

Rosamund Riley

From: GRO-A
Sent: 21 November 2011 17:58
To: Martin Harvey
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Subject: Re: Special NSSC Meeting - 28.11.11

Martin,

As per email I am just listing a few ideas as to the reduction of the reserves.

I know that we have briefly touched on the reserves being ring fenced for the use on a special insurance fund which may help those left when a registrant dies.

I think whilst this may be a good idea in theory there are certain areas that we need to discuss before taking this idea further and certainly I personally do not believe that the total reserve should be allocated towards this.

There are many changes happening at the moment, among these it is now reported that the government are not increasing benefits next year so in effect this constitutes a cut to the registrants income.

Also motability is changing in the way it operates next year which I believe will alter the way in which many of our registrants lease/purchase vehicles.

I would personally like to see approximately half the reserves used for a form on insurance payout and the rest or at least part go towards raising income to registrants as mentioned before at the nssc.

We can reintroduce certain payments with the proviso that these will only be paid whilst funds allow so as not to set precedents as to the expected level of income, this may include annual payments towards vehicle upkeep, winter payments, etc if paid in this way we would not have to revisit the payment scales that we discussed before.

The insurance scheme I certainly do not believe would require the total of the MFT reserves as they stand at the moment, indeed there would be no point allocating the total to this as we would be no further forward, we would still have a large reserve which would not be reduced greatly on a year to year basis.

There are also problems of payments, after all who is paid? there are registrants who either live alone, or have no dependants so who in these and many other similar cases would receive payments.

The final point but one which we should not lose sight of is the way the benefits system is changing and the possibility of registrants losing in some cases a large proportion of their income and whilst the increase in regular payments was a major step forward this would be undone when and if things change as mentioned by mr GRO-A with regularity.

What we were after as a board was to provide as much financial independence as possible for registrants without just paying monies out blindly, this I believe we can do and still prove that it is done for the right reasons.

Just a few thoughts for the meeting

Regards

GRO-A

Sent from my iPad

On 16 Nov 2011, at 23:08, "Martin Harvey" <martin@GRO-C> wrote:

To Martin Harvey & the NSCC Committee

Whilst I appreciate Martin comments that this won't be an easy exercise, I strongly hope that as a committee, we don't take the option of ring fencing the entire 4million for Insurance purposes, as in my mind that would be the easy option and I feel we would be failing in our duty if that happened. After referring to Funding long term survival by Peter Stevens and Martin Harvey published November 2005. These are my thoughts regarding the surplus 4million and they are based on registrants needs.

Long term survival since the original capital payments has resulted in acute poverty for many of MFT registrants. Payments over the years from MFT have been far from sufficient to make up for the erosion of capital values and the inability to have had earnings which most people enjoy, or indeed for the sort of life that these people would have expected to lead. Although registrations income went up a short while ago it must not be forgotten that for years some beneficiaries had an increasingly impoverished existence that meant they fell further behind that of life of their compatriots, let alone the sort of life they would have expected had their treatments by the NHS not infected them.

My first proposal is Housing cost needs. To illustrate my point I would like to quote Appendix C – Housing from Funding long term survival, page 14 & paragraph 1&4 of page15

The survey of MFT registrants undertaken as part of the Review showed that about 55% of respondents lived in owner-occupied homes. This is reflected in the high and increasing frequency of requests for MFT assistance with financing home maintenance, repair and alteration (the latter usually comprising adaptations either to accommodate decreasing mobility caused by haemophilia or to provide home treatment and rest separate from normal household areas).

Besides such alterations, houses needs constant attention to maintenance and, from time to time repair. The latest available Expenditure and Food Survey (2003-2004) gave average figures for that year of £8.20 per week (nearly £430 annually) for maintenance and repair and £22.80/week (close to £1,200 annually) for adaptations and improvements, which included double –glazing and central heating, two items for which MFT has always provided help because of the need for registrants to live in warm and draught free environments. These figures were respectively 26% and 40% higher than the levels two years earlier, reflecting both the greater degree of attention given to such activities nowadays and the tendency for such costs to rise much faster than general inflation. The equivalent aggregate figure now might, therefore, be of the order of £2,100 annually.

This is an annual figure for an average household and does not take into account the extra modifications and maintenance to the home necessary as a result of living with the joint conditions of haemophilia and HIV (and, generally, HCV). Results taken from this year's registrant survey make clear that there is a large and ongoing need for financial assistance in all aspects of housing maintenance and repair. As the physical condition of registrant's declines, their need will only increase.

This can be coupled with the fact that as any house ages, the need for general maintenance and repair increases.

Responses to this survey graphically illustrate the need. 78%(200 people) expected to need help with home repair within the next three years, 66% with re-decoration, 54%with central heating, 49%with alterations (for example to accommodate wheelchairs, stair lifts, hand rails, special chairs and beds and so on). Because of registrants' disabilities all work on the home must be carried out by contractors, which would increase the Family Spending figures. The registrants' health also means that the length of time spent in the home is far greater than that of an average person, tending to increase both wear and tear and their sensitivity to it. Based on these figures and on MFT's experience, the figure of £2,100 would well be below the minimum average annual amount that one of our registrants needs to spend in order to keep housing serviceable and in adequate repair.

Gardens also involve expense, again often resulting from registrants' inability, over time, to manage the physical work themselves. MFT has given a number of grants to enable gardens to be made more useful to those whose disability is so impaired that they use wheelchairs or crutches, such as paving areas previously grassed, providing ramps in place of steps, and so on. More needs of this nature are to be expected.

Paragraph 1 of page 15

Another aspect of living conditions relates to furnishings and equipment. MFT's registrants' health puts a particular premium on laundry and refrigeration equipment, impaired and declining mobility requires sound floor coverings, so that carpets need earlier replacement than normal. In the recent survey two-thirds of respondents stated a need for a fridge or freezer for storage of medical supplies, and nearly half for more powerful laundry equipment. 55% expected to need to replace carpet to eliminate tripping hazards or because of neuropathy. Bedding, also, needs frequent replacement. All these add to the financial burdens of living with haemophilia, HIV and HCV.

Paragraph 4 of page 15

Taking all these aspects into consideration, the Trustees believe that they should be able to provide assistance of, on average, £10,000 annually to each of its owner-occupier registrants to provide for the physical aspects of their home environment, and of £5,000 on average for those who rent their homes. This is an annual outlay of nearly £3 million.

My proposal is that £2,500 is given to beneficiaries for housing costs accrued over the years. Total £900,000

Proposal 2. Transport costs.

The cost of Transport is now very high with beneficiaries having little choice in using transport as the majority have three diseases to cope with, Haemophilia, HIV, HEP C which means many trips to hospitals at great expense and many are in cars that are

essential as the need to park close to the unit is important and many cannot use public transport.

For those that can drive or have cars driven for them adaptations and upgrades are frequently necessary to their vehicles. Larger cars are needed to accommodate a wheelchair, cars are needed with large doors and more leg room that can be used by those with little knee or ankle movement and some cars have to be automatic for those with joint problems. MFT policy was focused on encouraging registrant to use vehicles provided by Motobility where necessary financing deposits if a deposit –free vehicle was not suitable. My proposal is that due to health needs and the importance of having a car, (it is not an option but a medical necessity) I would like to see £2,000 given now and every 3 years thereafter. The same sum would also be available for those for whom a car is not appropriate but need other forms of mobility. Cost £720,000 recurring every three years.

Proposal 3 Heating.

People with joint damage are often inactive and feel the cold. That combined with HIV and Haemophilia consequently need to avoid common winter infections, which leads to greatly increased demands for heating. This extra demand for heating means that the beneficiaries' energy bills, especially over winter months are greatly increased. At present each beneficiary receives from MFT a one off payment of £500.00 which can be put towards the extra costs of staying warm in winter. The additional cost of maintaining a warm, dry environment, together with the frequent need for bathing and laundry resulting from HIV infection adds to that the extortionate cost of energy, I feel £500.00 is not enough and would like to see it rise to £1,000. Total £180,000

My 4th proposal involves reinstating the supplement that was an additional £61.00 monthly supplement for those beneficiaries who received the middle or higher care component of Disability Living Allowance.

This was given pre Archer on the basis that it was a health related supplement and to my knowledge beneficiaries' health needs are still the same pre Archer and post Archer. I would like to quote from "Funding long term survival" regarding the supplement.

"These monthly payments are not means tested because from the outset, Trustees have believed that the health conditions of all registrants have cost implications that over-ride any individual financial circumstances and that can in any case change with little warning"

As I mentioned if a beneficiaries health has improved since this supplement was withdrawn they would not be in receipt of Care Component for DLA but those who's health is the same if not worse and should have this supplement reinstated.

Cost ????

My final proposal would be to reinstate a respite grant on the grounds of need to alleviate stress in beneficiaries' life. Again I would like to quote from "Funding long term survival" Appendix E – Dealing with stress page 18

Living with haemophilia and HIV and, for most MFT registrants, HCV, together with the associated therapeutic regimes, is a source of considerable stress. Stress is an inevitable concomitant of life for most people. However, for MFT's registrants, stress levels are much higher than for most people and the deleterious effects of such stress, both on the progression and treatment for their viral infections and on their propensity to bleed and on the progression and treatment of their viral infections and on their propensity to belled and on non-medical aspects of their lives, must be alleviated by every means possible.

There are innumerable causes of such stress on registrants. The Oxford and Sheffield Survey of People with Hepatitis C and Haemophilia undertaken by the Haemophilia Society took evidence from 93 people who cited such things as uncertainty about the rare of progression of disease, fear of exposure, inability to have a normal social or family life, inability to work (full-time or even at all) and perpetual fatigue. All of these causes of stress are greatly amplified when HIV infection is included, with fear of exposure especially magnified- even in 2005 HIV-positive people are stigmatised and harassed, and it was as recently as w2004 that MFT assisted a registrant to move home to escape persecution.

It should also be noted that the hereditary nature of haemophilia, together with the close links between people with haemophilia (especially those infected with HIV), mean that all surviving registrants have known many people, relatives, or friends, who have died. One registrant reported not long ago that, aged less than 50; he had attended nearly 100 funerals. The mental stress of such knowledge is profound.

MFT's 2005 survey of registrants showed how individuals deal with this stress:

- *Holidays, respite breaks, weekends away, ect. were indicated by 50% of respondents*
- *Hobbies (43%)*
- *Computers/the internet (32%)*
- *Other – TV, DVDs, videos, games machines, listening to music (59%)*

It is clear that respite breaks, holidays and long weekends all have an important role to play in coping with illnesses. The importance of having the opportunity to leave the house and visit different surroundings and people in order to reduce stress and improve mental well-being, cannot be underestimated. Request for financial help for such breaks are often supported by registrants' physicians.

MFT currently has a guideline limit of £1,000 annually for grants for all respite breaks, which is barely enough to pay for a single two-week family holiday. Trustees in exceptional circumstances exceed this guideline, but current resources do not permit a more generous – and more realistically helpful – guideline. Trustees believe that a reasonable minimum annual expenditure on all means of reducing stress should be £2,000 for each registrant and his family, or about £3/4 million.

I would like to see a grant given each year of £1,500, as a need to alleviate stress in beneficiaries.

Cost £540.000 annually

In the past the MFT emphasis was to help beneficiaries if they were ill, my proposals are based on a need to help as much as the NSCC reasonably can to keep each beneficiary as healthy as possible. Whilst I appreciate need normally refers to those in financial need, however, as set out in objects of the trust, financial need is not an absolute term and as Trustees we have the discretion as to how to assess whether a person is in need. And I feel that my proposals are appropriate and in accordance with MFT objects and that my proposals would go some way to giving beneficiaries a Full life – not just Existence.

My figures are based on 320 living primary beneficiaries, and 40 living infected intimates.

I would like my proposals to be on the agenda so the NSCC can have a full and frank debate.