

ALPHABETICAL GLOSSARY OF TERMS

vCJD COMPENSATION SCHEME

<u>TERM</u>	<u>MEANING</u>
Abbreviated Minutes	Abbreviated Minutes of all Trustees' meeting can be found on the vCJD Main Trust website at www.vcjd.co.uk.
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.
BSE	Abbreviation for Bovine Spongiform Encephalopathy.
Care Package	A Care Package was announced by the Secretary of State in October 2000 and came into effect progressively between November 2000 and March 2001. It was designed specifically to provide care and support for Victims of vCJD and their families. For further information contact the CJD Surveillance Unit on 0207 736 3220.
Care	Gratuitous Care - compensation can be claimed where care has been provided by Qualifiers or

Non Qualifying Carers before 31 March 2001 or implementation of a Care Package for a Victim, whichever is the earlier . An hourly rate of £5.22 is payable under the Scheme. This represents the average standard hourly rate of the National Joint Council for Government Services as adopted by Crossroads Caring for Carers for 1998-2000. Ceilings on the number of hours of care per day that can be claimed for each 'stage' of the illness have been adopted by the Trustees to reflect the approach of the Courts to assessing care claims at common law. Dr Richard Knight and Margaret Leitch 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 gratuitous care can be assessed so as to ensure that claims are dealt with in a fair and objective manner.

Purchased Care - it is possible to make a claim for compensation where costs has been purchased for the Victim before 31 March 2001 or the date of the implementation of the Care Package for the Victim, whichever is the earlier.

Travel for providing Care - reasonable travel costs and hotel accommodation costs incurred in providing care before 31 March 2001 or the date of implementation of the Care Package for the Victim, whichever is the earlier. Mileage incurred for providing care is compensated at the rate of 21p per mile. This represents what would be received in the relevant table for running costs in the AA Motoring Costs (2000), in the Professional Negligence Bar Association Facts and Figures.

Expenditure incurred in providing care or for alleviating the suffering of the Victim - claims under this heading include, for example, increases in heating costs, subject to a specific limit. The Trustees usually deduct 25% to reflect the heating costs (or other similar costs) that would have been incurred in any event. This is consistent with the approach that would be adopted by a Court in assessing damages at common law.

Carers' Loss of earnings	<p>Loss of earnings of a Carer as a result of providing care to the Victim which has caused particular hardship can be claimed. This claim can be made in relation to care that has been provided before and/or after the implementation of the Care Package on 31 March 2001. Employment details will need to be provided as well as evidence of particular hardship.</p>
CJD	<p>Abbreviation for Creutzfeld Jakob disease.</p>
31 March 2001	<p>31 March 2001 is the last possible date by which a claimant can make a claim for gratuitous care, purchased care, travel for providing care or expenditure incurred in providing care for or alleviating the suffering of the Victim. It was intended that, by this date, the Care Package would have been fully implemented and benefited all Victims and their families. If a Victim and his/her family received the benefit of the Care Package prior to 31 March 2001, then gratuitous care, purchased care, travel for providing care and expenditure for the purpose of caring for or alleviating the suffering of the Victim can only be claimed up until implementation of the Care Package in respect of that Victim.</p>
Date of Initial Diagnosis	<p>In respect of any individual Victim, this is the date that the Trustees in their discretion decide that the Victim was first reasonably suspected as suffering from vCJD. This date is relevant to the award for the Basic Sum and for Experience of the Family. A Victim whose Date of Initial Diagnosis was before 26th October 2000, will be awarded £125,000 for the Basic Sum rather than £120,000 and the award for Experience of the Family will be £10,000 rather than £5,000. The difference is to try to go some way to recognise the added difficulties experienced by the earlier families before the Care Package was introduced.</p>
Discretionary Fund	<p>The compensation fund has been divided into two separate funds, one of which is the</p>

	<p>Discretionary Fund, for which £5 million was initially allocated. The other fund is called the Main Fund.</p> <p>The Trustees made representations in the Autumn of 2004 to the Secretary of State for an increase in the amount of funds in the Discretionary Fund so that more money would be available for the families under discretionary heads of claim. The Secretary of State agreed that £3 million could be transferred from the Main Fund to the Discretionary Fund paid bringing the total available to £8 million.</p>
Dependant	<p>Compensation can be paid to the Victim's spouse, partner and/or children and/or other person/s who have been, at or after the Relevant Time, substantially maintained financially or otherwise by the Victim.</p>
Dependency sum	<p>A claim can be made by Dependents for compensation in the years following the Victim's death. There is a detailed mechanism set out in the Trust Deed for calculating the amounts to be paid. The basis of assessment is broadly based on the principles which the Court would apply in a claim for damages at Common Law but it is simplified from the common law model so that it is easier to calculate and administer. Evidence is required of net earnings earned in the three years prior to the onset of symptoms and the highest annual salary of these three years is then used in the calculations. Evidence is usually provided by way of P60 or tax returns/business accounts etc.</p>
Eligibility	<p>In order to be entitled to compensation, two requirements must be met: the Victim must have been diagnosed as suffering from vCJD on the balance of probabilities (ie 51%) and also must have been resident in the UK for at least 5 years between 1982 and 1996. Confirmation that these requirements have been met is provided by the CJD Surveillance Unit in Edinburgh.</p>

Experience of the Family	A basic sum of £5,000 (or £10,000 if the diagnosis was first reasonably suspected before 26 th October 2000) is payable to the family of each Victim in respect of their experience of having a close family member suffer from vCJD.
Form of Acknowledgement	There is a standard Form of Acknowledgement for each award that can be claimed under the Scheme. The appropriate Forms must be signed by the claimants (or by their solicitors on their behalf) before compensation can be released.
Funeral Expenses	Subject to certain requirements, you can claim for reasonable funeral expenses in respect of the Victim. Wherever possible, documentary evidence should be provided in support of a claim.
Grants of Representation/Confirmation	<p>Probate - the Grant of Probate confirms the Executors' legal title to administer the estate in accordance with the provisions of the Will. Probate will usually need to be obtained before the Trustees make decisions regarding payment of compensation.</p> <p>Letters of Administration - this is similar to the Grant of Probate but needs to be obtained where the Victim died without making a Will. The powers to administer the estate commence when the Letters of Administration are granted. Prior to the grant, Personal Representatives can only deal with essential matters eg making funeral arrangements and ascertaining the estate's assets and liabilities.</p>
Interim Payment	In appropriate circumstances, the Trustees are willing to make interim payments of compensation during the life of the Victim of vCJD, before the Main Application Form has been submitted. Payment can usually be released within 48 hours. As this procedure can incur considerable legal costs, there must be a genuine urgent need for payment to be approved (ie usually where the Victim is alive).

Interim Trusts	Two interim trusts were set up which enabled payments to be made by the Department of Health before the vCJD Main Trust had been finalised. These have now been closed and payment is now only paid from the vCJD Main Trust.
Intestacy	A person who dies without having made a Will is said to have died 'intestate'. Distribution of the Victim's estate will be governed by the 'intestacy rules'.
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.
Main Application Form	The Main Application Form has to be completed and submitted to the Trustees, with sufficient information to enable them to calculate the full amount of compensation which is due in each case to the Victim and their family.
Main Fund	The compensation fund has been divided into two separate funds, one of which is the Main Fund, for which £62.5 million has been allocated. The other fund is the Discretionary Fund.
Mandatory Care	A basic sum of £5,000 is payable where a Qualifier or Non Qualifying Carer has been significantly involved in the care of the Victim. This award is set at £5,000 and, unlike the claim for gratuitous care, can be claimed whether the care was provided before or after the implementation of the Care Package or 31 March 2001.
National CJD Surveillance Unit	The national independent research unit for monitoring and surveillance of CJD within the

	<p>UK. Dr Richard Knight, Consultant Neurologist, of the CJD Surveillance Unit at the Western General Hospital in Edinburgh has been appointed as Special Advisor to the Trustees. The eligibility requirements of diagnosis and residency must be provided by Dr Knight, or one of his colleagues.</p>
<p>Non-Qualifying Carer</p>	<p>Compensation can be paid to any person who is not a Qualifier but was significantly involved in caring for the Victim at or after the Relevant Time.</p>
<p>Onset of symptoms</p>	<p>The date that the Trustees in their discretion may decide was the date upon which the Victim was first noted as suffering to a significant degree from symptoms which were subsequently attributed to vCJD.</p>
<p>Particular Hardship</p>	<p>This is the requirement which needs to be satisfied where a claim is being made under the following heads: carers' or victim's loss of earnings causing particular hardship, where the claimant has suffered an identifiable psychiatric condition causing particular financial or emotional hardship, where a Dependant's award calculated in the usual way would be significantly less than it would be if based on the earnings potential of the Victim and would cause the Dependents to suffer particular hardship, where a Dependant would suffer particular hardship because she/he is unable to obtain adequate life insurance or mortgage insurance protection insurance without paying a substantial additional premium as a result of his/her relationship with the Victim. Whilst the Trustees recognise that all relatives who have lost a loved one to vCJD have suffered hardship, the Trust Deed states that payments can only be made under these heads of claim if the hardship is <u>particular</u> (ie more than 'normal' or 'usual'). A psychiatric report will need to be provided in support of a claim where a claim is being made for a psychiatric condition causing particular financial or emotional hardship. If a claim is being made for particular hardship of a financial nature, documentary evidence of loss</p>

	of earnings, outgoing expenses etc will need to be provided.
Partner	Where the Victim is unmarried but has a partner, that partner may be a Qualifier (see below) as long as they satisfy the definition of 'Partner' under the Trust Deed. The Partner of the Victim is any person who the Trustees in their discretion decide (i) is or was living in the same household as the Victim at or after the Relevant Time (ii) has or had been living with the Victim for a period of at least 2 years and (iii) was living during the whole of that period as the husband or wife of or as the partner in a hetero or homosexual union with the Victim.
Part-Payment	Where appropriate, the Trustees may agree to make a part- payment of compensation before the Main Application Form has been completed but after the Victim has died. The request for a part- payment will be dealt with as a priority by the Trustees at the next Trustees' meeting, and should only be made if there is urgent need funds.
Personal Representative	This is the person appointed to administer the Victim's estate (including the compensation monies if it is paid into the Estate). They may also be referred to as the Executor/Executrix or the Administrator.
Psychiatric injury	A single sum of £5,000 may be paid where a Qualifier has suffered an identifiable psychiatric condition lasting longer than a calendar month as a result of a loved one having contracted vCJD. Medical evidence, usually from the claimant's GP, is required in support of any claim and additional payments may be made where the psychiatric condition has caused particular financial or emotional hardship.
Qualifier	Compensation can be paid to the Victim or to an individual who is, at or after the Relevant Time either a 'Qualifier' or a 'Non Qualifying Carer'. The definition of Qualifier in the Trust Deed is

	<p>deliberately wide so as not to unfairly exclude anyone from being entitled to make a claim. Broadly, a Qualifier is someone who is related to the Victim either through blood or through marriage or someone who is a Dependant of the Victim. An individual is also a Qualifier if they were treated by the Victim as his child or parent.</p>
<p>Real and Personal Property</p>	<p>Reasonable costs, subject to a limit, can be claimed where personal items were purchased for the Victim and also for limited alterations to property to mitigate the effect of vCJD.</p>
<p>Relevant Time</p>	<p>The importance of the Relevant Time is that it determines whether a person qualifies for compensation under certain heads of claim. The Relevant Time is, in respect of any individual Victim, whichever is the earlier of the date arising 2 years before the date of the Victim's death and the date arising 6 months before the Date of Initial Diagnosis.</p>
<p>Separate Claim Form for Care</p>	<p>This form must be completed, signed and dated where a Qualifier or Non Qualifying Carer is making a claim for gratuitous or purchased care.</p>
<p>Trust Deed</p>	<p>The vCJD Compensation Scheme is governed by a Trust Deed which was signed by the Trustees on 15 March 2002. A copy of this can be found on the vCJD website. The Trust Deed sets out the payments that the Trustees can make and to whom. The Trustees are legally obliged to make payment in accordance with the Trust Deed and therefore if a claim falls outside the terms of the Trust Deed, the Trustees are not able to pay it. The terms of the Trust Deed were negotiated and established by the Department of Health and representatives of the family group at that time before the Trustees were appointed.</p>
<p>Trustees</p>	<p>The seven Trustees were appointed by the Secretary of State and form an independent public body which has been given the task of</p>

	<p>administering payment of compensation to vCJD Victims and their families. The Trustees are not part of the Government. They have sole responsibility for making the decisions relating to the claims. Their details can be found on the vCJD website at www.vcjd.co.uk.</p>
<p>Trustees' meeting</p>	<p>The Trustees meet approximately every six to eight weeks to make decisions in relation to particular claims for compensation and also to resolve/discuss matters of principle or any other issues relating to the vCJD Compensation Scheme generally.</p>
<p>vCJD</p>	<p>Abbreviation for variant Creutzfeld Jakob disease.</p>
<p>Victim's Group</p>	<p>The Victim and all persons who are Qualifiers in respect of that Victim.</p>
<p>Victim's Loss of Earnings</p>	<p>Payments may be made where a Victim has suffered loss of earnings that has caused particular hardship to himself/herself and his/her Dependents.</p>