

pRogReSsion

News & Information for CADS Clients from CADS Consumer Team



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Greetings CADS clients,

It's been a busy time for the consumer team. As part of our roles within CADS we have been promoting various campaigns including Support. Don't Punish which we talked about in the last issue. In July there was World Hepatitis Day and this month there is International Overdose Awareness Day.

All of these campaigns are important to us personally: we have experienced hepatitis whether directly or alongside our family and friends. We have lost people to overdose, and we have experienced the stigma and discrimination associated with alcohol and drug use and in some cases, with treatment especially opioid treatment which so many people do not understand.

Overdose is usually associated with heroin or opioids but actually, you can OD on any substance including alcohol.

Have you ever known someone who's so drunk you think they're dead? Their breathing becomes so laboured

and slow that you have to get them up and moving? That is overdose.

Or the person who is so wired they have jerky twitchy tics; they might be overdosing on methamphetamine.

It's easy to learn to recognise and respond to overdose. We've put some links on p5. Please arm yourself with this knowledge. It can literally be the difference between life and death.

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As always there is change happening. Not only is the entire health system undergoing massive change but the way CADS does things is changing too. On p2 Marc talks about the new process for people wanting a medically managed withdrawal. We will be looking for your feedback on this new pathway so please feel free to contact Marc on 021 982 432 or use the other options to provide feedback (see back page).

One of the areas we pay a lot of attention to is stigma and discrimination. So many people who use alcohol and other drugs

experience direct and indirect stigma and, as strange as it might seem, so do many people who are utilising harm reduction measures like opioid substitution treatment and clean injecting equipment.

Renee talks about the experiences she has been told about by people attending community pharmacies to purchase injecting equipment and she suggests ways you might want to take action.

Stigma was also front and centre at the NZ Drug Foundation's forums held in June. It has a massive impact on people's willingness to engage in healthcare as discussed on p6.

The team tries to ensure we use inclusive non-stigmatising language and a friend of the team describes how challenging this can be when new terms appear on p7.

And on p4 Andrew tackles a couple of perennial issues for clients with AOTS - third party information and hassles in hospital. He details how these can be dealt with by the service and by clients.

Til the next issue **play safe** Sheridan (CADS consumer advisor)



Please tell us about your experience of CADS by taking part in the Specialist Mental Health and Addictions Services survey which you can access via this QR code



And if you take part in a CADS group you can provide feedback via www.cads.org.nz/feedback/feedback-about-a-group/

UPCOMING CHANGES AND PEER SUPPORT

MARC —MEDICALLY MANAGED WITHDRAWAL SERVICES CONSUMER LIAISON

The last couple of months have been very busy for us. We've been training new staff members and making some changes to the way people access both Medically Managed Withdrawal Service (MMWS) and Community Home Detox Service (CHDS).

The goal is to improve the quality and efficiency of our services so clients get the best care possible. So what are these changes and how will they affect CADS clients?

The main change is that from 25 September clients will be asked to go to their local CADS units for an assessment with a CADS clinician rather than contacting the medically managed withdrawal services directly and waiting for an assessment.

The assessment is about gathering relevant info to help determine the most suitable treatment option for each client, based on their individual needs and preferences.

The CADS clinician will then talk to the CHDS nurses about the options— some clients may not need a medically managed withdrawal so may be offered a CADS counselling treatment journey, which involves regular sessions with a CADS counsellor to address their substance use and related issues. Other clients may need a medically assisted withdrawal; that could be an in-patient admission at MMWS or, if they have the necessary supports and conditions, they may be offered support from CHDS to do a safe and comfortable withdrawal at home.

Anyone waiting for admission will be able to get ongoing support from their local CADS unit while waiting

for their withdrawal date. This support could be through phone calls or maybe something else if possible.

It also means that clients will be connected to their local CADS unit and the range of supports that are offered there, such as group programmes, education sessions, peer support and aftercare planning right from the start, rather than after doing a medically managed withdrawal.



Making this change will allow CHDS to support more people doing withdrawals at home so will save some clients from having to spend a week in our MMWS facility.

We understand that some clients may prefer to do their withdrawal at home, where they can be close to their family, friends and community. However, we also recognise that home withdrawals are not suitable for everyone, and some clients may need or prefer the 24/7 medical supervision and care that MMWS provides. So CADS will continue to offer both options and work with clients to find the best fit for them.

An exciting development in the last year is the introduction of peer support at MMWS.

Peer support specialists are people who have lived experience of substance use and recovery, and who can offer emotional and

practical support to clients who are going through a withdrawal. At MMWS you will see them at the morning and evening groups, where they share their stories and insights, facilitate discussions and answer questions.

The peer support specialists are also a part of the group programme. Skyler does Art groups to help people find their own creativity and express themselves through different media. Ben works with clients during their free time, when they may feel bored or restless. He has organised various activities, such as games, puzzles and art supplies, to keep people entertained and engaged. These activities are also helpful for developing new skills, coping strategies and hobbies that can support recovery.

They also check in with clients during their stay, have a chat with them, listen to their concerns and help them with their recovery planning.

We are very happy with the positive impact that peer support has had on our service and our clients. We believe peer support is a valuable addition to our team and our programme, as it offers a unique perspective and a relatable connection for our clients.

Now that we have had peer support in the unit for over a year, we thought it would be a good time to evaluate the roles and find out how clients and staff have experienced the new roles.

If you have filled out a client survey at MMWS, your feedback will be going into the evaluation through the peer support questions in the survey.

ACTING AGAINST STIGMA FROM RENEE

—COUNSELLING SERVICES NORTH, WEST, SOUTH, CENTRAL & CAP CONSUMER LIAISON

You can't deny the fact that people judge. Is this a natural human trait? Or do we learn it growing up?

From what I know, having experienced an issue with drugs is seen by many in a negative way.

We say we try to keep people safe ... have local pharmacies where you can purchase safe and clean needles.

It's hard walking into a place and asking to buy a needle. And sometimes it's not a good experience, unless you go into town to the needle exchange.

So you enter nervously with a smile and a quiet voice and clients tell us this is what they experience:

- † *I always hope I get this one lady who is very pleasant and discrete. She is fast and knows exactly what I am talking about.*
- † *I have had to instruct the person serving me on size and colour, you know, what it looks like. Then they yell out to a co-worker and ask how to ring it up. By then everyone knows why you are there.*
- † *They seem so nice until you tell them what you are after, then it's all over their face that you are instant scum.*
- † *Do some of these people not get some training around this? Why are they part of the exchange if they don't know what they are doing?*
- † *One time I wasn't even given a bag, just a few loose needles.*
- † *The word "junkie" always comes into my mind, you can see them thinking it.*

I don't mean to pick on these not so great experiences. But I am pointing out that discrimination and stigma is still strong out there.

I wonder if anyone is thinking, 'this person is good by coming and looking after their needle use, being safe'. You don't know why they are there or what it's for and it is none of anyone business. Maybe they are for grandma's diabetes?



I challenge and encourage anyone who witnesses this or experiences this to speak up.

Perhaps the people in pharmacies are not aware how their face changes and what that looks like in the mirror. Maybe they are not aware that they are being judgemental.

If you are the person guiding them through the transaction, ask if they've had any training about needle use, or maybe refresher trainings would help. Suggest they contact ADIO. Make a call.

Let's try clear some of this shame and stigma out there. I am sure pipe shops don't have the same issues.

Feed back so future generations are not shamed. Tell them to get advice from the needle exchange in town.

While we are on the subject of feedback ...

I would like to send out a big thank you to those who took part in our group evaluations. I cannot stress how much we value your opinion when it comes to the service.

Clients come first and if something is not working, then we need to know about it. That way we can find ways of what works best for you.

One of my favourite parts of my job is clearing the suggestion boxes. I'm the lucky one that gets to read the comments first, the lovely compliments that I enjoy reading out to the team at the monthly meeting.

I always notice how many folk read the folder in reception that have client stories in. (It's the blue folder with the picture above on the cover)

I know many of our clients like to leave their story when they leave CADS. It brings hope to whomever is in that waiting room, perhaps for the first time. If you are interested, it does not have to be a story of your journey, it can be a poem or some art. Get in touch with me and we will organise it? It'd be good to have some new stories please.

Another quick and easy way to have your say is on our website www.cads.org.nz

All these avenues are confidential, in fact if you are not comfortable, you don't have to leave your name at all.

Finally, a big shout out to clients at CADS SOUTH! You guys are amazing with feedback! In one month I can receive more than another sites whole years worth! Keep it coming! We love hearing from you!

**The harms caused by the war on drugs can no longer be ignored.
It's time to leave behind harmful politics, ideology and prejudice.**

 @SDPcampaign

 /supportdontpunish

 www.supportdontpunish.org

**Support.
Don't
punish.**

#SupportDontPunish

HOSPITAL HASSLES AND THIRD PARTY INFO

- ANDREW AUCKLAND OPIOID TREATMENT SERVICE (AOTS) CONSUMER LIAISON

Hello to readers of pRogReSsion.

AOTS have been quite busy recently, welcoming quite a few new staff in the last few months. They are being orientated and trained.

Also the service is working to meet the health needs of an aging client group. Half of AOTS' 1200 clients are over 45 years old; around 250 of those are over the age of 60.

Soon we will be conducting the annual AOTS survey. The survey is an important part of the Consumer Teams effort to gather client feedback. So please be sure to fill out a survey form when they appear in AOTS units in October. Phone calls and feedback through the suggestion boxes are also a means to gather client feedback. Thank you to all who have contributed.

HOSPITAL HASSLES

Recently several clients have spoken about negative experiences they have had during hospital admissions. Unfortunately OST clients often have difficult, stigmatising experiences when presenting at hospitals. The most common experience reported is under-treatment for pain.

Once hospital staff learn the patient is on OST it seems there is an assumption that the patient is on the hunt for drugs. (This was commonly expressed when Sheridan attended the Drug Foundation forum. See p6)

Another common experience is the mistaken assumption that the daily maintenance dose of methadone or buprenorphine should provide any pain relief required. Clients have also encountered health professionals who worry that any additional pain relief over their daily OST may cause

an overdose. None of this will come as a surprise to experienced OST clients.

To minimise the chance of being exposed to this kind of treatment there are a few steps clients can take:

- It is crucial for OST clients to inform their Key worker if they know they will be going into hospital
- Once in hospital, whether it's a planned visit or otherwise, it is important to ask staff at hospital to call AOTS so the service can advise the hospital on your behalf.
- Also useful are AOTS Pain Management wallet cards which advise how to proceed in regard to pain management and also invite hospital staff to call the service.

THIRD PARTY INFO



There has also been feedback/queries about how AOTS deals with third party information. It is not unusual for AOTS to receive third party information in the form of phone calls, related in person by someone, or notes in the suggestion box. People have all kinds of reasons for contacting the service in this way.

Sometimes they are or claim to be concerned about someone's safety,

they may believe they are reporting illegal activity, sometimes it is a family member expressing concern.

When clients are eager to report to the service about some other client's nefarious activity it is sometimes more of a reflection on the person reporting than anything else. Treatment and recovery tend to progress better when people concentrate on their own situation than on other clients' situations.

There is not a lot AOTS can do to stop this kind of thing. When third parties contact AOTS in this way staff are trained to be careful to protect client/patient confidentiality and act in line with the Health Information Privacy Code 2020. For example just because a caller indicates that they 'know' such and such is a client staff are careful not to confirm anything either way.

From a client point of view there is understandable concern about how these calls are handled. Every year there are queries about this from clients. There are plenty of situations where the information might be questionable.

In the past there have been instances where third parties convey false information presumably to cause inconvenience to someone they have a problem with. The service is well aware of the potential for this to occur and treats such information with caution.

No-one, least of all staff working at AOTS, wants to allow the service to be used as a weapon in people's tit for tat personal feuds. It is most definitely not what AOTS is here for.

AUGUST 31 INTERNATIONAL OVERDOSE AWARENESS DAY

Although the day will have passed by the time you read this, it is important that we pass on information to you about International Overdose Awareness Day (IOAD).

It is the world's largest annual campaign to end overdose, remember without stigma those who have died from overdose, and acknowledge the grief of the family and friends left behind.

This year's theme is about acknowledging people in our communities who are affected by overdose but might go unseen—the family whanau and friends grieving the loss of a loved one; workers/kaimahi in healthcare and support services extending strength and compassion; and first responders who selflessly assume the role of lifesaver.

Too often people are left to bear the burden of dealing with death by

overdose on their own and in silence.

Most of us in the Consumer team know of families who have kept the true cause of their loved one's death hidden because they are ashamed and embarrassed. The stigma of death by OD is alive and well.

It's easy to recognise and respond to an OD if you know what you are looking for. Of course different substances—including alcohol—produce different symptoms.



And sometimes people haven't taken what they think they have—which is why drug checking is so important.

To find out about drug checking go to <https://thelevel>

And to learn how to recognise and respond to different substances go to [Overdose Basics - International Overdose Awareness Day \(overdoseday.com\)](https://overdoseday.com)

If someone stops breathing you need to ensure they get oxygen. You can save a life with rescue breathing/ mouth-to-mouth resuscitation—gently blowing air into a person's mouth helps supply them with vital oxygen until medical help arrives.

To reduce death by overdose CADS AOTS supplies clients with Naloxone kits. We know these have saved lives. If you're an AOTS client you can ask your key worker or doctor for a kit.

ACCESSING ZERO DATA

ANDREW CONTINUES ...

Clients should feel assured that just because someone has called the service in this spirit it does not mean the service will act on the information nor allow it to impact the shaping of a client's treatment or recovery plan.

If clients feel that a third party is attempting to intervene in their care in this way they should talk to their key worker about it.

Feel free to get in touch about any of these issues.

That is all for now.

Stay well and stay safe.

Zero Data is available to anyone using a mobile device connected to the Spark, Skinny, One NZ, 2degrees, Slingshot or Orcon mobile networks.

When you visit websites through Zero Data all data usage is charged back to the government agencies that sponsor the websites you visit.

All you need to do is make sure your mobile data is turned on before you visit Zero Data.

A green ribbon across the top of the website will show you're on Zero Data.

It is not available for any device using a broadband/fibre connection like when your mobile device is connected to your home internet via Wi-Fi.

Some website content such as online payment systems may be unavailable through Zero Data.

You'll receive an error message if you try to access non-sponsored content or go to a non-sponsored website.

You may be able to access non-sponsored content without using any of your data via a free internet connection at your local library, educational institution or marae.

SHERIDAN ATTENDS THE NZ DRUG FOUNDATION SYMPOSIUM

At the end of June I was invited to be on a panel at the Drug Foundation's symposium on Unmet Health Need and to co-facilitate a workshop at the inaugural Living & Lived Experience Forum which happened the following day.

The symposium on Unmet Health Need was held in the grand banquet hall at the Beehive as it was co-hosted by the Cross-Party Group for Mental Health and Addiction. There must have been about 200 people attending -many people with their own lived experience of drug use.

International speakers included

- ⇒ Arild Knutsen, Leader of the Association for Humane Drug Policies, Norway
- ⇒ Sione Crawford (a Kiwi) CEO of Harm Reduction Victoria Australia
- ⇒ Kirsten Horsburgh, CEO of Scottish Drugs Forum

All had interesting things to say but perhaps the one that sticks in my memory is Arild's comment "I'm a nice guy—and I use drugs".



Long-time readers of pRogReSsion may recall a 2009 campaign in the UK where London buses bore signs saying Nice people use drugs.

Sadly the campaign was pulled by the billboard advertising company that booked the bus campaign on behalf of Release, a leading drugs and humans rights charity.

The billboard company was worried about possible complaints so pulled the campaign before any complaints had been received—which highlights how difficult it can be to have a grown-up conversation about drugs and drug policy.

I have taken on board the need to always include the word 'humane' when talking about drug policy as there are many policies around the world which are simply inhumane.

Well done to the Drug Foundation and the Cross-Party Group for providing a space for people to come together to talk about this stuff.

About 60—80 people attended the Living & Lived Experience Forum the next day. There were a number of workshops aimed at looking at the changes needed in the health care system for people who use drugs/ PUD.

Some people spoke of what can only be described as unsatisfactory experiences in the health care system. And unfortunately, negative experiences then stop people engaging with the system and getting the care they need. As one person said

Our experiences in the health care system thus far do not comfort us when thinking about needing care again.

Several people talked about the consequences of being labelled as "drug seeking", "non-compliant" and "too complex" and then being denied health care services.

There was overwhelming agreement that a harm reduction approach is the only way to go with drug policy and practice.

We already practice harm reduction in so many ways, it's logical to take the same approach to people using drugs.



Harm reduction acknowledges that people who take drugs are human with autonomy and agency. Current models treat people who use drugs like naughty children who don't know what's good for them

There was a desire for health professionals to be better educated about drugs and harm reduction. Some people talked about doctors dishing out drugs because they didn't know what else to offer while others spoke of the challenges they have faced in getting pain relief because they are taking OST. As one person said *it's all or nothing!*

The CADS Consumer team have for many years been involved in presenting to pharmacy students, midwives, nurses, psychiatric registrars and med school students about the experiences of people who use alcohol and other drugs. We hope that the conversations we have with health care professionals ripple out to the wider sector but there is still so much work to do.

Hopefully the info gathered from these two days will continue to reverberate throughout the halls of power and beyond.

When I'm voting this year, I will be checking out each party's drug policies—to see if they are humane.

WHAT IS LIVED EXPERIENCE?

One of the constantly changing things in AOD/alcohol and other drug treatment is the language used. Over the years words have taken on new meanings, new words have been introduced, and some have been dropped.

There is a lot of discussion amongst the consumer workforce about the words we use. Even the word 'consumer' is contentious. Some prefer 'service user' but this excludes the people who don't use services.

In an attempt to be inclusive the term 'lived experience' has recently appeared throughout the health environment. But what exactly is lived experience? Rhonda, a close friend of the CADS Consumer Team shares her thoughts:

When I'm asked, what is lived experience, I think how long is a piece of string?

The idea that there's a universally agreed definition that covers all experiences is a fallacy. Particularly when the determination and understanding resides with the people and communities in which the experience belongings.

I think back to when I first started using the term 'lived experience' which was over a decade ago. The term was used as a way of acknowledging our colleagues within the addiction sector who we shared a lived experience with, but fundamentally worked in different ways.

As consumer advisors working in alcohol and other drug services our lived experience needed to be both overt and stated.

Like most things, language grows, changes, and evolves, sometimes taking on a whole new meaning and is certainly case with the term 'lived experience'.

An example of this would be family and whānau identifying with the term of lived experience.

More recently, I've heard people claiming lived experience due to having worked in mental health or addiction sector for x-amount of years.

I had to think about that one. I suppose you could say family and whānau have a lived experience, and while their experience didn't reflect my own, the experience remains real and valid from their perspective.

While I understand that the workforce's experiences are unlikely to reflect my experience or family and whānau, does that mean that their experience of working in the space is not valid?

Fortunately, I have people who I can discuss this with and most importantly, challenge my thinking. So, as I was laying out what I know,

observed and hear about lived experience my friend was doing her usual thing, doodling.

The concentric circle chart below is a visual image of our conversation.

What I like about this concept first and foremost is that it's inclusive, while recognising and validating the unique experiences. It also provides a framework to help navigate what voice or perspective may need to be considered at any given time.

I share my thoughts and my friend's doodling to continue the conversation and to show how layered the terms we can be. Hopefully it helps our evolving understanding as opposed to just having one definition of lived experience.



CONTACTING THE CONSUMER TEAM

- † Marc (Medical Detox Services) is available Mon, Tues, Wed and Fri 9am—3pm and is based at Medically Managed Withdrawal Service and Pitman House
- † Renee (CADS Counselling Service and CADS Abstinence Programme) is here Mon—Thurs 9am—3pm and can meet up with clients at any CADS unit
- † Andrew (AOTS Consumer Liaison) works Tues - Fri 9am—3pm. Altho based at Pitman House Andrew can meet up with clients at any CADS unit
- † Sheridan works with all the CADS teams and is available 8.30-5pm Mon—Fri. You can call her directly on 09 845 7520 or text or call 021 760 319



If you need to speak with one of us **phone 09 815 5830** & reception will connect you to someone from the Consumer Team

Each of the consumer team can be contacted by calling or texting us on:

- † Andrew 09 815 5830 ext. 45568
or 021 325 597
- † Marc 021 982 432 (no landline)
- † Renee 021 592 143 (no landline)
- † Sheridan 09 915 5830 ext. 45520 or 021 760 319

TELL US WHAT YOU THINK

Providing feedback to CADS is easy: you can phone or text us, use the suggestion boxes, the complaints process or you can email us by going to www.cads.org.nz and clicking on Email Us Now

This opens another page where you can give feedback about...

a Group »
the service »
the website »



You can also make a complaint on-line. Although all online complaints come to the Consumer Advisor they are managed and investigated by the manager of the service not by the consumer team).



You can email the Consumer Team via the Consumer Advisor at (it's a long email address sorry)

cadsconsumeradvisor@waitematadhb.govt.nz

**All of the Consumer Team can be contacted on 815-5830
or the Consumer Advisor can be called direct
on 09 845-7520**

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

We need to hear from you if we are to accurately present consumer opinions and experiences so please feel free to get in touch. We look forward to hearing from you.