

PE1179/A

Mrs Zoe Tough
Assistant Clerk to the Public Petitions Committee
The Scottish Parliament
Room TG.01
Edinburgh
EH99 1SP

17th November 2008

Dear Mrs Tough

Response to Committee Consideration of Petition PE1179

Thank you for your letter dated 10th September 2008 regarding the above petition. The Princess Royal Trust for Carers welcomes the opportunity to respond to the specific issues raised in the petition and to the discussion during the official report of the committee's meeting of 9th September 2008.

Our response to the issues raised in the petition is noted below.

Petition by Helen Moran, on behalf of the Bain Injury Awareness Campaign, calling on the Scottish Parliament to urge Scottish Government to introduce a separate and distinct health and community care client category of 'acquired brain injury' to ensure that people with acquired brain injury and their carers get the services and support that they need and agencies can plan and deliver services more effectively.

1. The network of twenty-nine Princess Royal Trust Carers Centres provide services and support to carers of all ages and caring situations and are currently in contact with over 50,000 adult carers and 3,500 young carers across Scotland. Some of the caring situations that our network of Carers Centres come into contact with are families where a loved one has suffered an acquired brain injury. Such a caring situation has a devastating impact on not only the patient but on the lives of each of the family members. These families are the real victims of such an illness and they often suffer more than the head injured person, as they are more likely to have an accurate insight into the problems that lie ahead.
2. Carers in such situations experience high levels of anxiety and depression, having to deal with the care of their loved one during the years after the injury. They witness their loved one's loss of capacity and control over their lives. There are few if any individual services that will meet the complex needs of their loved one. This leads to carers having to consult and negotiate with a wide range of health and community care service providers.
3. Many of our Carers Centres have very good links and close working relationships with specialist service groups such as Headway, to help support carers within such a complex caring situation. The Care 21 report on the

Future of Unpaid Care in Scotland cited that all carers need good, clear, illness specific information and support. Acquired brain injury is clinically separate to mental illness. Although some of the symptoms can be similar, people with acquired brain injury are not mentally ill. Their mental illness is just one factor, along with many other symptoms, which sit within other physical and complex disabilities. This often results in people with acquired brain injury slipping between the cracks, with their carers 'left to get on with things unsupported.'

4. Given the complex nature of acquired brain injury and the fact that its treatment and support sits across a wide range of health and community care service fields, there is an even greater need for cohesive and well coordinated delivery of services and support. The personalisation agenda needs to make specific mention to acquired brain injury in the development of its work at a national level.
5. NHS Carer Information Strategies provide a duty on Health Boards across Scotland to identify and support carers and to ensure that they have appropriate access to information, advice and support services. The strategy also requires Health Boards to ensure that hospital discharge protocols recognise the role of family carers and involve them in any discharge plans. Implementation of these strategies is still at an early stage, but should include training for health board staff on complex caring situations such as acquired brain injury.
6. The complex nature of the care required for a loved one who has suffered an acquired brain injury crosses many areas of health and community care planning and provision. The Princess Royal Trust for Carers believes that all carers need timely and appropriate support to assist them in their caring role. The Trust would request that the Petitions Committee make recommendation to Scottish Government to give particular consideration to this group to ensure improved mainstreaming of services to better meet the needs of this very complex caring situation.

Yours Sincerely
Carole Cochrane, Acting Chief Executive
The Princess Royal Trust for Carers