DV

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From the Minister of State

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Honorary Secretary
The Haemophilia Society
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23 September 1975

Dear Mr Prothero.

Thank you for your letter of 20 August about the treatment of haemophiliacs.

Production within the NHS of AHG concentrate, during the first six months of 1975 was some 15 per cent up in comparison with the corresponding period last year. I accept that even with this increase production falls far short of what is needed but it is still too early to see any results from the extra money to which you refer. The arrangements which we had to make to use this money efficiently were complex and have taken some time to organise; I have pointed out on many occasions that I have never expected that the first effects would be felt much before the end of this year. In the light of estimates which have recently been made by Regions I now hope that in about a year we will be able to meet some 2/3rds of the present requirements and that within two years we may be able to reach the target recommended to us by the Expert Group on the Treatment of Haemophilia.

This is not as soon as you, and we, would wish but the main reason why the programme cannot be completed earlier is that in several Regions extensive alterations taking many months have to be made to the Transfusion Centres before they are in a position to provide more plasma. Meanwhile, of course, Health Authorities are free to purchase AHG concentrate from commercial firms when individual cases merit it. With medical advice they can best judge the individual cases and balance the needs taking into account the number of demands on their limited resources. I understand and share your concern for haemophilic patients but we have to face the fact that AHG concentrate is one of the many costly treatments which is competing for priority; there are many other aspects of patient care which also have priority and it is not possible to meet all demands.

Turning now to the question of attendance allowance, as you know the medical requirements for it are not based on the disabled person having a particular disability. The allowance is intended for those severely disabled people who need a great deal of help from another person either by day <u>and</u> night (for the higher rate) or by day <u>or</u> night (for the lower rate). Whether any particular person satisfies the medical requirements for the allowance is a question specifically reserved for the Attendance Allowance Board, an independent statutory authority set up under the Act which introduced the allowance. The Board in turn are bound by the requirements of legislation which, as I have explained, relate to the amount of attention or supervision required because of a person's disablement rather than on the type of disabling condition. Often reports of decisions which appear to be anomalous arise from the belief that certain types of disablement always involve the same requirement of attention or supervision. This is not so, and with attendance allowance the prime concern is not the nature of the disablement but whether it is so severe in the individual case that it warrants attention or supervision to the extent described in the statutory provisions. Each case is considered individually on its facts. In view of the independent status of the Board, I cannot, of course, interfere with their decisions and neither would it be proper for me to comment on their decisions in individual cases. If, however, you consider that any of your members measure up to the above conditions but are not receiving the allowance or are not receiving it at the appropriate rate, may I suggest that they be advised to write to the Attendance Allowance Unit, Norcross, Blackpool, to ask for a review.

Finally, I turn to what you say about the Government's decision that severely disabled haemophiliacs will no longer be entitled to be supplied with a car instead of a three-wheeler if they are found eligible for help after the commencement of the mobility allowance scheme.

When Ministers examined the whole problem of mobility help very thoroughly last year, in the light of Lady Sharp's Report and the comments made on it by disabled people's organisations, the point that struck us most forcibly was that any scheme based on provision of vehicles by the Department or allowances to those running cars would leave out people who were unable to drive or to nominate someone to drive a car for them. The severely disabled people excluded in this way from the present scheme include many of those most at risk of being socially isolated by their handicaps. We reached the conclusion that the most fundamental requirement of a just scheme was that it should not, while improving benefits for drivers or car owners, continue to leave outside equally disabled people who lacked even those advantages.

This is the main reason why we decided that for the future we would provide cash and not cars, with freedom of choice on how to spend the cash. Once we had settled this, it did not seem fair that we should provide benefits of greater value for just a few. In equity, we felt we could not justify the continued provision of cars for new applicants once the mobility allowance had become available. Greater equity has been a major theme of our whole new approach.

However, none of the two or three hundred haemophiliacs who already have a Ministry car is going to be deprived of it as a result of this change in future policy. Existing people who benefit will be entitled to keep their cars, and to have them replaced when necessary, so long as they continue to satisfy the conditions which applied when the car was issued.

Because eligibility for mobility allowance will not be confined to drivers or car owners, the new benefit will go to many more people - possibly 100,000 more than the 50,000 who now get the Department's vehicles or private car allowances. The total cost will be three times that of the present scheme, even after allowing for the effect of recovery of some part of the allowance by way of income tax. We fully recognise that at £5 a week the allowance is not going to be large enough by itself to enable a disabled person to buy and run his own car. It would be very gratifying to us if we were able to pay more, but unfortunately in these times of financial stringency that is just not possible.

We cannot do all we might like, but I am sure we have got our basic priorities right both in trebling the Government's spending on mobility for disabled people and in ceasing to treat drivers more favourably than others. I have no doubt that severely disabled haemophiliacs who cannot drive and who therefore get no help at all at present would support this view.

I would be happy to discuss these matters if you feel a meeting would be worthwhile and if you ring my office we can fix an appointment.

Yours sincerely

[redacted]

DR DAVID OWEN