UN#92

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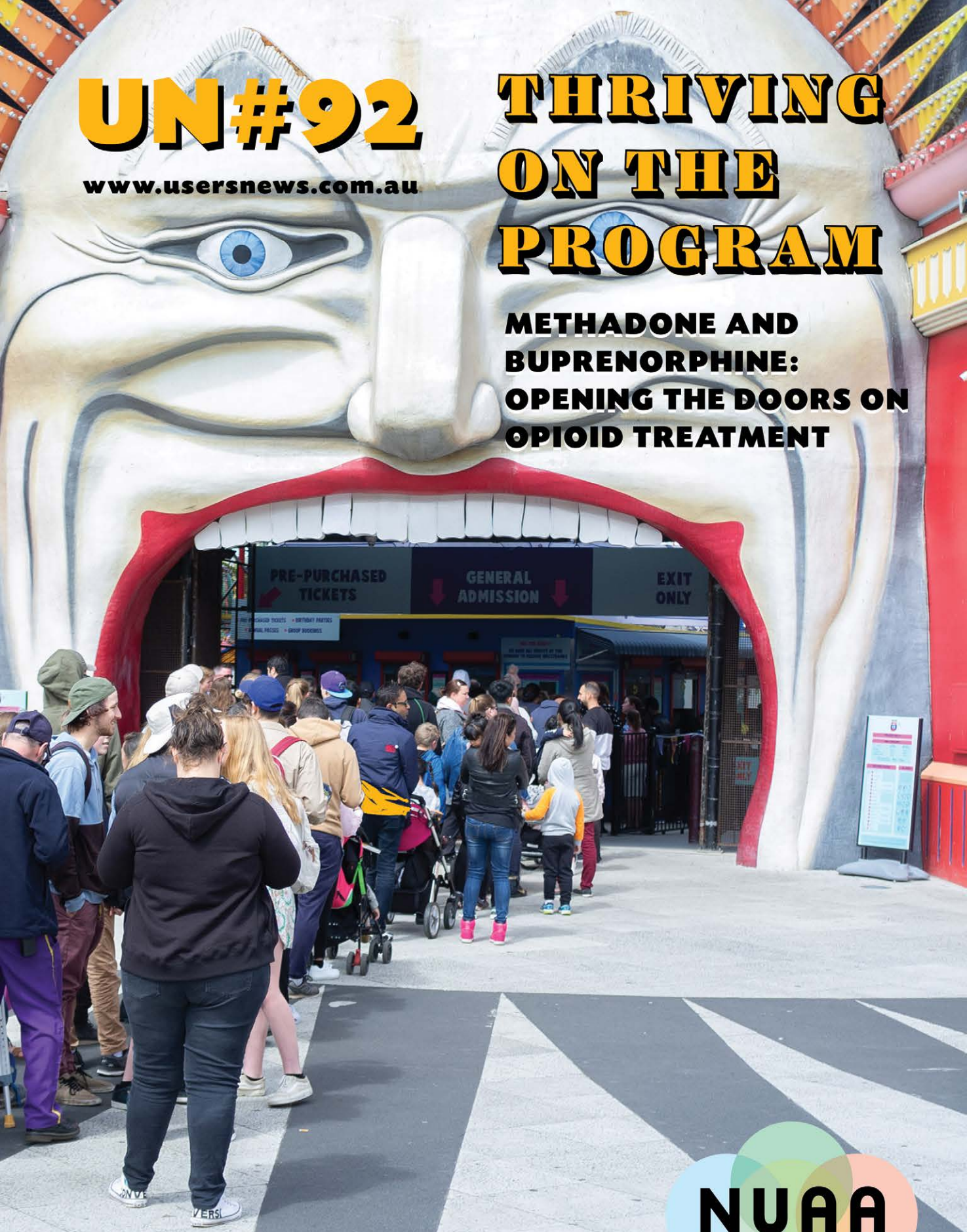
THRIVING ON THE PROGRAM

METHADONE AND BUPRENORPHINE: OPENING THE DOORS ON OPIOID TREATMENT



NUAA
NSW USERS AND AIDS ASSOCIATION

WINTER 2020

Language **matters**

Language is powerful—especially when talking about alcohol and other drugs and the people who use them. Stigmatising language reinforces negative stereotypes. "Person-centred" language focuses on the person, not their substance use.

When working with people who use alcohol and other drugs...

try this	instead of this
substance use, non-prescribed use	abuse · misuse · problem use · non-compliant use
person who uses/injects drugs	drug user/abuser
person with a dependence on...	addict · junkie · druggie · alcoholic
person experiencing drug dependence	suffering from addiction · has a drug habit
person who has stopped using drugs	clean · sober · drug-free
person with lived experience of drug dependence	ex-addict · former addict · used to be a...
person disagrees	lacks insight · in denial · resistant · unmotivated
treatment has not been effective/chooses not to	not engaged · non-compliant
person's needs are not being met	drug seeking · manipulative · splitting
currently using drugs	using again · fallen off the wagon · had a setback
no longer using drugs	stayed clean · maintained recovery
positive/negative urine drug screen	dirty/clean urine
used/unused syringe	dirty/clean needle · dirties
pharmacotherapy is treatment	replacing one drug for another

Adapted from *Language Matters* from the National Council for Behavioural Health, United States (2015) and Matua Raki, New Zealand (2016).

NADA network of alcohol and other drugs agencies

NUAA NSW USERS AND AIDS ASSOCIATION

USERS'S NEWS No. 92

There is so much we would have liked to include in this issue, but we couldn't fit it all in! We think that we've done a lot, and hope that it helps you with some life choices and answers some questions you may have been wondering about.

Over the last few months, we've been busy working on NUAA's new Consumer Guidelines for the Opioid Treatment Program (OTP). This is a booklet which aims to answer anything and everything you might want to know about the OTP, and also comes with a series of 7 topic-focused booklets. It will be out later this year and will be available at NSPs, OTP clinics, and pretty much anywhere you can find a copy of User's News. If you haven't got your hands on it by August, give us a ring and let us know - we will mail you the full series!

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EDITORIAL

IT WORKS FOR ME

It Was The Change I Needed

I'd been using methadone bought "off the streets" for a long time before I ever went on a program. I always had a bottle as an insurance plan for any time I couldn't get on for whatever reason – for when I needed to be somewhere, usually work. I actually found I needed very little; a few mLs kept me ok til lunch-time at least, when I could usually get some gear. I saw it purely as a detox aid, a tonic to hold off withdrawal symptoms.

I never wanted to go on a program. To me, that meant going from an undercover user who "passed" in the straight world, to a card-carrying junkie, a fully-licenced fuck up. My use was no-one's business but my own and I liked it like that.

Then I feel pregnant. I was in love, had a cool warehouse, and had a fabulous career working two great jobs, as well as another two that were purely syringe-fillers. I was nearly 40, and one of my friends was already on the IVF program, regretting her childless state. I couldn't see a reason to terminate my child.

I was told by a doctor that if I didn't go on methadone immediately that I wouldn't be allowed to leave the hospital with my baby. Was that enough of a reason to terminate her? It actually took me about 30 seconds to think it through. Papa don't preach, I'm keeping my baby.

The alternative was to stop using of course, but I had already failed that one on several occasions, most recently at risk of miscarriage. I knew methadone was addictive, but I also knew I couldn't be worse off and maybe I'd be better off. Forget four shots a day and four incomes going up my arm.

They call it "liquid handcuffs" but for me the freedom was instant.

It wasn't just the money, though that was significant enough for me to drop two of my jobs and focus on the ones that fitted with my chosen career. It was that - for the first time in a long time - I had woken up without being in withdrawal. My habit had got to the point where my wake up shot never made it to morning, so this was a real novelty. The other thing that changed was a massive reduction in the time and energy I spent chasing gear. My depression lifted; I felt lighter. In short, my life was no longer dominated by using. Once the baby came, I knew I could never have looked after a child on a habit.

I became a fan of methadone and I still am. It has given me far more than it ever took away. I've been known to say: "Having a baby saved my life." Maybe that's true but going on methadone sure helped.

I'm not saying the program wasn't time-consuming and even humiliating at times, but I had lucked into a good GP. I dosed at a private clinic at first then at some great chemists in the community.

Fast forward 17 years and I am still dependent on methadone and the choices it gives me.

I try to do something about the things that don't work so well with the OTP. For several years I was a consumer representative on a Ministry of Health pharmacotherapy committee, and over the last year I have helped train prescribers and dosers. I help my peers understand their rights and responsibilities on the program. I even advocate for people who are having problems.

Methadone is not for everyone, but it is for me.

Would I rather have a prescription for heroin? Darn tootin' – methadone isn't a pleasure drug for me, it's a tool, a treatment. Heroin is the one I love, and I'm a faithful old thing.

Do I still use? Yes, I can't leave it alone, but these days it is more likely to be on my terms, when I say it's convenient.

Do I believe that the stability I have in my life is at least partly thanks to methadone? Yes. Yes I do.

Some people say they feel stressed about being dependent on the OTP, and it is true that from time to time I worry about nuclear holocaust, spending months withdrawing cold without even a rogue aspirin, while zombies threaten my very existence. I am even a little concerned about the government destabilising and kicking everyone off the program. Or time shifting and I wake up to a twin universe where no-one knows who I am and methadone hasn't been invented.

But all in all, I'm pretty secure that it will all roll on, that common sense will continue to prevail and the program will remain funded, takeaways and all.

Yeah, I get annoyed by the stigma and discrimination, but I copped worse before I was on it and I've learned that people actually despise fat people even more than drug users. The haters can be pretty extreme though. I remember one anti-drug campaigner saying she would rather her son was dead than on methadone. I often wondered how their relationship developed after that public statement. But there are also heaps of fantastic people associated with the program and I have the pleasure of knowing some incredibly amazing OTP doctors, nurses and chemists whom I am proud to call friends.

Methadone and bupe aren't right for every opioid user. It's just another choice. There are lots of ways to use and not use, and many roads to treatment. I had travelled a lot of them without finding what I needed before I eventually got onto methadone. For me, it's been useful. If I think I don't need it any more I'll get off it. But that day isn't today.

Love Leah xx

VALE ANNIE & JACK

We Say Goodbye to Two Members of the NUAA Family

Annie Cranston

Annie Cranston was the (beautiful) face of NUAA's Needle and Syringe Program (NSP) for close to 15 years (1998–2013). When she sadly passed on from breast cancer on 25 January 2019, she left behind many devastated friends and colleagues.

Annie was liked and respected by all she came in contact with – staff, service users and industry allies alike. She loved her job and was fabulous at it; she very much regretted having to resign due to ill health.

Annie genuinely cared about the health of everyone who came through the door. Her kind and open manner, combined with her lived experience and exceptional knowledge of harm reduction, consolidated NUAA's reputation as a caring, non-discriminatory service offering accurate, up-to-date peer advice and expertise.

Here is what some of the NUAA staff said about her – "and so say all of us":

> Annie always had a smile on her face and made everyone feel welcome at NUAA's NSP. If I close my eyes, I can still hear her giving harm reduction advice to people coming through the door: "Don't forget to swab your spoon! Only use the inside of the cotton ball!..." Annie was a rare person who never had a mean word to say about anyone. In fact, the exact opposite is true - Annie always had a kind word for everyone and always saw the best in people (even when I thought they didn't deserve it!).
>
> Annie was one of the kindest people I have ever met. She was a beautiful person who opened her heart to everyone. She would walk into work and give everyone a hug – and when you had been hugged by Annie, you knew it! She went out of her way to connect with people. She remembered things about people – the names of their kids, their dogs, the things important to them, and she asked about them every time she saw them. The service users loved her. She gave great advice with an open heart. She was 100% genuine. It broke her heart to leave NUAA and it has broken mine that she has left us.
>
> Working with Annie was always a hoot and a laugh – she made work enjoyable. When I started at NUAA, I was disappointed that I didn't get an office upstairs - my desk was down in the NSP - but when I had to move upstairs the thing I missed most was no longer sharing a space with Annie. I missed our gossip sessions over a cuppa and a cigarette - and yes, we did occasionally get work done. Even though Annie was sick and ended up having to leave NUAA for her health, she always felt bigger than life and had amazing stories to tell about her life adventures and travels. She definitely lived life to the fullest and she will be missed. Every time I swab a spoon, I remember her advice (she was big on swabbing) and her smile.
>
> The things I remember most about Annie are her kindness and her gentleness. She was always genuinely interested in people and took the time to make them feel comfortable and cared for. You often hear it said that someone is a "people person"; well Annie was more a "people whisperer". She made you feel special. She could really calm people down – she was great at de-escalating drama. She didn't have a jot of judgmentalism or discrimination about her. She respected the choices that people made and stood tall as a user herself. She will be sorely missed, but she has left a vast and sparkling Annie-shaped legacy.

Jack Walsh

Jack Walsh, partner to User's News' editor Leah McLeod for over 20 years, died of a brain tumour on 5 March 2019.

Jack was crazily supportive and proud of Leah's association with NUAA over the years, and that included hearing/reading/viewing every raw article-in-progress, cover mock-up and comic script for UN since Issue #67, and Insider's News since the beginning. He would have been upset to know that he had contributed to this edition (#92) going out late.

Jack started using in his teens and loved to tell stories of matchboxes filled with rock that he hid in his Indian motorbike. That's when he got hep C and getting it cured with the new treatments was cause for great celebration, especially after failing with interferon. He spent the last 17 years on methadone. It wasn't anything to do with how he died, but he did it so he could look after his family, so it had a lot to do with how he lived.

If you hung around the Cross in the 90s or early 2000s, you may have known Jack. He spent several years working at St Vincent's Hospital in Darlinghurst - as a detox worker at Gorman House and on the phones at the Alcohol and Drug Information Service (ADIS), and then as a Health Education Officer at Kirketon Road (KRC). He was well known among peers for giving people boxes of fits and water in a time when equipment was eked out in limited supply, 1 at a time. He gave respect and kindness in king-size amounts as well. He was fiercely protective of vulnerable people, because he knew what it felt like. He was particularly proud of walking the first Gay and Lesbian Mardi Gras march in support. Sadly when he was 'outed' at work as a user, he found himself on the pointy end of stigma and discrimination.

His last brush with stigma and discrimination came about 30 hours before he died. He had not had methadone or illicit drugs for a few months. He had become bed-ridden and incontinent, and then he lost his abilities to eat, speak, or recognise anyone. He was unconscious and struggling for each breath when this nurse hand-over was overheard: "This is John Walsh. He has a history of drug abuse…".

Jack was of course, like all of us, so much more than a drug user. He was funny, loving, smart, and a talented artist, musician and poet. He was the primary carer for Leah's and his daughter and he did that with pride. He loved his eldest daughter from a previous marriage wholeheartedly. He had an abiding interest in cryptozoology. His deepest regret was that he never connected with a Blue Mountains yowie, although he might have seen one from the train once. Let's hope that right now he's sitting around a campfire with some yowies in the great beyond.

Jack spent his last days on a morphine drip. We call this a silver lining.

He will be remembered with love. May he rest in peaches.

STOP PRESS.....STOP PRESS.....STOP PRESS.....STOP PRESS.....

ASPEN, THE MAKER OF METHADONE SYRUP IN AUSTRALIA, HAS ANNOUNCED A CHANGE IN THE COLOUR OF METHADONE.

A different dye is being used.

The change has been approved by the Australian Therapeutic Goods Administration (TGA).

If you are concerned about the new formula, we encourage you to talk to your prescriber. You may be able to move to Biodone or Suboxone or change your dose.

You can also make a complaint about side effects and the lack of information and consultation regarding the change. Go to the TGA website (*www.tga.gov.au/reporting-problems*) or contact the Adverse Medicine Events on 1300 134 237, Monday to Friday from 9 AM to 5 PM. You can also call us at NUAA on 1800 644 412 or 02 8354 7300.

STOP PRESS.....STOP PRESS.....STOP PRESS.....STOP PRESS.....

Lewis's Letter

LOOKING FOR STABILITY

Lewis is currently in jail. He injected for the first time in jail and got hep C there. Once he wanted to stop, his attempts to get on methadone inside got him nowhere. He wrote to us to call for methadone and bupe on demand for NSW inmates.

Dear User's News,

The first time I used was in jail, when I first got locked up 6 years ago.

I've got big holes in my arm from that crash initiation. I learnt how to inject under stressful conditions, having to always rush, and using old, blunt jail fits that mutilate your veins. I know that seems crazy, but it felt worth it at the time. I was at my lowest. I didn't care about myself because I felt that no-one cared about me. I needed to get away from the crap in my head and there aren't many other distractions in jail.

It wasn't long before I wanted to stop, and from what I knew about methadone I felt it would help. I learnt the hard way that it's rare to get on methadone in jail – you usually have to already be on the program outside to get on it, and even then, there's no guarantee.

I started slashing up my arms because I was trying to draw attention to how upset and stressed I was, in the hope they would put me on a program. But that didn't work.

I told them I would do anything to get on methadone, even get HIV. That meant I didn't care about sharing, didn't care about getting hep C or infections or anything. I did get hep C in here. I didn't want to stay alive and healthy - the exact opposite. I wanted to draw attention to how dangerous using was in jail, in the hope they would put me on a program. I got quite messy, but I didn't get methadone.

I did get put on a Suboxone pre-release program to prepare me for getting out. But it was a detox program and wasn't ongoing, so I was vulnerable to overdose. I ended up overdosing on fentanyl within a couple of days of getting out. Luckily, I was with friends who knew what was going on and I'm still here to tell the tale.

I got on methadone soon after, but it wasn't long before I had new warrants and the police were hanging around the clinic looking for me. Of course,

"I started slashing up my arms because I was trying to draw attention to how upset and stressed I was, in the hope they would put me on a program."

I just stopped picking up. Most people on the run just stop picking up their dose because if you are at a clinic where you have to pick up daily, they know just where to find you, once a day.

Of course, I started using again straight away. I was picked up anyway and went back to jail. My plan to get on methadone outside and be on a program if I went back to jail had failed miserably. I was no longer on methadone, so I couldn't get onto a program in jail.

So I kept using once I got to jail. Again, I begged to get back on methadone. However, it just wasn't on offer.

I have my ups and downs, and sometimes all I think about is having a shot. I've come to the conclusion that it's important to do what you can, when you can, to be safe if you are using in here and I'm on treatment for my hep C.

I really believe the methadone or buprenorphine (Suboxone) program should be available for everyone in jail who wants it. I think they need to do it if they are serious about reducing injecting in jail and stopping the spread of hep C. It's my personal opinion that by not putting people on methadone or bupe on request, they are basically pushing drugs into jails and encouraging everything that comes from that.

Thanks for a great mag,

Lewis.

Dear Lewis,

Thanks for your letter. Sorry to hear you've been doing it tough but thank you for raising some really important issues about the Opioid Treatment Program in jail.

We agree that it's important that inmates who want and need methadone or buprenorphine should be getting it.

We are told it is a budget issue – anyone on a program knows how time-consuming getting dosed is, and the amount of personnel needed to dose inmates daily is huge. Diversion is obviously another issue of concern to Corrective Services. Some jails don't dose at all.

Things could change with the new long-lasting injections of buprenorphine – see the article in this mag. This new format will allow people to have a depot (pronounced dee-poh) injection of bupe weekly, fortnightly or monthly, so it's easy on the resources and it's impossible to divert. There is a trial being held in one of the smaller jails, so we will see how it all pans out soon.

We think this is a great option for inmates and welcome any product that will increase the capacity for inmates to access the program. Our concern is that we do not want to see depot bupe as the only product on offer in NSW jails simply because it is convenient. There has not been a suggestion that people on methadone will be transferred to depot bupe, and let's hope it stays that way. People who are already on methadone should be able to continue that treatment, and should not be required to transfer.

We will keep an eye on the progress of doing in our jails and keep UN readers posted.

Best wishes,

Leah

Australia is a member of the United Nations, which is an organisation made up of the governments of countries all around the world.

The United Nations says that all prisoners should receive the same level of access to health care as any other citizen.

"Prisoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation."

The United Nations (1990) Principles for the Treatment of Prisoners (Principle 9)

The World Health Organisation puts it in other words. It says that "health services should be equivalent to what it provided in the country as a whole".

YOU HAVE A CHOICE

DEPENDENT ON OPIOIDS AND WANNA GET A GRIP?

If you're thinking about starting on an Opioid Treatment Program, there's a lot of competing information about what to do and what's available.

Should you try a private clinic, a public clinic, or dose at a pharmacy? Many people end up trying more than one option because different things work for different people at different times in their lives. What worked when you were single and jobless is not going to work when you have kids and work every day.

Here is some info, as well as opinions and advice from other people on the program.

WHY THE OPIOID TREATMENT PROGRAM (OTP)?

Sometimes people go on the OTP in a rush, because they are worried about withdrawing from whatever opioid they are using and see it as a way forward. They don't stop to think about it too much.

However, there are other options for working through opioid dependency. You could detox either at home (with or without the support of a Drug and Alcohol Service) or at a detoxification unit. Other options include staying at a long- or medium-term live-in rehab, such as a therapeutic community; attending a day program to get some skills around controlling your using; seeing a counsellor and/or drug and alcohol worker; or trying peer-based groups like SMART Recovery or Narcotics Anonymous (a '12-step program' similar to Alcoholics Anonymous).

Look into your choices and keep an open mind about different options. User's News Issue #87 (The Treatment Edition) gives a run-down of different treatment options, with stories by peers who have tried them. You can find these articles on our website at *www.usersnews.com.au*

Jack

"I've been on methadone for over 7 years now, with a few short breaks - three months once and a week here or there when I've been trying to get off it. I'm really struggling with going to a private clinic and having to pay for it. Initially, I thought that methadone would be easy to get off, but that's absolutely not the case. To be honest, I think that starting the program was one of the worst decisions I've ever made."

Sally

"To be honest, If I'd known when I started methadone that you became stable and didn't get stoned, I wouldn't have started it because now I just need it to feel normal."

Cindy

"I have always worked – usually more than 1 job and sometimes up to 4 – and used from my pay. When I went on the program, I had maxed out all my cards, borrowed from everyone I know and was way behind in rent, looking homelessness in the face. Getting on methadone meant that I didn't fall over the edge. From that first dose, I felt the freedom of not waking up sick and having to find the money to feel well enough to work, not having to battle through work hanging out, trying to act normal when I was in the toilet half the time. I felt I had control for the first time in a long time. I could even use sometimes without feeling drowned by it all. Yeah, there are rules, but if you tell me you don't have all that with using, then you haven't used like I have. Don't whine to me about cost and not being treated with respect. It's not like you even have a few dollars for a coffee when you use a few times a day, and you don't get a lot of respect as a user – sucking up for credit, borrowing money, scamming, arguing with your straight friends and family. My life is out-of-sight better now."

Pete

"They don't call methadone the "liquid handcuffs" for nothing. I'm sick of jumping through hoops. My life is just about going to the clinic every day and being treated like shit. I thought I would be on it for a couple of years, tops, but it's been 12 now. I went on it too young; I had only been using a year. I wish I hadn't rushed into it and had tried a few more other things to get my use under control before going straight to methadone."

Jane

"I have been on methadone twice and it hasn't helped either time. The first time I kept using and ended up selling my dose. The second time was after a car accident and I was on oxies for pain. My doctor got this idea that I was too dependent on the oxies and that the 'done would help me get off them. But it does nothing for the pain. She seems to think it's all sorted and when I complain about pain that I am drug seeking. It seems to be all about her and nothing about the realities of me living with pain. So now I am back to using and that whole cycle."

Neil

"The thing I like about methadone is that it is fantastic for depression. I have never found an anti-depressant that I like. Gear worked of course but it's a hard life – too expensive, too risky. Being on methadone I can feel relaxed and not stressed. I don't have the problems that went with using too much – which seems to be the only way I know how to use without methadone. I still use sometimes, but with methadone on board, it's under control – a couple of times a week instead of a couple of times a day."

Brian

"Methadone took the chaos out of my life. I've been on it for years now and it has meant that I can live life on my own terms. Even though there are the obvious restrictions, I am able to be a fully functioning citizen. There aren't many things I can't do now. I'm heading overseas in a couple of weeks for work. That wouldn't have happened for me before the program."

Jim

"I really don't want to use anymore. There's a lot of reasons why. When I am on Suboxone, I don't use. When I am off it, I do. It's that simple for me. I'm not on a high dose and I know that eventually I'll be off it for good without needing to use any opioids at all. For me, that will be freedom. In the meantime, I use the help I'm offered."

Private Clinic	Public Clinic	Doctor/Pharmacy
How does it work?		
You can see a prescriber and get dosed in the same place. Prescribers usually won't let you dose anywhere else, even though they are supposed to allow you to take your script to the doser of your choice (i.e. pharmacy).	You can see a prescriber and get dosed in the same place. After your dose is stabilised, you can take your script to a pharmacy or private clinic if you prefer to be dosed elsewhere, but you'll have to pay the relevant dosing fees.	You see a GP or Addiction Specialist working at a medical practice in the community, then dose at a pharmacy or private clinic (you'll typically have to start dosing at a clinic, and can move to a pharmacy once your dose is stabilised).
How often will I need to see the doctor?		
Usually prescribers see patients weekly but may do monthly once you have been there a while.	You need to see your prescriber every 3 to 4 months.	Doctors can decide how long between scripts – we have heard everything from a week to 6 months.
What other services and support are a available?		
May or may not have support staff like psychologists, support for hep C etc – varies between clinics.	Has various support staff, including social workers, psychologists, and hep C clinicians doing testing and treatment.	Some prescribers will see you for general health issues and make referrals to other services through a Mental Health Plan etc.
How much will it cost?		
Expensive. There is a sign-up fee and daily dispensing fee. Extra cost for takeaways.	Free.	Cost of GP appointment (unless bulk billed), plus cost of medication/ dispensing fee. There is no set fee, so it will vary.
Can I get takeaways?		
Easier to get takeaways.	Hard to get takeaways/ not generally available.	Depends on the doctor.
How easy will it be to access the service?		
Rarely a waiting list; Long opening/dosing hours.	Usually a waiting list; Dosing hours can be much shorter and restrictive.	Usually a waiting list; Dosing hours are typically much shorter and restrictive.

Freda

"I don't have a choice. There are no private prescribers in the whole of the Blue Mountains. Unless I want to travel to Sydney all the time, I'm stuck at a public clinic. I love that it's free, but I hate having to go every single day. I hate feeling watched."

Sam

"I have a great chemist. At first, I was worried because I had to get my picture taken and got the talk about "if you shoplift from us, you're gone" and I felt really pissed off about that. Then we went through the whole thing of me having to wait until everyone else was served first. But I worked out that was them trying to be confidential, not wanting to dose me in front of other people. When I made it clear that didn't bother me, it changed. I also made sure I came in at the same time, or rang them to let them know, so they would have my dose and takeaways ready for me. It's turned out really well."

Nik

"I'm at a private clinic, basically because they could get me in straight away and it was easy. I was pretty desperate to get on as soon as possible and they got me into a doctor and the paperwork done super fast. I don't think it's any better or worse than anywhere else. The nurses are really nice and always ask about my kids, my course, all that sort of stuff. They even gave me a present when my last baby was born. "

Lee

"I started at a private clinic because they started me straight away. But it does cost a lot and my prescriber won't let me dose anywhere else, even though I've moved and I'm close to a good chemist. That's annoying. You get the feeling they're just about money. You shouldn't have to commit crimes or give up one of your doses to pay for your methadone!"

Jen

"I'm at a private clinic and I have had a lot of trouble with them telling me I'm behind with money when I'm not. They don't EFTPOS so I have to pay in cash and then half the time you can't read the ink. I also don't like how often I have to see my doctor every fortnight, or the number of urines they make you do. The queues are brutal too. You feel like everything they do is motivated by money and once you're there, you're stuck unless you can find a GP [prescriber] who can fit you in."

Stan

"I'm at a public clinic, which I stay at because it's free. But you never get a takeaway except for really unusual circumstances. There are heaps of people dosing so you always have to wait in line. One day I'd had a few drinks the night before and was a bit bleary-eyed, so they got it in their head that I am a drinker and keep breathalysing me. That first day, they only half dosed me. Since then it's always at 0, so I don't know why they keep doing it. That week they did it 5 days in a row. Plus the NSP is in the same building, so if you use they know and insist on urines and half-dose you."

Bill

"I have been at a public clinic for 13 years. They're trying to get all the people who've been there a long time to switch to a pharmacy, but I'm resisting. I can't afford it. The staff are really great and my doctor is fantastic. Takeaways would be good, but it's an option I can't afford."

Emma

"I live in a regional area and there aren't many choices where I am. I wasn't happy living without takeaways because I work so it was just murder racing around and getting stressed in a queue every day. So I found a doctor and chemist in an outer suburb of Sydney to transfer to. It's about an hour and a half away but it's worth it for me. Because I've been on a long time and I work and my doctor is happy with my urines, I only have to get dosed once a week and I get takeaways for the other days, then I see my doctor every 3 months. I mean, heaps of people commute every day for work with a much longer trip than I do. And there is no queue at the other end. Sometimes it feels a hassle, but no more than having to do grocery shopping or housework or any of those other boring things in life you have to do."

"METHADONE TOOK THE CHAOS OUT OF MY LIFE."

Alice

"Last time I got out of jail I ended up at a private clinic, because I wanted takeaways. Worse decision I ever made. Now I can't get back to the public clinic where I have been dosed over 10 years. I felt really safe and supported there. It wasn't worth it to move."

A Note On Prescribers:

In order to be a prescriber, doctors do a course to learn about the OTP (called the Opioid Treatment Accreditation Course or OTAC) followed by an exam. The course includes a talk from a NUAA member on the program.

All doctors have a limit on how many patients they can prescribe for. Generally, this limit is 200 patients who dose in community pharmacies or private clinics, or up to 300 patients who dose in public OTP clinics.

Any doctor - including your local family GP - can prescribe for up to 20 buprenorphine patients (including starting them) and 10 methadone patients (taking over patients on a stable dose), without having to do the OTAC or other special training. Ask NUAA for more info if you would like to approach your doctor about this.

ADVICE

Marcus

"If you wanna start on methadone, don't go too high. The higher your dose, the harder it is to go down. And don't try using on your dose, it'll just make your life harder and is a waste. If you're thinking about getting on the methadone program, just try to get on it as soon as possible. You don't wanna get locked up, cos jail is not very fun."

Pete

"My advice to people thinking about starting the program? Just do it. Give it a try at least because it does work. It's better than using, then waking up feeling like shit every day. Just give it a shot – no pun intended."

Aaron

"If I had advice for newbies, it would be to have a good and honest chat with your doctor. Think about the end result of going on it, and where you want to go with it. And for heaven's sake, don't inject. It'll just make you end up using more."

David

"If you're going to go on the program, do it and stick to it. Don't get swayed by trying to get abstinent. Get stable before you try to do anything else – mentally, emotionally and financially stable. Being on the program isn't the end of the world – it's the beginning of something good."

Sandy

"To be honest, If I'd known when I started methadone that you became stable and didn't get stoned, I wouldn't have started it because now I just need it to feel normal. I think methadone is better to help detox. If you can buy takeaways, get 200mg worth and have 40mg over 5 days to get off heroin, then you won't be hanging out for it. But you also won't be saturated by methadone, so you won't get sick from that either."

Ace

"When I was on bupe, the tablet (Subutex) was alright, but as soon as I hit the film (Suboxone) it was no good. If I could I would go back on Subutex for sure. Make sure you do your research to find out what's right for you, because everyone's different."

James

"Think about your decision very carefully – it should only be a last resort. I got on methadone not knowing that a lot of people stay on it for the rest of their lives. To be honest, I think that starting the program was one of the worst decisions I've ever made, especially seeing I'd only been on heroin for 6 months before then."

Kelsy

"My advice to people thinking of starting on the program is to really think about it. It's a long-term decision. Consider your options. Five days detox and then stopping cold turkey with the support of those around you? Or a long-term commitment to pharmaceuticals that you might not be able to break."

A Note on Stigma & Discrimination

We've spoken to lots of people on OTP who have experienced different - and sometimes all - available services. There is no sense that one type of service discriminates more than others. People have had both great and dreadful experiences at both private and public OTP clinics, general practice clinics and pharmacies.

In general, we are treated differently. What other patient groups would be discriminated against like we are? Imagine if all pregnant women were given a lecture about shop-lifting when they started going to a new pharmacy. Or a doctor refused to prescribe to anyone with a heart condition. Or diabetics had to go in every day to get their insulin injected by a nurse. But people seeking treatment for opioid use are regularly treated as if we are bad people, looking for a free hit.

People who are employed in OTP are from the general community. Some discriminate, some don't. Some have experience with harm reduction, some don't. It can feel like the luck of the draw, but everyone has the right to be cared for with respect and knowledge every time they engage with a health professional. There is no excuse for a health professional to be poorly trained or treat people badly.

If you are discriminated against, make a complaint. NUAA does anti-stigma and discrimination training that might benefit all staff. And if you are choosing a service to attend and you know anyone on the program, ask what they think of their clinic/pharmacy to help you make an informed decision.

"I WISH I HAD TRIED A FEW OTHER THINGS TO GET MY USE UNDER CONTROL FIRST."

YOU HAVE A CHOICE

WHICH MEDICATION?

So you've decided to start an OTP program - what next? One of the first things you should think about is what medication you want to try. What options are available? What are the differences between Suboxone, Subutex, methadone syrup, and Biodone? And what about these new injectable bupe medications everyone's talking about?

A lot of people will swap between medications at different points on the OTP. Some people prefer bupe, while others like the 'done. If you're not happy with the OTP medication you're on right now, it might be worth thinking about swapping to something else.

Have a read of what your peers are saying, and get the facts about the different types of medication across the next few pages.

Methadone vs Buprenorphine: Which way should you go?

If you have decided that OTP might be for you, you need to choose which medication you want to be on. Be guided by the info below, your own experience, your prescriber's opinion, and what your peers tell you.

Methadone	Buprenorphine
Methadone is a long-lasting opioid. It is a 'full agonist' of opioid receptors (which means you get the full pleasurable opioid effect).	Buprenorphine is a long-lasting opioid. However, it is only a 'partial agonist' of opioid receptors (which means you only get some of the pleasurable opioid effect).
It prevents withdrawal symptoms and craving for opioids. A single dose lasts for up to 24 hours.	It prevents withdrawal symptoms and craving for opioids. A single dose lasts for 24 hours or it can be doubled up to last for 48 hours.
In Australia, methadone comes as Methadone Syrup or Biodone Forte Oral Liquid. Methadone has several additives whereas Biodone is only mixed with water and colour.	In Australia, buprenorphine comes in two formulations; Subutex, which contains only buprenorphine, and Suboxone, which includes naloxone (AKA Narcan). Naloxone is an 'antagonist' of opioid receptors, which means it blocks the effects of opioids. The naloxone only has an effect if it is injected.
Methadone/Biodone is sipped as an oral solution. In NSW, it's not supposed to be diluted with water/juice/cordial, which is done in other states.	Subutex is a pill and Suboxone is a strip. Both are taken sublingually meaning you put the pill/strip under the tongue until it dissolves and is gone.

Methadone is often attributed to causing tooth decay due to its high sugar content. However, all opioids (including methadone and buprenorphine) reduce the amount of saliva made in your mouth, which leads to an increase in bacteria in your mouth. This is known as Xerostomia, or 'Dry Mouth Syndrome'.

You can counter this by chewing sugar-free gum, drinking lots of water, and using special dental products – ask your prescriber for more information.

Both buprenorphine and methadone are dependence-forming, just like other opioids. While they can help you stabilise your drug consumption, it is important to note that many people struggle with reducing their doses and coming off methadone or buprenorphine programs.

Danny

"I'm on methadone right now – I've also been on bupe. I found that on bupe, it was difficult to continue holding it, the taste was really bad so I wanted to swallow it, but if I did it wouldn't work and then I'd be hanging out heaps. I find that methadone kicks in quicker and holds you quicker. Bupe is much slower and takes a while to start holding you. I like that quicker come up."

Pat

"I was on methadone then moved to Subutex when my son was born. When I was on bupe, I decided that I didn't want to use anymore. I was confident I could stay abstinent and deal with my issues without using. I went back to methadone when my son was much older because I didn't have any reason to not use. I'm on a small dose of methadone so I can still get a result from having a shot. Things may change again."

Eliza

"I didn't realise how stoned I was on methadone until I moved onto bupe. On bupe, my head seemed a lot clearer and I had a lot more energy. It was a lot more like being straight. I liked being able to think and I ended up doing more – getting out and participating in life more."

Kath

"I knew all these people who had been on methadone for years and years, but it didn't seem like that for people on bupe. My doctor told me bupe was easier to come off. I didn't want the program to be a dead end for me, so I decided on bupe. It's worked well for me. I'm coming down now and it's going ok."

Marly

"I swapped over to methadone because when I was on the bupe, if someone offered me gear, I couldn't stop myself – even when if I did it, it made me sick. But being on methadone, I know gear is just wasted on me, so I don't bother with it."

Alex

"I've been on methadone and bupe. I found that when I was on bupe, it was easier to control my substance intake. You can skip a dose if you want to use, but you have to plan it. If you're on methadone you can use whenever you want, although you need a lot more gear and it's not really worth it."

Bella

"I went on methadone because I'd been buying it on the street for years, so I kind of knew what I was getting. Bupe was a bit of an unknown and I was nervous about things, like what if I had an accident and they needed to give me opioids – would I go into precipitated withdrawal? There were too many things I didn't understand, so I stayed with what I know."

Lorenzo

"I found it really hard to sleep on Suboxone, and it made me get really sweaty and hyperactive which is why I wanted to switch back to methadone. But when I raised it with my doctor, he acted like I was just doing it so I could start using again."

Justin

"I reckon switching from methadone to Suboxone was the best choice I made in my treatment – it gave me my energy back and cleared my head, which is what I needed for my daughter."

Stephanie

"I swapped over to methadone because Suboxone straight up doesn't work for me, I was hanging out every morning before I got my dose."

Karen

"When I switched from methadone to bupe, it cleared my head and killed my urge to drink alcohol. I started feeling a lot of emotions and memories I had been blocking out for so long, with gear, and then with 'done and alcohol. Being on Suboxone made me feel all this shit again – my mental health wasn't ready for that, and I felt like I had no release at all."

Milly

"Bupe gave me way too much energy. But when I'm on methadone, I have to be around people I trust in the afternoons, because it hits me like a tonne of bricks and I often go on the nod."

Tanya

"I have ADHD and found that Suboxone made it worse - I was a lot more hyperactive when I was on it."

What's the difference between methadone syrup and Biodone?

Both these products are methadone, but the simple answer is that Biodone has the additives removed from it. "Methadone" is the general name for the drug and "Biodone" is a brand name. You usually can only get one or the other, and it's not your choice. At pharmacies, it has a lot to do with the company they have an account with - one mob sells methadone syrup and the other sells Biodone. It's really rare to get to choose between the two. A lot of clinics use Biodone because it's healthier. Some stay with the syrup because a lot of people on the OTP prefer it.

Methadone Syrup	Biodone Forte Oral Liquid
In Australia, this is amber-coloured syrup with an aromatic smell and a lingering, unpleasant taste.	In Australia, this is a clear, pink/red solution with a momentary unpleasant taste.
Active ingredient is methadone hydrochloride at a ratio of 5mg per each mL. This means a dose of 100mg is 20mL of syrup.	Active ingredient is also methadone hydrochloride at a ratio of 5mg peach each mL. This means a dose of 100mg is 20mL of liquid.
Methadone syrup also contains caramel colouring, ethanol (a form of alcohol), glycerol and sorbitol (sweeteners with a laxative effect), sodium benzoate (a preservative that helps reduce bacteria and fungus), purified water and flavour (pharmaceutical 503978A – yes, they make it taste like that on purpose).	Other ingredients in Biodone Forte are: Purified water, colour (permicol red).
Methadone syrup is sticky and thick. If you're going to inject it, you need to dilute it at least 1:1 with water and filter it through both a red and a blue wheel filter. There will also be a lot of liquid, so you should use a butterfly/ winged infusion set or a large barrel syringe. See the article on injecting in this issue.	Biodone contains no additives, making it safer to inject than methadone syrup. Be sure to run it through a blue/bacterial wheel filter first. You will also need a large barrel syringe, and may also need a winged infusion set (butterfly) depending on dose and syringe size..

Garth

"I've used both and didn't notice much difference to be honest. Except with methadone, the taste stays in your mouth longer. Biodone tastes worse but once you've swallowed it, the taste goes. "

Gina

"Biodone just doesn't seem to hold me as long as methadone. I know they say they're the same, but I know what I feel. I had to go up on my dose when my clinic moved to Biodone and it still didn't hold me the full 24 hours. I prefer methadone every time."

What's the difference between buprenorphine products Subutex and Suboxone?

Suboxone	Subutex
Suboxone contains buprenorphine and naloxone at a 4:1 ratio as the active ingredients.	Subutex only contains buprenorphine as the active ingredient. It also contains binders such as lactose, mannitol and cornstarch.
Suboxone is a sublingual film, which means it is absorbed under your tongue. It is also referred to as 'bupe strips', or wafers.	Subutex is buprenorphine as an uncoated tablet, which is meant to be consumed sublingually (under your tongue). Subutex is also reported to have a different taste to Suboxone, and some people prefer it for this reason.
Suboxone has a lower 'abuse potential', because if you inject it, the naloxone may send you into precipitated withdrawals. At the least, you won't feel the bupe for at least 2 hours.	Subutex is considered to have a higher 'abuse potential' than Suboxone, because it doesn't contain naloxone. This is one of the reasons it is not prescribed very often anymore.
Some people say Suboxone gives them lots of energy and has an almost stimulating effect.	A lot of people say Subutex has a more traditional opioid-like 'depressant' feel than Suboxone.

Joel

"Suboxone doesn't agree with me. It makes me feel ill. When my clinic changed from Subutex to Suboxone, I went looking for a doctor who would listen to me and prescribe Subutex for me. Luckily, I found one, or else I would have been using again. I couldn't have stayed on Suboxone."

Nina

"I've only ever known Suboxone. It works fine and I don't have a problem with it. I've never tried to inject it, so the naloxone is no problem for me. It does the job and keeps me away from using the needle every day."

Ezy

"I was on Subutex years ago, and then was made to swap when Suboxone first came out. I found bupe alright, the only trouble was that every time I put the Suboxone films it in my mouth I wanted to chuck up. The taste was BAD. When I was on bupe, being on the tablet was alright, but as soon as I hit the film it was no good. I'm on methadone now, but if they brought back Subutex at my clinic I would go on that for sure. It's too easy to use on top of methadone. When you have bupe in you, it doesn't matter how much you use, you're not going to feel it."

Blair's Story

VALE LUKE IN SUPPORT OF SUBOXONE

Best friends Blair and Luke met in rehab and went to NA together. Both achieved abstinence, but sadly Luke was shamed because he was supported by a Suboxone prescription. People around him embraced the myth that buprenorphine and methadone are "just legal highs". The fact is, these drugs are part of a legitimate and important treatment option, overseen by specialist doctors. In the end, stigma and discrimination caused a preventable death.

I had started work for the morning at a city coffee stand when I heard that my best friend Luke had died. We had been close friends from the day I met him in Odyssey House a year prior. We had many similarities.

When we both left rehab, I managed to stay abstinent, while he swung in and out of drug use. I will never forget that unbearable feeling of being torn three ways, among tending to his girlfriend Danielle's anguish as she screamed hysterically into the phone; the annoyed looks of the customers lining up for their morning coffee fix; and my own desire to run far away, even into the arm of the same drug that stole my best friend. Anywhere but behind that coffee stand.

The last time I saw Luke was in the musty lounge of the inner-city halfway house we both shared with 12 otherwise homeless men. He was a few days into his Suboxone withdrawal, his body spread across the old damaged recliner, detox sweat lining his face, his legs occasionally jerking as we tried to make light of the situation.

I reminded him that when he felt well enough, I would drive him again to 12-step meetings. Then he'd proudly identify as "clean" to those he felt didn't accept him while he was on Suboxone. This was my attempt to keep his eyes on the prize.

A few nights prior, I had dragged him to the local NA meeting at a nearby church. During the intermission, the chairperson called out the obligatory "clean-time" countdown, as group members stood to acknowledge their respective times spent abstinent from all drugs and alcohol.

"The newcomer is the most important person in the room. Is anyone 'clean' one day?" One teenage guy stood. The room clapped and a group member behind him patted him on the back as he received his first white-tag.

"And has anyone used drugs today, or is anyone on drug-replacement?"

I looked over to Luke, who was considered as part of this category, having been on Suboxone for months, I was unsure if he'd own up to being on "drug-replacement", a category of people who are sometimes looked down on by some people in NA. He sighed and stood. He was the only one. The room clapped, he received his obligatory pat on the back. I was proud of him, but as he sat back down all I saw on his face was a look of shame. After the meeting, we sat on a bench outside, shared a cigarette and debriefed.

"I gotta get off this Suboxone shit bro. I hate not being 'clean'."

I reminded him again that there was no rush, that people can have a good quality of life on Suboxone.

"Besides the way you use," I reminded him, "it's better to be on Suboxone than to be dead. You've been Narcan'd 5 times this year, man. Don't forget."

But my reminder wasn't enough. Within a day of that meeting, Luke had been to see a doctor and received a script for Valium, and the staff at the halfway house cleared him to do a home detox.

Six days later, on his pay day, Luke was found dead on the top story of a housing commission flat car-park. When a passer-by saw his legs sticking out from between two cars, he rushed to find a doctor from the nearby Community Health Clinic, but it was already too late. The pale colour of death had taken him. They estimated he had stopped breathing at least 20 minutes prior.

In the coroner's report, the doctor who found him mentioned that Luke looked "otherwise healthy, like someone who hadn't used for a while". And he was right. Luke hadn't used heroin for months while he was on Suboxone. The only time he wasn't injecting heroin was when he was on Suboxone.

It's obvious to me now that, from the Luke left rehab, it was largely Suboxone keeping him alive. It was Suboxone that allowed me to have those precious, few, good months with my friend. We had some really good times. He was funny, lovable and laid-back with a quick, dry wit. I miss him dearly to this day.

Before Luke's funeral I found it difficult to grieve, to cry, and to express any form of hurt. But as I helped carry his coffin and felt the weight of my best mate on my shoulder, and as I heard the sound of Danielle's impassioned cries as she pleaded with the sky, "Please don't take my boy!", my tears flowed for the first time in years.

As tragic as the loss of Luke was to me, it wasn't the first time I'd lost a best friend to heroin shortly after they stopped taking their drug replacement. Both times the survivor's guilt was swift, merciless and suffocating.

As a dependent heroin user, I became quite familiar with death. Familiar is the right word, because I never really got used to it. But this isn't a story about me. It's about a friend who would likely be alive today if he didn't feel compelled to stop taking his life-saving medication. This story, and the many lives lost to overdose, should remind us all that "we can't get abstinent once we're six foot under".

Editor's Note:

We at NUAA don't use the word "clean" to refer to someone who is abstinent or has stopped using drugs, or to imply someone is not living with a blood-borne virus (BBV) such as hep C or HIV. "Clean" is a stigmatising word that implies that people who use drugs or have a BBV are "dirty".
Having said that, we have used the word "clean" in this article because the piece is about a person struggling with the Narcotics Anonymous (NA) definition of abstinence. The word "clean" is used widely in NA culture and its stigmatising nature is at the centre of the story.
We encourage you to use other words that do not discriminate. Check out the language guide on the inside front cover of this edition for words that are best left behind us and some alternatives we prefer.

Stigma kills. Acceptance empowers.

THE SHOT THAT LASTS A MONTH

THERE'S A NEW BUPRENORPHINE IN TOWN!

We told you about the research trials for a new OTP medication back in UN #87. It's finally happening! In November 2018, the Australian Therapeutic Goods Administration (TGA) approved Buvidal®, a bupe product to be injected weekly or monthly.

What is it?

Buvidal is a slow-release formulation of buprenorphine. It's a clear yellow liquid in a pre-filled syringe and comes in two forms; Buvidal® Weekly and Buvidal® Monthly. Depending on which you're prescribed, you'll get an injection once a week or once a month. It's a slow release, so one injection will hold you for that entire length of time. Buvidal is a buprenorphine-only product like Subutex. It does not contain Naloxone like Suboxone.

Buvidal should be injected slowly and completely into the subcutaneous tissue of different areas (buttock, thigh, abdomen, or upper arm), provided there is enough subcutaneous tissue.

Clinical trials have shown it works better than Suboxone in helping you stay abstinent.

Buvidal has also passed all the safety tests the Australian authorities require. It does have a side effect in some people of skin irritation at the site where it's injected.

How does it work?

Buvidal is given by subcutaneous injection (some of us know this as "subcut" or "skin popping"). It can be injected into your butt, thigh, abdomen, or upper arm. The injection must be done by a doctor or nurse. The clinical guidelines are still being written, but because it's an injection you will either need to go to an opioid treatment clinic, or have it done in your prescriber's specialist or general practice clinic.

Once injected, the liquid turns into a "depot", which is like a gel that slowly breaks down and releases the buprenorphine. When the buprenorphine is released, it blocks the feel-good effects of other opioids, stops withdrawal, and reduces craving.

Buvidal Weekly comes in 8mg, 16mg, 24mg and 32mg doses. Buvidal Monthly comes in 64mg, 96mg, and 128mg doses. The doses are higher because it's spread out across the entire week/month.

Even the prescribers are excited!

"The introduction of Buvidal represents the most significant development in over 15 years of opioid dependence treatment in Australia. The flexibility of weekly and monthly injection depots will make treatment much more convenient for patients, reducing the costs and inconvenience of daily dosing, and should serve to lessen the stigma experienced by many patients."

Professor Nick Lintzeris,

Director of Drug & Alcohol Services, South East Sydney Local Health District and the Division of Addiction Medicine, Central Clinical School, University of Sydney.

What are the benefits?

There are many reasons why you might want to consider trying Buvidal.

In short, Buvidal works, it's safer and you will save time, stress and money.

Buvidal is great for people who would like to be abstinent but find it hard to stop using on methadone and Suboxone. Because there is a low chance that you will feel the effect of opioids once you have Buvidal in your system, you will have made big steps towards abstinence for the next week or month.

The biggest win is that you will only be dosed once a week or once a month (depending on which product you are on), without having to go into battle for your takeaways every time you see your doctor. This will buy you a lot more time and flexibility so you can work, study, raise a family, go on holiday or live in a rural area with a smile on your face.

Another plus is that less dosing means saving money on daily dosing fees. To know exactly how it will affect costs, we need to see how they decide to fund it. For those people dosing at a public clinic for financial reasons, but who find it stressful to attend every day (because they get triggered by people from their past or by people dealing drugs, or because they don't feel safe for whatever reason), it could mean they can finally move on and still get a free service. That helps everyone because it frees up a place at a public clinic for a newbie at a time they really need that extra support.

Buvidal could also reduce some of the stigma and discrimination that people on the program often face as a result of lack of privacy. No more hanging around a clinic or public appearances at a chemist in a small town to peg you as "one of them".

Buvidal can also provide a solution for those who struggle with the responsibility or storage of takeaways. Find it hard to not inject your dose? Getting hassled by people for your takeaways? Worry your kids will get into your supply? Buvidal removes the problems with takeaways (because you don't get any!) but gives you the advantages of at least 6 takeaways a week! Because Buvidal is administered by a healthcare professional, there's no risk of people who haven't been prescribed it (such as children) accidentally taking it.

Is Buvidal for me?

It's important to remember that different things work for different people – there's no one-size-fits-all treatment. We think that Buvidal will be great for some people, like those trying to stop using completely or who struggle with regular pickups.

Other people like to be in control and able to skip doses when they want, perhaps so they have the option to still enjoy themselves while on the program. In that case, you might be better off on Suboxone or Subutex.

Trials in prisons have been running for several months. At the moment, it's impossible to get on opioid treatment in jail because of the time and staff needed to dose inmates, as well as fears around diversion and standovers. Buvidal could be a real game changer. Our challenge will be to make sure that methadone and Subutex/Suboxone don't disappear as options.

Can I try it? When can I start?

Buvidal has just been approved for use in Australia, and clinical guidelines are currently being written so everyone knows the rules. There are also decisions being made around how it will be funded. There's a lot to iron out.

If you're currently on bupe and stable, you can be transitioned to Buvidal as soon as it's available. However, until at least mid-2019, Buvidal's distribution will be limited to public clinics. It's currently being trialled throughout NSW. Those people who like it will be able to stay on it, then other people will have the opportunity to start, or move across from their current form of OTP medication. After that, once any teething problems have been sorted, including finalising guidelines and funding, it will be available through doctors and private clinics.

We advise you to talk to your prescriber about Buvidal if you're interested in trying it out. It won't be long til you get the chance.

Double Depot

There will be two brands of depot bupe: Buvidal and Sublocade. Buvidal is the one currently being trialled. Sublocade is waiting on final government approval. We understand Sublocade will have different dose sizes and there may be other small differences, but they are essentially the same drug taken the same way. We are guessing it will be down to your doctor and clinic which one they use and that (as usual) we won't get a choice of brand.

THE SHOT THAT LASTS A MONTH

Gary's Story

WHY IT WORKS FOR ME

We wanted to bring you a user story around Buvidal, but at the moment everyone on it is attached to an academic research study. That means we can't get their names and they can't do media stories. However, we did do a story when an unnamed buprenorphine depot injection in a monthly dose was trialled in early 2017 for UN#87 (the Treatment Edition). We decided to reprint that story rather than leave you guessing. Thanks to Gary for putting it out there yet again.

I've always been in conflict with myself about my drug use. I like drugs but I hate what comes with it. I hate when I have no food, no cigarettes because I've had a shitty $50 taste. I hate knowing what the result is going to be but doing it anyway. I really don't like being controlled by my drug use.

I'm 50 now, and I've been on and off the Opioid Treatment Program (OTP) eight times. Two of those times I have been on bupe. This is my ninth attempt. I've always used OTP to stop using, then got off it when I felt ready. So far, I've ended up using again and had to get back on. But I'll never give up trying.

I put my hand up for the monthly buprenorphine injecting trial because I was over going to the clinic every day. My goal is to not use and get off OTP, so my clinic wasn't a healthy place for me to be every day. There are a lot of people there who, for one reason or another, don't want to stop using or are having trouble stopping. They may be just starting out on OTP, have just come out of jail, or simply have been on the program a long time and are comfortable with using while on OTP. So there can be a lot of wheeling and dealing going on – people asking you to score for them or trying to sell pills or whatever. It's in your face.

Apart from the drug use, there's always drama, people pushing in, arguing and so on. All in all, I found it a real drain going there every day. I am so glad I am out of that. There is nothing I miss about the clinic.

Having said that, I did feel a bit lost when I first got on the injections. I would wake up and have nowhere to go. I would be looking for a drink or a pill to fill the gap. Going to the clinic gave me direction in the morning and I have had to find ways to deal with that – other things to do.

Change came to me through caring for my nephew. I started looking after him, dropping him off and picking him up from school for my sister and being involved in my family a lot more. It gave me something to do and was really positive. It's really been wonderful finding new things to get me up in the morning, to get me motivated about my life.

I've also made some decisions about my future and I'm starting a course in March.

The great thing about being away from the clinic environment is that you are not faced with drugs on a daily basis, you are not faced with being a daily drug user. You are just a person. I don't think about drugs at all now.

As far as being on the bupe injections goes, I don't feel anything different. It's exactly the same as being on it every day. It's not like there is anything in your arm that you can feel, it's not an implant. When you get the injection, it pinches for a couple of seconds, but there is no pain. It's all very easy.

I've been on the injection trial for nearly a year now I have two injections left and then I am off the bupe. I really think this will be it because I have dealt with the daily thing, I have moved away from being around people who use and I have found new routines, new things to do with my time.

I would absolutely recommend the monthly injections, especially if you want to not use and/or you've got a job or things to do in your day and don't want to be tied to having to pick up a dose every day or even every few days. I don't regret it for a moment.

Knowledge is Power!

After what felt like years of waiting, the new guidelines for the methadone and buprenorphine program came out last year. This document, the *NSW Clinical Guidelines: Treatment of Opioid Dependence – 2018*, is what prescribers, nurses and clinic staff refer to when treating people on the Opioid Treatment Program (OTP).

It's great that this document is out because now doctors and nurses are up to date with what is expected of them.

But what about us? It's a thick, wordy booklet, and not easy for everyone to understand. That's why NUAA have spent the last few months translating it into another set of resources for us – the Consumer Guidelines to OTP!

Our Consumer Guidelines got bigger and bigger the more we talked to people about what they want. As well as the Consumer Guidelines, we developed an extra set of standalone resources which cover a range of different topics.

1. Starter's Guide to OTP – Everything you've ever wanted to know about starting on methadone or buprenorphine

2. Pain Management – What to do if you're in extra pain while on OTP.

3. Pregnancy and Parenting – Info about being pregnant while on OTP, the support available for mums and dads, and how to stay on the good side of Family and Community Services (FACS, formerly known as DOCS).

4. Maintenance – Find out more about what it's like to be on the program for a long time, changing your dose, and takeaways!

5. Exiting Treatment – Are you thinking about reducing or stopping taking your methadone or bupe? Let's talk about ways to come off, whether you're ready, withdrawals and how to cope with them, and the support you can get once you've exited treatment.

6. Regional and Rural OTP – Opioid treatment in regional and rural NSW has some different challenges than in Sydney, so we've tried to make it as easy for you as possible with this resource!

7. Consumer Rights and Responsibilities – Want to learn about your legal rights and what you can expect from the NSW and Australian health care system? What about dealing with police while on the program? This guide explains your rights and responsibilities while on the program, and how to make complaints if you feel like you're not being treated fairly.

What's so special about NUAA's guidelines?

Our version is easy-to-read and has everything you could possibly want to know about being on methadone and buprenorphine – written by people who use drugs, for people who use drugs.

As well as using the information in the Clinical Guidelines, we talked to regular doctors, addiction medicine specialists, pharmacists, and policy-makers to get their point of view on OTP. Not only that, we went out to towns across NSW to run focus groups with people who are on bupe or methadone, to find out what issues they thought were important and to hear about their experiences on the program. The result is a set of resources made specifically for you, no matter where you are on your treatment journey, and we are excited and proud to share it with our community.

What's in NUAA's Consumer Guidelines to OTP?

Our Consumer Guidelines to OTP has information about loads of topics. It explains how to start a treatment program, what being on the program is like, your options for medication and clinics (including depot bupe), information about injecting, using other drugs and medications, your rights and responsibilities, and how to get extra support.

We also bust myths about driving and travelling on the program, pregnancy and parenting, and the side effects of OTP medication. It has info on how to go about reducing your dose and stopping treatment, what happens if you end up in hospital or jail, and what you can do if you're being treated unfairly or discriminated against.

We started with the Ministry for Health's Clinical Guidelines on how they want the OTP run, written for health professionals involved in prescribing and dosing.

We then went and talked to people on the program, in both the city and the country, and we found out that there were a few things we were missing – for example, information about different treatment options (not just methadone and buprenorphine), and specific stuff for people in regional and rural areas. From these focus groups, we decided to develop an extra set of resources, so as well as the main Consumer Guidelines, the project expanded to include seven stand-alone guides. These are smaller booklets about specific topics, so you don't feel you are wading through masses of info to find out what you need to know.

Where can I get a copy?

NUAA's Consumer Guidelines to OTP will be out very soon, and they will be distributed across NSW to NSPs, chemists, OTP clinics and some medical practices and healthcare clinics - anyone who needs a copy will be able to get one. If you'd like your own copy of any of our resources, get in touch with us and we'll send one out to you. You can contact NUAA by email at **nuaa@nuaa.org.au**, or by phone on **(02) 8354 7300** or **1800 644 413 (free call).**

Don't Worry, Be Happy

10 WAYS FOR A SMOOTHER RIDE ON THE PROGRAM

Being on the Opiate Treatment Program (OTP) can be complicated, as there are a lot of rules and regulations. We often feel like we are not in control, but there are many things we can do to make our lives easier, and steps we can take to reduce stress and conflict.

Throughout Australia, there are a number of phone services that support people on the program. In NSW, we have the Opiate Treatment Line (OTL), an information service that also registers complaints. In Victoria, this service is run by peers, which means everyone you talk to has lived experience of OTP. Victoria's Pharmacotherapy Advocacy Mediation Support (PAMS), operates out of NUAA's sister organisation Harm Reduction Victoria (HRV). PAMS supports people on the program by hooking them up with services, helping with transfers and resolving disputes.

User's News caught up with PAMS co-ordinator Sarah Lord to get the benefit of her years of experience in giving information, solving problems and advocating for Victorians on OTP. She told us that most questions and complaints about the program relate to the 10 things in this article. We have made them relevant to NSW and we think that once you understand these, you will be a lot happier.

Never forget methadone and buprenorphine are strong opiates.

Listed as Schedule 8 (S8), methadone and buprenorphine are in the category of "Controlled Drugs", "Restricted Drugs" and "Drugs of Addiction". This type of drugs is regulated by government with strict legal controls around its supply. The possession of these drugs without a prescription is an offence. If they are not taken as directed or the wrong people get hold of them (anyone without an opiate tolerance which is most of the population!), they can kill.

The strength and risk of overdose that comes with strong opiates means that prescribers, dispensers and patients (that's you) have serious legal and ethical obligations and responsibilities. As a user who is used to buying strong opiates (including methadone) off the street, you might see the associated paperwork and regulations as power games and discrimination – and sometimes it is – but the rules are there to keep everyone safe (including you).

Make sure you always have a valid script.

It's your responsibility to make sure the pharmacy or clinic has a valid script. If your script is out of date, you cannot be dosed, so keep your eye on when it expires.

Some pharmacies and clinics will give you a reminder that you are about to need a new script and takeaways should have the script date on the label.

Sarah suggests that, before you walk out the door of your last appointment, you book the next appointment with your prescriber for the day before your script expires. Then, put it in your phone as an alarm or make a sign for your fridge. If you're at a clinic, ask them to remind you the day before. Some GPs have SMS reminder services you can use.

Keeping appointments is essential. If you miss too many, your prescriber may decide to exit you, even if you have great excuses. They may update a script by phone in an emergency (like your child is in hospital) but usually they will want proof and may do it only once.

Ask to be informed about when your prescriber will be away from the office and make sure you get the name and number of their locum (replacement doctor).

Because OTP meds are drugs of dependence, you always need to be able to get in touch with your prescriber or their replacement. It is your doctor's responsibility to nominate a *locum* (replacement doctor). Ask your prescriber who you should call in an emergency if you can't get hold of them.

Usually, if you are at a clinic or a big GP practice, you will be given another doctor there, or you can ask to see one. If your prescriber works alone and they haven't told you who to contact, call your closest public clinic for help. Just be aware that they will need to see you, and that depends on a prescriber having an available appointment.

Allow plenty of time to sort out changes to your program and ask for help early.

Have you ever heard the expression "Your lack of planning is not my emergency"? This means you should not expect other people to run around fixing your now "urgent" problem because you put off dealing with it or simply didn't allow enough time to get the job done.

Anything that involves negotiating people, technology and approval processes – so basically everything in OTP – will take time. If you need to involve other people, respect them by getting things moving as soon as you can. Make appointments with time to spare, organise holidays and transfers as soon as possible, ask people how long they need to do what you are asking and build in extra time in case something goes wrong. Remember, you are not the only one who has to travel or organise children.

If you are having a problem or dispute that may threaten your program, reach out for help straight away.

As a rule, get onto things as early in the week and as early in the day as you can. Here's a tip: it's almost impossible to get something sorted on a Friday afternoon for the weekend.

Paying for your dose is a priority and it's your responsibility.

Sarah says she tells people: "You have two main priorities – your rent and your dose. Everything else is negotiable." Chemists and clinics may give you credit – and they often will give you a few days' grace – but they have no obligation to dose you unless you pay their dosing fee. This is a fee you willingly agreed to pay when you began with that dispenser. It is irrelevant that OTP medications are drugs of addiction. You can also be charged for missed doses, so even if you miss a dose because you can't afford it at the time, you may still owe for it. Even if you can get credit, only use it in an emergency and catch up as soon as possible – it adds up quickly.

Always pay with an ATM card if you can.

A lot of disputes are about money. If you always pay with your card, you will always have a record that you can call upon. It can be hard to organise receipts, and the ink on some receipts fades with time. By always using your ATM card, you can always provide proof that you have paid your bill.

If your service or chemist doesn't do card payments, they are legally obligated to give you a receipt for any amount over $75 and must give you a receipt on request no more than one week after you ask for it. Always collect your receipt, even when you are in a hurry, and keep them in the same place so you can refer back to them if there is a dispute.

The price of OTP meds is out of your control so it's no use getting upset about it.

In NSW, there are no restrictions on how much you can be charged for your OTP medication.

Medications on the Pharmaceutical Benefits Scheme (PBS) have a built-in profit margin, but methadone and bupe don't. The actual medication is free, courtesy of the Commonwealth Government, but your chemist or private clinic does not get paid a dosing fee. To allow chemists and private clinics to get paid for their services, they charge an administration fee. Unfortunately, there is no government guidance on how much the fee should be and dispensers can charge whatever they want.

Those of us lucky enough to have a choice about where we want to be dosed can compare prices before we decide. If price is more important to you than the freedom of takeaways, public clinics are free. Otherwise we just have to suck it up. You can write to state and/or federal Ministers for Health to complain, but this one is taking a lot of lobbying by a lot of people over a long time and it's not looking like being sorted any time soon.

There is no hard and fast rule about takeaways – it's entirely up to your prescriber.

The Clinical Guidelines allow for people to get a takeaway dose after they have been on the program for at least three months. Because Suboxone is a safer drug than methadone, patients on Suboxone can access more takeaways, legally up to a month's worth but more usually up to four doses a week. It is recommended that people on methadone have a maximum of four takeaway doses a week. It is also recommended that those takeaways be split – that is, not four days worth in a row.

However, whether you get takeaways, how many you get and any special conditions, depends on your prescriber. They can give you however many takeaways they want, from none to six per week, plus public holidays and larger amounts for holidays, as long as they clearly document the reasons for their decisions. They might also give you more or less at different times, depending on circumstances.

It is important to realise that prescribers have a serious legal and ethical responsibility, because methadone and buprenorphine are "Controlled Drugs" that can be dangerous if taken the wrong way or by the wrong people.

It is up to your prescriber to assess the risks of giving you takeaways, balance that against your needs and make a decision. No individual thing should be a deal breaker or maker – it's about the whole picture. The sorts of things they might consider include:

- **how long you have been on the program and how well they know you;**
- **the size of your daily dose and how many mLs of medication will be "out there" as takeaways;**
- **whether you pick up your dose regularly;**
- **how well you follow the rules of your clinic/service;**
- **if you can and will store your dose safely, by having safe and stable living conditions and understanding OTP meds are fatal in the wrong hands;**
- **how helpful takeaways would be in terms of participation in life (work, study and family responsibilities);**
- **how difficult daily pickup is for you in terms of location (transport issues; living in a regional or remote area), opening hours (getting to work/uni, getting kids to school) or general health (how mobile you are);**
- **how often you present intoxicated or test positive for illicit drugs;**
- **any history of injecting or diverting your dose.**

Your prescriber's particular issues will also come into play. They will consider the rules of their practice/clinic and what occurs with other patients, including good and bad experiences they have had. It may not seem fair that you are judged by the behaviour of others, but a prescriber who has been involved in an OTP overdose case is going to be more conservative with takeaways. Also, a more experienced prescriber may be comfortable giving more takeaways whereas a newer prescriber may prefer to keep strictly to the guidelines. A prescriber who has recently been reviewed by the Ministry of Health because they have several patients on high numbers of takeaways may decide to cut the numbers of takeaways all their patients are on.

If staff dispensing your medication are not honouring your prescription and you are not getting the takeaways you should, let your prescriber know as soon as possible.

There can be a lot more to going away then just getting a few takeaways. Learn the process and plan it properly.

If you want to go away and need to sort out your medication, allow plenty of time to arrange everything. Do your research and don't assume it will be a simple matter to get things like extra takeaways or a transfer. Ask your doctor what paperwork they need from you – things like plane/bus tickets and invitations or official letters.

If you are going away and need to sort out your medication, you need to know the rules and get the process moving early. Talk to your prescriber about your plans to travel before they're set in stone. That way, you can make sure they will be able to help you, and you won't be disappointed last minute if they can't. They will need to see tickets and other details.

Don't assume you will get takeaways. Some doctors may prefer to do a transfer to another service instead. This means you will be dosed from a new chemist or clinic. This is fairly easy if it is within your own state, but if you are going interstate you will need to find out the rules. Every state has different arrangements. For example, if you are going to Tasmania or the Northern Territory it is not a simple matter of going to a clinic or chemist there and picking up your dose. You must see a prescriber registered in that particular state/territory and be dosed under their prescription. This means appointments and paperwork. Make sure you take ID with you.

If you are going overseas, different countries have different rules. For example, you can't take methadone into Japan, only buprenorphine. You can't take any OTP medication to Singapore and Russia – they are illegal even on a script. And Lebanon will only allow 5 days' worth of a restricted medication. Do your research about the countries where you are going. You need to take all your paperwork – including a letter from your prescriber, a copy of the script that has been certified (stamped/initialled) by your doctor and a statement on your doctor's letterhead with all your medications listed on it. Make sure they do NOT refer to illegal drug use, drug dependency or the Opiate Treatment Program – the reason you are prescribed OTP meds should be for a "medical condition". Make sure all your medication is in its original packaging with your name on it – you need to look legit. Medication issues can depend on purely subjective opinions of the customs official on duty that day. There may also be special forms you need to fill out to carry a "Drug of Addiction", depending on where you go.

Remember if you are getting extra takeaways, you will need to give your chemist plenty of notice – especially if you are getting Physeptone (methadone tablets), which they may have to order in.

You are responsible for your dose, so look after your takeaways

If you lose your takeaways, have them stolen or taken by police, vomit a dose, or if it leaks out of the bottle, you are unlikely to get them replaced. If you do, you will need to see your doctor for an appointment, get a new script and then pay for the replacements. Your doctor may do it once but is unlikely to do it again – or at least for another 10 years or so.

People also report being lectured by their doctor when they confessed to losing takeaways. Other doctors have responded by cutting the number of weekly takeaways or refusing further requests for holiday takeaways.

So look after your takeaways. Check the lids are tight. Keep your doses in a locked medical cabinet. Don't leave them in your bag or out on the bench. They do NOT need to be kept in the fridge.

Just a tip about air travel - always carry your takeaways in you hand luggage. This is because they can leak or evaporate in the baggage compartment. Also, your luggage may get lost - if you are going to Brisbane but your bags end up in Perth, you will have an unhappy holiday.

Damien's Story

SMALL TOWN SYNDROME

Damien doses in a small village in regional NSW and has been on methadone for 12 years.

I've lived on the outskirts of a small village in Northern NSW since 1976 and started on the methadone program 12 years ago. There's only one clinic here; the next closest one is 50 kilometres away.

The clinic is small, and the staff are friendly – they go out of their way to make you feel like a person, and you can have a decent conversation with the nurses. The only thing is, you have to jump through a lot of hoops, more if you want takeaways.

I know some of the rules are standard across all clinics, but things are different when you live in a small town. Everyone knows everyone, which can be good or bad.

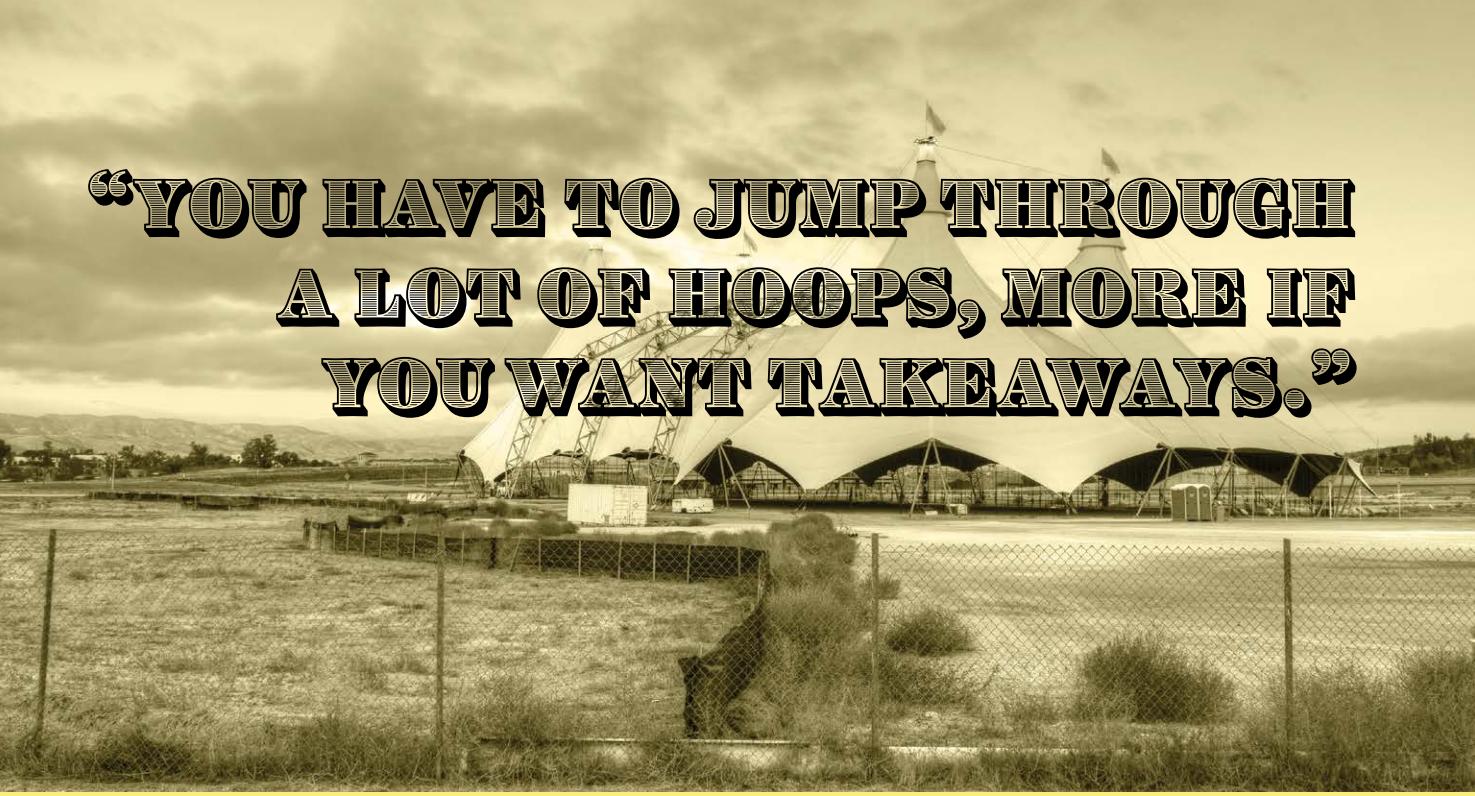
I go to the clinic early in the morning, and there's usually about 20 of us there – all the out of towners. It opens again later, and that's when the townies get dosed, entering via the hospital or through the back so no one sees.

The cops drive past the clinic real slow with their smartphones out, taking photos – maybe they have a database of who uses, or maybe it's just to intimidate us. On the way back from the clinic the other day, they pulled up my flat mate's car, made us get out then asked him where he'd just been. He said the methadone clinic and the policewoman said "oh, so you're a junkie then," and accused him of selling me drugs. I tried to explain he was handing me grocery money and she just pushed me hard in the chest and told me to step away.

There are some awfully specific and restrictive rules at my clinic. For example, you're not allowed to come into town on the days that your takeaways cover you for, which is really hard. It isn't really enforced anymore, but the clinic can use it against you if they so choose. I get that the rule is there to stop people diverting their doses or trying to score, but we still need to live our lives!

Another of the rules restricts any social interactions between us and the staff at the clinic. One of the workers upstairs knows I love Dr Who and the Dune movies, so she started giving me DVDs and USB sticks of films she thought would interest me. The big bosses in charge of the clinic didn't like that – they don't live here, so they don't understand the social dynamics of living in a small town.

Similarly, one young fellow here had nowhere to wash his clothes, so a nurse did his laundry at home as a favor. Someone snitched to the bosses, and she got in a lot of trouble. There is to be no social interaction between 'us' and 'them'!



"YOU HAVE TO JUMP THROUGH A LOT OF HOOPS, MORE IF YOU WANT TAKEAWAYS."

You can get takeaways when you're on the program – as long as you play the game. It's not too hard, you just have to be on the program for a while and provide a drug-negative urine sample. Abstinence is the only option.

People are treated differently depending on their 'risk' level – there are six options, ranging from having someone standing directly in front of you watching you pee, to just doing it yourself. Dye is added to the toilet cistern water to stop you diluting your sample. It's dehumanising.

If you're caught with benzos in your system, you lose your takeaways instantly. They retested my urine 3 times to make sure I had enough Valium in it to take my takeaways off me for 6 weeks – I'd only had half a Valium the week before to help me sleep.

Of course, there are always going to be people who try to get around the system, because living without takeaways is simply too hard, especially when you have to travel to get dosed. I remember once, 6 people lost their takeaways in one go. They were all getting urine from one dude on the program who wasn't using, but he was on psych meds and didn't think to tell them. Everyone thought they were getting drug-free urine, and they were – except they all tested positive for the same anti-psychotic medication.

I've never faced any stigma from the clinic staff directly though – most of them are really friendly and supportive. I remember once I had no money for my dose – it's $5 for each takeaway, which isn't always easy to scrounge up. I went in anyway and one of the nurses – my favourite – gave me credit. She told me she couldn't bear to see anyone go without.

All in all, the disadvantages outweigh the advantages of being on the program for me. That includes the fact that I've tried to stop but I couldn't handle the withdrawals. If I had my time over, I would have tried to find some other way to stop using. I wish I'd known more about the side effects, including how hard it is to get off. I think I'll be on methadone for the rest of my life.

WHAT ARE YOUR RIGHTS...

and what to do if you're not happy

What are your rights on the Opioid Treatment Program (OTP)? Check out what the Australian Charter of Healthcare Rights and the NSW OTP Clinical Guidelines have to say about it.

Not all prescribers do things the same way, and they definitely don't all do the basics well. So what do you do if you are not happy with your care? You deserve the best but sometimes it's a compromise, like all relationships. Here are some tips about what to do if your prescriber and/or service falls short – especially if you can't just move to a new service.

YOU HAVE RIGHTS

The Australian Charter of Healthcare Rights

The Australian Charter of Healthcare Rights explains what every patient, not just those on the OTP, can expect from the health system.

The table below shows the Charter and explains what your rights means.

My Rights	What This Means
Access – I have a right to health care.	I can access services to address my healthcare needs.
Safety – I have a right to receive safe and high-quality care.	I receive safe and high-quality health services, provided with professional care, skill and competence.
Respect – I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.
Communication – I have a right to be informed about services, treatment options and costs in a clear and open way.	I receive open, timely and appropriate communication about my health care in a way I can understand.
Participation – I have a right to be included in decisions and choices about my care.	I may join in making decisions and choices about my care and about health service planning.
Privacy – I have a right to privacy and confidentiality of my personal information.	My personal privacy is maintained and proper handling of my personal health and other information is assured.
Comment – I have a right to comment on my care and have my concerns addressed.	I can comment on or complain about my care and have my concerns dealt with properly and promptly.

NSW Clinical Guidelines: Patient rights and responsibilities

While on OTP you have certain rights as a patient, as well as responsibilities. Knowing your rights means that you know what to expect while on the program. This helps you know if certain things are just part of the process or if they are unfair.

The *NSW Clinical Guidelines: Treatment of Opioid Dependence* is the document that healthcare providers must follow when treating people on the program.

The Guidelines tell us that while on the program, you have the right to:

• be treated with consideration and respect and without bias or discrimination.

• privacy – this means that your file and test results are confidential. Keep in mind that the new My Health Record electronic file may mean that your info goes wider than it used to and that if you have a file at a public clinic, your info can be accessed by health care workers at all public hospitals in your area.

• be advised of all info about the OTP – treatment, what might happen, risks, side and after-effects – and told about other ways you can be treated. This must be explained to you clearly and in a way you understand. This information is important, especially about what can happen if you use other drugs, when you might overdose and whether you can drive safely.

• refuse to have students in your appointment and refuse to be involved in research.

• be provided with a trained interpreter if English isn't your first language, and be provided with culturally appropriate support when requested.

• know who your prescriber and heath care workers are – this means knowing their first and last names, the job they do at the service, and what and where they studied.

• get other health care or a second opinion; refuse treatment; or withdraw consent at any time.

• expect to be safe as far as where and how you are dosed. You can also seek legal advice if you think the service has been negligent and you have ended up hurt.

• have a family member, friend, carer or professional person come to your appointments to help you.

• be given info about costs before you start and if they change while you are on the program.

• make a complaint and be told how to complain.

As patient, you also have responsibilities to:

• work with your prescriber and other workers towards your individual treatment plan.

• not be violent or threaten anyone with violence. This one is a deal breaker – you will get thrown off the program if you . If you have trouble keeping your anxiety or temper under control and you're worried about this, talk to the staff about getting some counselling ASAP.

• treat all doctors, chemists, nurses and other workers with respect.

• be aware that your driving will be affected when you start on the OTP or if you change your dose, or if you use other drugs or alcohol. Don't drive or operate heavy machinery if your prescriber tells you not to.

What you deserve from your prescriber and other health care staff

• Your OTP prescriber and healthcare staff should follow the *Australian Charter of Healthcare Rights*

• They should follow the *NSW Clinical Guidelines: Treatment of Opioid Dependence*, and have a good understanding of patients' rights and responsibilities according to the NSW Ministry of Health.

• They should show an understanding of "real world" drug use, or at least be willing to listen to you when you talk about the realities of your life.

• They should have a clear understanding of harm reduction – and support it!

• Your prescriber should know you should be in charge when it comes to choices about your health care. They should treat you with respect and kindness, listen to you, encourage your opinions and questions and allow you enough time for a meaningful consultation. They should never make decisions for you, but instead give you advice and info to help you decide.

• As this is often long-term treatment, your prescriber should help you to make your program something you can live with. They should also recognise that you have an important long-term relationship and be willing to work on making that work for both of you.

• When discussing takeaway doses with you, your prescriber should take into account travel, child care and other carer responsibilities, work/study and personal disabilities. You get and lose takeaways based on how the treatment is working for you over time – they should never be removed as a punishment for a one-off event.

• Urine drug screens shouldn't be used as a trap or to shame you, but rather for motivation (compare it to weighing yourself when you're try to lose weight).

• They should make appointments based on your need, not on some "clinic policy" (e.g. fortnightly forever), and they shouldn't 'over-service' you by making you see them too often or do too many urine tests.

WHAT TO DO IF YOU ARE NOT HAPPY WITH YOUR CARE

Getting advice

If your prescriber is not up to scratch, you have some options. Sometimes, you might be able to go to a new service, but because of the shortage of OTP providers (especially in rural areas) this is not always possible.

Instead, you may have to learn some skills on how to get along with better with your healthcare providers. If this doesn't work, you should know how to make a complaint that won't wreck your OTP arrangement.

Before you start, you might like to get some advice about your particular situation by:

- talking to a peer at NUAA | (8354 7300 or free-call 1800 644 413); or
- calling the Opiate Treatment Line (OTL) | (free-call 1800 642 428).

Moving on

If you live in an area where there are various treatment options, voting with your feet and looking for a new prescriber is sometimes the easiest way of improving your health care in the long term. Here are some tips:

- Do your research. Talk to other people on the program about their prescribers. Call OTL to find out what other services are in your area. If you are at a public clinic, find out which other prescribers work there and talk to their patients.
- Work out what is important to you and what is a deal breaker. For example, some people can put up with travelling a long way to their doctor if they have a respectful and kind prescriber with whom they can have an honest relationship. Others are willing to sacrifice "nice" for someone who bulk-bills and always has an appointment at the last minute, or will see their prescriber every fortnight if they can get 6 takeaways a week. Sometimes it's about money, and people will sacrifice takeaways and other freedoms for a spot at a free clinic. Think about what you want and ask your peers about their experiences.
- If you have a great GP, you can ask them to prescribe your methadone or buprenorphine for you instead of your current prescriber. Any GP can prescribe for a small number of people without any special training and they can be supported by an OTP specialist by calling the Drug and Alcohol Specialist Advisory Service (DASAS) line on (02) 9361 8006 or toll-free 1800 023 687. It helps if you have been on the program a while and are on a steady dose. Just remember that sometimes doctors who aren't trained in drug and alcohol issues may be more conservative when dealing with a restricted medication like methadone or bupe – so be prepared for fewer takeaways and more urines. Of course this isn't always true, especially if they have known you a long time.
- A new prescriber may do a "reset" and treat you like a newbie until they get to know you, but if you end up in a better situation long-term, it may be worth it.
- A new prescriber will need your old doctor to 'exit' you from their care. Doctors cannot refuse to do this when asked.
- You may want to send your old doctor a polite note as to why you decided to change services. Be careful not to burn any bridges in case your paths need to cross again.

Talking to your prescriber

If you don't have the option to move services or would rather try and stay where you are, the first step is to work on making your relationship with your prescriber better.

You can go a couple of ways with this – a big meeting to raise all the issues at once or a slow repair, one appointment at a time.

Fronting your prescriber

If things have come to a head, you may need to deal with things straight away. Go "old school" and talk to them (very calmly) to get your cards on the table. Here are some tips:

- Book a long appointment so you have time to deal with the problem.
- Take some notes with you to help you keep to the point and say the things you need to say.
- If it would help, take a friend or family member with you for support – make it someone you admire for their communication skills.
- Be calm, controlled and co-operative.
- Start by thanking your doctor for their care and the service they have provided so far. Talk about how helpful OTP is for you and how much you value their involvement in the program.
- Think of something that is working about your health care that they may have helped you with and talk about that in a positive way.
- You can tell them you would like to have an honest relationship with them, so you are getting the best health outcomes possible.
- Let them know that you feel they are not listening to you or respecting your opinion about certain things, and name those things (e.g. too frequent appointments, refusing takeaways, pushing you to go up/down on your dose etc.).
- Maybe talk about the positive way other doctors have treated you or your friends in the past and what you admire about those prescribers, including how they have handled the things you are having trouble with at the moment.
- Ask if they will consider making changes in your relationship or the way your OTP is managed (e.g. fewer appointments, more takeaways, letting you take the lead on dose changes).
- Ask them what they would want from you in order to make them more comfortable to make those changes (e.g. regular contact by phone, guarantees about takeaway storage, working out a care plan). Sometimes prescribers behave as they do because they have medico-legal responsibilities and regulations they need to follow. They need to know you understand that OTP medications are very strong, restricted medicines and that you take your responsibilities to the program seriously.
- You could ask them to call DASAS (02 9361 8006 or toll-free 1800 023 687) – the advice line for clinicians - to find out what the industry standard is on the things you are concerned about.
- Thank them for listening to you and make sure you finish up on good terms – especially if changing doctors isn't an option for you because of the lack of services where you live.
- Don't expect them to change instantly, it may take a little time for them to adjust their thinking.

Working with your doctor over time

If you live in a rural/remote area and don't have many options, you might be concerned about losing your only chance at getting OTP. Your only option may be to work on improving your relationship over time.

• Take a representative with you to your regular appointments so there is another point of view. They can tell you if you are being over-sensitive or if your prescriber is actually giving you sub-standard care. If there is a major break-down in your relationship with your doctor, make your support person some sort of professional, like a community worker or even a church worker. If you are lucky enough to have a peer worker at your clinic, use them.

• Over time, show your doctor you are responsible and trustworthy by meeting your responsibilities on the program.

• Check in with them at each appointment – ask if they are happy with your relationship and the way you are working with them. Let them know how they could support you better.

• Be calm, courteous and patient, even when things aren't going your way. Losing your cool will only set you back.

• Let your doctor know you better by telling them your story. Talk about your family, your job, your hobbies during your appointments. The better they know you, the more supportive they are likely to be.

• Gently challenge them from time to time with clear arguments e.g. tell them why 2 weekly appointments stops you moving ahead in your life, why you don't need regular monitoring (on a stable dose for a long time, clear urines) and suggest trying 3 weekly appointments for 3 months to see if it works for you both. Go for small changes made gradually but bring it up every time you see them.

Making a complaint

If all that doesn't work, go next level and make a formal complaint.

It helps if you can show how you have tried to fix things in an informal way, so if you have tried to talk things through with your prescriber or service, know that all that work wasn't for nothing.

It's not always possible to talk it through first, because the discrimination and power imbalance are just too great. Sometimes you need to go straight to the protection of a formal process.

You can't be thrown off the program for making a formal complaint.

Complaining to the service

Your first step in the formal process is to complain directly to the organisation your prescriber works for. Unless your prescriber is in business for themselves, you can make a complaint to your prescriber's service. If it is a public health clinic, you can go through the Local Health District to the senior doctor or manager. For a private clinic, try the owner or manager. Doctors in private practice may have a senior doctor or practice partner above them or a practice manager that co-ordinates the practice.

Here are some tips:

• Find out what the complaint process is at the service – every service will have one.

• It is always better to make a formal complaint in writing. Not only is it taken more seriously, no-one can add in words you don't mean or take something the wrong way. Get someone to check it for sense and typos. If you don't have anyone to help, call NUAA and we can find you a peer mentor to help you.

• Be calm and courteous in your written complaint and in all dealings with the service.

• Keep a diary so you have a record of events when you go to make your complaint.

• Give specific examples of where you feel your rights have been overlooked in terms of the "Australian Charter of Healthcare Rights" and/or the OTP guidelines.

• Include dates, incidents and circumstances.

• Be clear about what you want changed, e.g. you can ask for certain decisions to be reconsidered (e.g. the number of takeaways you are allowed) or that the doctor or other staff be given stigma and discrimination training (NUAA provides great courses).

• As part of a service's complaints process, they will have to get back to you within a certain number of days. If they haven't, send them a polite reminder.

Making a complaint through the Health Care Complaints Commission (HCCC)

If you didn't get a reasonable response when you complained to the service or if the care you received from your prescriber was particularly bad or harmful, you can file a formal complaint with the office of the NSW HCCC (1800 043 159 or www.hccc.nsw.gov.au).

The HCCC gives you a voice and provides some protection against a service making things harder for you if you complain about them.

In general, you can complain to the HCCC about the professional conduct of a health practitioner and/or the clinical care and treatment provided by an individual or organisation. Note that they cannot make a health care provider treat you if they don't want to or to change their fees.

You should talk to staff at the HCCC first as they can tell you how to lodge a complaint. There is a form to use and they will even help you write your complaint.

Paul's Story

MASSIVE DOSE

Paul has been on methadone for nearly 30 years and is currently on 420mg daily due to his ultra-rapid metabolism.

I'm on a massive daily dose of methadone – 420mg, which works to be 92mL of syrup. This is how I start my day; I wake up, have 2 Valiums and 2 clonazepam (which I take for my Central Nervous System damage), a couple of cones, and then I go to the chemist to get my dose.

I have an ultra-rapid metabolism – I eat like a horse but am very skinny. I can't get fat. My body just processes everything quickly, so I naturally have a high tolerance. I've never overdosed in my life, I've never dropped from heroin, and I've never been Narcan'd. Not once. In fact, I've only thrown up from heroin once, and it was the first shot I ever had.

I guess it makes sense then that I have a high tolerance for methadone. I'm not the only person who has this problem either – I know someone who's on 600mg and know of someone in Chicago on 850mg.

Back when I was living in Sydney, I was dosing at a public clinic and wasn't getting any takeaways so I would come in every single day to dose. One day, I had an appointment with the doctor, and he saw my eyes – my pupils were as big as golf balls! I was on 200mg at the time. The doctor asked me "did you miss your dose yesterday" and I said no. He asked me, "have you had any ice or speed?" and I offered to piss in a cup for him right there and then!

When my urine drug test came up negative, he told me that with special authority I could get on more than 200mg. I had to do what is known as 'peak and trough' tests – they test the levels of methadone in your blood just before you dose, and then about 5 hours afterwards. What the tests showed were that, for me, 200mg of methadone had the effects of what the average person got from 50-75mg.

I had to have five different specialists go over my results, and they all came to the same conclusion – 200mg wasn't enough for me. When I found out, it made complete sense, because the whole time I was on the program before then I was using up to two grams of heroin on top daily… and would still always be sick! This was back in 1999, so I've been on an incredibly high dose for 20 years now, and on the program for 8 years on top of that.

I dose at a public clinic in a regional town – it's not perfect, but I can bear it. I'm a trusted patient – all my urine samples have shown that I'm not using opioids on top of my dose. My doctor does the right thing by me, and I've been on their books since 1993. I have health check-ups regularly, and my heart is all good. My liver is a bit conked out, I have breathing problems, and blood cancer to top it all off.

For the first six years that I was on the program, I was injecting all my takeaways – I still love the needle to this day, although I'm not injecting opioids anymore. But my doctor back then gave it to me straight – he explained that if I didn't stop shooting my doses, chances are I'd end up with endocarditis, deep vein thrombosis, or toxic shock. I pulled up after that conversation.

Truth is, I feel fine being on the program. I'll be on it the rest of my life, and I'm totally comfortable with that. I know that with my body and my health I need to be on it forever. I know that it's not a smart idea to try come off it because I'd start using again. I don't want to use heroin at all on the dose I'm on now – on very rare occasions I still shoot a bit of cocaine as a little treat.

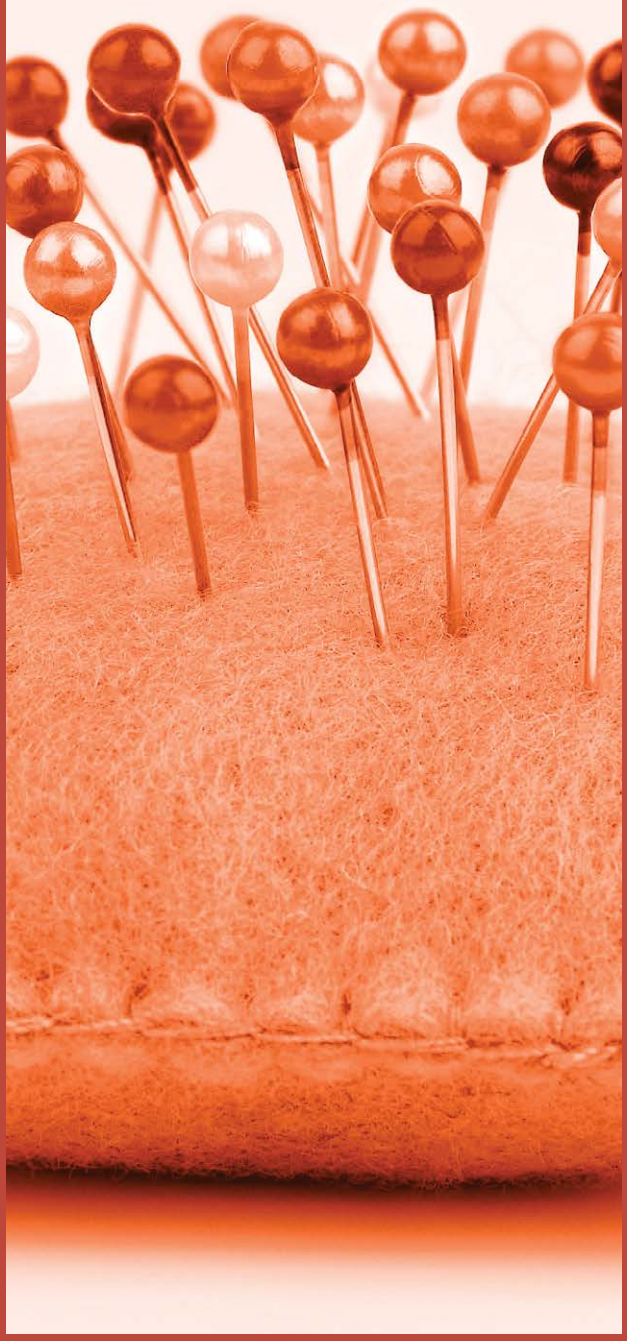
I'm no longer sticking needles into myself daily, and I'm not going back to that life – not when I'm stable on the program. I'm refusing to let myself end up back on the streets, doing crime, getting pinched, and going back to prison. I'm older now and it's not the same game. I'm not on methadone for the fun of it, I'm on it to live a life. I'm simply happy to be on the program and not be a human pin cushion anymore.

High Doses

Some people will need higher than usual doses of methadone or buprenorphine for it to work properly for them. This might be because they have a high tolerance or an unusually fast metabolism.

Doses above 200mg of methadone or 32mg of buprenorphine per day need special approval from NSW Health, which your doctor will need to apply for.

I'M SIMPLY HAPPY TO BE ON THE PROGRAM AND NOT BE A HUMAN PIN CUSHION ANYMORE.



LOOKING AT SIDE EFFECTS

What are they and how to cope

All drugs have side effects, and there can be problems from being on any drug long-term. If you look at the Consumer Medicines Information leaflet for any medication, you will find a list of side effects, contra-indications (drugs that don't work together), and ways to avoid having a bad reaction to the drug.

Opioids aren't any different.

These days, some users think of heroin as having positive health effects, and that methadone and bupe are the baddies. It just ain't so.

What we do hate is not being told up front what the side effects are and how to deal with them, so we can make decisions based on the facts.

We certainly don't want to become dependent on a prescribed drug with strict regulatory controls without understanding what we are getting ourselves in for.

Here are some of the side effects of opioids in general, and methadone and bupe specifically, and how you can deal with them.

Side Effects

All opioids (e.g. heroin, fentanyl, oxies, methadone) have a range of effects. Some are desirable and some aren't.

If you're starting on methadone or bupe, you would have been using street and/or pharmaceutical opioids for a while, so you'll probably be used to many of the side effects. You might not notice or even experience them anymore. Either way, some of the side effects should go away after the first month or so.

Here are some common side effects from being on methadone, buprenorphine, and other opioids, to help you better understand what to expect and how to manage them. If these are ongoing issues for you, you should talk to your doctor/prescriber about them – you might need to adjust your dose or change medication.

Dependency and Withdrawals

You might think it's all a bit obvious to say that all opioids, whether derived naturally or manufactured in a lab, are habit-forming. But one of the biggest complaints we get about methadone and bupe is that people didn't realise how hard it was going to be to come off them. They are harder to withdraw from than heroin and that keeps a lot of people on the program longer than they want.

The thing is, the reason they work so well as a treatment is the very thing that makes them harder to get off. We only need to dose every 24 hours (and can double dose with bupe to make it last 48 hours) and it builds up in our system so we get that even, stabilising effect.

The 'half-life' of a drug is a way to measure how long drugs last in our bodies. Half-life is the time it takes for half the dose to break down or leave the body. Heroin has a half-life of between 3 and 10 minutes, after which your body turns it into morphine. Morphine has a half-life of 20 minutes to 6 hours. Because of its shorter half-life, you can detox from a heroin habit in around 4 to 7 days.

On the other hand, methadone's half-life is between 8 and 60 hours, and buprenorphine's half-life is between 24 and 42 hours. Their long half-lives make them suitable for opioid treatment because it provides a stable and even drug-experience and you only need to dose once a day or less. The disadvantage is that once you stop taking them, the detox takes much longer.

The symptoms of withdrawal from methadone and buprenorphine are the same as other opiates. You will experience flu-like symptoms, sleeplessness, diarrhoea, cramps, anxiety, irritability, depression and cravings.

What can I do about it?

You can't avoid dependency if you are on a program. However, when it comes to getting off it, you can make withdrawal easier. It's all about planning, coming off gradually and treating your withdrawal symptoms.

When it comes time to withdraw from methadone and buprenorphine, the best technique is to reduce to as small a dose as you can. Some people find that swapping from methadone to bupe (or vice versa) when they've reduced to a small dose can also make withdrawal easier.

Ask your doctor and other support health workers as well as your friends and peers to help you deal with the pain and anxiety that comes with detox. The most successful approaches combine a mix of tactics, like exercising and eating healthily, medication, and counselling. Meditating, massages, yoga, and alternative medicine (like acupuncture and herbal remedies) can also be helpful for some people.

Hormonal Issues

High doses of opioids can affect sex hormones – both street opioids (e.g. heroin) and prescription opioids (e.g. methadone and bupe) will do this.

Taking opioids can cause sexual dysfunction (low libido) for male and female users. This might just mean being less interested in sex, or it could mean you can't get or stay turned on.

While there are links between reduced testosterone and opioid use, there are many other reasons why someone might experience sexual problems, including depression, stress, sleep issues, smoking and menopause.

In women, hormonal issues can lead to irregular periods. Women on the OTP also often go through menopause earlier than 48-55 years old, which is typical for the rest of the population, although more research is needed in this area.

It's easy to think you need to go up on your dose, because the symptoms of menopause are similar to opioid withdrawal. Menopause can also reduce your sex drive.

What can I do about it?

A good place to start with the libido issue is to think about what else could be making you feel this way. Are you too busy or too stressed? Is it about the demands of parenthood? Do you find it challenging to hook up without a load of drugs on board? Keep in mind that part of the problem can also be related to too much alcohol, tobacco and some other drugs.

Older women having lighter and irregular periods should see their GP for tests to find out if they are starting menopause. There are hormone replacement treatments and other medications which can help with menopausal symptoms. Younger women with low sex drive can also access hormone replacement in some circumstances.

Men with low sex drive should see their doctor to have their testosterone levels checked. If they're low, they may get replacement therapy.

Ask for a referral to a specialist if your GP doesn't have any answers for you.

Poor Sleep

People on opioids often don't sleep well. You might get night sweats, have problems with breathing and snoring (sleep apnea), or wake up mid-sleep (often to urinate). Sleep problems can lead to poor concentration, a lack of energy throughout the day, headaches, depressed mood, and sexual dysfunction.

Poor sleep might happen for a variety of reasons, some related to opioids. Sleep apnea is when your airways are partially or completely blocked while sleeping – this can be made worse by opioids but might also be a sign of larger issues (like heart problems).

What can I do about it?

Talk to your GP to find out if your sleep issues are something to be concerned about (you might have to do a sleep study). Anxiety, depression or stress may be the cause. Your GP can help you make a Mental Health Plan – from there, you might try counselling or a course of anti-depressants.

Alternatively, your prescriber can help you tweak your dose or suggest a better time to dose. Your dose may be too low, causing withdrawals at night, or you may be having your dose too late at night which could be overly stimulating.

There are also plenty of things you can do to help yourself if you are having trouble sleeping. There are some great books and websites with tips and techniques about how to get yourself into a healthy sleep pattern. These include going to bed and waking up at the same times each night, not reading in bed, not eating or drinking coffee after a certain time, practising meditation, getting massages and exercising each day so you are tired out for bedtime.

Weight

A lot of people think that opioids can make them gain or lose weight, although there is little evidence to suggest this. Using opioids can cause your body to retain more fluid, which might contribute to weight gain – this is more common in women than men.

Some people put on weight while on the program, but this is more likely because on the program you'll be running around less and eating more. Other medications, such as antidepressants, can also affect your weight.

What can I do about it?

You'll probably have more money for food while you're on the program, so it's a good idea to look at a healthy eating plan. Think about limiting junk foods you might buy to "reward" yourself for not using.

Some people find themselves looking to sugary foods when lacking in energy, which can cause weight gain. It might be better to think about what else could be contributing to low energy, such as your sleep pattern, depression, and/or anxiety, and see if these need to be sorted.

Talk to your doctor if you're concerned about weight change and get a long-term food and exercise plan to support you when gaining or losing weight.

Heart Issues

Opioids can affect your heart in a range of ways, primarily because they are 'depressant' drugs which slow down your central nervous system. Some heart-related side effects of methadone, bupe and other opioids are low blood pressure, slow or irregular heart rate, and a faint heartbeat.

There are some ways that methadone specifically can interact with other substances which can affect the way your heart beats. If you have a family history of heart problems, it's worth talking to your prescriber about it. If you are on a high dose, your prescriber may want you to do some tests to see how your heart is functioning.

Bone and Muscle Pain

A lot of people think that being on an opioid treatment program can lead to your bones 'rotting', or that the 'methadone gets in your bones'. This is a myth.

Some men on the OTP have low bone mass density. However, studies suggest that this is mainly from using street opioids (e.g. heroin), and is simply picked up while on the program. All long-term opioid use can decrease sex-hormone levels, especially in men, which can lead to low-density bone and osteoporosis.

Tobacco smoking, poor diet, living with HIV and heavy alcohol use also contribute to issues with your bone and muscle health.

What can I do about it?

If you are feeling aches and pains in your bones and muscles, it's more likely a sign of minor withdrawals, so if this problem persists you may need to go up on your dose.

Getting the right nutrients in your diet is important too, so make sure you're eating foods high in calcium (such as dark leafy greens, tofu, and dairy products). You could also talk to your doctor about trying calcium and magnesium supplements.

Drowsiness

Feeling drowsy is a common side effect of opioid use. High doses of any opioid will cause drowsiness, ranging from mild tiredness to finding it difficult to stay awake. Mixing your OTP meds with other depressant drugs (e.g. opioids, benzos, pregabalin/Lyrica, and alcohol) can make the drowsniess even more extreme.

What can I do about it?

If you're feeling constantly drowsy, you should talk to your GP to rule out any medical conditions (e.g. sleep apnea, hepatitis, heart problems). It could be that your dose is too high, so talk to your prescriber about adjusting it.

In the short-term, if you are noddy try getting some fresh air and keeping your body moving. Don't drive or operate heavy machinery. Not only might you fall asleep at the wheel, your concentration and coordination are affected. We would miss you dreadfully if anything were to happen.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29
7

Constipation

Some people experience constipation from using opioids. Opioids bind to the stomach (gut), causing blockages. This is especially common when you take large, regular doses of opioids, and can be a frustrating problem to deal with.

What can I do about it?

Prevention is better than cure, so the simplest thing is to avoid constipation by eating more fibre (wholegrain or multigrain bread, nuts and cereals), as well as lots of fruit and vegetables. Drinking lots of water is essential. Hot drinks, tea and coffee may also help get things moving. Prunes or warm prune juice is famous (or infamous) for ending constipation.

Exercising regularly will also help: a 10-minute run, some light stretches and yoga are particularly good at helping with constipation. Going to the toilet at the same time each day can also help.

Some people experiencing a blockage will simply delay a shot or dose until they experience withdrawal symptoms, including loose stools. A bit radical, but if the alternative is the pain and inconvenience that comes with a blocked back passage, it may be worth it.

We prefer you try this gold medal standard for helping to push out a blockage. Set the scene properly – give yourself time and privacy, flood your intestines by drinking heaps of water and do some butt squeezes. Then get on the toilet, raising your feet up off the floor by putting them on a low box. Even going tippy-toes can help. You want to get all your muscles in the best place to push, and for that you need a position that is closer to squatting than sitting up straight on a seat. You can actually buy products that are the right height (google “toilet foot stool” or “squatty potty”) but the trick is to be squatting, so raise your legs around 20 to 30 cm.

You can also try pharmacy medicines, like laxatives and stool softeners. If you do end up with an extremely serious case of an ‘impacted’ stool (when your intestines are full of hard, dry matter that you just can’t push out), try a suppository from the pharmacy (they go in the anus and draw water into the intestines). If that doesn’t work, you may need an enema. You can go to your GP or a private Colon Health Clinic for this, or you can learn to do it yourself at home. Then take every step to stop it happening again!

Nausea

Some people experience nausea (feeling sick to the stomach) when they’re on the program. There are several reasons you could feel this way. Nausea in the mornings might be a sign that you’re hanging out – you might want to talk to your doctor about changing your dose. People can also feel queasy if they go up on their dose too quickly.

What can I do about it?

Methadone or bupe just don’t sit well with some people, so if you’re experiencing ongoing nausea past the first month of treatment you might want to talk to your prescriber about trying the other medication. Lying down, as horizontal and still as possible, can sometimes help reduce nausea caused by opioids.

If you get regular nausea (like with migraines or pregnancy), you might want talk to your prescriber about splitting your dose (having part in the morning and part in the afternoon). You could also ask them about going on Physeptone, which is the tablet form of methadone. They may not agree but you can only try.

Headaches

Headaches are a common side effect in the early days of opioid treatment, while your body is getting used to your medication. You might also get headaches if you go up or down on your dose.

What can I do about it?

Unfortunately, there isn’t a lot you can do about them – your best bet is to drink lots of water and try to get enough sleep. Over-the-counter, non-opioid painkillers like Ibuprofen (Neurofen), Paracetamol (Panadol) or Aspirin can also help. If your headaches persist for more than a month after being on a stable dose, talk to your doctor about them, as they may be symptoms of a larger issue.

Dental Issues

Another myth of being on methadone or buprenorphine is that it 'rots your teeth' – this just isn't true! It may be that when you get on OTP you start noticing this stuff more, but chances are it's partly about ageing and partly about not getting to the dentist when you should because of the high cost. Teeth are also damaged by smoking, vomiting, drinking alcohol, bad diet, not brushing and flossing enough, not drinking enough water, and injuries to the mouth.

The biggest culprit is probably 'Dry Mouth Syndrome', aka Xerostomia, which is a condition where your mouth doesn't produce enough saliva. Dry Mouth is common – it is a side effect of over 300 medications, including all opioids (street drugs as well as methadone and buprenorphine), and anything starting with 'anti' – like antidepressants, anticoagulants and antibiotics.

Using stimulants also has its own problems, including the fallout from grinding your teeth.

What can I do about it?

The best ways to deal with dental issues while on methadone, buprenorphine, or any other opioids, is to keep good oral hygiene in general. Try to brush and floss your teeth twice a day and, if possible, aim to get to the dentist to get your teeth professionally cleaned.

Limiting the amount of processed and sugary foods you eat and avoiding acidic or carbonated drinks can also help keep your teeth in good condition. Dentists tell us the #1 best thing you can do for your teeth is to not smoke.

It's also important to avoid your mouth staying dry for long periods of time. There are special products on the market to treat Dry Mouth Syndrome. You should also chew sugar-free gum after eating to increase your saliva, drink tap water regularly and sip water whenever you notice your mouth is dry.

Sweating

Another very common side effect from methadone and bupe is sweating more than usual – about 45% of patients experience this. Sweating might be because of the effects that opioids have on the part of our brain that controls body temperature, but we don't know for sure.

Methadone sweats seem to be much worse than sweating from bupe or other opioids.

What can I do about it?

If you're sweating a lot, it's best to ask your doctor what they think, as it could be a sign of another issue like kidney problems or an infection. Sweating can also be a sign of withdrawals, so if you're experiencing other withdrawal symptoms you might need to go up on your dose.

Excessive sweating is also a symptom for some people who have hepatitis C, so if you have hep C and get it treated, there is a good chance your sweating might stop or ease up.

When you sweat, your body loses fluids, so to avoid getting dehydrated you should aim to drink at least 2 litres of water each day.

If it's not from withdrawals or other health conditions, you could think about reducing your dose, although that won't help everyone. You may need to treat the side effects.

You might want to try using a high end "clinical strength" anti-perspirant/deodorant marketed to people who sweat a lot. (Note: anti-perspirants stop sweat; deodorants stop smell). There is even a gel that stops your face sweating (great for wearing under make-up). Talk to your doctor or chemist about the different sprays, gels and even tablets designed to help. Put products on when you wake up and before you go to bed, and as many times during the day as you need it. It can also help to apply talcum powder to your sheets and to your body where you sweat the most.

There are other things you can do to help. Think about your clothes (and your sheets etc.). Synthetic fabrics will make you sweat more, and loose clothing will help you control your sweating better. Diet also makes a difference – do some research or get a referral to a dietician, because some foods make you sweat more. Getting sweat out through exercise often helps control it at other times.

One more simple tip: if you don't want to arrive somewhere in a flustered, sweaty mess, allow yourself plenty of time to get there so you don't have to rush!

NUAA

NSW USERS AND AIDS ASSOCIATION

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INJECTING YOUR DOSE

Stories and best practice tips from peers and professionals.

In an issue that focuses on the OTP, we thought it was important to hear from people who inject their doses.

There are a lot of reasons people might choose to do this – to avoid the nausea that comes with oral dosing, because they like using needles, or just simply because they prefer the faster come up.

Here are 3 stories from people who choose to inject their methadone or buprenorphine, focusing on why they do it, and how to be as safe as possible.

Carrie's Story

I started using heroin on and off in my late teens, and I'm in my 50s now. In the earlier days I was a poly-drug user, but given a choice of drugs, it's always been heroin. The first time I went on methadone was back in the early 1990s, and I must admit, I didn't like being on the program and went off it after a while. I've recently returned to the methadone program and have been on it for about three years now.

There are a couple of reasons why I inject methadone. First, I find it comes on a lot stronger. When I inject methadone, I think its effects don't last as long as when I drink it, but I get a more euphoric feeling from injecting. The other reason I do it is I suffer from really bad migraines, and taking the syrup orally is something that really sets off my nausea – sometimes I just can't keep my dose down. I've been in the clinic before, taken my dose, and have thrown it straight back up. For me, injecting is sometimes the best way to dose.

Methadone in Australia mostly comes in a pretty thick syrup. Not only is syrup painful to inject, it damages your veins, so most people dilute it with water. Diluting it means there's a lot more liquid to inject, so it's important to use a large-barrel syringe or butterfly infusion set so you don't have to keep changing your fit. The syrup is filled with colours and dyes and isn't sterile, so you need to filter it before you inject to remove all that. I use a wheel filter.

BECAUSE YOU CAN'T TALK ABOUT IT ANYWHERE ELSE, TALKING ABOUT INJECTING METHADONE WITH YOUR PEERS IS IMPORTANT.

After I left the program, I was buying methadone diverted by people on the program. I thought it was better than using street heroin. It's not a big market though – most people aren't diverting methadone to make a profit. There are a lot of different reasons why people divert. Perhaps someone they're close with can't get on the program, so they divert a bit so their partner or friend won't be sick. People often divert just to pay for their own treatment – they're willing to be being sick for one day if it means they're alright the rest of the week. If you're not working, treatment costs can take a big chunk of your money. Most people would prefer not to divert, but sometimes the reality is you have to pay the bills.

Simply being on the program carries stigma, whether or not you inject your doses. On one occasion, my partner ended up in emergency and I told the nurses he was on methadone – next minute, they were all double gloved. You become very wary of what you share. Of course, any injecting marks you have, no matter what you're injecting, carries stigma with it. I was once at a local medical centre, and the GP grabbed me and tried to pull my jumper up, exclaiming "what have you got on your arm!?" Having a doctor grab your arm because they see track marks is a very uncomfortable experience. Injecting has such a bad reputation that you just have to hide it. You know that through sharing that information in a medical setting, you're not necessarily going to be helping yourself. Because you can't talk about it anywhere else, talking about injecting methadone with your peers is important. How else can you share safety tips? No doctor will help you with it.

Having said that, there's no social element to my actual injecting. While I know other people who inject methadone, it's a solo thing for me. Maybe that's partly my age – things were different when I was younger and buying diverted methadone. Injecting methadone is not something I do with other people. It's simply something you do just to feel normal sometimes.

Samantha's Story

I've been a methadone injector for almost 25 years and it's been one of the better choices I've made around my drug use. Ideally, like most people, if heroin was freely available that would be my drug of choice. If we had a hydromorphone program here, I'd be on it. Without these options, I've found a way to make injecting methadone work for me.

Injecting methadone has helped me to stop using heroin, so much so that these days I don't even have a heroin dealer. I have a job, a stable long-term relationship and even a mortgage. Having to maintain a heroin habit taught me how to budget, how to be tight with money and how to live on close to nothing. When my partner and I stopped using heroin, we continued that lifestyle of living tight and saving money. Pretty quickly we ended up having five grand in the bank and we thought "Wow! How did that happen? Maybe we can save for a house deposit!". If we'd been spending all our money on gear that never would have happened.

Don't get me wrong, I do have days where my drug use can affect my work attendance. Sometimes I have a dirty shot, and that affects me. I'm getting older, I'm 49, so I'm not bouncing back like I used to. I imagine my immune system isn't as good as it used to be. Some days I have to go without a dose and I think that makes me more prone to sickness and catching colds. Sometimes I don't sleep that well.

Some years back I switched from methadone to Biodone. It has less additives and isn't as thick so it's safer to inject and it won't screw your veins up as much. However, both carry risk of contamination — if any part of the dispensing equipment is dirty, your dose can be contaminated and make you sick. Because of this you need to use a blue bacteria wheel filter. I've had dirty hits and I've had what I call a 'grimy'. It's like a mild dirty hit: you get a slight headache and you feel a bit grimy.

I worry about sounding like a poster girl for shooting methadone, but it's mostly been positive for me. Not being able to pay bills and rent, really freaking about getting evicted; those worries have been taken away from me because I've been injecting methadone rather than heroin. When you're worried about housing, you've got no food and you're living on porridge, it's not a very happy life.

I'm at the point now where my veins are getting quite damaged. I have to make a decision about injecting into my groin or neck. That's always been a no-go for me, and I still think that it's a line that I don't want to cross. My partner's not in the same place, men generally have better veins, but he's not far behind me. It's causing tension in the home, stress about where to go from here.

Even though I'm about to run out of veins and it's probably going to finish soon, I'm glad I've made the choice to inject methadone. I know that's a pretty controversial thing to say. It's not perfect but it's helped make things work for me while waiting for an injectable pharmacotherapy to become available.

INJECTING METHADONE HAS HELPED ME TO STOP USING HEROIN, SO MUCH SO THAT THESE DAYS I DON'T EVEN HAVE A HEROIN DEALER.

Miranda's Story

I injected Suboxone for quite some time, eventually coming off the program. But by the time that happened, I was getting 100% takeaways… of which 100% were injected.

I had about five friends OD and die in the Cabramatta heroin glut in the late 1990s, but I was a stimulant user. I didn't start using opiates until I got a badly infected tooth when I was about 30. Neither the doctor or the dentist gave me antibiotics and painkillers, and it was just getting worse and worse. My friends were still using opiates, so I just tapped into it. I could get a pack of MS Contin (morphine) for $15, and my partner at the time could access acetic acid through his job. We started making our own homebake (heroin).

By the time the doctors realised I had gangrene in my infected jaw, I had a physical dependency on opioids. I'd started injecting it at that point – I just tried it myself one day and thought 'I can work this out'. I did, it was easy, and I liked it. That's the start of my dance with steel.

We had good jobs and, for a while, good money. We racked up about $80,000 in debt on credit cards, and then one day it all dried up. We couldn't even take our stuff to the hock shop – it was the weekend and it was closed. I just remember being so sick. The following Monday I went to a private clinic and started on methadone, eventually swapping over to Suboxone.

I was well-behaved for quite some time on the program, but I still thought about wanting to inject a lot, and my ex-partner read online about safely injecting Suboxone. After trying it, it became the way I would always take it. It never gave me a high or a rush though. I just did it because I like the needle.

I started escalating my injecting behaviour around Suboxone, although I wasn't taking more of it. I just increased the number of needles I stuck in myself each day by having smaller shots more often, up to 10 a day. I became an expert in how to do it safely.

If you're going to be injecting bupe, it's important you look after yourself. Make sure you filter your mix, preferably through both a red and a blue wheel filter to get all the gunk out. You could also use Sterifilts, cotton wool, or even cigarette filters. Anything is better than nothing when it comes to filtering.

I moved from the city to deep suburbia, so I had to transfer to a new private clinic – this place was my only option because the public clinic had a huge waiting list. It was here I found that private doctors can do what they like. For example, we were made to sign a Medicare form saying he saw us for a 20-minute consultation – you were seen for a minute at most if you were lucky. Once, I had codeine in my system that I took for migraines. When I tested positive for it, the doctor threatened to kick me out and said I would be put on daily dosing if it was found again. He told me that it was more important for my wellbeing that my dose was monitored daily, rather than me holding down a full-time job and being able to pay for my mortgage. I came off the program because of the way that I was treated by this doctor.

All I can say is that injecting my doses made it a bitch to detox from. I've heard from so many people that Suboxone was easy to get off, but that was absolutely not the case for me – I was experiencing detox symptoms for about 12 weeks after my last dose.

If somebody thinks you're a user, it can be a ticket for them to treat you like shit – this is definitely true in medical and clinical settings. People can have a lot of power over you if you're dependent on drugs, and some people love that. As long as drug users are viewed as Other, or as less than people, then that imbalance of power will always be an issue.

Injecting Bupe

Reducing the Harms

There are two main forms of buprenorphine for OTP at the moment - Suboxone (which has naloxone added) and Subutex. If you're going to inject bupe, there are a few important things to remember to stay safe.

As with injecting all drugs, use your whole arsenal of harm reduction tricks and tips! Take your time, use new, sterile equipment, wash your hands, swab, use the smallest gauge needle you can and inject slowly.

If injecting Suboxone, dissolve the film in warm/hot water in a Stericup®, or a swabbed spoon. Once it's dissolved, wait for your mix to cool down before you filter it.

If injecting Subutex, crush the tablets as fine as possible and soak in cold water. Don't soak in hot water!

Use a particle wheel filter (red) to get rid of the gums, starches and additives in Suboxone and the chalk/binders in Subutex that can end up hardened in your veins or organs.

Also use a bacterial (blue) wheel filter, especially if the film or tablet has been in someone's mouth.

If your mix is still gluggy or too thick after you filter, add some more water and re-filter.

Drew

"I'm on Subutex at the moment. One of the things I like about NUAA is that they give out wheel filters. Subutex has cornstarch in it, which makes it harder to inject – it turns into gravy when you mix it with water, so I use wheel filters to fix that up."

Injecting Methadone

Reducing the Harms

Methadone in Australia comes as methadone syrup or Biodone. The active ingredient in both is methadone hydrochloride.

Here are some methadone-specific tips to reduce harm if you're planning on injecting your dose.

Dilute Your Dose

Veins don't like thick sticky syrup! In order to inject methadone syrup, you must dilute it with water. However, injecting a large amount of liquid can damage your veins. A compromise is to go for a 1:1 ratio, adding the same amount of water as methadone.

Filter First

The syrup isn't produced to be injected and the dispensing machines aren't sterile – neither are the cups or bottles your dose is dispensed into.

Using wheel filters will help remove the additives and germs. If you don't filter, you're increasing the risk of dirty shots, infections, vein damage and organ failure.

There are 2 wheel filters, but we recommend the **blue** for methadone and Biodone. A **red** wheel filter (1.2 microns) removes larger particles – especially useful for filtering pills, while the finer **blue** wheel filter (0.22 micron) removes bacteria.

Using a bacteria wheel filter is particularly important if the methadone you intend to inject has been diverted and did time inside someone's mouth. Remember to use a new wheel filter each time - they aren't effective if you reuse them.

Go Slow and Be Gentle

You need to inject methadone very slowly because there is a lot of liquid.

Going slow will reduce the risk of blowing your veins out. People who inject methadone regularly tell us that their veins have deteriorated very quickly since they started, but that injecting very slowly, including having some wait time during the process, really helps.

Butterflies and Bigger Barrels

When you water down your dose, you're going to end up with a lot of liquid to inject.

You will need specialist equipment to avoid the vein damage, discomfort and difficulty that comes with injecting several times in a row. You will need to use a large barrel syringe (10 to 20ml) and a winged infusion set or "butterfly", especially useful for holding the needle in place if you need to change barrels.

NSPs do not provide this equipment, but they are available from chemists or online at a reasonable price. These are single use items that should not be reused or shared.

Try Biodone!

If you are injecting your doses, see if you can swap to a clinic or pharmacy that dispenses Biodone instead of methadone syrup.

Biodone is less harmful to inject than methadone. Methadone is a thick syrup with many additives, while Biodone is a water-based medication. Although they have the same active ingredient - methadone hydrochloride - the additives make all the difference (see page 24 for more information).

You don't need to water Biodone down – you can shoot it straight, so you are injecting a smaller amount of liquid. That means less damage to your veins.

Although Biodone is less harmful to inject, you still need to use a bacterial wheel filter and follow the other harm reduction tips in this article.

ROAD SENSE

ARE YOU FIT TO DRIVE ON THE OTP?

Frequently Asked Questions (FAQ)

People ask us all the time – what are the rules around driving on the Opioid Treatment Program (OTP)? Can I drive? Do I have to tell the police that I am on the program? How can people on the program be safe while driving?

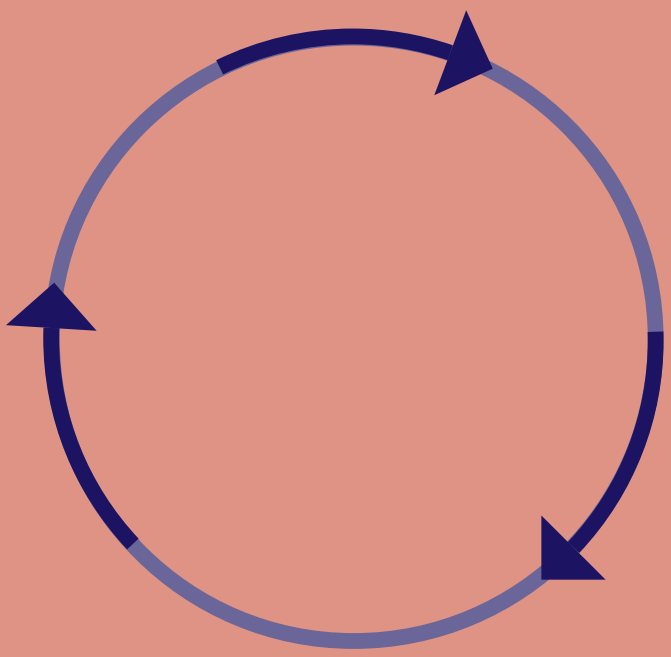
These Frequently Asked Questions come direct from community consultations and our answers straight from official sources. Get up-to-date information on the effect of drugs on your driving; the regulations that apply to driving on methadone (methadone syrup or Biodone) and buprenorphine (Suboxone or Subutex); ways to avoid risky behaviour; and the processes of roadside drug testing.

How Can Drug Use Affect My Driving?

It's easy to forget how complex the task of driving is. Driving requires many skills, and we're constantly checking the road and traffic conditions and making decisions. Driving involves sensing, knowing, and doing. It is important to clearly understand what is going on around us and then respond.

SENSING

seeing, hearing, spatial judgement (knowing things like where the car is on the road; how far away it is from other cars, people and objects; and how soon you will reach a corner, stop sign, pedestrian etc.)



DOING

muscle power, coordination

KNOWING

attention, concentration, understanding, memory, insight, judgement, decision making, reaction time

Driving is a complicated task, and along with sensing, knowing and doing there are other things that affect your driving. Below is a summary of some other things that can also impact on your driving:

Driving experience: Your current driving experience can play a large role in driving safety. However, even if you have years of experience behind the wheel, you still need to play it safe. Regardless of who is at fault, even the most experienced of drivers can be in an accident.

Weather: Driving on a warm sunny day is a lot different to a cold morning with fog or snow, or an afternoon with heavy rain that affects your ability to see the road in front. Considering the weather and how it will impact on your driving is critical to driving safety. Play it safe and reduce your speed or pull over for a break if needed.

Time of day: Driving at night or in the direction of the sun can pose a risk to your safety if not adequately managed. Slow down or take a break if tired, particularly if you find you are struggling to see in front of your vehicle.

Road conditions: Road conditions can unexpectedly change. You should always be vigilant and safe while driving, regardless of the road being highway grade or a local road. Consider the impact of things such as debris, accidents, emergency vehicles, pedestrians and other vehicles on the road.

Speeding: Not only is speeding illegal, meaning it can lead to a fine, loss of points or loss of your licence, it can also impact your ability to control you vehicle and respond appropriately. Everyone has the responsibility to drive safely and stick to the speed limit..

Erratic driving: Driving erratically puts your safety at risk, as well as the safety of others on the road and nearby pedestrians. If you're caught driving erratically, the police may also pull you over and you could be fined.

Illness or injury: Being sick or injured can affect your driving skills. Talk to your doctor about your current illnesses and injuries - they will be able to give you advice about whether you should be driving.

Lack of sleep: Driving after not sleeping for 17 hours is the equivalent of driving with a blood alcohol level of 0.05% (which is the limit for drink driving). Generally, people don't notice if lack of sleep is affecting their driving and often find it hard to tell whether they're too drowsy to drive.

Mood and Emotions: Your mood or frame of mind can have a big impact on your driving ability. If you are feeling angry, depressed, or stressed it is important to recognise that these emotions can alter your ability to drive.

Medications: Be particularly mindful of sedating medications, such as benzodiazepines (like Xanax® or Valium®), and the risks around taking multiple medications at the same time. Some medications can also have a greater impact on you when taken with alcohol or illicit substances. Talk to your doctor or pharmacist about how your medications may impact your driving ability. If you ever feel sedated from a medication, play it safe and don't drive.

Alcohol: You should not be driving if you consume alcohol while on methadone or buprenorphine. Not only that, but if you have had a few drinks you would most likely be over the legal blood alcohol limit and should not be driving anyway.

Illicit substances: Not only is it illegal to drive if you're under the influence of illicit drugs, it's also incredibly dangerous. Drugs can stay in your system long after you take them, and this could show up in a Mobile Drug Test (MDT) or blood test. The safest thing for yourself and others is not to drive if you've taken, or are planning on taking, any illicit substances.

We ask you to remember this: methadone and buprenorphine are prescribed medications you take as part of a treatment program to improve your health and well-being, no matter what the public opinion is or how much you are discriminated against. You have rights as well as responsibilities. Stand tall. Be proud.

How does my methadone or buprenorphine medication affect my driving?

There is good evidence that driving or operating heavy machinery after dosing with methadone or buprenorphine does not increase your risk of accident or injury. However, this doesn't mean you will always be ok to drive. You should be on a stable dose of methadone or buprenorphine before driving. Also consider that a range of medications and drugs (especially alcohol, benzodiazepines, and cannabis) can affect your driving.

For example, if you are more sedated than usual from lack of sleep or using alcohol or other drugs, you can be less attentive and run the risk of a "micro-sleep" (or "nod"). If you have missed a dose and are in withdrawal your muscles can be jerky and less powerful, or you might be teary and sneezy which could affect your sight. Co-ordination, judgement and reaction time can all be affected.

You are more likely to be affected in the first weeks after starting your medication, when you are going up or down on your dose, if you miss doses or take more than your prescribed dose. The first four weeks of starting methadone and the first two weeks of starting buprenorphine are especially high-risk periods where you should avoid driving.

During these higher-risk time, you should seek alternative transport instead of driving - check the end of this article for tips on how to get around if you're not safe to drive.

Can other medications or drugs combine to affect my driving?

Driving can be far less safe if you also use other drugs or alcohol on top of your dose. Adding in prescription medications, such as other opioids, 'benzos', anti-epileptics, anti-depressants, anti-psychotics, and/or pregabalin (known as Lyrica®, and given for nerve pain, anxiety and epilepsy) can really make a difference to how well you drive.

You should talk to your doctor or pharmacist if the medications you are taking can increase your fatigue, make you more sleepy, or can impact on your driving ability. Do not assume that you are safe to drive.

Are there other safety factors to think about?

There are many things you need to think about to make sure you are safe to drive. Even when you are on a steady dose and aren't using other drugs or alcohol, being tired, emotional or sick will affect how you drive. It's important to know when you are safe and when you are not.

It's also vital you keep your car in good condition, checking brakes, mirrors, headlights, blinkers and so on to make sure your car works properly and safely.

How can I know if I am safe to drive?

Ask your doctor or pharmacist, who can give you advice about whether or not it is safe for you to drive. Check the label on your medications, as some can affect how you drive. If a drug is prescribed to you and you are taking it exactly as advised, you will know how to manage the risks.

You should also use your common sense. People often know when they shouldn't be driving.

You should not drive when under the influence of illicit drugs, even if you use them daily. There are simply too many things that can change the way the drug might affect you..

Are there rules about when I can't drive if I am on a methadone or buprenorphine program?

You are ok to drive if you are stable on your dose and are not affected by significant amounts of other medications or drugs. Driving gets safer when your body and brain get used to taking the same dose for methadone or buprenorphine over a long period of time. You should not drive for several days following any dose change.

Missing or increasing your dose, as well as changing your route of administration (like injecting it), may impact your ability to drive safely.

The *NSW Clinical Guidelines: Treatment of Opioid Dependence (2018)* recommends not driving 4 weeks after you begin a methadone program and being especially careful for 3-5 days if you change your dose by 5mg or more. With buprenorphine, you should not drive for 2 weeks after you begin a program and being especially careful for 3-5 days after a change of dose."

	Do Not Drive	Drive
Methadone (Biodone Forte® or Methadone Syrup®)	4 weeks from start	4 weeks from start
Methadone (Biodone Forte® or Methadone Syrup®)	2 weeks from start	3-5 days after dose change

How do I get guidance about when I should drive?

One of the responsibilities of your healthcare providers (including pharmacists, clinic nurses, case workers, peer workers and doctors) is to help ensure your safety while taking medication. This includes advising you about driving safely.

The best thing you can do is to talk honestly with your doctors about your fitness to drive. You should make them aware of all your current stresses and challenges, as well as all the medications you are taking - especially if your doctor didn't prescribe them.

Then you should ask them to explain the effects those drugs may have on your ability to drive and offer some advice about when you should or shouldn't be driving. You can also ask your pharmacist, clinic nurse, or peer worker, as they will be able to give you advice as well. Don't forget you can even contact the Opioid Treatment Line (OTL) or the NSW Users and AIDS Association (NUAA) to give you advice.

You should also talk in a general way about how illicit drugs and/or alcohol might add to the mix in your case.

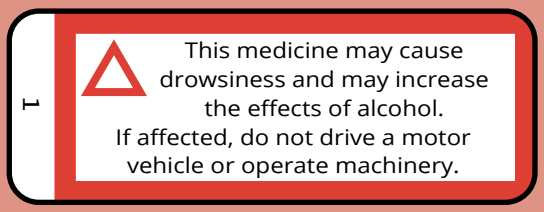
Can I get a card from the doctor to give police to say I am on a program?

There is no need for a card. You do not have to tell police you are on a program and Mobile Drug Tests do not test for opioids.

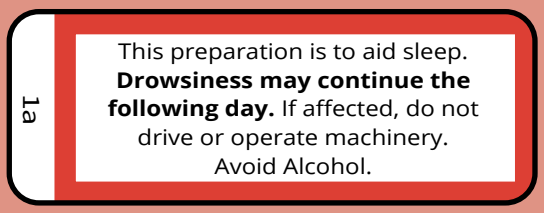
Why is it my responsibility to know when I am fit to drive?

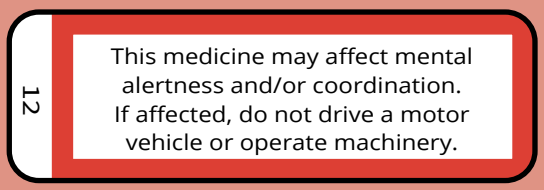
It is your responsibility to be able to recognise when you may not be fit to drive. Your safety and the safety of others depends on it.

Many medications that cause sedation or drowsiness are required to have labels by the Therapeutic Goods Administration (TGA). The TGA is part of the Commonwealth Department of Health and its role is to keep Australians safe through regulating medications. You may notice that methadone and buprenorphine are labelled with the following:



If you get takeaways you would have seen this label on your medication bottles or packs. This labelling means that it is your responsibility to think about how the medication affects you, to not mix it with alcohol, and not to drive if you are feeling drowsy. Other medications that you are prescribed may also have one of the labels below as well.





There are many other medications that can also affect your driving, including some over-the-counter medications such as cold and flu tablets. Be sure to follow the advice on the label or product information sheet inside, speak to your doctor about the medications you are currently taking, and speak to your pharmacist for more information or if you are unsure about anything.

Different people are affected differently – gender, body size, and general health can all play a part in how quickly a person processes drugs or how much they are affected by different drugs. It comes back to you as an individual to understand or seek information from healthcare providers if you are unsure.

It is important to be able to recognise when you may not be fit to drive. Your safety and the safety of others depends on it.

What if I ignore my doctor's advice about driving? Are there legal implications?

Your healthcare provider has a responsibility to your safety and to the safety of the community. So, if you ignore their advice to stop driving, they may have to report you to the Roads and Maritime Service (RMS). The RMS will then assess whether you require additional driving aids to assist your medical condition (such as hand-operated breaking) to drive safely or whether a conditional licence is appropriate. In some cases, you may need to stop driving completely. These decisions are made by the RMS with input from your doctor and other healthcare providers.

It is also important to recognise that if you have a medical condition that impacts your ability to drive safely long-term you also have an obligation to inform RMS. Such medical conditions can include: epilepsy, seizures, diabetes, heart disease, dementia, and sleep disorders, among others.

If you attend treatment while intoxicated and intend to drive, the clinic nurses, doctors, and/or pharmacists also have a duty of care to ensure your safety and the safety of the community. This means they might even contact the police. It will also result in either a reduced dose, your dose being withheld, or being asked to return later in the day.

When can I be tested by police conducting Mobile Drug Testing (MDT)?

NSW Police can test drivers for drugs anytime or anywhere for no reason at all. MDT is random. However, there are other reasons the police might pull you over, including:

- something about you or your vehicle makes a police officer suspicious of you
- a police officer knows you as a person who uses drugs
- you are driving oddly or dangerously
- you are in an accident

For more information about Mobile Drug Testing, look at the NSW Government's 'Transport for NSW' website - *www.transport.nsw.gov.au*

What drugs are tested in Mobile Drug Testing (MDT)?

By using saliva sticks, MDT tests for:

- ecstasy (MDMA)
- methamphetamine (including speed and ice).
- cannabis
- cocaine

Roadside drug tests do not test for OTP medication or other opioids.


10

Will drug use only show up on a Mobile Drug Test (MDT) if I'm stoned?

MDT does not test for drug impairment. It tests for the presence of drugs. The test may come up positive for drugs, even several days after using them. It's hard to know how many days after using you might test positive. Drugs stay in people's bodies for different lengths of time, depending on things like gender, weight and general health. Drugs also tend to stay longer in people's bodies if they are living with kidney disease, liver disease or cirrhosis of the liver.

A one-off use of a drug will pass through your body more quickly than if you have used for several days in a row. When thinking about how long drugs stay in your body, consider that small amounts may remain within your system for more than a week.

What do I have to tell the police if I am stopped for a Mobile Drug Test (MDT)?

Remember: you don't have to tell police anything except your name, date of birth and address as well as showing your driver's licence. If they ask you about your recent or habitual drug use, you do not have to tell them anything, even if the MDT comes up positive.

You also do not have to tell police you are on a treatment program.

If you are stopped for an MDT, the best advice is to be polite and courteous and say as little as possible.

Passengers in the vehicle are not subject to MDT unless: 1) the passenger is supervising a learner driver, or 2) if the police reasonably believe the person was driving the vehicle, such as witnessing the drivers changing seats prior to approaching police. Additionally, passengers don't have to tell the police about the driver's drug use or if the driver is on a treatment program.

What happens if a roadside drug test is positive?

If your MDT test is positive, you'll be taken to a roadside testing van or bus, or back to a police station to provide a saliva sample. This sample will also be tested and, if positive, you'll be banned from driving for 24 hours. All samples are sent to a laboratory for analysis. If the laboratory confirms the positive roadside result, police will contact you and charge you with driving with the presence of an illegal drug. You might lose your licence for a period of time and be required to pay a fine.

If you test positive for illicit drugs and have been driving erratically, you may be charged with driving under the influence (DUI). This is a more serious charge and you could lose your licence for a longer period of time and be required to pay a larger fine.

If you test positive for prescription drugs, you might be charged with DUI if you are driving dangerously.

Remember that if you drive with the presence of an illegal drug, your insurance and registration are null and void. This could have significant financial repercussions if you have an accident.

What happens if a driver is pulled over and they are affected by an illicit drug or a medical treatment?

It is important to remember that it is illegal to drive if you are under the influence of any drug.

If a person passes a roadside breath test or drug test, but the police officer believes they are under the influence of a drug, they might make the driver complete a sobriety assessment. Police can make this call based on how the person is driving, or how they look or behave when they get pulled over.

If the driver fails or refuses the assessment, the police officer can arrest them and require them to undergo blood and urine testing. These tests can identify a wide range of illegal drugs and medications, including opioids and OTP medication, and also shows how much are in the driver's blood. This can show whether the medication is taken as prescribed, as well as if other drugs are present.

The results, along with police observations at the roadside, can be used as the basis for charging a driver with the offence of driving under the influence of a drug. This is a serious offence with heavy penalties including fine and loss of licence.

What happens if a driver who is taking an opioid replacement treatment is involved in a fatal crash?

In NSW, all drivers who are involved in fatal crashes, or serious crashes where a person may die, can be taken for mandatory blood and urine tests. The tests can identify a wide range of illegal drugs and medication, including opioids and opioid treatment and the concentration in the blood. This can show whether a treatment has been taken in a therapeutic dose as prescribed, and whether other drugs are present.

All fatal crashes are investigated by NSW Police, and the results of the tests may be taken into account if a driver is charged with an offence.

Remember that if you drive with the presence of an illegal drug in your system, your insurance and registration are not valid. This could have significant financial repercussions if you have an accident – for example, you may be responsible for paying for any damage you cause.

Can the police search my car or undertake a person search if my Mobile Drug Test (MDT) comes back positive?

A police officer can search a person if they have reasonable grounds to suspect that the person has a prohibited drug in their possession. They can also search a vehicle if they have reasonable grounds to suspect that it contains a prohibited drug, or that one of the passengers has a prohibited drug in their possession or control.

A positive drug test can be considered reasonable grounds to conduct a search of a person, their belongings and their vehicle. However, police can only ask the person to remove outer layers of clothing, hats or footwear. The police cannot conduct a strip search in a place other than a police station unless the seriousness and urgency of the circumstances makes the search necessary.

Police also have additional powers to search persons upon or after arrest. As noted above, police may arrest a person who refuses a drug test or whose sample tests positive. Police may search a person at the time or after their arrest if they suspect on reasonable grounds that it is prudent to do so in order to determine whether the person is carrying a prohibited drug, drug-related items or any other objects that may be connected to an alleged crime or provide evidence of a crime having been committed.

Are there circumstances where a Mobile Drug Test (MDT) comes back negative but a person is sent off for a more complex drug test that checks for additional substances?

If a driver does an MDT and result comes back negative, the police do not have the power to force the driver to undergo further testing, such a blood and/or urine sample testing.

However, if you are behaving in a way that makes the police officer suspect you are intoxicated, or if you refuse to provide a saliva sample, the police can require you to do a blood and/or urine drug test. Police can also require a driver or person sitting next to a learner driver to undergo blood and urine testing if the learner driver has been involved in a potentially fatal accident.

How am I going to get around if I'm not safe to drive?

Explore your options and plan ahead to make sure you get from point A to point B in one piece.

Your family, friends and neighbours are good options for transport and are often happy to support you while you adjust to treatment, especially if you explain you are trying to keep everyone safe and make important changes to your life.

You could try asking people on the program who live near you if you could car pool. Put a sign up on the notice board at your clinic. If you have been on the program for a while, think about others who are new and maybe offer them a lift to and from the clinic. Have a chat to the staff at your clinic, such as the Nurse Unit Manager (NUM) or peer workers, for what might be available.

You might also ask your local Council, community groups or charities. For example, some charities or church groups have volunteers that might give you a lift to the clinic or help with things like health needs or shopping while you get stable on your dose. You won't know if you don't ask. If your clinic is at a hospital you may be able to take advantage of free buses that go from the hospital to the nearest train station.

Public transport is an option, depending on where you live. Check out what is available in your area. Trip Planner is a great web site for planning NSW travel.

There are times you might be more cashed up and can catch a taxi or a ride-share service (like Go Catch, Ola, or Uber), or even splitting the fare with someone. It can certainly be worth it to keep you, your family and your community safe, but admittedly for most of us it's only a short-term option.

For some people it is possible to go low tech – walking, skateboarding, riding a bike, or even a horse! Just remember that riding a bike or horse on the open road is the same as driving in terms of being drug tested.

Recently there was a fatal accident that involved a driver on methadone. It started a wave of stigma and discrimination against people on the OTP in the media. It also raised the question for the Ministry of Health and the Roads and Traffic Authority: how can we keep everyone safe on the roads and at the same time support the OTP? As part of the answer, they decided to do a website that had information for doctors and people on the OTP around the responsibilities of drivers who are prescribed an S8 medication. NUAA was asked to help with the consumer part of the project and we consulted with drivers on the OTP as part of this. These pages of UN, as well as a couple of video interviews, are what will soon be up on the website. Check it out!

www.drivingsafety.com.au

Do I have any other options so I can drive and still take care of my health needs?

Methadone is an opioid and depending on the amount you are prescribed, when you were last dosed and how long you have been on the program, you might feel sedated from time to time. People on buprenorphine tend to say they feel more alert. Because of this, the guidelines around methadone call for greater care and longer safety lead times than those that apply to buprenorphine.

If you prefer driving or need to drive to get around, it might be worth discussing with your prescriber about swapping over to buprenorphine. This can be particularly helpful if you need to balance the use of 'benzos', anti-depressants or other meds that have a sedating effect.

Where can I find out more information?

For more information about how to stay safe while driving, try searching these online:

- Austroads Assessing Fitness to Drive - this is aimed at health professionals to assist them in assessing their patient's ability to drive
- NSW Clinical Guidelines: Treatment of Opioid Dependence - There is a full version and an abbreviated version online, plus NUAA's consumer version coming out soon!
- Transport for NSW Centre for Road Safety. Staying Safe: Illegal Drugs.

If you can't find what you're looking for, you can always contact NUAA and we will do our best to help you out.

Take Our Quiz

We made up this quiz to get you thinking about how much you know about driving on the OTP. Are you ready to get out there or do you need to have another look at the FAQs to learn more about keeping yourself and others safe?

1. You've started on methadone (Methadone or Biodone) in the last 4 weeks, or buprenorphine (Suboxone or Subutex) in the last 2 weeks. At the moment, there is ____

a. An increased risk when driving
b. No increased risk when driving

Answer:
a.. There is an increased risk with driving during the first couple of weeks of treatment. Your body and brain will still be getting used to your medication and taking it will affect you more during these periods. You shouldn't be behind the wheel! If you are starting on methadone, you shouldn't be driving for at least the first 4 weeks. If you are on buprenorphine you shouldn't be driving for at least the first 2 weeks.
We discuss when it is safe and unsafe to drive while on these medication in our FAQs. For more information, check out the article before this one.

2. In the last 5 days, you've changed your buprenorphine dose. Is there an increased risk to driving in this situation?

a. No, there is no increased risk when driving.
b. Yes, there is an increased risk when driving.

Answer:
b. There is an increased risk when driving after your medication dose has changed. Changing your dose can be a bit of a shock to your body, so it is risky to be driving until your new dose has stabilised. You should be cautious in the first 3-5 days after any dose change. See if you can get around some other way during this period. Have a look at our FAQs for more information on alternate transport options.

3. You usually take your dose orally, but today you decided to inject it. You feel like you're alright to drive – are you?

a. Yes - I'm still taking the same dose so it's not a problem

b. No

Answer:

b. No. Even if it's the same dose, changing the way you take it changes the way it affects you. When you inject something, it hits you faster and harder, but it will also wears off quicker. Even if you feel like you're fine to drive, there is still a risk. Caution: injecting Suboxone can throw you into withdrawal, especially if you've been using opioids on top of your OTP medication. This can make driving especially dangerous.

4. You are driving home from the clinic after taking your regular dose and a police officer pulls you over for a Mobile Drug Test (MDT). You haven't used any illicit drugs today, but you have in the last few days. What happens when you take the test?

a. The test comes up negative for any drugs.

b. The test comes up positive for opioids but negative for illicit drugs.

c. The test comes up positive for illicit drugs.

d. Unsure

Answer:

d. Unsure. Mobile drug tests do not test for opioids at the moment, but if you have used cannabis, cocaine, speed, meth, or MDMA recently, they may show up even after several days. (How many days will depend on factors like your weight and general health). It's best not to drive if you have used illicit drugs recently, even if you feel you are safe doing so.

For more information about MDTs, look at the FAQ's in the article before this quiz.

5. You have taken less than your prescribed dose today or have skipped your dose completely. Do you think you should be driving today?

a. No, there is an increased risk if I were to drive today.

b. Yes, it will be fine for me to drive today.

Answer:

a. There is an increased risk to your safety if you were to drive today. It is only safe to drive when you are used to your dose. Any changes to that will increase the chance of you getting in a car accident. Have a look at our FAQs for more information on alternate transport options to get around that day.

6. If you missed your dose this morning but took other opioids to make up for it and feel fine, you are safe to drive.

a. True

b. False

Answer:

b. False. Driving if you have missed a dose is dangerous, and so is driving if you have taken street opioids. These two situations do not cancel each other out – don't get behind the wheel! Have a look at our FAQs for more information on alternate transport options.

7. You have been on the same regular dose for 4 weeks, but in a rare one-off you missed your dose yesterday. You had your dose this morning, so you are safe to drive. True or false?

a. True
b. False

Answer:
b. False. Missing a dose yesterday might mean your dose today affects you differently. If you aren't feeling safe to drive, don't do it! If you miss more than one dose it is highly likely that you are not safe to drive and should be reassessed by your doctor.

8. You took your normal methadone dose this morning, but it made you nauseous and you vomited it up. The nurse told you that it's fine and you would have absorbed it. Later that day you are feeling a bit strange. Should you be driving?

a. Yes
b. No

Answer:
b. No. If you're feeling unwell, listen to your body. If in doubt, don't take the chance on the road. It's always better to be safe than sorry.

9. You took your regular buprenorphine dose this morning and had a few alcoholic drinks with lunch about an hour ago. Is it risky to drive?

a. Yes
b. No

Answer:
a. Yes, it is risky to be driving. It's only safe to drive on methadone and buprenorphine if you haven't had any other drugs or alcohol. Besides, even if it was only a few drinks, you are most likely still over the legal blood alcohol limit.

10. You are prescribed Valium® or another 'benzo' and take it with your buprenorphine dose in the morning. How safe is it to drive?

a. Unsafe – Mixing these two drugs greatly increases your risk of car accident – definitely don't drive
b. Unsure – It's worth asking your doctor if they think you should take extra care driving
c. Safe – You are prescribed both opioids and benzos, so they won't affect your driving.
d. Very safe – It makes you more relaxed while your driving and as a result you drive less aggressively and don't speed.

Answer:
b. Unsure. Two lots of depressant drugs together may mean you are far more likely to have an accident – even if they are prescribed. You need to be particularly careful when taking a 'benzo' with other medications, as they can greatly impact on your fitness to drive. This is a complex one. Ask your doctor for their advice and take the advice!

See our FAQs, where we discuss how medications can impact on your driving safety.

GETTING OFF THE OTP

Everyone is going to have different expectations about being on the Opioid Treatment Program (OTP), depending on who they are, their circumstances, and what they want to get out of it. There is no 'right' amount of time to be on the OTP for. Some people are happy to stay on the program for a long time or even forever, while others plan to leave it behind them once they have achieved their specific treatment goals.

Just remember – opioid dependence is a legitimate medical condition, and OTP medications are used to treat it. There is no shame in being on the program, and you should stay on it for as long as it's still working for you.

Many people don't come off the program even if they really want to, because they are worried about how difficult it might be. Knowing what to expect from withdrawal and how to reduce the discomfort will make the idea of coming off your OTP medication a lot less scary.

Are You Ready?

There are a lot of good reasons why people think about leaving treatment – you might have had enough of the stigma from being on the OTP, or it could be about the amount of time that appointments and dosing take. All reasons are valid, but you should think carefully about your choices. Be honest with yourself – are you ready?

The best reason for leaving OTP is that you feel in charge of your drug use (whatever that means for you) and feel that your life would be easier and better if you were no longer on the program. For most people it takes at least a year or two on the program to get to this point.

You might be ready to leave treatment if you:

- Are on top of your mental and physical health
- Have stopped using illicit drugs
- Have stable housing and support from friends or family
- Have important commitments to focus on such as study, family, or work
- Have an interest or hobby to focus on (like art, music, or sport)

If you have some of these things in place, you're much more likely to successfully exit OTP and not relapse into problematic drug use. If you leave the program before you are ready, you could be undoing months or years worth of hard work.

If you are thinking of leaving OTP, you should ask your prescriber and other healthcare staff, such as your nurses or psychologist, for their advice. They can look at your situation and can let you know what they think – they may be concerned it's too early, or they could completely support your attempt. If they are concerned, find out why and what they think you need to change before you leave treatment. At the end of the day, you get the final say as to whether to stay on the program – your prescriber is not allowed to refuse to help you exit.

Overdose

It's important to remember there is an increased risk of overdose if you start using opioids again after exiting the program due to reduced tolerance. If you do decide to start using heroin or other opioids again, keep in mind that your tolerance will be greatly reduced – an amount which you would've hardly felt before may now be enough to kill you! For this reason, always have naloxone on hand if you are using opioids. Talk to your doctor/prescriber about getting a script for take-home naloxone (for the PBS discount) or buy it over the counter at a pharmacy. If money is a major issue, ask a drug and alcohol service if they are running free overdose courses where they give you naloxone to take away with you.

Ways to Come Off

You have several options if you want to leave treatment.

Cold Turkey

Going 'cold turkey' is quitting something abruptly. For OTP, this would mean one day just stopping taking your regular dose, without coming down from it at all. We all know someone who has done it, and some don't use again but most do. Going cold turkey is strongly discouraged – the withdrawals are really bad and last many months. Stopping treatment suddenly means you're more likely to start using other drugs or end up back on the program, usually because you finally give in.

Residential rehab

There are residential rehabilitation programs which can help you in exiting from the program. Residential rehabs suit people who feel they need to get right away from their lives in order to get their drug use under control. These are medium to long-term options, and often include a support period – perhaps at a half-way house after you leave. There are two options – staying on the program and stopping all illicit drugs and alcohol (called selective withdrawal) or reducing off the program as well as other drugs. Sometimes people start by coming off illicits then decide to go the whole way once their head clears a bit.

Tapering

Tapering, also known as titration, is the most common and most successful approach to exit the program. Tapering is when you slowly reduce your dose, usually over a few months, while still living your normal life. Every time you drop down on your dose you will experience some level of withdrawal symptoms, which will get more intense the closer your dose gets to zero. These withdrawal symptoms usually peak between 1-4 weeks after your last dose.

Withdrawals

As you stop taking methadone or bupe, you will go through withdrawals. These are often more uncomfortable and last longer than withdrawing from other opioids because 'done and bupe stay in your system much longer.

Common symptoms include sweating, restlessness/poor sleep, muscle/bone/joint pains, anxiety, aggression, depression, diarrhoea, and flu-like symptoms such as fevers, runny eyes and nose, and sneezing. If you slowly reduce your dose, every step down will bring on a new round of withdrawal symptoms, which will usually last between four and 14 days.

This will get harder towards the end, because, while you may be coming down by only 5mg at a time, you are reducing by a larger percentage of your dose each time. For example, reducing by 5mg from 100mg is a twentieth of your dose, whereas 5mg from 20mg is a quarter of your dose. It makes sense that you will feel it more, so a lot of people choose to go slower at the end.

If you're on methadone, you might want to consider swapping over to bupe while reducing your dose because the withdrawal symptoms are often easier to deal with. Most people who do this reduce their methadone dose to around 30mg and then swap to a low dose of buprenorphine. From there, you can continue going down on your dose. Remember though, it's a myth that withdrawal from bupe is a walk in the park (read Clyde's story, coming up next).

When you stop dosing completely, some withdrawal symptoms might linger for months. A lot of people feel depressed and have trouble sleeping after this final dose reduction. One option is to consider going on a short course of anti-depressants. You also may benefit from staying at a detox centre or rehab while making the last reduction – here, you can receive the support you need from trained healthcare professionals while going through withdrawals. Talk to your doctor about how to manage this final jump – they can help point you in the right direction.

If you're having trouble with the withdrawal but still want to exit, there are ways to deal with the problems or feelings that are coming up. Your prescriber or GP can help you with working through withdrawal symptoms, and you can always wait until you get used to a smaller dose to start reducing again.

Symptom Relief

Withdrawing from opioids is never going to be pleasant, but it's not the scary thing we build it up to be either. There are ways you can make it easier. The first thing to do is talk to your doctor. Tell them you are worried and a bit scared and need them to do everything in their power to make this a success for you – and that means helping you manage the withdrawal symptoms.

You also need to make the time to be unwell. Check out how many sick days you are owed at work so you know what you have to play with. Talk to your doctor about writing medical certificates (you can get these from chemists too for around $15 to $25). Get them to write "medical condition" as the reason! There aren't many workplaces where saying you're coming off an OTP is a good option, but if your employer knows about your treatment they may be sympathetic. Work out what times of the day you feel least well and schedule your activities – maybe come to work later or leave earlier if you can.

Non-opioid painkillers such as paracetamol, aspirin or ibuprofen (Nurofen) and anti-inflammatory medication such as Voltaren can help ease aches and pains in your muscles and bones. We get in our heads that only opioids will do the job, but it's honestly not so. Sports cream like Deep Heat and Tiger Balm can also help with sore muscles. There is also medication that your doctor can prescribe to help with nausea, stomach aches and diarrhoea.

Making sure that you're eating well is also important, as your body will be under a lot of strain. Taking a multi-vitamin supplement will make sure you're getting the nutrients you need, as well as having a diet with lots of fruit, vegetables, whole grains and legumes.

You can also try natural remedies. Echinacea is available at most chemists and can help with the head-cold symptoms of opioid withdrawal. Taking ginseng will ease your fatigue and give you an energy boost. Some people try other alternative medicines like acupuncture.

Your sleep will be affected for some time. Valerian root or a melatonin supplement will make falling to sleep easier, but it's also important to get into a normal sleep routine. That means training your body to go to bed at a reasonable hour and wake up around the same time each day. You might want to talk to your doctor about seeing a sleep specialist. There has been a lot of research about "sleep hygiene" and there are many tips and tricks associated with improving your sleep patterns.

Post-Detox

While exiting treatment is hard, staying off opioids completely is harder – your schedule will change, and it might feel like the withdrawals and cravings will never end or that you're missing something in your life.

Having a solid support network makes staying off opioids a lot easier. This support network could include your friends, family, prescribing doctor, or caseworker. Your prescribing doctor and/or caseworker should continue to see you after you've exited treatment to make sure that you're coping okay. You could also attend support groups if there are any running in your area.

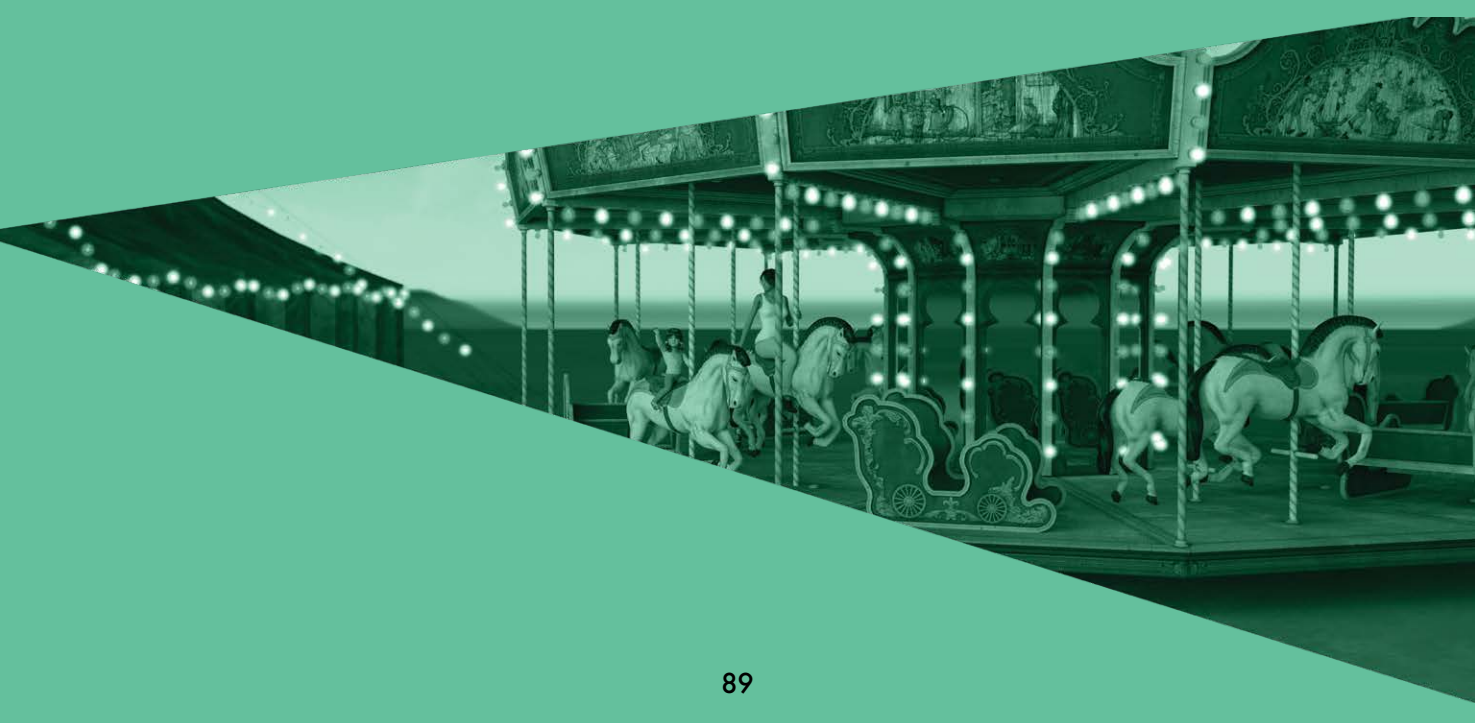
Most important is that you maintain the benefits you got from being on the program. For some, being on OTP means having stable living arrangements or holding down a job for the first time in many years, or it could mean that your personal relationships (friends, family) have improved. These improvements in your quality of life are the long-term goal of being on OTP, and it's important to keep focused upon them once you have left the program.

Changing Your Mind

Some people find that when they start reducing their dose, or stop completely, they wish that they hadn't! You might not be coping with withdrawals, could be feeling like you're losing control of your drug use, or may simply miss the benefits and routine of being on OTP.

It's totally okay to change your mind and stop reducing or start back on the program – there is no need to be ashamed or discouraged. The best option for you might be staying on OTP or starting again. There is no shame in returning to treatment, and it may result in better outcomes for you. A lot of people take multiple attempts to come off the program, and you can always try to exit the program again later if you choose, or you may benefit from being on OTP for the rest of your life.

Talk to your prescribing doctor about how you are finding exiting treatment, or if you have already left the program completely, arrange an appointment with your GP or another prescriber to discuss your options. Don't be afraid to ask for help from friends, family, or your doctor. Seeing a psychologist or counsellor can also help you adjust to life off the program.



Clydes's Story

RIDING THE DETOX ROLLERCOASTER

After two years of street-accessed pain relief, Clyde ended up on 4mg of Suboxone daily for 7 years. After 6 months of tapering down and detoxing, he is now off the Opioid Treatment Program completely!

This is my story about coming off buprenorphine. I'm here to say it can be done, but the road is rocky.

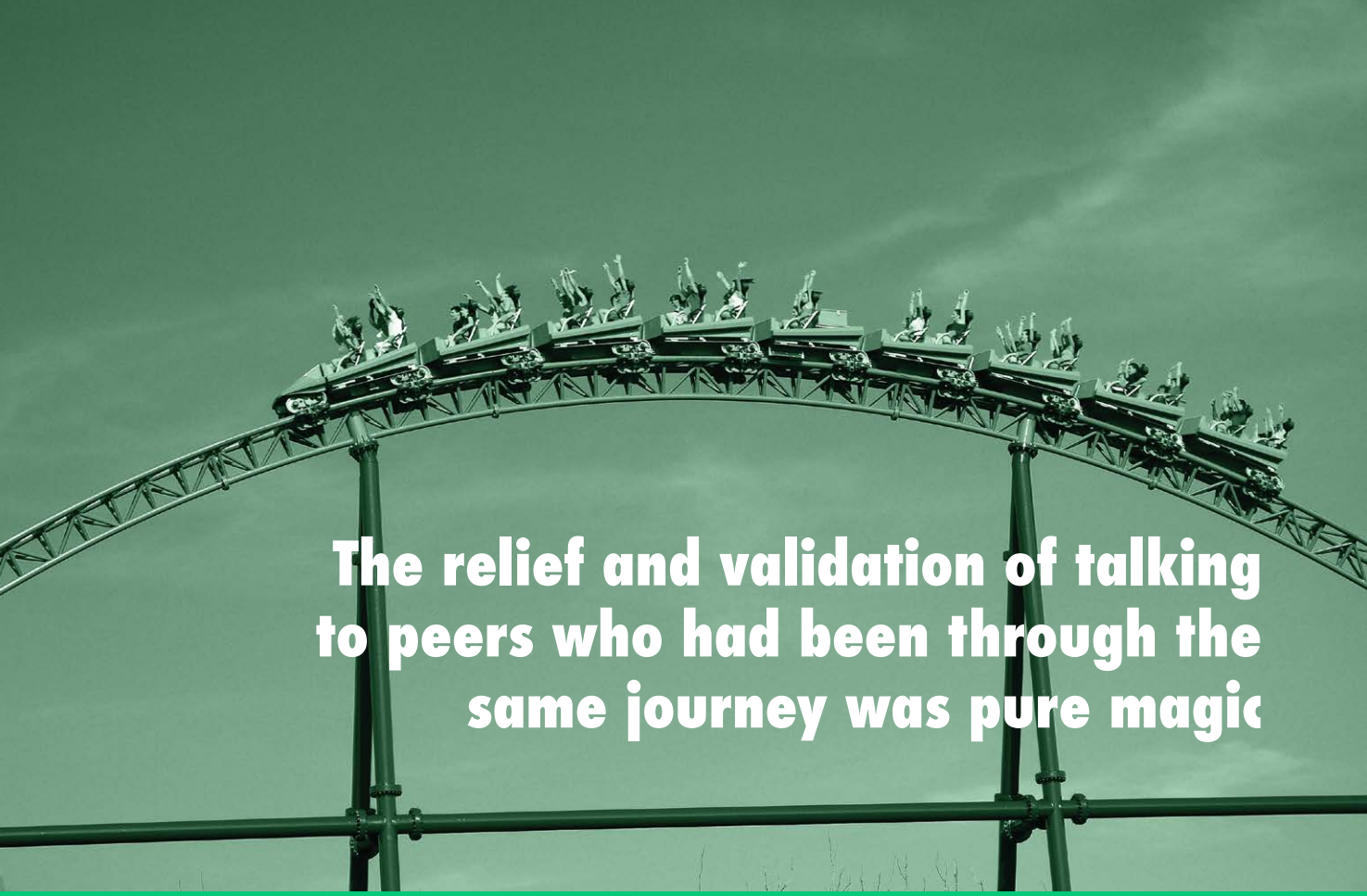
The only person I knew who'd come off maintenance bupe before was my partner James, who jumped off 4mg cold. He spent five days in a detox – the maximum time they allowed – and then came home, where he proceeded to rock back and forth on the couch for 10 days before starting using again. James ended up back on methadone. I thought he was being a drama queen and that he just couldn't take it, because someone had told me Suboxone was meant to be an easy detox.

I figured it would be easy if I did it the 'right' way – the way it was recommended. Slowly. I thought I was different, that I really wanted to do it and that James failed because he lacked proper motivation. Poor James. Now I know what he must have been going through and I wonder how he lasted as long as he did. Truth is, there is no one size fits all, and there is no such thing as an "easy" detox from a Suboxone maintenance program.

The experience was a nightmare for myself and people close to me. The withdrawals were horrible – when things got bad, I would lash out, or find myself in the depths of near-suicidal chemical depression. I was coming down in increments of 0.4mg every two or three weeks, and no decrease was the same as the one before. I had no way of knowing how long or intense the fallout would be each time.

Every time I dropped, the dosing staff shook their heads and asked if I'd really thought about what I'm doing. It's never about how well I'm going or how far I've come, but suspicion and doubt about my motivation. I feel like the staff always assumed there must be something else behind any positive step you take. For example, you're doing it because you're in trouble with the law; because you want to use other drugs; or because you're trying to impress someone. Never because you want to make a positive life change and feel this may be the way to go. Truth be told, the staff were one of the biggest reasons I had for wanting out – I was sick of being judged, underestimated, and treated like a child.

Since I started my Suboxone detox, I've talked to three others who tried to come off as well. Two of them ended up back on high doses of methadone, and the other back on Suboxone. Three of us agree that it feels like our ability to cry or have a belly laugh is gone, and none of us were offered support of any kind by the clinics who prescribed and dosed us.



The relief and validation of talking to peers who had been through the same journey was pure magic

Coming off Suboxone maintenance was unpredictable and bloody hard. I would cry a lot, fly into intense rages, and felt like I'd kill for a decent sleep. Experiencing these horrible withdrawals while being told it's all in your head is soul destroying. The relief and validation of talking to peers who had been through the same journey was pure magic – we could literally finish each other's sentences.

James warned me not to use while detoxing, that it would only prolong the inevitable. He said that when he used, he would feel ok for two or three days, but then the withdrawals would come on again, painful and slow. So instead I kept one of my 4mg takeaways for when it got too bad. Only once did I cut a slither off it and have some, when James reminded me it was there and almost begged me to. Although it wasn't a permanent fix, it felt completely worth it at the time.

Going from 0.8mg to 0.4mg was really painful, so for my last step down to nothing, I ended up switching to 1mg of methadone a day – 0.2mL of syrup. It was enough to ride out my withdrawals comfortably and coming off 1mg of methadone was a walk in the park. I was on that for about a month and then slid off. It was all over. I did something that, a year ago, seemed impossible.

If I could turn back time to when I started Suboxone, I would walk into that first consultation and make a clear plan with my doctor, with detox and exiting the program as the end goal. I wish that I made it clear to my prescriber that substance use isn't the only issue I have, because I would have benefited from regular counselling, complimentary therapy, and ongoing support. Don't expect them to make a plan for you, because in my experience they won't unless you ask. Be prepared and go in with a clear visual of a start, a middle, and end.

At a time when the experts are trialing long-lasting injections of buprenorphine, while telling anybody who asks about withdrawal or long-term effects that "according to the data, it doesn't sound like a problem", I believe we need to be very cautious. If you're thinking of starting on bupe maintenance, it's important to realise you are likely committing to many years or decades. Not weeks. Not months. Maintenance is a long-term treatment.

Suboxone detox is a roller coaster ride with definite ups and downs. For those detoxing or thinking about it, all I can say is this: it will be tough, but it is doable. There are good days and bad days, but eventually, it will all be okay. You just have to look after yourself – make sure you eat well, keep your fluids up, and are able to have some personal space when needed. And remember – the bad days are not forever, they're just part of the process.

Looking For Treatment?

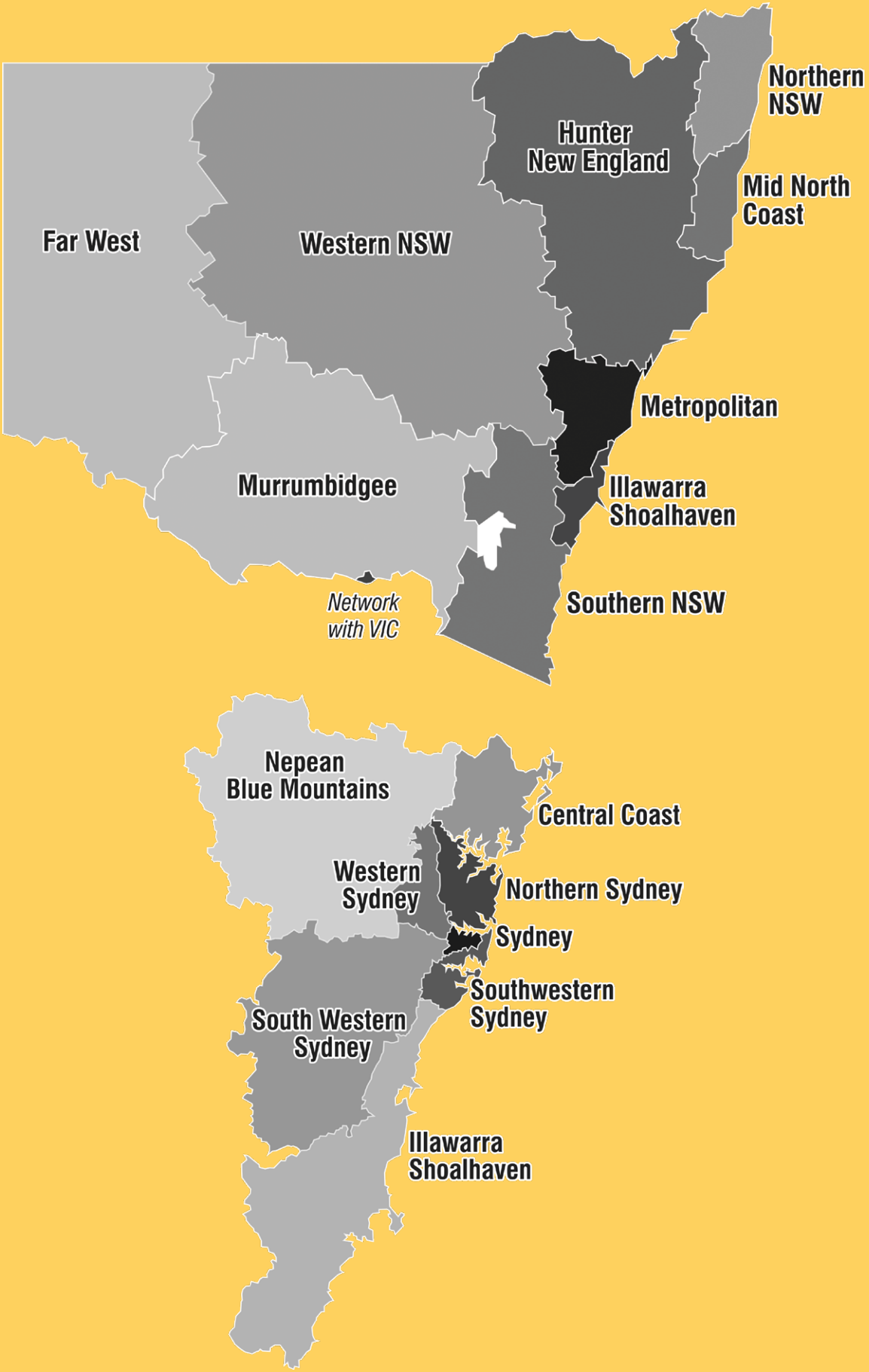
Advice about treatment, changing your use and other support

ADIS (Alcohol & Drug Information Service):	1800 422 599 (24HRS, 7 DAYS)
Family Drug Support:	1300 368 186 (24HRS, 7 DAYS)
NSW Users & AIDS Association (NUAA) :	1800 644 413 (Mon-Fri, 9 AM - 6 PM)
Opioid Treatment Line (OTL):	1800 642 428 (Mon-Fri, 9:30AM - 5 PM)
Stimulant Treatment Line:	1800 101 188 (24 HRS, 7 DAYS)
Youth Drugs & Alcohol Advice (YoDAA):	1800 458 685 (24 HRS, 7 DAYS)

Local Health District Drug and Alcohol Intake Lines

Want to find out about the local public services? Ask about detox services, counseling and OTP through these intake lines.

Central Coast	**02 4394 4880**
Illawarra Shoalhaven	**1300 652 226**
Nepean Blue Mountains	**1300 661 050** (24/7 service)
Northern Sydney	**1300 889 788**
South Eastern Sydney	**(02) 9332 8777** (Northern)
	(02) 9113 2944 (Central)
South Western Sydney	**(02) 9616 8586**
Sydney	**(02) 9515 6311**
Western Sydney	**(02) 9840 3355**
Far West	**1300 662 263**
Hunter New England	**1300 660 059**
Mid North Coast	**1300 662 263**
Murrumbidgee	**1800 800 944**
Northern NSW	**(02) 6620 7600; (07) 55067010** (Tweed Heads);
	(02) 6620 7600 (Lismore)
Southern NSW	**1800 809 423**
Western NSW	**1300 887 000**


Northern NSW
Hunter New England
Mid North Coast
Far West
Western NSW
Metropolitan
Murrumbidgee
Illawarra Shoalhaven
Network with VIC
Southern NSW
Nepean Blue Mountains
Central Coast
Western Sydney
Northern Sydney
Sydney
Southwestern Sydney
South Western Sydney
Illawarra Shoalhaven

WHERE TO SCORE FITS

These are only some of the NSP outlets in NSW. If you can't contact them through the number listed, or if don't know the nearest NSP in your area, ring ADIS on (02) 9361 8000 or 1800 422 599

Key to Available Services

CL - Clinic/Nurse
D - Dispensing Machine
C - Hep C Treatment/Testing
N - Naloxone Training
O - Outreach

Location	Phone No.	CL	D	C	N	O
Albury	60581800	✗	✓	✓	✗	✗
Armidale (Inverell/Tamworth)	0427851011	✓	✗	✗	✗	✗
Auburn Community Health	87594000	✗	✓	✗	✗	✗
Ballina	66206105	✗	✓	✗	✗	✓
Bankstown	97802777	✗	✗	✗	✗	✗
Bathurst	63305850	✗	✓	✓	✗	✗
Bega	64929620	✓	✗	✓	✗	✗
Blacktown	98314037	✓	✓	✓	✗	✓
Bowral Community Health	48618000	✗	✓	✗	✗	✗
Brookvale	93885110	✗	✓	✗	✗	✗
Byron Bay	66399675	✗	✓	✗	✗	✓
Campbelltown,Liverpool, Camden Hospital ED	87386650	✗	✓	✓	✗	✗
Canterbury HARM	97182636	✗	✗	✓	✓	✗
Cooma	64553201	✓	✓	✗	✗	✗
Dubbo	68412489	✗	✓	✓	✗	✗
Gosford	43202753	✗	✓	✓	✗	✓
Goulburn S East	48273913	✓	✓	✓	✗	✗
Grafton	66418712	✓	✓	✓	✗	✓
Hornsby	94779530	✗	✓	✗	✗	✗
Ingleburn Community Health	47822133	✗	✗	✗	✗	✗
Katoomba / Blue Mountains	47822133	✗	✓	✗	✗	✗
Kings Cross KRC	93602766	✓	✓	✓	✓	✓
Lismore HARM	66222222	✗	✓	✗	✗	✓
Liverpool	87386650	✗	✓	✗	✗	✗
Manly	99772666	✓	✗	✓	✓	✗
Marrickville HARM	95620434	✗	✓	✗	✗	✗
Moree	67570000	✗	✓	✗	✗	✗
Moruya	44741561	✓	✓	✗	✗	✗

Location	Phone No.	CL	D	C	N	O
Mt Druitt	98811334	✓	✗	✗	✗	✓
Murwillumbah	66709400	✗	✓	✗	✗	✓
Narellan Community Health	46403500	✗	✗	✗	✗	✗
Narooma	44762344	✓	✗	✓	✗	✗
Newcastle Harm Min Prgm	40164519	✓	✗	✗	✗	✗
Nimbin	66891500	✗	✓	✗	✗	✓
Orange	63928600	✓	✓	✓	✗	✗
Parramatta	96875326	✓	✓	✓	✓	✓
Penrith/St Marys	47343996	✓	✓	✓	✓	✓
Port Macquarie	65882915	✓	✓	✓	✗	✓
Queanbeyan	61507150	✓	✓	✓	✗	✗
Redfern HARM	93950400	✓	✓	✓	✓	✗
Rosemeadow Community Health	46334100	✗	✗	✗	✗	✗
St George	91132944	✗	✓	✗	✗	✗
St Leonards	94629040	✗	✓	✗	✗	✓
Surry Hills ACON	94629040	✓	✗	✓	✗	✓
Surry Hills NUAA	83547343	✓	✓	✓	✓	✗
Sutherland	95221046	✗	✓	✓	✓	✗
Sydney Hospital	93827440	✗	✓	✓	✓	✗
Tahmoor	46836000	✗	✗	✗	✗	✗
Taree	65929315	✓	✓	✓	✗	✗
Tweed Heads	0755067540	✗	✓	✗	✗	✓
Wagga Wagga	69386411	✗	✓	✓	✗	✗
Windsor	45605714	✗	✓	✗	✗	✗
Wollongong/Port Kembla	42751529	✗	✗	✓	✓	✓
Yass	62263833	✗	✓	✗	✗	✗
Young	63828888	✗	✗	✗	✗	✗

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Contact the UN Editor to discuss contributing your story to UN. Letters to the Editor can be sent by email or to the NUAA PO Box. Artwork and cartoons welcomed.

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NUAA is the peer-run drug user organisation

GET INVOLVED!

BECOME A MEMBER!

Members, including people in prison, receive print editions of User's News and Invitations to community events including training and consultations

VOLUNTEER

NUAA is looking for volunteers for its Needle and Syringe Program and DanceWize - our new harm reduction program at NSW music festivals

PARTICIPATE IN TRAINING.

NUAA conducts harm reduction and overdose prevention training across the state – register your interest and we'll let you know when we're in the area

Find out how to take the next step!

Check out our website **www.nuaa.org.au** or email **nuaa@nuaa.org.au** or call us on **02 354 7300** or **1800 644 413.**