

# The DIY ethic

Although injecting drug use is the main route of transmission for the hepatitis C virus, there are surprisingly few hep C support groups specifically for drug users.

**David Gilliver** hears from a service user who decided, with help from the local BBV nurse, to set up her own

According to a recent report from the Advisory Council on the Misuse of Drugs (ACMD), the number of people infected with hepatitis C in England and Wales could be anywhere between 120,000 and 300,000 (*DDN*, 9 March, page 5), and it is estimated that up to 90 per cent of these infections were acquired through injecting drug use.

Oddly, given that drug use is by far the most common form of transmission, the number of hepatitis C support groups specifically designed for drug users remains tiny. Frustrated by this, one service user in Islington, north London, decided to set one up herself.

'I was about to start hepatitis C treatment and there were no support groups for drug users at all,' says Sarah Lucas. 'I asked Victoria, my hep C nurse, what could be done about it and she said she'd help me set up a group.'

Victoria Leenders has been blood borne virus specialist nurse at Camden and Islington NHS Foundation Trust since late 2006. 'The first lot of clients I'd seen were about to go on treatment and there just weren't any support groups around that were specific to people with a substance misuse background,' she says. 'There were support groups out there for people in treatment but Sarah said it would be nice to have something more specific and more local so it kind of just grew from there.'

The first group was held last August, with seven people attending. Attendance numbers have doubled since then and there is now a core of people who attend every session, held on the last Friday of the month. 'Sometimes people will come once and not come back, or float in and out, but there's a core of about 10 to 12 people who always come,' says Lucas. 'Before this there was no support at all – there was Victoria, but there's only so much she can do.'

The aim is to bring people – who often would have no one else they could comfortably talk to about their condition – together and offer a confidential environment where they can be open with others going through the same things. The sessions are also used to pass on useful information about treatment options and procedures.

After setting up the group with Leenders' help, Lucas now co-facilitates it with her and although based in Islington, clients from the neighbouring borough of Camden are also able to attend. 'Clients talk,' says Leenders. 'We thought we can't just turn away people because they aren't in the borough.'

What makes the group especially lively and informative is that it's made up of people at various stages of treatment. 'Some are pretty scared – they've just found out they've got hep C,' says Lucas. 'Some are scared of going into treatment, some have done treatment and it's worked, some have done treatment and it hasn't worked, and some people are having treatment at the moment, like myself, so it's all different stages.'

'We've got people who come who don't know how to tell their family,' adds Leenders. 'There's a real variety of people there. Someone from the group is

having a biopsy tomorrow and Sarah's going to escort them there and be a bit of a buddy for them, because their reason for coming to the group was that they were worried about the biopsy – it's quite an invasive procedure – so the support is there outside the group as well.'

Feedback from key workers and service users has been excellent, with many service users hoping the initiative will be able to expand, time and resources permitting. 'It's very educational – you constantly get people coming away saying "I didn't know that"' says Leenders. 'They're really proud of the group, and it's great to be part of something like this – it's been a huge success. I know how difficult it can be to engage with some clients so to get them to come to a group once a month is amazing.'

The group also features guest speakers covering a range of relevant subjects. 'We've just had a dietician and next time we're having a psychologist come to talk about emotions and managing moods, because the treatment can affect anger levels and make people quite depressed,' says Leenders. In the last six months the group has also branched out into teaching, with core members taking it in turns to accompany Leenders to drug services, schools, hostels and housing associations to raise awareness of hep C, and the aim is to expand this to other venues next year, including job centres and prisons.

Involving service users in these teaching sessions has had a powerful effect on group members, says Lucas. 'It really helps boost their confidence. It's helped me a lot, because my confidence was really bad, but now I feel really good about myself, I feel great. We're trying to get everyone involved – they love it because you're giving them responsibility and trusting them, and not many people trust drug users. When you say to them "come and help" it makes them feel good.' Lucas lives in a St Mungo's shelter and has also been training St Mungo's staff on hep C and HIV alongside Leenders: 'It's like the roles are reversed,' she says.

The fact that the group – which is promoted through flyers in drug services and pharmacies as well as by email, service user forums, word of mouth and the Hepatitis C Trust website – has taken off so dramatically clearly demonstrates a substantial unmet need. 'It's become a really established, successful group, and there are always more and more new people wanting to come,' says Leenders. 'I've constantly got messages on my phone asking about it. With a lot of the substance misuse groups we run we have to encourage people to come by saying 'you'll get a £5 Morrisons voucher' but with this we don't have any of that – people just want to come to the group.'

And, crucially, not only do people want to attend, but they also actively participate. 'People really open up,' says Sarah. 'There's no one that just sits there, everyone's really open in the group, talking about their feelings. They find it really helpful. I've been doing groups since I was 18 in rehabs and things like that and it can be really hard to talk in groups, but when you come to the hep C group



everyone wants to talk because they know they're with people who are going through the same thing. It's not like talking to a doctor or a nurse who really haven't got a clue what you're going through.'

Did she feel that the professionals she's dealt with had any genuine understanding of what it's like to live with hepatitis C? "No," she says. "You can be lucky and get the odd person who understands – that you don't have those boundaries with – like Victoria, but generally they haven't got a clue, they just pump you with medicine. You go and tell them how you feel and it's "have another tablet". It's not really helping, but that's how it is."

The Hepatitis C Trust has been extremely supportive of the group, but it seems odd that there are so other few similar initiatives. 'There's one in Manchester (*DDN*, 9 February, page 6),' says Leenders. 'But when we were setting it up we really did look around – the Hep C Trust has loads of support groups but there wasn't anything specific to substance misuse. It may have changed because we did our research before we set the group up, but my understanding is that there isn't anything like this, or if there is it's very local and small scale and doesn't have the involvement of someone like me who works with the NHS.'

So what are the plans for the future – how would they like to see the group develop? 'I'd like to see it spread it out to other boroughs and work with hepatitis clinics,' says Leenders. 'We've been working with UCL Hospital hepatology clinic, which has broadened the group and helped to promote it – we would have missed out on a big chunk of people, because it's not just for people in treatment on methadone, it's for anybody with a drug problem. It would be great ultimately to see it as an established trust providing funding.'

As it is, they're just trying to manage the ever-increasing number of clients who want to attend. 'At the last group we had about 15 people, and we were thinking "wow, this is really big"' she continues. 'I was getting concerned that we might have to cap it soon, before it gets too much, but we haven't got to that stage yet. We could make the meetings more frequent but I'm not sure they'd generate the same level of discourse.'

Leenders is going on maternity leave later in the year, and the plan is that Lucas then takes over completely as facilitator, with a professional sitting in. 'Sarah has got the respect of the others, which can be really difficult for a service user working in that kind of environment,' says Leenders. 'It's worked really well.'

Lucas is also going to college in August, and doing a placement with a drug project outreach team. 'I want to work with homeless people and drug users, because I was there for a long time,' she says. 'I'd really like to set this up in other boroughs and other areas, carry it on and help other people, because people feel really isolated so we need more things like this – not just for hep C but HIV as well.'

'I've got a son who's ten and I see him every weekend. When I tell him what I'm doing it makes him feel proud, instead of saying "mum's just on benefits". He's really proud of me now.'

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