



PE1499/A

Muscular Dystrophy Campaign response to petition PE1499 on creating suitable respite services for younger disabled adults with life-limiting conditions

In responding to the above petition, we would like to begin by acknowledging Robert Watson's excellent petition presentation at the Scottish Parliament and for the powerful oral evidence both he and Kyle Kelly provided to the Public Petitions Committee on the 26th November.

The Muscular Dystrophy Campaign is fully supportive of the petition and of the need to ensure that alternative provision is established following the Children's Hospice Association Scotland's (CHAS) decision to withdraw its services for young disabled adults. Whilst we accept that CHAS' decision was based on the increased demand its services were experiencing from disabled children, we are also deeply concerned that there is now no appropriate hospice and respite facilities for young disabled adults. This will place a further burden on these individuals and their families, who already face additional strain through living with a long term disabling condition. Consequently, new provision must be established as a matter of urgency.

Evidencing Need

Following CHAS' decision to withdraw its services for young disabled adults, the Muscular Dystrophy Campaign has been conducting a survey into Hospice and Respite Services in Scotland, which seeks the views of Scottish people and their families living with neuromuscular conditions. Responses have so far reflected the huge value that families place on these services and the widespread concern that the decision to withdraw them for young disabled adults has caused.

Our survey has shown that 70% of respondents very strongly agree that the impact would be terrible if respite/hospice provision in the area was stopped, with 20% strongly agreeing and 10% agreeing. 70% of those responding strongly agree that these services are vital for their families' quality of life, with 10% strongly agreeing and 10% agreeing. One respondent commented:

"It is the only time my husband and I get a break and time to recharge our batteries and the only time our son gets a break from us, as otherwise we are caring 24/7"

Many have drawn attention to a lack of appropriate facilities in both children's and adult hospices. Young disabled adults are too old for children's services but adult hospice and respite facilities cater for conditions such as dementia and are not an appropriate setting for this age group. Robert Watson commented:



“There are no suitable respite facilities in my area for my needs. All the available services in my area cater for those with learning disabilities or much older people with terminal conditions such as cancer, or other conditions like dementia. These are not appropriate places for a 28 year old man like me with a physical disability to have to go to.”

The Cross Party Group on Muscular Dystrophy in the Scottish Parliament, for which the Muscular Dystrophy Campaign provides organisational support, met in December to discuss hospice and respite provision for this age group. The group was joined by representatives of the Scottish Government, Healthcare Improvement Scotland and families from across Scotland affected by neuromuscular conditions. Those attending agreed on the importance of hospice and respite facilities for young disabled adults and the significance of the gap in provision that has now emerged. One young woman described how hospice and respite facilities would reduce the burden on her family and help her to feel like a ‘daughter, sister and girlfriend’, rather than a patient in her own home.

The group agreed that the scale of the problem is likely to be significant, stretching beyond those young adults who currently use CHAS’ facilities. We are currently looking at obtaining CHAS’ data on young disabled adults accessing their services, as well as additional data from organisations including Local Authorities and the Care Inspectorate in order to fully evidence need. Given improvements in care and life expectancy, the number of young disabled adults affected is set to increase with time.

Solutions

The Cross Party Group discussed the need to bring together organisations from across the spectrum in order to establish a solution, including patient organisations, the Scottish Government, Health Boards and hospice providers. The Muscular Dystrophy Campaign supports this call and we want to work constructively with all these organisations. In particular, we wish to ensure that any solution is a long term one. To this end, we see an important role for Health Boards across Scotland in funding alternative provision, as this would provide long term security for these vital services.

We recognise that this issue affects not only young adults with neuromuscular conditions, but all young disabled adults affected by many different conditions. As such, we are seeking to engage with other charities and organisations that work with young disabled adults who will also be affected by these changes.

We look forward to the debate on the issue in the Scottish Parliament in the spring and the opportunity it provides to stress the need to the Scottish Government for appropriate hospice and respite facilities for young disabled adults. The Scottish Government can play a major part in securing alternative provision, through support



for funding initiatives and leading on facilitating discussions with interested organisations on how a solution can best be reached.

We shall continue to work constructively with Government, NHS Scotland, local authorities and other organisations and look forward to playing a full and leading role in establishing a solution to this alarming gap in care.