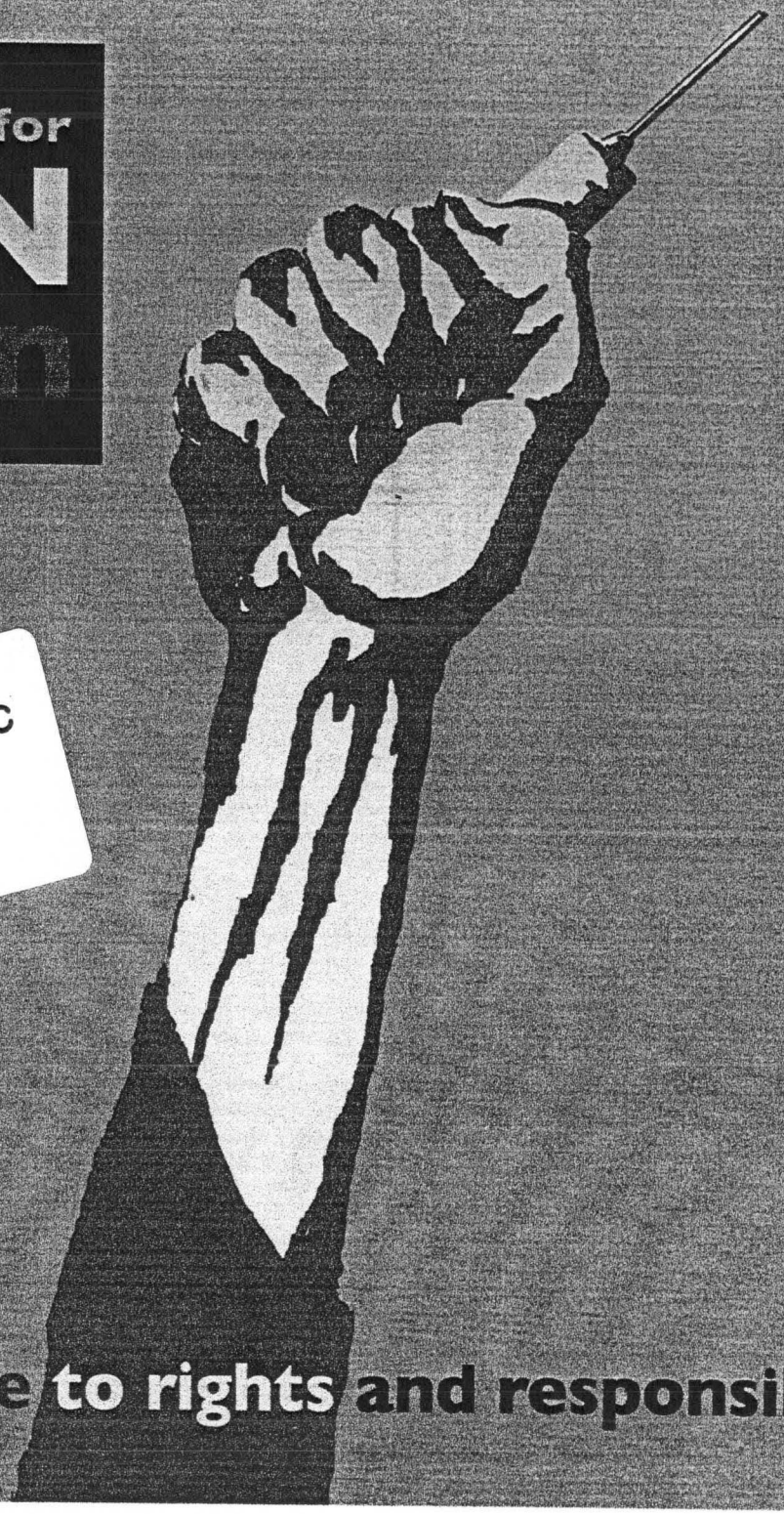
Out-patient treatment for HEROIN Addiction



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a service-users' guide to rights and responsibilities

Contents

Introduction

Why this booklet?

There are some important changes currently taking place in the way that drug treatment is delivered. Until very recently, treatment was something that was imposed on people with drug problems, rather than a genuine partnership between treatment providers and consumers. Finally, that model has started to change.

Today, drug treatment services are trying to catch up with other areas of the NHS by ensuring that they consult as widely as possible with service users in order to ensure that drug treatment becomes a real therapeutic alliance with both partners pursuing common goals.

While only the most starry-eyed optimist believes that such a revolution will happen overnight, there can be no doubt that user involvement and consultation in the planning and delivery of services is finally on the agenda. This year, for the first time ever, Drug Action Teams (the body responsible for commissioning treatment services in every area) have had to submit their intentions regarding service user involvement to the National Treatment Agency as part of their Treatment Plan for the year.

What this means is that all across the UK, people who use drug treatment services will start to see changes in the way those agencies relate to their client group. In some cases, this may be little more than extra questionnaires about what you think of the service. Elsewhere though, it means the employment of user advocates (people employed to negotiate on your behalf when you feel you're getting a rough deal from your clinic) or the establishment of service user forums – places where you can get together with others and express your concerns about the way your treatment service is run.

This booklet is intended to play a part in this process. Its aim is to help people who are seeking or already receiving treatment for heroin addiction to get the best treatment that they possibly can. In order to do that, we have to understand the nature of the treatment contract – both the responsibilities that a treatment provider has to you as a patient, and also the responsibilities that you have, primarily to yourself, but also to the wider community.

The main purposes of this guide then, are to

- educate you about the principles underlying the provision of treatment.
- help you to identify what sort of service best suits your needs.
- make the most of the drug treatment services that are available.

However, the booklet also has a secondary purpose, which is to help you to identify less effective services, and to negotiate effectively when the treatment you receive is inadequate or inappropriate.

As we go through the various sections of this guide, we will attempt to highlight those principles, and hopefully this will assist you in evaluating your treatment and negotiating with your provider.

Our view is that a good treatment service is one that can offer methadone maintenance, delivered in a timely fashion, to all who wish it, and provided in a manner consistent with the research evidence. The very best services may also offer a wider range of treatment options such as diamorphine prescribing, injectable methadone ampoules and a range of appropriate interventions for people who also have cocaine dependency problems.

Sadly, we are acutely aware that there are many areas where the treatment on offer fails to meet these high standards. One recent evaluation of British treatment provision showed that the best performing services were able to achieve reductions in illicit heroin use that were three times greater than the less effective services. There are a range of reasons why this should be the case, but one of the most likely is the failure to apply those principles of treatment that reflect established best practice.

Our goal in doing this is not to cause trouble (though you can't make an omelette without breaking a few eggs) but to help promote the process of change in order to improve the quality of drug treatment services for everybody.

There are parts of this booklet where the language and ideas expressed may be difficult. While we have tried our best to explain things as simply as possible, we understand that this is a difficult and complicated area. In an attempt to simplify things, each section has a list of key points to remember, and the final section contains advice on where to go if you need help, so if you are having problems understanding what we're trying to say, those sections may be helpful.

Some Background History

Key Points

- Different people have different ideas about what 'addiction' is and how it should be treated.
- Some people see it as an 'illness' and others as 'bad behaviour'.
- When people become addicted to heroin there are good reasons for seeing it as a medical problem.
- Treatment can help people to become stable or drug-free but it usually takes a few goes before getting it right.

How ideas about addiction affect your treatment.

There have traditionally been wide variations in the type of treatment on offer, both in the UK and elsewhere. Some services are happy to provide maintenance prescribing, some will only offer detoxification, in conjunction with some form of 'counselling'. Others won't offer any prescribing at all.

The rationale behind the various treatments offered depends largely upon the model of addiction that has been embraced by the treatment providers. Prior to the 1960's there were two competing models of addiction, these shaped our ideas about what to do about it. In the USA heroin addiction was viewed as criminal behaviour. Simply being known to be an addict was sufficient to be sent to prison for long periods. Here in the UK, addiction was seen as a medical problem. This resulted in the old 'British System' that allowed doctors to 'maintain' people with heroin prescriptions.

During the 1970's and 80's this situation switched somewhat. US researchers and treatment providers began to adopt the medical model of addiction, while here in the UK a view that addiction is just another form of 'bad behaviour' began to dominate. As a result, support for the old British System began to decline.

The truth is that any model of something as complex as addiction will be just that – a simplified model. Today, we recognize that there are many paths into addiction, and many different approaches to treatment.

So what evidence supports the view that heroin addiction is a medical disorder?

At present causation is poorly understood. Our best guess is that there are multiple pathways to the condition with genetic, environmental and behavioural aspects all having a part to play. It is these factors that account for why many, many people may experiment with heroin, but only a small proportion will go on to develop a full-blown addiction.

However, once dependence has been established there are various characteristics that make it reasonable to treat it as a medical condition.

Firstly, there is strong consistency in the medical history and symptoms of opiate dependent people, regardless of the culture or ethnic background that they come from. Addictive behaviour is not culturally specific.

Secondly, craving produces repeated administration, despite various powerful social pressures and medical consequences that should push people towards stopping their use.

Thirdly, there is a strong tendency to relapse, even when people have had long periods of abstinence, whether voluntary or involuntary.

Finally, there is a significant body of research that shows continued exposure to opiates induces pathophysiological changes in the brain. These changes persist for long periods and in some people may well be irreversible.

These characteristics mean that heroin addiction is more than just 'a bad habit' that can be overcome simply through going through a few days withdrawal (which as we all know, is no worse than a 'bad cold').

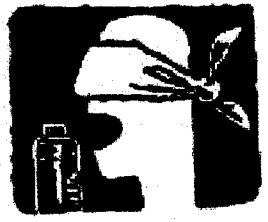
Heroin addiction, the doctors say, is a 'chronic and relapsing condition'. This means that it usually lasts for several years (the average length of a habit is believed to be twelve years) and that even if you do become drug free, there's a good chance you'll go back to using several times before finally staying off for good.

However, it is also treatable; although the various treatments are rarely 100% successful and it often takes repeated attempts before a patient achieves stability, let alone abstinence.

Getting Into Treatment

Key Points

- Getting the right treatment is important; services should find out what you want and need (detox, rehab or prescribed medicine).
- If you are young or have lots of problems this may take a bit longer.
- Treatment stands a better chance if it starts as soon as possible.
- There are standards (2-3 weeks) that services have to aim for.



Accessing services.

There is widespread consensus about several factors that are important in producing good treatment outcomes - one of these is that good treatment should be available without hindrance or delay. When you approach a treatment provider, the first thing you'll want to know is exactly how long you're going to have to wait before your treatment will begin.

The National Treatment Agency, a special health authority charged with the task of improving drug treatment in the UK, has mounted an initiative to reduce all waiting times by 2004 to a maximum of three weeks for community based prescribing and two weeks for GP prescribing and in-patient detox. Although these are currently targets, all services are supposed to be moving towards these as a matter of some priority.

So just why is it that waiting times are so long in some areas?

In some places, waiting lists may be a consequence of just too many people and not enough services. However, in others, waiting times are a consequence of services being run to serve the needs of those who work for them rather than those who use them. Protracted referral systems, overly-cumbersome assessments, punitive and arbitrary dose titration procedures and unnecessary counselling may all play some role in keeping waiting-lists higher than need be.

If you're unhappy about your waiting time – which should be measured from the time when you present to the service, to the time that the appropriate treatment begins – try to find out the reasons why you've waited so long. (If you think your treatment service has practices that cause unnecessary delays see 'Negotiating Change and Challenging Bad Practice' page 11).

What type of treatment?

Some people, on realizing that they have a problem, will immediately opt for abstinence and will be successful. Others may struggle with detox after detox, before eventually succeeding. Still others may never succeed. Although there is a range of treatments available for heroin addiction, not all of them will be appropriate for everybody. Many people who are well motivated can and do achieve abstinence. However, a sizeable majority of people who are desperate to make changes in their lifestyles go through in-patient detoxification and long-term residential rehabilitation regimes yet fail to achieve or sustain a drug-free lifestyle.

As a consequence, the most commonly used treatment for heroin addiction is some form of community substitute prescribing programme, with methadone being the drug most often used.

In the past, treatment services traditionally attempted to coerce patients into seeking abstinence whether that person felt they were ready for it or not. Not only is this approach wasteful (denying a scarce resource to those who could make the best use of it), it also reinforces a sense of failure and therefore undermines the very credibility of treatment in the eyes of the patient.

All of the various reviews of British treatment services have emphasized the importance of systematic assessment and appropriate matching of patient with the appropriate treatment. Effective assessment is therefore critical and another recognized factor in producing good outcomes.

Unfortunately, in the past some services have used assessment as a strategy to control uptake of treatment, undermining the principle that treatment should occur without hindrance or delay.

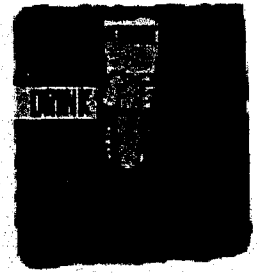
For some of us (particularly young people or those with complex needs such as coexisting psychiatric or other medical problems) a detailed assessment will be desirable before commencing treatment.

On the other hand, many of us have already been around the block several times. We already have a clear idea of what sort of treatment we want -whether it be methadone maintenance, out-patient detoxification, etc. In such circumstances there is no obvious reason why treatment should be delayed. In this situation complex assessments can become just another obstacle (see 'Negotiating Change and Challenging Bad Practice' page 11).

Prescribing Services

Key Points

- Taking methadone regularly has been shown to be a good treatment for heroin addiction providing it is at a high enough dose.
- How high that dose should be is different for different people, but it has to be enough to stop cravings and to block heroin if it's taken on top.
- There are better treatments than methadone for detox.
- A few places can use heroin as treatment but it may be difficult to get on and there will be a lot of strings attached.



So what's so good about Methadone?

The evidence in support of methadone maintenance as the most effective treatment for opiate addiction is overwhelmingly conclusive. A recent statement by independent scientific experts summarized the evidence on methadone maintenance:

- The safety and efficacy of methadone maintenance has been conclusively established.
- When provided properly, with medical and social support, methadone has the highest chance of being effective.
- 80% of people discharged from methadone maintenance relapse within one year.
- Methadone maintenance reduces social exclusion: people in methadone maintenance earn more than twice as much as those suffering from untreated opiate addiction.
- Deaths of people in methadone maintenance are one third of those among the untreated population.

There is incontrovertible evidence that methadone maintenance treatment also results in marked reductions in criminal activity, bacterial infections, endocarditis, thrombophlebitis, Hepatitis B and C, HIV and AIDS, sexually transmitted diseases and alcohol abuse. In short, the evidence for methadone maintenance is now overwhelming. Nevertheless, it is not as successful as it could be, for a variety of reasons. These are some of the identified obstacles to success of methadone treatment:

Stigma and prejudice – opiate dependent people are not regarded as patients needing treatment, but as criminals, scum, the lowest of the low. Drug dependent people are viewed as social inferiors or recalcitrant criminals -sometimes even by those people who earn their living in drug treatment services.

Balance of regulations - there is an obvious need to reduce leakage and keep drug-related deaths to a minimum; however, many treatment providers are using such issues as devices to over-regulate treatment. This has the effect of increasing costs and lengthening waiting lists. It also leads to a higher than necessary drop-out rate due to the unreasonable burden imposed upon patients, and the conflicts between the need for treatment and the desire to lead a normal life.

Inadequate dosing – in the past, methadone treatment providers tended to see themselves as advocating either 'low dose' or 'high dose' positions. One commentator has noted on the tendency of the 'low dose' advocates to present themselves as 'stern, caring, conservative parents' who were critical of others as 'liberal, permissive and enabling'.

Today, the research evidence is so overwhelming that it is nonsense to think in terms of 'low dose' and 'high dose' arguing that an adequate dose of methadone is one that provides the desired response for the patient, for an adequate period of time, with sufficient margin for effectiveness and safety.

The desired response is one that:

- Prevents withdrawal symptoms for 24 hours or more
- Reduces or eliminates any craving for opiates
- Blocks the euphoric effects of any illicitly acquired opiates

So just how high should my methadone dose be?

Obviously, this differs with different individuals. We have already mentioned the National Treatment Agency (NTA), which is currently in the process of

encouraging (or cajoling) treatment services into offering treatment based on the evidence. The aim is that all areas should have a full range of treatment options available, and that one of those should be methadone maintenance provided in a manner consistent with the good practice guidelines issued by the Department of Health (The 1999 'Orange Guidelines') and the NTA.

The NTA (2003) guidelines report that, "The evidence as it stands suggests that: higher doses are better than lower doses at retaining patients in treatment and optimising outcomes".

In many areas though, the only methadone treatment on offer is a reduction course. Unlike methadone maintenance, there is no research evidence showing that methadone is a particularly effective drug to use in outpatient detoxification; in fact, the evidence is exactly to the contrary.

As the NTA (2003) guidelines say, "Methadone as an agent for detoxification is problematic for a number of reasons including its relative addictiveness and long duration of action". Drug users have known this for many years; this is why many of us when genuinely seeking detoxification (rather than just a breather from scoring on the street) would opt for weaker, short-acting opiates such as dihydrocodeine.

As a patient, you need to be absolutely clear about your needs. A useful analogy to heroin addiction is that of diabetes. A great many diabetics would be able to avoid any problems if they were simply prepared to stick to a very limited and rigid diet. However, very few find themselves able to stick to such a diet, and as a result, they rely upon drugs to maximize their stability and enable them to lead a normal life.

Methadone and other forms of opioid agonist maintenance fulfil a similar role to insulin. For those people who are unwilling or unable, for whatever reasons, to manage to sustain abstinence from drugs and drug use, maintenance treatment can provide the stability that allows them to lead a relatively normal life.

If you want maintenance treatment (whether long or short term) then you need to say so, and say so explicitly. You have no reason to be ashamed or embarrassed about asking for it. It's the most successful recognized treatment for dependence on heroin and other opiates.

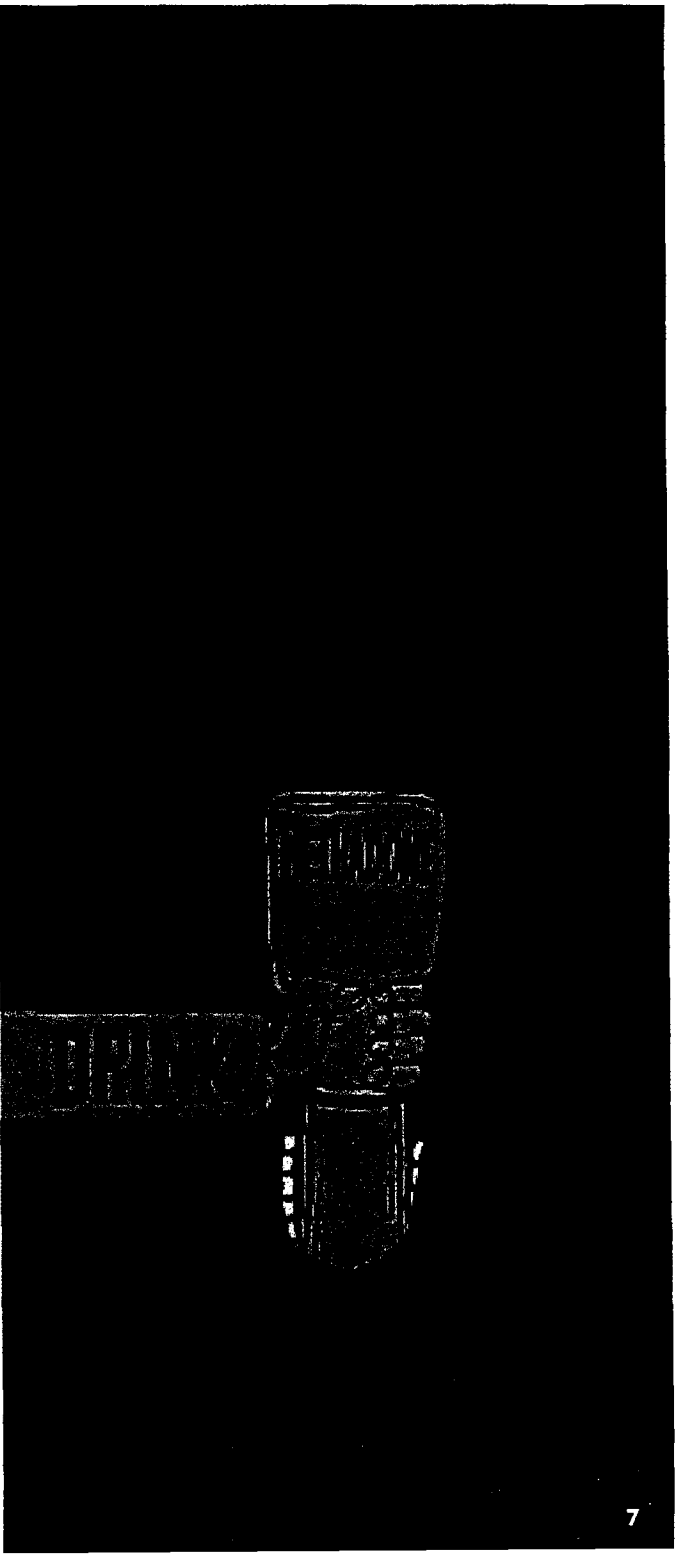
If you are concerned about your treatment options see 'Negotiating Change and Challenging Bad Practice' page 11.

Heroin maintenance?

Although some services currently offer diamorphine to a small number of patients they feel don't respond well to methadone, it's a very small number of services that offer it and an even smaller number of patients who receive it.

The Home Secretary, David Blunkett, has recently indicated that he'd like to see some expansion in heroin prescribing, and there are a number of research projects currently underway. However, it's unlikely that any expansion in heroin maintenance will resemble the old 'British System' and it seems far more likely that the people who get it will be the people who are currently being labelled 'non-responders', i.e. those who don't respond well to methadone maintenance treatment and are the most chaotic and the most criminally active patients. If there is an expansion in heroin treatment, then it's likely that those who are accepted will be expected to use the drug under supervised conditions in 'fixing rooms', turning up twice or three times a day to use their dose.

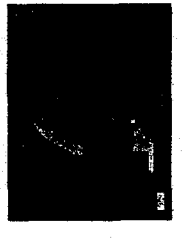
Do you still want it under those circumstances? If so see 'Negotiating Change and Challenging Bad Practice' page 11.



Rights and Responsibilities

KEY POINTS

- You are entitled to good treatment services, but these cost money and in return you will be expected to keep your end of the bargain by turning up, not using on top and to make some changes in your lifestyle.
- Treatment is provided to make you healthier and to stop drug crimes.
- Don't become a 'meth-potato': do stuff.
- Your care plan should help you to deal with any medical and social problems that you think you have, and set some short and longer-term goals that you believe you can achieve.



So now for the responsibilities...

To summarize what we've said so far then : if you are someone with an opiate problem and are seeking drug treatment, then you have a right to receive treatment that is supported by the evidence, regardless of where you live. You should be able to access this treatment in a prompt and timely manner. There should be no artificial barriers to access.

Although the menu of available options may be wider in some areas, at the very least, methadone maintenance using oral methadone in adequate therapeutic doses should be available to anyone who wants it. This should not be part of a coerced detoxification programme -indeed, if you are seeking detoxification then there are other drugs that are much more appropriate for this purpose.

However, as a patient of drug treatment you also have certain responsibilities. It's a two way street here. Clinics aren't shooting galleries and doctors aren't just dealers. In order to get the free supply of legal drugs that you're seeking, you really need to keep your end of the bargain.

Life on the Care Plan.

The best way to make the most out of your treatment is to understand exactly what it is that is going on, what expectations the system has of you and what you can expect of it. So far we've gone into some detail explaining what you can expect from the system. Now we're going to talk for a little while about what the system expects from you.

The central component of your treatment isn't your drug or your dose, it's a thing called a Care Plan or the Treatment Plan. This document is generally drawn up as a result of the discussions between you and your keyworker and it should outline your short, medium and long-term treatment objectives. Treatment workers have traditionally had a strong tendency to impose their own goals on patients, then get all disappointed when you didn't attain the goals that they'd set for you. Well, what a surprise!

If you've read this far, then you obviously have the desire and the capacity to be a well-informed patient. As such you should be more than capable of weighing up the various options that confront you, and deciding which best suits your needs.

For some people, their goal may be to become drug free in the short or medium term. For others, they may feel that the best outcome they can hope for is to secure and maintain a high level of stability on some form of maintenance. Either of these are widely accepted as satisfactory treatment goals, and you should not allow your drugs worker to attempt to impose goals that you feel are either unrealistic or unattainable.

However, if a particular treatment isn't working, then you cannot reasonably expect your service to continue to provide it for you. That would be downright stupid. The indicators of how well drug treatment works include improvements in health and social functioning, and reductions in crime and illegal drug taking.

What does this all mean?

If you want a maintenance script and you want to keep it, then you'd better keep your end of the bargain. This includes:

Keeping appointments -- if you do have to cancel, a phone call and an explanation are easy to make. After all, you never had any problems calling your dealer, did you?

Clean urines -- while drug tests should never be used as a device for punishing patients in drug treatment, without clean urine tests it's unlikely that you'll find yourself moving away from daily pick-ups and supervised consumption.

Stopping grafting and getting a job -ultimately, you have to ask yourself what you want from drug treatment. If your goal is to achieve stability, to improve your quality of life, treatment can give you a powerful helping hand. However, you do have to do your own part, and make a commitment to changing your own lifestyle - by not using street drugs, not using in a chaotic fashion, not stealing, and while not everyone will be able to get a job, you'll be expected to at least try and take advantage of the other supporting services on offer such as structured day care programmes, employment training, etc.

Treatment! What is it good for?

Aside from the drugs, what else can we expect from our treatment providers?

The first goal of treatment is to attract and retain patients. Unless it can do this, it really is good for nothing. In the past, some services really haven't been very effective at this process.

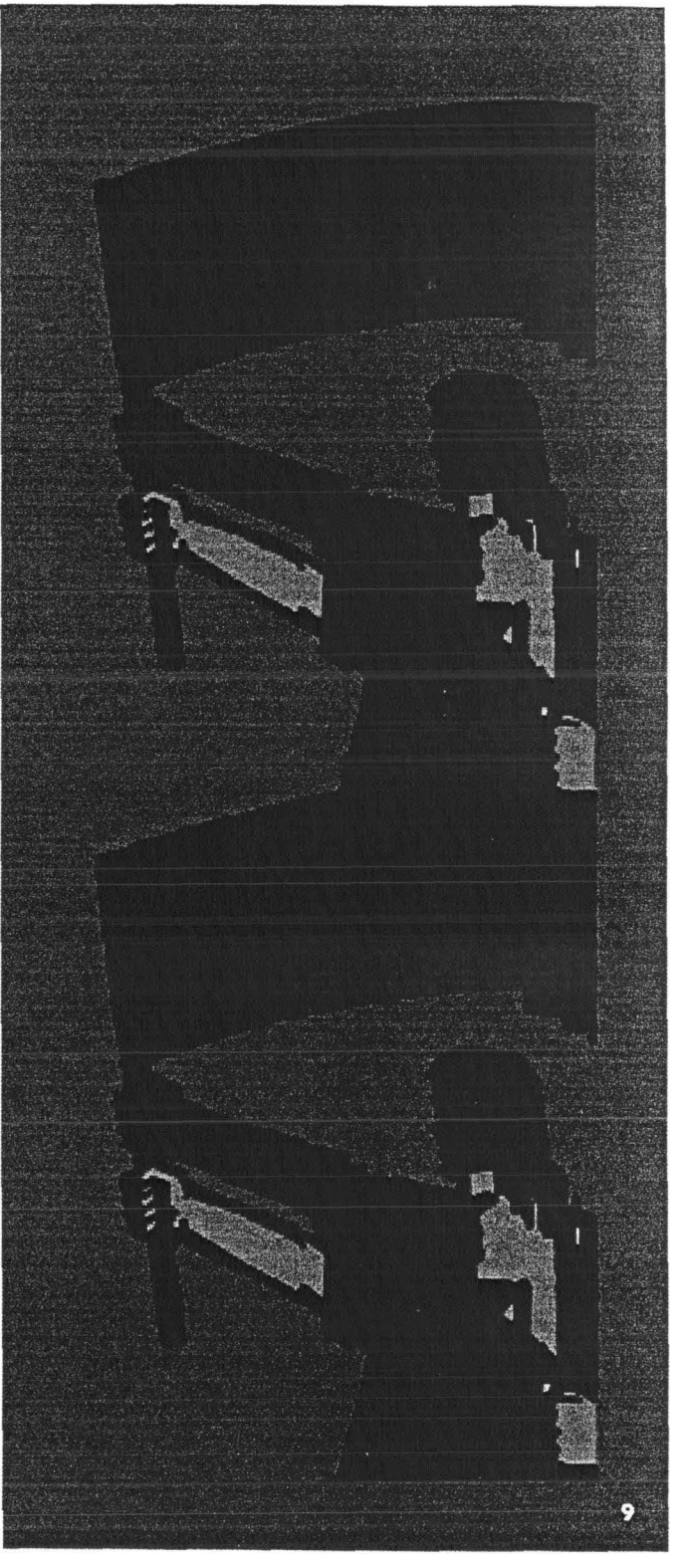
After having managed to attract and stabilize their patients then, a good drug treatment service will next begin to address the various health needs that the patient has. It has recently become quite clear that a very high proportion of people suffering from drug-related problems also have large numbers of psychiatric problems.

This doesn't mean that just because you take drugs people think that you're mad. On the contrary, it's much more likely that those of us who suffer from some undiagnosed psychiatric disorder, such as depression, bi-polar disorder, attention deficit disorder etc. turn to illicit drug use as a form of self-medication.

Treatment providers should address any of these problems that are not currently being treated. Similarly, any medical problems, whether they be related to drug use, such as thrombosis, hepatitis, infections, abscesses etc. or just general medical problems that can affect anyone. If the service does not have the staff or facilities to treat these issues on-site, then they should be able to refer you to and liaise with another service that can provide such help.

Once the health issues have been dealt with, your treatment provider should then be able to offer you support and advice on a range of issues that can support you through the process of stabilization and rehabilitation, such as housing and debt advice. For some people there can be a tendency to become passive consumers of treatment, stuck in limbo, not moving on; so try to get involved with work, training, education etc.

Again, it is unlikely that services will have these facilities on-site, but they should be able to refer to and liaise with specialist services that can help you to deal with these issues effectively.



Stability and Beyond

Key Points

- Heroin addiction is often a long-term problem involving laspes and relapses.
- Becoming stable on methadone (or other maintenance treatments) is an achievement; for some people it can take a long time.
- Doing a detox is a personal decision that needs to be thought about carefully to make sure that it's the right choice at the right time.
- If you do decide to do a detox there are treatment like lofexidine (Britlofex), buprenorphine (Subutex) and naltrexone that can help.

Getting over grafting.

As we've said, one of the main characteristics of opiate dependency is that it lasts for a very long time -and that most people who suffer from this problem will have periods when they get better, and periods when they get worse.

Unenlightened treatment providers like to take the credit when the patient gets better, and blame the patient when he or she gets worse. Enlightened providers, in contrast, recognize that this cyclical tendency is a characteristic of the condition, and that allocating blame is a pointless and futile enterprise.

Thus although abstinence from drug use is an idealized end-goal, we recognize that this period can take many, many years. Some people may never achieve abstinence and in this case the major goal of most drug treatment is to stability and an improvement in social functioning.

Of course, the fact that it can help us to accomplish this doesn't mean that it will do so automatically. For many of us, our old lifestyle is very deeply ingrained -it's all that we've known, and sustained profound behaviour change can sometimes take a very long time to achieve.

Nonetheless, many of us can and do achieve this stability through methadone and heroin maintenance, and there is no reason whatsoever why, having managed to do so, we should be coerced into putting this stability at risk as a sop to the outmoded and outdated treatment ideology of people with no real insight into our lives and experiences.

To detoxify, or not to detoxify?

Some people have a relatively brief problem, a short treatment episode and then move on. Others have a much longer, more protracted problem. For many of us, methadone maintenance is a lifeline that allows us to hold down a job, have a safe and sane family life for the first time in many years, make a break with acquisitive crime and stop taking the sort of risks with our health that lead to an early death.

Nevertheless, there will always be some people who, having managed to stabilize their use, wish to go on and attempt to detoxify completely. For those people who wish to pursue such a course of action, all drug treatment services should offer a humane detoxification programme.

Today, the evidence is pretty clear that there is no real advantage to using methadone for detoxification from opioids. Lofexidine (Britlofex) has shown real advantages in clinical trials, or if an opiate is preferred, then buprenorphine (Subutex) is another option, and your doctor can also provide additional symptomatic relief to address the problems of insomnia, diarrhoea, muscle pain, cramps etc. when necessary.

After detoxification, you might also wish to look into the possibility of using naltrexone for a period, in order to help prevent any possible relapse.

There are a great many people who are desperate to stop the use of opiates. Some of these people will succeed the first time they try, others will try a hundred times and still continue to relapse. Other people will be comfortable with methadone maintenance as a treatment option and may never try to detox.

Whatever category you fall into, it is important to realize that the decision to detoxify should always lie with the patient. It's an essential option for those who want it, and we've yet to hear of anywhere that doesn't offer it; but if detoxification is the only thing that is on offer at your clinic and you're looking for something different, then it's time that you took action.

Activism and User Involvement

Key Points

- Treatment works better if you are actively involved in making any decisions.
- If a particular treatment isn't working you can't expect it to carry on.
- If there are things about your treatment or your Care Plan that you are unhappy about, you should ask polite questions about them.
- If you feel you have a good argument but cannot get an answer, you can get advice from a service-user advocate, representative or organisation (see next section).
- If need be, you (or they) can write to the manager of the service, to your Drug Action Team or to your NTA regional manager.

Partners in prevention.

The research clearly shows that treatment works best when the patient plays an active role in a collaborative relationship between provider and receiver. In the past, treatment providers tended to see patients as passive consumers of treatment -- it was something that was done 'to' us, rather than something that we both do together. Again, enlightened treatment providers are starting to take this view.

By playing a more active role in your treatment, you're much more likely to get the sort of outcome that you're seeking. Part of that process is embracing those aspects of treatment that work for you, and offering a constructive critique of those things that seem irrational, arbitrary and unjust.

We've already mentioned the care plan or treatment plan. This document should be agreed upon as a collaborative process between patient and worker. However, ultimately, the choice about what treatment options are most suitable must lie with the patient, and not with the provider. If it doesn't work for us then everybody looses. Of course, if a particular course of treatment is not showing benefits after a reasonable period, treatment providers cannot be expected to keep on doing something that doesn't work.

On the other hand though, if a treatment provider isn't prepared to offer you a legitimate treatment modality with a sound evidence base, or makes arbitrary or capricious decisions regarding your treatment, then such behaviour must be challenged.

Negotiating change and challenging bad practice.

So far we have tried to describe how to make a reasonable judgement about how good (or bad) a treatment service is, and what can justifiably be expected from us as service users in return. We are aware that in the past there were common problems such as :

- Practices that cause unnecessary delays or long waiting lists (e.g. long assessments, unwanted 'counselling').
- Non-availability of treatment that you believe is most appropriate for your needs (e.g. long-term methadone maintenance, heroin prescribing, appropriate detox regimes).
- Non-negotiation of treatment components (e.g. insufficient dosage, inappropriate goal setting, unwanted care plan components).

If your service does not provide the treatment that you believe to be most appropriate for your needs, or is not able to provide it within a reasonable time frame, then you should begin to negotiate changes. We suggest that you respectfully challenge such practices and ask in whose interests they are being perpetuated. If this proves unfruitful then you should complain, and see your complaint through to a satisfactory explanation or resolution.

Where to start.

The first place to raise your concerns should be with your keyworker. You can do it informally at this level -simply ask them why they don't do what it is that you believe they should be doing, or why they do something that you feel they shouldn't. Quite frequently this will be enough to clear up any misunderstandings and have the issue resolved.

Sometimes you may find that your problem is with an individual worker; however, on most issues they are likely to seek to resolve most problems amicably. Often, all it will take is a request to speak to that particular worker's supervisor or line manager. Occasionally though, staff will feel the need to back each other up; alternatively the thing that you wish to challenge might be an aspect of clinic policy. Under these circumstances, a formal response may be necessary.

If this is the case, I suggest that you keep careful notes so that your claims are accurate with regard to date, time and what you claim was said to you. Then, when you do make your formal complaint, make it in the form of a letter. If this is all looking a bit tricky, check out the 'People that can help' section.

Getting to grips with your case notes.

If your complaint relates to an aspect of your care, you should first try and examine your case notes. You have a right of access to these, except in situations where child protection issues are involved. Even in this situation you can still have access to the rest of your case file.

You have an absolute right to see these; a good drugs worker should show them to you at the end of every session, and should have you initial them as a true and accurate record of what was discussed. Unfortunately, at the moment such behaviour may still be pretty rare.

You will need to put in a formal request to see your file. The first stage in this process then, is to familiarize yourself with your care plan and the rest of your case notes. You have a right to expect to be left alone in a room with them for as long as it takes you to do this. Take along a pen and paper in order to take detailed notes and make transcripts of anything that illustrates any bad practices or supports your case.

Taking things further.

In some cases, the keyworker may be following his/her agency's policy and will be unable to make any difference. They may even be personally sympathetic to your problem and want to work in a different way, but if something is a policy of the agency, their role is to implement this policy not to undermine it.

In these circumstances, your next step has to be to take up the issue with the manager of the service. When you reach this stage, you will be well advised to make your complaints in writing.

Ask your keyworker who the clinical manager of that service is. Your particular service may be one part of a larger collection of drug services across your particular district, for example, as part of a health trust. In this case, you should try and identify the clinical director of the trust and address your correspondence to them as well, also sending a copy to the manager of the particular branch that you use.

This first letter should be clear and polite and lay out the nature of your problem and the underlying reasons. Give them a reasonable amount of time to reply and to look into the problem.

If your complaint concerns an issue related to your treatment (for example, the service has made a decision that you think is not in your best interest or may have negative consequences), then you can ask for a review of the decision.

If you are dissatisfied with the outcome of the review, then you have the right to ask for a second opinion. If you do ask for a second opinion, you may want to think about which particular doctor or service you would like to provide such an opinion.

If your complaint is on a matter of clinic policy rather than a matter of your treatment, you may think it more appropriate to go outside of the clinic system completely with your complaint.

For example, if you believe that methadone maintenance is the most appropriate treatment for you at this time, and you are told that this particular clinic doesn't offer maintenance at all, then you will need to write to the Drug Action Team.

Similarly, if a worker or a doctor tells you that the clinic has a maximum cap on methadone doses, or you are unable to get an appointment at your clinic within a reasonable period of time, or your clinic puts up obstacles that make it difficult for you to be seen etc. then you should write to your local Drug Action Team and ask them :

- if they are aware that they commission services that ignore evidence-based treatment,
- whether they intend to commission services that do offer treatment options based on the available research,
- if not, how they mean to address this problem with their commissioning.

You should also send a copy of any such letter to the National Treatment Agency, who are charged with the responsibility for reducing waiting lists and improving the quality of drug treatment to ensure that it is consistent with the research evidence.

If you are requesting less common treatments (e.g. heroin prescribing) you should write to your clinic and to your local DAT coordinator telling them that you believe that you would benefit from this particular treatment and asking if there are any plans to make it available in your area.

If at any time you feel out of your depth or you're unhappy about the outcome you can ask if there is a Service User Representative or Advocate you can talk to. Failing that you might want to contact your local DAT coordinator or NTA regional manager to discuss local issues.

Getting back-up

People who can help.

If you have problems writing letters, feel you lack the confidence or the issue is too urgent for you to wait for the correspondence to take its course, you may want to seek out somebody that can advocate on your behalf.

The Alliance (formally the Methadone Alliance) runs a national advocacy service for people who are having problems with drug treatment. Although they are at present a relatively small organization, they offer cover across the UK and will certainly be able to advise you on the best way to proceed. They may be prepared to handle your case on your behalf, particularly if they have an advocacy worker in your area. If not and you are interested in this type of work, you can talk to them about the possibility of training in this kind of role yourself.

Alternatively your area may have a local user group -- a group of service users or drug users who have come together in an attempt to try and have their views heard, and to have some impact on service delivery and how responsive they are to the needs of service users. Ask around and see if there's anything in your area. Contact the National Drug Users Development Agency (NDUDA) and see if they can hook you up with a local group. If one doesn't exist, why not think about starting your own?

Finally, you can also approach your local branch of your Patients Advice and Liaison Service (PALS). Although this service isn't drug treatment specific, they may still be able to offer support and help you with writing letters, making phone calls etc.

In conclusion

Although there is still a good deal of bad practice to be found out there, there is a growing recognition (at the highest levels) that drug services are going to have to change.

Many people and many organizations are trying to bring these changes about, but ultimately the only people who can bring these issues to light are us, the patients.

In the past people have had worries about making complaints against the services that they use because they've feared that the staff would use their power over the prescription pad to victimize troublemakers.

In our experience this very rarely happens; once the problem is resolved, people move on and get on with the new regime.

Ultimately, treatment providers and treatment consumers should have exactly the same goal –the provision of good, high quality drug treatment services to everyone that wants or needs them.

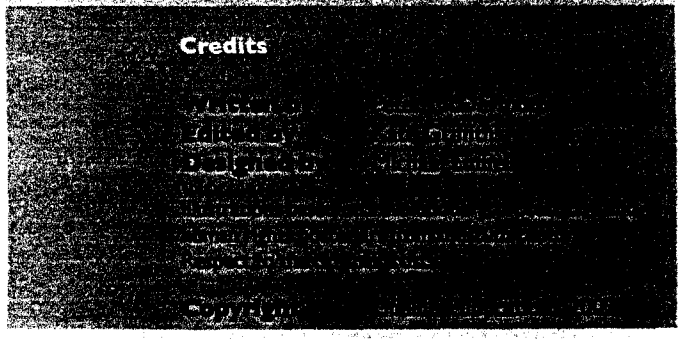
If providers have an ideological objection to certain types of treatment, then they should get on with providing the sorts of treatment that they are comfortable with, and leave the stuff that they don't want to do to others. Similarly, if patients don't want a particular type of treatment, then nobody should be forcing that upon them.

Ultimately, good treatment is all about options and choices, and the more of them that we have available, the better it is for everybody.

Reading Matter

If you're keen (and you'd have to be) there are some documents that you can refer to, these include :

- Department of Health (1999) Drug Misuse and Dependence- Guidelines on Clinical Management (known affectionately as the 'Orange Guidelines').
- NTA (2003) Prescribing services for drug misuse.
- SCODA (1999) Quality in Alcohol and Drug Services – Organisational Standards.
- Department of Health (2002) Models of Care for substance misuse treatment- promoting quality, efficiency and effectiveness in drug misuse treatment services.



Contacts, numbers & addresses

The (Methadone) Alliance
P.O. Box 32168
London N4 1XP
The helpline is open from 12 noon to 4pm Mon to Fri
Tel : 020 8374 4395
Fax : 07971 678468
www.methadone.org.uk

National Drug Users Development Agency (NDUDA)
Tel : 020 8986 5475

Patient Advice and Liaison Services (PALS)
Contact your local NHS Trust
(The NHS Plan announced the commitment to establish PALS in every NHS Trust by April 2002)

Independent Complaints Advice Service (ICAS)
Contact through your local PALS (see above) or get more info from: www.doh.gov.uk/complaints/advocacyservice.htm

Drug Action Teams (DATs),
Drug and Alcohol Action Teams (DAATs)
Crime and Disorder Reduction Partnerships (CDRPs).
You can find contact numbers and addresses on the Government's 'Tackling Drugs' web site: www.drugs.gov.uk/DATDirectory

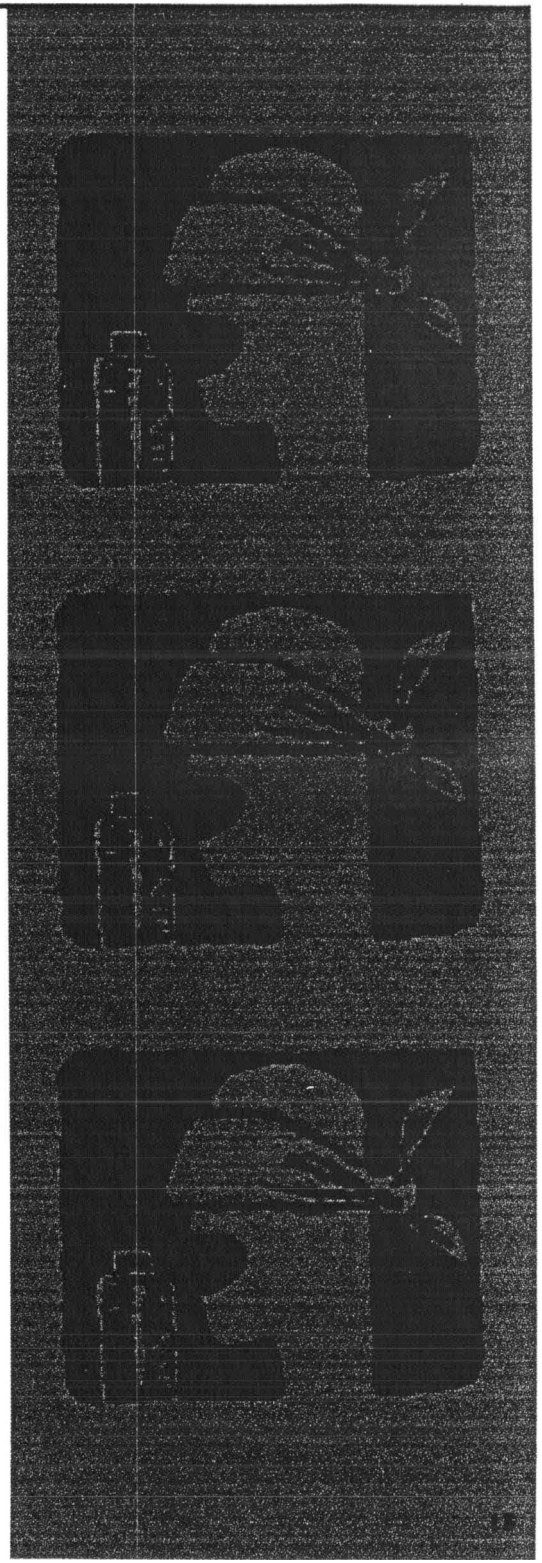
The National Treatment Agency
Hannibal House
Elephant and Castle
London SE1 6TE
Tel : 020 7972 2214
Email : nta.enquiries@nta.gsi.gov.uk
www.nta.nhs.uk

Glossary

Words and abbreviations that we have used or that you may come across.

Acute – Sharp or severe but short-lived.
Addiction – Dependence on repeated use for the comfort of mind or body.
Advocacy – Acting with or for another person in order to provide support or argue their case.
Arbitrary – Formed from mere opinion.
Attention deficit disorder – A condition involving a persistent inability to concentrate or perform tasks without becoming distracted.
Behavioural – Relating to actions or habits.
Bi-polar disorder – A condition involving extreme alternations between euphoria and depression.
Britlofex – Brand name for lofexidine.
Buprenorphine –A drug that is an opioid mixed agonist-antagonist so will both block and displace opiates.
Subutex – A brand name for buprenorphine.
Capricious – Unpredictable or unaccountable changes in mind.
Care Plan – An outline of the planned treatment that has been agreed between a practitioner and a patient.
Chronic – Lasting over a long time.
Commissioner – A representative from local organisations (e.g. Health, Social Services, Local Authority, Police etc.) who make decisions about which treatments or other services to purchase from providers for drug users (also see Joint Commissioning).
Commissioning – The process by which services for drug users are purchased from providers.
Consensus statement – Collectively agreed response.
Crime and Disorder Reduction Partnerships – A panel of representatives from local organisations including Health, Social Services, Local Authority, Police etc who make decisions about local crime and disorder issues and responses. In some areas the DATs and the CDRPs have combined into a single committee.
Critique – A critical review.
Dependence – Being unable to do without.
Diamorphine – Pharmacologically produced heroin.
Dose titration – Adjusting a dose to achieve the desired effect.
Drug Action Teams – A panel of representatives from local organisations including Health, Social Services, Local Authority, Police etc who make decisions about local drugs issues and responses (also see Crime and Disorder Reduction Partnerships).
Depression –A condition involving persistent sadness.
Detoxification – Reduction or removal of the drug from your body.
Drug and Alcohol Action Teams – Same as the DAT but including local alcohol issues and responses (also see Crime and Disorder Reduction Partnerships).
DAT Annual Treatment Plan – The yearly 'action plan' drawn up by the DAT Co-ordinator in order to deliver services according to the local and national priorities identified by the Ten Year Strategy, DAT, Providers and Service Users etc.
DAT Co-ordinator – Person who implements the work of the Drug Action Teams.
Efficacy – Ability to produce the desired effect.
Endocarditis – Inflammation of the inner lining of the heart and the heart valves.
Environmental – Relating to previous or current surroundings.
Genetic – Biologically inherited.
Hepatitis – Inflammation of the liver, in some cases due to a virus (e.g. hepatitis B, hepatitis C etc.).
Joint Commissioning – A panel of representatives from local organisations including Health, Social Services, Local Authority, Police etc who work together to make decisions about which treatments to purchase from providers for drug users.
Lofexidine – A drug used to help relieve some of the symptoms (but not the cravings) of opiate withdrawal.
Methadone – A long acting opioid agonist.
Models of Care – A manual published by the Department of Health that provides guidance for Commissioners and Providers about the types of services that should be available and how they can work together effectively.
Naltrexone – An opioid antagonist.
National Treatment Agency – A special health authority that was set up to improve treatment services for drug users.
Opiate /opioid – Any narcotic containing opium, opium derivatives or opium-like properties.
Opioid agonist – A drug that is attracted to the same receptor site as opiates and triggers a biochemical response.
Opioid antagonist – A drug that counteracts the action of opiates by binding to a receptor but without triggering a biochemical response.
Patho-physiological – Disease that affects the functioning of the body.
Patient and Public Involvement Forum – Members of the public who form an independent group in each Primary Care Trust and Hospital Trust; their role is to ensure the NHS takes a more patient-centred approach.
Primary Care Trust – An NHS organisations that plans and secures the provision and integration of local health care such as GP's, hospitals, dentists, pharmacists etc.
Providers – Organisations (drug services, GP clinics etc) who provide treatment to drug users.
Psychiatric – Relating to the management of mental illness, emotional and behavioural problems.
Punitive – Inflicting punishment.
QuADS – A manual that sets out a range of different standards that drug and alcohol services must work towards achieving, including service user consultation / representation.
Recalcitrant – Uncontrollably disobedient.
Ten Year Strategy – The Government's strategy to tackle drug problems, originally written in 1998 and updated in 2002. This is now co-ordinated by a Home Office management group including representatives from the NTA and ACPO.
Therapeutic alliance – Services and patients working together to improve treatment.
Thromophlebitis – Inflammation of a vein that causes a blood clot.
Treatment modality – A particular type or method of treatment.
Treatment Plan – (1) DAT Annual Treatment plan or (2) Care Plan.

ACPO : The Association of Chief Police Officers.
CDRPs : Crime and Disorder Reduction Partnerships
DAATs : Drug and Alcohol Action Teams.
DATs : Drug Action Teams.
JCU : Joint Commissioning Unit.
LAAM - a long acting opioid agonist.
MOC : Models of Care.
NTA : National Treatment Agency.
PALS : Patient Advice & Liaison Services.
QuADS : Quality in Alcohol and Drug Services.



Lifeline Publications Guidelines

AIMS To outline a range of treatment options for heroin addiction, in particular relating to the substitute prescribing of methadone, including the identification of potential problems in accessing services, stabilising on methadone and detoxification services. In addition the publication seeks to highlight both the rights and responsibilities of people requiring treatment for heroin addiction.

AUDIENCE People who are seeking or receiving treatment for heroin addiction, and those interested in user-support, representation and advocacy.

CONTENT No explicit language and imagery.

FUNDING Self-financed.

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http://www.lifeline.org.uk

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