

*** THIS GUIDANCE NOTE IS ONLY RELEVANT FOR VICTIMS DIAGNOSED AS SUFFERING FROM vCJD ON OR AFTER 31 MARCH 2010. IF THE DATE OF DIAGNOSIS IS BEFORE THAT DATE, PLEASE CLICK HERE FOR THE NOTE YOU REQUIRE. ***

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 were held, and details of the Scheme were announced on 1st October 2001. The Government 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 first Trust Deed on 15 March 2002. In early 2010, following representations made by the Trustees to the Department of Health and consultation with interested parties, the Department of Health agreed to a revision of the Scheme in order to simplify the procedure for making payments to Victims and their families. A revised Trust Deed was signed by the Trustees on 12 February 2010 and contains two versions of the Scheme, the first applies to Victims diagnosed on or before 30 March 2010 and the second applies to Victims diagnosed on or after 31 March 2010.

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 Dave Joad, Family Representative
- Mr Roger Tomkins, Family Representative
- Mr Richard Vallance, Retired Solicitor

- Ms Elaine Motion, Solicitor (Scotland)
- Dr David Stevens, Consultant Neurologist
- Mrs Angela Westoby, Haemophilia Nurse Specialist

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 Jamie Green at Fieldfisher (Secretariat to the Trustees) at Riverbank House, 2 Swan Lane, London EC4R 3TT, telephone number 020 7861 4000.

The information below is intended to provide a reasonably detailed overview of the revised vCJD Compensation Scheme for Victims diagnosed on or after 31 March 2010, although it has not been practical to repeat all the details here. The terms of the new Scheme are contained in the new Trust Deed dated 12 February 2010, with which the Trustees have to comply.

If you wish to make a claim for compensation, or have any questions, please do not hesitate to contact Jonathan Zimmern or Jamie Green at Fieldfisher 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.

Professor 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 the end of the Main Application Form or the Application Form for an Interim Payment and return it to Jonathan Zimmern or Jamie Green at Fieldfisher at the above address, who will then liaise with Professor 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 Professor 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 at least £120,000 shall be paid to the Victim, some or all of which can be paid during the Victim's life. The Basic Sum will be increased annually to reflect the impact of inflation upon the award. Any increase is at the absolute discretion of the Trustees and Fieldfisher will be able to advise you of the figure which will be recoverable in your case.

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 basic sum of £40,000 is payable to the family of each Victim in respect of their experience of having a close family member suffering from and dying from vCJD. In addition, where one or more members of the family or close friends (such as a boyfriend/girlfriend) have been actively involved in caring for the Victim during his illness from vCJD. A further £5,000 is payable to the family to be divided between those individuals concerned.

If care was provided by members of the family or close friends before the date of a Care Package for the Victim or before 31 March 2001, whichever is the earlier, you will need to contact Fieldfisher. It is anticipated that this will be unlikely as the date of the Victim's Diagnosis will have been on or after 30 March 2010.

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. 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.

5. 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 because, for example, the law 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 Jamie Green at Fieldfisher 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, Fieldfisher 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.

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 Professor Knight at the CJD Surveillance Unit? If not, please sign the Authority and return it to Jonathan Zimmern or Jamie Green at Fieldfisher.
- 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 Professor Knight at the CJD Surveillance Unit? If not, please sign the Authority and return it to Jonathan Zimmern or Jamie Green at Fieldfisher.
- 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 Jamie Green at Fieldfisher at the above address. If you require any assistance to complete the forms, please contact Jonathan Zimmern or Jamie Green 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 Jonathan Zimmern or Jamie Green 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 Jamie Green on the above number.