Interferon alfa and ribavirin for the treatment of mild chronic hepatitis C – part review of existing guidance no 75

Personal statement by Charles Gore, patient expert

I am writing this statement as someone who has had chronic hepatitis C and obtained a sustained virological response after taking a course of pegylated interferon and ribavirin. As such these are my own views, which are entirely personal rather than general, and should not be taken to be those of The Hepatitis C Trust for whom I work.

Probably by the time I was diagnosed with hepatitis C, and certainly by the time I had my first biopsy 3 years later, I already had cirrhosis. I was extremely ill and truly believed that I was going to be an invalid for life, even though this was and so far remains compensated cirrhosis. Since successfully completing interferon and ribavirin treatment, I am enormously better and capable of leading a full and busy life and am extremely grateful and pleased that I had the opportunity to do treatment. I do not, however, have the same stamina and energy of those of my friends of similar age who do not have liver disease. I still have cirrhosis and indeed now have a degree of portal hypertension. On the advice of 2 consultants I also have ultrasound scans every 6 months to check for liver cancer.

Having experienced the progression of liver disease caused by hepatitis C, I know I would have liked to have had the opportunity to do treatment years ago, in fact as early as possible when younger age and less fibrosis would have given me the best chance of success. Although I was genotype 3, I was 44 and cirrhotic when I did treatment and consider myself lucky that it worked. I am also convinced that the side effects I experienced and which forced me off treatment after 8 months – chronic pancreatitis and resulting type 1 insulin-dependent diabetes – would not have occurred had I done treatment much earlier (the only other 2 people that I know personally who SS developed insulin-dependent diabetes had cirrhosis).

What I would not have liked, years ago, would have been to be told that I could not have treatment because my disease was too mild; that I should wait for the window between moderate and severe disease (cirrhosis is definitely best avoided); that I should try to get this window to coincide with a period when I could afford to be ill for a considerable period and when I would not want to conceive children; that in the meanwhile I should just get on with my life, scared to mention this virus to anyone for fear of immediately being labelled a ‘junkie’, unable to afford life assurance, incapable of getting the type of mortgage I wanted, worried about unintentionally infecting others, particularly those close to me and now, following recent proposals from the Crown Prosecution Service, at risk of imprisonment if I infected anyone during sex (blood to blood transmission is certainly possible during sex).

Being offered treatment does not automatically mean accepting it. I have 2 friends of my age who have genotype 1 hepatitis C and mild disease. They have decided that they will not do treatment for the moment because they think the potential side effects over a whole year are simply too nasty for a 50% chance of a clearing the virus. They continue

to be regularly monitored and await the next generation of anti-viral drugs. Their behaviour suggests that extending the indication to mild disease will not cause an unmanageable surge in demand for this technology.

I have another friend, however, who believes he was infected through drug using when he was 20. When he was 38 he had a biopsy and was diagnosed with very mild disease. There was no effective treatment available at that time. He decided that he would therefore ignore his hepatitis. This he has done ever since. He is now 48 and continues to drink regularly, though 'not excessively'. Although he is one of my oldest friends, I have only been back in touch with him in the last 4 years. I have explained to him that there is effective treatment available now and that I have successfully completed it but unfortunately he is now so much a public figure that he believes he simply cannot afford to do treatment because it would inevitably mean revealing his hepatitis C and he is convinced that, because of the continuing stigma, to do so would destroy him. 10 years ago he was not a public figure and, had treatment been available, he might well have done it. In other words, the longer the period in which treatment is on offer, the more chance for patients to find a suitable time to do it.

I have another friend, a 31 year old woman, who is about to start treatment principally because she wants to have children and does not want to risk infecting them. She has genotype 3 and her consultant has agreed to treat her without histological classification. Given her assumed length of infection, her age, her sex and her lifestyle it is likely that she has only mild disease and might easily, with a different consultant, be denied treatment, perhaps until past child-bearing age. She should not have to rely on living in the right part of the country and having input from me as to which consultant to see.

I would also like to make a point about the wording of TA 75. I have just come across someone who has been refused treatment despite having severe extra-hepatic symptoms on the grounds that his biopsy has shown that he has mild disease. TA 75 says 'people with symptoms of extra-hepatic HCV infection sufficient to impair quality of life, may be treated on clinical grounds without prior histological classification' and he has been told that, having had a mild histological classification, this section (1.6) does not apply to him and he cannot have treatment. As a patient expert for TA 75 I was quite certain that the intention was to allow treatment for those with severe extra-hepatic symptoms *regardless* of histological classification, rather than simply without biopsy (why should biopsy be more difficult for those with symptoms?). With ever-increasing pressure on NHS funds, PCTs will continue to be tempted look for ways to avoid treating patients. Extending this the indication for this technology to those with mild disease would avoid this problem.

My experience is that, in as far as it is possible to generalize, people with hepatitis C find it hard to speak up for themselves, partly because of the stigma and partly because of the debilitating nature of the disease. This is very different, for example, from the situation with cancer patients, who seem to be very successful in getting PCTs to pay for the drugs they need. People with hepatitis C are therefore particularly dependent on NICE to issue clear and unequivocal guidelines giving them access to the drugs that offer them freedom from this illness. As a patient, I would urge NICE to make this effective technology available to everyone with chronic hepatitis C.