

## Briefing for PS(PH) for meeting with Michael Ancram QC MP

1. Mr Ancram has been corresponding with DH Ministers for some time on the subject of **GRO-A** a victim of vCJD. A copy of the latest correspondence is attached. He is now seeking a meeting with MS(Q), which we understand has been passed on to PS(PH), to discuss this and the wider issues flowing from this case.

### Issues

The **GRO-A** case

2. The vCJD Trust has been considering this difficult case which they consider cannot be covered by the compensation scheme as it stands. They consider it necessary to buy a house for the use of the victim and his mother, during the former's lifetime. They originally refused to consider the possibility of purchasing a house for the use of **GRO-A** and his mother, but they are now reconsidering. There are complex legal issues around this, on which a further submission to Ministers is in preparation, to be accompanied by a formal proposal from the vCJD Trust.
3. In short, the Trust Deed would only allow this if the Secretary of State agrees to increase the "Basic Sum" (a major item of compensation payment laid down in the Deed) from £120k to £445K, just for this case. This would not involve a payment of an additional £325k to the **GRO-A** family. The sum paid for this house will be repayable into the Trust on its sale, subject to what sale price may be achieved at the relevant time.

### Lines to take

4. I understand that the Trust has been reconsidering its earlier refusal, but there are clearly some complex legal issues involved. My officials and legal advisers are examining the issues, with the Trust's solicitors. **GRO-C**
5. It is for the Trust to reach a conclusion on this, and then to make any representations to the Secretary of State as may be necessary. I expect to receive a submission on this shortly.

### Background

6. **GRO-A** (age 21) was diagnosed by the CJD Surveillance Unit with possible vCJD on 27 June 2003. He was accepted as a Victim by the vCJD Trust in 30 June 2003. (Background on the vCJD Trust is at Annex [x].) **GRO-A** lives in Wiltshire, spending half of his time at his mother's flat in **GRO-A** and the other half at his father's house in **GRO-A** (some 20 miles away). His parents are divorced, but share **GRO-A**'s care in an amicable way. The vCJD Trust has already paid a total of £120k into two trusts – one held by **GRO-A**'s father and by his mother and their respective solicitors.
7. Since 2003 **GRO-A** and three others have been receiving experimental treatment involving the use of a drug pentosan polysulphate (PPS). This

experimental trial has reached no conclusions yet, but it is believed (at least by vCJD victims' representatives) to hold promise. A recent paper on PPS is attached at annex C. In any case, [GRO-A] has survived for just over 2 years, which compares favourably with the average life expectancy. It is the possibility of increased longevity of vCJD victims that begins to raise problems for the vCJD Trust.

8. Mr [GRO-A]'s house and general care arrangements are agreed to be satisfactory. However the vCJD Trust and the National CJD Surveillance Unit agree that Mrs [GRO-A]'s flat is seriously unsuitable for the care of [GRO-A]. Together with [GRO-A] District Council Housing Department and the local PCT, they have considered alternative arrangements. [GRO-A] DC has been unable to identify suitable social housing within its limited stock. Looking over a wider geographical area has been ruled out, since Mrs [GRO-A] wishes to remain in [GRO-A]. A fuller account of the position, from Mrs [GRO-A]'s viewpoint, is set out in a recent letter from her solicitor to the vCJD Trust, at Annex [x]. The solicitor argues that the proper course for the vCJD Trust to take would be to buy outright a substantial property, to let it to [GRO-A] during his lifetime, and to re-possess it for sale on his death.
9. Initially, the vCJD Trust took the view that, as a matter of policy, this was not a course of action they could or should take. Subsequently, the Trustees have reconsidered this case, and have now decided in principle that they would countenance such a proposal. A suitable property has been identified, at a price of £285k. The vCJD Trust now proposes to: satisfy itself on the usual issues connected with purchase of property; arrange suitable estate management services; establish the treatment for housing benefit of any rent they may charge; and to secure satisfactory terms for recovering vacant possession.
10. The Trustees have considered their powers in this case, and have concluded that the Trust Deed would not straightforwardly permit them to buy and let a property in this way. However the Trustees consider that the Deed does make provision for them to exceed the standard limit per case, which is defined in the Deed as the "Basic Sum". The Trustees therefore propose that, as provided in the Deed, the Secretary of State should exercise her power to agree a specific increase in the Basic Sum, in this case only, so as to permit the total expenditure of £325k envisaged for this case.

**Q The DH is acting too slowly on this case, which involves real suffering for [GRO-A] and his mother**

A We have every sympathy with the very difficult situation of [GRO-A] and his family and the Trust is doing everything in its power to resolve the problem. The requirements of Mrs [GRO-A] are, however very specific and the legal issues are complex and it is taking time on both counts. I am aware that the Local Authority and the PCT are providing a lot of support.

**Q Can the vCJD Trust Fund afford to buy the house concerned?**

A The cost of the house is not an issue *per se*, although the Fund was not designed to cover purchase of property.

**Q Should there be a new / additional Trust Fund set up for this purpose?**

A The Department do not intend to set up any further funds of this nature. This proposed purchase of a property is seen as an exception rather than as a new direction.

Longer term care - The CJD 'Care Fund'

- 11 The Care Fund was announced by the Government in response to the Bovine Spongiform Encephalopathy (BSE) Inquiry Report on 26 October 2000.

Its purpose is to ensure a speedy service response following diagnosis and improvements in the quality of care for patients

- 12 The Care Fund is used to support patients in the community and to pay for those elements of the care package that cannot be readily supplied by local health and social services. The Fund is to supplement local health and social care provision for people with CJD; it does not replace it

The Care Fund is available for people with all types of CJD in any part of the UK

**What can the Care Fund be used for?**

- 13 The Care Fund can be used to commission or purchase any service, item of equipment or necessary capital adaptation which health or social services have the legal ability to supply. It can be used, for instance, for any major housing adaptations needed to nurse the patient at home. It can be used to buy in night sitters or other care agents from the private sector because of any shortages in local services, and to purchase respite care.

- 14 If appropriate it can also pay for bereavement counselling for surviving relatives, assistance with childcare and access to an adapted motor vehicle. In addition, the fund will pay for additional nursing or social care support and equipment needed by most CJD patients, such as an appropriate wheelchair (with head and neck support), a recliner chair, a hoist, a hospital bed, a stair lift and suitable bathing/toilet facilities.

- 15 Care packages for individual patients will vary according to their individual needs and it is not possible to be prescriptive about what each care package should contain. What is needed is a package that will provide the appropriate level of care at home both for the patient and for their family, in order to make sure people are able to return home as soon as possible.

- 16 The Government has made an undertaking that users of non-residential social services suffering from any form of CJD should not undergo a charge assessment, but be treated as automatically exempt.

**How do local statutory bodies gain access to the Care Fund?**

- 17 Access to the Care Fund is through the National CJD Surveillance Unit. One of the National CJD care co-ordinators, based at the Unit, will consider applications for Care Fund monies. The patient's key worker should discuss with the care co-

ordinator any potential claim against the Care Fund. Decisions on eligibility are made by the Department of Health in the light of his advice.

What payments have been made in respect of **GRO-A** ?

Invoices for 2005/06 to date are shown below.

Organisation	Invoice No	Invoice Amount	Date Paid by the DH
Wiltshire County Council	<b>GRO-A</b>	£280.00	29/06/2005
Wiltshire County Council		£45.00	29/06/2005
Wiltshire County Council		£300.00	29/06/2005
Wiltshire County Council		£58.75	29/06/2005
Wiltshire County Council		£320.00	29/06/2005
Wiltshire County Council		£199.05	29/06/2005
Wiltshire County Council		£130.00	26/07/2005
Wiltshire County Council		£180.00	26/07/2005
Wiltshire County Council		£120.00	29/07/2005
Wiltshire County Council		£84.25	29/07/2005

#### Administration of the 'Care Fund'

- 18 Access to the Care Fund is through the National CJD Surveillance Unit.
- 19 The National CJD Care Co-ordinators based at the Unit, will consider applications for Care Fund monies. The current guidance says that the care co-ordinator should be invited to case conferences of people with CJD. At this point, the patient's key worker should discuss with the National Care Co-ordinator any potential claim against the Care Fund.

#### Care Packages

- 20 The Care Fund is available to supplement local care provision for all strains of CJD rather than replace it - health and social services are still required to provide the necessary elements of the individual patient's care package. Care packages for individual patients will vary according to their individual needs and it is not possible to be prescriptive about what each care package should contain. What is needed is a package that will provide the appropriate level of care at home both for the patient and for their family.
- 21 However, it may not be possible to provide all the elements of an individual's care package quickly enough from local resources. In these circumstances the Care Fund can be used to make sure people are able to return home as quickly as possible. The Care Fund can be used, for instance, for any major housing adaptations needed to nurse the patient at home and assist with transport. It can be used to buy in night sitters or other care agents from the private sector, because of any shortages in local services, and to purchase respite care and assist with the provision of complementary therapy. The Care Fund can also be used to pay for bereavement counselling for families if services are not readily available locally. The guiding principle is that funds can be used to commission or purchase any

service, item of equipment or necessary capital adaptation which health or social services have the legal ability to supply.

### **Local Authority charges for non-residential social care**

- 22 The Government has made an undertaking that users of non-residential social services suffering from any form of CJD should not undergo a charge assessment, but is treated as automatically exempt.

#### **Action**

- 23 Once payment from the Care Fund is agreed with the senior national CJD care co-ordinator, an invoice can be raised. The invoice can be raised by either the relevant health authority or social service departments, according to the composition of the individual care package. If it is agreed that both health and social elements should be supported in a single individual's care package, two separate invoices will be needed. All invoices should be sent to the Unit, depending on who was responsible for the particular patient, who will proceed to forward them to the Department of Health with a recommendation for payment from the Fund. The final decision on payment rests with the Department; the Department has not to-date declined to authorise any payments.
- 24 HAs and SSDs should not await payment before supplying agreed goods and services.
- 25 Given the rapidly deteriorating nature of CJD, the elements of the care package will need regular review and any additional payments from the care fund should be negotiated with the national care co-ordinators.

#### **CJD Advice Network**

- 26 A group of health professionals and charity staff with previous experience of caring for patients with CJD and their families. They are available by telephone contact to share their experiences and provide advice and information relevant to their specific discipline to those professionals presently caring for a patient with CJD.

- 27 Disciplines involved include;

Neurologist	District Nurse
Counsellor	Social Worker
Charity representatives	Occupational Therapist
Dentist	Physiotherapist
Dietician	Speech Therapist
General Practitioner	Nurse Specialists
Community Psychiatric Nurse	Consultant Virologist

Further information and contact details about the Advice Network is available from the National Care Team'.

- 28 CJDSU can provide help and advice to the family. They will also work with local service providers to ensure that they are aware of the guidance, have identified a key worker and have the necessary arrangements in place. The care co-ordinator can put NHS and social service staff in touch with people with hands on experience in caring for patients with CJD and who may be able to help with practical problems of care.