Health Matters

Health Consumers' Council (WA) Inc. Magazine

August 2019

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HEALTH CONSUMERS' COUNCIL

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HEALTH CONSUMERS' COUNCIL

Health Consumers' Council

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Cover image: Health Consumers' Council: World Kindness Day 2018

The April 2019 edition incorrectly identified an image of Frank Smith on page 18.

Foreword

Welcome to the August 2019 edition of Health Matters, which is dedicated to the very important topics of self-advocacy and peer support.

Self-advocacy and peer support are two elements that are closely connected with informed consent. It is only by advocating for yourself, learning as much as you can, and feeling OK about asking questions that you can get the best health care.

Peer support can help with this on several levels – there is nothing as powerful as seeing someone further down the recovery journey, and being able to talk about the lifestyle impacts of your condition with someone who really gets it. Peers are also a great source of information, often providing links to the latest research, providing suggestions for doctors who are familiar with your issues, and reminding patients of the importance of advocating for their own health.

Informed consent is a fundamental consumer right. And to exercise that right, we need to know that a) it's OK to ask questions, and b) it's also OK to say "can I think about this" or even "no" to suggested treatments.

I sincerely hope the articles in this edition are useful for you, and that they spark in you the curiosity to become more invested in your own health care. No one has more at stake than you when it comes to your health, and being informed can put you back in control of what you say yes to, and just as importantly, what you can say no to.

Clare Mullen, Tania Harris, Pip Brennan and Karen Lipio celebrating NAIDOC Week

NAIDOC Week

NAIDOC Week (7 – 14 July) is a time to celebrate the history, culture and achievements of Aboriginal and Torres Strait Islander peoples. The theme this year was Voice. Treaty. Truth.

During the week, we released three videos and the full report from our Aboriginal Patient Experience themed event held in April. The theme at this event was "Kindness, connection, community: see the whole person" or as said in Noongar "Djinang Kwop Wirrin" (See Good Spirit). The videos are available online at **www.hconc.org.au/services/hccpxhome/**

We are also currently working on a project to design a training package to help address some of the barriers Aboriginal and Torres Strait Islander peoples experience in accessing healthcare. You can read more about this on page 9.

We closed out NAIDOC week by attending the Breakfast at Langford Aboriginal Association, where we enjoyed the usual hospitality, creativity and positivity that we always experience when attending this venue.

Board award finalist

We were excited to be named a finalist in the Engaging Young Leaders on Aged and Community Boards Difference Maker Diversity Awards in the Not-for-Profit category, for championing diversity in the board room.

We are currently reviewing applications for new board members to fill three board positions at our Annual General Meeting on 12th November.

Pip Brennan
Executive Director
Health Consumers' Council

Four decades of consumer advocacy

Mitch Messer

Mitch Messer has been a consumer advocate for almost 40 years and was one of the early founders of the Health Consumers' Council. He remains a member of the Health Consumers' Council, and is a passionate advocate for Cystic Fibrosis. He is a consumer advisor for Telethon Kids Institute, and a consumer representative with the WA Drug Evaluation Panel.

In recognition of our 25th anniversary, Mitch spoke about the early days of Health Consumers' Council, and what drives him to continue his work in the advocacy space.

You've been a consumer advocate for almost four decades. What first sparked your interest in getting involved in this area?

I got involved in it through personal involvement with Cystic Fibrosis WA, because I have Cystic Fibrosis (CF). I always saw the value in that organisation being able to provide support and a voice for the CF community. I joined when I was 18 and became the president of the organisation when I was 22, so I've been involved in advocacy roles since then.

When I got involved with the Health Advisory Network, which was a Health Department initiative, I recognised the value of working as a network. I figured if we all got together we'd have a much stronger voice.

What has your involvement with Health Consumers' Council been over the years?

I was involved in the formation of the Health Consumers' Council. It started with the Health Advisory Network, which had a consumer and a provider arm. Over time, we talked to the government about focusing on the consumer arm, and it changed to the Health Consumer Network. It was provided by the government to advise the minister specifically about consumers' needs, but wasn't able to act independently. We lobbied to get the funding separately so we could form an independent organisation. We were successful and that led to the formation of the Health Consumers' Council.

I was involved from the beginning, as a member of the board and eventually I became the chair of the board. After that I was involved as a member and a consumer representative for many years. I re-joined the board in 2010, became the chairperson again in 2012. I also did a stint as the acting Executive Director while the Director was on sick leave. I stepped down at the AGM in 2013 after filling my lifetime quota.

What was the focus for Health Consumers' Council in those early days?

When it was first started the goal was to try and make sure there was a consumer voice in health care, because prior to that there hadn't been, or if there was it was very hit and miss. Talking to and listening to consumers wasn't a priority. We wanted to get policy makers to see that they should talk to consumers first, and include us in conversations, because it would give the system and individuals a better outcome. We thought consumers should be involved in all the discussions in health care and policy areas.

One of the very first services was the advocacy service. Until then there was nothing available at the time to help people deal with the health system, and we knew that people needed help navigating it.

How did people respond to establishment of Health Consumers' Council?

Because the Health Consumer Network had a group of members already, when Health Consumers' Council came along people saw it as a real opportunity. We had strong support from the community and consumer organisations that were around at the time.

I think it's taken a long time, and there's still a lot of work to do, but we've come a long way from the beginnings where there was very little consumer input in health care. Now consumers are involved across the health sector. You wouldn't expect any big issues to be talked about without having the consumer voice included.

What are some examples you can think of where Health Consumers' Council made a real impact for consumers?

Health Consumers' Council has auspiced a number of organisations over the years to help them get off the ground and that's been a really positive thing. Health Consumers' Council has the ability to help bring groups together and then set them off on their own path, providing mentorship for organisations. One of the first organisations we helped auspice was the Mental Health Law Centre. I think this was an important function of the Council.

It is also important to note that all the health services and hospitals now have community or consumer advisory councils, which they didn't have before Health Consumers' Council came along.

I think every day you can see the benefits of the Health Consumers' Council in the community.

Why are you passionate about the need for consumer input in decision making? What drives you?

I'm driven to continue my advocacy and support for consumer advocacy because I see the benefit that comes from it. When the consumer is involved in decision making from planning to implementation and review, services improve. They're able to respond better and support the community, and be much more efficient as well – that is better for all, including the government, the health services and the people who work in them. We have a better system when consumers are involved in it.

I am passionate about consumer involvement, because I see where we've come from, but also where we can go.

What do you think the future holds for consumer advocates and patient-centred care?

I think the future is bright, as long as we continue to push. There are still people who think they don't need consumer advocates and community involvement in policy. We need to continue to push for it because the future is better with consumer engagement and consumer involvement.

Without it, we're going to have half-baked solutions. There are still a lot of ways the system can be improved, especially if you talk to all the people involved in the system. And by not including consumers you'll miss those opportunities, and everyone will be worse off for it. Consumers need to be seen as full and equal partners in that process. And while we've come a long way we're not there yet.

> "I think everyday you can see the benefits of the Health Consumers' Council in the community. "

1994 - 2019

Celebrating 25 years

Informed Consent

PIP BRENNAN, HEALTH CONSUMERS' COUNCIL EXECUTIVE DIRECTOR

It's OK to ask

In 2017, a Senate Inquiry Recommendation spelled out how a medical practitioner should undertake informed consent. Does that not give one pause? I mean, shouldn't that always be happening?

Let me quote the recommendation that appeared in the final report of the Senate Inquiry[1] into the number of women impacted by transvaginal mesh implants and other matters:

"The committee recommends that the Australian Commission on Safety and Quality in Health Care prepare guidance material on effective informed consent processes, with a view to ensuring that a dialogue between a medical practitioner and patient should:

- clarify the rationale for the proposed treatment;
- discuss the range of alternate treatment options available and their attendant risks and benefits;
- discuss the likely success and potential complications of the recommended treatment as they relate to the individual patient;
- provide an opportunity for the patient to ask questions; and
- confirm that the individual patient has understood the information discussed."

Consent is a vexed issue, and there are many barriers to it working well.

It's true that we don't know what we don't know – but being empowered to ask can really change how a consultation proceeds. The 5 Questions to Ask Your Doctor (Choosing Wisely) and the Question Builder Tool (Australian Commission on Safety and Quality in Health Care) are two resources that can help put you back in control of what you say yes to, and just as importantly, what you can say no to.

It's your body – no one else has anywhere near the stake in the outcome of a health care episode as you do, so by all means, ask.

1: https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MeshImplants/~/media/Committees/clac_ctte/MeshImplants/report.pdf

Procedure Specific Information Sheets

Written information about your treatment

There are about 60,000 things that can go wrong with a human body, 6000 drugs and 4000 procedures you can do. When you are trying to work out the best pathway of care for your circumstances, it can be very useful to get information about a proposed procedure in writing, preferably prior to your consultant appointment.

The WA Department of Health recommends the use of Procedure Specific Information Sheets which are available for use by public sector staff.

Procedure Specific Information Sheets are written by qualified and practicing consultant surgeons and physicians, with input from other relevant health professionals such as specialist nurses and midwives. They are updated frequently to reflect changes in clinical practice, medico-legal developments and to incorporate clinical and patient feedback.

They use simple language, and many are available in languages other than English. There are also Easy Read versions available for some procedures for patients who have literacy difficulties.

We have one page versions on our website, free to download. These shorter versions provide a summary of specific procedures and are a good starting point for your list of questions to ask your doctor. You can view them at:

www.hconc.org.au/procedure-specific-information-sheets/

When you see your doctor, ask for the full four-page version.

Choosing Wisely

Questions to ask your doctor

When it comes to medical tests and treatments, more is not always better. Some medical tests, treatments, and procedures provide little benefit, may be expensive or may have alternative options.

It is important to take guidance from your doctor around your treatment, as they can assess your case on an individual basis taking into account your medical history, current medications, lifestyle and family history. But it is just as important to know you are allowed to be involved in making decisions around your healthcare – you have the right to ask questions and get more information, so that you can make decisions based on a good understanding of what you're having done and why. You will pay the ultimate price if things don't go well, so you really do have the right to a shared process of decision making.

A lot of people think "I'm not a doctor, I wouldn't even know what to ask." That's where Choosing Wisely, and the 5 Questions to ask your doctor, come in.

Choosing Wisely Australia is an initiative of NPS MedicineWise in partnership with Australia's health professional colleges, societies and associations. It aims to start conversations between health service providers and consumers about tests, treatments and procedures. Because a huge step towards advocating for your own health is creating a culture where people feel it is OK to ask questions of their doctors.

The 5 Questions serve as a conversation starter and an empowerment tool for consumers who aren't comfortable asking questions or don't know what to ask. Once you're better informed, you can be more active in making decisions about your healthcare.

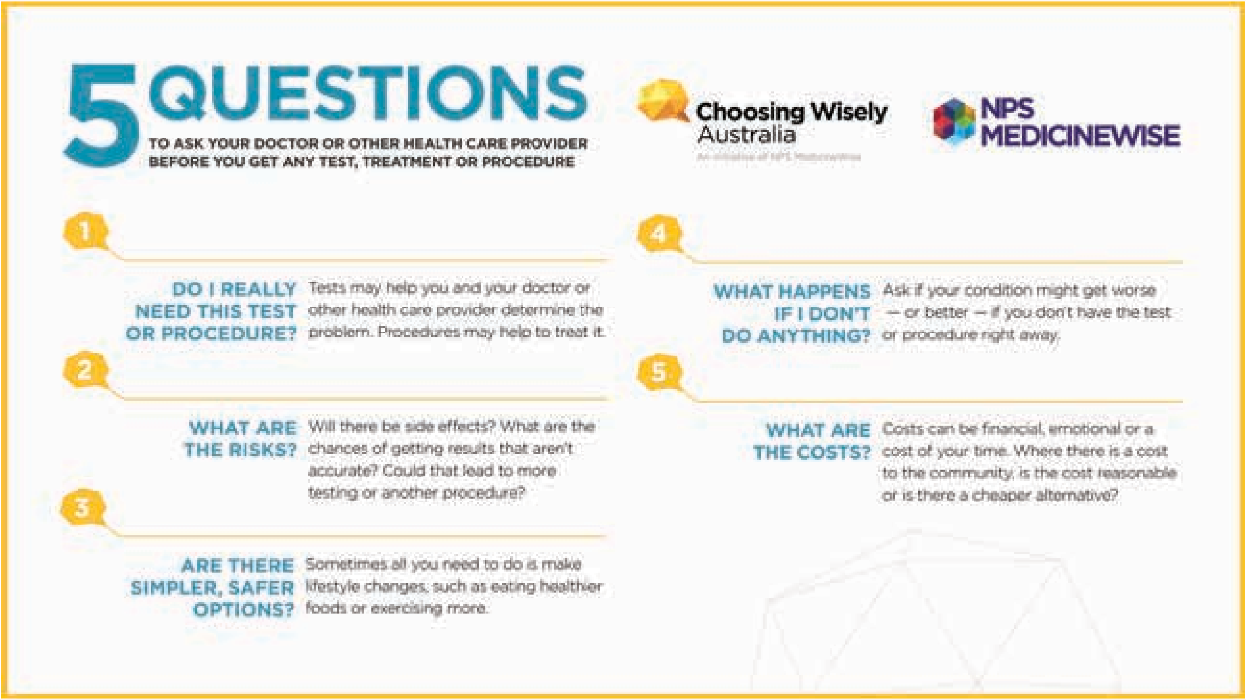
Choosing Wisely Australia also challenges the way we think about healthcare, questioning the notion 'more is better'. When it comes to tests, treatments and procedures, there may be alternatives that are easier, cheaper, less time consuming or that have less risks, so it helps to know all of the options before you make a decision. And sometimes, doing nothing is the right choice.

Using the 5 Questions will help you end up with the right amount of care — not too much and not too little.

The ideal scenario is where patients will be prepared with questions to ask their doctors about treatments and planned investigations. In response, doctors will make time in their consultations for patients to ask questions, and then provide the information needed to make an informed and shared decision about their healthcare options.

You can find the 5 Questions online at **www.hconc.org.au/wp-content/uploads/2019/01/5-questions-to-ask-your-doctor-before-you-get-any-test-treatment-or-procedure-old.pdf**

And in languages other than English at **www.hconc.org.au/five-questions-to-ask-your-doctor-before-you-get-any-test-or-treatment-languages-other-than-english/**



5 QUESTIONS
TO ASK YOUR DOCTOR OR OTHER HEALTH CARE PROVIDER BEFORE YOU GET ANY TEST, TREATMENT OR PROCEDURE

Choosing Wisely Australia

NPS MEDICINEWISE

1 **DO I REALLY NEED THIS TEST OR PROCEDURE?** Tests may help you and your doctor or other health care provider determine the problem. Procedures may help to treat it.

2 **WHAT ARE THE RISKS?** Will there be side effects? What are the chances of getting results that aren't accurate? Could that lead to more testing or another procedure?

3 **ARE THERE SIMPLER, SAFER OPTIONS?** Sometimes all you need to do is make lifestyle changes, such as eating healthier foods or exercising more.

4 **WHAT HAPPENS IF I DON'T DO ANYTHING?** Ask if your condition might get worse — or better — if you don't have the test or procedure right away.

5 **WHAT ARE THE COSTS?** Costs can be financial, emotional or a cost of your time. Where there is a cost to the community, is the cost reasonable or is there a cheaper alternative?

A more positive health experience

Empowering Health Consumers with Disabilities

Over the last few months, we've been working with People With disabilities WA on a joint project which aims to empower consumers with a disability to have a more positive experience when accessing the health system.

Through this project, a diverse group of people provided suggestions, advice and expertise on the content and format of communication as well as training needs of people with disability.

This information was then used to deliver eight sessions to people with disability, their carers and families across Perth, Northam and Bunbury, with an online session added due to consumer feedback. One of the participants from the working group took part in the presentations, sharing their own experiences of Western Australian health care.

The information and health resources we gathered are being distributed in user-friendly ways to improve knowledge on healthcare needs and services available.

The sessions covered topics including rights, ideas for getting better care, where to go for help, medical records and information sharing, and navigating the health system.

Feedback from the sessions has been very positive and during the presentation there have been lots of questions around each of the topics.

When we asked attendees 'what makes a good GP' and 'how should services engage with you' there was a lot of agreement that using less jargon, being more personable and using different communication methods is important. People also noted they wanted GPs who saw them as a whole person, and took time to listen, review previous appointments, and explain things clearly.

The Empowering Health Consumers with Disabilities team has produced two information booklets to help people with disability get better health care. These are available on our website:

www.hconc.org.au/projects/empowering-consumers-with-a-disability/

Aboriginal Patient Advocacy Training Program

Empowering Aboriginal and Torres Strait Islander peoples

Aboriginal people make up 3.8 per cent of the Western Australian population, and yet have the greatest health needs of any group in the state.

At HCC, we're committed to ensuring Aboriginal health is a core part of our focus, with an emphasis on engaging with communities to ensure Aboriginal people are aware of their health rights and are able to have their say and participate in health care reform.

Aboriginal people often face barriers to healthcare that include lack of access to services due to remote locations, difficulty making the journey to access services, inappropriate and culturally incompetent services, lack of interpreters, institutional racism, and a lack of understanding of their rights. In addition to this, the underlying issues of social and economic exclusion can contribute to poor indigenous health outcomes.

George Newhouse, Principal Lawyer for the Sydney-based National Justice Project, approached Health Consumers' Council, Aboriginal Health Council of WA and Bila Muuji Aboriginal Corporation Health Services to design a training package to help address some of these barriers. The training has been developed in WA but will have the ability to be tailored to different states and regions across Australia.

The program is targeted at community members, social workers, Aboriginal community leaders and employees of local Aboriginal land councils, but there will be no restrictions on who can take part.

The aim of the training is to improve Aboriginal people's access to healthcare by training workers and community members in basic advocacy skills, health system navigation knowledge, health rights knowledge, and information on recognising racism that exists in our health system. The training will cover how to give feedback and make a complaint, when to refer, self-care and other important topics.

The project also aims to empower Aboriginal communities and individuals by increasing their knowledge of the health system, complaints processes, health rights and available supports, to contribute to a reduction in poor health outcomes and mortality among Aboriginal people.

The project will be officially launched in the second half of 2019.

Artist: Brian Ward

Peer Support

RHIANWEN BERESFORD, CONVENOR OF THE WA PEER SUPPORTERS' NETWORK

A vison for Western Australia

Together with other members of our network, I have this vision for peer support. It's where every Western Australian knows what peer support is and can access it if they want to.

If that sounds way off into the distant future, bear in mind that the term might not be well known, but that peer support is already happening. In the same way people in a caring role often don't know they are carers, many people offer peer support without realising that's what they do.

Peer support happens across all sectors and walks of life. If you're using your own experience to help someone through a similar experience, that's peer support – whether you're doing it in an informal way with friends or family, or helping others in the wider community.

Of course, some peer support is more significant than others. Although I can relate to someone that's grazed their knee, I don't need to reach out to someone with a shared experience when it happens to me.

But some experiences are hard (or great and hard at the same time). Some experiences change our sense of identity or our future. Some make us doubt ourselves, or swamp us with grief, or overwhelm us. Some take a big learning curve, or require us to change how we live our life. And some experiences across our lives leave us feeling different, stigmatised or discriminated.

For these bigger things in life, talking to someone who has had similar experience can help a lot.

We're often drawn to people with similar experiences and this common ground can build trust, a sense of rapport and good conversations that lead to great friendships. Because of this many of our freely formed friendships and relationships have some 'peer' elements, whether we call it 'peer support' or not.

So if it's happening a lot behind the scenes, why does it matter if we call it 'peer support', make it common knowledge, and have more options to access it if we want to?

Firstly, broad community awareness of peer support can help with meeting our needs and increase our capacity for self-advocacy. It makes it easier for one person to say, 'I want peer support' and another to say 'Yep, I can do that'.

Secondly, like any relationship, some peer support relationships are healthier and more helpful than others. The more awareness there is, the more people will be interested in learning and growing skills to build the best peer support relationships they can.

Most importantly, until there is greater awareness and understanding, lots of people are facing experiences alone when they might want to reach out to a peer. This includes people in situations where they can't reach out and build new friendships, such as when they are home-bound, in hospital or socially isolated. It includes times when people need peer support urgently because a major, sudden change has happened in their lives and there's no-one in their networks that has had a similar experience. It includes times when someone can only safely talk to their peers because of the stigma or discrimination they've faced, but there aren't peer programs matching their experiences to safely reach out to. In these sorts of situations, peer groups, programs and services can be important options for people, and with greater awareness these programs will become more available.

Peer support is an idea gaining groundswell and there are many people reaching out to offer peer support, who are making it easier to access when people want to. If we each take a little time to notice it around us, and see where else it has potential, a world where everyone has these options becomes very, very possible.

Alliance Against Depression

MAYA CHERIAN, ALLIANCE AGAINST DEPRESSION TRAINER

Talking about mental health

Good mental health is fundamental to the wellbeing of individuals, families and communities. The strong link between depression and suicide requires a focus on encouraging people to talk about their mental health, and to visit their GP for treatment and care.

The European Alliance Against Depression (EAAD), established in Germany, is based on evaluated trials and is recognised as the world's best practice for the care of people with depression and in the reduction of suicide. It can be adapted to meet the specific cultural and regional needs of a community and has been successfully implemented internationally.

The initial implementation of the EAAD framework in the trial region of Nuremberg, Germany resulted in a 24 per cent reduction in suicidal acts within a two-year period. It draws our focus on the individual, the community and the system together. It suggests four well-integrated pillars of focus or interventions within a community can increase the diagnosis and treatment of depression and reduce suicide.

WA Primary Health Alliance (WAPHA) is leading the implementation of EAAD as a key strategic approach to achieving the vision of improved health equity in WA. In Western Australia, the EAAD will be referred to as the Alliance Against Depression (AAD).

The AAD Framework

It is essential to include care providers, the broad public, media, different stakeholders, patients and relatives simultaneously to make this Alliance a success.

Establishing a local AAD helps a community work together on:

- Public awareness campaigns to reduce stigma associated with depression and suicide
- Support for high-risk groups, patients and their families
- Localised training for health professionals, including GPs
- Education activities on depression and suicide for community members and leaders.

This evidence-based approach aims to build strong connected communities, which can continue to recognise depression and respond to local needs and concerns.

An AAD Coordination Centre has been established at WAPHA to support local WA Alliances. WAPHA believes AAD is translatable to all communities irrespective of race, gender, sexual orientation, geographical location etc. WAPHA is committed to working within high-risk communities including LGBTQI people, young people, Aboriginal people, older populations, people with disabilities, and other vulnerable communities. The AAD framework indicates the need for a contextualised response which may look different dependent on the community and place.

All local Alliances start with a small number of people wanting to improve the mental health and wellbeing of their community. The AAD Coordination Centre is here to help with a suite of resources, handbook, toolkit, case studies and coordination support.

Find out more by emailing alliance@wapha.org.au, calling (08) 6278 7948 or visiting phexchange.wapha.org.au/AAD

Life after a spinal cord injury

Support, experience and advice

Every day in Australia, someone suffers a spinal cord injury. Whether it be a workplace, vehicle or sports accident, permanent paralysis is always unexpected.

The Paraplegic Benefit Fund (PBF Australia) is a registered not for profit charity that supports people who have experienced spinal cord injuries. It was established by the late WA spinal surgeon Sir George Bedbrook 35 years ago, when he saw the physical, emotional and financial effects a newly acquired spinal injury had on the patient.

PBF Australia aims to create greater awareness of spinal cord injury risks, with the goal of reducing the impact and incidence of spinal cord injury in Australia. But they are a unique charity in that they offer ways to help people move forward after a spinal cord injury, including providing qualifying members with a benefit of up to $250,000 paid within weeks of experiencing a spinal cord injury.

They also provide an invaluable peer support program at Fiona Stanley Hospital, Spinal Injuries Ward. The initial weeks and months in hospital following a spinal cord injury can be incredibly daunting. The newly injured must adjust to their new life with reduced mobility and all the associated challenges.

“Spinal cord injuries are indiscriminate,” PBF Australia’s Peer Support WA Coordinator Richard Higgins said.

“It doesn’t matter how old you are, how young you are, what colour your skin is, what sexual orientation, how much money you’ve got in the bank – it can happen to anyone. That’s the problem, people think ‘it would never happen to me’, but it does. It did. I was one of the unfortunate few.

“For all the patients in the spinal ward, it’s a massive, massive change.”

PBF Australia’s Peer Support Program supports new spinal cord injury rehabilitation patients to move forward with confidence. The peer support team, who are all living with a permanent spinal cord injury, offer non-clinical advice, mobility skills training and emotional support to patients and their families, enabling a person who has experienced a spinal cord injury to continue to live a vibrant and independent life.

Richard joined the Peer Support Program as a result of his own experience in a spinal unit at a hospital in England. While there, he met a former patient who helped him overcome the traumatic experience.

“1989 was a great year and a rubbish year for me. 26th May 1989 I had my accident, and just over 3 weeks before that I got married. It was my first week back at work after my honeymoon that I broke my back in a motorbike accident. I was 24 at the time.

“It was very traumatic, I was emotionally just a mess, completely. When I was transferred to the spinal unit at the hospital, there was a form of peer support, not officially called that but that’s what it was, and ex-patients used to come in and talk to new patients.

“There was a guy called Joe Lawrence who is unfortunately not with us anymore, but I credit him for where I am now. I was in a particularly dark place because I was young, just got married, and all my plans had gone out the window, and I had to readjust. Joe came in and spoke to me, and I’ve always remembered that, and always held that close to heart.

“I was introduced to PBF Australia about 13 years ago. The Peer Support Program was just starting, and we’d roll in and see patients, very similar to how Joe came to see me.”

Since then the program has been developed to have a more formal structure, supporting the incredible work of the doctors, nurses, occupational therapists and physiotherapists in the unit.

“Life’s too short, it’s not a dress rehearsal, people have got to get out there and live it. You’re just doing it from a sitting position. That’s it, really. Everything else is manageable, and doable.”

The team, comprising Richard and Hilary, who are paraplegics, and Scott, who is quadriplegic, go into the ward at Fiona Stanley twice a week and liaise with the education nurse to identify who needs their assistance.

“If they’ve got a question that they feel a bit silly asking a doctor, they can ask us. We always say, if you’re game enough to ask we’re game enough to answer. And we’re not judgemental.

“There’s a lot of power in knowing what’s going to happen to them, to know what to expect. The more they’re forearmed the more they’re prepared, instead of being hit with something unexpected later on, that’s like another slam, another loss.

“You’ve got to embrace disability. Usually that word, embrace, is used in a positive way, but if you embrace your disability and you own it, you manage it – it doesn’t manage you.

“And the moment you accept your disability, that is the moment your life will start moving forward and you can start doing, start travelling, start going out enjoying yourself.”

Richard said he gets an enormous sense of gratification from knowing he’s helped someone overcome something that could have otherwise taken years to come to terms with. By passing on his own experience and paying forward what he’s learned over the years, he and the team can help people with spinal cord injuries circumnavigate their new lives.

“I’m a paraplegic, I’ve lost the use of half my body, and I had some dark periods in the first couple of years with my injury, and even though I still had issues to deal with I came out of that hospital feeling empowered. And that’s because of the help I was given all those years ago by Joe Lawrence. I’ll never forget him. He inspired me, and helped me to do it, and I want to pass that on.

“As difficult as it is, you’ve got to come to terms with it. Own it. And move on in life. It’s hard, but you really can’t just stop.

“There’s life out there, and once you accept your disability, it’s there to go out and grab, and live. Life’s too short, it’s not a dress rehearsal, people have got to get out there and live it. You’re just doing it from a sitting position. That’s it, really. Everything else is manageable, and doable.”

The benefits of having people who are living with a spinal cord injury providing personal knowledge and experience to newly injured patients and their families cannot be underestimated. PBF Australia’s Peer Support Program shows that life can, and does, go on with a spinal cord injury.

If you are interested in becoming a PBF Australia member, please go to www.pbf.asn.au/membership/ for more information.

PBF Australia’s Peer Support Program is looking for partners or sponsorships to help them continue to deliver this life-changing service. If you are interested in working with them, please contact Richard at rhiggins@pbf.asn.au

WA Pelvic Mesh Support Group

Support, experience and advice

Mesh Awareness Day 2018

There are many women around the world suffering debilitating side effects from having pelvic mesh implanted for stress urinary incontinence, pelvic organ prolapse and rectopexy procedures. The problems relating to pelvic mesh have been labelled as one of Australia's biggest health scandals, with the suffering of many women across the country being poorly managed for too long.

WA Pelvic Mesh Support Group aims to raise awareness and provide support to women suffering physical and emotional complications from having mesh surgery. For these women, the complications of their treatment can be serious and life-changing. Ongoing anxiety, trauma, managing persistent pelvic pain, and the many impacts on daily life are just some of the challenges they face. This group provides a safe space for women to share their experiences and strategies for survival.

The group works closely with Health Consumers' Council and King Edward Memorial Hospital, advocating for patients and their physical and psychological needs. The group also assists in obtaining relevant hospital records and reporting adverse events to the Therapeutic Goods Administration, and holds monthly support groups in liaison with Women's Health and Family Services.

Louise Tompkins played a key role in getting the WA group up and running, after initially joining the Australian Pelvic Mesh Support Group started by Caz Chisholm. After meeting with other Perth women and Health Consumers' Council Executive Director Pip Brennan to discuss the senate inquiry, Louise realised there was a real need for a support system in WA.

"It was so emotional to actually sit there with other women that were in the same situation, and that was like the light bulb moment, we say. I put a call out for WA women to see if they wanted to meet up, and 23 women turned up. That was in early 2017, and we've now got 179 members in the Facebook group," Louise said.

"It was just about being able to really talk to each other and support each other. I can't tell you how impactful that has been for all of us; to meet other people that are in the same situation after wondering what is wrong with you for so many years."

According to Louise, many women are not aware that the pain, fatigue and auto-immune conditions they experience could be linked to their mesh surgery. What's more, some women don't even know they've had mesh inserted.

"A big part of the WA group is to provide awareness, really get the message out there, because there are women coming forward all the time. We have a very long way to go as there is little publicity on the subject and women are still being implanted without being fully aware of the risks," Louise said.

WA Pelvic Mesh Support Group has received vital support from ConnectGroups, who provided a grant towards a website and leaflets to help the group continue to reach out to women in need.

"We just want to help raise awareness both in the medical profession and to women who are sitting at home wondering what's wrong with them and not putting two and two together. We can help them, we've been through the pathway of reporting complications, getting records, and going all the way through to looking at what their options are and deciding whether removal is right for them.

"The biggest thing, the most powerful thing, and I think every woman in the group would agree, is knowing 'I'm not on my own'. Or 'it's not all in my head'. It's a huge issue, and its heartbreaking really."

The feedback the group has received from its members has been tremendous, and there is no doubt their support has had a huge impact on the lives of many mesh injured women.

"As a result of the senate inquiry there were a number of recommendations made which included retrospective audits, prospective audits of mesh that has been used and the amount of complications it's caused.

"But I think looking forward for us it's about awareness. Ideally we would like a moratorium on the use of all pelvic mesh until retrospective audits have been carried out and the true figures of these complications are known.

"The Federal Minister for Health, Greg Hunt, issued an apology last year to all women affected but in the real world nothing has really changed. What we want is the acknowledgement that these complications are real for us and for women to be able to make fully informed decisions knowing the true risks of these surgeries.

"Our sights are set on getting help from the medical profession for women who are suffering because they're just not getting the help they need. Many still feel dismissed or their doctors know nothing about the potential complications of pelvic mesh surgery. Our aim is to work with King Edward Memorial Hospital Pelvic Mesh Complications Clinic, work with the health department, get the support, and really really help them."

Screening of The Bleeding Edge

If you have symptoms that may be related to mesh surgery please call the King Edward Memorial Hospital Pelvic Mesh contact line on 1800 962 202

You can join the WA Pelvic Mesh Support Group at www.facebook.com/groups/wapelvicmesh/ and keep an eye out for the website, WA Mesh Awareness, which will be launched soon.

ConnectGroups

ANTONELLA SEGRE, CONNECTGROUPS CHIEF EXECUTIVE OFFICER

The value of support groups and the link to social prescribing

ConnectGroups is the peak body for Support Groups in WA. Its core service delivery contributes to better well-being outcomes for individuals, families and carers experiencing a health or well-being challenge, life situation or crisis by referring them to its extensive network of Support Group members (600+.) It assists the establishment, management and growth of Support Groups in WA through the provision of training and resources, mentoring, access to pathways to build new networks, and research and advocacy to raise awareness of the issues Support Groups face.

Individuals and families who share their experiences in dealing with stressful life problems and situations see a Support Group as a 'first step' to recovery and self-empowerment. Support Groups have been shown to improve health conditions and prevent problems associated with chronic illness and mental ill health in both the short and long term. They extend the value and impact of the service system by providing low or no cost support to people in the community that are proportionally over-represented in the service system, particularly in health.

With WA's Support Group sector made up of a mixture of both funded and unfunded groups of varying size and capabilities, the need for stable sector support, development and advocacy remains a high priority for ConnectGroups, who recognises the broadness of its membership. This inclusiveness helps ConnectGroups to support families regardless of a group's level of capability. Diverse Support Groups also provide valuable insight into which individuals, families or communities are falling through gaps in existing services.

'Social Prescribing' is the means by which health professionals, local councils, and community organisations can link individuals, families and carers into non-clinical community-based services.

Social prescribing provides meaningful benefit and value to societal health and wellbeing. Evidence demonstrates that three principle benefits can result: improvement in mental health outcomes, improvement in community wellbeing, and reduction of social exclusion. Many health care practitioners are already social prescribing but are unaware of it.

ConnectGroups has been operating in this space since 1984. It currently runs two specific innovative social prescribing models which address four of the WA Sustainable Health Review recommendation areas.

In January 2019, ConnectGroups, supported by Lotterywest and in collaboration with Health Consumers' Council and South Metropolitan Health Service, launched the Community Link Booth at Fiona Stanley Hospital. The initiative is mentioned in the Sustainable Health Review Report as an innovation to help address isolation and the persistent inequity in health and mental health outcomes that can stem from chronic conditions.

The Community Link Booth model sits within the social prescribing philosophy where individuals are provided with the tools to better self-manage their health journey. It is a scalable model that supports health care practitioners to more effectively utilise primary care resources. The model is designed to reduce GP and Emergency Department re-presentations, and hospital re-admissions by connecting patients and families at the hospital discharge point with referral pathways to peer Support Groups, community services, in-home services, and other supports specific to their needs.

"This is all part of doing things differently, recognising that the answer to many of our health issues lie beyond the hospital wall. The Community Link Booth is a vital link between hospitals, patients, and community support providers in WA," Health Consumers' Council Executive Director Pip Brennan said.

WA Ambulance Services

Health Consumers' Council, together with Marketing for Change, has partnered with the Western Australia (WA) Department of Health to gather consumer opinions on the WA ambulance service – because we know the best way to improve something is to gain feedback from the people who use it.

If you have called or used an ambulance in WA in the past five years we'd like to hear from you. How was your experience? What was the wait time like? Were the ambulance staff friendly and efficient? Do you have any ideas on how things could be improved?

If you are based in Western Australia and have used an ambulance either in an emergency or for a planned transfer, please contact us on (08) 922 3422 or on info@hconc.org.au

Sharing your story can make our health service better.

Ambulance service survey and public consultation coming soon.

Register your interest at info@hconc.org.au with "ambo" in the subject line.

The Question Builder tool

Helping you ask the important questions

Health Direct, in partnership with Australian Commission on Safety and Quality in Healthcare, created the Question Builder tool to help people prepare for a medical appointment by creating a list of questions to ask the doctor.

One of the best ways to communicate with your doctor and be more involved in decisions made about your health is by asking questions.

By working through a series of steps on the Question Builder website, you can create a list of the most important questions to ask your doctor and you can prepare for the questions you may be asked too.

Question Builder helps you ask your doctor questions that are important to you about your health and care, whether you:

- have new symptoms
- are having a checkup
- are managing a chronic health condition
- are discussing a medicine, a test or surgery.

This preparation will help you get more out of the time with your doctor and help you to remember everything you want to ask.

Don't be afraid to ask questions – it is important to understand your healthcare options and make decisions about your care with your doctor.

Once you've put together your list of questions, you can print it out to have on hand during your appointment. You can also email a copy to someone who is coming to your appointment with you.

Give the Question Builder a try for your next appointment:

www.healthdirect.gov.au/question-builder

Empowering men to be proactive

Western Australian Men's Health and Wellbeing Policy

In a WA first, the state government has committed to improving health outcomes for all men and boys in the state.

In addition to helping men reach their potential and be supported to enjoy a long and high quality life, improving the health of men and boys will have a positive flow on effect for their partners and families, the community and the economy.

The Western Australian Men's Health and Wellbeing Policy, which was released during Men's Health Week, recognises that supporting the health and wellbeing of men needs to be a whole-of-community issue – including a focus on promoting and facilitating men's healthy living and strengthening health and community service delivery to men.

Currently in WA, males experience a higher rate of suicide, cancer, type 2 diabetes, heart and lung disease and stroke than women. More than 77 per cent of WA males are overweight or obese, more than 14 per cent smoke, and more than 31 per cent exceed alcohol consumption guidelines, which is the highest figure in Australia.

"There are many fundamental and compelling reasons to develop this policy and for our Government's commitment to do more for men's health across the state," Health Minister Roger Cook said.

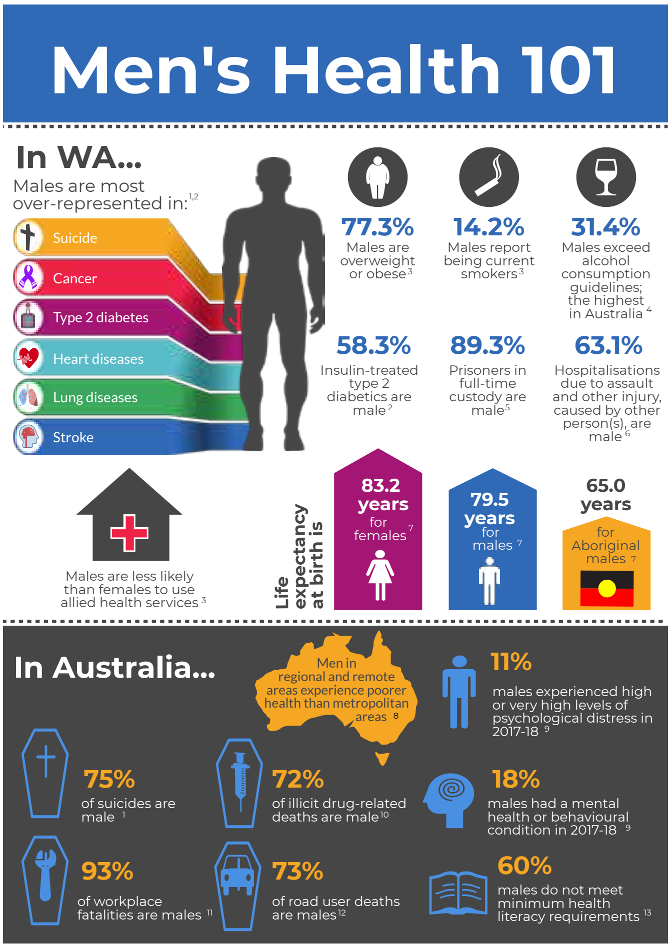
"This is a much needed piece of work which outlines clear goals and areas requiring action where men and boys are at higher risk.

"It will lead to real gains, tangible actions and health improvements for men and boys, and for all those working with them, in communities across our state."

The three goals listed in the Policy are:

1. **Men are empowered to be proactive in managing their health and wellbeing**
2. **Men have equitable access to services (including prevention and early intervention initiatives) that meet their needs**
3. **Men's health and wellbeing needs are monitored, evaluated and inform continual improvement of programs, services and initiatives.**

The policy pays particular attention to at-risk populations, including men living with mental illness, Aboriginal men, men living in rural and remote areas, men with disability, males with diverse sexualities (including intersex and those with transgender experience), men directly impacted by fly in, fly out work, and men from culturally and linguistically diverse backgrounds.



Safe, accessible and equitable

Western Australian Women's Health and Wellbeing Policy

When it comes to health, women and men have vastly different needs, opportunities and obstacles. For women, we know that issues such as gender based violence, lower incomes and disabilities can make accessing health services problematic. On top of this, women have specific health needs related to sexuality, pregnancy, fertility, postnatal, gynaecological illness, chronic illness and mental health.

As women are often the key to maintaining healthy families and tend to access the health system more than men, it is vital that health services in Western Australia are accessible and safe, and provide the right services for the issues being experienced by women and girls throughout WA.

In March this year, Health Minister Roger Cook announced consultation would begin for the new State Policy on Women's Health and Wellbeing. Designed to complement the recently released Western Australian Men's Health and Wellbeing Policy, the new Policy will focus on inequalities in health outcomes between women and men, and in population risk groups of girls and women.

"If we are to achieve equality – in health and in other aspects of life – it is important that we listen to women about what is important to them and the changes they want to see," Women's Interests Minister Simone McGurk said.

The new Policy will identify action areas for WA that align with the priorities contained in the soon to be released National Women's Health Strategy 2020 – 2030 and the McGowan Government's Women's Plan, currently under development by the Department of Communities.

Community consultation has recently closed and the policy is expected to be released at the Women's Health Conference on 2nd September.

A framework of supportive strategies

SHEREE MEARS, HEALTH CONSUMERS' COUNCIL OPERATIONS MANAGER

Western Australian LGBTI Health Strategy

"Individually we are broken by shame, isolation and discrimination, collectively we gain strength to share our stories and let our voice be heard."

LGBTI populations have faced decades of inequitable treatment, stigma, exclusion, isolation, discrimination and abuse. Throughout the development of the WA Lesbian, Gay, Bisexual, Transgender, Intersex (LGBTI) Health Strategy, which will provide a framework to raise awareness of the specific health and mental health challenges of LGBTI people, and my involvement with the reference group, I have heard firsthand the extent of the damage this treatment has caused for people. It is these stories of people's real experiences of care in the health system that have reinforced the need for this strategy to be adopted and integrated into everyday practice.

The strategy aims to raise awareness of the physical health and mental wellbeing of LGBTI people across the lifespan and to provide a framework of supporting strategies to enhance equity in access and health outcomes.

Overall, 14 workshops were held across WA, attracting input from LGBTI community representatives and more than 500 participants in the consultation. This data provided the reference group with raw material to determine key themes, priorities, quotes and recommendations. Mostly, it highlighted that many voices may have remained silent, which demonstrates some of the barriers and challenges that the strategy seeks to address.

Members of the reference group have drawn from personal experience, deep reflections and insight as well as the hundreds of stories that were heard and the understanding that thousands of lives have been negatively impacted. The opportunity to participate in forming this strategy has created a hope for change in the future.

The Strategy is currently being reviewed by the Health Minister.

Sustainable Health Review

PIP BRENNAN, HEALTH CONSUMERS' COUNCIL EXECUTIVE DIRECTOR

Making it real

On the 1st of July we convened a Consumer, Carer, Family and Community Representative Networking session about the Sustainable Health Review (SHR). Presentations were provided by myself as former Chair of the Sustainable Health Review's Consumer & Carer Reference Group and SHR panel member, and Leon McIvor, WA Health's Acting Assistant Director General of Strategy and Governance and also former panel member.

Questions were solicited through an event registration form, and included:

- What is the plan for implementation?
- Who will be joining Hugo Mascie-Taylor on the independent panel that oversees the implementation?
- What new approaches to citizen and community partnership are the implementation team looking at already?
- What thinking has there been so far to support the culture change required inside the health system to implement all the feedback that comes through the new models of partnership?

Some key points from the WA Health presentation included:

- Strategies and recommendations come as an interdependent package and do not lend themselves to cherry picking.
- Executive directors of Area Health Services will be working as leaders in the health system on recommendations, alongside WA Health System Manager staff on specific recommendations. Watch this space.
- The Sustainable Health Review Implementation Support Unit is currently being established, with staff being actively recruited. [Nicole O'Keefe has now been appointed Assistant Director General of Strategy and Governance and will be taking on the role from 2nd September.]
- There is still no formal announcement of the Independent Oversight Committee members, other than Huge Mascie-Taylor.

After the presentations, feedback was sought as part of a facilitated workshop. Some of the responses included:

Consumer, Carer and Community Engagement

- The major dependency for SHR recommendations is how you engage with consumers and carers. It cannot still be one person on a committee. What about quotas/targets that we measure? Have co-leads that come from outside health.
- Look at models of consumer empowerment – particularly for chronic disease.
- Create a Consumer and Community Advisory Council at the Department of Health that is accessible for consumers to tell their stories (membership from all district health services/health service providers).
- Only use the term co-design if you genuinely do it.

Engaging with staff

- Many frontline staff are already working very hard to deliver services.
- Identify the influencers of change (i.e. the 3%) who may not necessarily be the formalised line managers.
- Implementation must involve collaboration with frontline staff – not leaving them to be at the end of a top down approach.

What can you do practically in your role? What will you do differently after today?

- Spend time working out where I can influence using SHR
- Involve fellow CAC members in our own sites
- Develop a CAC stakeholder/community engagement plan
- Encourage members of my network to contribute
- Talk about SHR more
- Promote Patient Opinion
- Look for "co-design" commitment in policy/frameworks

We will continue to post updates as the SHR Implementation progresses. If you have ideas you want to explore at your health service level, we encourage you to do so and keep us posted. We have a web page here: **www.hconc.org.au/what-we-do/policy-development/sustainable-health-review-consumer-view/**

Putting theory into practice

This year, the Health Consumers' Council Advocacy Service again welcomed a social work student to join us as part of her placement requirements. We were so impressed by Sam that she is now a permanent part of the team!

Here's what Sam had to say about her placement experience.

"Being a student on placement can be difficult and stressful; we are having to use our brains in ways we have not yet done in applying theoretical knowledge into practical skills. We are constantly being given feedback from supervisors, co-workers and consumers and then having to digest it, apply it and incorporate it into future interactions.

"Placement for social work students is full-time (37.5 hours a week, for 14 weeks) and unpaid, so not only are we having to adjust to placement but also juggling our personal lives, running households, and for some part-time jobs. To say that placement can be overwhelming at times would be an understatement.

"However, there is amazing learning that takes place while on placement; for me there was finally a connection from the theoretical knowledge to the practical as I finally got to see the humanness behind those theories.

"Before starting my degree, I often thought that I wanted to do social work because I wanted to give back and help others. However, as I worked my way through my placement hours at Health Consumers' Council I came to realise that I was not just giving, but that I was also taking and learning.

"My lecturer at Curtin University has reminded us that no one sets out to be a subject for social work students to learn from; as such, I feel very privileged that so many health consumers have been able to share their stories with me, and allowed for me to play a part in their journey, and ultimately allowed me to learn and grow as a future social worker.

"For this, I am thankful to all that have contributed to my journey through placement and for those to come, as I know that my learning will not stop here, for we are life-long learners."

> "I finally got to see the humanness behind the theories."

Health Consumers' Council at Patient Experience Week

Updates

School for Change Agents

School for Change Agents has wrapped for another year, after six webinars and sessions discussing how we can incorporate the learnings into everyday life. A key message from the School is the value of staying connected with others in our change agent roles. We've started up a Facebook group to continue discussions and we are looking at the best ways we can use it to support change agents across the health system. If you have ideas or suggestions please let us know – or just jump into the group! www.facebook.com/groups/WAschoolforchangeagents/

State Cancer Plan

We've been working with the Department of Health as they develop the WA Cancer Plan 2020-2025. Our role was to determine consumer priorities and perspectives on cancer control and cancer research in WA in order to guide the development of the plan and to ensure it is patient centric. We obtained consumer perspectives through online surveys and heard personal experiences through written stories and videos.

The Cancer Services forum was held on 26th July, and we provided a video of consumer stories, one written story, and a presentation including the 170+ survey responses we received.

Health Literacy (rights and responsibilities in healthcare)

Red Cross runs information sessions for newly arrived migrants on a continuous basis. Our Cultural Diversity officer Karen has presented at several of these sessions to provide an additional perspective to help migrants understand WA's health system. She has also presented at English conversation classes held at community libraries. Through these sessions we have seen a need for extra information and plan to develop a series of short videos on health literacy topics.

Partners in Change Obesity Collaborative

A draft action plan has been developed by the Department of Health and has been circulated for consultation to the consumers who expressed interest in the project. DoH also invited consumers who participated in the consultation process to be photographed for possible inclusion in the final published report.

Health Engagement Network

The Network is an online community for people interested in the practice of consumer, carer and community engagement. The latest meeting was held on 31st July and marked one year since the Network was launched. The theme of the meeting was conversations of change, exploring how people can express different opinions while also maintaining productive relationships. The session was facilitated by Joel Levin of Aha! Consulting (on a pro bono basis) and Clare Mullen of Health Consumers' Council.

Data and Privacy

The WA Government is proposing to introduce a whole-of-government framework to meet the twin priorities of protecting Western Australians' privacy and enabling information to be safely used for their benefit. A public information session will be held at the State Library on September 4, 2019 at 5.30-6.30pm. For more information about the session and how to register: https://www.eventbrite.com.au/e/privacy-and-responsible-information-sharing-public-information-session-tickets-66850546785

The consultation period will run until the end of October with written submissions due by Friday November 1, 2019. Health Consumers' Council is running a consumer, carer and community consultation session on 2nd October, at The RISE in Maylands.

The government's consultation website is at www.wa.gov.au/privacyproject

Dates for the Diary

Empowering Health Consumers with Disabilities Workshops

Online session

Thursday 15th August 2019, 11am – 12pm

To register or for more information: www.hconc.org.au/projects/empowering-consumers-with-a-disability/

Supporting Communities Forum: “Where’s the line between the public good and my privacy? Community Conversation on Privacy and Responsible Information Sharing”

2nd October, more details to follow

Palliative Care Summit

Saturday 24th August, Perth Convention and Exhibition Centre

For more information and to register: www.hconc.org.au/palliative-care-in-wa/

Women’s Health Conference

2nd September, Perth Convention and Exhibition Centre

Register at www.eventbrite.com.au/e/lifting-the-profile-on-womens-health-wa-womens-health-conference-tickets-62343328574

City of Rockingham Seniors and Carers Expo

11 October, 10am – 2pm, Mike Barnett Sports Complex

Health Consumers’ Council will have a stall at this event – come along and say hi!

rockingham.wa.gov.au/Services/Seniors/Seniors-and-Carers-Expo

Health Consumers’ Council Annual General Meeting

12 November, 5pm – 7pm

Members are invited to join us for our AGM

North Metropolitan TAFE, 140 Royal Street, Room D102. Street parking is available

HEALTH CONSUMERS'
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Health Consumers' Council

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Opening hours

Monday - Friday 9.00am - 4.30pm
Closed Public Holidays