

Volume 4 / Issue 9, 2017

[Lead Article](#)

[Committee Vacancies](#)

[Sponsorship](#)

[Opportunity](#)

[Health Policy &
Research Update](#)

[Health Literacy](#)

[Items of Interest](#)

[Local Events](#)

THANK YOU FOR THE WARM WELCOME!

With Darlene attending Health Consumers Queensland's Annual Forum it fell to me to provide the cover story for *Consumer Bites*. For those who haven't met me, my name is Kathryn Dwan and I took on the role of Manager, Policy and Research earlier this year. I am a health sociologist by training and have spent most of my working life in universities. However, I'm delighted to be working closer to issues that really matter to me. Another benefit of joining the HCCA team is the pleasure of working with such intelligent and caring people. And I don't just mean the terrific staff. Thank you to everyone for the warm welcome I have received!

HAVE THE NDIS FUNDING CHANGES AFFECTED YOU?

The measure of a country's greatness should be based on how well it cares for its most vulnerable populations. (Mahatma Gandhi)

The first anniversary of the [National Disability Insurance Scheme \(NDIS\)](#) is fast approaching and as a nation we can be proud that Australia has introduced a system through which people who need help can get it. This is not to say that the system is perfect or even adequate, but I believe its very existence says something important about Australia as a nation.

While the NDIS's priority is to ensure that people with disabilities continue to get the support they need, the changes have been significant, and the costs – physical, emotional and financial – have been borne mainly by the people most needing support.

The ACT Council of Social Services ([ACT Council of Social Services \(ACTCOSS\)](#)) is wanting to hear from people affected by these changes. A collection of the most compelling and representative accounts will be published as [Stories of Transition](#). This publication will then be used as an advocacy tool to encourage governments to address identified gaps and maintain the standard of services.

If you use aged care, disability, housing or any other social service in the ACT, rely on the NDIS, and have a story to tell, then please contact Hal Judge by email hal.judge@actcoss.org.au or phone 6202-7277.

Kathryn Dwan
Manager, Policy & Research

Consumer Representatives Training

HCCA are undertaking a review of the Consumer Representatives Training. We are interested to hear your feedback. What has worked well, what could be improved, what would you like to see more of and what is important to you to learn about?

Please get in touch with Sally Deacon, Manager for Consumer & Community Participation at sallydeacon@hcca.org.au or Kate Gorman, Consumer Representatives Program Coordinator at kategorman@hcca.org.au.

COMMITTEE VACANCIES

The ACT Gene Technology Advisory Council

The Gene Technology Advisory Council (GTAC) investigates issues relating to Genetically Modified (GM) food plants and provides advice to the Minister and ACT Government. In addition, the Council is asked to investigate matters referred to it by the Minister for Health and provide advice in relation to research trials, issue of licenses and current developments in relation to gene technology.

Under subsection 11(2) of the Act, the GTAC consists of eight members, appointed by the Minister for Health, on the nomination of organisations such as Health Care Consumers Association.

This committee requires a good level of knowledge of gene technology. It rarely meets face to face, however its members regularly receive documents for comment via email. The successful applicant will be able to access, read and return comment on documents using email.

If you are interested in this opportunity please contact Kate on kategorman@hcca.org.au or call 6230 7800 as soon as possible.

SPONSORSHIP OPPORTUNITY (closes Tuesday 13 June)

Affordable, Accessible, Appropriate Housing for Older Australians

COTA Australia National Policy Forum, Thursday 22 June 2017, National Press Club, Canberra

Housing security is a basic human need and human right. This year's COTA National Policy Forum will place the spotlight on what housing means in later life and explore current policy issues and future trends around housing for older Australians. The Forum will bring together an exciting line-up of policy makers, academics, consumers, advocates and others to discuss some of the pressing housing issues of our time and how they affect older people. These issues include:

- What does the crisis in housing affordability and availability mean for current and future groups of older people?
- Should the home be viewed as a financial asset to be leveraged to help fund retirement years?
- What do older people need and want in their housing?
- What kinds of housing supports well-being in later life?
- What are the key challenges facing older renters?
- Why are there increasing rates of homelessness amongst older people and how can this be turned around?

HCCA will sponsor two consumer representatives to attend the Forum. Sponsorship includes the cost of the event and transport assistance, if required. Consumer representatives who are sponsored by HCCA to attend events are requested to provide a report to HCCA so that other members can find out about and benefit from items of interest presented at the event. If you are interested in attending this forum please complete an expression of interest, or call Kate at the HCCA office on 6230 7800 for assistance or more information about this.

HEALTH POLICY & RESEARCH UPDATE

As usual, the Policy and Research Team have been hard at work:

- Sarah and Kathryn Briant learnt a lot from [training in the palliative approach](#) provided by Clare Holland House
- Kathryn Briant coordinated and submitted HCCA's response to the Independent Review of Accreditation Systems within the National Registration and Accreditation Scheme for Health Professions
- Sarah has started scheduling interviews for the palliative care project, while we wait for ethical approval from Calvary.
- Kathryn Dwan submitted a grant to the ACT Heritage Grants Program to archive the history of HCCA for the upcoming 40th year anniversary. This was only possible with considerable 11th hour help from Sarah, Kathryn Briant, Darlene and Khalia. More information can be found under Items of Interest.
- The ACT Health ethics committee advised HCCA that we do not need ethical clearance to undertake our after-hours study. Kathryn Dwan is checking that we will still be able to publish our results in peer reviewed journals in the future.

Consumer Handout Committee, ACT Health

Since joining HCCA I have reviewed several consumer handouts. Recently I learned that Canberra Hospital has a clear process for developing handouts. Ideally staff work with the Health Literacy Officer at ACT Health before submitting their handout for review. She can help them with their choice of words, tone and layout.

My first meeting as part of the Consumer Handout Committee warmed my heart. Eight intelligent, consumer-centred people offered helpful suggestions on how to improve consumer handouts.

Kathryn Dwan
Manager, Policy & Research

Have you (or a loved one) received or wanted to receive palliative care at home?

Then we are keen to hear from you, especially if home-based palliative care was not offered or you could not access it. This ACT Health funded project is focused on the experiences of older people and the unpaid caregivers of older people.

To participate, you'll need to:

- be aged 55 or older and receiving palliative care services; or
- be a caregiver for a loved one or family member who is currently receiving palliative care and is over 55 years; or
- have previously been a caregiver for a loved one aged 55 or older who received palliative care (within the last five years).

Participants in this project will take part in a semi-structured interview with HCCA Policy Officer, Sarah Spiller. Sarah will also work with each participant to create an *Experience Wheel*. This is a one-page image that shows your key positive and negative experiences of healthcare services, and the areas you identify as requiring improvement.

If you are interested in taking part in the project or would like to find out more, please speak with Sarah Spiller or Kathryn Dwan by calling 02 6273 8000 or emailing sarahspiller@hcca.org.au.

HEALTH LITERACY

Draft Health Literacy Position statement

Darlene emailed the draft position statement to members for comment last week (16 May). Thanks to the many members who have already commented on the draft document. We have received contributions from people holidaying in sunny Spain and not-so-sunny Scotland. I will collate all the comments before drafting a second version for the Executive Committee to consider. A few members asked what we mean by HCCA becoming a “health literate organisation”.

A [health literate organisation](#) makes it easier for people to take care of their health. It does this by making information and services easier to find, understand, and use. Many of the characteristics of health literate organisations apply equally well to HCCA. For instance, in a health literate organisation

- health literacy is integral to its mission, structure and operations
- the organisation helps its workforce to become health literate, and
- content is provided that is easy to understand and act on.

One way to improve our own work is to use a [readability app](#). I got this article down from a Grade 11 reading level to that of Grade 6.

We are still open to feedback on the draft, so please do speak with Kathryn Dwan or email her at kathryndwan@hcca.org.au.

Palliative approach

Q. What is the palliative approach?

A. Death, dying and bereavement are seen as an integral part of life. The palliative approach helps address the problems of people with a life-limiting illness. It tries to improve their quality of life and those of their family and carers. Relief of suffering is vital and includes psycho-social and spiritual needs. Ideally this type of care is provided in the community by GPs, community nurses and allied health professionals.

Q. What is specialist palliative care?

A. Specialist palliative care is provided to patients with complex needs and troublesome symptoms. Its team members have special training in palliative. A person can receive specialist care in a variety of locations (e.g. hospitals, hospices, residential aged care services, homes). Sometimes a person has complex symptoms that are best managed by admitting them as an inpatient for a short time before returning them to their usual care in the community.

Q. What is home based palliative care?

A. Home based palliative care brings the palliative approach to where a person usually lives. Theoretically it should also be available at aged care facilities. Both specialist and primary care providers can deliver home based palliative care. It really depends on a person's needs.

Q. What does Calvary Clare Holland House provide?

A. [Clare Holland House](#) is a specialist palliative care service and well known for its inpatient hospice. People are most commonly admitted for pain and symptom management, respite care and terminal care. However, it also offers specialist palliative care to out-patients and to people in the community through its Community Specialist Palliative Care Services.

Navigating the Health System: Finding the Right Health Service for You

This was the name of the presentation Claudia Cresswell, HCCA Health Literacy Project Officer, gave to 23 people at The Grove retirement village in mid-May. People seemed surprised to discover there was a GP service that would come to your home 'like in the old days' (National Home Doctor Service), that you could phone [Healthdirect](#) at any time, and that the [Walk-In Centre](#) offered a range of services and extended times. The other services covered were ACT Health information on-line, mental health services such as [mindhealthconnect](#), pharmacy, GP and emergency services.

Everyone indicated that the 1.5 hour presentation was useful and that they were now more confident that they would access the right service at the right time for the right treatment.

'It was a good presentation of basic health services and their availability'.

This presentation is one of a range that HCCA is updating or developing for people with chronic conditions and those from culturally and linguistically diverse backgrounds.

ITEMS OF INTEREST

The health care system needs you!

That's the short title of a project HCCA submitted to ACT Heritage Grants Program last week.

Next year HCCA celebrates 40 years as a health consumer advocacy organisation. In October 2018 HCCA will be the longest running such organisation in Australia.

The grant will help us collect oral histories and create an archive. From there we plan to develop a short publication, an accompanying web page, and a traveling exhibition. These three products will tell our story, celebrate our successes, and encourage the community to get involved in making a difference. We will know whether we are successful in September.

Primary Care

Palliative Care \$8.3 Million Budget Boost

After the announcement of the 2017-18 Federal Budget on Tuesday 9 May, there will be an \$8.3 million increase to funding for Primary Health Networks (PHNs) to coordinate the care of

people going through palliative care. CEO of Palliative Care Liz Callaghan said that this funding boost will have tremendous benefits for the quality of life of people going through palliative care services. Coordinating palliative care through PHNs will offer better support services for people who wish to die at home, while also enabling families to spend more time together to maximise the effectiveness of palliative care services at home. PHNs will also be able to collect and use data to help determine future improvements in the end-of-life care sector, and could also work together with the existing National Standards Assessment Program and the Palliative Care Outcomes Collaboration for better service planning. [Click here if you would like to read the full article about the Palliative Care funding boost.](#)

Latest news from CHN

Read all the latest news from the [Capital Health Network](#):

- [Health InterACTION issue 42](#)
- [2/52 Health Care Bulletin](#)

ITEMS OF INTEREST (CONT.)

Private Health Insurance – calls for reform

[The Consumers Health Forum of Australia](#) (CHF) have released a media statement on how private health insurance (PHI) reform is desperately needed to create equality in our health system. Public patients are waiting twice as long as private patients for elective surgery in public hospitals, and PHI companies are profiting. CHF CEO Leanne Wells said ‘The stark differences in public hospital waiting times, while heavily subsidised health funds generate accelerating profits, reveal a dire need for reform’. The consumer’s wallet size rather than their clinical need determines whether or not they receive treatment on time. The Australian Government must review PHI rebates and policies to ensure that patients are receiving quality, timely care based on their condition and not their socioeconomic background. [Click here to read the full media release from CHF.](#)

Health of Older People

To age better, eat better - Article

[The Harvard Gazette](#) has recently written an article on the relationship between diet and ageing. Head of the Department of Nutrition at the Harvard TH Chan School of Public Health, Mr Frank Hu, suggests that based on research, eating a Mediterranean based diet can improve the way we age, and can reduce our risks of developing obesity related chronic conditions and some degenerative diseases. Mr Hu says ‘The evidence is very encouraging because, even old people, when they improve their diet quality, the risks of getting chronic diseases and mortality can be reduced, and longevity can be improved’. The Mediterranean diet consists of eating more fish, legumes, unrefined wholegrains and olive oil and eating less red meat and processed foods, as they are known to be related to developing health problems. Each person is different, therefore each person should adjust the diet to their own needs such as food preferences and cultural patterns and should allow for the occasional indulgence. [To read more about healthy eating and ageing, click here.](#)

Safety and Quality

The Importance of Health Technology Assessment

As new health technology becomes more available in Australia, it is important for consumers to know the safety, quality and efficiency of these new technologies. The [Therapeutic Goods Administration](#) (TGA) are responsible for evaluating new health technologies to be available for consumers to purchase and use. In making decisions the TGA is guided by three different consumer involved advisory committees:

1. [Pharmaceuticals benefits Advisory Committee](#)
2. [Medical Services Advisory Committee](#)
3. [Prostheses List Advisory Committee](#)

These advisory committees determine whether certain health technologies should receive government subsidisation to provide a wide range of cost-effective, accessible health technologies to consumers. There is also a Health Technology Assessments Consultative Committee whose goal is to bring community and consumer evidence and views into the health technology assessments process. Consumers are encouraged to share their thoughts and to report any adverse events that arise from using TGA approved health technologies in order to improve the safety and quality of health technologies. [Click here](#) if you would like to read more about the assessment of health technologies in Australia.

Mental Health

National Mental Health Commission Community Forum

On 23 March 2017, Executive Director Darlene Cox attended the National Mental Health Commission’s Community Forum. At the forum, there were discussions on consumer experiences and the impacts the NDIS has on mental health consumers. The Mental Health Commission have provided a letter with the summaries of these discussions for you to read. Please find the letter from the Commission attached with this newsletter.

Health Promotion Officer Positions - WCHM

[The Women's Centre for Health Matters Inc.](#) (WCHM) has 3 permanent Health Promotion Officer positions available. Two positions are part-time for approximately 30 hours per week between the hours of 9am – 5pm (or as negotiated with the Executive Director) until 30 June 2017. One position is full time for 37.5 hours per week.

Health Promotion Officers in WCHM will work within a social determinants of health framework to promote a gendered understanding of health and wellbeing issues for ACT women.

The positions work under the general direction of, and are responsible to the Deputy CEO, under the overview of the CEO. The salary will be paid at the Social, Community, Home Care and Disability Services Industry (SCHaDS) Award 2010 level 6.1 (\$35.66 per hour gross, with superannuation paid in addition). It is a genuine occupational qualification to be female for this position.

Application close 5pm Wednesday 31 May 2017. [Please click for more information.](#)

COTA ACT Free Energy Workshop

Council of the Ageing (COTA) ACT have partnered with ActewAGL to provide consumers information on how you can save on your energy bills this winter. Learn about how energy escapes your home, energy usage and tips to keep you and your house warm. Afternoon tea is provided and attendees will also receive a gift bag including energy saving information, hand warmers, temperature magnet, water bottles and more.

Date: Thursday 25 May, 2017

Time: 2pm

Location: Hughes Community Centre Hall, Wisdom Street Hughes

Cost: Free

RSVP: For catering purposes, please call 02 6282 3777 or email

communityed@cotaact.org.au

LOCAL EVENTS

World Elder Abuse Awareness Day Forum

Legal Aid ACT will be running a free forum coinciding with World Elder Abuse Awareness Day 2017. ACT Attorney-General Gordon Ramsay MLA will deliver the opening address and an expert panel will discuss the topic of accessing and supporting older clients experiencing abuse in the ACT.

The panel will consist of representatives from:

- ACT Disability, Aged and Carer Advocacy Service (ADACAS);
- ACT Policing, Rehabilitation, Aged and Community Care (RACC);
- ACT Public Trustee and Guardian; and
- Legal Aid ACT.

Date: Thursday 15 June 2017

Time: 10:00am – 12:00pm

Location: Legal Aid ACT, 2 Allsop Street Canberra

Cost: Free

RSVP: Please RSVP by Friday 9 June to carol.benda@legalaidact.org.au

Integrated Cultures ACT Inc and Integrated Women's Network Workshop: Better Health Management

To celebrate its 5th anniversary, Integrated Women's Network and Integrated Cultures ACT will be hosting a workshop on how to better manage your health. The workshop will cover:

- Preventative health
- Management of chronic conditions
- Information on alternative therapies including yoga, meditation and mindfulness

Light refreshments will be provided.

Date: Sunday 21 May 2017

Time: 2:00pm – 5:00pm

Location: Conference Room 1, Gungahlin Library, Corner of Hibberson and Gozzard Streets. Please enter from the library door on the street opposite Bunnings.

Cost: Free

RSVP: Please RSVP to iwomensnetwork@gmail.com

LOCAL EVENTS (CONT.)

Let's Talk Dementia Session

Alzheimer's ACT will be holding a free information session for anyone caring for people with dementia or for people who have an interest in learning more about dementia. The session will cover basic information such as the definition of dementia, its causes and impacts, and the latest statistics and research into dementia.

Date: Monday 19 June 2017

Time: 1:30pm – 2:30pm

Location: 159 Maribyrnong Avenue, Kaleen

RSVP: Please RSVP by calling 02 6255 0722 or by emailing act.admin@alzheimersact.org.

Contact Us

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Please note that Consumer Bites provides a small snippet of health related articles our members might find interesting to consider, ponder and analyse. The HCCA does not purport to endorse any opinions or the veracity of claims contained within the articles.

Consumer Bites is the fortnightly newsletter from
Health Care Consumers' Association ACT

Editor: Khalia Lee



Australian Government

National Mental Health Commission

Dear Community Forum Participant,

Thank you for taking the time to attend the National Mental Health Commission's Community Forum on 23 March 2017 in Canberra, and for sharing your experiences with us. Commissioners valued the opportunity to engage directly with you and will use the experiences you shared to inform the work of the Commission.

Commissioners heard some important information about the experience of people in the ACT in relation to the implementation of the National Disability Insurance Scheme. The Commission has written to the Minister for Health and the Minister for Social Services, highlighting the following experiences:

- Overall, most people realised that it is still early on in the implementation process and that more time is needed to bed down the system and its processes. However, many described the process as 'evolving' which meant that people felt very uncertain about what they could reasonably expect.
- No definition of psychosocial disability is available and it was described by one provider as a process of trial and error to work out who might qualify and who will be deemed ineligible.
- There are problems with delays in assessments and delays in packages being approved and delays in services being available. This seems predominantly to be related to workforce and skills challenges. Delays of up to nine months seem to be not uncommon.
- There is a lack of consistency in what might be included within a package. Carers in particular feel that their needs are overlooked.
- The promise of choice and control through individualised funding packages seems not to have been realised as yet. Many people reported they are not able to access a coordinator and have to self-manage their package, yet don't have the knowledge or skills to do so. Others described a significant loss of the aspirations that were the focus of the service delivered by Partners in Recovery, replaced instead by services that do little to foster hope and support dreams and recovery.
- Many service providers are experiencing significant upheaval. Some have left the market; others have come into the market. Overall, however, there does not seem to be a good understanding of psychosocial disability, particularly from those working as planners.
- Group based programs which previously offered social contact have disappeared, as the funding model makes it inherently difficult for service providers to offer these. The loss of these programs has been keenly felt by many.

- There are challenges when the consumer does not want to engage with the NDIS. There are challenges around standards being upheld. There are challenges with workforce. The pricing structure of the NDIS has meant that Certificate IV workers previously engaged in the sector are no longer affordable and they have largely been replaced by unqualified less expensive workers who appear to turn over at a higher rate, presumably moving to better paid positions when they can gain them.
- Crisis support remains problematic, with most needing to rely on the mental health inpatient system when other options are not available. There is little evidence to date of packages being able to rapidly scale up when needed most.
- The promise of continuity of support is welcomed but in reality, no one understands what it really means and hence what they can really expect.
- There is universal concern about the pending loss of the previous programs – Partners in Recovery, Day to Day Living, Personal Helpers and Mentors and Mental Health Respite – although it is acknowledged that their funding is continuing in a transitional process until 2019. It appears that no new participants are being accepted in to these programs, so if you are not in one of these programs now, there is no support able to be made available to you.
- Even when the NDIS is rolled-out in all regions (full roll-out will not be until 2019/20), many participants will not be eligible for an individual funding package under the NDIS. There is minimal information currently available about the ILC services that are to be made available.
- There is a very significant level of concern about what will happen to the large number of individuals with severe and persistent or episodic mental illness who will not be deemed eligible for psychosocial support under the NDIS.

The Commission acknowledges the huge opportunity the NDIS offers as well as the enormous challenges it presents, particularly in these early days. The Commission is clear that accountability for resolving the issues outlined above rests across governments, including the Commonwealth and State and Territories, and will continue to hold all governments accountable through our independent monitoring and reporting. Please keep an eye on the Commission's website for our further work in this space.

Thank you again for your participation in the Community Forum and sharing your experiences with us.

Yours sincerely,



Dr Peggy Brown MB, BS (Hons) FRANZCP AFACHSM
Chief Executive Officer
Commissioner

11 May 2017

Info Sheet: “Stories of Transition”

This is an ACTCOSS initiative similar to ‘Stories of Home’ 2016.

Aim: The Stories of Transition publication will be a compilation of data and stories of Canberra citizens who have experienced the both the benefits and frustrations of the transitions in government funded community services.

Issues: including the clients of disability, aged care and housing services etc.

Purpose: The publication will be an advocacy tool for Canberra citizens and social service organisations to encourage governments to address gaps and maintain the standard of services. This is part of our program of advocacy around the need to maintain underpinning social infrastructure as the ACT undergoes a number of key funding and service transitions during 2017 and beyond.

Audience: Decision makers, particularly ACT and Commonwealth Government Ministers, MPs, government officials. Secondary audiences: People who access services and ACTCOSS member organisations.

Confidentiality: Clients’ privacy will be diligently protected—names and identifying info will be confidential-ized.

Contents: We will collect up to 20 stories and select the most compelling and representative of a wide range of services – So there is no guarantee we will use a particular story. We need cross-section of stories from citizens/clients, staff and board members.

Process: Craig / Hal are happy to:

1. conduct face-to-face interviews – approx. 1 hour
2. record interviews
3. draft stories
4. send draft stories back to you for amendments and clearance
5. then get sign off from you
6. pay a participants \$75 per story (i.e. one payment for a story from a family)

Contact officer: Hal Judge, ACTCOSS Policy Officer, (Tue-Fri) phone 6202 7277 email hal.judge@actcoss.org.au

Website: <http://www.actcoss.org.au/take-action/stories-transition>

- If you are interested in contributing, we will email you the details.

ACTCOSS 27 April 2017