PETER STEVENS

INTERVIEW

Interview with **Peter Stevens** on 20 December 2007 at Alliance House

You have been a trustee of the Macfarlane Trust from its inception in 1998 until 1992 and from 1999 until earlier this year (2007). You were Chairman from 2000 until your retirement in January 2007. You are currently a trustee and the chairman of the Eileen Trust and I have read your evidence to the Archer Inquiry on behalf of the Board of the Eileen Trust. It is about the Macfarlane Trust, however, that I wish to ask you questions.

Your two sons were born with severe haemophilia and whilst one son was co-infected with HIV/Hep C and died in 1989, your other son, who was infected with Hep C, is alive and currently well. Whilst you clearly have had more than your share of personal tragedy, you are almost uniquely positioned, with your experience, to provide an understanding of the changes that have taken place in the MFT community over the past 20 years.

When the Macfarlane Trust was first established in 1988 with the initial £10m and two subsequent amounts were provided of a capital nature to be distributed by the Trust (the last in 1991), the life expectancy of the registrant community was no more than a few years. Did you regard the payments made back then by the Government as adequate/generous?

I think, looking back, it is difficult to avoid hindsight, but looking back the Trustees thought that the funding to the Trust was inadequate to do what we believed to be necessary. It was subsequent to the Trust being set up that the two capital payments were made, first of all the £20,000 ex gratia payment to all those affected and then, a year later, the more substantial capital settlement which was made to avoid litigation. I think there was a feeling among the Macfarlane Trustees that the combination of those two was more helpful, particularly to the family men. I think there probably was a feeling at the time that the payment being made to the young, unmarried boys was a bit niggardly. [It was a stage payment of the second capital sum (settlement payment)]. But I think, in the context of an expectation of a short 5-7 year life expectancy there was a feeling that, whereas much more would have been very welcome and that these payments were doing nothing by way of compensation, nevertheless in pragmatic political terms, that perhaps it wasn't so bad by 1991 when the settlement payment had gone through. But even then, the Trustees of the Macfarlane Trust just thinking purely of the ongoing [one] still felt that we ourselves were insufficiently funded to do what we believed to be necessary, even with that short life expectancy.

Given that for roughly a third of all registrants, who have survived to this day, their last 'substantial' capital payment was more than 15 years ago (and acknowledging that, as a condition of receipt, waivers to pursue compensation through litigation had to be signed) how would you describe the Government's response to this tragedy?

I think I would say it has been niggardly, if you like, and completely driven by political considerations in that this is a very small community of people, with very little political clout and that, once the Trust was set up and the two capital payments were made, it was really impossible for those affected or the Society to make any substantial political case for anything else.

And when you talk about the society do you mean the Haemophilia Society?

I mean the Haemophilia Society – I keep on using the word 'society' because the Trust only exists because of campaigning by the Society over quite a prolonged period of time. So, although we are fairly distant from them now, it was the Society who effectively brought the Trust into being.

So I would say that successive Governments have been entirely pragmatic. They've dealt with the issue at the time in a way that was, by the standards of the time, probably acceptable in political terms and they haven't really had to do anything since. I had no doubt at all that, had they had the benefit of hindsight in 1988 and been told that a third of the people affected would still be alive twenty years later, they would not have done what they did. I think it would have been a different course of action and probably they would have resorted to individual settlements …… to the capital payments, along the lines they did. I doubt if they would have set up the Trust. I think the Trust was a short term fix and I am sure, for political reasons at the time, the Major government were looking for things to do. I think they were caught out by the lack of favourable response, which was why they then introduced the two capital payments and then, at that stage, I think they thought: 'Well okay that's done and dusted, these people have only a couple more years to go and we're off the hook'.

What do you see as the most striking change(s) over the past 20 years?
Is it the health/survival of the registrant community?
Is it the individual registrant's ability to meet their respective needs?
Is it the attitude of registrants, their partners and dependents?
Is it medical advances in, for example, anti-retroviral drugs?
Is it the Government's attitude and/or response to MFT's community of care?
Is it something else?

I think you list the reasonable options. I would say that the most striking change is the health and survival of those who have survived, so that reflects another of the options, which is the medical advances. And, within that group of survivors, the ability of a substantial proportion of them to meet their needs is also probably a change in our understanding of what was likely to be the case, although I daresay a lot of them were pretty independent and able to cope right from day one.

Do you feel there has been any noticeable change in MFT's community of care during the past 4-5 years and, if so, in what respect(s)?

Yes, I don't think it's a hugely significant change but I think, generally, there is a greater independence of mind that I think people seem to be more prepared to accept the help. I don't think they have any choice but to accept the help, but also to accept the social and financial circumstances in which they are standing and to get on with it, which may, I think, be a function of what the Macfarlane Trust has done over the last 5-7 years. But also I think, possibly, an understanding by people that their chances of survival are now as much dependent on things other than their

HIV. The drug regime, brutal though it can be, is actually fairly successful; that is my understanding. I remember Mark Winter saying three years ago, I think it was now, that our group of people have the same sort of life expectancy as a bunch of middle aged smokers. Given that, from what I can see, most of them are a bunch of middle aged smokers, I found that was quite illuminating and although I don't think that particular remark has been widely circulated round the community, nevertheless I feel the majority of them do seem to be now accepting and getting on with things.

Do you think the partnership group which is a relatively new thing is a good thing, in terms of allowing people to discuss but not to get too upset about things, or do you think that they have made things a little bit more difficult for other registrants?

Probably both of those - I suspect those aren't alternatives. Most of the people in the Partnership Group are the people who are prepared to give it their time and their efforts so they tend to be the activists if you like: those, who either have something to say or welcome a platform, even if they haven't got anything to say. So the ability to have those people sitting round a table, a few times a year, sounding off and expressing their views to the Trust, whether or not the Trust takes any notice of them, helps them. Yes I think they can annoy some of the other people; on the other hand it's a safety valve that lets off steam.

Do you feel there has been any noticeable change in the Government's attitude during the past 4-5 years and, if so, in what respect(s)?

I think, candidly, no. I think we have come to understand better the Government's attitude, including in that the attitude of the officials. I think we now understand that, for some time now, they've said this issue is done and dusted in political terms. "We will keep it going, but we have no great sense of obligation to do anything of any significant value to you in the future. We will just keep on going until such time as we can draw this thing to a close".

What do you see as the most important contribution made by the Board of Trustees of MFT during your time as chairman?

I think it was probably the appointment of Martin Harvey as Chief Executive. His predecessor has many fine attributes, but was not doing a good job in that role and one of my regrets is that I didn't seize that particular nettle earlier enough, but then we might never have got Martin. But I think we do now have somebody who's got the right mixture of professionalism and compassion running the Trust, and some of the changes, directly affecting beneficiaries, that have come in since 2000 would not have been made without him.

Is there anything you would have liked to have seen achieved that was not and, if so, what would that be? And, if you had your time as Chairman of MFT over again, would you have done anything differently?

Well, I suppose I would like to be able to claim credit for the recent reform of the way reg. payments are made, so it's now household income based, rather than the

strange system that had developed over the years. The method of determining need now is much more sensitive, I think, to the family's economic needs. I think it's not yet sufficiently sensitive but the principle has been established and, I think, the Board of Trustees, over the years to come, will be able to make it more sensitive; particularly, to ensure that the households that don't really need the money, given the fact that we don't have enough of it, don't receive quite as much priority as those whose economic circumstances are very difficult.
One of the things the Trust did in 2001 was to tell the Government that we were going to increase our rate of disbursements by 50%, from £2m a year to £3m a year roughly, because I had been surprised that the Trust was still operating at a level of £2m a year in 1999 and 2000. This was the same level as we established in 1988 when we had said; "well, we've got £10m; we don't know whether it's ever going to be topped up. With investment income, we should be able to make that last about seven years, if we spend it at £2m a year and that will probably just about see us through, which was the expectation in those days. Subsequently, the Government had, when asked, provided a top-up, but it did seem to be strange we were still doing that in 2000. So, we took the bull by the horns and changed what we were doing. The Minister was not pleased, but it only took about a year and a half for the Government to adapt their level of funding to match our level of spending. We did take a permanent hit on our reserves, from which we have never actually recovered. I suppose, again, with the benefit of hindsight, the other thing I would have done would have been to hit the Government earlier and harder, particularly given the official we were dealing with at that time, who was intelligent, compassionate and I think malleable. Since then we've had some very hard-nosed officials to deal with, from whom we've got no change at all.

Given the current political climate and Treasury constraints, coupled with the fact that MFT's Business Case presented to the Government in 2006 for an effective doubling of annual funding (and additional capital payments for registrants) fell on deaf ears, what strategy or strategies would you recommend to the Board of Trustees to follow to secure adequate financial resources to meet the present and future needs of its community of care?

I suppose my answer to that question really indicates why I am now in retirement from the Trust. I don't know an answer, other than the one that we have tried and so far been unsuccessful. We've made a very logical, evidence-based case for more funding; we've secured support from a number of politicians from both Houses, although I have to confess mostly on the opposition side; and we have discussed this business case with the officials and with a Minister and got nowhere. I don't know another way of going about it because, as I said earlier, the issue now has no political clout whatsoever.

So I take it from that answer that, a suggestion that the Macfarlane Trust adopts or advocates, supports or pursues a public policy, such as 'No Fault Compensation', wouldn't necessarily be considered by you to be a worthwhile strategy to raise the profile of the Trust?

It would be a strategy to raise the profile but I don't think it would be worthwhile, in the sense of getting any results, and I think, if it achieved any success in terms of raising the profile, then you have to consider what the Government spin would be and Government would certainly draw attention to the sums of money that the Trust has spent over the years and the ex gratia and capital payments that were made to our people over the years. They would express these in present day values and say to the Daily Mail, 'Is it reasonable that these 370

or 360 people should receive any greater help?' and I think it would be a very difficult public relations task to overcome that spin.

But, if you were to compare the settlement that has been made with the variant CJD victims, it appears to be far more generous, with an average payout of over a quarter of a million pounds, which is substantially in excess, even at present day values, of what was paid out to the MFT's community of care. Would you say that that might now be a new argument to put forward, by doing comparisons such as this?

It would be an argument to put forward. I think it would be new in detail although I'm not sure whether it's too new in concept because, after all, this case did refer to the chap who won three quarters of a million pounds after an HTLV3 infection. That, of course, was an out of court settlement, when there was legal action pending under product liability and I think the Government knew that they actually had no defence, so they settled. I can't remember whether the CJD was getting close to court or not, whether that settlement was done purely on ex gratia terms or whether again that was in response to a looming law case; I just can't remember. I still think that the Government will say "then was then and now is now".

And the fact that with Thalidomide, there was a drug company that was prepared to put up substantial funds, again providing far greater returns to those that had suffered; trying to compare that case with the Government, where they might say, "well, there was product liability or there was potential negligence", which they have always denied in the case of the contaminated blood.

Yes - I don't know. I know you're going to ask about Archer and there is a possibility that Archer will produce sufficient grounds to show people there is a merit in taking this through European courts. I don't think one can get anywhere in this country but, unlike the CJD, the blood contamination is an international issue, a global issue and some countries have been notably more generous than ours. Now, of course, the numbers involved in those other countries may be much lower but, nevertheless, there is, within the European context, equity. It would be a difficult case to make because, after all, in some countries there would be no response at all, such as in the USA and there would be absolutely nothing forthcoming. But Canada has been generous, Ireland has been generous, so there might be something to be done, on a European level, if Archer comes up with the right answer.

Even with the statutory limitations problems?

I think even with the statutory limitations problems, because apart from anything else the waiver of litigation that people had to sign for the settlement payment, I think, can be shown to be unfair. There was inequity of knowledge.

So what are you hoping for from Archer?

I am hoping for something along these lines. A firm statement that the settlement payment was unfair and that, in international terms, the overall response has been inadequate. I would also like to believe that Archer would draw attention to the fact that there was sufficient knowledge in the system that somebody should have blown

a whistle. That isn't actually my belief but I would like to think, from all the evidence they have, they would say that it is the job of civil servants to protect the public, as well as ministers, and that the civil servants should have been aware of the number of warnings and have stopped it happening.

What do you expect to happen from Archer?

Nothing like that because I think they've run out of money and they're going to produce a much shorter, more anodyne report than I think everybody is hoping.

One of the problems with the registrant community – this is a question that I am putting to you separately – is that with the younger members of the community, there is a problem getting them into or back into work. Do you have any views on this?

I don't know how to fix it because I suspect it isn't a question of attitude on their part. I suspect many of them are trying quite hard but the combination of haemophilia, with its physical difficulties, and HIV and Hepatitis C and the inability to deal with stress, for example, that makes people, potentially, very difficult to employ.

Do you think that if the Government were to waive all tax on income earned, as is the case in Israel, that this might have a significant effect, because in Israel there are, apparently, a lot of very successful people who work and have got on with their lives and are earning relatively large sums of money because they've got this tax break?

Yes, I think that sounds very good because, apart from anything else, people could then start at a much lower level of income and, undoubtedly, at the moment, there are some of them who are in the benefits trap anyway and that the only jobs they can get are poorly paid and they then go into whatever is a 90% or something marginal tax rate; so, yes, that sounds a great idea. This maybe something that the Government could introduce quietly, after all there is the waiver at the moment on the regular payments people receive from the Trust, so that they don't have to declare it for Social Benefit purposes. And the capital money they have received from the Trust, and they do receive free prescriptions, for example, are free of tax as well. The only other operation, I am aware of, that has those benefits is the London Bombings Survivors Fund. So yes, something like that could probably be introduced very quietly - just an order in the House that nobody would notice.

Before I come to my final question I have noted that three responses to the questionnaire were from women who said that they were directly contaminated with NHS blood products. As it's very unusual for women to have haemophilia are you aware of these cases or are they probably persons Von willebrand who contracted HIV?

I'm certainly aware of the fact that certainly one female registrant has Von Willebrands, but, after all, the Macfarlane Trust is not limited to people with haemophilia; in fact, it's for people with bleeding disorders, so it is quite acceptable, as it were, that there should be people in that position.

So I turn to my final question which is:
As the Macfarlane Trust is a registered charity and governed by charity law, albeit wholly funded by government, it is consequently limited to what it can and cannot do.
Would you consider direct action by its 'community of care' to be an appropriate response or inappropriate if Archer's conclusions are ignored?

I think it would be entirely appropriate and they would probably be either joined by or led by the Haemophilia Society and I think that would be wholly appropriate. They would risk arousing public reaction against them along the lines I have described earlier. I think direct action, with or without the leadership or assistance of the Society, would be perfectly appropriate, if Archer were to come up with some recommendations that were more in line with my hopes and my expectations, and the Government were to ignore them. It would risk arousing some public antagonism but that's a risk that will have to be weighed at the time. Those who would want to take that action would also have to consider the effect of those who wouldn't, if there are, whatever it may be – 360 registrants. Some of them don't want to know anything about this; they just want to get on with their lives. Maybe they are, in relative terms, the lucky ones that, at the moment, for health or financial reasons, are able to do that. There are I think a substantial proportion, who don't want to be active and, therefore, this might upset them and might risk, in some cases, blowing their cover as maybe they haven't come out. So that's the danger.

Peter Stevens, thank you very much indeed.