

Story Telling Session – Hepatitis C

I was diagnosed as having Chronic Hepatitis C in 2004 and underwent 24 weeks of treatment that year. I had an extremely difficult time on treatment and although I did return to work afterwards, the news that the treatment hadn't worked left me shattered and depressed.

Because of the stigma around Hepatitis C I had not felt able to be entirely honest with my colleagues.

I used the internet to gather information about Hepatitis C. but found that the information from the NHS was not particularly patient centred and that the abbreviations and technical language used made me more confused.

I remember thinking that nobody should be allowed to endure what I had without proper support and information and if changes needed to be made, then someone had to take ownership.

My GP was organising a patient forum and was looking for volunteers so I joined as I saw this as a way of getting involving in community issues. This led to a request to become a Local Advisory Council member with the Scottish Health Council. I was open about my illness and found the staff very understanding who did not treat me as an invalid and ensured I could contribute in a way that suited me.

I became a patient representative on a Blood Borne Virus Strategy Group with my local NHS Board. Through my involvement with this I found that on paper the Boards were involving patients but in reality the staff involved with patients had no idea. My impressions from the first meeting were less than enthusiastic as the meeting chair arrived 30 minutes late and furthermore I had to wait almost a year before I was paid back for the expense of attending meetings. Why should I have to resource the NHS?

It was obvious to me that no-one (except the clinical staff) had bothered to find out about my illness, my circumstances and whether I needed any special help to contribute. Through all of this I was supported by fellow Local Advisory Council members and staff at the Scottish Health Council in understanding the endless documents, financial spreadsheets etc that I was asked to read and comment upon.

As a patient representative I had imagined that the Board would help me to contact fellow patients to better represent them. I made some business cards giving my contact details and nursing staff handed these to patients who they felt would benefit from speaking to another patient.

I wrote an article about experience of Hepatitis C which was published in local and national newspapers. I eventually put an advertisement in the local papers, got some help from a drug company representative and invited patients to meet and form a self help group. The first night we were able to agree a constitution and elect a management group. I hadn't wanted to go down the committee route as this involves a lot of work – I only wanted to help support patients.

I had been involved with a local Community Health Group through my GP's patient forum and luckily had met some good people who assisted by drafting the application for our group to apply for financial assistance and accompanied me when this was discussed at their board meeting. The outcome was successful and this now meant that expenses would be covered.

Over the coming months different members of the group came along to the Community Health Group meetings where they were welcomed and listened to which led to the group becoming involved in the community.

The group has many vulnerable members and they need lots of reassurance. I treat them with respect, letting them choose what and how they contribute taking cognisance of their individual needs. It is important to understand your volunteers' failings / strengths and make allowances, give them respect, listen and action their suggestions if appropriate.

Now, I am the Scottish Officer for The Hepatitis C Trust helping patients all over Scotland to make a contribution, listen to what they have to say and inform Health Protection and the Scottish Government. I will also support them in their role as patient representatives with their NHS Boards.

One of the members of our group has taken on the role I held with The Blood Borne Virus and Hepatitis C groups. I attended their first meeting with them and will do so until they feel comfortable and was encouraged that they contributed at this. I'm not sure if the members of the group appreciated how difficult it is for people with HIV / Hepatitis C to speak to them.

The group's main problems are the administrative demands on them - minutes, funding applications and of course the endless evaluation of what they have done. I went to a volunteer managers' forum recently and one of the things to come out was that everyone was concerned about having to apply to each separate PPF, CHP etc for funding. We also discussed whether we should only take volunteers who can do funding applications, performance reviews etc. It feels like the community voluntary sector is being over burdened by bureaucracy.