

**SUBJECT TO LEGAL PROFESSIONAL PRIVILEGE**

**vCJD TRUST**

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**BRIEFING NOTE  
FOR SECRETARY OF STATE**

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**Introduction**

1. This Note is to identify some of the issues raised by Sir Robert Owen's proposal to alter the vCJD Compensation Scheme and to propose an approach for the Secretary of State to take at her meeting with him on 19 July 2006.

**Summary**

2. It is important to recognise that the Trustees are finding it difficult to administer discretionary payments for whatever reason. Accordingly, there are significant arguments in favour of seeking to simplify that part of the Scheme.
3. Sir Robert Owen's proposals need to be given serious consideration. It may be appropriate to involve Leading Counsel, Justin Fenwick QC, who jointly advised in relation to setting up the original scheme. There are significant risks in altering the scheme in the radical manner suggested in relation to the balance of the 250 people for whom it was intended to provide. However, it is likely that at least some alterations could be made applying a principled approach in order to address the difficulties stated by the Trustees.
4. It is suggested that at the meeting on 19 July the Secretary of State should provide a holding response indicating that careful consideration will be given to the proposals, legal advice taken and a considered response provided as soon as possible. Further information should be sought on the nature and extent of the

difficulties which it is claimed the Trustees have faced and the extent to which these are likely to continue in the future.

**Approach taken to compensation under the Scheme compared with common law compensation**

5. In October 2000, the report of the BSE Inquiry was laid before Parliament. Shortly after publication, the Government, without any admission of liability, announced that it intended "to put in place financial arrangements to benefit the sufferers from variant CJD (vCJD) and their families". It set up a no fault compensation scheme which is now governed and operated by the vCJD Trust.
6. Throughout discussions with representatives of the families, the objective of setting up this no fault compensation scheme was clearly stated, namely that it should provide a solution based on a significant but not excessive discount from sums which would be recoverable at common law in the event of proof of negligence, but arranged in a flexible manner so as to provide for the particular problems associated with vCJD and its development in the United Kingdom.
7. For this reason, the rules laid down in respect of compensation for pain and suffering, care and loss of earnings and dependency were somewhat lower than might have been recovered in a common law action if successful. They were also standardised in an attempt to make calculations easier and save worry and expense. This will have led in certain circumstances to higher payments than would have been made with a more detailed investigation at common law, but in other cases to a slightly lower result.
8. By contrast, there were two areas in which the final package was substantially more generous than would have been available at common law:
  - a. Firstly, provision was made within the discretionary fund for payments to family members both for the experience of watching the suffering of a loved one from vCJD and for any psychiatric injury and its consequences

that they suffered as a result. These family members would be 'secondary victims' at common law and not entitled to any award.

- b. Secondly, in respect of the victim's own suffering ("the Basic Sum"), an additional £50,000 was agreed to be paid for the first 250 victims, which meant that the sums awarded for pain and suffering were very substantially higher than would have been recovered at common law i.e. £120,000/£125,000 in total.<sup>1</sup>
9. Against that background, a sum of £67.5 million was provided to the Trust which was a cautious estimate of a sum which was likely to exceed most reasonable expectations of the amount which would be payable, based on a variety of assumptions as to the marital status, earning capacity, number and age of dependants of likely victims. This sum was intended to provide a moderate provision for meeting costs incurred to date and expected to be incurred by the Trustees and families in administering the Trust.
  10. Of the total sum, a limited sum of £5M was originally allocated to the Discretionary Fund which was intended to cater for the *exceptional* case e.g. the high earning heart surgeon who died of vCJD leaving his family suffering serious financial hardship or a case where a family member suffered particular psychiatric damage or financial hardship as a result of a victim's illness or death. A further £3M was transferred from the general to the Discretionary Fund in 2005 following representations from Sir Robert.

#### **Proposals for amending the Scheme**

11. Sir Robert Owen is now proposing a radical overhaul of the Scheme for cases diagnosed after March 2007 so that there will be just 2 elements to compensation:

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<sup>1</sup> The original provision was for £70,000/£75,000 intended to represent a sum that might be awarded as general damages by a court. The difference in the figures is because an additional £5,000 was provided for those victims whose date of diagnosis preceded publication of the BSE Inquiry report on 26 October 2000 in recognition of the additional hardship and anxiety experienced by the earlier victims and their families as a result of the uncertainty over diagnosis and problems with care.

- a. a significant lump sum payable in all cases based on an average of the sums paid in the claims processed to date net of any dependency payment (it would seem from the draft varied Trust Deed that this will be about £200k in each case).
- b. where the victim has dependants compensation for dependency calculated in accordance with the Second Schedule of the existing scheme.

12. The reasons given for the change are:

- a. the considerable difficulty in administering the scheme which has given rise to distress on the part of families in providing information and by virtue of the Trust making comparative judgments as to degree of emotional and financial hardship and has prolonged the time to process claims;
- b. that the cost of administering the scheme would be reduced dramatically;
- c. that the position of victims has changed dramatically as a result of treatment with pentosan polysulphate (PPS) such that victims are now living much longer and it is important that the whole of the award is available for the benefit of the victim at the earliest possible stage
- d. that the proposed revision will only apply to a cohort not yet in existence and not those on whose behalf the original scheme was negotiated.

13. If the Secretary of State agrees to the proposal for change, the Trust intends to consult the various families' representative groups and their solicitors.

#### **Potential problems and risks**

14. The most significant risk associated with Sir Robert Owen's proposal is that the existing Scheme was intended to provide for 250 victims in terms of the monetary provision - there have been 161 victims so far and this figure is only growing slowly (5 per year for 2005) so it might be said that for the balance of the group of 250 the individuals concerned had a legitimate expectation of being paid out under and in accordance with the terms of the original Scheme. This will



potentially provide a basis for judicial review by any unhappy net loser under the new Scheme from the remaining cohort of 89 or so victims on the ground of irrationality and an act inconsistent with legitimate expectations. It will not be possible to obtain to avoid the risk of this by obtaining consent to the variation in the Scheme when the new cohort diagnosed after March 2007 has by definition not come into being yet.

15. In order to minimise the risk of a successful judicial review, there would need to be a principled basis for any amendment to the Scheme. The fact that the Trustees are finding it difficult to administer a limited discretionary fund according to relative need and hardship, when this is often the task with which trustees are faced, is unlikely to provide a sufficiently sound basis for such amendment.
16. A further problem with the proposal is that it will overcompensate some families in that they will receive as of right sums which were intended to be discretionary (e.g. some non-dependents will get £200k rather than the £120k they would otherwise only be entitled to). This would also side-step the current limitations on the Discretionary Fund which were intentionally put in place in order to avoid limitless claims/payments from the Discretionary Fund.
17. In the case of net losers under the new proposal (who would have obtained more under the original Scheme) a further risk which needs to be considered is that the further the Scheme is removed from the analogy with common law damages (on which the existing Scheme is based), the more likely it will be that there will be a disparity in some cases between the sum received and common law damages. This could encourage someone to pursue the BSE/vCJD civil litigation (which is currently stayed pending the making of final payments from the vCJD Trust). There is no requirement under the Scheme to compromise a civil claim but any person who receives sums has to give credit for those in any subsequent litigation brought against the Department. It is in the Department's interest that any sums paid out approximate to any sums which might be recovered in civil litigation so far as possible in order to reduce the incentive to bring litigation.

18. Whereas there are currently disparities of treatment that families may find invidious, there would still be disparities under this proposal between what the existing cohort received and what the new cohort will receive in terms of amounts.
19. The fact that problems have been caused by failure by the families to provide necessary information (due to distress or whatever other reason) is not necessarily a good reason for changing the scheme. The families are obtaining sums in the alternative to litigation - which would have caused much more stress, distress and the need to substantiate a claim. The Trust can reasonably refuse to deal with a claim, apart from the basic payment, until it is provided with the necessary information and should have a valid defence to any criticism based on delay as a result.

#### **Areas where it might be possible to amend the Scheme**

20. Although this will need careful consideration with Leading Counsel, there may be a principled basis for altering the provision for discretionary payments to the family based on the fact that victims are now living much longer as a result of PPS treatment than was the case at the time the Scheme was negotiated (then life expectancy from diagnosis was an average of about 9 months) such that payments are directed to a greater extent towards the victim rather than the family by way of discretionary payments. The desirability and effect of this will need to be considered. It would inevitably have the effect that more money is going to the victim and less to the family than under the current Scheme and this could in itself produce unhappiness on the part of the family.
21. Consideration can also be given to whether it is possible to alter the definition of "Qualifiers" so that it limits the category of person who may apply to those entitled under a will or intestacy. However, it should be noted that the intention behind the original Scheme was that there should be freedom for the money to go to those who actually provided the care or whom the Trustees otherwise considered should in fairness receive the money rather than those nominally

entitled under a will or intestacy who may have had little or no involvement with the deceased and his care.

#### **Course of action**

22. Further detailed consideration needs to be given to the proposed amendments to the scheme. Consideration will also be given to taking further legal advice from Justin Fenwick QC so that a considered response can be provided to Sir Robert Owen in due course.

23. In the meantime, a holding response is recommended:

- a. recognising that the Trustees are finding it difficult to administer the Discretionary Fund (for whatever reason) and that there is therefore a significant argument in favour of seeking to identify whether the scheme could be made to work any better in that regard; but
- b. indicating that the proposals will be given detailed consideration including obtaining legal advice and that a considered response will be provided in due course.

24. It would be helpful if further information can be sought from Sir Robert Owen at the meeting evidencing the alleged difficulties, for example:

- a. given that it is not unusual for trustees to have to use their discretion to administer limited funds on the basis of need and hardship, why have they found this task so difficult?
- b. why have legal costs (both those of the Trust's own secretariat and those of the families' solicitors, Irwin Mitchell – who also received £1.6M from the Department of Health for their costs in setting up the Scheme) not been controlled in the way that was anticipated bearing in mind that costs were always going to come out of the Main Fund?
- c. it has been suggested that the failure to provide or piecemeal provision of information has caused problems (which is obviously a matter for the

victim's family or solicitors) – what has been done or could be done to avoid this problem in the future?

- d. one example has been given of c.90 people connected with one victim suggesting that they were "Qualifiers" for payment under the Scheme – this is likely to be atypical – to what extent is the definition in the Scheme causing problems in other cases?

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