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APPG on Haemophilia and Contaminated Blood, 10th September 2014

Diana Johnson MP introduced the purpose of the meeting as being for members to understand the arrangements for people affected by the contaminated blood scandal. The key areas to cover are:

- The different funds and trusts that exist.
- Where there could be changes and improvements to the schemes on offer
- Understanding arrangements which have grown up over time.

Jan Barlow, Chief Executive of the Caxton Foundation and the Macfarlane Trust

JB referred to the slides in the pack which explain the 5 different organisations set up to support victims of the contaminated blood scandal. There are two companies which handle non-discretionary payments and 3 charities below them which handle discretionary payments.

Funding

£33m of funding is spent by these organisations each year. Of this, the charities disperse £4.5m in discretionary payments. The charities are there to give additional support to those in need. However, the discretionary element is small in terms of the financial support given. The potential number of beneficiaries for each charity are:

Macfarlane Trust – c700
Eileen Trust – 18
Caxton Foundation - >700

Some beneficiaries have received up to £0.5m (tax free) from the funds for which they are eligible.

Each of the organisations supports different sub-sections of the contaminated blood community. Internally, the organisations consider there is scope for rationalisation to one company and one charity. Co-infected people get non-discretionary from both sources but discretionary payments only from one side or another (usually the Macfarlane Trust).

There is a charitable need test for discretionary payments and the beneficiaries may be widows or dependents. However, non-discretionary payments stop when the victim dies, which means a large tax-free income will stop.

There are a lot of differences between the Macfarlane Trust/Eileen Trust and the Caxton Foundation. One-third of Caxton beneficiaries are at Skipton stage 1 and most are at Skipton stage 2. Therefore the people with Hepatitis C are behind those with HIV.

The Caxton Foundation and the Macfarlane Trust are restricted in the support they can offer owing to their funding. A funding bid for the Macfarlane Trust has recently failed and they may have to cut back their work if funding is not forthcoming. The Caxton Foundation have also had a funding bid declined. This may mean they have to reduce their budget by one-third.

The Macfarlane Trust has reserves. This is historic because at its origins the Macfarlane Trust was seen as a short-term organisation. They are now having to use those reserves but they are being very careful about how the money is spent so that a buffer remains and they hope that next year the Department of Health is able to provide some money. £800,000 was allocated from reserves last year for home improvements for beneficiaries but there is a risk that the Department of Health will not give them further money in future.

The Caxton Foundation was set up without reserves.

When the non-discretionary payments were established, the charity funding was reduced.

The discretionary payments are linked to September CPI. People typically get £700-£5,000 per year from the Macfarlane Trust and people tend to depend on these payments even though they are discretionary. The fact that they are running a deficit is a worry.

It is worth noting that none of the beneficiaries of the MFET and Macfarlane Trust are below the poverty line. However, there are Caxton Foundation beneficiaries who are below the poverty line because they have very low incomes. They need grants and will only get above the poverty line through regular payments. However, this is unlikely to happy with current funding.

They only have a grants programme of £190,000 and the same people tend to be coming back time and again.

The highest grant given in the past 12 months (through either stream) is £30,000.

The charities have supported travel and hotel expenses for hospital appointments.

Staffing and Chinese Walls

There are 9 members of staff for all 5 organisations. While 8 of them all sit in the same room they have to behave as though they are in different locations owing to data protection issues and this also means that information is not passed between the different organisations. For example, if someone is registered with the Macfarlane Trust, they cannot pass their personal information on to the Skipton Fund without their specific consent.

DJ suggested that consent could be obtained upfront but JD said that the problem was that the different organisations had been set up at different times over the past 25 years. DJ suggested that they should go back retrospectively to simplify the processes. JB suggested that they could look at this but that people would always be informed of the other funds.

Governance

There are 30 board members across the 5 organisations.

Websites

There are 4 websites (the Eileen Trust does not have one). They link to one another but do not necessarily look the same (but they are working on this). This is a consequence of the different organisations going online at different times.

Telephone System

The issues have been overcome since a new system was put in place in the past 12 months.

Roger Evans, Chair of the Macfarlane Trust and Co-Chari of MFET

There used to be more than 1,200 Macfarlane beneficiaries but now only about 309 of the original ones are still alive. There are also around 60 infected widows. The mortality rate has decreased over the years. Nevertheless, there is a large community of widow, children and surviving individuals who are now 25 years older than they were when Macfarlane was first established (the youngest is now 30) and these people could need up to 40 years' more support. The question is whether the Macfarlane Trust has the structures in place to deal with this, especially as haemophilia is a difficult condition to live with, irrespective of infection. The structures of the Macfarlane Trust were not designed for a long-lived organisation and are not suitable for the long term.

Individuals need to be in a position to manage their own lives financially. Prior to the Archer Report, the top regular payment would be around £2,500 and almost everything else required a grant. Now that regular payments are made through MFET, Macfarlane beneficiaries may receive £22,000-£38,000 per year (with an annual increase based on September CPI). The widow community now has a regular income of £19,000. This puts all those infected with HIV through contaminated blood in a position to manage their own affairs. There is a small minority who have found it hard to adjust to this.

There have not been many complaints about confidentiality. Every beneficiary has a number and so the grants committee cannot identify individuals.

Mr Evans recognises that there is huge potential to simplify the Macfarlane Trust but he considers that the bigger issue is how to handle the long-term situation. His preference would be to give everyone affected a lump sum payment but this would be ambitious in terms of tracing everyone. However, he does not think that the current arrangements will be tenable in 20-30 years' time.

Charles Lister, Co-Chair of the Caxton Foundation

The Caxton Foundation was wet up in October 2011 as a charity to provide discreet support to Hepatitis C victims and it works with a wide cross-section of beneficiaries.

Initially people did not get enough information about what information was needed to process an application and there were a number of mistakes in handling applications. They have now increased the number of applications which can be signed off by staff. Those which can be signed off this way are governed either by monetary level or type of grant. For example, a carer may need a respite care and this can be signed off quickly in the office rather than have to wait for a meeting of the welfare committee.

The process for making a grant request is now explained on the Foundation's website (it was not there a year ago). They do not declare financial values on the website but they have a list outlining key areas where people can apply for money. However, they have to take a view on how far 'charitable need' takes them. Ultimately, decisions are based on need but they try not to treat people differentially. Typically, people apply for:

- Household items
- Home repairs
- Adjustments to accommodate disability (e.g. installing a downstairs toilet)
- Kitchens that can be accessed at wheelchair level

- Debt

The coinfected have to go either to the Macfarlane or Eileen Trust. They cannot come to the Caxton Foundation if they are refused.

Sir Peter Bottomley suggested writing to the Charity Commission asking for all 5 bodies to be amalgamated.

JB pointed out that if amalgamated they would have to offer parity to everyone who could claim. She said they would not want different streams of funding aimed at different people – there cannot be losers in this and at the moment the differences are huge.

DJ said that this work sits alongside the review Alistair Burt is doing with Downing Street.

A number of new treatments are coming in for Hepatitis C and the charity is afraid the Government may think that less money will be needed as a result. However, some people who have been out of work for a long time may not easily be able to resume if they become clear of the infection.

Conclusion

The second phase of the inquiry will be sending out a survey (via You Gov) via the trusts and funds in the next 7-10 days. These will also be used as a basis for the report.