

RESTRICTED – POLICY

To: Secretary of State

GRO-C

From: Caroline Flint

Date: 22 July 2006

Cc: Lord Warner
Liz Kendall

MACFARLANE AND EILEEN TRUSTS

On Wednesday [12 July] I met a deputation from these two Trusts led by the Chairman, Peter Stevens (who chairs both Trusts) and some of their "registrants". The Trusts had previously submitted a "business case" for increasing their total funding by DH from around £3m to over £7m a year. The present pressure on central budgets simply does not provide for that kind of increase – and I am not convinced that their case is strong enough. But this is an emotive issue, and I should be grateful for your views.

The Macfarlane Trust was set up in 1988 in response to the plight of haemophiliacs who had been inadvertently infected with HIV through NHS blood products. The (very much smaller) Eileen Trust was set up in 1993 to do the same for non-haemophiliacs. Successive governments have maintained this commitment. Hazel Blears, when in my seat, agreed a three-year settlement of £3m per year for the period 2003/4 to 2005/6. The Trusts now regard that settlement as "up for renegotiation" for 2006/7 onwards.

When the Macfarlane Trust was set up, the prognosis for HIV was poor. Beneficiaries were effectively told they had only a few years to live, so they made no long-term plans with the capital sums they received from the Trust. Nor did the Trust take a long-term view of its continuing support functions. Now, though HIV is serious and treatment is unpleasant, life expectancy is substantial. The Trust believes that their underlying purpose has changed, and it is no longer enough for them to make payments to registrants averaging some £6000 per year each. Longevity brings additional costs.

In fact, DH's funding to the Trust has enabled them to roughly double the average annual payment to registrants, in real terms, over the lifetime of the Trust. This is mainly due, unhappily, to the fact that, of the original 1200 registrants, less than 400 are left, rather than to DH's generosity.

The Trusts were always intended to supplement existing statutory provision. They were not intended to make alternative provision, nor did they imply fault by the NHS. At the meeting some concerns were raised about how registrants didn't always claim their rightful statutory entitlements because of fear of "exposure" to friends and neighbours. I was not convinced that some of the expenses mentioned in the meeting and in the business case were appropriate to the Trusts.

However, clearly the terms of the Trusts were based on what was felt to be the need at the time and a view that both Trusts were expected to be short lived. Nearly 20 years on and they are still very much needed. For the Eileen Trust, although presently very few registrants, there is potential for new registrants to be identified in coming years and the Trust expects still to be running in 20 years time.

The Trusts believe their underlying role has changed from one in which payments were provided to ease registrants remaining few years to assisting people to live in relative physical comfort and managing "unplanned for" costs such as housing maintenance, washing machines, costs in raising children. While some registrants earn their living, most cannot and so have no pension and no financial security.

The Trusts describe their current claim is the first comprehensive review of what they are doing. That may be so, but officials have, all along, informally briefed the Trusts that additional funding would be unlikely. In response, the Trusts' Chief Executive has, equally informally, indicated to officials that they understood this, at least at the senior level.

The present central budget setting round has left no room for a significant increase in funding, beyond perhaps up to a 10% one-off increase which would mean £400k across both Trusts (£350k for the Macfarlane Trust and £50k for the Eileen Trust). This is obviously well short of their demand. Given the steady decline in registrants for the Macfarlane Trust, flat cash funding may be, objectively, all that is necessary.

I understand that when the Trust approached officials for increased funding in January 2005, officials told the Trust to prepare a realistic business case but made it clear the amount initially requested was unlikely to be met. My concerns are that DH having told the Trust to provide a business case (and therefore tacitly supported this review) hadn't really thought through how to deal with the outcome. As a consequence we're left with little resource to offer but no real answers to the challenge that the Trusts are not able to cope with the needs of registrants today based on the original presumptions.

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