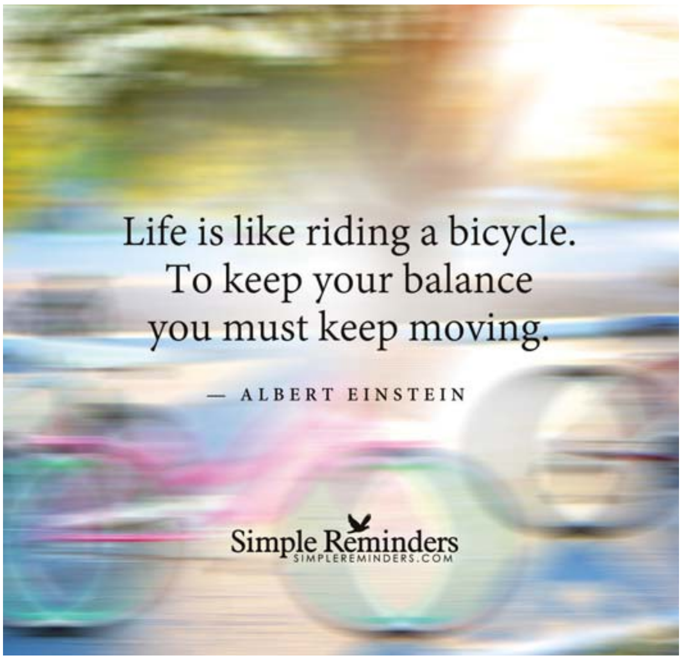
They also believed that they were kept ill-informed of what was happening during their labour and birth and were talked down to by both midwives and doctors. On every single measure, immigrant women believed that the current system of maternity care had failed to meet their needs.

Despite improvements in maternity care and an increase in continuity of care models, the survey data suggests such improvements have failed to translate to the experiences of immigrant women. It is therefore important that any future models of care are explicitly personalised to meet the needs of immigrant women and their families.

Authors: Yelland J et al. Reference: Midwifery 2015;31(7):664-70
Source: Midwifery Research Review Issue 3 2015 (Research review publication 4 (www.researchreview.com.au)

Keep moving to keep moving

Frank Smith | Health Matters Contributor



EXERCISE is essential for older people to maintain health, mental activity and reduce the risk of diseases such as Alzheimer's disease and heart attacks.

But a survey of older people in aged care, carried out at Curtin University exercise scientist and researcher, Dr Elissa Burton shows that many older people have little interest in going to a gym.

"They preferred to get their exercise doing household chores, gardening or going for walks," she said.

Dr Burton said these finding probably apply to most people in the older age group, whether living at home or in residential care.

After an injury or illness, physiotherapists often prescribe structured exercises. These exercises will target the injured area but once the injury has healed, older people often disregard them and return to their usual routines, which are often not very active.

However, all is not lost. There are ways of making household chores and gardening effective as a way of improving strength and balance.

"When you are doing the dishes or working round the house, try standing on one leg for (say) 20 seconds. Then change to the other leg. Find something like a bench top to hold on to at first than repeat, without holding on, as you get better.

"Weights are important for maintaining strength. pulling a resistance elastic band several times a day give the same exercise as lifting weights, or lift the washing basket from the knees, not the back.

Also practise getting up from a chair or the toilet without using your hands.

"Eighty percent of older people find that difficult. Get up and sit down several times a day.

"Hanging out the washing is another opportunity to exercise. So long as it is safe try standing on tip toe when pegging out clothes."

Exercise is good for both physical and mental health. Studies show exercise improves concentration, prevents depression and delays the onset of Alzheimer's disease.

"It is good to undertake a mix of the things you enjoy when taking exercise. Tai chi is good for balance and lawn bowls provides good gentle exercise. You need to keep doing it so you don't lose it. Try to keep active every day.

"Younger people with elderly parents can help by suggesting going for a walk when visiting them, perhaps then having coffee in a local café. Get them doing things that they enjoy.

"But do not try to do too much at once. For people who have been inactive help them to build up their activity gradually," she said.

Dr Burton said it is worth considering wrist mounted fitness monitors. They keep track of heart rate, exercise and sleep patterns. Curtin is about to start a study of the use of Fit Bits in November.

"There have been plenty of studies of younger people but we are going to look at the effect on older people for the first time," she said.

Readers who would consider volunteering should contact the School of Physiotherapy and exercise science on (08) 9266 4644.

CCE Program: The year that was and looking forward

Louise Ford Consumer & Community Engagement Manager | HCC

Pictured: Wendy Rose, Laura Elkin (HCC), Dr Geok Pheck Pee and Ruth Sims at Fiona Stanley Hospital for Diversity Dialogues: Creating a more culturally aware hospital, October 2015

Overwhelmingly 2015 was a successful year for the Program. It was, of course, not without its' challenges but these were vastly overshadowed by positive changes and achievements. Some achievements were also challenges, for example facilitating 35 workshops around the State for the Dental Health Service in a fairly brief time frame!

Amongst the positives for the Program were:

- The employment of Steph Newell as the Program Coordinator, Steph's knowledge and experience are a great bonus

- The 'new look' of the new contract with the Department of Health; this brings the Program into a more contemporary era that focuses on outcomes and also enables it to function more broadly

- The upgrading of an existing data base that now allows much improved compilation of workshop evaluations for Program development and marketing purposes

- A growing recognition of Diversity Dialogues as a positive means of informing health care staff re working cross culturally

- Increasing interest from health care providers in becoming better informed about consumer engagement

- The recognition of the Program and the HCC having the skills and capacity to develop and facilitate focus groups, workshops and staff development sessions

- Ongoing requests for Cultural Competency workshops

- Continued positive feedback regarding the workshops and forums the Program develops and facilitates

- The ability of the Program to be able to develop further with two staff members now in place

- Increased opportunities for Fee for Service activities

Other Program achievements included:

- Facilitating fifty three workshops including Consumer Rep Skills Development, Cultural Competency (metro and regional), Partnering with Consumers and Engaging with Consumers

- Organising, coordinating and facilitating two Diversity Dialogues forums which, between them, attracted over one hundred people

- Providing over seventy consumer comment/ engagement opportunities (promotion via eNews and the HCC's website) e.g. focus group participation requests and comment on publications

- Placing seven Consumer Representatives – five out of twelve requests received no response when promoted

- Promoting requests for consumer representative for other agencies

Data analysis of 565 workshop evaluations shows that:

- 94% of people who attended cultural competency workshops found them to be 'good' or 'very good'

- 94% 'agreed' they would be better placed to apply CC in their workplace

- 97% 'agreed' or 'strongly agreed' it was a positive learning experience

- 76% of people who attended consumer rep workshops found them to be 'good' or 'very good'

- 88% of people who attended consumer rep workshops 'agreed' or 'strongly agreed' they would be able to use the skills in their role

- 90% of people who attended Diversity Dialogues Forums found them to be 'good' or 'very good'

- 95% 'agreed' or 'strongly agreed' they had increased knowledge or awareness on the topic

Looking forward, what is 2016 likely to look like? To a great extent the Program will be shaped by HCC's new five-year funding contract (with the WA Health Department) which interfaces with HCC's Strategic Plan for 2015-2020. What will this mean for the Consumer and Community Engagement Program?

As the Contract has a focus on outcomes it means that all activities will need to be measurable. Therefore each activity we undertake will be required to demonstrate how it:

- informed
- encouraged/supported positive change
- benefitted and
- complied with Contract requirements

The above actions and/or effects will be applicable to activities/services we provide to both providers and consumers. Activities will, for example, include workshops, forums and community education. All will request feedback from participants so that outcomes can be measured and demonstrate how they meet our contractual obligations. Under the new Contract there is also a focus on community engagement including with CaLD (Culturally and Linguistically Diverse) communities. The Health Department recognises that there can be significant barriers to accessing health care for people from these communities.

A second Consumer Representative Skills Development Workshop will be developed to ensure Representatives are upskilled and fully conversant with current trends and developments. Specific sessions with a focus on a particular area (e.g. Patient Safety, how to conduct a survey) will also be held to ensure Representatives are provided with ongoing skill development opportunities. These sessions will include video conferencing and on-line sessions. With increased focus on accountability (for all) as well as outcomes it is imperative that people take up opportunities for personal and professional development.

These are just a few of the changes that are taking place within the Program and the way in which its services are provided. It is timely to remember that change is not always comfortable but without change life would not be as we know it today. I think it will be an interesting and exciting year ahead and I look forward to you joining the journey.

HEALTH CONSUMERS' COUNCIL
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