

vCJD Trust

Guidance Note for Compensation

A. Introduction

The Secretary of State announced in October 2000 that the Government would pay compensation to the victims of vCJD and their families. The Trustees recognise that money cannot adequately compensate for the loss of a loved one to vCJD, but it is hoped that it will go some way towards reflecting the trauma and tragedy suffered by victims and their families. Payments made whilst the victim is alive may also go some way towards alleviating their suffering.

Consultations with representatives of families affected by vCJD have been held, and details of the scheme were announced on 1st October 2001. The Government has allocated the sum of £67.5 million for up to the first 250 cases.

The total number of cases of vCJD is uncertain, and the Government will review the scheme if the total exceeds 250.

Two interim trusts were set up, which enabled payments to be made by the Department of Health to victims and their families before the vCJD Main Trust had been finalised. Both of the interim trusts have been closed, and compensation will now be paid only from the vCJD Main Trust. The Trustees signed the Trust Deed on 15th March 2002.

There are seven Trustees, who have been appointed by the Secretary of State from a wide range of relevant disciplines and experience.

The Honourable Mr Justice Owen (Chairman), High Court Judge
Mr David Churchill, Family Representative
Mr Roger Tomkins, Family Representative
Mr John Melville Williams, QC
Ms Elaine Motion, Solicitor (Scotland)
Dr David Stevens, Consultant Neurologist
Mrs Vicky Vidler, Nurse Consultant (Paediatric Haematology)

Further details of the Trustees are available on the Trustees' website at www.vcjdtrust.co.uk under the section 'The Trustees', or by contacting Jonathan Zimmern or Edwina Rawson at Charles Russell, Solicitors (Secretariat to the Trustees) at 8-10 New Fetter Lane, London EC4A 1RS, telephone number 020 7203 5000.

The information below is intended to provide a reasonably detailed overview of the vCJD compensation scheme, although it has not been practical to repeat all the details here. The terms of the scheme are contained in a Trust Deed, with which the Trustees have to comply. The Trustees have succeeded in making a number of substantial alterations to the scheme, which have had the effect of increasing the payments to victims and their families.

If you wish to make a claim for compensation, or have any questions, please do not hesitate to contact Jonathan Zimmern or Edwina Rawson at Charles Russell, Solicitors, on the details above. Please refer to **Section F – Making a Claim**.

B. Eligibility for compensation

Compensation is only available to victims who have suffered vCJD, and their families and carers. Before a claim can be considered, the Trustees will need to be satisfied that the two eligibility requirements as set out in the Trust Deed have been met; first, that the victim suffered vCJD on the legal test of the balance of probabilities, which means that the victim was at least 51% likely to have suffered vCJD, and secondly, that he or she was resident in the UK for at least 5 years between 1982 and 1996.

Dr Knight, Consultant Neurologist, of the CJD Surveillance Unit at the Western General Hospital, Edinburgh, has been appointed as Special Adviser to the Trustees; and the confirmations of diagnosis and residency must be obtained from him, or one of his colleagues. The easiest way to obtain these is to sign the Authority which is at page 30 of the Main Application Form or page 6 of the Application Form for an Interim Payment and return it to Edwina Rawson at Charles Russell Solicitors, at the above address, who will then liaise with Dr Knight, or one of his colleagues, on your behalf.

C. Who is entitled to compensation

Payments under the scheme can be made to the victim during his or her life, and to 'Qualifiers'. The definition of 'Qualifiers' in the Trust Deed is very wide, and includes all of the Victim's immediate and more remote family. It also includes the family of any spouse or (in some circumstances) partner. However, more remote family members will only receive compensation if the Trustees think it appropriate, which will usually require there to have been contact with the Victim.

- ❖ Spouse, or a partner of the victim who was living in the same household for at least 2 years as husband or wife or as a partner in a hetero or homosexual relationship.
- ❖ Ancestor or descendant of the victim
- ❖ Children of the victim
- ❖ Brothers, sisters, aunts or uncles, half-brothers, half-sisters, brothers-in-law, sisters-in-law, or their children.
- ❖ Dependants of the victim, being those whom the victim financially maintained.
- ❖ Carers who do not fall within any of the above, but who were significantly involved in caring for the victim.

D. Principles that have been adopted by the Trustees

As mentioned, payments under the scheme have to be made in accordance with the provisions of the Trust Deed. The Trustees, however, are given a discretion in relation to some payments, and where this has been exercised, the general approach has been to apply principles that essentially reflect the approach of the Courts to the assessment of damages at common law.

The Trustees have obtained from Dr Knight, with assistance from Gordon McLean, the Care Coordinator at the National CJD Surveillance Unit, a description of the physiological stages of vCJD and the implications at each stage for the victim's care requirements. This document was used as a reference point when the Trustees decided what principles to adopt for awarding compensation for gratuitous care, and is used by the Trustees when assessing the claims for care.

E. Payments under the scheme

The payments under the scheme are explained below.

1. Basic Sum

A sum of £120,000 (or £125,000 if the diagnosis was first reasonably suspected before 26 October 2000) shall be paid to the Victim, some or all of which can be paid during the Victim's life. If a balance of the Basic Sum remains to be paid after the Victim has died, the Trustees have a discretion as to how that balance should be distributed. As a general approach, the majority will normally be paid into the Victim's estate to reflect the conventional sum that would be awarded at common law by a Court for pain and suffering of the Victim. When considering the remaining balance, the Trustees will consider the evidence of any contribution to the Victim's care and well being by those entitled to an interest in the Estate, and whether awarding the whole of the Basic Sum to the Estate would result in unfairness. Only in exceptional circumstances will the Trustees agree to make payment outside the terms of a Will.

2. Experience of the Family

A sum of £5,000 (£10,000 if the diagnosis was first reasonably suspected before 26th October 2000) will be shared between the victim's family.

A further single sum of £5,000 will be shared between the carers who have been significantly involved in care.

Any carer's interim payments previously paid by the Department of Health will be deducted from these payments. The balance due may be nil in some circumstances.

3. Costs

Subject to certain requirements, claims can be made for:

- ❖ Reasonable funeral expenses.
- ❖ The costs of personal items purchased for the victim.

❖ Alterations to property.

It is important that documentary evidence, for example invoices or bank statements, is submitted to support the claim for funeral and other expenses. The Trustees are acutely aware that the burden of locating the documentary evidence may cause distress, but it will considerably increase the likelihood of the payments being made.

Personal items that have been reimbursed to date have included, for example, bedding, special foods, tracksuits and other comfortable clothes for the victim. A number of claims have been submitted for expenses which the Trustees do not have the power to grant as they are not within the terms of the Trust Deed, for example the costs of cancelled holidays and weddings. Invalid claims have also been submitted for expenses which were not incurred for the benefit of the victim, for example those incurred after he or she has died.

Claims for alterations of property which could be allowed under the Trust Deed have included, for example, the widening of doors in the home and installation of a shower for the victim.

The Trustees have adopted the principles that documentary evidence is required for claims of more than £3,000 for funeral expenses and/or for claims for more than £300 for personal items.

4. Care

Payments in relation to care that has been provided before the earlier of either 31st March 2001 and the implementation of a Care Package (as announced by the Secretary of State in October 2000) may be made in respect of the following:

- ❖ Care that has been purchased for the victim.
- ❖ Care that has been provided gratuitously by the family and others.
- ❖ Travel costs (including mileage) and hotel accommodation costs incurred in providing care.
- ❖ Any other expenditure incurred in providing care or for alleviating the suffering of the victim, subject to a specified limit.
- ❖ Loss of earnings of a carer as a result of providing care to the victim which has caused **particular** financial hardship. Payments for gratuitous care will be deducted from this sum. Loss of earnings claims can be made by carers for care provided before and/or after the introduction of a Care Package at 31 March 2001.

The difficulties relating to the meaning of **particular** hardship are considered below under the heading Psychiatric Injury. Only a small number of claims for carers' loss of earnings causing particular financial hardship have been made to date. The Trustees have considered the principles applicable to these claims and further guidance can be obtained from the Guidance Note in relation to Carers' Loss of Earnings on the vCJD Website. Broadly, the Trustees have adopted similar principles to those for claims for financial hardship as a result of a psychiatric condition. It will be important to establish that it was the provision of care that caused the loss of earnings.

In relation to gratuitous care, and as mentioned above, Dr Knight and Gordon McLean of the CJD Surveillance Unit provided a description of the stages of illness and the impact on the victim's care requirements. This has been used by the Trustees to establish a framework within which care can be assessed so as to ensure that claims are dealt with in a fair and objective manner.

An hourly rate of £5.22 is payable under the scheme for gratuitous care. This represents the average of the standard hourly rate of the National Joint Council for Government Services as adopted by Crossroads Caring for Carers for 1998-2000, spinal point 8. Ceilings on the number of hours that can be claimed at each stage have been adopted by the Trustees to reflect the approach of the Courts to assessing care claims at common law.

Mileage incurred for providing care is compensated at the rate of £0.21 per mile. This represents what would be received in a claim for common law damages in the Courts, and is based on the average figure in the relevant table for running costs in the AA Motoring Costs (2000), in the PNBA (Professional Negligence Bar Association) Facts and Figures.

Claims within the category of any other expenditure incurred in providing care or for alleviating the suffering of the victim include, for example, additional heating costs. If necessary, the Trustees will make a deduction of usually 25% to reflect the heating costs (or other similar costs) that would have been incurred in any event. This is also consistent with the approach that would be adopted by a Court in assessing damages at common law.

5. Psychiatric Injury

A single sum of £5,000 may be paid where a family member has suffered an identifiable psychiatric condition lasting longer than a calendar month as a result of a loved having contracted vCJD. Additional payments may be made where the psychiatric condition causes **particular** financial or emotional hardship.

Claims for the £5,000 single sum must ordinarily be supported by medical evidence of the diagnosis of a psychiatric injury. Such evidence may be provided by a GP rather than from a psychiatrist. Claims for any additional payments must be supported by a report from a psychiatrist. Medical evidence is required because under the terms of the Trust Deed claims can only be made for an identifiable psychiatric condition 'falling within the definitions contained in ICD-10 or DSM-IV', and it would not be possible for the Trustees to make this assessment without the aid of medical opinion. Charles Russell, Solicitors, can take the necessary steps to obtain the evidence on your behalf. It is, of course, open to you to submit a claim without a report from a GP or Psychiatrist, although the claim is less likely to be successful as it will not meet the requirements of the Trust Deed.

You will note that the claim for payments in addition to the £5,000 single sum requires there to have been a psychiatric condition which causes **particular** financial or emotional hardship. The Trustees have established a number of principles in relation to these claims. Guidance Notes on Assessment of Particular Hardship are available on the Trustees' website at www.vcjdtrust.co.uk or by contacting Jonathan Zimmern or Edwina Rawson at Charles Russell, Solicitors on 020 7203 5000.

The meaning of **particular** hardship and applying this concept to the claims is extremely difficult. The first problem is that the Trustees have to decide what is meant by **particular** financial or emotional hardship. The Trustees recognise that all relatives who have lost a loved one to vCJD have suffered hardship; however, the Trust Deed states that payments can

only be made if the hardship is **particular**. To make this assessment, the Trustees have no option but to consider all claims for hardship and make a comparison between them so that they can identify the claims where the hardship is at the 'normal' or 'usual' level of severity and those where the hardship is more than 'normal' or 'usual', i.e. **particular**. This, in itself, is an invidious task, but is necessary under the present Scheme.

The second problem is that, in order to make the assessment between the 'normal' or 'usual' level of severity and claims where the hardship is more than 'normal' or 'usual', family members will normally have to produce a Witness Statement to the Trustees that sets out why their suffering is above and beyond that of other families. This is a distressing task for the family members, but is necessary under the present Scheme.

The third problem relates to the costs involved in preparing the claims to meet the requirements of the Trust Deed. As mentioned, a Witness Statement will normally be required setting out why the family member's hardship is **particular**. If a claim is being made for financial hardship, this Statement will have to include a detailed consideration of loss of earnings (and documents to support these), outgoing expenses before and after the psychiatric condition, and the effect of receipt of the Basic Sum on hardship. Calculations will also be required to ascertain net available income before the psychiatric condition began and available income thereafter. The Trustees are concerned that there is no doubt that this process will incur considerable solicitors' and Trustees' fees, which are likely to be disproportionate to the amount of compensation available to meet these claims, even if the Discretionary Fund is increased (see below).

For the above reasons, the Trustees have suggested to the Department of Health and to Irwin Mitchell that the Scheme should be simplified by negotiation, possibly by removing the requirement for particular hardship. However any amendment will have to be supported by the families as well as the Department of Health, and at a meeting on 6 September 2004 attended by representatives of the Department of Health, Irwin Mitchell and Charles Russell, Solicitors, it became clear that it was unrealistic for the Trustees to hope that a simplification of the original scheme incorporated in the Trust Deed can be negotiated between the parties, i.e. the Department of Health and Irwin Mitchell. No proposals have been put forward by the parties as to what could be introduced to replace particular hardship and it seems that no amendment will be made in order to make the process less stressful for the families and cost-effective in terms of solicitors' and Trustees' fees.

The fourth problem is that the Trustees are concerned that the Discretionary Fund will not be sufficient to adequately compensate the claims for particular hardship. They therefore made representations to the Secretary of State for further funds to be made available and £3 million was transferred from the Main Fund into the Discretionary Fund. However, it has been made clear that sufficient funds are unlikely to be made available to compensate financial losses in full.

Sir Robert Owen met the Secretary of State on 25 October 2004 to discuss the above issues, and details of the outcome of that meeting are available on the website.

6. Victim's loss of earnings

Payments may be made where a victim has suffered loss of earnings that has caused particular hardship to himself/herself and his/her dependants.

No claims for Victim's loss of earnings have been made to date, and the meaning of particular hardship in this context has not had to be considered by the Trustees. It is, however, likely that the principles adopted by the Trustees in relation to financial hardship as a result of a psychiatric condition will be particularly relevant.

7. Dependants

Compensation may be paid to the victim's spouse, partner and/or children and/or other family members who were maintained financially by the victim.

The calculation of the amount payable is set out in the Trust Deed, and requires the Trustees to assess the highest net annual earnings for the three-year period prior to the start of the victim's symptoms. It is, therefore, important to submit sufficient documentary evidence to enable the Trustees to make this assessment, and failure to do so will lead to delay in the claim being processed.

If you have been employed, the evidence most likely to satisfy the terms of the Trust Deed is P60s, which the Secretariat can obtain for you on your behalf, if requested to do so. Alternatively, tax assessments/calculations, letters from the relevant employers and accountant's should be obtained, and again the Secretariat can assist with this. If you are unemployed, confirmation should be obtained from your benefits office, if possible.

Any dependants' interim payments which have previously been made by the Department of Health will be deducted from the amount paid by the Trustees for dependency.

8. Life insurance

Life insurance or mortgage protection insurance payments may be made where a dependant of the victim suffers particular hardship because he/she is unable to obtain adequate life insurance or mortgage protection insurance without paying a substantial additional premium because of his/her relationship with the victim.

No claims under this heading have been made to date and the meaning of particular hardship in this context has not had to be considered by the Trustees.

F. Making a claim

It is important that you provide the Trustees with names and contact details of all of the victim's relatives and carers. If, for example, you are a spouse and making a claim, you should either include the claims of the victim's parents and other relatives with your own, or provide the Trustees with contact details so that the Trustees can find out whether they want to make a claim. If you are a divorced or separated parent, you should provide details of the victim's mother or father, as appropriate.

There have been a number of cases where payment has had to be delayed because contact details have not been provided, particularly for an estranged parent of the victim. This is important as the following example will show. The law essentially provides that where the victim died without having made a Will, and without a spouse or children, the victim's

parents, brothers and sisters are entitled to share the victim's estate into which the Basic Sum will be paid. However, the Trustees are not obliged to follow the law in this respect, and have discretion to make a different apportionment if they consider it to be appropriate.

There are two procedures for making claims for compensation.

Interim Applications

If the victim is alive, then a claim for an interim payment can be made by completing a short standard form, the Application Form for Interim Payment, and by satisfying the Trustees that the eligibility requirements of diagnosis and residency, as mentioned above, have been met. The quickest way to obtain these confirmations is to sign the Authority on page 6 of the Application Form for Interim Payment and return it to Jonathan Zimmern or Edwina Rawson, at Charles Russell, Solicitors, at the above address, who will obtain them on your behalf.

The Trustees recognise that there could be exceptional circumstances where an expense needs to be met from compensation before the Main Application has been completed, even though the victim has died. In these cases, an application should be made for a part-payment (rather than an interim payment) of compensation which will be dealt with as a priority at the next Trustees' meeting. The Trustees will need to be satisfied that payment is being made to the appropriate recipient. Payment will be dealt with as a priority after the meeting, once the administrative matters have been dealt with.

If a claimant has a problem with creditors, Charles Russell, Solicitors, will be willing to speak to them direct to advise of the position, including when payment is likely to be made.

Part-payments should only be sought in exceptional circumstances, particularly as they require documentation to be prepared, circulated, considered, and the requisite administrative work to be done on two occasions rather than one. This increases the legal and Trustees' fees in administering the Scheme.

Main Applications

There is a separate form, the Main Application for Compensation, to be completed when a claim for full compensation is being made. If care was provided to the victim before the earlier of the 31st March 2001 and the introduction of a Care Package (as announced by the Secretary of State in October 2000), the Separate Claim Form for Care will also have to be completed.

Checklist

To avoid delay in your claim being processed, please consider the following before submitting your application:

For interim applications where the victim is alive:

- 1 Have you obtained the confirmations of diagnosis and residency from Dr Knight at the CJD Surveillance Unit? If not, please sign the Authority and return it to Jonathan Zimmern or Edwina Rawson at Charles Russell, Solicitors.
- 2 Have you completed the form as fully as possible?
- 3 If the victim is capable of managing his or her own affairs, have you provided a short letter from his or her GP confirming this?

4 Have you signed the form?

For a full application for compensation:

1 Have you obtained the confirmations of diagnosis and residency from Dr Knight at the CJD Surveillance Unit? If not, please sign the Authority and return it to Jonathan Zimmern or Edwina Rawson at Charles Russell, Solicitors.

2 Have you contacted other members of the victim's family who may have a claim, either by way of being a relative, carer, or being a person in receipt of financial maintenance?

If so, have you included their contact details and details of their claims. Your claim will be dealt with quicker if you provide everyone's details on one form. If, for example, a victim's parent has died, please make this clear.

If not, have you provided their contact details so that the Trustees can make contact direct?

3 Have you provided as much detail as possible in the form?

4 Have you provide documentary evidence for expenses, and/or earnings for the victim and his or her partner?

5 Have you signed the forms?

Availability of Forms

All of the forms are available on the vCJD Trust's website at www.vcjdtrust.co.uk. Copies can also be obtained from Jonathan Zimmern or Edwina Rawson at Charles Russell, Solicitors, at the above address. If you require any assistance to complete the forms, please contact Jonathan Zimmern or Edwina Rawson on the number on page 2 of this Guidance Note who will be able to provide assistance.

The completed forms should then be sent to Edwina Rawson at the above address. A Report and Summary (in the form of spreadsheets for the calculations) will then be prepared and submitted to the Trustees for consideration at one of the subsequent meetings.

We hope that this information has been helpful. If you have any further questions, please do not hesitate to contact Jonathan Zimmern or Edwina Rawson on the above number.
