



HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

HEALTH MATTERS

Health Consumers' Council WA (Inc) Newsletter

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MESSAGE TO MEMBERS

The 9th May 2014 will be my last day at Health Consumers' Council (HCC) before I start my 12 months maternity leave. It's hard to believe it's been 2 years since I started with HCC and all that has happened in that time.

I want to take this opportunity to thank the Board, staff and in particular Frank, for being so understanding throughout my pregnancy, especially while I was suffering from sickness. I'll definitely miss working with this team, as it's filled with such fantastic people who are so passionate about their roles and I thank them for making the last 2 years here so memorable.

It gives me great pleasure to advise that the very talented Lucy Carter will be stepping into the role and we will have a new Administrative Assistant starting in April.

I wish the board, staff & members all the best and I look forward to seeing you all next year.

Amy McGregor, Operations Manager

Cover: Stroke survivor Peter Coghlan with wife Jade. His article 'Don't give up, keep fighting: A message of hope for survivors of stroke is available within these pages.

FORWARD



The only thing certain about change is that it will continue to happen. While health as a profession is careful to balance rapid adoption against increasing risk, new breakthroughs in research are made seemingly every day.

I find it fascinating the amount of work which is being done on health related matters. But there is still room for more collaboration to undertake health research WITH us, not FOR us.

There is also a clear need for more simple and population based functional research. And we at the Health Consumers' Council have been engaging with internal and external stakeholders regarding ways that we can greatly improve the patient journey. This is often at no extra or with reduced costs.

We have been negotiating with the Department of Health and the Consumers' Health Forum, the national body, to develop and incorporate patient journeys into ways to improve and streamline processes within hospitals.

Allow me to give you two small examples; my condition means that I have spent considerable time in Intensive Care. While I receive chemo, I am on a PCA (patient controlled analgesia) and baseline morphine. For most of the first week I am in la-la land dealing with the real problem of morphine 'dreams' and not able to fully understand the treatment and ongoing management issues which affect me. The 'rules' of ICU mean that the 'magic' doors cannot possibly be opened to allow family access while the specialist does their round at 7 am.

So to find out how I was progressing from the doctor, my wife would tag along as a pretend 'student' with the Professor when he came into my room. Breaking the rules, yes, but also getting an understanding of what was happening with me and being able to translate where I was and how I was travelling was priceless. So which is more important and how do we manage the needs of ICU with the needs of the patient and family?

By talking together. Ex-patients, carers, families and professionals need to objectively assess the benefits and risks of knowing what is happening and being informed in a timely manner of the health plan. Being an active partner in making that plan happen is an essential component, in theory.

Recently, I was in St John of God Subiaco for a minor follow-up procedure. Every room has an accessible whiteboard which allows patient specific information to be displayed (unlike behind your head as in most public hospitals). Important matters such as allergies and mobility can be recorded. But from a patient perspective, having your nurse able to write their name where you can see it is important when working together to get you up and about. But more importantly, there is a part of the whiteboard which allows family and carers to ask

questions of the doctor regarding the care, recovery and progress of their loved one.

At a one off cost of about \$15 per bed with the ability to get a message through to the doctor, we might not have to have pretend students sneaking onto the wards to be able to help.

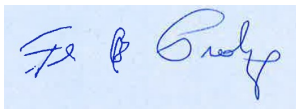
Another simple solution which they use in NSW, is that they issue deep vein thrombosis (DVT) socks which have silicon treads on the soles. This means that the risk of falls and slippage is greatly reduced. Reducing falls is one of the greatest cryptic issues in hospitals. At only a couple of cents per pair, the total cost would be recovered with a single avoided accident and be a resounding win-win for patients and the health system.

We can look for improvements throughout the system. We as consumers have a responsibility to reduce the behavioural incidents that occur in hospitals and health service areas. We ask for respect but must also be prepared to give it in return.

When we work cooperatively on solutions, we gain a better understanding of the perspectives of the 'other side'. Patients, carers and the HCC can help to understand the anger, fear, frustration and impotence of many consumers and their carers when navigating the health system. When we understand, we can rationally communicate and manage those concerns, and when they are being managed cooperatively, consumers and the community can also feel like part of the solution, rather than just the whinging problem.

We are all on the same side, wanting an effective and efficient health system. And the solutions don't always come at a Rolls Royce price. So how about we start with the small and simple. Like how about putting decent coffee in the ICU waiting room, so the poor people who wait and stress and come to terms with a place nobody wants to be at least have something to drink.

Until next time...

A handwritten signature in blue ink, appearing to read 'Frank Prokop', is displayed on a light blue rectangular background.

Frank Prokop
Executive Director

PREVENT CHILDREN FALLING LIKE AUTUMN LEAVES

Katherine Celenza
Kidsafe WA

More children die from injury than from cancer, asthma and infectious diseases combined and falls are the leading cause of injury hospitalisation for children under 15 years. Injury presentations to Princess Margaret Hospital ED account for a quarter of the total presentations with the majority of these cases being children under five years.



The home is the most common location for injuries to occur, which isn't surprising as it is the location where children under five spend the majority of their time. Children are learning new skills every day and therefore it's common that they may fall over while trying to crawl, walk, run or play. Typically children will fall over and get up with no more than a bruise or a bump. However, some sustain more serious injuries.

For this reason it is important to implement some safety practices around the home to prevent a child falling, like the autumn leaves. Kidsafe WA has some tips to help prevent fall injuries:

- Never leave infants unattended on raised surfaces
- Ensure sides of cots are up and secured
- Always use safety harnesses in highchairs and strollers
- Use gates at the top and bottom of stairs
- Don't place furniture near windows or large toys in cots; children may use them to climb up and out
- Use play equipment suitable for children's age and stage of development
- Use protective gear during sports and helmets on bikes
- **Supervise** children and help them learn new skills

Kidsafe WA is commencing a new strategy to promote child injury prevention around the home by conducting a Child Safety Forum and guided tour of the Safety Demonstration House once a month. This tour will cover child injury prevention tips, safety products, information and resources for parents to create a child safe home environment. For more information or to register your interest visit www.kidsafewa.com.au/homesafetyprogram.html

TAKING S.T.E.P.S IN THE RIGHT DIRECTION WHEN MANAGING PAIN

Carly Parry
Advocate HCC

Increasingly consumers are contacting the HCC with issues around their persistent/ chronic pain which follows an injury or operation and persists for months into years.



Image Source: MIH Medline Plus, Safely managing chronic pain

Recently I attended the Self Training & Education in Pain Sessions (STEPS). This FREE program takes place over two days at Fremantle Hospital and requires a referral from a health professional. Initially designed for 4th year medical students, it was later identified as a useful tool for consumers. The sessions are run by a behavioural medicine specialist, an occupational therapist, a physiotherapist and a pain specialist doctor.

The information and advice provided covers the most effective management strategies for persistent pain, including movement and exercise, pacing everyday activities and information on medications and procedures. Their solution is that there is no stand -alone way of 'fixing' persistent pain, instead we need to respond with a whole person approach. People experiencing chronic pain often develop a belief that the pain will 'never go' and will remain for the rest of their lives. This can be dangerous, resulting in feelings of helplessness and

depression, which can contribute to making pain levels higher and longer lasting.

STEPS examines the impacts of personal 'loads' such as stress, depression, social withdrawal, loss of job, family breakdown and repeated treatment failures and how these have a role in making pain much worse. Throughout the two days there are references made about the central nervous system and how central sensitisation can occur in people with pain. This means that after detecting pain signals the nerve pathways can react more easily. The pain pathways change from a calm road to a chaotic multi-lane highway. The program explains that consumers can better manage persistent pain by treating it as its own disease requiring treatment beyond medication. Self-management, supported by occupational, physical and psychological therapies can help retrain the nervous system.

The program offers a broad approach, that through active management in addition to medical intervention consumers are likely to have better outcomes. Furthermore, quality improvement is only achievable through self-management; hardly surprising when opioid medicines only offer around 30% pain reduction.

The belief that pain is just a medical issue results in GP's and patients trying to 'Fix' the problem, rather than taking other factors into account. Consumers often find themselves on a journey of countless MRI's, X-RAYS and surgical procedures but their pain persists. Often they have been given conflicting advice from health professionals. They are told by some to push through the pain and by others to rest as much as possible. STEPS encourage pacing your activity, accepting that some tenderness is ok but not to let pain become the guide; people in pain can associate pain with movement so they limit their activity. This is dangerous because too much rest causes additional muscle tension and in fact pacing outcomes will improve pain management longer term. Supported by real-time relaxation, the consumer can focus the brain to respond to pain rather than trying to escape it.

STEPS offers consumers tools to help manage their pain. The best results are achieved through taking on some of the responsibility themselves and not relying totally on medication and procedures.

Fremantle Hospital also offers a 5 week group program, 'Pain Understanding and Management Program (PUMP)'. This program aims to help improve function and quality of life. It provides better symptom management through practical skills building and education. Each session involves individualised exercise, stretching and strengthening as well as education on physiology, healing, posture and goal setting.

Speak to your GP or other health professional if you think you could benefit from STEPS and/or PUMP.

SORRY, I FORGOT YOU WERE G.O.D

Jenni Ibrahim

Health Consumer

The legendary attitude problems of surgeons are reported by doctors themselves. Here an American MD muses on how he decided what to specialise in.

'We hear that paediatricians wear bow ties, are short, and love to laugh and play; that surgeons are decisive but arrogant; that proceduralists* are "scoping for dollars", that orthopaedists have long hairy arms that reach to the floor, that family doctors are the best balanced, etc.' 'The surgeon is expected to know what to do, to do it well, and to do it fast (better outcomes with less time under anaesthesia). As a nurse said, "The surgeon is **like a god in the Operating Room.**"' (www.kevinmd.com/blog/2011/10/decision-surgeon.html)



Image source: blogs.wsj.com

Is it a mere coincidence that when the letters G.O.D. are reversed you get D.O.G.? Not only man's best friend but also my favourite acronym for Delusions Of Grandeur.

I once complained to my dentist about the attitude of an oral surgeon to whom he'd referred me. His reply, "Technically he's one of the best, but if he had better communication skills he probably wouldn't have become a surgeon." This conversation trained me to set the bar low when consulting a surgeon. I've rarely had to luckily.

However my dentist was telling me something important. Surgery is a highly skilled technical role. Sure, surgeons don't want to lose any patients, but much of that is achieved by carefully screening potential candidates and having a good anaesthetist. Everyone would want a surgeon with the best technical skills. But I still have to ask, why can't you have both technical expertise and good communication skills?

You may know people who remain frustrated with pain and other problems for many months after surgery. Yet when they tell their surgeon about their ongoing post-operative problems they don't seem too interested; maybe even appearing dismissive. For some surgeons, if the technical aspects of the operation went to plan, any problems the patient experiences seem not to be the surgeon's worry at all.

Not all surgeons are like this. But many are. Well then, if these concerns aren't the surgeon's concern, whose concern are they?

It may be that the patient didn't ask enough questions **beforehand** or the surgeon didn't explain clearly enough. Some surgeons are so keen to operate and some patients place so much hope in surgery that neither considers the possibility of **not** having the surgery. What are the possible benefits and risks? How often do possible complications occur?

Some years ago, my father had a back problem. Over several years he'd visited many health professionals hoping to improve it. He didn't so much have pain, just 'discomfort', but his posture was like the number 7. He was bent over, almost at right angles. Eventually he wound up at an orthopaedic surgeon's rooms. By this time my father was 88.

You need a laminectomy**, the surgeon told him glancing less than briefly at his Department of Veterans Affairs Gold Card, which would of course cover the costs.

A laminectomy is major back surgery. An incision is made into the backbone to get access to the structures associated with the spinal cord. The operation is carried out to relieve pressure on the spinal cord or the spinal nerves, to remove herniated inter-vertebral discs, or to remove tumours.



Image source: seniorplanet.org

"If you don't have this surgery you could end up in a wheel chair for the rest of your life", the surgeon urged my father. From the other side of Australia I urged him equally strongly to find out the risks of this serious surgery on someone of his age and condition. I doubt that he asked. All he and his wife heard was "wheel chair". He had the surgery, developed complications and died before being discharged.

Why do many surgeon's lack good communication skills? Is it because they think they know best? Or is it because you place your life in their hands? Is that why they think they are God?



*Proceduralist is the American term for physician, usually a specialist or subspecialist, who performs diagnostic or therapeutic procedures (medical-dictionary.thefreedictionary.com)

**A laminectomy is major back surgery. An incision is made into the backbone to access the structures around the spinal cord. It's done to relieve pressure on the spinal cord or the spinal nerves, or to remove herniated discs or tumours.

Thank you to Diane Bowyer and Petrina Lawrence for their comments on an earlier draft.

WHAT TO CONSIDER WHEN SEEKING ELECTIVE SURGERY

If you are contemplating elective surgery, if you can, get more than one opinion and ask others who may know about the skills, qualifications and outcomes of a particular surgeon.

When you initially visit a surgeon look at how the consulting rooms are used. Some have a sausage factory arrangement consulting three or four patients in quick succession. This is efficient for them, less than fully attentive to you though.

Find online blogs or ask a range of people about their experiences. Yours is a unique situation, but finding out about the experiences of others can still be useful provided you consider them in context. There are discussion forums too you may like to join. But take a balanced view about what you read.

Questions to ask your surgeon

- What is the operation (procedure) that you recommend?
- What is your experience with this procedure? Make sure your GP refers you to a surgeon who specialises in this. For example, orthopaedic surgeons specialise in particular parts of the body, e.g. hips, shoulders, spine.
- Why is this procedure necessary at this time?
- What are the options if I don't go ahead with it? What other treatments are available? What would be the longer term outcome of not having surgery?
- What is the anticipated outcome of the procedure?
- What kind of anaesthesia is required for the procedure?
- What are the specific risks that this procedure involves? Ask how often each complication occurs?
- Are you happy for me to seek a second opinion?
- What is the recovery process after this procedure?
- Will I need rehabilitation or physiotherapy?
- Ask about who will help you manage post operative pain.
- Often a surgeon is less interested in you afterwards, if the "carpentry" is to the surgeon's satisfaction. If you suspect complications after surgery ask for appropriate tests to be carried out. Seek another opinion if necessary.
- Find someone who will willingly be your partner in managing your health.
- How much of this procedure is covered by Medicare and my private health insurance?
(Mind the gap! Costs can blow out if you are not a public patient.)

Most of this information applies particularly to elective surgery. If you need emergency surgery there may be little time to evaluate your options.

Sources: www.betterhealth.vic.gov.au & www.hopkinsmedicine.org/healthlibrary/conditions/surgical_care_questions_to_ask_before_surgery_85,P01409/

THE ECONOMIC VIABILITY OF UTILISING INTERPRETER SERVICES IN A HEALTH CARE SETTING

Louise Ford
Program Coordinator, HCC

For a number of years there has been discussion about the cost of using interpreters, not only in dollars, but also the cost in time. These comments come not only from the health sector; they arise in all community orientated services, government and non-government, that have contact with people from Culturally and Linguistically Diverse backgrounds (CaLD). Whilst the focus in this article is on new and emerging communities, that language barriers are also an issue for many Aboriginal people accessing health care.

Always my first thought is that it would be a useful exercise if those passing comment on the cost of interpreters could imagine themselves in an environment where they were unable to communicate or understand what was being said to them. To build on this picture, imagine that any writing that is visible is not...readily understood and you begin to get the picture.

يولد جميع الناس أحراراً متساوين في الكرامة والحقوق. وقد وهبوا
عقلاً وضميراً وعليهم ان يعامل بعضهم بعضاً بروح الإخاء.

Watu wote wamezaliwa huru, hadhi na haki zao ni sawa. Wote wamejaliwa akili na dhamiri, hivyo yapasa watendeane kindugu.



Image Source: Queensland Health Interpreter Service

And this is only the tip of the iceberg for many people now accessing the WA health system. To return to the question of viability, I would suggest that the cost of *not* using interpreters is

far greater. Some of these costs are not measurable because they are human costs – the costs to pride and dignity. Not using interpreters also undermines our recognition of ‘rights’ in that all people, as health consumers, have the right to a range of principles that begin with “to be treated with care, consideration and decency”. (See HCC’s website) To not be provided with interpreter services violates this very first principle and the other principles must become compromised.

It has taken some time but the public health sector has recognised the need for, and importance of, the use of interpreters in the health system by publishing and implementing the WA Health Services Language Policy (2011). The Policy applies the existing WA Language Services Policy (2008) and shapes it to meet “the unique conditions and complexities of the public health system.” The development of such a Policy strongly indicates the health sector has realised that by not having clear guidelines it does indeed jeopardise the universal right to health (Article 12).

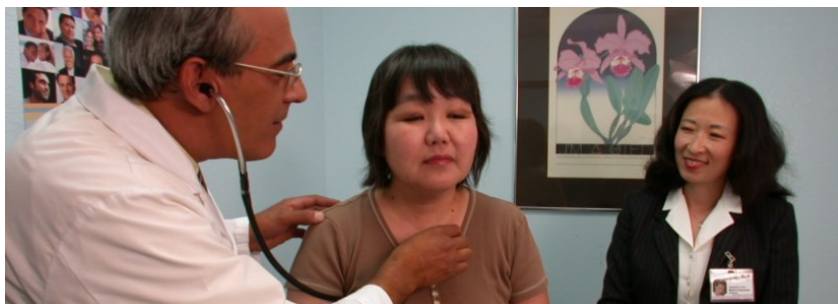


Image Source: chiaonline.org

A further cost is the social one which occurs when people are disenfranchised. Furthermore, a paper, published in 2008 by PASS International (“Is the use of interpreters in medical consultations justified? A critical review of the literature”) states that “From a human rights perspective, the improvement of clinical communication with migrant patients should receive the highest priority. Moreover, failure to promote health-care access for immigrants and their families also carries implications for their integration.” This statement demonstrates one aspect of the correlation between lack of equal access to services and ensuing difficulties in adjusting to a new country, society and culture. These difficulties do, in the long run, add significantly to the economic costs of re-settlement.

Social disadvantage aside, the study covers many aspects of health care and the consequences of little or no access to interpreter services. One example cited is that of patients with diabetes, “If the intervention of an interpreter helps to prevent one case of diabetic foot with gangrene, due to the increased quality of care and preventative measures, his yearly full time salary (€ 40,000.00, Cofetis, 2007) is fully recovered in avoided medical costs to the NHC.”

The findings presented in this study indicate that access to professional interpreters and bi-lingual health professionals adds considerably to the quality of care the patients receive and the satisfaction they experience. Both help to reduce inequities. It also found that the use of professional interpreters reduced the cost of services for and to people as well as their

“utilisation of medical services, particularly in emergency services.”

Based on available data the study did not find whether using interpreting services reduces total costs. It did indicate that there is a better use of resources and therefore better prevention and treatment of disease when interpreters are used. In short the additional costs of employing interpreters are outweighed by the “costs accrued due to gaps in health care access and current medical costs for patients” who do not have the required language skills.

Overall findings in general were that the “intervention of professional interpreters contributes or can contribute to:

1. Improved patient and health professional satisfaction
2. The guarantee of medical ethics in relation to informed consent and confidentiality
3. The improvement of treatment comprehension and adherence
4. The improvement of health education and information
5. The increase of efficacy and efficiency of time used during consultation, although the time in absolute terms is unlikely to be reduced
6. The improvement of access to care, above all to preventive medicine and mental health - which in turn contributes to equity in health care
7. The reduction of the risk of medical errors
8. The improvement of efficacy and efficiency of referrals to specialists
9. The reduction of unnecessary costs due to:
 - a. Diagnostic tests
 - b. Treatments
 - c. Length of stay
 - d. Repeated visits to different health care providers”

In conclusion, it appears that from an economic point of view there is a great deal to be gained by working with interpreters. Whilst it may not reduce costs while a person is in the health system, the overall benefit reduces costs in many other ways. For example, impact to an individuals emotional and psychological well-being, to society and to communities is reduced. The utilisation of interpreters also means that we, as a society, are upholding a basic right articulated in Article 12 of the Universal Declaration of Human Rights – The Universal Right to Health.

Footnote: The writing that some of you may not have been able to read is Arabic; the one you could read but perhaps could not understand is Swahili. Both were Article 1 of the Universal Declaration of Human Rights:

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.”

WHAT IS COELIAC DISEASE?

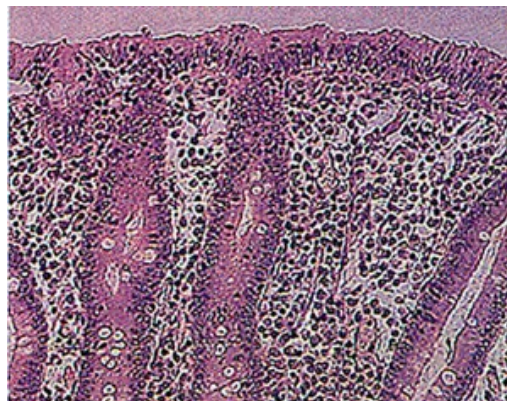
Julie Curlow

CEO Coeliac Foundation WA

Coeliac disease is an auto-immune disease where the body attacks itself if gluten is eaten. Within the bowel are numerous tiny finger like projections, called villi, which help the body to absorb nutrients. In a person with coeliac disease the villi become flattened and the area inflamed so that the area available to absorb nutrients is dramatically reduced. A number of serious health consequences can result if the condition is not diagnosed and treated properly.



Healthy villi



Damaged villi

Who gets coeliac disease?

Coeliac disease is genetic and affects men, women and children at any stage of life. New Australian research indicates that 1 in 60 women and 1 in 80 men have coeliac disease, yet a staggering 80% are undiagnosed¹. That means in Australia there are currently an estimated 272,000 people with undiagnosed coeliac disease!

Why is the diagnosis rate so low?

The diagnosis process is simple however some people commence a gluten free diet prior to being tested and that can result in false negative results.

Secondly coeliac disease has well over 300 non-specific symptoms that don't always affect the digestive system which makes diagnosis difficult.

What are the symptoms of coeliac disease?

Symptoms can range from mild to severe. The most common symptoms are:

- Iron deficient anaemia
- Bloating
- Diarrhoea but also constipation
- Nausea and vomiting
- Unexpected weight loss or gain

- Children may fail to thrive which means they don't gain weight and grow as expected.

Other symptoms include lethargy, depression, infertility and skin rashes.

How are people diagnosed?

Diagnosis is straight forward. Firstly you have a blood test to measure the level of various antibodies. If that is positive, then your doctor will refer you to a gastroenterologist to have a small bowel biopsy.

Importance of Diagnosis

People with a higher risk of coeliac disease includes, but is not limited to, the following:

- Autoimmune thyroid disease
- Type 1 diabetes
- Rheumatoid arthritis
- Anaemia
- Osteoporosis

Upcoming Events

If you think you are at risk of coeliac disease or want to know more, we will be presenting an overview of coeliac disease and eating gluten free at:

Date	Type	Event	Location
19-22 June	Exhibitor	Every Woman Expo*	Perth
27-28 August	Exhibitor	Dowerin Field Day*	Dowerin

*Terms and conditions apply.



For more information about Coeliac Disease and upcoming events you can contact Coeliac Western Australia on (08) 9451 9255/ 1300 458 836 or wa@coeliac.org.au

Sources: 1 Anderson, RP et al; A novel sero-genetic approach determines the community prevalence of celiac disease and informs improved diagnostic pathways. *BMC Medicine* 2013, **11**:188.

2 Bourgey M, Calcagno G, Tinto N, et al; HLA related genetic risk for coeliac disease. *Gut*. 2007 Aug;56 (8):1054-9.

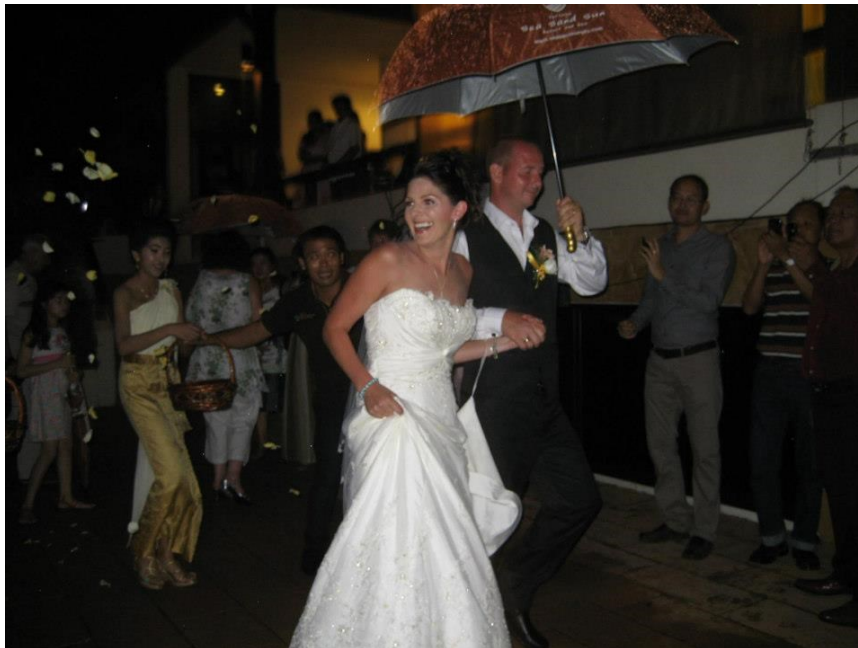
DON'T GIVE UP, KEEP FIGHTING

A MESSAGE OF HOPE FOR SURVIVORS OF STROKE

Peter Coghlan
Health Consumer

Hello my name is Peter Coghlan aged 36. I had a major stroke in 2011 after I banged my head on a piece of concrete, leaving me in a state called Locked-in Syndrome (LiS). This basically means the part of the brain that is the wiring box to the body is totally wiped out!

I was only able to blink, but my vision was up and down only. I was unable to eat or drink. Even oxygen had to be reintroduced slowly over a week. I had no movement for a month. My experience daily was getting rolled about the bed, crapping myself and getting constantly changed like a baby. I was hoisted out of bed like a bag of spuds.



Peter and Jade on their wedding day in Thailand. Peter achieved his goal of walking down the aisle.

It is hard to paint a picture of just how bad it was. I asked to die more than once. The reason I want to share my story is because there are so many stroke victims in the wider community. I would like to create awareness, but above all, share a message of hope to those who have all but given up.

I was in a coma. I was a totally paralysed dribbling mess with no hope. You must keep fighting, don't ever give up.

Don't always believe what you're told, they only know what they've been told. The brain can do extraordinary things if you keep willing it and **I am not the only one**. I have written a book on my nightmare, because my condition was so bad and my fight was so hard.

My goal was to walk down the aisle and marry my beautiful wife Jade. We tied the knot in Thailand in November 2012. Now I can drive and walk up and down stairs. I'm not quite running yet, however I did complete the Perth City to Surf 12km Fun Run. I had bleeding feet but I did it!

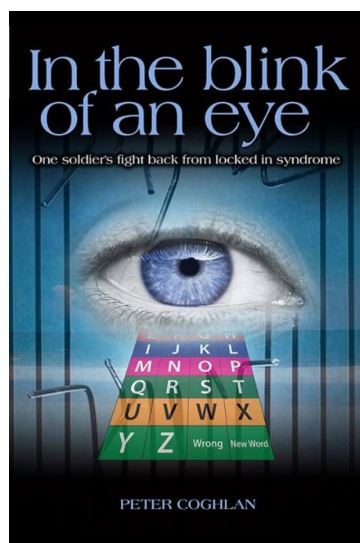
I now have my own cleaning company and go to my local Kingway Good Life Gym. My wife trains with me sometimes, both trying for our own goals. Mine is to run, and I will do it!

We are just scratching the surface of what the brain can achieve. I am now a proud volunteer for my old stroke ward at Shenton Park Rehabilitation Hospital with Friends of Royal Perth Hospital and am a valued member of the best stroke group in WA, Northern Suburbs Stroke Support Group. I would highly recommend it them.

We talk about how our stroke affects us and day trips are often organised. We have a laugh; everybody is so friendly. A bit too many cakes for my liking as I am trying to get my stomach muscles back, but all ages and people with different strokes are welcome.

We are so lucky here in WA for the great support groups like Lotterywest who converted my car for free, as Jade and I had financial difficulties after what happened. I am hoping to get back to 100 percent in the next few years and no one is telling me otherwise. I hope many more stroke survivors out there start thinking the same. If you honestly try hard every day you too can get your life back on track.

Don't ever EVER give in, things can change!!!



If you would like to read more about Peter Coghlan's amazing story his book is called 'In the Blink of an Eye'.

JOURNEY TO CONSTITUTIONAL RECOGNITION

Laura Elkin Aboriginal Advocacy Manger HCC



Elders Ben Taylor, Margaret Culbong and Cedric Jacobs lead the Journey to Recognition in Fremantle 10th March.

The Aboriginal Advocacy Program was proud to be among over 300 people as the Journey to Recognition recommenced from Fremantle and began making its way through the south-west of WA.

The event also officially launched the Fremantle Aboriginal Cultural Centre on Arthur Head by Fremantle Mayor, Brad Pettitt and Aboriginal community members who had worked with the council to develop the idea.

The Journey to Recognition began in Melbourne in May 2013, and has already covered 16,000 kilometres around Australia. Over 160,000 Australians have already pledged their support for a referendum to, for the first time, add acknowledgement of Aboriginal and Torres Strait Islander peoples to our national Constitution and to remove discriminatory sections.

An Expert Panel consisting of Aboriginal leaders, constitutional experts and parliamentarians, consulted nationally and reported to the Prime Minister in January 2012. They recommended that Australians should vote in a referendum to:

- **Remove** Section 25 – which says the States can ban people from voting based on their race;
- **Remove** section 51(xxvi) – which can be used to pass laws that discriminate against people based on their race;
- **Insert** a new section 51A - to recognise Aboriginal and Torres Strait Islander peoples and

to preserve the Australian Government's ability to pass laws for the benefit of Aboriginal and Torres Strait Islander peoples;

- **Insert** a new section 116A, banning racial discrimination by government; and
- **Insert** a new section 127A, recognising Aboriginal and Torres Strait Islander languages were this country's first tongues, while confirming that English is Australia's national language.

The Parliament has now appointed a Joint Select Committee on *Constitutional Recognition of Aboriginal and Torres Strait Islander peoples* to finalise the words that would form the amendment to the Constitution. It will be chaired by the two Aboriginal members of the Parliament, with Ken Wyatt MP as the Chair and Senator Nova Peris as the Deputy Chair. The Government also announced that the draft wording will be finalised by the end of 2014.

For further information and to show your support go to the Recognise website: www.recognise.org.au/about

3RD NATIONAL ELDER ABUSE CONFERENCE

Advocare is proud to be at the forefront of combating elder abuse in Australia and will host the 3rd National Elder Abuse Conference. Entitled 'Unlocking Solutions', our organising committee will embrace a program that looks into all aspects of elder abuse.

Already regarded by industry leaders as a must attend event, this conference will bring together dynamic global experts to share information on topics that will assist in elder abuse research, intervention and policy. There will also be plenty of opportunities for networking, reacquainting with old colleagues and meeting new ones.

The two day conference will be followed by a unique one day workshop which will look at the practical and theoretical applications that arise from the conference.

Delegates are encouraged to attend from different professions, as unlocking solutions to elder abuse requires a collaborative effort from all counterparts. Register your interest at www.elderabuse2014.com for the conference and workshop and help change the outcome for thousands of elder abuse victims in Australia.

Advocare
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**unlocking
solutions**



**Third National Elder
Abuse Conference**
3 & 4 September 2014
Hyatt Regency Perth

DIVERSITY DIALOGUES FORUM

MEN'S HEALTH

Louise Ford

Consumer Participation Coordinator, HCC

Invited guest speakers for the Forum were Assaad, the FICT (Families in Cultural Transition) Program Coordinator at ASeTTS (Association for Services to Torture and Trauma Survivors), and Nelson, a leader in the Rwandan community who has spent much time working with refugees in South Africa. The focus of the Forum was whether or not there are barriers to men from new and emerging /CaLD communities accessing health care and if so what those barriers may be and how to address them.



Assaad, FICT Program Coordinator, ASeTTS & Nelson leader in the Rwandan Community in Perth

General points were made about men's attitudes towards discussing their health and included that:

- Poverty (in their country of origin) can limit people's access to international information
- Talking about ill health can be thought of as weakness
- Members of CaLD communities can be 'shy'; mainstream needs to be more open and welcoming
- In many cultures in the Great Lakes area of Africa men are 'kings' in their families; they like to be in control and not be seen to need help/support

Factors and barriers that can and do impact on men's health were also discussed and many points were made, these included:

- Many African parents are struggling. Frequently the children/youth adjust well to life in Australia but the parents tend to adhere to their culture because that is what they know best and believe in
- Several factors impact on men's mental health including trauma from past experiences, unemployment, lack of education or non-acceptance of their qualifications and work

experiences by Australian employers

- The culture here is very different for African men and impacts on both their emotional (mental) and physical health
- The definition of health – the concept of health is holistic here; it is different in other cultures where being unwell doesn't necessarily mean being unhealthy.
- Loss of male authority in the family can and does trigger emotional (mental) health issues
- Men with issues around sexuality are, traditionally, counselled by their elders in the community
- Some discussions are 'taboo' for men, particularly around sexuality and sexual health. It is useful for medical practitioners to be aware of this particularly when encouraging men to have prostate cancer checks etc.

The latter part of the Forum focused on thinking about and identifying ways to overcome barriers.

Suggestions made were that health service providers:

- Respect and value people and show this
- Accept differences
- Ensure patients are confident and comfortable
- Try to provide male to male service provision. A young graduate may not be trusted (as they are not old enough to have wisdom) and, if female, may not be provided with the required health information because of youth and gender

Recommended strategies to assist in addressing barriers were:

- Survey communities re their access to health care; include questions about how people perceive health care service provision and how they can be encouraged to access services
- Communities and service providers to be encouraged to access each other so there is communication and engagement on both sides

Other strategies were recommended that will be discussed with the Department of Health.

In summing up, it is apparent that there are commonalities across cultures with regard to men talking about and addressing health issues. This includes mainstream Australian men who frequently demonstrate similar reluctance to 'share' personal information about themselves with anyone apart from those nearest and dearest. However it is also apparent that men from CaLD/new and emerging communities face further barriers. Those include language and culture as well as having to learn to navigate a new system of health care, and different delivery, beliefs and values.

The Health Consumers' Council would like to extend sincere thanks to Assaad and Nelson for being prepared to contribute their time, knowledge and experience to the Forum, these are greatly appreciated.

A TIME TO LIVE AND A TIME TO DIE

Murray Hindle

President, West Australia Voluntary Euthanasia Society (Inc)

Whilst most of us agree that an individual should have the final say in the manner of his or her death, there is reluctance within us to recognise and confront our own mortality. Yet without becoming fixated and morbid it is a subject that we must all address and the sooner this is done the better.

Death is not just something that happens to someone else. It is important that the wishes relating to our death are understood by our loved ones and the health professionals in whose care we will finally end up. These wishes can be set out in a Living Will or Advance Health Directive (AHD) and supported by an Enduring Power of Guardianship (EPG). Once these documents have been completed they must be discussed with your family and doctor to avoid any ambiguity regarding end of life choice.

Given Australia's increasingly ageing population, the question of morality and cost of keeping a dying family member alive, only to postpone the inevitable painful and prolonged end, must be addressed. The advance of medical science has given the promise and therefore an unrealistic expectation of prolonging the process of death.

WAVES' quest is to have carefully safeguarded voluntary euthanasia legislation passed through the Parliament of Western Australia to give WA citizens with a terminal illness an end of life choice. A change in the law, which will give people the power to decide to die at a time of their own choosing, with dignity, pain free, and in the presence of loved ones. But this change can only take place if we grasp every opportunity to make our feelings known to elected representatives, especially when VE Bills are presented.

As health consumers we must ask ourselves who are the beneficiaries of life extending research, the scientists, the aged care providers or the public? Who will get the treatment, who will miss out, and who will pay?

We must also ask if funds that are currently being spent on lives that will be lost irrespective of medical intervention could be better spent on lives worth saving.



The West Australian Voluntary Euthanasia Society (WAVES) has been a member of the Health Consumers' Council for a number of years without overt attempts to influence the issue of community health. The HCC encourages informed debate on health related topics and encourages members to suitably seek information before making any final decisions.



Copies of Preparing an Advance Health Directive booklet and Advance Health Directive Form are available at the Health Consumers' Council. For copies please call (08) 9221 3422 or email info@hconc.org.au with your name and postal address.

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- Be kept up to date about health issues
- Be able to have your say on health policy as a Consumer Representative
- Work with community groups and health-related organisations
- Work to make the health system more responsive to consumers

The council has three categories of membership - Individual, Organisation and Associate. Individual membership is free. There's a small fee for Organisation and Associate membership (invoices are sent out at the beginning of the financial year).

Contact us on (08) 9221 3422 or info@hconc.org.au to register your interest!



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