



## Karumah Update July 2019



### From the Coordinator

Due to being sick with the flu, I have not been able to get this newsletter out in June as usual, so it is a month late, apologies, but here it is.

The end of the financial year is here, and Karumah has had another full year on our events calendar, we are very much on track with our funding obligations and in fact have kicked more than a few balls past the goal post. Our funding continues and therefore we are able to continue providing services to people living with HIV in the Hunter region. This year is a special anniversary year for us, 30 years - quite an accomplishment, and all those who have carried the flag and been involved with Karumah on any level over those 30 years should be very proud of this organisation. From humble beginnings to a thriving community service Karumah has adapted and changed with the times. CONGRATULATIONS to all those who have contributed to that.



### Karumah Memberships

Memberships are due for the new year starting on 1st July 2017 - \$5.00 will get you

- full membership;
- discounted rates on all Karumah activities, events and workshops
- Vote at the Annual General Meeting on Karumahs constitutional changes
- Vote to elect the Karumah Board of Directors during annual elections

### Karumah Board

The board plays an important role in overseeing the strategic direction and providing leadership for Karumah. Karumah is always looking for quality board members who can provide such skills as - leadership - finance - promotion - strategic planning - governance - work health and safety (WHS) - resourcing and advocacy. If you feel you have something to offer Karumahs board and have 5 hours to spare a year (board meets quarterly) please let us know.

### Karumah and the NDIS

Karumah has just passed accreditation again as NDIS providers in the NSW region. If you or anyone you know believes they are eligible for the NDIS, and would like a hand making an application, please don't hesitate to contact Catherine or myself for more information. Those with existing packages, Karumah provides a number of services. 0047 003 386 or [casemanager@karumah.com.au](mailto:casemanager@karumah.com.au)



## Karumah and the NDIS



Eligibility for the NDIS can be confusing for many people so here is some information which we hope makes it easy

- You must be under 65 years of age to be eligible for the NDIS, of course if you are over 65 you can access Aged Care assistance.
- The NDIS is only available to people who live in Australia, have Australian citizenship, or a permanent visa or protected special category visa.
- You could be eligible if you usually need support from a person because of a permanent and significant disability
- Also if you use special equipment because of a permanent and significant disability.
- You will need documents to support your claim. You can work with your treating health professionals to provide your evidence of disability e.g. GP - Paediatrician - Orthopaedic surgeon - occupational therapist - Speech Pathologist - Neurologist - Psychologist - Psychiatrist -
- It is important to remember that the person helping you to gather your disability evidence will not be able to tell you if you meet the NDIS requirement, only the NDIA can make this decision.

### **For those NDIS participants with a plan already, here is some information about plan reviews.**

Your plan review is an opportunity for you to check if your supports are working for you and they are helping you work towards and achieve your goals. Depending on your preference plan review can be done face-to-face or over the phone, You are welcome to bring along or include in the call, a family member, friend, advocate or other person when your plan is reviewed.

Your first NDIS plan review usually falls 12 months after your plan started. If you haven't heard from the NDIS 6 weeks prior, call them on 1800 800 110 or find and call your nearest office. If you feel your needs are unlikely to change and you don't think you will need a plan review in 12 months time, the NDIS can offer you a future plan up to 24 months.

The NDIS is designed to increase a person's skill and independence so they can live a better life. As you work towards and achieve your goals, the amount of support you need will likely change. If a service, early intervention support or assistive technology has increased your independence and decreased your need for additional support, you may need less funding or no longer need any funding through an NDIS plan. This means you may not need NDIS funding now, but you can contact us again in the future if you need to.

People who have episodic disability (a disability where the impact on your day-to-day life fluctuates) may also see their NDIS funding levels change over time, just as their disability changes over time.

I hope this has been helpful, if you have any questions about getting a plan or work-hesitate to contact Catherine 0447 003 386

ing with your existing plan please don't  
or [casemanager@karumah.com.au](mailto:casemanager@karumah.com.au)



**NDIS & Karumah**  
Restoring Dignity





## It is time to renew your Karumah membership.

It's that time of year again \$5.00 will get you full membership; discounted rates on all Karumah activities, events and workshops. Karumah members contribute to work in HIV prevention, health promotion, advocacy, care and support. We're grateful for your financial support, participation in focus groups and research, volunteering, attending fundraising and other special events as well as providing valuable feedback on our services and campaigns.

### As a financial member you can:

- Vote at the Annual General Meeting on Karumahs constitutional changes
- Vote to elect the Karumah Board of Directors during annual elections
- Enjoy discounted attendance at social events and workshops

Please download the forms from Karumahs website and either fill it in and scan and email through to us or post it in. You can also call in and pick up a membership renewal from Catherine



thank  
you

One of our valued clients at Karumah hosted a Facebook funding on her birthday recently and named Karumah as the recipient. It has taken a while to come through, but it arrived this week. We received a cheque for \$190.00 which will go towards Karumah programs for people living with HIV.

**So a big thank you, you know who you are, it is greatly appreciated.**



## Slow Cooker Lamb Shanks Korma



### Ingredients.

- 6 French-trimmed lamb shanks
- 1 brown onion, thinly sliced
- 4cm piece fresh ginger, peeled, finely grated
- 3 garlic cloves, crushed
- Half cup korma paste
- 3 tomatoes, roughly chopped
- 300ml pure cream
- 1 cinnamon stick
- 2 teaspoons poppy seeds
- Half cup loosely packed fresh coriander sprigs
- 1 long green chilli, thinly sliced
- Third cup roasted unsalted cashews, roughly chopped
- Steamed basmati rice, to serve
- Mini pappadums, to serve

### Method

1. Place shanks, onion, ginger, garlic, paste, tomato, cream, cinnamon, poppy seeds, add half cup water in the bowl of a 5.5 litre slow cooker. Season with salt and pepper. Cover, cook on low for 8 hours or high for 4 hours until shanks are tender. Using a large metal spoon, skim excess fat.
2. Combine coriander, chilli and cashews in a small bowl. Transfer shanks and sauce mixture to a serving dish, sprinkle with coriander mixture. Serve with rice and pappadums.



Flu Shot Time, if you haven't had your shot yet please make sure you get it, both ACON and the Pacific Clinic have the vaccinations now.



The Dried Blood Spot (DBS) HIV test is a new, free, easy, private and accurate way to test for HIV. It involves a few drops of blood that you collect from yourself at home. You return the DBS HIV test in a reply paid envelope and receive the result by phone, text or email. You don't need to go to a clinic or a doctor to do this test

Visit [www.hivtest.health.nsw.gov.au](http://www.hivtest.health.nsw.gov.au)  
to see if you're eligible for this innovative HIV test

**Access to HIV medicines has improved - HIV medicines are free, you can get them from the hospital pharmacy or your local chemist—The choice is yours.**

You can continue to collect your HIV medication from the hospital pharmacy in the same way as you have in the past, since 1 July 2015, you've had the option to have your HIV medications dispensed through your local community pharmacy (chemist) or through a hospital pharmacy. If you take HIV medications, they are free from 1 October 2015. This applies to all NSW residents regardless of whether you get HIV medicines dispensed from a hospital pharmacy or a community pharmacy (chemist). Your privacy will be maintained in the same way by a hospital pharmacy or by a chemist.

Using the technology



## Aly - Community Support and Promotions Officer



After a pretty sunny autumn, winter is truly upon us at last - I hope you're all staying warm!

It's been another busy few weeks in Community Support & Promotion with interviews and submissions for the 30th Anniversary in full swing and plenty of upcoming events and initiatives.

Thank you to those who attended our Men's Health BBQ earlier this month, we would have loved more of a crowd but lovely weather and some great presenters from Relationships Australia were not wasted on those who came along. We get a lot of requests for BBQs but we need stronger numbers to keep providing them.

Fortnightly Peer Catch Ups have been going particularly strong lately and we'd love to see that grow even more so. Every second Thursday at the Wickham Park Hotel from 12:30 pm, come share a \$6 lunch with some good company. If you need assistance with transport, you can contact Catherine or me and we can arrange a lift or carpool to help get you there. We'd love to see some new faces!

The dates for the next Peer Leader Group and Positive Hunter Heterosexuals lunch events are now in the calendar. These events are roaming and this time around both will be held in Maitland. We're really looking forward to growing these two networks within the Karumah community.

Our stories project is off to an amazing start - we're aiming for 30 participants for 30 years and we're already over twenty! There is still time to get involved if you're interested. You can write your own or I can interview you, either way, they will all be published in a beautiful physical book which will be launched at an event in September. If you would like to get involved, please email or call me, let Catherine or myself know when you see us or sign up via this online form: <https://forms.gle/dU9G3VxDpQL8pD7z7>

We have two exciting getaway events planned for this year, with our Women's Wellness Retreat in Clarence Town coming up between July 19-21 and then our annual Karumah Getaway happening at Catalina Bay in late November. Details for the annual retreat will be out later this year but if you're a woman in the Karumah community (including partners, carers, supporters, family, etc.), you can RSVP to Aly or Catherine via phone, email or in person.

I'm also excited to announce a new initiative called Karumah Explorers! This will be a series of events based around group outings or experiences and aims to reduce isolation and promote community. Stay tuned for information on our first couple of trial events coming soon.

And finally, if you've not already, be sure to like our Facebook page to stay up to date on events and for information on HIV and wellness related news! Just type 'Karumah' in the search bar or go to <https://www.facebook.com/karumahonline/> and click the 'Like' button.

The cold weather can sometimes make it harder to get out and socialize and can generally make us feel a little blue, staying connected to other people is one of the best ways we can look after ourselves over winter and hopefully Karumah events can help with that.

See You Soon,

Aly James

*Community Support & Promotions Officer*

## Do you have to tell your boss that you're HIV positive

Jordan Hurst



One of the biggest fears of people living with HIV is having to disclose their status to their employer, risking possible discrimination. The good news is that in most professions, you are not legally required to tell an employer, or prospective employer, that you are HIV positive with only a few exceptions, the main one being healthcare. Doctors, nurses and dentists who perform Exposure Prone Procedures (EPPs) are required to disclose their HIV status. EPPs include procedures performed in a confined body cavity where there is poor visibility and a risk of being cut by implements, teeth or bones. HIV positive healthcare workers are currently not permitted to perform EPPs. If you are positive you won't be accepted into the Defence Forces, and if you contract HIV while working for the ADF, you will most likely be discharged from the service.

People working in the aviation and mining industries undergo regular medical assessments to check their fitness to work without risk to their or others health and safety. If you are affected by your HIV medication while working in a mine, you have a duty of care to tell your supervisor, but you do not need to disclose what the medication is for. According to Civil Aviation Safety Authority rules, if you contract HIV while working as a pilot or air traffic controller, you must stop working and notify the Designated Aviation Medical Examiner. Finally, sex workers in Queensland do not need to disclose to clients that they are HIV positive but are not permitted to work in a licensed brothel. They can offer services privately as sole operators, and like all sex workers in Queensland, must use condoms or dams for sexual intercourse or oral sex. If your employer takes adverse action against you after you disclose your HIV status like giving you the sack, or reducing your hours, you may have a claim for unlawful discrimination, and should seek urgent legal advice. **If you have suffered discrimination on the basis of your HIV status, we can help. Please call Discrimination Claims today on 1300 853 837**



**July 2019**

- Wednesday 3rd July      Karumah Explorers: Newcastle Art Gallery 2pm
- Thursday 11th July      ‘Peer Catch Up’ - Wickham Park Hotel 12:30pm
- Saturday 13th July      Peer Leader Group Lunch—Billabongs Restaurant 12pm
- Friday 19th to Sunday 21st      Karumah Women’s Wellness Retreat
- Thursday 25th July      Peer Catch Up’ - Wickham Park Hotel 12:30pm

**August 2019**

- Wednesday 7th August      Pozhet Drop-In—Camperdown
- Thursday 8th August      ‘Peer Catch Up’ - Wickham Park Hotel 12:30pm
- Thursday 8th August      The Golden Hammer - 2019 Bobby Goldsmith Foundation Auction
- Saturday 10th August      Karumah Explorers: Maitland Aroma Coffee & Chocolate Festival 11am
- Thursday 22nd August      ‘Peer Catch Up’ - Wickham Park Hotel 12:30pm
- Sunday 25th August      “Connect Out West”—Lunch at Rocco’s Ristorante Liverpool

**September 2019**

- Wednesday 4th September      Pozhet Drop-In Camperdown

 **pozhet**

# Weekend Retreat

**2019**



## HETEROSEXUAL MEN AND WOMEN LIVING WITH HIV & PARTNERS

BERRY, NSW

FRIDAY 25 – SUNDAY 27 OCTOBER 2019

- **Discussions** treatment decisions, disclosure & tackling stigma
- **Build HIV resilience**, share health information
- **Fun and challenging activities**  
meet new friends for support
- **Stories & connection**  
with heterosexual peers across NSW
- **Accommodation, activities and meals provided for free**



Applications open on 2 July and  
close on 20 September 2019

### For more information or an application:



[pozhet@pozhet.org.au](mailto:pozhet@pozhet.org.au)



1800 812 404



[www.pozhet.org.au](http://www.pozhet.org.au)



3/18 Marsden St Camperdown  
NSW 2050

A partnership event with South Eastern Sydney HIV and Related Programs Unit

## Uluru Northern Territory



One of Karumah's service users recently made a journey to the Northern Territory to Uluru, according to her it was the most spiritually uplifting time of her life and the photo above represents the 'birthing' place and 'women's business' from our indigenous sisters. She was permitted to write her mother's name on a piece of paper and place it under a rock to symbolise her mother joining her on the journey that should have happened together.

It is unusual for an indigenous lady to agree to such a thing for the memory of a non-indigenous person, according to our service user, and it is with great pride she wished to share her experience with you.



## **Re: PLHIV and Ageing Community Survey – Royal Commission into Aged Care Quality and Safety**

**Survey Background** - The Australian Government is holding a Royal Commission into Aged Care Quality and Safety. The Royal Commission will provide Australian people living with HIV (PLHIV), their partners, carers, family and friends, HIV service providers and Aged Care services with a rare opportunity to make clear to the Australian Government, the current and future Aged Care service needs of PLHIV in all Australian states and territories.

To advance this objective, Positive Life NSW and NAPWHA will write a submission to the Royal Commission. The submission will closely align with the Royal Commission's Terms of Reference and provide qualitative and quantitative data on the following:

- Whether Aged Care services meet the needs of Australian PLHIV (current and future) and whether the quality of services is acceptable, or needs to be improved?
- Whether there are PLHIV who need Aged Care services, but are ineligible (system gaps, for example, PLHIV under age 65 years)?
- If there is evidence of mistreatment, abuse or discrimination of PLHIV in the Aged Care service system and how the abuse, mistreatment or discrimination manifests?
- How services would best be provided to PLHIV with neurocognitive disorders? and;
- Preference about where PLHIV would like to receive Aged Care services (at home, in a residential Aged Care facility, in another type of facility/model of care) and why?

To provide PLHIV and others associated with the care of PLHIV with an opportunity to provide this advice, Positive Life has developed an anonymous online survey. The survey will target: PLHIV; the partners, carers, friends and family members of PLHIV; HIV service providers, and; Aged Care service providers. The survey has been peer-reviewed by individuals from each of the four target groups.

The issue of PLHIV and ageing has been discussed within the HIV sector for at least the last decade. Although there has been published international literature on the issue of HIV and ageing in European and American studies, the Royal Commission will be most interested in Australian research that clearly articulates the current and projected needs for Aged Care service over the next 10 to 20-years. Data from this survey will play an important role in providing this information.

**Survey Distribution** - To achieve feedback from all jurisdictions, we're asking for your support to distribute the survey link to:

- PLHIV and their partners, carers, and family members in your jurisdiction
- HIV services providers (particularly clinicians, allied health and NGO HIV support workers etc.). You will know which service providers in your jurisdiction would be best qualified and more likely to provide information
- Paper copies of the survey will also be available (upon request from Positive Life NSW)

Below is the link to the online survey for distribution. The link can be copied into an internet browser to access the survey.

<https://www.surveymonkey.com/r/PLHIVAgedCareSurvey>

## AskDocQ: U=U means if a person with HIV is undetectable, they can't pass it on

DR FIONA BISSHOP 3 MONTHS AGO



Unfortunately, a recent survey showed that not all health care providers are spreading the U=U message. This may be because they are not aware, and some because they have not yet read up on the scientific facts or they may remain unconvinced that the risk is actually zero and are not on board with the message. They need to look at the hard evidence: PARTNERS 2 had 77,000 acts of condomless anal sex between positive and negative men, Opposites Attract had 12,000 acts.

That's 89,000 times that guys had anal sex without condoms and there was not a single transmission. Now I'm not a statistician, but I think I can safely say that those figures are very convincing for zero risk. Not just reduced risk, not just extremely unlikely, but no risk. What about viral blips you might ask? A blip is when someone who is usually undetectable has a blood test that shows a detectable but very low level of virus in their blood, usually less than 200 copies per ml. All of the studies I mentioned used cut-offs for undetectable of between 200 and 400 copies per ml, so their definition of undetectable was higher than the definition used by our laboratories in Australia, which varies from 20 to 40 copies per ml between labs.

In other words, most low level blips would still have been counted as undetectable in the studies, and there were no transmissions. So blips should not negate the U=U message. How long does someone have to be undetectable before U=U applies? This is a good question but technically if they have achieved undetectable status and are still taking their meds every day, they should stay undetectable, so U=U should apply straight away. How often should viral load be checked? When someone first starts their meds their viral load is checked every three months, but once they have been undetectable for six to 12 months we can become more relaxed about monitoring, and tests need only be performed every six months.

## U = U Cont'd

Some would say for someone who has been undetectable and stable on treatment for years they could even go to a single annual blood test. If they keep taking their meds every day, nothing should change. Currently there is no cure for HIV, but being undetectable on treatment means a person with HIV can live a normal healthy life, and along with that should be a normal sex life, free from anxiety or guilt. It's a human right. People with HIV are entitled to a life free of stigma and fear of transmission to their intimate partners, and the U=U message helps deliver this

### **Physical Symptoms of Stress** EAP Assist.



Our bodies are equipped to deal with temporary stressors by activating our 'fight or flight response' which causes our heart to beat more quickly, our blood pressure to increase, our breathing to quicken and our muscles to tense. In addition, our immune system responds to a perceived threat by amping up the production of disease-fighting white blood cells and dumping the stress hormone cortisol into our bloodstream. Once the crisis has been dealt with, in most cases our immune system settles back into our regular state of being or homeostatic.

However, when stress lasts for an extended period of time, our bodies can begin to break down. Such a state of overstimulation is not viable and will lead to problems, which can include a variety of physical symptoms that you may not associate with stress. Examples include;

Digestive problems - including an upset stomach, nausea, burping, heartburn, gas, diarrhoea and or constipation. Stress often affects digestion by decreasing the production of stomach acids and altering how quickly food moves through your body. Also, since stress can cause increased muscle tension, this can put pressure on your stomach and the rest of your gastrointestinal tract.

Changes in appetite - The stress hormone cortisol is linked to cravings for sugar or fat, which can lead to overeating. Also sleep quality is often compromised when we're stressed, and insufficient sleep causes levels of ghrelin (hormone which increases appetite) to amp up, while levels of leptin (hormone linked to feelings of satiety) decrease.

## Stress Cont'd

Headaches - Stress hormones like adrenalin and cortisol trigger vascular changes that can bring on a tension headache or migraine, either during the stressful period or the following "let-down" period. In other words you might develop a pounding headache in the midst of a tense business meeting, or it may hit you once you're kicking back on the weekend.

Stress can also cause - Weight gain - Aches, pains, and tense muscles - Low energy, tiredness, weakness and fatigue - Chest pain, rapid heart rate and heart palpitations - Breathing and respiratory changes - Insomnia and daytime sleepiness - Frequent colds and infections - High blood sugar - Decrease in sexual desire - Hair loss - Acne and Skin Irritations -

Here are some strategies to manage stress - they can vary according to the source of our anxiety. Some options include

- Regular exercise
- Sufficient sleep
- Healthy nutrition
- Practicing relaxation techniques (meditation, yoga, deep breathing, tai chi, massage)
- Time with family and friends
- Maintaining a sense of humour
- Therapy and/or support groups
- Setting aside times for hobbies (books, music)
- Identify triggers (I.e. not getting enough sleep)
- Learning new coping strategies to deal with challenges

Since we differ in what we consider stressful, it's important to determine your personal threshold for stress. What might provoke anxiety in someone else might not bother you, and vice versa. Also symptoms of stress vary from person to person, and in many cases can be identical to symptoms produced by medical condition stemming from other cause. Finally, whether or not you're currently undergoing a stressful time, put aside some undisturbed time on a regular basis to check in with yourself and how you're feeling. During meditation or just sitting quietly. Mentally scan your body for aches, pains and other symptoms that may indicate the need for stress management.



## In Health Affairs: Large Positive returns on HIV treatment.

In 2014 the Joint United Nations Programme on HIV/AIDS (UNAIDS) established 90-90-90 treatment targets for the treatment of HIV. These goals include 90 percent of people with HIV will know their status; 90 percent will receive appropriate treatment; and 90 percent will suppress the virus. Steven Forsythe of Avenir Health and co-authors evaluated data used by UNAIDS to calculate that in the period 1995-2015, antiretroviral therapy (ART) averted 9.5 million deaths worldwide, with global economic benefits of \$1.05 trillion. The authors also found that for every \$1 spent on ART, \$3.50 in benefits was realized globally. Including future projections, the authors estimated that in 1995-2030, approximately 40.2 million new HIV infections could be averted (more than twice as many deaths as occurred during World War I), with economic gains reaching \$4.02 trillion in 2030. With different countries achieving different results for the different targets, the authors recommend analyses of national treatment program performance to enhance overall benefits and efficiency.

Also in the issue:

- Epidemiological And Health Systems Implications Of Evolving HIV And Hypertension In South Africa And Kenya; Brianna Osetinsky of Brown University and co-authors  
The Impact Of Price Regulation On The Availability Of New Drugs In Germany; Ariel Stern of Harvard Business School and co-authors

## Sexual Disease surge sparks national call to action

The Northern Territory is rallying the states for a stronger response to the ongoing syphilis outbreak, high rates of HIV diagnoses and sexually transmitted infection in indigenous communities. A surge in syphilis cases was first reported in north-west Queensland in 2011 and since then has also been observed in the NT, Western Australia and South Australia. According to the latest figures, released on Friday, there have been 2786 cases - including 60 in May. The HIV rate among heterosexual people in indigenous communities has also been rising - even as new diagnoses continue to decline at a national level - while there are higher rates of gonorrhoea than in non-indigenous communities, some strains becoming antibiotic resistant.



While health ministers had agreed to a national response to the syphilis outbreak and the federal government committed more funding to test and treat more people NT Health Minister Natasha Fyles has told her interstate counterparts there are gaps in the approach. The move comes as the commonwealth considers the implementation plans for various national blood borne virus (BBV) and sexually transmissible infection (STI) strategies, having set aside another \$45.4 million in the budget.

In the medical Journal of Australia yesterday, health experts reflected on the high rate of infections, and poor use of antibiotics, that has fuelled the spread of antibiotic superbugs in indigenous communities. They noted 95% of children received at least one antibiotic prescription and 47 % received at least 6 - before their first birthday, and resistance “will likely continue increasing unless infections are prevented, thus reducing the need for antibiotic use”.

## Media Release

### HIV still not in decline for everyone

**PositiveLifeNSW**  
the voice of people with HIV since 1988

Positive Life NSW celebrates the continued significant decline in HIV notifications amongst gay and bisexual men (GBM), as announced by the Kirby Institute's National HIV Quarterly Report in Sydney last week

Today's environment consists of the accessibility of PrEP for men who have sex with men (MSM) alongside an increasing uptake and awareness of HIV testing in the broader community and the engagement of people living with HIV (PLWH) starting HIV treatment earlier has made a lasting impact on HIV transmission. These factors demonstrate the partnerships and "Incredible commitment from government, healthcare, community and research sectors to eliminate HIV transmission in Australia", said Professor Rebecca Guy, head of the Kirby Institutes Surveillance Evaluation and Research Program.

Although the report revealed a 30% drop in new HIV diagnosis in GBM/MSM there has been no similar decrease in the rates amongst heterosexual people or Indigenous people. The ratio of heterosexual notifications have actually increased from one in every five diagnoses to one in every four diagnosed over the past two years, which is due to the reduction among MSM. "These latest figures are a great story for GBM and MSM," said Acting CEO Neil Fraser, "However the inequity in our messaging towards heterosexual people, Indigenous people, overseas-born MSM, and people from culturally and linguistically diverse (CALD) background about the risk of HIV is thrown into stark contrast more than ever." he said.

"Targeting identified 'at-risk' through public health messaging, often believe the HIV prevention message is irrelevant to them." "HIV is not restricted to any single group of people," he said "Anyone who is sexually active is at risk of contracting HIV."

"Unfortunately, heterosexual people, Indigenous people, people from CALD backgrounds and overseas-born MSM live with HIV for between four to ten years before they are diagnosed, which means they risk transmitting HIV to their sexual partners, unknowing," said Robert Agati, President of Positive Life. "this delay has a considerable impact on their long-term health," he said "especially when early diagnosis and early treatment means people living with HIV can live long and healthy lives, and also halt onward HIV transmission." "GBM and MSM have been exposed to at least 30 years of HIV prevention messaging," said Mr Fraser, "We can play a strong role in raising community awareness of the risk of HIV along with those of us living with HIV who use Treatment as Prevention (TasP) to reduce HIV transmission."

"As we approach the count down to the virtual elimination of HIV transmission by 2025, we believe it's time for all people who are sexually active regardless of orientation or gender be offered comprehensive and culturally appropriate sexual health screening, including HIV testing." said Mr Fraser "Let's leave no one behind."



## Celebrating his 100th birthday - Meet the Oldest Known Person Living with HIV, POZ

Celebrating a 100th birthday would be a milestone for anyone. But for Miguel, known as ‘the Lisbon Patient,’ his upcoming centennial in the spring is also of importance to the global HIV community. He is the oldest documented person living with the virus. What’s more, his viral load is undetectable, and he is in wonderful geriatric health - he’s even able to live alone and care for himself.



“This guy (is) like an icon of hope for people living with HIV.” HIV specialist Giovanni Guaraldi, MD, told Canada’s CTV News, in a profile on Miguel. Because of the persistence of HIV stigma, Miguel and his family requested that his face not be shown and his real name not be used. The nickname “the Lisbon Patient” was coined in a case study soon to be published.

According to CTV News, Miguel was diagnosed with AIDS in 2004 when he arrived at a hospital near Lisbon with rare forms of colitis and lymphoma and a low CD4 count. He was 84 and had no idea he was HIV positive. He and his doctors believe he contracted the virus through heterosexual contact.

Ines Pintassilgo, a medical resident who works with Miguel, said his health and longevity can be attributed to the facts that he takes his HIV meds daily and has lived a healthy and active life.

“I think he teaches us that you can live with HIV as long as you have all the other background and lifestyles and comorbidities under control,” Pintassilgo told CTV News. “I would say, of course, HIV maybe plays a little role in this, but if it’s well-managed and well controlled it will not be that big (of an) issue.”

Miguel offers a different insight, “The reason why I have reached such a long age is because every day when I go to bed I make a cup of lemon tea,” he said via a translator. “The good slice of lemon with the rind and the pulp and everything. It would boil for five minutes, and in the end I would add a good teaspoon of honey.”

HIV specialist Guaraldi finds more than a little inspiration in Miguel’s case. “I believe that the message is not to give more years to life, but to give more life to years - this is what we want for the future for our patients.” said Guaraldi, who works at the University of Modena in Italy. “I believe that the Lisbon Patient is a sign of hope for people living with HIV to say you still have the capacity not just to live longer but to live in health, to experience healthy aging ....He is a proof of principle for us researchers and doctors to say we can provide better care to people.”





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## Karumah Thursday Lunches

Wickham Park Hotel come along for good food and good company, meals only \$6 for Karumah members. Held every 4 weeks see calendar for dates

### Dates



Thursday 11th July 12.30pm

Thursday 25th July 12.30pm

Thursday 8th August 12.30

Thursday 22nd August 12.30



## Positive Life Farewell CEO, Craig Cooper - 31st May 2019

Positive Life NSW announces the resignation of their Chief Executive Officer, Craig Cooper, after five years of leadership. The Board supports his decision to pursue his career within the not-for-profit sector, though they are sorry to see him go.

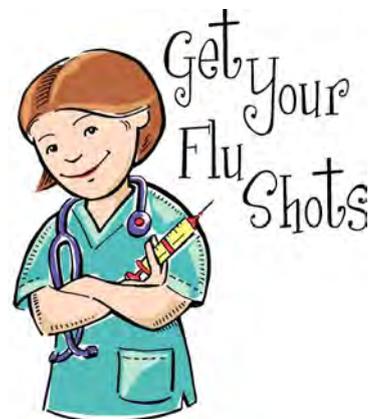
As an interim arrangement, the Board has appointed Neil Fraser and Craig Andrews as co CEO's to manage the ongoing implementation of Positive Life's strategic direction and to ensure the continuity of the agency, while the Board expedites recruitment and selection for a permanent CEO.

## ACON farewells Wez Saunders

ACON loses an icon in the industry, with Wez Saunders retiring after many years of dedicated service. Karumah wishes him all the best.



## Get your Flu Shots at Pacific Clinic or ACON they are now available.



## **From the Case manager;-**

Well I must say it is about time we had a bit of a chill in the air to clean out the sinuses and remind us we are alive! Welcome winter and a shout out to all our volunteers as Volunteer Week has just passed!

Karumah has had a recent NDIS audit and we welcome the accreditation that was the result. Please feel free to pass on our details to any of your friends or family members who have a package of care and would prefer a more personalized approach than they may already receive.

I have been out meeting up with people and guiding some of their journeys as requested. I do seem to have a huge and ongoing response to the suggestion of TIM (The Institute of Many) which is an online platform directly targeted at PLWHIV only. Claiming to be the largest grassroots movement for People Living with HIV and allow those very people to find support, online and in person if they so desire. Join private communities on Facebook, find out about events and learn about ongoing campaigns. <https://theinstituteofmany.org/> If you haven't already connected I thoroughly recommend you doing so as it is proving to be a safe space for building capacity and knowledge around HIV.

I have learned some great information in the last few weeks where I have had the opportunity to obtain some professional development and would like to share with you that there are to be many changes to NSW Carers and Carers Australia in the coming months. They will amalgamate to form Carer Gateway, which will provide more practical advice, education and support services. I will post the new website address but be mindful that it is still being developed and should be active from 1 July 2019. <https://www.carergateway.gov.au/> There will be support available around also connecting with other carers and an online platform for ongoing discussion. This is also the location for respite services, (Commonwealth Respite and Carelink Centre) and there will be some brokerage services should people be in need. Please contact me if this applies to you.

I have discovered (with the help of others...) that there are also a number of tools available via Apps on the smart phone devices for those of you that are interested and have access to this technology. This app provides daily CBT from a robot that can encourage you to do self-care in relation to identified areas of concern. Woebot <https://www.woebot.io/> Also there is Calm which assists with meditation and sleep... <https://www.calm.com/> Mindspot which provides free online assessment and treatment for anxiety and depression, allowing for education and information along with strategies and treatments via courses conducted on this platform... <https://mindspot.org.au/>

In addition, there is PERX, a tool driving adherence to clinical treatment plans and improving patient outcomes by rewarding scheduled tasks completion and treatment compliance. Prizes often comprising of recreational vouchers etc. Thank you to all those parties who have guided me to these very useful tools. Your personal feedback on any or all of these tools would be highly valued.

As always, there are ongoing studies and surveys available, capturing the data for the HIV Futures studies are highly important and I would direct you to <http://www.hivfutures.org.au/> should you require a hard copy please contact me on 0447 003386. And a further survey focusing on the needs of PLWHIV as they age and what services need to be considered and incorporated. Please consider filling out this as well <https://www.surveymonkey.com/r/PLHIVAgedCareSurvey>.

Hoping some of this information can be useful and I look forward to hearing your responses as I see you.