

The diamorphine shortage of 2004 resulted in disruption to many users' prescriptions and a switch to methadone and other alternatives. Two and a half years later Plymouth User Forum tell **DDN** about the real impact on those involved.

## When the diamorphine dried up



When the Department of Health warned of a supply problem with diamorphine in December 2004, doctors were told to conserve stocks for patients in greatest need of the opiate painkiller, and to use 'alternative medicines' wherever possible.

Patients in acute and chronic pain were obviously top priority for the dwindling supply. Which left the rest: those who had been prescribed diamorphine – pharmaceutical heroin – as a last resort for their opiate dependency, and who were now confronted with the prospect of adapting to an alternative.

Distraught feedback followed the prolonged uncertainty of the situation, with calls for a swift resolution from service users, their advocates, and from caring consultants who were faced with the unhappy task of separating patients from a drug that had given them back a measurable quality of life. An article written at the time by a service user representative, a consultant, a community psychiatric nurse and a specialist registrar (*DDN*, 25 July 2005, page 9) illustrated the impact the crisis was having on some of the most vulnerable people in the UK and their families.

Two and a half years on, Julie, Stuart and Jules of Plymouth User Forum (PUF) have gathered to talk about a survey they conducted at the height of the crisis. There are lessons to be learned from it they say, which go beyond problems with the supply factory. It adds up to a story of poor communication from the top, lack of trust in service users, and a misplaced faith in methadone as the only substitute.

Their call to arms began in the summer of diamorphine deprivation, July 2005. 'Originally we were just trying to get ammunition to get our scripts back,' says Stuart, who along with Julie has been maintained on diamorphine for more than a decade. Researching the situation on the internet and persistently phoning up the supply companies gave them the information that stocks were still available, despite the shortage – a totally different scenario to that presented to them by their consultant, who refused to consider maintaining their scripts.

With valuable support from their DAAT and PCT, they exercised their right as patients to a second opinion, and were transferred to a sympathetic consultant in neighbouring Cornwall, who reinstated their diamorphine scripts and placed them in the regular care of a prescribing GP.

For Julie and Stuart, life regained balance and normality. But the turmoil they had experienced, and the brick wall they had hit with their local consultant, compelled them to find out more about how the shortage had affected local service users. Just as important to them, they wanted to demonstrate the drug's life-transforming potential to consultants that they suspected saw diamorphine merely as an expensive option that they 'wanted to get rid of by the back door', and who were all too willing to substitute methadone.

With help from the local university and their 'brilliant, supportive DAAT', they drafted and redrafted their survey for local service users until the questions were open and unbiased. Then, with a cover sheet assuring confidentiality, they arranged

for it to be posted out to 28 affected service users and returned to the DAAT, so that all personal information was protected.

Their questions covered details of the respondent's previous diamorphine script; information about the substitute drug they had been prescribed and whether there were side effects. They asked about whether they had used other drugs on top of the new script; if they had had contact with drug dealers; been engaged in criminal activity; and spent money on illegal drugs – before and after the diamorphine script had stopped. They asked their respondents to compare a range of possible symptoms, up to overdose, before and after diamorphine; and asked them to also tick boxes relating to social, family, financial, housing, work or training problems. Having given a picture of life before and after the script was withdrawn, their respondents were asked about how supportive local treatment staff had been and whether they had been actively engaged in decisions.

The 12 respondents (a 46.5 per cent return rate) reported back that they were all now on methadone – nine by injection and three orally. PUF's summary report records that 11 out of 12 of them recorded side effects with their methadone, including headaches, back pains in the kidney area, severe constipation, and vein damage. One had stated: 'It makes me too drowsy for normal living and has generally made me feel unwell and unhealthy.'

Eleven respondents had used drugs or alcohol on top, and most had turned to heroin, benzodiazepines, or both. Eleven had increased their contact with drug dealers. All 12 reported spending daily on illicit drugs since losing their diamorphine – nine of whom had used no illicit drugs before the script had been stopped.

The chaotic picture continued to build through 22 reports of serious drug-related incidents, where there had been none on diamorphine; increased criminal activity; and escalating social and family problems. One respondent stated: 'This situation has caused financial chaos, three court orders, one of which relates to rent on our council property from which my husband, two children and myself were almost evicted. I am suffering from lumps and abscesses on my arms from street heroin.' All 12 who responded said they would have liked to have been offered alternatives to methadone.

Trying to distribute the survey revealed a climate of fear among patients that alarmed the members of PUF. 'When we were doing the survey, we had so many people say "we really want to fill it in, but we're worried about what'll happen and who'll know about it",' says Julie. 'We had to say several times, "don't put your name" and really reinforce that, because people were too scared. They were worried that they would never get their script back.'

The situation seems to have bred mistrust generally, they report, with many service users reluctant to raise problems with their treatment. 'People are very scared of upsetting the appercart, because it's so easy to retaliate against someone on a prescription,' says Stuart. 'You've got so much power when you're writing someone a prescription – their life's in your hands.'

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'Even when we told people they could come to us in person and we'd take their grievance anonymously back to whoever – the service provider, the DAAT or whoever needs to be approached about it – they're still nervous about speaking to us,' adds Jules.

The two diamorphine patients among them, Julie and Stuart, are grateful for a DAAT that encouraged them to stand up for their rights, and they are determined to persevere with helping others do the same. Diamorphine stocks are now rebuilding, but supplies are still short: there are people throughout the country waiting for the return of their prescriptions. Most clients in Plymouth have now had at least half of their diamorphine script reinstated.

Jules has a slightly different reason for 'believing vehemently' in the chance of a diamorphine script. On a methadone script for more than 20 years, he likes 'to make it [his] life's mission to campaign against the evils of methadone for anything other than a short-term intervention'.

'It's the most wonderful short-term intervention in the world for getting people off diamorphine,' he begins to explain. 'But once you've done it for years...' Stuart picks up where Jules tails off: 'There's supposed to be a choice. The NTA say there are these options and they're supposed to be available. And they're not. In effect, if you go in for treatment, you're going to get oral methadone, or Subutex possibly. For anything else, you've got to be at death's door for years.'

Having conducted the survey, the group admits that 'no-one took a lot of notice', and that 'it didn't make a difference locally'. But its purpose was greater than to make noise about the shortage.

'We hoped that by having it checked for independence and non bias by statisticians, we'd show consultants that it's not just people screaming about what's been done wrong to them, but that we're intelligent articulate people who can research something and put it in writing,' says Jules. 'All consultants should be challenged... it's a very old-fashioned way of looking at things if people are frightened to complain.'

Their manifesto has one main aim: to help service users back to a normal life – and that includes all the usual trappings of a home, job, money, family, friends. They are worried that the success of diamorphine will be judged on the new

programme of trials, where the patient has to attend a clinic or chemist several times a day.

'How can you live a normal life, how can you try and get your life together under these rules?,' asks Julie, who just the other day had to assure a locum that her diamorphine was not dispensed under supervised consumption – 'he just assumed, as it's the norm now'.

Jules adds his concerns on supervised consumption: 'The whole point of a script is that it's supposed to improve people's stability and life, then if they want to come off it later they can. But if you're making people's life more difficult, no matter how good the medication is, it's self-defeating... "We'll get you on methadone and then we'll see if we can get you a job": it's self-defeating if you've got to go into a chemist's twice a day to drink your methadone.'

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For PUF, the diamorphine crisis demonstrated what happens when you pull the rug of a stable script from under someone's feet. While some service users were cautious about committing their negative experiences to paper, the death certificates of two other local patients spoke for them.

Having lost their diamorphine scripts, the couple went off the rails on internet Valium and alcohol. 'They came to one of our meetings and were asleep on the table,' says Julie. Two weeks later, according to the police who came to find out a bit about their backgrounds, one stabbed the other while they were 'out of their faces' on Valium and alcohol.

The couple appear as statistics in the carefully worded survey results, but PUF heeded the statistician's advice that they could not assume a link with the diamorphine shortage. 'You'd never get anybody to say that was because of the shortage,' says Julie. 'But it was – because he'd been stable for ten years.'

'These aren't just facts and figures, it's impacting on people's lives,' adds Jules. 'And when someone hasn't got a life to be impacted upon anymore, that's as serious as it gets really.' **DDN**