

VARIANT CREUTZFELDT JAKOB DISEASE

Setting Up The vCJD Trust - Operations and Lessons for the Future

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Abstract

John Melville Williams Q.C. sets out the background to the setting up of the vCJD Trust, describes how it operates and identifies key points that may be relevant for future no fault compensation schemes. *ML*

Introduction

In October 2000 the report of The BSE Inquiry², chaired by Lord Phillips, was laid before Parliament. Shortly after the publication of the report the Government announced that it intended “to put in place financial arrangements to benefit the sufferers from variant CJD

¹. John Melville Williams is one of the Trustees under the Trust and would like to thank the other trustees and the Trust solicitors, Charles Russell, for their help in this article. Any views expressed are his own.

² The full title of the Inquiry was “The Inquiry into BSE and Variant CJD in the United Kingdom”. The members of the Inquiry were: Lord Phillips of Worth Matravers, Mrs June Bridgeman, CB and Professor Malcolm Ferguson-Smith FRCS. The full inquiry report can be found at: www.bseinquiry.gov.uk.

(vCJD) and their families". The compensation scheme set up as a result is now governed and operated by The vCJD Trust. The Government has committed a total of £67.5m to the scheme, budgeting for 250 victims. If the numbers rise above that level the funding will be reviewed. By February 1st 2004 there had been 146 confirmed cases, including six victims who were still alive. This is a major no-fault compensation scheme by which the Government, without an admission of liability, accepted the responsibility for compensating those who have suffered. Thus it could form a model, or at least may be some sort of precedent or give some guidance, for other no fault schemes in the future. The background circumstances, the matters leading to the Inquiry, the Inquiry itself and the development of the Trust and compensation scheme, as well as the actual operation of the Trust are therefore of general interest.

Variant Creutzfeldt Jakob Disease

Creutzfeldt-Jakob Disease (CJD) in its classical form was first described in the 1920s and is predominantly a sporadic disease, with no identifiable cause. 85 per cent of CJD cases are sporadic, the remainder, other than vCJD cases, being iatrogenic (accidentally transmitted from one patient to another as a result of medical interventions) or familial. It is a rare disease and sporadic CJD occurs throughout the world at a similar rate of about one case per million of the population per year. Around 10 per cent of all CJD cases are associated with gene mutations. Fewer than 1 per cent of all cases are iatrogenic. In sporadic cases the average age at onset is between 55 and 75. In 1996 researchers from the National CJD Surveillance Unit (NCJDSU) in Edinburgh³ identified a previously unrecognised disease pattern, New Variant CJD, now known just as variant CJD. It is a similar neuro-degenerative disease to CJD but the average age at onset, around 27, was much younger than in cases of sporadic CJD. Since the early research it may be that the average age at onset has changed somewhat but it characteristically much lower than in classical CJD cases. There are other differences too, for instance at post mortem examination on microscopic examination, brain tissue displays a significantly different pattern. In the progress and development of symptoms there are also distinct differences.

The disease strikes me, after over 40 years of personal injury practice, much of it in disease

³ See *The Lancet* 6 April 1996; 347:921-925, Will, Ironside & Zeidler.

cases, as being the most horrific imaginable. While there are significant variations between one patient and another its characteristic symptoms are broadly similar and are set out in the Inquiry Report together with diagnostic criteria. The Report also contains a description of the science of the disease⁴. Variant CJD, the hitherto unrecognised variant of CJD, is characterised clinically by a progressive neuropsychiatric disorder leading to ataxia, dementia and myoclonus (or chorea) without the typical EEG appearance of CJD. The clinical features as summarised, categorised as “relatively non-specific”, and as described in the Report are as follows:

- (1) An early age of onset or death (average 27.6 years, range 18-41 years, at that time of the early investigation though the average may have changed somewhat and the range is now from early teens to the 70's).
- (2) A prolonged duration of illness compared with sporadic CJD, (average 13.1 months, range 4-24 months).
- (3) A predominantly psychiatric presentation including anxiety, depression, withdrawal and progressive behavioural changes.
- (4) The first evidence of neurological involvement in some patients was dysaesthesiae in the limbs and/or face.
- (5) Development of a cerebellar syndrome with problems with gait and limb muscle coordination after a period of weeks or months.
- (6) Development of forgetfulness and memory disturbance, often late in the clinical course, which progressed to severe cognitive impairment in the majority of cases.
- (7) Development of muscle twitching or spasms in the majority of patients (myoclonus), preceded by purposeless involuntary movements in some (chorea), with EEG appearances typical of sporadic CJD absent.

The diagnostic criteria for Variant CJD can be found on the Department of Health website containing monthly statistics for CJD.⁵

Before the BSE Report - early developments

On 21st May 1995 the first recorded death from vCJD occurred. Stephen Churchill was only 19 and the pattern of his illness and death did not fit classical CJD, which was predominantly a disease of the elderly while he was young. His parents were not satisfied and were determined to get to the bottom of the what and the why. This determination grew when it was suggested in the media that vCJD (as it came to be called) might be caused by BSE infected meat entering the food chain. Other cases soon followed the first death and the media exposure led the families to get together. A family network developed to give support and to

⁴ See Chapter 2 of the Report.

⁵ See www.gnn.gov.uk

endeavour to discover the truth about this strange and horrible illness leading to seemingly inevitable death that so frequently struck the young. The unusual and terrible features of the disease attracted more media attention. There was a World in Action program in August 1995 and a lot of comment in the press in which the suggestion that this disease was related to BSE affected beef entering the food chain gained credence. The idea that BSE contaminated beef had entered the food chain was very alarming. In consequence the families campaigned vigorously for a public inquiry but this was rejected by the Government who asserted that there was no issue for a public inquiry to consider. Eventually, however, on March 20th 1996, Stephen Dorrell, Secretary of State for Health, announced in Parliament that a new disease, New Variant CJD, had been identified in 10 people who had died and that it was most likely related to BSE. Despite this there was still no public inquiry. The families' campaigning continued and intensified. New cases were diagnosed and further deaths occurred increasing the number of families involved and with them the demand for a public inquiry⁶.

In the absence of any agreement to set up a public inquiry the families decided that they should consider litigation to establish the truth and so decided to instruct solicitors with a view to claiming against the Government. In the Summer of 1996 Irwin Mitchell were instructed. They continue to act for most of the families claiming under the Trust. In 1997 the families formally formed the "New Variant CJD Families Association". Finally in December 1997 the demand for a public inquiry was met, and the setting up of the inquiry was announced. Lord Phillips was named as Chairman in January 1998. Also in December 1997 the Association was renamed "The Human BSE Foundation"⁷.

The unusual, complex and, early in its course, non specific features of the disease made diagnosis and the establishment of appropriate care regimes for sufferers extremely difficult, particularly during the early years after the identification of the disease. These problems were reviewed comprehensively in a study dated February 1999 by Dr Margaret Douglas, Dr Harry Campbell and Professor Robert Will.⁸ It was recognised that care provision was not only very variable over the country but also that the needs of patients with vCJD were often not well or fully understood. These concerns led to discussions and negotiations between representatives of The Human BSE Foundation, and The Department of Health and the National CJD Surveillance Unit, which took place before the publication of the report. As a result in October 2000 a care package was put in place for victims of vCJD under the overall supervision of the NCJDSU, this is also available to people suffering from other forms of CJD. The care package, which is under the supervision of the NCJDSU, has been in place

⁶ The National CJD Surveillance Unit in Edinburgh has recorded onsets and deaths for the early years as follows:

1994: 8 onsets; no deaths	1995: 10 onsets; 3 deaths
1996: 11 onsets; 10 deaths;	1997: 14 onsets; 10 deaths;
1998: 17 onsets; 18 deaths.	

⁷ See www.hbsef.org

⁸ Of the National CJD Care unit formed within the Surveillance Unit, See www.cjd.ed.uk/carerep

since October 2000.

The BSE Inquiry and surrounding investigations, including discussions on the introduction of a care package, had revealed that there was an urgent need for improvement in the response to vCJD. The need was for speedier diagnosis, informed advice and timely assistance followed by a co-ordinated care package. Through the package guidance is given to the NHS and local social service departments. An advice network was set up to disseminate information on best practice and to facilitate care provision. In addition where local provision is inadequate or not available part of the scheme is to ensure that gaps in services will be filled.

After the report - the First and Second Interim Trusts

The report of the BSE Inquiry had concluded that BSE probably originated from a novel source early in the 1970s - possibly a single cow or other animal that developed the disease as a consequence of a gene mutation. It explained that BSE developed into an epidemic because of practice of rendering cattle offal to produce animal protein in the form of meat and bone meal (MBM) and including MBM in compound cattle feed. This resulted in the recycling and wide distribution of the BSE agent. The view of the Spongiform Encephalopathy Advisory Committee (SEAC) is that the most likely explanation of the vCJD cases is exposure to the BSE agent. In consequence of this the Government announced soon after the publication of the report that financial provision would be made for the victims and their families.

In November 2000 the Deputy Chief Medical Officer met some of the families and their legal representatives to discuss options for the compensation scheme. In December agreement was reached within Government on the principles to be applied. Shortly thereafter discussions and negotiations between legal representatives of the Department of Health and the families ensued on the scope, structure and terms of the financial package to be put in place. A full discussion document was drafted in May 2001 which formed the basis of the discussions and of the main vCJD Trust when it was put into effect. In February 2001 the Government announced that interim payments of £25,000 would be made to victims and the first 6 of these were paid to living sufferers on 15th March. Payments then were to be made through the agency of the First Interim Trust dated 10th April 2001. Between April and September interim payments of £25,000 each were made to the majority of families. The First Interim Trust was followed by the Second Interim Trust of 11th December 2001 with similar provisions. Following the March payments a special dispensation was made so that income related social security benefits were not affected by these payments and in April the regulations were amended so that on the assessment of income related and other benefits vCJD compensation payments would be disregarded.

The Interim Trusts served as a vehicle for payments to be made before the terms of the final, main, trust were agreed. Both of them have now been closed and money paid under either of them is taken into account in the payments made under the Main Trust now it is in force.

The Main VCJD Trust

Introductory Matters:

The negotiations reached a successful conclusion and on 28th September 2001 the Government announced details of the scheme. The fund has been set up to compensate those who have suffered or are suffering from vCJD and their families. It is a notable feature of this scheme that the compensation level is at or near 100% of what might be awarded at common law and in some instances recognises claims where they would not be recognised at law.⁹ The scheme does not preclude victims, their families, administrators or executors from taking proceedings against the Crown or any other body but, if they do, any sums paid under the Trust must be taken into account in any award of damages. The monies paid into the Trust are held in two funds, the Main Fund and the Discretionary Fund. Whether a particular payment comes from the Main or the Discretionary Fund is of importance and this will be discussed further below.

In November 2001 Sir Robert Owen was invited to become chairman of the Trust and on the 4th February 2002 the appointment of the other 6 Trustees was announced. The Trust deed itself was signed on 15th March 2002. Since then as a result of experience in running the scheme some limited amendments to the Trust deed have been made, pursuant to Clause 34.1 of the Trust deed, so as to make it more effective or to deal with anomalies which had become apparent during the application of its provisions. Under that Clause the Trustees, no less frequently than once a year “shall ---- consider whether the trust powers and provisions ---- are adequate to enable” them “to act for the best interests of the beneficiaries” and if the powers are not adequate they may, with the written consent of the Secretary of State, “amend vary or alter the powers and provisions”.

Following a preliminary meeting in February 2002 the Trustees met in March 2002 and had presentations by Dr Richard Knight Consultant Neurologist of the NCJDSU on vCJD itself and Gordon McLean, the National Care Co-ordinator of the NCJDSU, who spoke about the care arrangements and the care package. Dr Knight has been appointed as Special Advisor to the Trustees. Mr McLean is available to give advice to the Trustees as and when required.. The Trustees also appointed Charles Russell as solicitors to the Trust.

A web site has been set up, www.vcjdtrust.co.uk. This contains information about the Trust and the compensation scheme, summary minutes of Trustees’ meetings and details of how claims can be made, including online forms which can be downloaded. It contains a number of contact names and addresses and useful links to other organisations.

Payments under the Trust

⁹ E.g. Claims for psychiatric injury by people who would be classified as secondary victims by the courts and whose claims would fail because they would not qualify by reason of the application of the “control mechanisms”.

The Declaration of Trust sets out that: “The Secretary of State for Health on behalf of Her Majesty’s Government wishes to provide funds by way of compensation in respect of persons who suffered or are suffering from the disease known as variant Creutzfeldt-Jakob disease (vCJD) to be held and applied in accordance with the trusts ---.” The funds are provided in a manner “which does not prohibit such persons or their families from taking legal proceedings against the Crown and/or related bodies ---- but wishes to ensure so far as possible that ---- the sums paid under” the trusts “are taken into account in the computation of damages ---- .” The recitals then provide for the payment of monies by the Secretary of State into the Trust fund. In addition the balance of any funds still held in the Second Interim Trust were to be paid into the Trust, but there would be no funds from any other source.

Payments under the Trust basically depend on a victim and/or his family establishing eligibility. Once eligibility has been established, in addition to the victim, payments can be made to what are called “Qualifiers” and, in certain circumstances, “Non-Qualifying Carers”. Payments are made under various heads, which include certain basic sums, sums for some expenses, sums for participation in care, loss of dependency claims, loss of earnings claims and sums payable as a result of psychiatric injury caused by the vCJD suffered by the victim. Some of these payments are from the Discretionary rather than the Main fund. There could be problems arising from this as the sums available in the Discretionary Fund are much more limited than those in the Main Fund. An outline of the position under the various heads follows and, where appropriate I will point out some of the problems or difficulties which may arise.

Eligibility:

To establish eligibility under Clause 1.12 of the deed two factors have to be addressed, first that the victim is or was suffering from vCJD and second that the vCJD was contracted as a result of the exposure to bovine products in the United Kingdom during a specified period. Whether a person is or was a victim of vCJD has to be certified in writing by the NCJDSU either while still alive or following a post mortem after death. The expectation in the Trust deed in its original form was that the certification would be to a reasonable degree of medical probability which was taken to mean 95% probability. This however, strictly construed, raised the possibility of genuine claimants not passing the qualification test, so a recent amendment to the deed, made by the Trustees, introduces as the standard of proof that the NCJDSU’s confirmation in writing is “on the balance of probabilities”. By Clause 1.12.2 the Trustees have to be satisfied, again on the balance of probabilities, that the victim contracted vCJD as a result either of exposure to bovine products purchased in the UK “which came from cattle reared and slaughtered” in the UK or otherwise as a result of exposure in the UK to BSE or vCJD. The Trustees may, and normally do, take as sufficient evidence of this evidence that the victim was present in the UK for “not less than 5 years between 1982 and 1996”. A written statement that the Secretary of State is satisfied that the victim contracted it as a result of such exposure may also be accepted. As far as the residency question is concerned in virtually all the cases the Trustees have been satisfied by the 5 year residence rule.

Clause 1.13 contains a definition of “a confirmed victim” as a victim, whom, following death and any post mortem examination, the NCJDSU has confirmed in writing was on the balance

of probabilities suffering from vCJD prior to his death.” It seems to be the case that recently several families have been reluctant to allow post mortems so that the balance of probabilities provision is clearly needed. This reluctance could be partly the result of the adverse publicity arising from the Alder Hay enquiry.

There are two dates, as well as the date of death if it has occurred, for each victim which are important and affect some of the claims or payments. These are the “date of initial diagnosis” and the “relevant time”, (see Clause 1.15). I will deal further with their importance below. The date of first diagnosis means “such date as the Trustees in their discretion reasonably decide that the Victim was first reasonably suspected as suffering vCJD.” The phrase “reasonably suspected was added by amendment to ameliorate the arbitrary nature of the test arising from variability and uncertainty of diagnosis. The “relevant time” is whichever is the earlier of 2 years before the date of death and 6 months before the date of initial diagnosis.

Qualifiers

Qualifiers, including the recently added category of Non-Qualifying Carer, are the only persons who may be entitled to receive compensation payments under the scheme, other than the victim. They are defined in Clause 1.14. There are 7 categories of qualifier; they are

(1) “spouse or partner of the victim”;

A partner is defined and includes hetero or homosexual partners who are or were living in the same household as the victim at or after the relevant time and have or had been living in the same household for at least 2 years.

(2) a non-qualifying carer, who though not a qualifier, has, “after the Relevant Time in respect of the Victim been “significantly involved in caring for the Victim by reason of love and affection.”

This category was added by amendment because experience with claims showed that in many cases care was undertaken by people who fell outside the definition of partner, usually because of the 2 year provision, but who had significantly contributed to care. This is unsurprising when it is realised that many of the victims are or were young, often, for example in their early 20's.

(3) an ancestor or descendant of the victim;

(4) a person who the Trustees are reasonably satisfied is or was treated by the victim as his child;

(5) a person who the Trustees are reasonably satisfied is or was treated by the victim as his parent;

(6) a person who is or was a brother sister uncle or aunt of the victim or the issue of such person;

(7) a Dependant of the Victim.

In determining those relationships, where appropriate relationships by affinity are treated as relationship of consanguinity, relationships of the half blood are treated as of the full blood,

stepchildren and adopted children are treated as children and illegitimate children are treated as legitimate.

It will be seen that the range of potential claimants can be very large. Indeed in one case a total of 88 were identified and although nearly all had no desire or intention to claim the consequential investigations can be difficult and time consuming. That number is not particularly surprising and there have been several cases with 30 or 40 qualifiers, with sometimes as many as 20 wishing to claim. The difficulties can be particularly acute where families are estranged and perhaps in conflict. Unfortunately such situations lead to delays in the resolution of claims and sometimes resentment among the closest and most meritorious claimants. All those people who are entitled to make claims, together with the victim, are known as a "Victim's Group". Sometimes a single claim is made on behalf of all qualifiers but on occasion there may be more than one main claim form completed in which case consideration has to be co-ordinated to ensure that there is consistency as well as fairness.

Payments from the Main Fund:

The Basic Sum

The basic sum is payable in respect of any victim. There is a difference where the date of initial diagnosis was before 26th October 2000, the date of publication of the BSE Report. In the case of victims whose date of diagnosis was before that date the sum is £5,000 more than for those diagnosed later. The reason for this was the 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. The original provision was for £75,000 for those with the earlier date of diagnosis and £70,000 for the later cases. This was intended to represent a sum that might be awarded as general damages by a court. However the families campaigned for an increase in these basic sums and they were raised to £125,000 and £120,000.

The beneficiaries of payments of the basic sum are those prescribed under Clause 3.1.1. During the life of the victim in addition to any payment to the victim, payment may be made to a guardian appointed by the Court of Protection or Court of Session or Sheriff Court in Scotland, to an attorney who holds an enduring power of attorney, to the Court of Protection or any trustees of a trust of which the victim is a beneficiary. Otherwise the Trustees have a residual power to deal with the payment as they think fit. After the victim's death, the victim, then being a confirmed victim, any remaining part of the basic sum may be paid to the personal representatives of the victim, any qualifiers, any person who, or would have been, beneficially entitled to the victim's estate or any person whom the Trustees consider to have made a substantial contribution to the care of the victim.

While the amount to be paid under the basic sum provision does not cause any difficulty, issues can arise, depending on the circumstances, over to whom it should be paid in those

cases where payment is to be made after death. Where there is no conflict within the family a straightforward payment of the whole sum to the personal representatives will cause no problems as in such a case the distribution within the family will normally be agreed by them. Where on the other hand there is conflict within the family or, for example, the parents of a young adult victim have been divorced or separated since the victim's early childhood and the absent parent has an equal entitlement to inherit on intestacy, there may well be injustice in a substantial part of the basic sum going outside the family who have actually lived with the victim his whole life and endured the pain of his vCJD. In such circumstances, and it is surprising how many variations within families have emerged, the Trustees may feel that their discretion should be exercised so as to apportion the sum in order to meet the broad justice of the situation. There are three possible adverse consequences of this: first there is likely to be delay while the circumstances are properly investigated, second a feeling of resentment may be generated by the family as a result of further enquiries and at the end the decisions can lead to a feeling of injustice.

Experience of vCJD for the Family of the Victim:

For a claim under Clause 4.1 the date of initial diagnosis is also crucial. In cases where the initial diagnosis was before 26th October 2000 a sum of £10,000 is payable for this but if the diagnosis was after that date it is £5,000. The sum is payable in respect of each victim to one or more qualifiers in such shares as the Trustees shall determine. The apportionment is based on the evidence that the Trustees receive concerning the onset and development of the disease and its impact on, usually, family members.

Under Clause 4.2 a separate sum of £5,000 is to be paid to those qualifiers and non-qualifying carers who were significantly involved in the care of the victim, again in such shares as are appropriate. In respect of each of those sums any sum paid by way of carer's interim payment is to be deducted.

Questions of apportionment of these sums could, but don't seem to, cause many problems. In many if not most cases apportionment where it arises is dealt with by agreement amongst the family and the Trustees are happy to accede to any such agreement.

Other Financial Costs Incurred

These are costs incurred within the terms of Clause 5 of the Trust deed, and are payable out of the Main Fund. Clause 5 also includes some items payable from the Discretionary Fund which will be dealt with below. The first head is funeral expenses. Receipts are usually wanted and where the sum is large, arbitrarily treated as significantly in excess of £3,000, they are really essential.

Second by Clause 5.2 the Trustees may pay up to £10,000 (and in exceptional circumstances more) in respect of "the whole or any part of any expenditure incurred by the victim or by his

qualifiers on real or personal property or its repair alteration or improvement which the Trustees are reasonably satisfied was incurred as a direct result of the victim having suffered from vCJD and for the purpose of mitigating the effect of vCJD on the victim's life." It must be noted that this provision specifically relates to "real or personal property" and not, for instance, to additional services provided for entertainment, such as Sky TV, or for holidays. It is perhaps rather narrowly drawn and it has caused some dismay when the payment for an item clearly only spent to alleviate the victim's vCJD, but plainly outside its terms has been refused.

Where a person who is a beneficiary (i.e. a victim or qualifier) has reasonably spent money or incurred liabilities at a time after the date of the Trust, in making representations to or answering questions from the Trustees, the Trustees may reimburse that expenditure to or for the beneficiary concerned (Clause 7.1).

Dependency Claims

Where a confirmed victim has died leaving dependants the Trustees are to assess the dependency sum and pay it, after the deduction of any dependants' interim payments, to the dependants. The assessment of the dependency sum is to be carried out as specified in the second Schedule to the Trust deed. Broadly speaking the process prescribed by that Schedule, supported by other Schedules dealing with multipliers and the assessment of loss of earnings and pension claims, follows the scheme for the assessment of such claims at common law. However the structure and definitions in the scheme may cause problems, for example arising from the definition of "partner".

Psychiatric Injury

Under the broad heading "Experience of vCJD for the Family of the Victim" in Clause 4 claims for personal injury caused by a psychiatric condition are included. Under Clause 4.3.1. payments from the Main Fund may be made while under 4.3.2 payment is from the Discretionary Fund (see below).

4.3.1 payments of £5,000 may be made in any case to any qualifier who "has suffered a personal injury in the form of an identifiable psychiatric condition falling within the definitions contained in ICD-10 or DSM_IV (or their clinical equivalents) lasting longer than a calendar month and which ---- has been caused or materially aggravated by the fact that the Victim has contracted vCJD ---- :". These payments depend on medical certification, at least by a GP, but having regard to the ICD-10 classifications it would be surprising to find a close family member who has not so suffered. The Trustees, acting on advice, have prepared a check list for GP's concerned to help determine whether a person falls within the definition.

Payments from the Discretionary Fund:

The monies available for distribution from the Discretionary Fund are much more limited than those from the Main Fund. Depending on the construction of the Trust and the nature of the claims some of the potential claims on this fund, such as loss of earnings claims, could be very substantial. Thus it may be necessary to limit payments in some way so that the fund does not run out for later claims. Unless additional funds can be made available to the Discretionary Fund or a narrow interpretation of the potentially more generous provisions is applied, it will be inevitable that a cap has to be placed on payments under these various provisions. They are discussed further below.

Provisions for Care Payments:

Under Clause 5.3 where there has been expenditure on care or care has been provided gratuitously payments may be made to cover the cost of purchased care or the value, as calculated in accordance with the deed, of the gratuitous care. The items which are covered by this provision are: the cost of purchasing care by the victim or any qualifier, 75% of the reasonable value of gratuitous care provided by a qualifier or non-qualifying carer, reasonable cost of travel for care and any other expenditure incurred for the purpose of caring for or alleviating the suffering of the victim. This last can only exceed £2,500 in exceptional circumstances.

It is important to note first that by Clause 5.3 claims for care costs under this head can only be made for care provided “at a time or times prior to the earlier of (i) 31st March 2001 and (ii) the implementation of a Care Package in respect of that Victim ---- .” In several claims that the Trustees have received the applicants or their solicitors seem not to have realised that care claims under 5.3. could not be accepted after 31st March 2001. No doubt this caused raised expectations and unnecessary disappointment. In the assessment of the value of gratuitous care three things must be noted in addition to the dates: First the valuation is “reasonable” and is based on the kind of recognised care rates which will be familiar to personal injury practitioners. Second, in assessing the number of hours of care for which compensation should reasonably be paid, the Trustees, with the help of Dr Richard Knight, have established a pattern of appropriate hours of care in accordance with recognised stages in the development of the disease. Third after the calculation has been made the deed requires the trustees to discount the full value and pay only 75% of the total. It should also be noted that travelling and hotel expenses incurred must have been incurred “solely or predominantly for the purpose of providing” care.

Because of the cut off date most of the claims under this head have now been dealt with and, with those numbers and the amounts claimed, they have not caused a problem with the limitation in the size of the Discretionary Fund.

Carer’s Loss of Earnings:

Under Clause 5.4 where gratuitous care has been provided and the carer, whether a qualifier

or a non-qualifying carer has suffered “such loss of earnings ---- as to cause them particular hardship” the Trustees may pay “such sum as the trustees in their discretion think fit.” Thus it is a loss of earnings causing particular hardship so it does not follow that the “particular hardship” equates to the “loss of earnings” suffered. Any sum paid under this provision must first have deducted from it payments made to carers for gratuitous care under 5.3. Although it applies to victims who suffered vCJD both before and after 26th October 2000, the Clause itself does not contain any reference to any other date, in particular the 31st March 2001, this seems anomalous unless it is to be implied that the expression “such care as has been provided gratuitously ---- ” is intended to include only the gratuitous care which has been provided within the time limited by 5.3. and compensated under it.

The the expression “particular hardship”, the establishment of which is a requirement for payments under this clause and under 5.4 and 4.3.2, is not easy to construe. In 5.4 it plainly cannot be intended to include all situations in which a gratuitous carer has lost earnings, there must be something more and something which leads to greater hardship for the specific individual concerned than for the generality of people in a similar position, that seems to mean the general body of qualifiers. The issue of what is particular financial hardship is one which the trustees have still to resolve by establishing principles to be applied to all such claims.

Victim’s Loss of Earnings:

Where a victim suffered such a loss of earnings as to cause particular hardship to himself or his dependants Clause 5.5 enables a claim to be made. Again the question of the meaning and width of application of the expression “particular hardship” has to be considered. It also leads into the question of how other payments made under the scheme, which alleviate a victim’s or qualifier’s financial position, are to be taken into account if they resolve any financial hardship. Because of this and, bearing in mind the usual course of the disease, it is likely that the number of claims under this head will be limited.

Additional Payments to Dependants:

Dependency payments made under Clause 6, paid out of the Main Fund, may be supplemented from the Discretionary Fund under 6.2. where “the Trustees are satisfied that the amounts payable under 6.1, are very significantly less than the amounts which would be likely to be payable if the assessments required ---- were based on the future earnings potential of the Victim and that potential can be assessed with reasonable confidence ---- and the Qualifiers in respect of the Victim will suffer particular hardship if no additional payment is made” they may make additional payments. At the time of writing no payments under this provision have yet been made so it is hard to say how it will work out in practice or whether there will be a significant number of payments requested under it. Additional payments may also be made under 6.3 where the trustees are satisfied that the dependency of a child of the victim would have continued beyond the qualifier’s 21st birthday.

Life Insurance or Mortgage Protection - Particular Hardship:

Clause 7.2 enables payments to be made where any dependant of a confirmed victim “has or will suffer particular hardship because he is unable to obtain adequate life insurance or mortgage protection without paying a substantial additional premium as a direct result of his relationship with the victim”. Payments may be made towards the cost of such insurance.

No claims have been made under this head and it is unclear whether any and if so how many will be made.

Psychiatric Injury - Financial or Emotional Hardship:

There is a second heading in Clause 4, “Experience of vCJD for the Family of the Victim”; where the psychiatric injury gives rise to particular financial or emotional hardship the trustees may pay to any qualifier such further sum as they think fit. This provision is in Clause 4.3.2. In order to qualify for a payment under it, in addition to the three factors set out in 4.3 itself, namely (i) an identifiable psychiatric condition causing personal injury (ii) lasting more than one month, and (iii) which is caused or materially aggravated by the fact that the victim has contracted vCJD, the psychiatric condition must give rise or have given rise to “particular financial or emotional hardship”. Thus the expression “particular hardship” which occurs in 5.4 and 5.5. in respect of loss of earnings, recurs with the addition of particular emotional hardship. Sums applied for under this head could be very substantial. It is not difficult to imagine a psychiatric injury of such severity that the sufferer is unable to function either in his or her working or social life. The trustees have complete discretion as to the level of any payments made and a scale for awards has yet to be worked out. The causation issue could also raise difficult questions, both for emotional and financial hardship, in some cases. This can be so particularly where the financial hardship only develops a considerable time after the victim’s death, as it seems to have done in some cases.

For those suffering emotional hardship some guidance may be obtained from the Judicial Studies Board guidelines for psychiatric injury, certainly so as to help in grading the severity of any injury. Whether someone is suffering emotional hardship is likely to be a very subjective matter and it is possible that there will be considerable unhappiness when awards are made under this head where claims are allowed or disallowed in circumstances which are not understood by claimants. This problem may be aggravated by the fact that many family qualifiers are reluctant to go to a psychiatrist because the pain of discussing the victim and vCJD will re-open the past and may cause more pain.

Lessons for future schemes

This scheme is probably unique in that, without an admission of liability, the Government

have accepted their responsibility to provide funds for payments at a rate broadly comparable to common law damages. Indeed in at least two respects the scheme exceeds the common law. First in the level of the basic sums, notionally equating to general damages for pain, suffering and loss of amenity and second in the potential for payments to qualifiers suffering from psychiatric injury who, in law, would be “secondary victims” outside the common law controls and so not entitled to any award.

In many ways the Trust scheme, in its attempt to balance the needs of justice in the treatment of one case compared with another, has introduced too much complexity. The proper balance between certainty and justice is always going to be a difficult one to achieve. Furthermore it is likely to give rise to some dissatisfaction. For example, in individual qualifiers with legitimate claims who may find the psychiatric investigation in psychiatric injury claims to be difficult and harassing and so not only unnecessary but also unacceptable for a scheme designed to provide a simple straightforward and speedy way of dealing with their need. They are likely to remain unhappy with the way they have been treated under the scheme and a fixed payment procedure might have caused fewer grievances.

A scheme to be regarded as acceptable should provide an appropriate payment with the minimum of delay and without the need for repeated and painful persistent inquiries. As has been already mentioned there have been cases in which it has been necessary to pursue the search for family members who could claim as qualifiers but have not been in touch to set out their position. This problem arises especially where there are, or have been, family disputes.

The main message from work on the trust is that any future schemes should be simplified to the greatest extent possible. If beneficiaries understand that perfect justice (if there is such a thing) may have to be sacrificed to certainty and speed then it is likely that fewer complaints will be made.

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