

Why do we need user advocates?

User advocates are essential to making sure drug users have an effective relationship with their GP – while avoiding the mistakes of the past. The Alliance's senior advocate, Alan Joyce, explains.

The problems associated with drug use, from dependence to HIV, from Hepatitis C to psychosis, from cirrhosis to heart conditions, present complex challenges to general practitioners. Health consequences of problematic drug use go beyond the individual patient to impact on the family, other users, community, and society.

When treating problem drug use, GPs find themselves at what one could term a 'nodal point' where a number of different discourses, power struggles, and judicial, ethical, social, criminal, personal and political influences converge – both in the body of the user seeking treatment, and in the practice of the GP who is asked to treat them.

Historical precedents for this undoubtedly complex situation involving the GP and drug user, can help to demonstrate why user advocacy is of such importance. Consider the history of the medical treatment, diagnosis and care of women. We live within recall of a time when an unmarried woman with a child could find herself consigned to an institution for life. Predecessors of today's medical practitioners played an active role in diagnosing and treating women for 'aberrant sexuality', promiscuity, and 'hysteria'. Sadly some eminent members of the medical profession supported and thereby legitimised practices that would now be regarded as unethical, to put it mildly.

Likewise, consider the medical view of gay and lesbian sexuality before the gay rights movement of the late 1960s. Many eminent medical practitioners 'treated' homosexuality as an aberration, as a form of mental illness or obsessive dysfunctional behaviour that could not only be treated but 'cured', consigning 'sufferers' of this 'affliction' to all manner of cures and treatments – electro-shock therapy, psychoanalysis, institutionalisation in the asylums, barbiturates, sedatives, bromine – often with tragic consequences.

The drug user's condition is the focus of considerable social, political, cultural, religious and moral forces. Berridge and Edwards' *Opium and the People: Opiate use in 19th century England* along with Marek Kohn's *Dope Girls* and *Narcomania* show how these forces gave rise to the medical model of the opiate 'addict'. It is also evident that this medical model was itself the subject of considerable debate – not just in society, but also within medical science and practice.

It is no wonder then that the current treatment of the drug user in general practice is contingent not upon 'pure' medical science and a confirmed evidence base, but is dependent on the personal belief systems of the GP (and for that matter the specialist consultant) and upon the social, cultural and political forces

that impinge on them as a human being and member of society.

The problems that this would suggest are further compounded by the training that the aspiring medical practitioner will receive before they are qualified and beginning to practise. The figure given varies between training institutions, but it would appear that a total of somewhere between four and seven hours is spent on training doctors to treat problematic drug use and its consequent health and social problems.

In the absence of thorough and consistent training, it is inevitable that treatment of drug users will be a postcode lottery. Beacons of informed and enlightened best practice can be surrounded by areas where punishment and treatment, medical ethics and 'personal morality' have become interbred. In the absence of knowledge, it is likely to be a mixture of received wisdom, personal belief systems, moral judgement, overly restrictive and punitive 'practice' – as well as confusion – that will determine what treatment is given and what is refused.

These inconsistencies thrive against a backdrop of growing political and medical recognition that much of the treatment given to the drug user has been of negligible value or help to them and also to the communities in which they live. Put bluntly, much of the treatment has simply been poor or

failed. This has led to a political demand in the UK that those funded to provide treatment are also held professionally, fiscally, and socially accountable for its delivery and results and has led to the creation of the National Treatment Agency.

Alongside this 'top down' initiative, a 'bottom up' argument has grown louder, about what constitutes treatment and about the diagnosis and constitution of the user. In other areas of health – such as relating to HIV and mental health – change wasn't just 'top led'. It came through patients' advocacy movements, in response to pressure from people and communities who found themselves at the receiving end of contested diagnostic procedures and medical practice. In a similar way, it must be becoming increasingly evident to GPs that the diagnosis and treatment of drug users is increasingly subject to question and direct challenge from the patients, their families and carers. This is partly in response to changes in the NHS that speak about patients' rights, patients' charters, the 'expert patient', and a growing inclusion of patients in the decision-making processes that inform 'treatment practice'.

The emerging 'user consciousness' was also informed by the experiences and struggles of drug users in other countries. In the USA in the 1970s, the 'Group of 11' emerged in New York. Members of this group in turn founded and developed the first model of drug user advocacy, NAMA (National Alliance of Methadone Advocates). In Europe, partly as a legacy of the politicisation of many drug users and students during 1968, we saw the emergence of the JunkiesBond, the first drug users' union. Both NAMA and the JunkiesBond are vibrant, active user led organisations to this day.

In the UK, informed user activists emerged to be directly involved in the foundation of the harm reduction movement during the 1980s, in Liverpool, London and Manchester. Today this is reflected in the UK Harm Reduction Alliance and user groups' and advocates' open espousal of a 'harm reduction' led health and treatment agenda in the UK in the mid 1980s. We also witnessed the first UK example of 'direct' user activism – an organised protest in response to

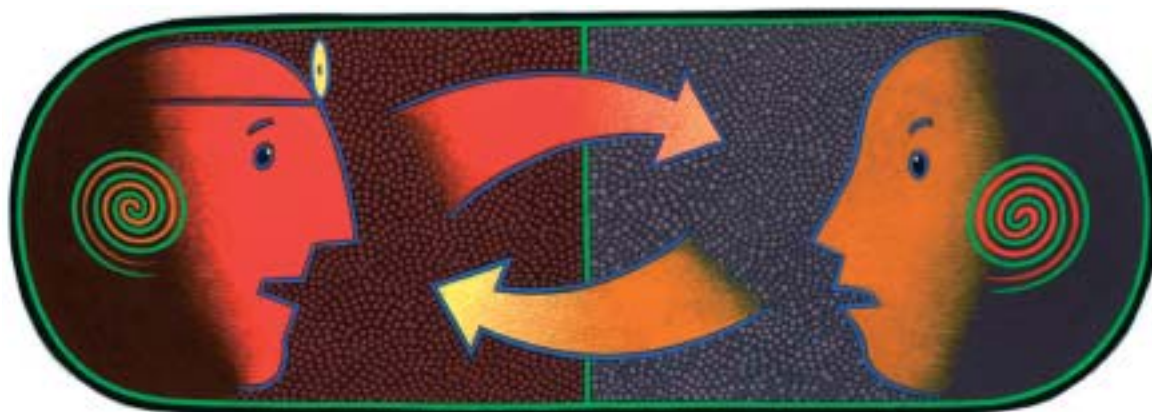
the punitive 'treatment' of Dr Ann Dally, a well-respected private doctor and specialist in the treatment of drug users, by the General Medical Council.

In 1998 a group of committed current and ex-service users joined with some supportive and sympathetic professionals to found a user led organisation and alliance in the UK, that would embrace the advocacy model as a way of articulating users' needs, defending their rights and promoting good treatment and practice. The Methadone Alliance, founded by Bill Nelles, was formed to ensure that drug users became actively involved in the debate about their treatment and care at every level. Through this team – now known as just 'The Alliance' – the idea of user advocacy was developed and put into practice.

Eight years later, there is still much to do. There is overt hostility on the part of some practitioners to the very idea of 'treating' drug users, exemplified in the words of one GP to a patient for whom I advocated: 'I am not here to provide you with free drugs. Come back when you are clean.' In other surgery windows, signs have proclaimed 'drug users are not welcome here' or 'drug users and their families will not be treated in this practice'. Less overt, but still common, is the intimidating surgery receptionist who discusses the patient's medical history or drug problem in front of other patients in the waiting room. The user feels so unwelcome at the practice that they leave and take their problem elsewhere.

If the user makes it beyond the surgery door to find a doctor who will treat them, they will still face continuing problems. One chronic problem is under prescribing – or more correctly, sub therapeutic dosing. Many GPs prescribe methadone at levels way below government guidelines, refusing to consider a realistic dose. Understandably patients continue using on top, or relapse, and treatment is routinely associated with poor outcomes.

Another common problem is punitive response to a user exhibiting symptoms of their condition. Opiate use is described as a chronic medical condition characterised by relapse. In no other branch of medical treatment would a



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patient exhibiting a classic symptom of their condition find their treatment withdrawn on 'punitive' grounds. Yet this is all too often the reality faced by the dependent opiate user experiencing problems with their condition – and quite often as a consequence of poor treatment and practice.

Overly rigid prescribing and dispensing practice can cause further problems. While it is understandable that supervised consumption may often be a necessary and appropriate measure to be taken when initiating, prescribing and stabilising the patient, it can all too often be applied in a dogmatic and inflexible manner that makes it very difficult for certain patients to remain in treatment – parents for example, or those users who are in work or full time education; those for whom the nearest chemist may be 10 miles away; or those who live in rural areas, where their identity as a user can become known due to the pharmacy's role in the local community.

Another common problem is a refusal by some GPs providing treatment to follow the science or evidence base – or even current guidelines. The right to exercise 'independent clinical judgement' is deployed as a fig leaf to cover what is, at best, down to poor training and ignorance – or at worst the doctor's imposition of their own personal morality and belief system

on the patient.

In some medical practitioners, this can give rise to a fixation on abstinence-based recovery. While for some users cessation of drug use is a laudable and achievable goal, for many others it is not. Other treatment options that focus on harm reduction and maintenance are denied to such patients. Sometimes this can have a drastic impact on treatment provision in a whole region, and we can identify such 'problem' areas by the number and type of cases we receive. Sadly, one can also identify such areas by high overdose and drug related mortality rates.

As the Alliance has grown and evolved, the need for user led advocacy has become increasingly apparent beyond the needs of just opiate users. Stimulant users for example find treatment difficult to obtain, a problem compounded by the lack of substitute medications. Even where a substitute medication, such as Dexedrine, could help, there is often a reluctance to undertake prescribing.

Another area where we are encountering growing problems is in relation to dependence on benzodiazepines. Where in the past they have been over prescribed, the benzo-dependent user can now find themselves subjected to poorly planned, and in some cases dangerous, cessation of prescribing and 'detox' plans.

We also find the Alliance increasingly called upon to provide advocacy and support to polydrug users, who may be concurrently dependent on opiates, benzos, alcohol or stimulants. Understandably this presents doctors engaging in treatment with a complex set of presentations and needs – which often results in poor treatment for one or all of the problems they face.

It is important to recognise that user led advocacy does not necessarily imply a confrontational and adversarial approach to the resolution of problems facing our clients. User led advocacy is about educating and empowering the user and the practitioner, about redressing the historical imbalance of power in the relationship between treatment provider and the drug user, and about encouraging the best practice possible, as widely as possible, in the hope that previous and present wrongs will be righted.

By listening to the patient's voice, both drug user and treatment provider will cease to find themselves in an enforced embrace characterised by mutual misunderstanding, incomprehension, distrust and antagonism, and become equals in a therapeutic alliance.

For more information on user advocacy, visit the Alliance's website, www.m-alliance.org.uk