

“Don’t give them what they want”

I left my home of Australia 10 years ago trying to find a way to get off heroin. I thought the beautiful scenery in Europe might inspire me, I thought London might show me a new way of looking at life. I thought I might find something that would interest me more than heroin. But I should have known that doing what many of my peers call a ‘geographical’ is very rarely the answer.

I had already been to a variety of treatment clinics and surgeries in Australia. I had had habits on heroin, cocaine, benzo’s, and a few other pharmaceuticals, but my treatment options, no matter where I went, were methadone, methadone and more methadone. I felt screwed by the time I came to England. I felt numb and I wasn’t well either. By the time I arrived, I was hanging out, sick, extremely tired and depressed and went to a hospital looking for some relief. I was offered a two week blind detox on methadone. Suffice to say, I remained sick. I felt like I was trapped and my head just kept wanting to be well. I was in a new city and hoping to find a bit of peace of mind, I had to begin to learn the ropes of the British prescribing system. Suffice to say, it has taken me another 10 years to finally land on my feet, with a script that suits me, Erin O’Mara, an individual with individual needs. After almost 20 years I can now look to a future – that’s what a tailored prescription has really meant..

To get to this point, I have attended around 10 different methadone programmes, 2 heroin prescribing programmes, seen numerous GP’s (both private and NHS), and sat with plenty of psych nurses, key workers, social workers, psychiatrists and counselors. I’ve been to rehabs in the country and detoxs in the city, made plenty of attempts at stabilizing and fought to come off completely with concoctions of pills gathered from anyone who would give them to me or using acupuncture, massages and herbal teas. It wasn’t that I didn’t try. I really did. Everything was riding on it. My life, my health, my liberty. But I just kept coming back to the same old blanket prescribing of methadone linctus – a drug that, while I know it helps many people, isn’t for all of us. Drug users are not born from the same mold, we all use for different reasons, we all take different drugs, we take differing amounts of different drugs and offering us variations on the same methadone theme, while helping many, is still going to leave thousands of us out in the cold. And how long can we afford to stay frozen out?

For many drug users, getting on the treatment rollercoaster means you are certainly in for a ride and a half. I have learnt that the right prescription is only half of the equation – the other half is the treatment and understanding you receive from your prescriber. It can be so hard to explain to some prescribers that it is the creation of the types of prescribing systems –that can cause so much difficulty in adhering to it. The clinics that offer only a 2 week break or holiday a year (no opportunities to mend familial bridges there then), the confusion or distrust around your intentions, the reducing of your script every time you take something else or have a need to top up your dose, having to turn up for dosing at inflexible times -whether you have to pick up your kids or go to work or uni or like being closely watched as you sit for 3 hours on a toilet to give a urine sample before you’re allowed to get your dose. I’ve been to a clinic where a girl burnt off her tracks with a cigarette because she was afraid the doctor would cut down their methadone if they found out she was still using on top. And, at that particular clinic, sadly she would have been right. Getting the treatment dose right is essential, finding the drug that suits that individual is critical, allowing room for maneuver or looking for other drug treatment alternatives is the most important of all.

Since leaving Australia where we were all prescribed methadone – no options, no alternatives to coming to the UK where there was some room for maneuver with prescribing has been an interesting experience. Heroin has always been my drug of choice and for me, methadone linctus just didn’t work. It didn’t work for me in Australia and it wasn’t working for me here. I looked everywhere for a more suitable script. I’ve tried morphine, slow release tablets and ampoules – which, while being a welcome relief from methadone, I found it incredibly constipating and uncomfortable and found myself again, unhappy, not wanting to take it and looking for something else. I will never forget that particular doctor who was then the first one to actually sit down with me and talk to me about what it was I felt I needed. But while we both

knew it was probably a diamorphine script, he was powerless to offer me it. Thus he offered me what we thought was the next best thing. Morphine. It wasn't that I didn't want it to work, I did, more than anything else in the world, but it just wasn't suitable for me.

It is so important to be able to offer alternatives to drug users when they come in looking for treatment. Generalisations about drugs and drug users are made without considering how cultural differences mediate and transform both the reality and meaning of a person's drug use. Younger users, older users, women, men, mothers, those on parole or probation, those with HIV and or Hep C, injectors, smokers, pill takers and snorters – how can we expect to support an individual with a chemical dependence if we are only prepared to offer them methadone?

It has taken years for methadone to be accepted by doctors, and still it is only by a minority. Without question it clearly works for some people and it certainly has a place in prescribing options. But there are other alternatives. At Black poppy we are receiving many letters about how helpful Subutex has been (mainly for detoxing) but many more letters from people wanting to know how they can encourage their doctor to prescribe it. We all know it's out there but where? How can one be prescribed it or is it too a lottery depending on your area or GP?

Morphine also holds an important place but is usually prescribed by private doctors and is prohibitively expensive. I have a good friend who has tried methadone unsuccessfully many times and finally went to a private doctor to try and get MST's or slow release morphine sulphate tablets. Because he can't stomach methadone linctus and doesn't want to inject methadone ampoules, his morphine script has meant every fortnight he has to resort to spending literally his entire benefit cheque on paying his chemist and his doctor and is still fifteen pounds short. His clothes are old, his cupboards are empty and he is fighting off a depression that threatens to jeopardize his whole stability. This is because he cannot find a single NHS doctor in his area to prescribe him morphine tablets – despite his private doctor offering support. The last time I saw him he was eating the only thing he had in his cupboard - tomato paste. Why?

There are many people who have either dropped out of the prescribing system altogether or regularly have to top up with additional drugs because the system just isn't geared for those with poly drug dependencies. While years ago many people just seemed to stick to using one or two drugs at a time, these days poly drug use has become the norm. How are doctors going to help support people if they can't or won't take on anyone who has multiple drug problems. This is 2003 and this is the way drugs are now taken. Both patients and doctors must be prepared to be open and have the courage to admit when something isn't working and be flexible when considering alternatives. It isn't easy. I know drug users can be difficult patients. When that doctor sitting opposite you seems to have the power to change your life – things do and can get emotional. For treatments to work we all have to be open and honest. The system has to let you be open and not punish you for what it sees as 'not conforming to the treatment'. Relapsing is part of stabilizing as well as part of 'the cure'.

For me, after years of searching for some stability – I was finally offered the chance to try diamorphine – or heroin on a script. It is extremely rare to get this chance and I believe the deciding factor was because I had recently contracted HIV.

Now I've had the opportunity to participate in 2 very different approaches to heroin prescribing - and it has taught me a great deal about how the differing structures, regulations and nuances behind the way heroin is administered to users, is critical to the success of the programme. For example: The first heroin script I received was back in 98, through a pilot project in London, whose aim it was to study the effectiveness of prescribing either pharmaceutical heroin, or methadone in injectable form to drug users.

The first error and one eventually admitted, was to limit the amount of diamorphine prescribed, to an unmanageably low 200mg. (The Swiss, The Dutch and others, myself included, have found 400 – 1000mg much more suitable). Pharmaceutical heroin does not have a long half life and to seriously underestimate the dosages required was to become a momentous error and one that would seriously jeopardise a person's ability to adhere to their prescription. With a median age range of 38 and an average injecting career of 19 years, many clients at this project had other drug problems, such as crack, benzodiazepines, alcohol or cocaine which I don't fully believe were taken on board at the time. The severely punitive clinic regulations or 'protocols', would

bear this out. i.e. anyone caught using any other drugs or 'topping up' their rather limited dose, would immediately be 'sanctioned' by way of a 30mg reduction in ones *daily* prescription, reducing even further ones ability to adhere to the programme. Once ones prescription began to lower, it was practically impossible not to 'top up' with something else, and so clients, myself included, were locked in a constant spiral of script alterations.

A stifling clinic environment would be the clinics 2nd fundamental error, where people would be unable to talk about their other drug issues for fear of a variety of repercussions. This would lead to an even more alarming situation where clients hid serious medical issues for fear of their prescription being stopped or being transferred back to methadone linctus.

The importance of maintaining an environment where users can talk openly and honestly to their keyworkers and consultants is a crucial element in a person's success on any drug treatment programme and this was no exception. A deeply unhappy client group had nowhere to go to complain about their treatment and having to attend to such a stressful and demoralising project promptly each morning in order to receive ones medication only exacerbated people's and my own depression and did little if nothing to improve the spirits of those attending.

Two years later, after a desperately unsuccessful period trying an injectable methadone prescription, I had developed a dire crack problem, was drinking alcohol regularly for the first time in my life, and began having regular seizures from increased benzodiazepine use.

It was at this time that, after an enormous effort and support from my GP Chris Ford, my mum, my local MP, (and bailing up the prescribing doctor at a conference I attended), I managed to secure a place at London's Maudsley hospital, where there was a doctor prescribing heroin to a small group of patients. I clearly remember my sense of complete and total desperation. I felt I could not go on any longer, that if they didn't help me I would be – I didn't know where I would be and that was the trouble. I felt that this was my last hope, that I'd tried everything. And I begged.... Most drug users know well the feeling of someone else, a doctor, having the power of your life in their hands, *every single day*. A script started or terminated making the difference between life and death, or misery and hope. Sometimes you end up *having to beg*...

I have now been on my heroin script for 2 _ years. My health has improved substantially and my HIV doctor is delighted – as is my mum and I. My moods and energy levels have improved considerably and so has my ability to contribute to life and my community. I founded and continue to work on what has become a National drug users' magazine called Black Poppy, and I am actively involved in drug user politics, journalism and harm reduction issues. It has been a difficult journey, but thanks to my mum, my mates and the open-mindedness of my doctor, who fully engages me in my treatment decisions and doesn't wave punishments in my face, I have stabilized and am well, for the first time in 18years of using opiates.

Now, I have somewhat of a vested interest in the campaign towards prescribing heroin – both here and overseas. Last year, my mum returned to Australia to live and while I would have liked to go with her, the thought of losing my heroin script after fighting so hard to get it, felt more than I could bear. I am HIV positive. There are going to be times when I will want to be near my family. Yet archaic laws in Australia forbid me from even entering the country with my prescription. How can this be legal? Anyone, on any other medication, would be permitted to continue that medication in another country but these basic human rights do not extend to drug users. The intense and totally unfounded hysteria that surrounds the prescribing of heroin to drug users sadly endures and has made the campaign to prescribe heroin in Australia a momentous task. Yet while campaigners look to the British System for guidance, it would be a mistake not to closely examine both its failings and successes. The potential for problems in importing a system that hasn't been culturally fine tuned for the British using community are great because to get it wrong, Britain may lose the chance to ever attempt it on a large scale again. The Swiss users have to return to their heroin prescribing clinic *3 times a day* to receive their heroin, watched over as they inject by a clinic nurse. Although the Swiss programme has had incredibly positive results, would English users blossom under such a severe restriction of an individual's freedom? Or if the dosage is not allowed to be adjusted to suit each individual, as occurred before at the London clinic, what chance is there of success?

While there is **undoubtedly** a role for the prescribing of heroin to heroin users, it is important to remember how crucial the role of the heroin user is in the planning, implementation and evolution

of a heroin programme – or any drug treatment programme for that matter. Users must be involved every step of the way and accepted, as other users of health services are, as an integral part of a treatment programmes development, with rights, responsibilities and a mutual respect for experience.

I know I'm fortunate. As an Aussie living in London, there are times when I have to pinch myself that this is real – I have a diamorphine prescription!. That the long and often harrowing road of 'substitute prescribing' has finally come to an end – and now I'm free to think about my future. But in the small silences that fall between me counting my blessings, I can't help but wonder whether it's all just been a bit to little, a bit too late. I question why it has taken 18 long years to get here? Why did I have to wait until I'd been chewed up and spat out of over 10 different treatment programmes and Dr's surgeries, of at least 4 rehabs and an uncountable number of detox attempts? Why did I have to wait until I'd 'finished' selling my young body to men, til I'd got sick and deeply depressed, til I'd used every vein in my body from my neck to my feet, til I'd contracted both HIV and Hep C? Yet doctors *can* prescribe heroin to people who are opiate dependant in the UK and indeed they have recently been encouraged to by our current Home secretary, David Blunkett. Are doctors prepared to start looking at other alternatives? Is the government going to stand behind them? Support each other - doctors who are prepared to look at other options – keep each other updated. As a drug user, I know what its like to be on the other side of the fence – and as a drug user, I also know there are courageous doctors out there who are trying to do their best but are often working in isolation, with little support.

Meanwhile, 96% of all opiate based prescriptions given out to British users, remains methadone and only 449 people currently receive a heroin prescription for opiate dependence. And I am one of them.

Unfortunately, I still hear the saying, '*Don't give them what they want*'. But it's not about want anymore. It's about need and its about our lives. I would just like to take this opportunity to thank those doctors who did go that little bit further and treated me and my needs individually. Their support has got me the prescription I needed and has allowed me to be here today.

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