



PUBLIC PETITION NO.

PE01499

Name of petitioner

Robert Watson on behalf of CHAS Young Adult Council (YAC)

Petition title

Creating suitable respite services for younger disabled adults with life-limiting conditions

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to work with charities to help create suitable respite facilities to support younger (aged between 21 and 45) disabled adults with life shortening conditions. Together, they should be working with other hospices and care providers to see if some could provide facilities for younger adults, or better still they should be committing funds towards creating new purpose built facilities for this age group.

Action taken to resolve issues of concern before submitting the petition

First of all, I set up an online petition in mid-May through the website “38 Degrees” about creating suitable adult respite facilities, and there was a positive response. By mid-August there were 1100 signatures, which is quite a lot in just 3 months, and this shows just how important an issue this is, because so many people feel very strongly about it.

Next, my parents and I contacted our local MSP Derek MacKay about the issue who passed the issue on to Michael Matheson. Mr Matheson's response was not at all helpful. He seemed to focus purely on the needs of carers, when the issue we have is centred around the needs of the parent's disabled sons/daughters. He talks about my parents contacting the Princess Royal Trust for Carers for them to get a break, but this doesn't solve the fact that there are no suitable respite facilities for me to go to, so where am I supposed to go while my parents are away somewhere having a break? He says that arranging and funding adult respite care is the responsibility of the local authority, but they cannot arrange and fund respite care when there are no suitable respite care facilities available – that is the point we have to keep repeating.

We then replied saying how unhappy we were with his response, and we then received a letter from the Health Minister Alex Neill. But again, Mr Neill just seems to focus on blaming local authorities, when really the government should be stepping in to deal with this issue. He also talks about “supporting young people to successfully prepare for their transition to adult services”, which again seems to ignore the fact that there are no suitable adult services to transition to!

Myself and another member of the YAC wrote a letter on behalf of a number of disabled young adults to the Muscular Dystrophy Campaign (MDC) Chief Executive Robert Meadowcroft to tell him about this issue, and he replied to us agreeing that respite

services are desperately needed for many people like us and our families. He assured us that the MDC will use their campaigns resources to address the need for access to hospice services and to influence parliament. They are keen to work with the YAC on this issue, but they also say that they need political support if this issue is to be resolved. They raised this issue at a recent Cross Party Group meeting on Muscular Dystrophy held at the Scottish Parliament, and Jackie Baillie has agreed to take these concerns forward. They are keen, as we are, to raise this issue as a subject for a formal debate in the Parliament.

I raised the issue of adult respite at an Action Duchenne lobby of Parliament in June, and afterwards Jim Eadie expressed to me that he would like to assist with this issue, as did Jackie Baillie. Indeed very recently the whole YAC was able to have a meeting with Ms Baillie where she reiterated her support of our campaign, and she gave us a lot of information on how we take our campaign forward. Having raised awareness through my petition, Ms Baillie feels that the only way we can take the campaign to the next level is to get political involvement, and she agrees with us that this issue really needs to be debated at parliament, to gain media interest which in turn will really raise the profile of the campaign and the issue of adult respite. Jackie Baillie and Jim Eadie have also now agreed to work together on this issue.

Petition background information

PLEASE NOTE: Throughout this section, and throughout the entire form for that matter, we use the term “younger adults” because there are suitable respite facilities for older adults and the elderly, but nowhere that is suitable for those who are too old for children's services. This is why we are defining a younger adult as someone who is between the age of 21 and 45.

What gave rise to the petition: For many years, I, along with many other young disabled people with life-limiting conditions, have used the services of the Children's Hospice Association Scotland (CHAS) for respite, going to the only 2 children's hospices in the country, Rachel House and Robin House. These provide end-of-life care for children with terminal illnesses and respite care for the families of young people with longer- term conditions. We, and our families, thought that we would always be able to use the services of CHAS for respite, as their original remit was that they would support the young person and their family “from the point of diagnosis until death, and beyond” (because CHAS also offer other services to families after their child has passed away, such as bereavement support and counselling).

But on the 8th of May 2013, CHAS announced that it was withdrawing it's services for those aged 21 and above, a decision that will impact on over 100 young adults and their families in Scotland alone, who will now need to look elsewhere for respite support. They are giving all of us young people over the age limit 3 years from this date to find alternative adult respite facilities before we will be stopped from using CHAS services, and after those 3 years every young person when they turn 21 will have to stop using CHAS services.

However, this is not a long timescale to find an alternative when after doing some research we discovered that there is nowhere else suitable for us to go to. The only existing respite care provider we found out about that may have been suitable charge hundreds/thousands of pounds for a stay, so this is unsuitable too at the moment as it is unaffordable for the majority of us. Currently, all adult hospice services are set up largely to cater for much older adults suffering from cancer and other terminal illnesses, and some of these hospices often don't provide respite breaks, just end-of-life care. They are just as unsuitable a place for our age group to go to as children's respite services are. It is great that because of medical advances many of us are living well into adulthood when in the past none of us would have been expected to. But no-one seems to have been prepared for this, and now we find ourselves in a position where we are too old to use children's respite services and yet too young for the available adult respite services. We find ourselves stuck in the middle with nowhere to go.

For more background information on the CHAS decision to withdraw its services, please refer to the following website links, stories that were printed in The Glasgow Herald newspaper dated 10 May 2013:-

<http://www.heraldscotland.com/news/home-news/young-adults-are-being-left-in-limbo-by-hospice-decision.21041635>

<http://www.heraldscotland.com/news/health/hospice-charity-sets-age-limit-on-services-for-young-people.21041823>

Why it is needed: Respite breaks are vitally important to disabled young adults with life-limiting conditions and their families, especially for the majority who still live at home with their parents, because it is the only time when the young adults get a break from their parents and for some they can be quite isolated at home so these breaks may be their only opportunity to socialise with others of a similar age, who also have the same or similar conditions and so they can relate to each other and discuss common problems that they may have. Equally as important if not more so is the break it gives families; regular respite breaks mean that the parents get a chance to relax and recharge their batteries, safe in the knowledge that their son/daughter is being well cared for and enjoying themselves.

However, without any respite services the parents will have to provide constant care 24 hours a day 365 days a year without a break which will lead to high stress levels for the parents, carer burnout and many other health problems, because caring for a disabled adult with a life-shortening condition is a full-time job. We need constant round the clock care which increases as our condition progresses, with ventilators being required to enable us to continue breathing as our lungs weaken, eventually some people require to be peg fed as they can no longer manage to eat, and heart medication is needed as our hearts deteriorate. Its not acceptable in any other job to be expected to work all year round without even a single day of rest, so why should it be acceptable in this case? So it is clear for all of the above reasons why suitable adult respite services are so crucial.

What action needs to be taken: We feel the Scottish government should be doing something to address this gap in provision, as they have the power and resources to make this happen. We need an adult respite facility which is designed to support younger disabled adults with life-limiting conditions nationwide, not one that is limited to people who live in a particular local authority, because it needs to be a place that everyone can benefit from. A place that is similar to what CHAS offers at their 2 hospices, but for those aged between 21 and 45. To achieve this, the Scottish Government should be working with the charities of the different conditions, such as the Muscular Dystrophy Campaign since a lot of the people who are affected by the lack of adult respite services have Duchenne Muscular Dystrophy, but we are aware that the lack of suitable adult respite services affects people with many other severe physical disabilities too, so they need to be in contact with as many of the charities as possible.

Together, they should be working with other hospices and care providers to see if some could provide facilities and suitable care for younger adults. For example if somewhere like Leuchie House could be made more affordable, or using an existing building that could be converted into a suitable adult respite facility. The most ideal solution though, and the one we are striving for, would be for them to commit funds towards creating new purpose built facilities for people of this age group with these conditions. There are purpose-built hospices specifically for conditions such as Cancer, e.g. Marie Curie, Accord Hospice. Why cant there be purpose built hospices specifically for Muscular Dystrophy sufferers, Multiple Sclerosis sufferers etc too?

There are many reasons why this action needs to be taken, as I have detailed in the "Why it is needed" section. There is a growing need for suitable facilities for this age group because thankfully, due to medical advances, more and more people with these severe physical disabilities are living far longer lives, through their late twenties, into their thirties and sometimes even beyond, so the desperate need for such facilities is only going to increase as the years go by. We want to concentrate on being able to

make the most of our lives while we are here, and to do that we need a good quality of life, and good respite care helps give us, and our families, just that.

PETITION: *Since we already have an online petition running, which has been running since May and has to date gathered 1131 signatures, we do not wish to have another e-petition set up on the Parliament's website, since we would have to start all over again from zero signatures. To view this petition and to see its current progress, please go to <http://you.38degrees.org.uk/p/adultrespite>*

Unique web address

<http://www.scottish.parliament.uk/GettingInvolved/Petitions/adultrespite>

Related information for petition

Do you wish your petition to be hosted on the Parliament's website to collect signatures online?

NO

How many signatures have you collected so far?

1131

Closing date for collecting signatures online

N/A

Comments to stimulate online discussion