

A positive pattern for Hep C services

➤ When Nigel O'Malley was diagnosed with Hepatitis C a decade ago, he found treatment options were limited, and support and information thin on the ground. He was told that he couldn't take Interferon – the only drug offered at the time, before the combined dose with Ribovirin became available – as it would be a 'pointless exercise', with only a 10 or 15 per cent chance of clearing the virus.

He was angry at the time, he says. After feeling helpless for a while, he decided to pick himself up, look at his diet, options for healthier living, and alternative therapies. His experience also gave him a particular mission when he began working as a volunteer at The CAAAD (Community Action Around Alcohol and Drugs) Project in Bristol.

'I wanted to set up some support for people with Hepatitis C, because a lot of the clients were still finding it difficult to get hold of good consistent information,' he explains. 'We began by looking for information and running a support group – but it didn't always meet their needs.' Eighteen months on, and still committed to the 'grass roots upwards development' of Hep C support, O'Malley needed to find paid work. He was in luck: the Drug Strategy Team (as Bristol call their DAT) offered CAAAD money to employ him part time as specialist hepatitis worker, and he was able to start galvanising a Hep C strategy for the whole of Bristol.

It was a big turning point, he says. Finally he had the go ahead to rally interest and get immersed in consultation – lots of it. Visiting other projects, being in their drop-in centres, distributing leaflets and meeting people to ask 'what do you want to see; how can things be improved?' produced the immediate feedback that there were gaps in knowledge and services that people were only too happy to put their heads together to address.

So as a first stage of the strategy, 'we began to offer training to other service providers,' says O'Malley. CAAAD already had good links with statutory services that provided testing, treatment and vaccinations, so he felt encouraged that testing could be made more accessible to the community.

Linking closely with Avon and Wiltshire Mental Health Partnership (AWP), 'who had the beginnings of a Hep project themselves', added momentum. In fact, he says, 'we met a lot of people who were

working quite disparately at the time, with very little knowledge of what anyone else was providing.'

Making these links with other services was invaluable for the client. 'One of the daunting things for clients, was not knowing what to expect on the journey from being tested, all the way to treatment,' O'Malley explains. 'So it was important to link in services and gain some knowledge and understanding of what they provided.'

The latest stage of the strategy has been to develop a documented care pathway, taking the client from the initial stage of where to get a test, all the way to the end of treatment. O'Malley waves a proof that's being prepared for a launch in June or July. At first glance the care pathway chart looks complicated, but on closer inspection it demonstrates very clearly your options at each stage of treatment. And if someone's not ready to access Hep C treatment, because they're still using: 'we'd look at what programmes we can get you into, what alternatives we can offer you, until you've stabilised or stopped injecting or drinking'. It can take up to 12 months to access treatment, while the patient undergoes tests – a liver scan and biopsy to establish which of six different types of the virus they have. This is not lost time, according to O'Malley, as it 'gives you time to go through a process in other areas of your life.'

This, really, is one of the main purposes that O'Malley has been driving towards: to engage a network of services that stop the fear and isolation of Hep C, as much as speeding up treatment.

He is quick to acknowledge that everyone reacts differently to the disease – both to the physical symptoms and to interacting with medical and support services. Some people find it difficult to get treatment, 'perhaps because it's difficult, perhaps because their circumstances aren't quite right'. But he has found that once they've engaged, even for a short while and been through part of the process, it makes it easier for them to return when the time is right.

To this end, Bristol's Harm Reduction Strategy Group aims to make contact with as many would-be clients as it can. Staff from CAAAD, who include a complex needs worker, drop-in support worker, outreach engagement worker, and volunteers – join partners including local drug projects, the mental health trust, PCT, drug strategy team, Health Protection

Being let down during his own Hepatitis C treatment a decade ago only made Nigel O'Malley more determined to make sure Bristol did more for clients in future. DDN reports on the creation of a dynamic and responsive network.

Agency, pharmacists, and researchers, in meeting regularly to discuss ways of reducing infections, as well as making sure people who are infected have all the support they need to get through treatment.

Service users are actively encouraged to play their part in consultation and feedback, and there are good links with service user groups, including UFO – Users for Organisation – the main body for service users in the area.

'We absolutely try our best to keep people engaged,' says O'Malley. 'And because there's such a range of services available, there's always the option of going to another.' Options are around workers as well: 'You can have a different worker in the same service. Anything that will help people engage with a service, we try and provide.'

Of course initial engagement isn't everything, and much of O'Malley's energy is directed at filling in the wider picture of essential needs. 'A lot of clients are homeless, and many have issues around trying to manage a tenancy,' he says. So the partnerships that work so well around treatment must extend to housing, social services, and all other aspects of life that underpin stability.

Housing shortages are as acute in Bristol as elsewhere, with many homeless people put up in bed and breakfasts. So information must go to B and B landlords, about directing people into services, while training is offered to hostel staff on Hepatitis and harm reduction. Where a client's stuck around others using drugs, and surrounded by temptation, O'Malley says Bristol's services pull together as best they can to get them into a support programme and re-housed if at all possible. He counts himself lucky that he has an agreement with Bristol City Council that he can nominate a dedicated number of clients each year as priority housing cases – as long as they are going to access treatment for their Hep C. 'Because of the lack of housing at the moment, that number is limited,' he says. 'It's an amazing start though.'

Proactive work extends to the local prison service. Bristol Prison are 'incredibly good' at providing information and advice to those infected. They vaccinate everybody who comes through the door, says O'Malley, and offer testing and treatment in prison. While it's difficult to get security clearance to take CAAAD's services into prison, a liaison nurse



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He knows what his clients are likely to go through – the exhaustion, headaches, and not wanting to be around people – but he is keen to point out that the treatment experience is different for each person, and that some clients 'come sailing through, hardly even knowing they're on it'.

When clients don't find things so easy, he likes to help them separate the side effects of treatment from the side effects of real life, he says. The Interferon can trigger depression and consuming bouts of self analysis 'that can be quite off track from what's really happening to you. So it's nice to be able to say all this retrospective and introspective stuff you're doing isn't quite the true story of what you're actually like as a person'.

He can also point them in the direction of feeling better in themselves along the way – a specialist acupuncturist is on hand at CAAAD, who does treatment in a quiet room at the top of the building, away from the drop-in. As well as helping to reduce the side effects of treatment and the symptoms of Hep C, 'it's time spent with a caring professional, it's not hurried'.

There's a lot to do before the care pathway document launches in the summer, but O'Malley is further motivated by the thought of the new pathways poster being pinned up in GPs' surgeries in the near future.

Although it's hard work, he is inspired by every sign that someone's journey through getting treatment has been made easier – particularly when he sees the commitment being made by clients.

'I've got a client at the moment who's suffering from such massive multiple health issues,' he reflects. 'To see him stay committed to get through and get treatment has just been humbling really.' **DDN**

Contact the Hep C service via CAAAD, by email at caaad@bartonhillsettlement.org.uk, or call 0117 9042200 between 10am and 4.30pm. The website is at www.caaad.org.uk.

from hepatology at Bristol Royal Infirmary visits regularly, and O'Malley and team are waiting to pick up people from prison and bring them to the service, as soon as they are released. 'We'll meet them and chat through what we offer,' he explains.

The team's caseload is getting busier, as more people discover where to find them, but O'Malley is confident that between them, they are well equipped to address complex needs. Everything is geared to working 'to the best advantage of the client'. So when someone accesses the service, they have a brief

assessment, their case is taken to the next team meeting where they look at the client's needs; then they work out who has the most appropriate experience and could offer the client the best service, and write to offer the client their first appointment.

O'Malley and colleagues have come a long way in developing care pathways over the last 18 months. His own journey through treatment is similarly making progress: he completed treatment just a month ago, and is just beginning to feel better, although slowly – 'each day's a little bit