

pRogReSsion

News & Information for CADS Clients from CADS Consumer Team



Issue 52

July - Oct
2016

Hello CADS clients

Firstly it is my great pleasure to welcome Andrew back to the CADS Consumer Team and to AOTS. Megan left the role in Feb and Andrew was the successful applicant after we interviewed in April.

Andrew is here 4 days a week and on Thursdays works at ADIO East St supporting the hep C clinic there. The two jobs fit really well together.

As many of you will know Pharmac has agreed to fund two new Hep C drugs: Harvoni and Viekira Pak. Yay!! The results of clinical trials using these two drugs have been really positive so it is hoped that more people will access treatment.

Andrew tells you more about it on p5.

It's important to recognise that Hep C isn't confined to people who've used drugs.

Other factors which can make people susceptible are people who:

- Had a tattoo or body piercing done with unsterile equipment



- Have lived or received medical attention in a country deemed high-risk such as South East Asia, China, Eastern Europe (including Russia), or the Middle East
- Had a blood transfusion or received blood products prior to 1992
- Have ever been in prison
- Were born to a mother living with hepatitis C.

CADS are looking at how to increase the number of people who get screened for Hep C so will be rolling out screening opportunities in the CADS units.

Please don't be offended if you are asked about possible exposure to hep C. It is nothing to be ashamed of

and the aim is to help people get the treatment they need. And in case you forgot: **July 28 is World Hepatitis Day.**

On June 26 was Support. Don't Punish day. This is a global campaign aimed at rethinking the response to drug use and drug users.

You can become part of the campaign by taking part in the photo project. Check it out on www.nzdf.org.nz or go to www.supportdontpunish.org

And now for something completely different: people often think the Consumer Team are advocates. We're not though we can help you if you need an ear or some advice.

On p6 are some tips about advocating for yourself and some examples of when a chat with the Consumer Team might be helpful.

We aim to have the next issue of pRogReSsion out in Nov so til then, keep warm and play safe

Sheridan (CADS Regional Consumer Advisor)

CADS CONSUMER TEAM AVAILABILITY

If you need to speak with one of us phone 815 5830 & reception will connect you to someone from the Consumer Team

- ✂ **Andrew** AOTS Consumer Liaison is available Mon, Tues, Wed and Fri 9am—4pm
- ✂ **Astrid** is at South one day a week and at Pitman House Detox Services (IPU and CHDS) Tues and Thurs
- ✂ **Marc** is available Mon, Tues, Wed and Fri 9am -3pm
- ✂ **Sheridan** is here during business hours Mon—Fri



MARC (COUNSELLING SERVICES CONSUMER LIAISON) - TO VAPE OR SMOKE?

Over the last few years there has been a growing amount of people using vaporisers rather than or as well as smoking.

I thought it is about time I found out what is the latest research saying about vaporisers. Is it a good harm reduction strategy or not?

So first off what are vaporisers and how do they work?

Well there are many different types. Most use low temperatures (from about 200c-300c) to evaporate the active substances given off as vapour which is inhaled.

Public Health England started a controversy by saying that “e-cigarettes are 95% safer than smoking cigarettes”.

This has had headlines all over the world including here in New Zealand.

Obviously if you don't smoke it is not a good idea to start vaporising as it is more harmful than not vaporising.

If you are smoking why you would vaporise? Well the studies say that it is by far safer.

This has a lot to do with the fact that you are not burning anything.

The act of burning—besides the high temperature (approx. 700c-1100c) needed to create the smoke—creates a lot of by-products including tar, carbon monoxide, carbon dioxide and others.

E-cigarette type vaporisers heat at about 200c-300c the liquid which is mostly propylene glycol and nicotine.

There are a lot of flavours that these liquids can come in. Have a read of the label.

Avoid Diacetyl which is a product that adds a buttery taste to things like microwave popcorn; apparently it can cause something called ‘popcorn lung’ which is very nasty.

Some of the other flavourings are also not so good so do some research.

There is some evidence that vaporisers operated at higher temperatures can emit formaldehyde which is also not good.



Nicotine is not supposed to be available in across the counter products in NZ.

So there are risks and dangers with vaping though as Public Health England said it is safer than smoking.

One of the interesting things to come out of the study was also about the way people smoke with vaporisers.

They tend to have a few puffs then put it down and come back later.

The researchers noticed this is different than cigarette smoking where people tend to smoke a whole cigarette so are consuming more than they would with a E-cigarette.

Vaporising/ vaping is an alternative to smoking and looks like it could be less harmful.

But as with all things it's good to do your own research and find out what works for you.

While I was looking into smoking I also came across some studies on Shisha.

If I listen to the talk from mates, shisha sounds fine. The information from studies were quite (shockingly) different to what I got told though.

Turns out that smoking Shisha is still smoking.

Although the smoke is passed through water and cooled somewhat it still carries all the same chemicals.

The way it is smoked means it is easier to take a larger amount of smoke into your lungs and it is smoked over a longer time—both of which cause more harm.

It seems that people also smoke more in a session when smoking Shisha.

It is true that some Shisha does not contain tobacco but this did not seem to stop the tars, heavy metals and other chemicals from being present in the smoke.

As with some of the vaporiser liquids, some of the additives in Shisha tobacco are somewhat questionable and could have very unexpected effects.

This is what you can expect from a largely unregulated market. It's another case of buyer beware. Do your research, find your own truth.

Did you know the alcohol drug helpline is now available 24 hours?

You can call them if you are concerned about your own or someone else's drinking or other drug use for friendly, confidential, non-judgmental advice and support. **It's your call.** Or check it out on www.alcoholdrughelp.org.nz/

From the website you can find out more about alcohol and drugs, read consumer stories, locate

alcohol  drug
HELPLINE
0800787797

WHAT DID WE LEARN FROM THE GLOBAL DRUG SURVEY 2015?



An overview of key findings

- The researcher says Ireland's reputation for heavy drinking is well deserved however Australia, Netherlands, UK and NZ can't be too smug; we weren't far behind
- Unlike other nationalities Kiwis don't mix tobacco in with their cannabis
- While high potency cannabis remains dominant we learned that butane hash oil (BHO) is starting to nudge its way into the cannabis using community
- synthetic cannabinoids continue to cause great concern. For the third year running these drugs were more likely to leave people needing emergency medical treatment than any other group
- NZ and Australia remain the priciest place to buy cocaine in the world
- Globally nitrous oxide is now ranked the 7th most popular drug in the world

For more interesting facts go to www.globaldrugsurvey.com

The survey happens each year usually in November and is run through media partners around the world including www.stuff.co.nz

EQUALLY WELL is a national project which aims to take action to improve health outcomes for NZers who experience problem with drugs and alcohol and/or mental distress.

It is a fact that those of us with these experiences have more than twice the mortality rate of the 'general population'.

Some of the health issues that will affect us are oral health problems, diabetes, obesity, chronic pain, high blood pressure, respiratory disease and cardiovascular disease.

Chronic (long-term) cannabis use is linked to impaired respiratory function and cancers, lung damage, bronchitis, cardiovascular disease and reproductive disorders

Methamphetamine dependence is linked to heart disease, oral health issues, cerebrovascular complications (conditions that affect the circulation of blood to the brain, causing limited or no blood flow to affected areas of the brain), heart disease and increased transmission of blood-borne viruses

Alcohol is linked to over 60 medical conditions including a range of cancers and liver disease.

Coordinated action is needed if people's life expectancy and physical health is to improve. Amongst other things people who experience mental illness and/or addiction need access to the same quality of care and treatment for physical illnesses as everybody else and in particular to have a right to assessment, screening and monitoring for physical illnesses.

If you would like more information on Equally Well visit www.tepou.co.nz/equallywell



EMAILING CADS VIA WWW.CADS.ORG.NZ

CADS website has had a revamp.

Hopefully people will find this version more attractive and easier to use.

The new software means the site works well on any size screen: computer, tablet or smartphone.

One of the facilities which has always been on the site but hasn't been well known is the ability to Send a message re Your Booked Appointment which you will find under the Contact tab.

It allows people who are *already CADS clients* to email their group facilitator,

keyworker, or counsellor if they:

- 👤 can't get to an appointment
- 👤 want to change an appointment
- 👤 let CADS know if they're going to be late tho you'd need to do this before 5pm if you're going to be late for a group that night as chances are the group facilitators won't get that msg in time (they will be preparing for group not sitting at their computers after 5pm)
- 👤 need to get some other message to CADS about a scheduled appointment/ group.

It's **not** designed for people to engage in long discussions about clinical issues: as you can imagine there are all sorts of guidelines and parameters around how staff engage with clients online as there is no way yet to ensure that information is 100% protected.

This is another helpful tool which many people have requested so it's good to be able to let you know that CADS heard your requests and that you can now email if you're needing to change an appointment.

Hello to all readers of Progression. I hope you are all safe and well..and warm. For me it is great to be back working at the Auckland Opioid Treatment Service (AOTS) and writing for pRogReSsion again.

For the last couple of years I have been working at Auckland Drug Information Outreach (ADIO). ADIO has been part of the harm reduction side of AOD landscape in Auckland for almost 30 years.

They have worked tirelessly to achieve their goals, sometimes against mountains of obstructive discrimination. It is largely due to ADIO's work that the HIV virus has never taken hold in Auckland's IV using community. For me it was great experience to work there and I feel they should be commended for their efforts.

I have been back at AOTS as consumer liaison since May 9th this year. Since then I have had quite a bit of feedback from AOTS clients especially about scripts and restabilisation.

Script expires

A number of people have talked with me about their scripts running out - turning up at the chemist and being told they need a new script before they can receive their meds.

When this happens without warning it can really mess with your plans for the day!

Clients are supposed to take responsibility for picking up scripts from their AOTS unit when they are due.

The prescription itself will have been prepared by AOTS staff and will be in your file at the appropriate unit (Pitman, AOTS West, South or North) waiting to be picked up.

This pick up is supposed to occur at some previously arranged date and time agreed upon by the client and their key worker.

In some cases (maybe when a client is sick) AOTS key workers will fax scripts to the chemist for clients or phone to remind them to pick it up. However this is not the norm.



Here's a helpful tip! A lot of clients put a reminder that their OST script is due in the organiser or calendar part of their mobile phone.

Obviously you need to select a date about a week before the current script expires....then when the phone sounds the reminder you know it's time to pick up your new script. This works well for many people.

Restabilisation

Sometimes stable clients become unstable. If the service feels a client is showing signs of instability or if a client

comes to an appointment and tells their key worker they have used "once or twice in the last month" then the client may be brought back to specialist service care (if they are in shared care) for restabilisation.

This might involve the loss of take-away doses, changes in dose amount, UDS tests, and extra appointments etc.

These are the things that the service does to help clients restabilise.

The feedback I've been getting is that people are feeling that their restabilisation period should be finite. It should not stretch on for months and months or years and years.

Of course everyone's situation and experience is different so its hard to make recommendations about this that will work for everyone. And treatment is individualised so what happens for one person won't necessarily happen for another.

But it is clear from the client feedback that people would like their restabilisation period to have a future focus. People want to be able to work towards the goal of returning to shared care or takeaways reinstated or whatever it is that works for them.

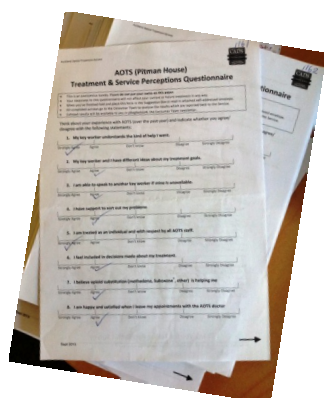
To be better informed about the experience of restabilisation the consumer team would like to hear from clients who have been through this themselves. What worked? What didn't?

Your feedback helps AOTS improve clients' experience. Give me (Andrew) a call on 815 5830 ext 5568

AOTS Survey

We are now running the 2016 AOTS Treatment & Service Perceptions Questionnaire. The survey forms are now printed and have been placed in reception areas, doctor's rooms and counselling rooms. Please take a few minutes to complete one and put it in the suggestion box or hand it to a staff member to pass on to the consumer team.

As always, all feedback is welcome. I am also happy to meet people for coffee and conversation. If you have some things you want to say about the service and your experience off it Please give me a call and we can schedule a time to meet...coffee on AOTS. Until next time...stay safe and take care.



Hepatitis C treatment

Many readers of this newsletter will be aware of the prevalence of hepatitis C (HCV) amongst people who inject drugs (PWID).

It's all over the place. Probably around 80% of IV drug users in New Zealand have had contact with HCV.

Back in the early 1990s you could get treatment with interferon. The success rate in that kind of treatment was only about 15% at that time.

Thankfully there have been huge advances in the treatment of HCV since those days. This is especially true of the last five years or so since the new antiviral medications came into use.

Instead of fighting the virus by boosting the immune system these newer antiviral medications attack the virus directly at a molecular level.

This approach has led to a **success rate of over 90%**.

These new improved treatment outcomes have continued improving.

Now after numerous clinical trials and discussions with medical experts Pharmac has funded two of the new direct antiviral molecular agents.

One of these will be available in October this year through GPs. This is great news for AOTS clients (or anyone else) who have tried, but failed, to get on clinical trials or clear the virus with other treatments or pathways.

Treatment would require a blood test, about 3 or 4 visits to the GP and run for approximately 12 weeks. The medication is in pill form.

It is irrelevant to treatment if a patient happens to be using drugs recreationally. The outcome will not be affected by this. The same goes if a patient is on Opiate Substitution Treatment (OST).

Liver clinic now available

between 2pm and 6pm

Tuesdays and Thursdays

at ADIO Central premises

10 East St Newton Auckland

Ph 09 356 7373.

At the ADIO Liver Clinic clients can get the hep C blood test and liver scan and get advice from the nurse on the best course of action for their situation.

After successful treatment for Hep C ... **congratulations! !**

Here is one thing worth keeping in mind: if you continue IV drug use you could easily re-infect if you share IV equipment.

So remember to stay safe, always use new equipment and keep injection sites clean.

ASTRID (DETOX AND COUNSELLING SERVICES CONSUMER LIAISON) ON WHAT'S HAPPENING AROUND THE SERVICES AND BEYOND

What is happening in Community & Home Detox Services

At the moment I'm spending 2 days per week (Tuesdays and Thursdays) in the clinic to speak to people about their experiences of using our walk-in clinic service.

The hours to access the walk-in clinic are 10.00-1.00pm everyday.

If you are interested in being part of this project and you come in on a day that I'm not there please let your clinic nurse know and she can pass on your details so I can call you.

What is happening in IPU

CADS In-patient unit is in the process of having some small renovations done. New paint and carpet will bring a fresh look and we look forward to re-vamping the Consumer Board and including consumer art on our walls.

What is happening at CADS South

If you live in Pukekohe and would like to access CADS Pukekohe alcohol and other drug counselling for the Franklin Community contact CADS South on (09) 2632000. It is an opportunity:

- 👤 to discuss and explore concerns relating to alcohol and other drug use
- 👤 for whanau/family involvement
- 👤 to support those concerned or affected by another person's alcohol and other drug use.

There are male and female counsellors available with Di and Brett (who are FAB!!).

If you would like to book an appointment or find out more information call CADS South.

This is a free service and run from Pukekohe Hospital.



What is happening in Counties Manukau

Each month I attend the Counties Manukau Alcohol and Other Drug Collaborative as a consumer leader to give a voice to CADS clients as well as other consumers in the Counties area.

I am there to present a consumer viewpoint to a range of alcohol and other drug projects in the Counties area.

If you would like to learn more I am available at CADS south on a Friday or leave me a message in the suggestion box.

WHAT CLIENTS TOLD US ABOUT CHDS

In 2015 20 people took part in the Community & Home Detox Services telephone survey. This is where Astrid (Consumer Liaison for Community & Home Detox Service) phones people who've done a detox with CHDS and talks with them about their experience of the service and how things are going for them now.

Admittedly it can be a challenge getting hold of people but she tries really hard to phone anyone who has engaged with the service.

Here's what the 20 people she spoke to had to say about their experience of the community and Home Detox Service:

- 95% Found the assessment process useful when they first came to CHDS
- 90% Felt very well informed about the detox/ withdrawal process though a small number of people talked about feeling compelled to give consent and had concerns about the use and sharing of information
- 90% Felt very well informed about the medication they were prescribed though there were requests for more info.
One person said I googled the name of the medication to get the info I wanted
- 75% Felt very well informed about what happens to their health information
- 80% Felt very well informed about the limits to confidentiality of their health info
- 95% Felt very well or reasonably informed about other services they might like to use.
People requested info for family members in particular where family can get the support they need and for more info about the post-detox support group and about health and nutrition
- 85% Felt their CHDS appointments were positive
- 75% Had gone on to use other treatment and recovery supports. Only 2 people (10%) said they had resumed drinking

A huge thank you to everyone who spoke with Astrid about being with CHDS. Please feel free to contact us any time with your thoughts about the service.



12 people said they had engaged with CADS Counselling Service groups and individual counselling while others had used AOTS (the opioid treatment service), the in-patient detox unit, the post-detox group, and Te Atea Marino (kaupapa Maori service)

To help their recovery people also went to places like Te Ara Hou, anger management group, the gym, took part in sports, and attended AA.

What people liked (in no particular order)

1. The walk-in clinic *because you can get there when you can; liked the chance to walk in with one person adding that it was the hardest step to take*
2. Being able to be visited at home. People said the staff were *friendly, discreet and didn't hang around*
3. The staff who people described as *great people; non-judgemental, professional, very kind, very supportive.*
Staff are brilliant. What a fantastic job you all do. Staff are very supportive.
I really liked them and I'm not afraid to go back if need to.
They answered all my family's questions ...

What could be improved (in no particular order)

1. Less waiting time for the CHDS Clinic because it adds to the anxiety people are already experiencing
2. For there to be more help with planning what people do next
3. More follow-up. People really appreciated the Consumer Liaison calling them. They liked the opportunity to provide feedback and were pleased that we genuinely wanted to know what they thought. Plus people recognised that the call is also 'a recovery check-up' - a chance to see how people are doing since leaving CHDS and offering info and advice if people needed/ wanted it. They said:
Thank you so much for talking to me. It's nice to know you care what I think and you were great to chat to
It's great to talk to someone with similar experiences to mine, I feel I can relate better to you.



TEN STEPS TO EFFECTIVELY ADVOCATING FOR YOURSELF

When people contact the consumer team they often say they want an advocate: someone to hear their frustration, anger, disappointment etc and to do something about it.

The CADS Consumer Team are not advocates however we can hear the people's concerns/ frustrations and give some ideas on where to from here. Working in CADS means we become familiar with the systems and structures of the health system as a whole and of CADS as a government-funded service so can help people use those systems to navigate their way through the bureaucracy and get their voices heard.

Often people really appreciate just talking to someone who knows what they're going through. For many that'll be enough. They feel heard and that is really important. Not feeling heard is another reason to get frustrated!!

We can work out what the person's options might be and leave it up to them to decide what they want to do: they might want to ask for a treatment review or get a second opinion. They might choose to make a complaint and we (like any CADS staff member) can take the person's complaint there and then.

We know it can all feel very structured and bureaucratic but please don't let that put you off.

It's important that CADS hear when people aren't happy or satisfied with the service or with their treatment. So if something annoys or frustrates you don't just sit on it—let us know.

If it turns out that the person does need an advocate we will direct them to the Health and Disability Advocacy Service (<http://advocacy.hdc.org.nz/>). Most often though people choose to advocate for themselves. It can be a good way of regaining a sense of control!

Here's some ideas on how you can do that adapted from the Health and Disability Advocacy Service and mentalhealthrecovery.com

1. **Be positive** and look for solutions rather than getting 'stuck' in the problem/ complaint
2. **Be clear.** We know this can be really hard especially if you're angry or upset but it really helps to be clear about your concern and how you want things changed. And if you're unhappy about a number of things it might take time for us to work out with the person exactly what the problem is—that's okay, we get there in the end
3. **Stay focused** on the current issue and what's happened (or not) for you. Don't allow yourself to be diverted onto other people's issues. What has happened for other people is their experience and if they are unhappy hopefully they will let us know. Also, going back over things that happened years ago is probably not going to help us find a solution now. So much has changed; the people, the treatments; the thinking about treatment ...
4. To help with number 2 and 3 it can be helpful to **write down beforehand what you want to say**. Include the list of issues and questions you want answered in case you forget
5. (As The Clash say) **Know your rights**. A lot of the info available to you in health services is about your rights. If you get offered info take it—you never know when it might come in handy.
6. **Get the facts**. This is where a conversation with the CADS Consumer Team can be useful. We can direct you to guidelines, policies etc.
7. **Decide what you want** to happen. It becomes easier to find a solution when everyone knows what the problem is and what you want as a result
8. **Make a plan**. The Consumer Team can also help you think of several ways to address the problem. You can then choose whichever action/s you want to take
9. **Get support** if you feel you need someone else to talk to or to listen. Supportive people are the ones who are there for you—they don't push their own agenda or dismiss your concerns as unimportant
10. **Target your efforts**. Who is the person/s or organization you need to deal with to get action on this matter? We can help you with that too. And if we don't know straight away we can find out
11. **Stand up for yourself assertively not aggressively**
It might be hard but losing your temper and lashing out at the other person or at the organization will probably lead to the conversation going nowhere
12. **Be prepared to compromise**. Some of the services are constrained by legislation and guidelines which mean they are unable to respond in exactly the way you would like them to. Look for common ground and where you can compromise



OPT IN to CADS TXT REMINDERS



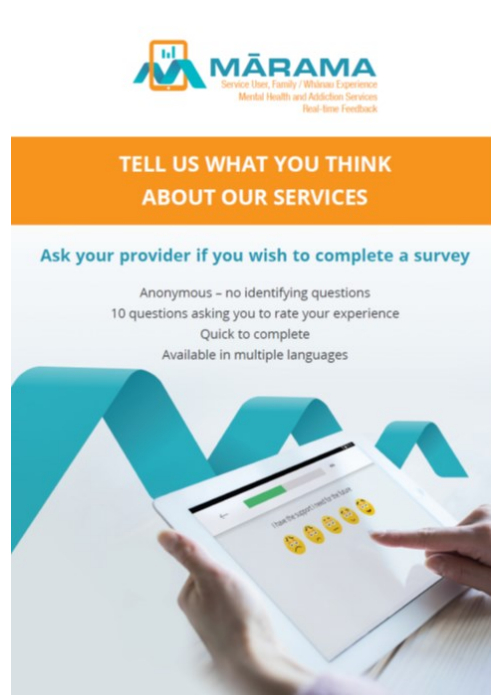
If you would like to receive a txt reminder about your appointments with CADS please tell your key worker, counsellor, or group facilitator

- ⇒ They will check with you that CADS have your correct mobile phone number
- ⇒ You will receive a text the day before your appointment is due
- ⇒ Reminders won't contain any identifying information – for privacy reasons only first names will be used and CADS won't be mentioned. Messages will look like this:

Hi Fred, u hv a meeting w Wilma 2moro Wed 22 Apr at 11:00am. If u can't come pls txt back or call 845-1818 or use <http://bit.ly/1DvPAIs> ref1163053

The website link has been added for clients who have no money to reply and no access to a freephone but who might have internet access available.

MARAMA: REAL TIME FEEDBACK



Keep an eye out for the Real Time Feedback survey on an ipad in each CADS unit.

It is a good way to pass on how you found our service and to give CADS and the Health and Disability Commission feedback about CADS.

TELL US WHAT YOU THINK

Providing feedback about CADS is easy.

To give your feedback to the Consumer Team you can use the suggestion boxes, meet us for Coffee & Conversation, ring us or email us on cadsconsumeradvisor@waitematadhb.govt.nz

You can also provide feedback online as well as make a complaint by going to www.cads.org.nz/contact/

Then click on one of these options

- [To give feedback about a group](#)
- [To give feedback about a service](#)
- [To give feedback about the website](#)
- [To make a complaint](#)

To make it quicker to get to www.cads.org.nz just use this QR code.

Keep an eye out at CADS services for QR codes which link to the Real Time Feedback (see above) which you can now do on your phone.



And of course you can go old school and phone us.

All of the Consumer Team can be contacted on 815-5830 or the Consumer Advisor can be called direct on 845-7520

Do leave a message if there's no-one there as we regularly clear our voicemail

If you like, you can give us your phone number and then we can call you as we need to – for example, if we need ideas about a specific issue it can be good to have a handful of clients we can contact to discuss the issue with

Your voice counts. We look forward to hearing from you.