

## response

# Methadone Maintenance Treatment: The Consumer Perspective

Name withheld by request

### Introduction

I have been asked to provide a consumer response to the two accompanying papers on issues surrounding Methadone Maintenance Treatment (MMT). There are over 3000 people receiving MMT currently, and the service varies widely around New Zealand. I can't possibly hope to speak for all of these people, even though I do have wide experience in the areas of consumer advice, advocacy, needle exchange, and liaison with treatment providers. However, I have talked to a lot of consumers from around New Zealand, looked in detail at national and regional guidelines, listened to treatment providers and the issues that they face, and had nearly seven years experience as a consumer myself.

The two papers raise several interesting issues. The paper by Phil Townshend *et al* is a powerful piece of writing, as it puts a name and a framework to the feelings and experiences of many many MMT consumers. The second paper is less specific, but also raises some interesting points. I have always found it interesting to see the illness I have analysed to bits – it feels a lot simpler to just *be* an addict, rather than to try to understand addiction. I also find it interesting that the treatment I use is analysed to death but seldom on medical grounds. Rather than specifically reply to the two papers, I will discuss MMT issues from a consumer perspective, concentrating on some of the issues raised in the two papers.

### Drug Treatment Options

There are few treatment options for people with addictions in our society. There is abstinence-based treatment, within which there are several choices – 12 Step, Rational Recovery, residential and non-residential treatment settings, group and one-on-one treatment settings, and within the one-on-one setting all of the various methods of counselling and therapy. The relapse rate from abstinence based treatment is very high, and it is very nearly 100% if the person seeking the treatment is doing so because of the wishes of others or because of society's pressure to be drug free. For people addicted to most non-opioid drugs, including alcohol, there is no other choice – find a way to

give up, or keep using/ drinking and do your best to do the least harm in the process.

People addicted to opioids have the added choice of drug based treatment programmes, although access to these programmes can be difficult. The research shows that these programmes work<sup>1</sup>, with results typically showing that drug use and other crime reduce by 50% each year a person is in treatment, and that employment rates and access to education and training also increase. However, this still only provides one other treatment option – abstinence or methadone. And almost everyone who attempts to access methadone treatment has already tried and failed to be abstinent several times – with waiting times being so high some people attempt detoxification/ abstinence several times while on the methadone waiting list.

### Drug Based Treatment and Access Issues

For most people who wish to access methadone maintenance treatment (MMT) abstinence is clearly not achievable. The choices become continuing to use, or MMT. Most people who put their names down on the waiting list do so when they are in a desperate situation. Few think ahead and put their names down 'just in case', as when people are using a lot but are not yet really messy they will usually still believe that giving up is possible. And some people do successfully give up for weeks or months, then binge for a while, and then repeat the cycle. This can sometimes go on for years, with the individual either eventually giving up, or eventually entering treatment after years of periodic use.

By the time most people put their names down for MMT they need it *now*. There are few places in New Zealand where this is possible. In Dunedin, the waiting list has rapidly increased from 3-4 months less that a year ago, to 12 months currently and in Christchurch the waiting time is 12-18 months. By the time a person reaches the top of the waiting list, they would just about sign away their soul to get on the programme. The paper by Phil Townshend discusses these issues in detail. For most consumers the relief of finally accessing MMT is often replaced in a few weeks or

months by a feelings of powerlessness and anger regarding the rules (or 'guidelines') of most MMT programmes. This does not mean that most consumers are in a state of constant anger at their MMT providers, and many people are almost entirely happy with the service that they receive. However, no other medical therapy is as restricted or governed by rules and regulations as methadone is.

### Guidelines for Treatment

Almost all consumers have reason to feel angry at the guidelines for treatment at some time. The description of 'liquid handcuffs' comes from the difficulty of doing anything that involves leaving the town/city where your chemist is situated. Holidays, work, school trips, and family occasions all involve either missing out, or a stressful juggle of pick-up days, take away doses, and/ or pharmacy transfers. No one can understand the stress of trying to get hold of your GP, who was meant to return your call for the past two days, because he hasn't faxed your methadone prescription to the pharmacy in another town yet, even though you saw him two weeks ago (and you've paid for the visit), and you are leaving tomorrow... unless you have been in that position (finally, when I rang the pharmacy at 5.30 that evening – yet another toll call I couldn't afford – they had received my script). I know people who have been forced to turn down work because they couldn't arrange a viable pharmacy pick-up regime with the clinic, and others who haven't had a holiday in years, because the logistics just become too complicated when they have to know where they are going to be as much as 5-6 weeks in advance (Christmas/January holiday requirements must be supplied to the clinic by early December).

All of these problems are a product of the laws surrounding the dispensing of methadone *and* the guidelines of each treatment provider. To be eligible for take away doses you must fulfil certain requirements ('safety' requirements). These vary from clinic to clinic, and are often the result of clinicians, personal philosophies on issues such as the use of cannabis (Christchurch and the West Coast), what constitutes safety (all clinics, but they all have slightly different definitions of safety), or the required outcomes of treatment (ditto). I don't doubt that these people are knowledgeable in their field, and that most of them genuinely care about their clients and their well being. However, the regional variations illustrate just how much clinicians' personal beliefs determine the guidelines. There is very little consumer consultation. The introduction of some Consumer Adviser positions and some consultation with groups such as the Methadone Monitoring Group in

Christchurch allow for some client input, but this is very limited.

It is not surprising that consumers feel angry having their lives limited by what is effectively the clinical opinions of their local treatment service. Older users talk of the sense of apprehension every time there is a change in the senior staff at their local service. Too many times in the past they have had their lives turned upside down by changing clinic policy caused by changing staff – hence a different version of the 'guidelines'.

Clinic staff often feel they are not in a position to fully trust their clients. Similarly I get angry at statements such as

"Typical addictive behaviour generally indicates that a counsellor is not in a position to trust his or her client, as demonstrated by the characteristic manipulative and deceptive nature of substance dependent individuals and their susceptibility towards certain actions which constitute breaches of the programme's protocols."

Most consumers feel that they are not in a position to be honest with their counsellor, as they will be punished for telling the truth. Their counsellor is there partly to see that clinic guidelines are enforced, making them part 'policeman' (/woman). This is not a situation conducive to building a trusting relationship, but it has little to do with the "manipulative and deceptive nature of substance dependent individuals", and a lot to do with self preservation, and trying to maintain what freedoms the individual has managed to achieve within clinic guidelines.

### Solutions, Ideas, Positive Changes

There are many very good aspects to MMT in New Zealand – it works, it reduces drug-related harm, and it enables over 3000 New Zealanders with a potentially debilitating illness to lead normal lives. The issues raised above can be summarised into two points:

- 1) Consent related issues, and the need to acknowledge that people accessing MMT will sign anything to access treatment
- 2) Regional guidelines, and the problems that national variations bring.

Phil Townshend suggests that contracts should be revisited once a client has been stable in MMT for some time. Another issue of importance is the defining of what is a successful outcomes for MMT. In her MA Thesis, Sheridan Pooley (Pooley, 1996) discusses the idea that consumers have very different ideas as to what constitutes a 'successful outcome'. Things such as not spending their food money on

drugs, having time to spend with the children, getting a part time job, going back to school, being able to afford to take the family on a holiday, being happy, not using as often, doing less shoplifting, being out of prison for X time, being able to concentrate on playing music, and only taking half of tomorrows take away today have been given by consumers I've talked to as examples of success. Being drug free may be a long term goal, but few consumers need to achieve this to feel that MMT is successful. Similarly, many consumers value the relationship they have with their caseworker or GP, but it is rarely seen by them in terms of the success or failure of MMT. And there's a difference between dis/satisfaction with the service as opposed to methadone treatment itself.

Most consumers would like a set of national guidelines, with some room for individual flexibility. Most consumers would like the opportunity to have input into drafting these guidelines, or for other consumers to be consulted on their behalf. When I was preparing a submission on the Draft National Methadone Protocols there was significant consumer input, however the layout was not consumer friendly. Most consumers either gave a separate written submission that addressed things important to them – addressing the categories in the draft document only in the most general terms - or they commented on one or two specific things. Significant consumer input into national guidelines would need to be done partly by verbal consultation, and would need to include each clinic actively seeking consumer input. The Draft National Guidelines still gave massive potential for regional differences. If this is not addressed in the final version then there will be no resolution to the problems caused by the regional variations in the guidelines.

### Consumer Representation

I have written little about consumer representation. I will finish by mentioning that Standard Nine of the National Mental Health Standards says that all services must include consumer input in all aspects of service provision. There are many ways that this could be done – some better than others – and it will probably take several years for consumers to develop our networks. But in the mean time, if every provider were to fulfil its obligations under Standard Nine then the consumers in the Consumer Advisor positions would be able to begin to develop these networks. This isn't only up to consumers - it is up to the services to fulfil their obligations under the National Mental Health Standards. A commitment by the services to true consumer representation and thereby developing a partnership approach is the only

way standard nine will be achieved. This would improve MMT and make it more consumer focussed while still allowing for the legal and safety requirements of the programme. The more often consumers and providers talk together, the more we will find common ground, and the more we will be able to resolve our differences.

### Summary

Methadone Maintenance Treatment in New Zealand provides a successful drug based treatment option for over 3000 opioid dependent people. Two of the major problems in treatment practices involve the treatment guidelines. Consumers will consent to almost anything in order to access treatment, so any contract should be renegotiated when the consumer has been in treatment for some time. The guidelines themselves have too much regional variation. There needs to be a set of national guidelines which incorporate the best elements of each programme as determined by the service users, otherwise the individual philosophies of clinic workers will continue to determine my, and the other consumers', quality of life. On the one hand they talk 'normalization' but on the other adhere to policies which do not support it. If anything they deny us the freedom to be normal. Increased consumer input, as laid out in Mental Health Standard Nine, would ensure adequate consumer input into resolving these problems. Failure to acknowledge these problems and seek the best solutions would prevent the very good MMT programme in New Zealand from achieving its full potential. It is in the best interests of the thousands of consumers and hundreds of providers to work together to find mutually beneficial solutions.

### Acknowledgements

I offer thanks to Sheridan Pooley for assistance in writing this response. Thanks also to the consumers who provided comments.

### Note

1 Research has been done by John Dobson and the Christchurch Methadone service, and Jocelyn Walker, Glenys Dore and CADs in Dunedin, amongst others. The results are all fairly similar, but I do not have access to the detailed findings.

### References

- Ministry of Health (2001). *Protocol for Methadone Maintenance Therapy in New Zealand, Draft for comment*. Wellington Ministry of Health. July.
- Pooley, S. (1996). *In Another Vein: The Social Consequence of Methadone Maintenance Treatment*.