

# vCJD Trust

Chairman: The Honourable Mr. Justice Owen

September 2006

Dear

## **vCJD Trust - Payments for Care**

On 23 June 2006 the Trustees agreed that we would reconsider the principles which we had established for payment of claims for care which had been provided to victims before the Care Package was made available prior to March 2001. We therefore gave the matter very careful consideration at our meeting on 16 August 2006 and reached the decision that the principles which we had adopted were both appropriate and fair. We did not consider that there were any compelling arguments for altering our earlier conclusions; and remain firmly of the view that our approach was a proper and appropriate exercise of our discretion for the principal reasons set out below.

First, the Trustees had decided these principles after careful consideration of the care requirements of those suffering from vCJD. That involved consulting Irwin Mitchell, solicitors for the majority of families, and Dr Richard Knight at the National vCJD Surveillance Unit. Dr Knight provided a breakdown of the stages of illness with general indications of the care requirements of each stage. Whilst we recognise that care requirements vary from individual to individual, Dr Knight's input was invaluable. Secondly we took into account the approach which is adopted by the Courts when assessing compensation for the provision of gratuitous care. In so doing we were able to draw upon the considerable experience of those Trustees who have practiced in the field of personal injury law. Although not bound by common law principles, there was obvious value in being guided by a proven approach to the difficult task of evaluating gratuitous care. Thirdly, and most importantly, we were able to draw on the personal experience of the Family Trustees.

Secondly we decided to cap the maximum number of claimable hours in order to ensure that sufficient money would be available to meet all future claims on the Discretionary Fund. But when at a later stage it became clear that there were sufficient funds to enable us, in the proper exercise of our discretion, to increase compensation for care, we resolved to increase the awards by 30%. The Minutes of the Meeting on 14 March 2003 record that we "decided it was appropriate to increase the

level of payment for such care in order to fully compensate those who have provided it". The effect of that uplift was broadly to compensate for 24 hours of care at the 'third' stage of the illness.

Third, a change of approach at this stage would have adverse consequences. We would be obliged to reconsider all claims for care, almost all of which were decided and paid some time ago. That would involve contacting many families who believe that their claims have been finalised, and who have moved on with their lives. We have no doubt that that would in some cases cause considerable distress.

We are very much aware that some have interpreted the approach that we have adopted in relation to this head of claim, as a failure fully to recognise what is involved in the care of the victims of this terrible disease. Our experience of dealing with over 103 claims has given us a profound insight into the care needs of its victims and into the deep distress and trauma suffered by those who have cared for the victims. We also recognise that many families have submitted claims, not primarily in order to secure financial compensation, but rather to receive some acknowledgement of all that they have suffered. But our role as Trustees is to administer a fund for the provision of financial compensation, a task that has presented considerable difficulties, in particular in relation to claims on the Discretionary Fund, and we would simply ask those who have been critical of our approach with regard to care to accept that we fully recognise all that they have done as is so movingly described in the accounts that they have given us of their care for their loved ones.

Yours Sincerely

The Honourable Mr. Justice Owen  
Chairman