

HEALTH MATTERS

Health Consumers' Council (WA) Inc. Magazine

Issue 3 2016



Burgundy
Multiple Myeloma



Lime
Lymphoma



Pink
Breast Cancer



Orange
Leukemia



Kelly Green
Kidney Cancer



Lavender
All Cancers



Gold
Childhood Cancers



Emerald
Green
Liver Cancer



Purple
Pancreatic &
Leiomyosarcoma



Yellow
Sarcoma/Bone/
Bladder Cancer



Teal
Ovarian
Cancer



Periwinkle
Blue
Esophageal &
Stomach Cancer



Peach
Uterine Cancer



Blue
Prostate
Cancer



Dark Blue
Colon Cancer



Black
Melanoma



Grey
Brain Cancer



Burgundy/
Ivory
Head & Neck Cancer



Clear
Lung Cancer



Teal/White
Cervical Cancer



Teal/Pink/
Blue
Thyroid Cancer

Chemo isn't the rest of my life...

After cancer treatment, not always the
end of the journey

You have mail: A lifesaving bowel cancer test

Good news for people diagnosed
with cancer - Health Care Home is coming!

Cancer Survivorship: What is it like for those
who have arrived as immigrants?

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Foreword



Winter Greetings

Welcome to Edition Three of Health Matters, with its theme of 'Cancer Survivorship – when treatment is over'. The publication of this edition of Health Matters will coincide with our partnership event with Cancer Council WA and Carers WA, 'After cancer treatment ends - Where to from here?', a community event to mark Daffodil Day 2016.

The theme of the next edition of Health Matters is on 'Voluntary Mental Health'. If you would like to submit an article, please contact HCC on info@hconc.org.au attention Lucy Palermo, so we can provide submission guidelines.

Patient Experience Week Wrap Up Patient Experience Week Event Series & Consumer Awards 2016

On April 28 and 29 this year, HCC branched out into the unknown, hosting of 8 separate events to mark Patient Experience Week. We finished the two days with our Consumer Excellence Awards. For a summarised report on Patient Experience, see page 24.

Preparations have already begun on Patient Experience Week Conference 2017. Stay tuned for updates.

Patient Experience Clinical Senate Debate December 2015

A key part of the work HCC will be doing in partnership with the Health Department is updating the Patient First materials in response to feedback that has been received from carers, consumers, clinicians and community members. Specifically, we are partnering

Cancer Survivorship - When the treatment is over

with WA Country Health Service and Royal Street's Quality Improvement and Change Management Unit. We will keep you posted on its progress.

The State News section provides an update on recent Clinical Senate Debates and their recommendations.

Staff

We have had a few comings and goings in the last three months, with our Operations Manager Meegan Taylor resigning to head off into pastures new. Similarly Advocate Gio Terni, has resigned. We wish them both the best with their future endeavours.

On 30th June 2016, HCC's federal funding for the Aboriginal Advocacy Program ceased. This has meant that after ten years HCC has had to bid a sad farewell to Laura Elkin. Laura is very well known to many of you and has worked with many communities in the last ten years. Laura's farewell was marked at our NAIDOC week celebration. Read more on page 17. HCC will still offer individual advocacy services with Tania Harris who remains on the team as one of the individual advocates under our State funding.

AGM & Q&A Session

Health Consumers' Council AGM will be held on Wednesday, 28th September. The AGM will be followed by a Q & A session on 'Consumer Engagement in the New World Order'. This is an unscripted session where panelists will give their views on, what consumer engagement will look like in the new world of devolved health services?

Panelists include; Director General of WA Health, Dr David Russell-Weisz, Child and Community Health Service Board Chair Ms Debbie Karasinski, North Metropolitan Board Consumer Representative Ms Michele Kosky, Area Health Service Executive Director Liz MacLeod and Royal Perth Group Director of Consumer Engagement Todd Gogol. More details are available on page 23.

Pip Brennan Executive Director Health Consumers' Council

Letters to the Editor...

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



Message from the Health Matters Editor

Dear Members,

This issue has been one close to my heart. While in the process of putting this together my family lost someone to cancer. Cancer is something that has touched all our lives. Most of us either know someone who has cancer, has survived cancer or has died from cancer.

It is through this medium that we can share real stories and can work together to improve treatment for future patients and better support those that have been left behind.

If you have a story you would like to share with Health Consumers' Council please use the contact details below.

Kind regards,

Lucy Palermo
Health Matters Editor

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

Only one consumer not enough on Area Health Service Boards

Dear Editor,

Have just finished reading issue 2, 2016 of the Health Consumers' Council magazine "Health Matters".

On page 11 in amongst the article on reforms and recommendations by the Clinical Senate was the statement that "a consumer is appointed as a member of the State Health Executive Forum or its equivalent after the implementation of the Health Service Boards", my question to this is - why only one consumer?

Even the most experienced consumer representative at times needs the support/backup at meetings of another consumer as the medical professionals at times still seem to think "what do you know? You don't have the piece of paper that says you know anything". Knowing that you have somebody sitting with you who thinks along similar lines can make you more effective. It also means that if one consumer can not attend a meeting there is a greater chance of the other consumer still being in attendance to make sure the consumers voice is still heard.

When the Health Service Boards begin, I am guessing they will tie in with the existing consumer advisory councils?

Margaret Ryan
Ballajura WA

Editor: We love your idea of more than one consumer on the State Health Executive Forum but HCC would love to see just one for a start! We think there will need to be ongoing pressure applied just to get one!

HCC is working very closely with the area health service Boards, which should liaise with all the hospital CACs in their area, as well hopefully as any consumer reps on community committees. HCC is actively engaging with the Interim Chairs to ensure consumer engagement is at the top of their list.

After cancer treatment, not always the end of the journey

Sandy McKiernan | Cancer Council WA



Picture supplied by Cancer Council WA

The end of active treatment can mean many things to people affected by cancer. The start of a “new life” often beckons with opportunity to live life a bit differently, whether that be lifestyle changes, overcoming previous bad habits or a wholesale change on where you thought you were headed. What is not always anticipated is that it can take some time to get life back on track and that ongoing information and support can often be required.

Cancer Council WA provides a unique range of FREE services and programs to people affected by cancer – be they diagnosed themselves or a carer or family member. Our range of services can be stepping stones to improved health and wellbeing during your cancer recovery.

Physical health

Cancer can leave you physically changed. Weight loss or gain, loss of strength and balance, lack of appetite and taste changes can be common after effects of treatment.

Current research supports exercise as the greatest potential to reverse or minimise treatment-related side effects and increase the overall quality and quantity of life in people with cancer. The significant benefits can include assisting with pain management, reducing fatigue, preventing weight gain, improving physical function and improving overall quality of life.

The Life Now Exercise Program is tailor-made for people who have been diagnosed within the last two years and who are undergoing or have completed cancer treatment. The FREE program runs for 12 weeks for an hour session twice a week, and is facilitated by an accredited exercise physiologist. The purpose of the program is to introduce exercise in a safe and supportive environment and to empower people to manage their own physical activity. No gym junkies or lycra are to be found – just other cancer patients regaining strength and fitness one class at a time.

If you are not yet ready for exercise you might like to try Yoga or Tai Chi – a little less energetic but with positive effects for people affected by cancer. www.cancerwa.asn.au/patients/support-and-services/life-now/

Mental Health

Sometimes it's keeping your mind in check. The question “will my cancer return” is a very common one and fear of cancer recurrence in the first months and for some even years after cancer treatment ends can be debilitating. Whilst it is not easy for even your doctors to predict this outcome, living in the present and focusing on living well can be valuable.

Life Now Mindfulness Relaxation and Life Now Meditation are two programs designed to do just that. Each term of six to eight weeks can teach you techniques to calm your mind and develop stress reduction and relaxation strategies that can be really helpful to reduce the stress of living with uncertainty.

Research shows these programs may reduce anxiety, improve mood, quality of life, sleep and provide pain relief.

Sometimes talking it through can be the key. Whether it is during treatment or out the other side, getting a handle on what has changed in your life can sometimes be best achieved by talking to people outside of your immediate family and friends. Cancer Support Groups offer the support of others who have similar experiences, are run by trained health professionals and peer leaders and can for many be the only space where sharing your cancer experience once treatment ends, can feel ok. Groups are not for everyone and an alternative would be seeing a professional Cancer Counsellor. Cancer Council WA has a small network of cancer experienced counsellors in both metro and regional WA. Access is FREE or low cost and can be face to face or even on the phone. www.cancerwa.asn.au/patients/coping-with-cancer/emotional-effects/

Healthy Living after Cancer program

Getting back to a healthy lifestyle after cancer is one of the most important things you can do for your health. Our Healthy Living after Cancer (HLaC) program offers free health coaching over the phone, with experienced cancer nurses. The program can help you get active, eat better and feel better, so that you can do more of the things that are important to you.

You'll receive up to 12 health coaching calls over a period of six months from a 13 11 20 Cancer Council nurse. The program is delivered entirely by telephone, so you can access it wherever you live in WA. A nurse will work with you to make healthy lifestyle changes by setting goals for physical activity and healthy eating. Our Cancer Council nurse will help you reach these goals by giving you support, helpful tips and motivation. www.cancerwa.asn.au/patients/staying-well/healthy-living-after-cancer/

Returning to Work

If you have been away from the workplace and are planning on returning there certainly can be a few hurdles. Returning after sickness can be overwhelming, or starting a new job or even job hunting when you have been out of action for a while can be quite scary. The Pro Bono Legal, Financial and Workplace Advisory service is a great program aimed to support the legal, financial and workplace issues of cancer. www.cancerwa.asn.au/patients/coping-with-cancer/coping-legal-financial/

Getting Started

Calling 13 11 20 and talking to one of our Cancer Nurses can be one of the best ways to start your

cancer recovery. Our nurses will work with you to find what suits you and your circumstances, no one solution fits all and you may find a range of our programs can help you to get back to a "new normal".

To find out about these and other programs call a Cancer Nurse on 13 11 20 and let us be your Compass through Cancer.

www.cancerwa.asn.au



Pictured: Audrey

Healthy Living after Cancer

Audrey is in her eighties and lives in a Wanneroo retirement village. She was treated for breast cancer and is currently taking part in the Cancer Council program, Healthy Living after Cancer.

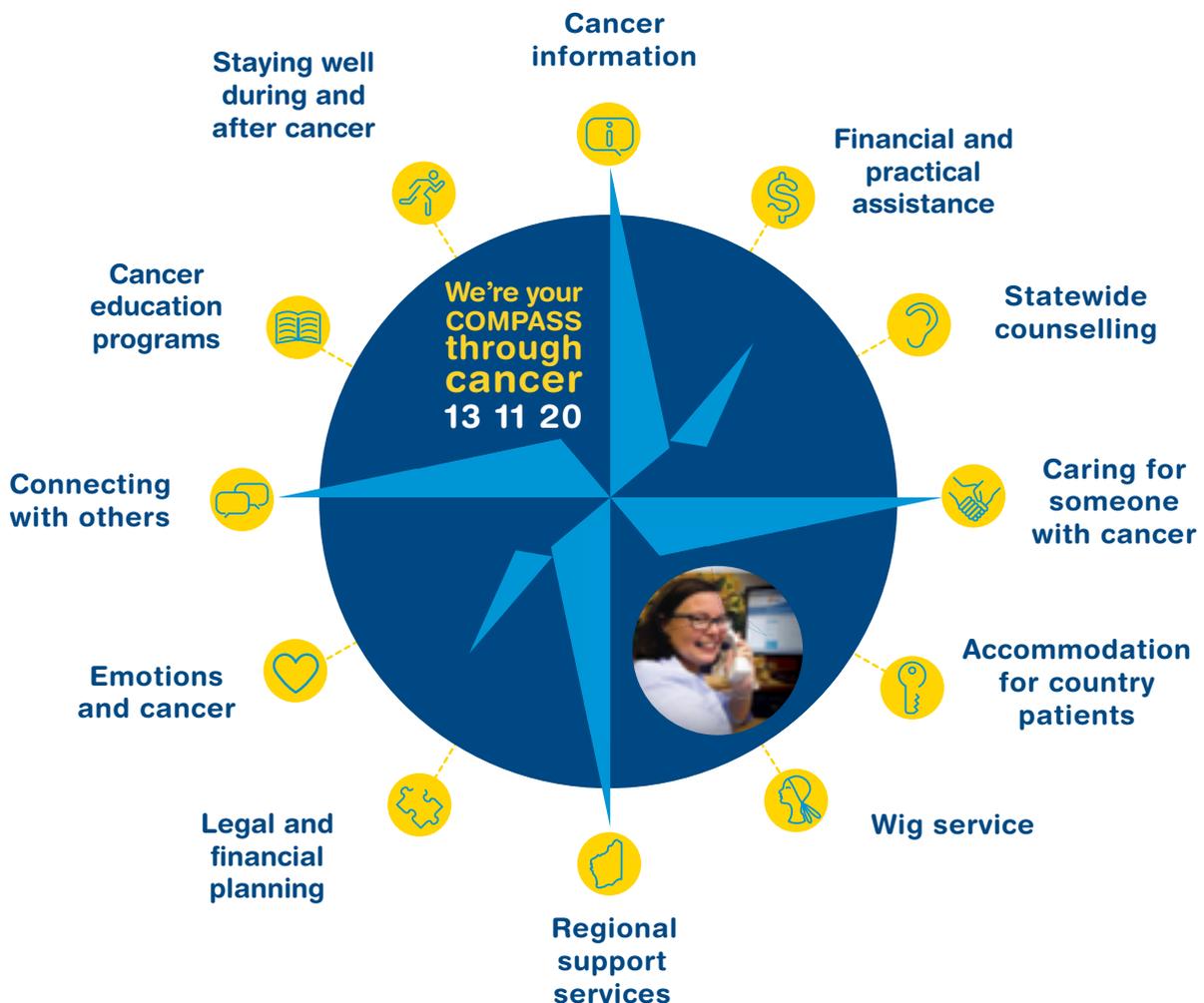
Healthy Living after Cancer is a telephone-based support program for people who have finished cancer treatment. Cancer Council 13 11 20 Nurses work with participants to help them achieve their physical activity and healthy eating goals. Audrey has been taking part in Healthy Living after Cancer since September last year and she has noticed some very positive benefits by taking part. She has increased her physical activity levels and said: "I'm walking further and feel much stronger."

Audrey also now feels more confident about being active; she said "I'm much more confident about getting out and about." Whilst she still takes her walking stick with her, she said that she feels ready to throw her walking stick away!



Not sure which way to turn?

Our range of services and programs can help guide the way



Call us on 13 11 20 for information and support for anything cancer-related

WA Cancer & Palliative Care Network (WACPCN) Survivorship Collaborative

Dr David Joske Clinical Haematologist | SCGH



Pictured: Dr David Joske

It is estimated there are 70,000 Western Australians currently living after a diagnosis of cancer (excluding minor skin cancers). For some, their cancer journey is a remote memory; for others, they are currently going through what may be intensive, complex and demanding multi-modality treatment. The optimum care of people after cancer and, where possible, full recovery and return to the complete spectrum of life - relationships, work, physical and mental good health, sexuality - has become internationally recognised as important, and labelled as Survivorship.

The term first appeared in an article in the New England Journal of Medicine by Fitzhugh Mullan, a specialist physician who described his own (in fact extraordinarily difficult) path after self-diagnosing metastatic cancer on his chest x-ray. He famously wrote, "Despite the success on the treatment front, we have done very little in a concerted and well-planned fashion to investigate and address the problems of survivors. It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them

on the dock to cough and splutter on their own in the belief that we have done all we can." (Mullan F. Seasons of Survival: Reflections of a Physician with Cancer. NEJM 1985; 313(4):270).

The WA Cancer and Palliative Care Network (WACPN) Survivorship Collaborative was instigated in late 2014 and has held four meetings. All interested health professionals are invited and we have representation across public and private health care providers, all disciplines including senior and junior medical, primary care physicians, nurses, allied health, universities and researchers, psycho-oncologists, Charities and Not-for-Profit and age-specific organisations such as Canteen.

Our goal is to promote the optimal recovery of Western Australians after a diagnosis of, and/or treatment for, cancer. This is to be achieved through improving clinical care, communication and education, and fostering research. Examples of such aims include identifying and agreeing upon appropriate tools and instruments for good survivorship, ensuring equality of access to good survivorship across age, geographical, cultural and linguistic barriers; promoting consumer awareness, dialogue across health stakeholders, greater involvement of the

2016 Federal Election

It's been a confusing cliff hanger of an election, with MediScare one feature of the election campaign. What has not featured however has been the cost of health care to consumers. Australia has the third highest out of pocket costs among wealthy nations. The Grattan Institute's Stephen Duckett wrote a very interesting blog on costs in health care. A summary of key points follows, and you can contact the Health Consumers' Council if you would like more information or a copy.

Duckett suggests that even with the "wafer thin" majority the new Federal government has, there are key actions that could be taken:

1. Better manage chronic disease
2. Improve end of life care
3. Reducing waste including excessive hospital costs
4. Harder to achieve reforms include:
5. Reducing unnecessary hospital admissions
6. Addressing high pathology payments
7. Reducing pharmaceutical prices
8. Updating the Medicare Schedule (work in progress)

The removal of bulk-bill incentives should be ditched, in Duckett's opinion.

Another key point of the blog is the uncertainty of costs for the consumer. When undertaking a referral for a patient to a specialist the GP usually has little idea of the cost impact on the consumer. Duckett makes a key point; "Medicare already holds information about the fees that specialists and general practitioners charge for each consultation or procedure. It should publish this."

Imagine being in a position to make informed financial consent as a patient. We are currently some way away from this.

The full blog can be accessed via <http://croakey.org/many-australians-pay-too-much-for-health-care-heres-what-the-government-needs-to-do/>

Reform Updates

The Medicare Benefits Schedule Review

Work continues on this significant project as the MBS schedule is worked through. It may interest you to know that after each meeting outcomes are published on the Federal Health department website. In April 2016 the Chair of the Review Taskforce Professor Bruce Robinson released a report which is available as a powerpoint. An interesting slide shows the top 15 Medicare Benefit Schedule items which account for most services – Item number 23, standard GP consult under 20-minutes accounts for just under \$90 million in the 2013-14 data, with the next item, 73928: Pathology – collection of a specimen in an approved collection centre accounts for \$20 million. Long GP consults (i.e. Longer than 20 minutes), Item number 36 accounts for just above \$10 million. The curve of the graph trails off after that. So it is vital that the work on the GP reforms continues, as this is where most of the MBS spending occurs. It is vital that we are getting value for this investment. It is reassuring to see the MBS Review presentation reference the Primary Care Review and know these two pieces of work are progressing in tandem.

The Primary Care Review

On 31st March 2016 the Federal government released the December 2015 report from the Primary Health Care Advisory Group entitled "Better Outcomes for people with Chronic and Complex Health Conditions. The report's fifteen recommendations cover these four areas:

- Appropriate and effective care
- System integration and improvement
- Payment mechanisms to support a better primary health care system
- Measuring the achievement of outcomes

Under the banner of appropriate and effective care are Health Care Homes, which are a mechanism for joined up care for patients including allied health specialists as well as the GP. 65,000 Australians will participate in a two-year trial of health care homes in up to 200 GP practises from July 2017. Health care homes can be voluntarily enrolled in by relevant patients i.e. those with complex and chronic conditions within the 200 or so nominated practices (yet to be announced).

You can view all of these reform updates and report on the Health Department website www.health.gov.au. Please contact us on 9221 3422 if you would like more information or a copy.

Statewide News

Pip Brennan Executive Director | HCC

Health Service Reform

From the 1st July 2016, WA Health Service Boards are no longer interim. The North, South and East Metropolitan Health Services, Child and Adolescent Health Services and WA Country Health Services are now devolved from WA Health. This reform will create a period of significant transition as the new arrangements bed down. By now all the Board members have been appointed and have undergone induction. As this is such a far-reaching reform in WA Health, we will be hosting a live Q&A Panel discussion with the Director General of WA Health, an Area Health Service Board Chair, Executive Director and Consumer Representative.

The full list of Board members appears below and you can access more information about health reforms from <http://ww2.health.wa.gov.au/boards>

East Metropolitan Health Service: Executive Director, Ms Liz MacLeod

Board Chair: Mr Ian Smith PSM

Deputy Chair: Mrs Suzie May

Board Members:

- Mr Peter Forbes
- Mr Ross Keesing
- Mr Richard Guit
- Ms Debra Zanella
- Prof Kingsley Faulkner AM
- Dr Hannah Seymour
- Dr Stephanie Trust
- Ms Geraldine Ennis PSM

South Metropolitan Area Health Service: Executive Director, Dr Robyn Lawrence

Board Chair: Mr Robert McDonald

Deputy Chair: Adjunct Associate Prof Robyn Collins

Board Members:

- Adjunct Associate Prof Kim Gibson
- Prof Julie Quinlivan
- Ms Fiona Stanton
- Mr David Rowe
- Ms Michelle Manook
- Ms Yvonne Parnell
- Mr Julian Henderson
- Prof Mark Khangure

North Metropolitan Health Service: Executive Director, Wayne Salvage

Board Chair: Prof Bryant Stokes AM

Deputy Chair: Associate Prof Rosanna Capolingua

Board Members

- Dr Margaret Crowley
- Dr Felicity Jefferies
- Ms Michele Kosky AM
- Mr Graham McHarrie
- Ms Maria Saraceni
- Prof Simon Towler
- Prof Grant Waterer
- Mr Geoff Mather

WA Country Health Service: Executive Director, Jeff Moffet

Board Chair: Dr Neale Fong

Deputy Chair: Ms Wendy Newman

Board Members:

- Mr Michael Hardy
- Dr Daniel Heredia
- Dr Kim Isaacs
- Mr Joshua Nisbet
- Mrs Mary Anne Stephens
- Mr Alan Ferris
- Ms Meredith Waters

Child and Adolescent Health Service: Executive Director Dr Frank Daly.

Board Chair: Ms Deborah Karasinski

Deputy Chair: Prof Geoffrey Dobb

Board Members:

- Dr Daniel McAullay
- Mr Brendan Ashdown
- Ms Kathleen Bozanic
- Ms Anne Donaldson
- Mr Peter Mott
- Mr Andrew Thompson
- Dr Alexius Julian

Clinical Senate Debate – SuperBugs

In March 2016 the first 2016 Clinical Senate debate was held on the topic of Superbugs. Six recommendations were endorsed:

- That WA Health implement an Electronic Prescribing System (EPS) that may be used across all health facilities and can capture prescribing data so it can be benchmarked and used to monitor compliance with therapeutic guidelines.
- WA Health to provide recurrent funding for, the Infection Control Automated Surveillance Technology (AST) system, support its

implementation, and be responsible for its maintenance.

- WA Health to develop, area health services to adopt, and hospital executive to promote a statewide framework for standardised training and education to ensure antimicrobial stewardship is everyone's business. Essential to this is the need to:
 - involve key end-users in program (re) design to ensure education is fit for purpose
 - target poor-performing disciplines and clinical areas
 - include prevention education i.e. IV cannulation, aseptic technique and hand hygiene.
- WA Health mandates each hospital undertake periodic antibiotic usage audits (e.g. National Antibiotic Prescribing Survey (NAPS) and results should be fed to area health services, boards and quality and safety committees for review. Comparative data for similar hospitals should be made publicly available after a three-year implementation process.
- WA Health must write to non-hospital health system managers (e.g. Aboriginal medical services, WA Primary Health Alliance (WAPHA), residential aged care facilities, General Practitioners) and ask them to ensure they have guidelines for antibiotic stewardship that includes consideration of surveillance activities and ability to feedback to their clinicians.
- WA Health ensures all 'clinicians' involved in invasive procedures demonstrate competence in aseptic technique. This could be facilitated by the Director General of Health writing to all WA University Vice Chancellors requesting them to ensure students in healthcare-related disciplines are assessed for competency in the practical demonstration of aseptic techniques. Within healthcare facilities, this could be facilitated through staff training.

Two recommendations were endorsed in principle:

- The Clinical Senate recommends development of a statewide policy of facility cleaning standards for WA Health. These will include:
 - standardised cleaning procedures that are evidence-based and standard use (detergent, bleach, water). WACHS have already done this body of work and it should be examined for applicability to be adapted statewide
 - encouragement for the vocational sector to develop short training courses for cleaning, which could be included as a desirable criterion in employment for

cleaners

- raising the profile of cleaning in facilities by having supervisors, minimum language requirements for cleaners and minimising use of casual/agency staff
- a requirement for feedback on cleaning outcomes and environmental monitoring to cleaning staff
- stipulation that audits for compliance with above processes are undertaken, which would be presented to health boards.
- That an Antimicrobial Stewardship Program is embedded within a safety and quality framework, that feeds agreed indicators to area Health Service Boards in addition to a central State committee.

One recommendation was not endorsed:

- That a communication and health promotion strategy to promote infection prevention and control and appropriate antibiotic usage be developed and implemented by consumer agencies and key WA Health experts. The strategy should use all contemporary messaging channels, and align with the National Safety and Quality Health Service Standards (NSQHSS). It should include elements to address vulnerable groups such as people living in residential aged care facilities, Aboriginals, prisoners and individuals at risk for transitioning in and out of hospital.

With the devolving of the area health service boards, implementing recommendations from the Clinical Senate is likely to be a more complex process. Key work has been undertaken to ensure that there is clarity in how the Senate's recommendations can be endorsed and implemented. The recent survey of Clinical Senate members elicited one written comment addressing this; "As debates at the Clinical Senate are relevant to Boards, the recommendations taken to the Department of Health should be submitted to Boards. Board Chairs should be invited to participate in the Clinical Senate." How it will exactly work is still to be determined.

June Clinical Senate Debate – Teaching, Training and Research

While the presentations from the June debate on Teaching Training and Research are available, the Recommendations won't be presented until the September debate. For all the Clinical Senate documents have a look at the WA Health Website using the link below. Contact us on 9221 3422 or info@hconc.org.au if you require a copy of the report. <http://ww2.health.wa.gov.au/Improving-WA-Health/Clinical-Senate-of-Western-Australia/Clinical-Senate-debates-and-publications/2016-Clinical-Senate-debates>

Advocacy: Consumers give Advocacy Service a big tick

Martin Whitely Advocacy, Policy & Research
Manager | HCC

As part of the obligations under our (2016-2021) new contract HCC began reporting to WA Health on the satisfaction level of consumers supported by our advocacy service. In order to determine what consumers' thought about the service a temporary employee phoned all consumers who had accessed HCC's advocacy service between January and March 2016 and who's cases had been closed.

Where consumers could not be contacted a message was left inviting them to participate by return phone call. Of the 53 consumers phoned 26 participated in the survey. Most of those who did not participate did not answer or return the call. A small number declined to participate.

Each consumer who participated was asked to rate their experience of the Advocacy Service from 1star to 5 stars on eight criteria;

1. How easily were you able to access the advocacy service?
2. How well did the HCC Advocacy Service understand the issues that you were concerned about?
3. How well did the advocate assist in communicating your point of view to health professionals?

To what extent did the HCC Advocate improve your knowledge about:

4. Treatment options?
5. Health professionals' role in providing care for you?
6. How healthcare services should engage with you?
7. The different agencies that can help you?
8. Your rights as a consumer?

	Q. 1	Q. 2	Q. 3	Q.4	Q.5	Q.6	Q.7	Q.8
5 star	24	26	17	7	10	10	13	16
4 star	0	0	0	0	0	0	0	0
3 star	2	0	2	0	3	1	1	2
2 star	0	0	0	0	0	0	0	0
1 star	2	0	0	0	0	0	0	0
N/A	0	0	4	16	9	12	10	8

Survey results for questions 1 to 8 detailed above.

9. What sort of support were you expecting from the HCC advocacy service?

Response Category	Number of responses	Percentage of total responses
Gained insight into case & health rights information	7	27%
Received first class service	3	11.5%
Didn't know what service to expect, happy with the service	3	11.5%
Supported me with my complaint	5	19.25%
*Other comments	5	19.25%
Didn't Respond	3	11.5%
Total respondents	26	100%

*Other comments included:

- Wanted to see if I was being paranoid and to get a quick response, these expectations were met. The advocate gave me confidence and validated I wasn't being silly. I was contacted within an hour of getting through to the HCC, very efficient.
- I didn't realise my case was finished. It still feels it is still open.
- Just wanted to explore options, it wasn't until the advocate pointed me in the right way that I understood I had a case. It was sorted in 10 minutes, very quick and efficient which wasn't expected.
- Hoping to at least speak to the person who has the power medically. Nothing was resolved but by no fault of the advocates.
- I was expecting more urgency and knowledge, sadly, I didn't feel like I received these.

The responses were generally positive about the advocacy service but some expressed dissatisfaction with the health service provider.

Chemo isn't the rest of my life...

Lucy Palermo Marketing & Communications
Coordinator | HCC



Pictured: Ainslie

Ainslie 35, is a wife and mother of two boys, 5 and 2 ½. She was diagnosed with breast cancer in January 2016 at 34 and is currently undergoing treatment. Her mother, a cancer survivor, was also diagnosed with breast cancer, but at 59. Apart from her age (less than 7% of breast cancer patients are under 40 at initial diagnosis) what makes her unusual is that Ainslie is a Radiographer, she meets patients everyday who are also battling cancer.

It started with a lump in the top outer quadrant of my left breast. My husband and I noticed it in December 2015. Because of my line of work, I decided I wasn't going to get it checked in December just before Christmas. When I was a junior Radiographer I would have people come in the week before Christmas with a cough only to discover they had lung cancer. No one wants bad news before Christmas. I knew I had to do something about it, but it wasn't until January 2016 that I saw a doctor. The first doctor I saw was awesome. She said 'Look I don't know what that is, you will need imaging of the breast. I don't want to alarm you, but here is a referral to a surgeon'. I think she was the best doctor I saw.

Because of my job I can distance myself from the situation, until I have to make a decision. If you don't work in the medical field and know some of the jargon, I think you could find it really difficult. For

example, I know of every biopsy done only approx. 80% are not cancer. Knowing that instantly puts people at ease. Unfortunately, someone has to fall into that 20% with cancer.

I went and had the ultrasound, because of my age (34) they do an ultrasound first. Following that it was decided I would need a mammogram. Because of my job I knew there was something wrong. The size of the lump and how quickly it had grown indicated to me that it was cancer. I had the mammogram and they recommended a biopsy. I had to go back and get a referral for a biopsy from a GP. I decided I couldn't wait until the previous GP was available so I saw a different doctor. As a male Doctor his approach was quite different, he said 'it will be nothing', I said to him, 'I don't think so'. I had the biopsy which confirmed it was breast cancer.

My grandmother died of oesophageal cancer. My Mum was always angry she went to the doctors alone to receive the news she had terminal cancer. It always upset my Mum that she was on her own when she got that information. But how is your poor GP meant to encourage you to bring someone in with you without upsetting you prior to the appointment. When my mother was diagnosed with Stage 2 breast cancer at 59 she wanted to shelter me from it, so she didn't bring me with her to any of the appointments. She has been lucky and hasn't had any problems since then. So I didn't have anyone with me when I received the news.

I had the referral for a surgeon, but I wasn't exactly sure where to go from here. The Mount Hospital runs the Perth Breast Clinic. This service starts from when you literally walk in saying I have a lump. You see a doctor, have your imaging, see a surgeon, etc, everything is done at the one centre. So I thought that was my best place to call. They were great, they put me in contact with my surgeon who actually used his lunch break to see me that morning, which was lovely of him. I said to him, 'I know it's cancer' and he said 'Ok it's cancer, you'll need surgery'. To make sure the cancer hadn't spread I had a CT scan performed of my chest, abdomen and pelvis and a bone scan.

That week I had to go into work and tell them I had cancer. One of my colleagues highly recommended an oncologist she knew, saying she had a special interest in women with breast cancer. She was nice

enough to make a phone call and got me in to see this oncologist. Then I was presented with two options, surgery or chemotherapy first. You have to wait and recover after surgery before you can have chemo and if you have chemo first your body also needs to recover before surgery. I chose chemo first. For me I couldn't wait. I wasn't comfortable with waiting after surgery to have chemo. The lump is only in one breast and hasn't spread anywhere as far as they know (the doctors). For me the thought of one little cancer cell getting out and spreading was horrible. I thought 'No, chemo first,' it made sense to me.

After I saw my oncologist I had my first session of Chemo four days later. It all happened pretty quickly. I had eight sessions of Chemo. I had four sessions of one drug and four of another. Going through chemo wasn't the best experience, but I think I found it easier because there was a possibility of an end in sight for me. This (chemo) isn't the rest of my life. It is a lucky thing that I have that hope.

I am currently recovering after chemo before my surgery. Until I have the surgery they can't be sure at what stage the cancer is, they think it is probably at Stage 2 or 3. When I go in for surgery they will perform something called sentinel lymph node scan. They inject a radioactive dye near the tumour so they see where the cancer could have spread. They first remove the lymph nodes that are directly associated with the tumour and test them for cancer cells. This helps the surgeon determine if you require a full lymph node clearance. I'm definitely not in stage 4 because it hasn't spread, but I'm further than stage 1 because it is too large.

Surgery is in late July. I had hoped that the entire process would happen at the same time. But a mastectomy with immediate reconstruction requires you to wait 3-4 months after chemo before surgery. But I don't want to wait. I struggled with the idea of leaving the tumour in, which is hopefully dead, but there is no proof. We came to the conclusion that I would have 3 surgeries. The first surgery is the mastectomy, during this they will insert a breast tissue expander. Over 6-8 weeks this will slowly be expanded until it is the right size. I will be unable to work during this time as I work with MRI machines and the expanders are not MRI safe. Once this has happened I will have an overnight stay to have the expander swapped for the breast implants requiring only a short stay in hospital. After some recovery time I will have a nipple reconstruction, cosmetic tattooing to complete the reconstruction.

Impact of Cancer on Family and Friends

I'm lucky that my boys are so young 5 and 2 ½. I

chose not to use the word 'cancer' with them. I believe the word has a negative connotation for people, like once you've got cancer your gone. However, there are so many survivors now this perception is starting to change. It did have a direct impact on them because I stopped working and at times I was too unwell to care for them by myself.

It is hard to tell with children how much it has impacted them emotionally because their mood can change so much, they are emotional little beings. For example, kids can get upset if they don't get chocolate cake for breakfast, even though this is something that wouldn't usually happen, little kids can be hard to read. It shocked them when I lost my hair, that was hard for them, especially my 5-year-old. My 2 ½ thinks it's fantastic that he can rub my head like I'm a Buddha statue.

Friends and family have been so supportive coming in when I couldn't manage, cleaning my house, making meals and taking my kids when I was too tired. My husband's work has also been amazing letting him have time off work to help when I was unwell, these things have really made a big difference. In general, it is ok but at times they never know what they're going to come home to, whether I'm feeling unwell or there is another family member there because I'm at a doctor's appointment. I hope they remember all the good-times. I hope that they remember how strong everyone was around them. I think that is a really positive thing for kids.

It has been hardest on my husband Adam. When we knew I had cancer, but we didn't know if it had spread that was difficult. I just knew in my heart and in my head that it hadn't spread, so I wasn't too stressed. But I was only battling the tumour and the journey that was ahead of me, he was having to come to terms with the fact he might lose his partner. He was left asking, what happens if? What happens if Ainslie isn't there anymore? What happens if I'm left with two boys and I have to explain to them she's gone? I think with anything like this the people left behind have it so much harder. He is a lot more positive now. He has always been positive, but I think knowing it hasn't spread, that we have a plan, we have made it this far and we have coped, has made a difference. Hopefully it doesn't get any harder than it this.

The support from my family and friends has been fantastic. I haven't needed to access the support group services available. In the beginning I thought about it and it's great to know they're there if I need them. It just isn't something I feel I need at the moment.

Besides my husband it affected my best friend a lot.

We both had children at the same time, our lives have been in sync. The thought that I might not be there was really hard for her. The majority of my colleagues are women, and I know my diagnosis was a shock to them. In our job we see people every day with cancer. You are able to sympathise and empathise with them, but at the end of the day it is not directly impacting your life. When it happens to someone you know it's sometimes too close to home. I think it makes you realise we are all vulnerable.

Overall I just feel grateful. Grateful that I have a great team of doctors and nurses looking after me, that I

have a fighting chance to enjoy a long and healthy life. But most of all grateful that I have an amazing number of family and friends around me to support my family and I through this hard time. Love and laughter from those around me is medicine for my soul.

Ainslie went in for surgery in late July. The surgery went well. After some tests she was given the wonderful news that she is now considered Cancer free. She is currently recovering and waiting for her reconstructive surgery.

Aboriginal Advocacy: Broome Training with CoMHWA

Tania Harris Aboriginal Advocate | HCC

In June the Health Consumers' Council partnered with Consumers of Mental Health WA (CoMHWA) to deliver training organised by the Kimberly Mental Health Service (KMHS) in Broome. The training was delivered in two parts. It was first targeted towards the health service, on the advantages of engaging and working with consumers of their service. The second part was delivered to mental health consumers and covered the basics of consumer representation.

After defrosting from Perth's very chilly winter, Laura and I went to a community meeting at the Broome Recovery Centre. There we met with some consumers and carers and described the training that was available. It was a great opportunity to meet some of the people who would be participating in the Consumer Representative training. Some shared their stories and experiences and asked any questions they had concerning the training.

Alicia Beckensale from CoMHWA and Laura Elkin from HCC delivered two sessions of Consumer Engagement training to staff from the KMHS. The first session was delivered at the Recovery Centre and via Video Conferencing, the second training session took place at the hospital where the participants were based. It was encouraging to find that the KMHS were positive about working with consumers, with strategies and plans already in place to boost consumer engagement.

The following day we delivered the Consumer Representative training to a group of mental health consumers at the Broome Recovery Centre. After the training the plan was for the group to hold their

first Consumer Advisory Group (CAG) meeting. The training went well, with minimal technical glitches and participation was high. The CAG meeting was also very positive, with a Chair and Secretary elected and the next meeting date confirmed. It was a long day, but the groups enthusiasm kept everyone going!

This training was the first in what we hope will lead to many collaborative partnerships with CoMHWA. It was a pleasure to work with Alicia, and to see the unique perspective consumers of mental health provide.

We all wish the best to the newly formed Consumer Advisory Group in Broome, and look forward to participating in some of their meetings via Video Conference and providing ongoing support. The willingness of consumers to be involved, have a say about their health care and to work alongside health services, can only benefit both consumers and the health service.

Consumer Engagement Training for Health Services

Health Consumers' Council (WA) offers a variety of training options for both Health Services and Consumers.

If you are interested in learning more about the training that is available, contact Health Consumers' Council (WA) on (08) 9221 3422 or info@hconc.org.au

You have mail: A lifesaving bowel cancer test

Frank Smith | Health Matters Contributor



Pictured Source: <https://www.bowelcanceraustralia.org/national-bowel-cancer-screening-program>

If you are in your early 70's you can expect an unusual birthday present in the post. A free bowel cancer testing kit will be posted out to all West Australians soon after their 70th and 74th birthday.

The screening kit is part of the National Bowel Cancer Screening Program (NBCSP), which previously has only been sent to people when they turn 50, 55, 60 and 65.

This is the first step by the Australian Government to meet its commitment to ensure all Australians aged 50-74 are eligible for screening every two years by 2020.

Eligible people will receive an immunochemical faecal occult blood test (iFOBT) kit in the mail. Complete in the comfort of your own home and post it off for analysis.

If the iFOBT finds blood, which only occurs in about seven percent of cases, it could be caused by haemorrhoids, Crone's disease or bowel cancer. This needs to be checked out.

Bowel cancer develops slowly from polyps that form on the lining of the bowel as people get older. These polyps often leek small amounts of blood into the faeces. Polyps look like small spots on the bowel lining or like cherries on stalks.

They are not necessarily malignant but some develop into cancers and are best checked out with a colonoscopy. If polyps are removed, the risk of bowel cancer is reduced.

The development of bowel cancer generally takes many years. It usually begins in the lining of the colon or rectum. Often, very small amounts of blood, which may not be able to be seen, are leaked from these cancers long before any symptoms develop. This blood is then passed into the faeces.

If untreated, it spreads deeper into the wall of the bowel. From there, it can spread to lymph nodes in the area. Later, bowel cancer can spread to the liver or lungs.

"The test is very specific with few false negatives. Blood in the faeces is not necessarily cancer. Only a small proportion are cancerous," said Colorectal surgeon, Professor Adrian Polglase. "But it is a signal to get your bowel checked out."

WA Health Gastroenterologist Dr Hooi Ee said the simple test could save your life. "Early bowel cancer has no symptoms, so those who screen for bowel cancer using iFOBT are more likely to have their cancer found at an earlier, less advanced stage, which means the treatment is less invasive and the chances of survival are better," Dr Ee said.

"I urge anyone who receives one of the kits in the mail, to do the test. It might be the best thing you can do for your health."

The testing program aims to prevent 70,000 deaths from bowel cancer in the next 40 years.

Cancer Council Western Australia Director Education and Research, Terry Slevin said the challenge was to get more people, and particularly men, to complete the test when they receive it in the post.

"More men than women are diagnosed with bowel cancer and more men than women die from the disease, yet fewer men do the test. We need to turn that around."

Bowel cancer kills more people each year than breast or prostate cancers, yet most cases can be cured if found early.

For more information about the National Bowel Cancer Screening Program go to www.cancerscreening.gov.au.

Cancer Survivorship: What is it like for those who have arrived as immigrants?

Louise Ford Consumer & Community Engagement Manager | HCC



Image Source: <http://www.arabicare.org.au/about>

Unfortunately, there appears to be little Australian based information available on this topic. What I have been able to find is titled "Cancer survivorship outcomes in immigrants.". The study was conducted in Australia and "compared health-related quality of life (QOL) and psychological morbidity in a population-based sample of first generation immigrant and Anglo-Australian cancer survivors." Those who participated in the research were Anglo-Australians and people of Greek, Arabic and Chinese heritage. The following is an abstract from that article:

"Background: Immigration is increasing world-wide. Cancer survivorship is now recognised as a period of difficult adjustment for all patients, and possibly more so for immigrants. We explored disparities in quality of life outcomes for immigrant (IM) versus Anglo-Australian (AA) cancer survivors.

Methods: In a cross-sectional design, cancer survivors were recruited through the New South Wales, Queensland and Victorian Cancer Registries in Australia. IM participants, their parents and grandparents were born in a country where Chinese, Greek, or Arabic is spoken and spoke one of those languages. AAs were born in Australia and spoke English. All were diagnosed with cancer 1-3 years previously. Questionnaires (completed in preferred language) included the Hospital Anxiety and Depression Scale (anxiety/depression), FACT-G (quality of life) and Supportive Care Needs Survey (unmet needs). Outcomes were compared between AA and IM groups in adjusted regression models that included age, gender, socio-economic status, education, marital status, religion, time since diagnosis and cancer type

(prostate, colorectal, breast and other).

Results: There were 599 participants (response rate 41%). Consent was unrelated to demographic and disease variables. AA and IM groups were similar except that immigrants had higher proportions in the low and highly educated groups ($p < 0.0001$), and higher socioeconomic status ($p = 0.0003$). In adjusted analyses (see table), IMs had clinically significant higher depression (possible range 0-21), greater unmet information and physical needs, and lower quality of life than AAs. The possible range for the latter three is 0-100.

Conclusions: Immigrants experience poorer outcomes in cancer survivorship, even after adjusting for socio-economic, demographic and disease differences. Interventions are required to improve their adjustment after cancer. Results highlight areas of unmet need that might be better addressed by the health system (particularly with regard to provision of information and support."

Outcome (Possible range)	Immigrant	Anglo-Australian	P
Depression (0-21)	4.6	2.7	<.0001
Unmet info needs (0-100)	19.2	10.7	<.0001
Unmet physical needs (0-100)	14.8	10.2	.0006
Quality of life (0-100)	76.6	82.7	<.0001

This article is available from the Journal of Clinical Oncology, 2012 ASCO Annual Meeting Abstracts. Vol 30, No 15_suppl (May 20 Supplement), 2012: 6111

Source: http://meeting.ascopubs.org/cgi/content/abstract/30/15_suppl/6111

While Australia has a high population of people who have migrated here, it does not necessarily support migrants in an equitable manner. According to the data detailed above there is a need for improved information delivery. The best method of providing the information is yet to be determined. Options include interpreters, translated materials, as well as providing culturally appropriate care to assist physical recovery and emotional and psychological well-being.

HCC NAIDOC celebrations and goodbye Laura!

Tania Harris Aboriginal Advocate | HCC



Pictured: Ilana Stack, Alana Loo, Laura Elkin, Lynette Reich and Barbara Ahmat in front of our NAIDOC tree

On Wednesday July 8th, HCC celebrated NAIDOC day for 2016 with a morning tea. It is important to remember NAIDOC was born from the fight for the rights and fair treatment of Aboriginal and Torres Strait people, and to give acknowledgement to the strong leaders of the past and present who continue to give voice to the concerns and inequity that still exists in our country.

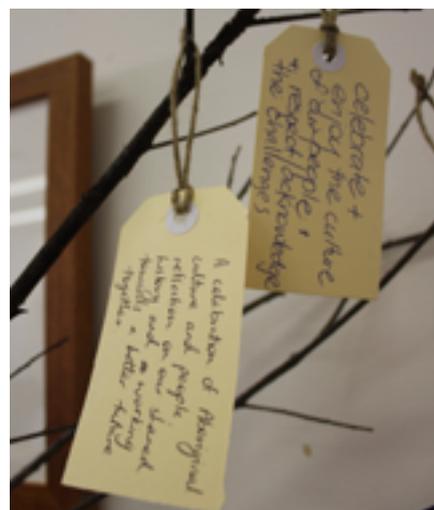
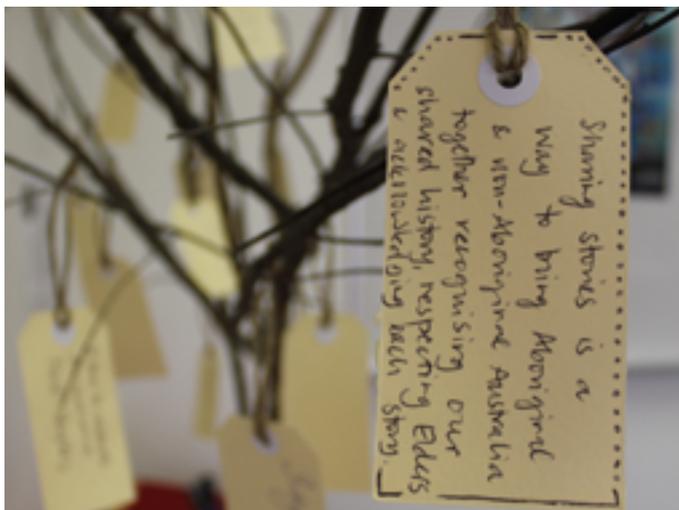
We asked our staff and guests to write a brief note about what NAIDOC meant to them, which was then displayed in a tree. Reading the notes was an indication of how important celebrating NAIDOC is becoming for all Australians, a celebration that we hope becomes more widespread with each year.

It was also a day where we got to thank and say

goodbye to the Manager of our Aboriginal Advocacy Program, Laura Elkin. Laura has been working in the program since its inception for the past 10 years. The non-renewal of funding for the program has meant that Laura has had leave HCC.

While HCC's commitment to Aboriginal people remains strong and the retention of our individual Aboriginal Advocate, Tania Harris will ensure the voice of Aboriginal health consumers remains a focus.

Laura is a huge loss to our organisation. Her knowledge, passion, amazing historical recall and energetic personality will be greatly missed. We have no doubt wherever she goes, Laura will continue to do good and meaningful work, and she leaves HCC with our best wishes for her future.



Good news for people diagnosed with cancer – Health Care Home is coming!

Tony Addiscott | Health Consumer



Pictured: Tony Addiscott

In Australia, relative five-year survival rates for all cancers increased from 47% in 1982-6 to around 61% in 1998-2004 (1). This figure lifted to 67% in 2008-12 (2). As more people survive cancer, how long a person lives is not the only focus; how well they are able to enjoy life after treatment is becoming increasingly important. As well as a treatment plan, cancer patients can now request a survivorship care plan (SCP) to help them transition from active treatment to living with cancer. Historically, this has been a problem.

A common definition of “survivorship” is the process of living with, through and beyond cancer. According to this definition, cancer survivorship begins at diagnosis and includes people who continue to receive treatment to reduce the risk of recurrence or to manage their cancer as a chronic disease (3).

Survivorship Care Plans are documents that provide details of a person’s cancer diagnosis and treatment, potential late and long-term effects arising from the cancer and its treatment, recommended follow-up

and strategies to help the patient remain well. They should contain information about:

- The cancer for which the survivor underwent treatment and the types of treatment they received;
- Short and long-term effects of treatment; what to be alert for and how frequently to visit the doctor for check-ups and screening (Including information about psychosocial effects);
- How the survivor’s follow-up care will be coordinated between the oncologist, GP and nurse etc., and who to contact between appointments;
- Lifestyle changes needed to reduce the risk and severity of treatment side effects, to prevent comorbid conditions and promote better health (including information about diet, smoking, alcohol, obesity and overweight, exercise and sun protection);
- Useful community resources should the survivor encounter employment, financial and/or insurance issues (1).

Survivors should be involved in a decision about who will oversee their ongoing long-term care after active treatment. Participating in follow-up care and keeping a medical support system in place are essential for maintaining both the survivor’s physical and emotional health. It also helps to reduce stress by allowing survivors to feel more in control as they transition back into everyday life. Some survivors continue to see their oncologist while others see their family GP or another health care professional (3). Oncologists and other cancer specialists often have severe time constraints however which make it difficult for them to coordinate care over extended periods. The consensus is that this role should be performed by the survivor’s GP and/or primary health care practice with their extended knowledge of the patient’s health history and the local network of physical and emotional health care providers.

Meeting this challenge in the primary health care sector is soon to be made easier by the advent of the Health Care Home (see Figure on following page). There is a changing emphasis in the primary health care sector to support, and encourage, this co-ordination and care to be held by GPs.

The Commonwealth Government recently announced



Image Source: (4)

its plan to introduce a Health Care Home model in selected Primary Health Networks (PHNs) across Australia. This model is an innovative approach to better coordinated primary healthcare for people with chronic and/or complex diseases.

Primary Health Networks have a wider remit to enhance primary care, expanding what is currently offered to patients and supporting general practice, and other primary care providers, to work at the top of their scope. In addition to the Commonwealth Government Health Care Home trials, the Perth North, Perth South and Country WA PHNs are already working with WA general practice to develop a separate, but complementary, trial to assist practices in moving towards delivering the principles of the Health Care Home.

This is all good news for patients, who into the future can expect:

- Greater peace of mind about access to continuing competent care
- Care that is patient-centred, continuing, coordinated and comprehensive
- Improved health equality
- Access to a comprehensive range of primary care services from their general practice
- Improved patient outcomes through better coordination
- Optimal use of IT for health recording and analytics, to enhance systemic innovation and

improvement and ensure delivery of the best possible patient outcomes (5).

How to implement survivorship care planning for Western Australians is currently being examined by a WA Health Cancer Survivorship Collaborative led by UWA Clinical Professor David Joske. WA should be well placed to bring these programmes together, integrating survivorship care planning into the range of primary care services offered by practices adopting the health care home approach. This will enable cancer survivors to regain and enjoy the best possible on-going quality of life.

Note: Information about the Health Care Home trials is available at <http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes> and information from the WA Primary Health Networks on their work is available at www.wapha.org.au.

Sources:

1. Survivorship care planning: Australian Cancer Survivorship Centre at the Peter MacCallum Cancer Centre, Melbourne Victoria
2. Cancer Australia
3. ASCOanswers; Cancer Survivorship ©2014 American Society of Clinical Oncologists
4. Source: WA Primary Health Alliance
5. RACGP: Vision for general practice and a sustainable health system; a summary

Supporting carers in Western Australia

Dean Beissel Carer Representation Coordinator |
Carers WA



Image Source: Stock Photos

Caring is becoming increasingly prevalent in our society and in 2015, it was estimated that it would cost the Australian Government \$60.9 billion to replace the unpaid care provided by all carers in our community. A carer is someone who provides unpaid care and support to a family member or friend who has a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who is frail aged.

In 2010, the Australian Institute of Health and Welfare estimated that there were 384,593 living with cancer in Australia. The majority of these people will be cared for by at least 1 family member or friend throughout their diagnosis, treatment and recovery.

Some other facts about carers in Australia:

- There are 2.86 million unpaid carers in Australia. More than 825,000 carers are primary carers.
- More than 17,100 carers in Western Australia are under 18 years of age.
- An estimated 42,900 carers in Western Australia are 65 years of age or over.
- Almost 80,000 carers live outside of the metropolitan area in Western Australia.
- Almost 45% of carers in very remote areas are Aboriginal and/or Torres Strait Islanders.
- Over 69.7% of primary carers are women.

Carers WA is dedicated to supporting family carers in their role by providing emotional and social support,

information, training and education, and a variety of programs to enhance overall wellbeing. Carers WA have professional counsellors who are dedicated to helping carers build resilience in their caring role, by creating a balance between caring responsibilities and self-care. Carers WA offer telephone counselling on 1800 007 332, a service which is available from 8am to 5pm, Monday to Friday and is free when calling from landlines. A call-back service is available for those calling from mobile phones. Carers WA also offer low cost face-to-face counselling and free email or Skype counselling.

"When caring for my young daughter with cancer, I accessed social support program and counselling from Carers WA. Social support was very good therapy because I was with people who understood what I was going through. I also accessed phone counselling, because I did not have time to access face-to-face counselling. At the time, I was feeling overwhelmed and needed to develop some emotional strategies for coping with and staying strong whilst caring for my daughter. Carers WA helped me with that." Angie.

If you are interested in any of our services please contact Carers WA on 1300 CARERS (1300 227 377) or email info@carerswa.asn.au. Membership is free for carers and includes the latest information on all our programs and services, as well as various other member benefits such as discounts and special offers. Please visit our website at www.carerswa.asn.au for more information.

Book review: Ahead of us

Pip Brennan Executive Director | HCC

At the Margaret River Writer's Festival in June, I attended a session hosted by Michael Cathcart from Radio National's "Books and Arts Daily". Cathcart was interviewing Dennis Haskell about his recently published book of poems, 'Ahead of us'. It is dedicated to his late wife Rhonda who died of ovarian cancer.

The first half of the book has poems that are pre-diagnosis, and the second half post-diagnosis. During the interview Dennis described their last pre-diagnosis moments, sitting in a hospital with Rhonda, trying to puzzle out what the sign "Ca" meant on the ward's wall, Dennis playfully thinking that it stood for California or some other desirable destination.

The session was exquisitely moving, and by the end of the reading there was not a dry eye in the house. The audio of the session is available here: <http://www.abc.net.au/radionational/programs/booksandarts/dennis-haskell/7629522>

'AFTER CHEMO

*Your hair is falling like thin rain,
Like mizzle, like long, silent,
Lightening snow...*

*In each corner of each room,
Swirled across the tiles,
I find them, these networks,
These fine cobwebs of you...' Dennis Haskell*

Dennis is donating proceeds of the sale of his book to the Cancer Council. Copies of his poetry book will be available for sale at 'After cancer treatment ends - Where to from here?', our partnership event with Cancer Council and Carers WA. Go to www.hconc.org.au for further details.

Disclosure: Dennis Haskell was my University Lecturer when I was undertaking a Literature degree in 1987 and I think he is an all-round wonderful human being.

Rest in peace, Lois Gatley - Shining a light on Lung Cancer

Pip Brennan Executive Director | HCC



Pictured: Lois Gatley

Last year I met Lois Gatley who had worked tirelessly all her life on a range of social justice issues. Her final cause was the stigma directed at lung cancer patients.

In 2013 she was diagnosed with Stage 4 Lung Cancer. Ms Gatley joined HCC and met with me to discuss her concerns. She ensured that last November for the 'Shine a Light on Lung Cancer' week, her story was shared in the media to highlight the stigma that lung cancer patients can experience. Not to mention significantly fewer research dollars for this particular cancer.

She pointed out that smoking is not the only trigger for lung cancer and noted "people make many life choices that have an impact on their health...let's not stigmatise any lifestyle choices that we make."

Sadly, Lois lost her battle with lung cancer in July.

The full article can be read by accessing the link below or contacting us for a copy: <http://health.thewest.com.au/news/2399/little-sympathy-for-lung-cancer>

Cancer Survivorship

Karen Taylor Survivorship Cancer Nurse
Coordinator | WA Cancer & Palliative Care Network



Pictured: Karen Taylor

“Survivorship” is the term that has been used to describe the time when treatment ends and the person with cancer is in remission. There are many definitions, but the broadest, from the National Coalition for Cancer Survivorship, defines survivorship as the “experience of living with, through and beyond a diagnosis of cancer and includes the impact on family, friends and caregivers”. Although the word “survivorship” or the term “cancer survivor” is widely disliked by many survivors and clinicians, there has been no agreement on what we could use instead that really sums up for all people the end of treatment and moving into follow-up.

Survivorship has become a major focus in many countries, including Australia, as survival rates increase. In Australia, for all cancers the 5 year survival rate after diagnosis is 66%. The reason for this trend is most likely related to improved treatment and supportive care. Unfortunately there are long term and late effects from the treatment and the cancer which can impact a person’s quality of life.

Lencie Wenden, in the summer 2016 edition of Health Matters has clearly captured what many people who finish active treatment go through. After having a huge amount of input from the hospital staff, family and friends, suddenly it all stops and people are expected to just get back to living their life. However these people have had a profound experience and they are no longer the same person. They must adjust to a ‘new normal’ and hope that family and friends can somehow understand this. For many this is harder to deal with than the treatment.

We have never really understood the experience of being a survivor because it is more than just medical surveillance. The current follow-up by doctors is often brief and does not explore other issues the person may have, or give information to support a healthy lifestyle change. We also know GPs are often left out of care after diagnosis and the information they get can be quite poor. Survivors often say the coordination of follow-up care between the hospital and the GP is not done well and they themselves do not feel like they can take control of this next step to ensure they are getting the right follow-up and screening.

The literature tells us there is a “teachable moment” after treatment stops where there is an opportunity to encourage healthy lifestyle behaviours. This includes helping people who have a very real fear of the cancer coming back which can stop them from getting on with their life. Having undergone the treatment and given the all clear, survivors need to be aware of the late effects of treatment that could happen in the future, what to look for, and which doctor (specialist or GP) they should see if they are worried about a symptom. As the risk of recurrence or second cancer is higher than the general population, these are very real concerns.

Survivorship care plans and treatment summaries have been suggested as one way to improve the communication between doctors on the disease, treatment given, recommend follow-up and healthy lifestyle information. Some studies have shown patients felt GPs would care for them better if they had these documents. So if these survivorship care plans are so good, why are we not using them for everyone? The biggest barrier is how time consuming they can be to create. We would like to give a personalised care plan to everyone as a general survivorship care plan might cause some anxiety around late effects that may not even occur for some people. There has also been discussion on who should be creating them, nurses or doctors or another health care person, and how should they be given to patients. An end of treatment clinic appointment could be used to tailor a survivorship care plan and treatment summary and give patient-centred information and resources. Newer ways of delivering survivorship care plans and treatment summaries are being developed through online or mobile technology that ensures the care plan goes

anywhere with the patient, are easily accessible, and easier to update.

The development of survivorship services in WA is growing. We have a Survivorship Multidisciplinary Collaborative led by Professor David Joske and there are a number of survivorship research projects happening for paediatric, young people and adults. A current research project led by Professor Leanne Monterosso has been the appointment of a Survivorship Cancer Nurse Coordinator funded jointly by the University of Notre Dame Australia and the WA Cancer and Palliative Care Network. In this position I have developed a nurse-led survivorship clinic for lymphoma patients at Sir Charles Gairdner Hospital where I run a nurse-led lymphoma survivorship clinic as a research project.

Without research and the evidence to show that

follow-up care is important, and more than just a medical check-up, services cannot be put in place. We have the evidence that a healthy lifestyle will help you recover from your cancer better and may decrease your risk of relapse. Although it can be very hard to think about spending any more time at the hospital after your treatment has ended, research we did in 2014 showed us that many long term survivors of lymphoma wish they had been given the opportunity for an end of treatment appointment as they felt this would have helped them transition into life after cancer treatment better. So if you have just finished, or are currently having treatment for lymphoma at Sir Charles Gairdner Hospital then you may be eligible for my study and I may be in contact with you, or you can contact me, I would love to hear from you. My contact details are Karen.Taylor@health.wa.gov.au or phone 0428 411 309.

Formal notice of HCC AGM

Pip Brennan Executive Director | HCC

You are invited to the 2016 Health Consumers' Council Annual General Meeting (AGM) of the members of the Health Consumers' Council of WA.

DATE: Wednesday, 28th September
TIME: Commences 5:30pm
LOCATION: Department of Health Lecture Theatre
D Block, 189 Royal Street, EAST PERTH

FOLLOWED BY A Q&A PANEL at 6:00pm
CONSUMER ENGAGEMENT IN THE NEW WORLD ORDER

What will consumer engagement look like in the new world of devolved health services?

This will be an unscripted, Q&A session (no prepared speeches) where we will hear the views of the Director General of WA Health, Dr David Russell-Weisz, Child and Community Health Service Board Chair Ms Debbie Karasinski, North Metropolitan Board Consumer Representative Ms Michele Kosky, Area Health Service Executive Director Liz MacLeod and Royal Perth Group Director of Consumer Engagement Todd Gogol.

Please join the Board & staff after for light refreshments.

RSVP (for catering purposes) by Wednesday 21st September
on 9221 3422 or via info@hconc.org.au.

Patient Experience Week Event Series Overview

Pip Brennan Executive Director | HCC



On the 28th and 29th April 2016 the Health Consumers' Council (HCC) hosted the inaugural 'Patient Experience Week (PXW) Event Series' at The Boulevard Centre in Floreat. We aligned with the international theme for 2016 Patient Experience - "Connecting for Patient Experience - We are ALL the Patient Experience". The crowd of up to 150 included health consumers, carers and community members, clinicians and health service providers as well as health professionals from primary to tertiary settings.

The Director General of WA Health formally opened the launch and highlighted that it is essential to have an organisational culture where staff feel valued and respected, and patients are treated with dignity and respect. He highlighted WA Health's commitment to developing a Compassionate Care initiative. Compassionate Care is about the way in which people relate to each other-the way staff treat each other and their patients. Jason Wolf, The Beryl Institute President, the international Patient Experience community, joined the opening from America via Zoom (a video conferencing technology) and highlighted 'Patient Experience' as a global movement with significant momentum.

Presentations throughout the two days included an interactive theatre performance, where the audience got to try different approaches to scenarios for a more patient centred outcome. There were presentations of different patient experience tools and techniques being developed in hospitals and universities by consumers, researchers and healthcare providers.

Panel discussions looked at the Aboriginal Patient Experience and different approaches to measuring the patient experience. There are audios, powerpoints and even videos of some sessions available on the HCC website. If you have any problem accessing these please get in touch with us.

Feedback from participants was positive to quote Russell McGowan, consumer advocate, "To all associated with the Patient Experience Week series of events in WA, congratulations! I attend many conferences as a consumer advocate and provider of consumer perspective, but have rarely benefitted so much from the energy boost your seminar and workshops provided me. This can best be summed up by me paraphrasing Michael Greco's quote from Don Berwick that we need to see patients as more than just data sources for the health system; we are energy sources as well."



The following responses were made by participants about what they would do differently after attending a PXW event.

Consumer

1) *Speak up - be a stronger advocate!* 2) *Engage with staff on committees more effectively!*

Provider

1) *Ensure clinical staff have time to treat patients as human beings.* 2) *Help patients to see clinicians as fellow human beings subject to stresses that patients can help address to ensure better quality of treatment/outcome*

Provider

1) *Engage consumers in the simple language they understand.* 2) *Understand the culture of the consumer.* 3) *Interconnected your services to consumer.*

Provider

1) *Communicate!! With colleagues & patients* 2) *Slow down - decrease the feeling/agenda of task orientated days* 3) *Consider the point of view of the consumers & staff members*

The full report is available here: <http://www.hconc.org.au/patient-experience-week/>. Preparation has already begun on the Patient Experience Week Conference 2017, stay tuned for updates.

Health Consumer Excellence Award Winners

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



Pictured: The team from CAMHS. Second from left Cheryl Holland, HCC Acting Chair & Second from right, Pip Brennan, HCC Executive Director

The Health Consumers' Council (HCC) Health Consumer Excellence Awards 2016 closed the Patient Experience Week Event Series. Since 1997 HCC has been celebrating the achievements of the unsung heroes in WA health with these awards. The awards recognise the achievements of individuals and organisations that go out of their way to make a difference in WA health. This year four awards were presented.

Health Organisation Award - An organisation that works effectively with consumers to improve their services.

St John of God Murdoch received a highly commended award with Child and Adolescent Mental Health Services (CAMHS) winning the award for working in partnership with consumers and carers in their design of the CAMHS Recovery Plan, design and implementation of the CAMHS Recovery Focused Care Training and re-design of CAMHS Gender Diversity Service.

Health Professional Award - A health professional that has demonstrated excellence in patient care.

Soya Schultz from Breastscreen WA received a highly commended award with Ted Dowling from Heart Health winning the award for his tireless work with Aboriginal patients. To quote one of his patients, "The work Ted does for Aboriginal people is significantly bridging the gap between Aboriginal and non-Aboriginal people. He is not just talking about creating change, he is doing it. This gives Aboriginal people from all over Western Australia the chance to look after their health, and makes RPH a better place for all of us."



Pictured: Ted Dowling & Pip Brennan HCC Executive Director

Rosemary Caithness Award - A person who has demonstrated outstanding service to health consumers

The winner was Marian Maughan, volunteer at Learning and Attentional Disorders Society (LADS). During her time at LADS, Marian has worked with, and collaborated with numerous health professionals, peers and consumers online. During her involvement with LADS, Marian has undertaken various executive roles, including vice president, president as well as an active member of the management board.



Pictured: Amanda Wilkes & Laura Elkin

Aboriginal and Torres Strait Islander Health Award - An Aboriginal/Torres Strait Islander who has demonstrated outstanding service to Aboriginal/Torres Strait Islander health consumers

The winner was Amanda Wilkes. Amanda tirelessly goes above and beyond to ensure health services both meet the needs of and engage with Aboriginal patients and families. Over many years Amanda has promoted consumer rights to Aboriginal community members in Perth, and assisted many to resolve a problem with a health service. Amanda is a tireless advocate and leader in working with hospital staff and community to ensure these roles are successful. She is committed to ensuring health services become cultural safe places for Aboriginal patients and staff.



**HEALTH CONSUMERS'
COUNCIL**
YOUR VOICE ON HEALTH

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