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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.

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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.

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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.

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The problem is that, despite informal official discouragement going back at least to last autumn, the Trusts have put forward a claim (in places rather over-egged) that they are not able to cope with the needs of registrants today based on the original presumptions.

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The Haemophilia Society, Parliamentarians particularly in the House of Lords and the media have been very vocal on this matter and are not likely to be content with a flat cash offer. It appears to me that we have the following options:

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1. Offer the same cash funding as hitherto.
2. Offer a modest increase of say £400k across the two Trusts (which can be found within the tight central budget settlement)

3. Offer either of the above, and a DH/Trusts working group to consider more fully the role of the Trusts and their responsibilities to registrants.

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Options 1 and 2 both present considerable challenges in terms of handling. If we take Option 2 (a small increase) for example which is the officials' second choice recommendation, I'm sure we can argue our position but the nature of this issue is highly personalised to individual's real life experiences. We will be highly criticised for dismissing the premise on which the review was undertaken - i.e. we have just found a bit of money linked to no strategic view of the needs of registrants. Option 3 provides some space to consider further some of the concerns but would imply some change to the Trusts. DH needs to be clear what direction that change would take, how to deliver it (Divert officials from other work? Commission an independent reviewer?), and whether in (say) a year's time there will be any more money available for these Trusts than there is now.

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This is and will be a high profile issue, unlikely to go away which I why I wanted to ensure you are fully aware and I would appreciate your views.

Happy to have a chat if required.