
ADVICE

1. I am asked to advise the Secretary of State as to the implications of proposed revisions to the vCJD Trust as proposed by the Trustees and Charles Russell who have acted as their solicitors since the inception of the Trust in March 2002.
2. In essence, the proposals involve the following changes:-
 - (a) the existing basic sum (for those diagnosed after the Phillips Report) will be increased from £120,000 (£70,000 plus the additional £50,000 promised to the first 250 victims by Alan Millburn when he was Secretary of State) to £200,000;
 - (b) the additional entitlements in respect of expenditure and discretionary payments in respect of loss of earnings, loss of earnings of carers and psychiatric injury suffered by close family, together with the sum of £10,000 for the experience of close family, will be removed;
 - (c) the allocation of these sums between family members will become the responsibility of a Trust consisting of family members and a professional Trustee in each case, with the costs of such Trustee and any legal advice to be met out of the individual family's trust funds;
 - (d) the payments for dependency will continue unchanged;
 - (e) with the removal of the Trustees' discretionary powers, the number of Trustees can be reduced from 7 to 3.
3. There is no doubt that the administration of the current Trust has proved extremely and unforeseeably expensive. The cumulative costs of Charles Russell for the year ending 5 April 2007 were £4.462 million and those of Irwin Mitchell, the principal firm of solicitors acting for Claimants, were £1.82 million, in each case including VAT and disbursements. Those sums must be looked at against total payments made out of the Trust of £20.01 million from the Main Fund and £3.57 million from the Discretionary Fund.

4. I have reviewed all the Minutes published on their website by the Trustees and the accounts published each year. It is clear from the Minutes of the meetings as well as from the representations made on behalf of the Trustees by Charles Russell that there are, in particular, two aspects which have caused real difficulty in administering the Trust:-
 - (a) problems in identifying who are the relevant Qualifiers or family members between whom the £5,000 for experience and £5,000 for care of the Victim should be divided and also to whom the basic sums may be paid instead of to the Victim's estate after their death;
 - (b) problems in establishing whether applicants meet the test of "particular financial hardship" and "particular emotional hardship".
5. The definition of Qualifier was deliberately made wide at the request of the families of the Victims because of concern that the people really close to the Victim during their illness may not have been their spouse (in the case of an estranged spouse) or both parents, but a sibling, grandparent or other person. The current definition of a Qualifier is:-

"Any person who in respect of the Victim is or was at or after the Relevant Time in respect of that Victim:-

 - (1) a spouse or partner of the Victim; or
 - (2) an ancestor or descendant of the Victim; or
 - (3) a person who the Trustees are reasonably satisfied on the balance of probabilities is or was treated by the Victim as his child; or
 - (4) a person who the Trustees are reasonably satisfied on the balance of probabilities is or was treated by the victim as his parent; or
 - (5) a person who is or was a brother, sister, uncle or aunt of the Victim or the issue of such person; and/or
 - (6) a Dependant of the Victim."
6. Clause 4.1, which dealt with a payment of £5,000 for the family's experience was to be paid to "such one or more of the Qualifiers in respect of each Victim and (if more than one) in such share or shares as the Trustees shall think fit". The further sum of £5,000 for care was to be paid to such Qualifiers or non-qualifying carers (defined as "somebody who was not a Qualifier but who was significantly involved in caring for

the Victim by reason of love and affection") to be divided between such persons "as they consider were significantly involved as aforesaid and (if more than one) in such share or shares as the Trustees shall think fit".

7. The provision for payment of basic sums after the Victim's death was to be divided amongst various categories including personal representatives, those entitled under the Victim's intestacy or Qualifiers "in such share or shares as the Trustees shall think fit".
8. In other words, there was intended to be a wide discretion but with the expectation that the sums would in general be divided between the immediate family.
9. In practice, it appears that the approach in all but exceptional cases has been, as one would expect, to pay the large amounts comprising the basic sum, in so far as not expended on the Victim during their life, to those entitled under the Victim's will or intestacy. It is only where that would work an injustice that the Trustees have considered exercising their discretion differently. It appears to me that that overriding discretion still remains important in cases where sums would go on an intestacy to a person estranged from the Victim when there is somebody such as a partner who the Victim would have been more likely to wish to benefit had they been able to make a will.
10. The real difficulty seems to have come in relation to the approach taken by the Trustees, no doubt on the advice of Charles Russell, as to identifying Qualifiers for compensation. The current guidelines on how to claim say the following in respect of Qualifiers:-

"The Trust Deed defines a potential Qualifier for compensation very widely and, in addition to the Victim's immediate relatives, includes all relatives by marriage and people treated as parents by the Victim. The potential Qualifiers will need to be contacted by Charles Russell, or the family solicitor, to ascertain whether they are appropriate recipients of compensation and, if so, whether they wish to make a claim. In relation to grandparents and other family members who have died, you should provide their names and when they died. The Trustees will need to decide whether payment shall be made into the deceased's relative's estate. ... To discharge their duties the Trustees obviously have to ensure that the appropriate people have been taken into account. It may transpire that the Trustees decide to make payment to only a small number of family members, but in order to reach this decision, the Trustees have to consider all of the potential recipients."

11. In the Minutes of the meeting of 2 December 2004 it was noted that:-

"In relation to Qualifiers, the Trustees reconsidered their approach to Qualifiers and affirm their view that a full and thorough investigation into potential Qualifiers is required. In some cases previously, details of family members had not been provided by the person making the claim and it transpired that other family members had valid claims."

12. It appears to me to be unfortunate that the Trustees have found themselves in a position where they were required to make such exhaustive investigations which clearly have taken time, incurred considerable cost and caused considerable distress to the families. I have no doubt that if William Henderson of Serle Court Chambers and Suzanne Marriott of Charles Russell, who together were responsible for the drafting of the Trust Deed, had advised that such an approach would be required, both sides and the Secretary of State would have agreed that the wording should be changed so as not to require such investigations. The issue is one of whether the discretionary element, to enable sums to be paid other than to immediate family in appropriate circumstances, is sufficiently important to justify the problems that have been caused or such more limited problems as would occur if some different wording was used.

13. In my view, the original intention could be preserved, with substantially less difficulties being caused, if either of the following alternative approaches was taken:-

- (a) the definition of Qualifiers could remain, but the Trustees should be required to pay sums otherwise payable to Qualifiers only to those who were living with the Victim in the same household for the majority of the 6 or 12 months immediately preceding the Victim's death or admission to hospital or hospice, unless the Trustees considered, on the basis of evidence provided to them, that it would be unjust so to limit it and that certain specified other Qualifiers should receive all or part of the payment; or
- (b) providing that these sums should form part of the Victim's estate, but to be distributed by the Victim's personal representatives as if subject to a wish but not a direction by the deceased in his will that such sums should be divided between those who had been involved in caring for the Victim during his illness.

14. The problems in relation to Particular Emotional and Particular Financial Hardship appear to have arisen from a combination of the difficulty of obtaining evidence of psychiatric injury and the agonising difficulty both

for families and Trustees of establishing whether the test which they had adopted was met. That test is defined in the alphabetical glossary of terms published by the Trustees as "more than 'normal' or 'usual' ". This seems to have given rise to a feeling by families that they have to show that their suffering, and by association their concern for the Victim, was greater than that of other families in the same position. This has understandably led to all sorts of unintended difficulties.

15. In my view, these difficulties could again be resolved by one of two mechanisms:-
 - (a) by replacing the word "particular" with some word intended to demonstrate that it is only in the most exceptional cases that such payments will be made; or
 - (b) providing that additional payments will be made in each case where the Trustees are satisfied on such evidence as they in their absolute discretion require that the particular psychiatric condition has lasted for more than 6 or 12 months respectively (in the case of emotional hardship) and/or that it has resulted in partial or total loss of earnings in those periods.
12. The position up to 7 January 2007 was, in respect of particular emotional hardship, 155 claims made of which 94 had been successful and where each successful claimant had received payment of £15,000. In respect of particular financial hardship claims in the same period, there had been 28 claims of which 18 were successful. Of those, six were awarded £40,000, seven £25,000 and five £10,000.
13. It would therefore seem reasonable to provide that those should be the sums which should be paid by the Trustees as a norm unless satisfied in their discretion that such sums should hereafter be increased for inflation.
14. It appears to me that those changes, together perhaps with a further change to increase all of the sums to take account of inflation since 2002, would deal with the principal problems encountered by the Trustees. It would also maintain the basic structure of the Scheme which was negotiated with the families and which the Secretary of State at the time agreed to put into place.
15. By contrast, the proposals put forward by the Trustees would radically change the nature of the Scheme in that they effectively make, apart from Dependency, a single payment, leaving it to the family to sort out how those sums are to be distributed, with the assistance of a professional Trustee.

16. There is again no doubt that the Trustees have had a difficult time because of conflicts within families as to the distribution of funds and because of difficulty in obtaining information on which to act. However, there is no doubt that there have been situations in which a straightforward payment to the estate to be distributed in accordance with an old will or the rules of intestacy, would not give rise to payments to those who have been closest to the Victim or made the greatest contribution to their care, and lost earnings or suffered psychiatric injury as a result. However, the proposed clause 3.1.2 provides that where there is a will giving rise to a valid grant of probate or equivalent, any sums not paid to the Victim during their life shall be paid to the executor/personal representatives to be held as an asset of the estate.
17. In the case of those who are intestate, the sums are to be paid to a professional Trustee who will be a Trustee together with the personal representative of the Victim under the rules of intestacy and shall be held on discretionary trusts:-
- "for the benefit of all or any one or more person or persons amongst the following and (if more than one) in such share or shares as the Intestacy Trustees shall think fit in their total discretion:- (a) the personal representative of the Victim; (b) any person or persons who are Qualifiers in respect of the Victim; (c) any one or more of the persons who are or would have been (if the Victim's estate had been sufficiently valuable) beneficially entitled to any part of the Victim's estate under the laws of intestacy; or (d) any person or persons who the Intestacy Trustees in their discretion consider to have made a substantial contribution to the care and wellbeing of the Victim."
18. In other words, the Intestacy Trustees have broadly the same discretion as the current Trustees of the vCJD Trust, except that they may act by majority and the professional Trustee has additional votes in essence to enable him to outvote the personal representatives.
19. Although this approach transfers the decision making task to the family and makes the costs come out of the available funds so that individuals may be more careful before raising issues and running up costs, I am bound to say that it appears that the effect of this could be extremely detrimental in the following respects:-
- (a) very difficult decisions which would trouble the current Trustees but which they have at least been able to deal with with detachment will be transferred to the immediate family who are likely already to be extremely distressed;

- (b) if there is significant dispute with significant costs being run up, this will deplete the funds which will be available for the family, with potentially little opportunity to prevent such challenges;
 - (c) the professional Trustee may well find it difficult to act in such circumstances and to know when to exercise his or her discretion so as to outvote the family;
 - (d) the identity of the personal representative and the choice of appropriate persons to act may give rise to difficulty.
 - (e) the costs of the professional Trustee could be large. Although I have been provided with figures for one Trustee, this is someone who has acted in a number of cases, so accumulating experience, and who has not had to duplicate the deliberations of the vCJD Trustees.
20. In effect, the proposal would tear up the carefully constructed mechanism which was intended to cater for difficult family situations and particular needs and hardship, and replace it either by paying all the sums into the estate or by passing the problem across to family trustees who will have the same difficulties. The only differences will be that the sums are to be divided according to their discretion, without reference to the particular categories set out in the original framework document and the current Trustees, and that the costs will come out of each Victim's sums.
21. There is a more fundamental problem in the Trustees' proposal which is the proposal that instead of the specific sums which have given rise to average payments including hardship of £170,000 (excluding dependency), there should be a round lump sum payment of £200,000. The effect, therefore, is that all future Victims will receive substantially more than the average for current Victims, including those who have lived through the most difficult period before the Inquiry. That would be without proof of any hardship or psychiatric condition.
22. The strong recommendation of Charles Russell on behalf of the Trustees is that any attempt to make this Scheme retrospective should be firmly resisted. In other words, those who have previously been compensated should not be given additional sums to match those to be paid to future Victims. This is understandable both in terms of the huge work and expense that has gone into deciding on the existing payments and because of practicality and finality.
23. However, it is clear that the proposals have already given rise to considerable concern amongst the previous Victims, as evidenced by

the proposed judicial review proceedings. It is understandable that those who were most involved in the earlier stages should be inclined to resent revisions to the Scheme which, if implemented for the Victims, would have resulted in larger sums being paid without the need to prove loss or hardship or psychiatric injury.

24. Further, and in my view critically, the calculations carried out by Messrs Saffrey Champness Accountants in their report of February 2007 proceed on the assumption that Dependency Payments will not be substantially greater in future than in the existing cohort. However, that ignores a fundamental fact of these events, namely that as the time since the last possible contamination with vCJD increases, more and more of the remaining Victims will be older and employed rather than a student or occupying a more senior position in their employment, thus being much more likely to have a family and to have reached a position on the employment market where they are earning larger sums, by comparison with the earlier Victims who have very often been young and without dependants, as demonstrated by the relatively low number of Dependency Claims. That is illustrated by the fact that out of 170 cases only 72 claims have been made for dependency.
25. On the figures put forward, if all future claims have the same average dependency as current dependency claims, there would only be a surplus of £1.1 million, before deduction of expenses. If it is assumed that the average dependency claim was £150,000 rather than £100,000, there would be a shortfall of £3 million.
26. In my view, these figures demonstrate conclusively that if the current proposals are met, there is a real risk of the funds provided by the Secretary of State being insufficient to cater for the first 250 Victims. That is particularly unfortunately where the sums put into the Trust deliberately allowed a significant safety margin, which looks likely to be achieved on the current form of the Trust (even with the very large sums paid out in respect to costs).
27. These matters do demonstrate clearly the importance of finding some mechanism to limit costs. I note that the Trustees have consistently stated in their publications on their website that families are encouraged to communicate directly with Charles Russell and should not normally need the help of solicitors, but nevertheless the costs have been very large. I would strongly recommend that any revision to the Trust Deed should include a limit on the amounts payable by the Trustees in respect of families' costs, possibly with a residual discretion in exceptional cases.
28. I would also note that under clause 12 of the Trust Deed, there is provision for the Department of Health to make available staff, office

premises and other administrative facilities. It does appear to me that a significant part of the problem has been caused by the expense of the work being carried out by Charles Russell and, in my view, consideration should be given to re-tendering or to the Secretary of State arranging for office premises and a dedicated administrative staff to be made available.

Summary and conclusions

29. It is plain that the greatest possible weight should be placed on the proposals put forward by the Trustees and in particular by Sir Robert Owen as an extremely experienced High Court Judge with knowledge of personal injury actions and indeed of group actions. It is plain that the Trustees have found it extremely difficult to administer the current Trust Deed. On the other hand, they have now successfully dealt with almost all claims for 170 Victims and the flow of new Victims is likely to be limited, in the absence of some change of trend, to a handful each year. In those circumstances, it seems unnecessary to substitute a new scheme.
30. On balance, although this is a matter for the Secretary of State in consultation with the Trustees, I consider that there are real dangers in pursuing the modifications proposed, which do not meet the original intentions for the Scheme and that an overhaul in the areas that I have identified, together with steps taken to reduce costs, would be an adequate solution. The experience of the successful administration of similar funds by the MacFarlane Trust may point the way forward. If the number of new cases decreases further, some arrangement whereby the Trust is administered by the MacFarlane Trust Trustees would seem desirable.

27 November 2007

Justin Fenwick QC

**Four New Square
Lincoln's Inn
London WC2A 3RJ**

RE vCJD TRUST

ADVICE

Mark Gidden
Department of Health