

16 APR 2012

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London

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12 April 2012

Martin Harvey
The Macfarlane Trust
Alliance House
FEEPOST LON729
12 Caxton Street
London
SW1H 0QS

Dear Martin,

I am writing to you with increasing concern over the contents of Russell Mishcon's letter to MFT beneficiaries.

Unfortunately, the letter contains something akin to an ultimatum, and shows little regard for the wishes of the people for whom the Trust is supposed to care. I have seen evidence of this before with the discovery that a senior member of MFT staff had branded us "the great unwashed".

You may, or may not be aware that the current proposals of home visits has caused widespread dismay in the beneficiary community (as evidenced by the amount of concern shown on the various forums.) There is much concern that the Trust has chosen to make this proposal without consulting in detail with the beneficiaries. Many feel that this is indicative of a continuing lack of respect towards beneficiaries.

I feel that the level of coercion implicit in Mr Mishcon's letter means that any consent you receive by way of responses will have been obtained under a form of duress and could therefore be invalid. This in turn could mean that the MFT fails to discharge their statutory duty to consider our Article 8 rights as a group with protected characteristics. In any case, this is an unfair way to treat people who are in need.

The fact that the reserves have been allowed to accumulate over the years is an egregious breach of duty, especially when so many of us have made genuine requests for financial help. (In my case I had to repay a loan for £4,000 and also, after coming to see you, you said that there shouldn't be a problem getting help from the Trust with my then credit card debt of over £7,000, yet a few days later, I received a letter saying that it had been passed to the NSCC and that they had declined my request for help.) Did you have substantial reserves then?

I personally feel that if the accumulated reserves cannot be divided up equally, then if the reserves date back 5 to 10 years, you should by rights backdate the requests we've made where we have either been turned down outright, or offered (in effect, forced to take) loans.

Now that there are so many registrants who also qualify for Skipton Stage II regular payments, I doubt very much that you will be looking seriously at their circumstances. I think that approach is wrong, because those who are eligible for Skipton Stage II are only being awarded that help because they are in increased medical need. Somehow, the MFT has managed to adopt the "charitable need" mantra, even though in Charity law your application of this is most questionable and probably would not withstand forensic scrutiny. For example, you know all too well that none of us are living in abject poverty apart from a few that would always be living that way simply - because their lifestyles and money management skills are lacking.

It is clear to me that there is overwhelming support for a fairer, simpler method of distribution and I do not accept that the Trust's charitable status prevents this. Given the lack of consultation, I cannot tell whether you have carefully considered other options. If you did, then you seem to have chosen the most objectionable of the possibilities!

I would like to ask you to please:

1. Suspend the current process until a broad consultation has taken place with all the beneficiaries (via the post), or through either a general meeting or a smaller meeting with a minimum of 15% of the beneficiaries.
2. Consider more equitable options for distributing the excess reserves as a matter of urgency. (My personal preference is that the funds be distributed on a *pro rata* basis.)
3. Ensure that any of the options being considered take into account our right to confidentiality and privacy. (Particularly in that the planned intrusion into people's homes is unnecessary and could potentially lead to a breach of our right to a private life under Article 8 of the HRA.)

I would also ask that you take this decision urgently in order to prevent further distress.

Kind regards,

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cc. Jason McCartney MP, APPG on Haemophilia
Chris James, Haemophilia Society.

5, 7, 7, 6, 1

28/7/11