



Give us a break

**Hospice and respite care for
young disabled adults in
Scotland**

Muscular Dystrophy Campaign

June 2014

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Introduction from Jackie Baillie MSP

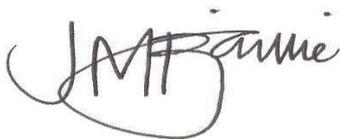
The evidence published in this report outlines the pressing need for the Scottish Government, Local Authorities and Health Boards to come together to find a solution to the alarming lack of hospice and respite care for young disabled adults in Scotland - for young men with Duchenne muscular dystrophy, people with other types of muscular dystrophy and neuromuscular conditions and long-term and rare conditions.

This issue gained wider attention in 2013 when, owing to increasing demand on its services for children, the Children's Hospice Association Scotland (CHAS) had to take the difficult decision to phase out over three years its provision for young adults, which will begin once a transition team is in place. Young people have spoken powerfully about how much they value CHAS' services. However, that the primary point of hospice and respite care for young adults has up until now been in a children's hospice itself draws attention to the absence of age appropriate facilities for this group. The Cross Party Group for Muscular Dystrophy in the Scottish Parliament and the Muscular Dystrophy Campaign are committed to supporting work to secure alternative provision.

However, the problem goes far beyond those young people currently supported by CHAS. As this report documents, young people experience a sharp cut-off point at the stage of transition in many areas of care, not least hospice and respite provision. Young people have told us, and our research confirms, that there are no suitable hospice or respite facilities for them to go to once they turn 18. Adult facilities across Scotland, while they do accept referrals for people aged 18 years and over, are in reality supporting much older people with terminal conditions and are not an appropriate setting for young people.

Through improvements in care and advances in medical knowledge, life-expectancy in Scotland is increasing. However, most coverage in the media focuses on the older population and omits the fact that for conditions such as Duchenne muscular dystrophy, life-expectancy can now extend into the late 20s, 30s or even 40s, provided the required standards of care and support are delivered. With continued improvements in care for Duchenne muscular dystrophy, and indeed other muscle-wasting conditions affecting young adults, the need for suitable facilities for these young men and women is only going to increase with time.

I would like to finish by putting on record our thanks to Robert Watson and the 'What About Us?' campaign. Robert, who is 28 and has Duchenne muscular dystrophy, has initiated and driven the campaign on hospice and respite facilities, notably giving powerful and moving evidence to the Petitions Committee in the Scottish Parliament.



Jackie Baillie, MSP for Dumbarton

Chair, Cross Party Group in the Scottish Parliament on Muscular Dystrophy



Executive summary

The Muscular Dystrophy Campaign began to compile evidence for this report on hospice and respite care for young adults following the announcement by the Children's Hospice Association Scotland (CHAS) of their proposals to phase out its services for young adults.

We took the decision to make this issue a key priority, and meetings have brought together people from across the spectrum - from young people and their families, representatives of CHAS and other hospice providers, to Healthcare Improvement Scotland and representatives of the Scottish Government. The Cross Party Group for Muscular Dystrophy has been a valuable forum for discussion, advice and support.

Besides CHAS' services, our report highlights that there remain no affordable or appropriate hospice and respite facilities for young disabled adults in Scotland. This is in spite of the value that many young people place on these services; one young woman with limb girdle muscular dystrophy, who wasn't able to access respite facilities, told us if she were to do so, she would feel like a 'daughter, sister and girlfriend', rather than a patient in her own home.

The evidence compiled in this report further illustrates this young woman's point and shows that young disabled adults greatly value the breaks that hospice and respite care afford them, as well as the social connections they can make with others in similar situations. However, this needs to be in an age-appropriate setting and not in facilities that predominately cater for much older people with other terminal conditions.

The challenge we now face is to ensure that such facilities are developed in the next three years, before the new upper age-limit comes into force for CHAS' services.

The Cross Party Group and the Muscular Dystrophy Campaign are calling on the organisations listed in this report to act on the following calls to action.

Calls to action

1. The absence of suitable hospice and respite facilities for young disabled adults is a Scotland-wide issue. Indeed, owing to the relatively small numbers of young people affected in each local authority area, we do not believe it would be realistic or feasible to secure provision in each area. An appropriate solution would need to be a national one and must bring together relevant organisations from across Scotland. Negotiations could be complex and protracted and would need to be led by an organisation with the resources to support this. In its response to Robert Watson's petition to the Scottish Parliament, the Scottish Government stated: 'we will explore the issues raised by the petition and the potential solutions with COSLA and other stakeholders'. **We call on the Cabinet Secretary for Health and Wellbeing to identify an individual who can lead a review on hospice and respite facilities for young adults. This individual will also take the lead in instigating discussions and engaging key stakeholders in the search for a solution to this shortage of provision, with a view to bringing forward costed proposals and an implementation plan.**
2. The recommended review of hospice and respite facilities should consider other service models for young adults with muscular dystrophy and related neuromuscular conditions, in addition to hospice services. For example, the Neuromuscular Centre (NMC) in Cheshire provides physiotherapy, hydrotherapy, benefits advice, IT skills and design training, in partnership with the local Further Education College. **Therefore, we call for the review to be thorough and wide-ranging in considering the services needed.**
3. In its response to Robert Watson's petition, the Scottish Partnership for Palliative Care states that 'whilst the financial costs of respite care fall on Local Authorities...the financial benefits tend to accrue to the NHS (in so far as respite care supports the health of the carer and prevents crisis admissions to hospital). It is to be hoped that ongoing moves to health and social care integration will address this issue of resource allocation'. We believe that the Public Bodies (Joint Working) (Scotland) Act may provide greater scope for collaboration. **We call on the 14 Health Boards and Local Authorities to enter round-table discussion on how to establish alternative provision, with a view to a jointly-funded initiative. While we acknowledge the charitable basis on which many hospices operate, we see statutory funding as the best means of providing long-term security for services for young adults.**
4. The needs of young adults must be at the heart of discussions on any new hospice and respite provision. This has added importance, given that clinical needs will often vary and so what suits one young person will not always be appropriate for another. **We call on the Scottish Government to build on the work of the Muscular Dystrophy Campaign and other patient organisations and consult fully with young adults on their needs and preferences for hospice and respite care.**
5. Specialist health professionals such as neuromuscular care advisors are among those closest to the care and support of young disabled adults. **We call on the Scottish Government and other stakeholders to include these professionals fully in any discussions to ensure that their wealth of expertise and knowledge is drawn upon.**

Robert Watson

Robert, who is 28, lives in Renfrewshire and has Duchenne muscular dystrophy. Robert began the 'What About Us?' campaign and initiated the debate on the shortage of suitable hospice and respite facilities in a powerful speech to the Petitions Committee in the Scottish Parliament. The full text of Robert's presentation is provided below:

"I bet that most of you in this room had a holiday this year - a chance to go somewhere different or to a place that you enjoy visiting for a break from the usual routine and the stresses of everyday life. That is what a respite break is like for us. How would you feel if you were told that you could never have a holiday again?"

That is the reality that people such as me, Kyle Kelly and our families who care for us face following the decision by the Children's Hospice Association Scotland to withdraw its services for people who are aged 21 and over, combined with the fact that there are no suitable adult respite facilities for our age group that we can move on to. Respite breaks are the only type of holiday that a lot of us can go on, so to lose the benefits that they bring would be devastating.



For me - I am sure that Kyle Kelly and most other young adults in the same situation would agree - the benefit of a respite break is that it is a chance for me to have a break away from my parents and from the usual routine. I can get up when I want, go to bed when I want and get a shower when I want, without that being set by the time when the care workers are due to come in.

A respite break is also a chance to socialise with other people of my age who have the same or similar conditions, so we can relate to each other. Because we live far from each other, I do not get the chance to see those friends outside respite breaks. A break helps us to get away from the isolation that we can feel from being at home most of the time. For some of us, it is our only chance to socialise. Like any other 28-year-old man, I just want to be out socialising and feeling independent. A respite break gives me the opportunity to do that.

Initially, the issue is affecting about 100 young adults and their families [in Scotland]. However, as the years go by and more young people reach the cut-off age of 21 - and who knows whether that might go down further, to 18, in future years? -the number of people who will need age-appropriate adult respite services will only keep increasing. It would be better to do something about the situation before things become too desperate.

There are no services for people in our age group - there is nothing between CHAS services for children and hospices for older adults who are in their 50s and 60s, who are mainly suffering from cancer and other terminal illnesses. We are asking, "What about us?", as we seem to be a forgotten group that is stuck in the middle. With advances in medical care and support, many people with severe physical disabilities such as Duchenne muscular dystrophy are now living significantly longer, but no one seems to have been prepared for that.

It seems that, as life-expectancy increases, the support that is available to us decreases. The adult respite care situation is another example of that strange paradox. I have

Duchenne muscular dystrophy and, because it is a progressive condition, my health will gradually get worse as I get older.

It must be remembered that my parents, who carry out the vast majority of my care, are also getting older, which means that their health will get worse too.

The average weekday for my dad begins at 6.15am and, by the time my parents have put me to bed, my dad sometimes does not get to bed until midnight. My parents sometimes do not even get a proper night's sleep if I need help during the night. My mum also has Duchenne [muscular dystrophy], albeit a milder form, so sometimes my dad is caring for two people. Both my parents have a number of health problems of their own - my mum also has diabetes, and my dad has a pacemaker - so respite breaks are vital for them to be able to relax and spend some time together as a couple, and recharge their batteries.

It is in the Government's best interest to provide funding for suitable adult respite services because those breaks enable my parents to continue their caring role in the long term. Without those breaks, it would become too difficult for my parents to continue to care for me, and it would cost the Government a lot more money to provide 24/7 care for me.

I hope that I have shown you all just how important it is for so many people that the Scottish Government does something about the lack of adult respite services and facilities. We need quality respite facilities to be created for younger adults who are living with severe physical disabilities in Scotland.

I hope that, with your help, Scotland can lead the way in creating those much-needed services”.

Summary of Evidence

1. CHAS

“ There is no respite/hospice provision in our area or the whole of Scotland suitable for my son apart from CHAS's services”.

Mother of a 28 year old man with Duchenne muscular dystrophy

The provision of hospice and respite care for young adults in Scotland is one that goes beyond the young adults who currently use CHAS' services.

In 2013 CHAS announced a Transition Policy which included an upper age of 21. This upper age will not come into effect until the recruitment of the CHAS Transition Team, and for any young adults currently using the CHAS services who are 21 or over there will be a three year period once the team is recruited where they will be fully supported through their own individual transition to the most appropriate services.

CHAS currently has a Phase 2 application underway to the National Lottery Fund to provide the funding for this Transitions Team. However, if unsuccessful, the Muscular Dystrophy Campaign understands that CHAS may fund the project itself

In discussions with CHAS, service users have identified the following themes as being particularly important at transition stage to enable them to 'live life to the full':

- physiotherapy
- social connections
- guardianship
- short breaks
- housing
- education
- alternative therapies.

We note with interest these comments and believe that these are key areas, particularly social connections and short breaks, and need to be at the heart of any alternative provision that emerges to fill the gap that currently exists in hospice and respite provision for young disabled adults.

In terms of statutory contributions to CHAS, for the financial year 2012/13, Rachel and Robin House received £637,000 from NHS Health Boards and £529,000 from Scottish Local Authorities.

2. Provision made by Health Boards

“ There is a gap in provision for people in between the ages of 21 and 50... we need up to date, modern facilities...continuation of care that occurs in childhood and teenage years.”

26 year old living with rigid spine syndrome

At the start of the year, the Muscular Dystrophy Campaign put in Freedom of Information requests to each Scottish Health Board, asking them to:

Outline any current funding that your Board provides to hospice and respite services in your area, where these services are, what they provide and what age ranges these facilities cater for?

Responses appear to demonstrate that while in theory the adult centres documented by Health Boards do cater for young adults, owing to the conditions and needs catered for, the majority of these service users may be much older. In addition, many of these centres are palliative care day units and do not provide the kind of overnight stays that give young people and their carers a meaningful break.

This illustrates the sharp cut-off point between children's and adults' hospice and respite services and the apparent absence of age-appropriate provision that exists between the age of 18 and older adulthood.

In the current absence of appropriate facilities, young adults have told us that they have been advised to access respite care homes for older people in their local Health Board area. This is clearly unsuitable and further underlines the need for appropriate respite facilities for this age group.

In its report, *A Framework for the Delivery of Palliative for Children & Young People in Scotland*, the Scottish Children and Young People's Palliative Care Executive Group (SCYPPEX) states that:

'Health Boards should develop local pathways for transition of young people with palliative care needs to appropriate adult services.'

This is a welcome recommendation and shows that Health Boards acknowledge the difficulties young people experience at transition stage. However, as our research and the comments of young disabled people demonstrate, there are no appropriate respite facilities for these young people to go to as young adults.

This was further highlighted in *Living and Dying Well: Reflecting on Progress*:

'Arrangements for facilitating transition from child to adult services varied greatly. In many Boards this appeared to be a work in progress. Leadership was sometimes vested in condition-specific MCNs rather than an individual professional. A recurrent comment was the lack of equivalent adult services to transition to.'

We now call on the 14 Health Boards to enter round-table discussions with interested parties and work towards establishing suitable facilities for young adults, as a matter of urgency.

3. Support from Local Authorities

“ A young person's hospice for patients between the ages of 16 and 35 is necessary in Scotland, providing care - physical, emotional and practical -throughout the course of the affected individuals life”.

Mother of a young girl with spinal muscular atrophy

As with Health Boards, local authorities in Scotland provide funding to hospice and respite facilities, either directly in their area or to national facilities such as CHAS.

We realise there is significant pressure on local authority budgets and any potential solution to the lack of respite care for young adults must be mindful of these constraints. We also recognise that owing to the relatively low numbers of potential service users in each Local Authority area, it would be unrealistic and unreasonable to expect each local authority to provide specific facilities in its own area. Nonetheless, a joint approach can be achieved by several local authorities acting together, in conjunction with Health Boards.

However, the response of the Convention of Scottish Local Authorities (COSLA) to Robert Watson's petition caused disappointment, and this response was subsequently adopted by other individual local authorities in Scotland. While the move to Self Directed Support and Direct Payments may offer young people a greater degree of flexibility, we do not believe this automatically negates the need for fixed premises offering respite and hospice care, which COSLA appears to suggest in its response. Indeed, a vital element of the current model at CHAS is a social one, providing an opportunity for young people to meet people of a similar age, facing similar challenges. This could theoretically occur on a holiday, but this would still not offer the continuity of regular social contact that many young people are asking for. Furthermore, the suggestion that support is offered 'in people's own homes' neither grasps the social need, nor the desire to access facilities outside of a home setting.

We now call on COSLA to engage with key stakeholders to work towards a solution before CHAS' new upper age-limit comes into force.

4. Snapshot of young people's and families' experiences

When CHAS announced its decision to phase out provision for service users over the age of 21, the Muscular Dystrophy Campaign conducted a survey and also began consulting young people to get a snapshot of their experiences of respite and hospice care in Scotland. We wanted to ascertain the value this age group places on such facilities and examine their hopes and fears for the future.

Of the young adults and families who completed our survey;

- **64 percent very strongly agreed and 21 percent strongly agreed that respite/hospice facilities were 'vital for my family's quality of life'**
- **92 percent reported limits to respite/hospice facilities in their local area**
- **64 percent very strongly agreed and 29 percent strongly agreed if the respite/hospice facilities in their local area were withdrawn the impact 'would be terrible'.**

To gather anecdotal evidence, we asked young people:

'What do you gain from your experience with respite/hospice facilities?'

Responses pointed to social and emotional benefits for service users, and comments from young people included:

'It gives me a chance to get a break from my parents and lets them get some time to themselves. It gives me a break from my routine and a chance to socialise and catch up with friends, some of whom I don't see outside of respite breaks.'

'It helps to give the young adult and their peers a chance to meet up and have time to talk to each other.'

'I get to be around other people with my disability and have some fun.'

'A time to Relax. recharge batteries.'

However, hospice and respite care benefit not only the young people who receive it, but also the families of these young people, many of whom act as primary carers:

'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.'

'Time for parents and carers to recharge.'

'A break from being a full-time carer and working full-time also.'

'Gives us a chance to recharge so as we can continue caring for our son.'

The Muscular Dystrophy Campaign wishes to use this report and subsequent consultation and debate to ascertain the model of respite provision that would be most suitable for young people. To this end, we tried to find out the kind of facilities that young people and families valued. We asked:

‘In your view, what are the most important aspects of respite/hospice provision that need to be developed?’

Young people and families told us:

‘The provision of respite for physically disabled people once they become too old for children's services but while they are still far too young to be forced to go somewhere which is full of far older people is without a doubt the most important aspect. We need age-appropriate respite services which don't just focus on end of life care.’

‘[The opportunity for] Group gathering with other young adults with Duchenne muscular dystrophy.’

‘Open to all neuromuscular conditions for adults as I find it seems to be more for cancer patients in this area.’

‘Up-to-date, modern facilities. Less like an old folk's home, more relaxing. Continuation of care that occurs in childhood and teenage years.’

With an acknowledged shortage of appropriate facilities, we were also interested to find out about people's experiences of trying to access age-appropriate respite facilities in Scotland, so we asked;

‘Are there limits to respite/hospice provision in your area?’

Responses all reflected the lack of appealing facilities for young adults, as well as the difficulties faced in accessing those that are available:

‘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.’

‘We have tried to access respite through our social worker and been contacted by a nurse specialist attached to the child and family services team within our local authority, however, respite was not offered. There is no opportunity for overnight respite within the home either.’

‘There is a gap in provision for people between the ages of 21 and 50. Services are not appropriate and undermine the entire point of respite.’

‘There is no respite/hospice provision in our area or the whole of Scotland suitable for my son apart from CHAS's services’

Suitable hospice and respite care for young adults and their families is crucial and the Muscular Dystrophy Campaign's consultation serves to underline this point further. We now look forward to using the findings of the survey and the recommendations in this report to find age-appropriate new facilities for young adults in Scotland.

About the Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign is the leading UK charity fighting muscular dystrophy and related neuromuscular conditions. The charity is dedicated to beating these conditions by finding treatments and cures and by improving the lives of everyone affected by them. Founded in 1959, the Muscular Dystrophy Campaign takes the lead in investing in world-class research to effective treatments and ultimately cures. People also rely on the charity to provide to expert information, advocacy and community support, and to signpost them to effective specialist services.

The charity also works closely with parliamentarians and clinicians in Scotland and across the UK to ensure all people living with neuromuscular conditions have equal access to high-quality health and social care services.

What is muscular dystrophy?

There are approximately 60 forms of muscular dystrophy and related neuromuscular conditions. The conditions cause the muscles to weaken and waste over time, leading to increasing disability. The conditions may affect not only the muscles in the limbs, but also those of the heart and lungs, sometimes significantly shortening life-expectancy. Approximately 6,000 people in Scotland are affected by muscular dystrophy or a related neuromuscular condition.

Many of the conditions are low incidence, rare conditions, with some regarded as very rare or ultra-orphan. Muscular dystrophy and related neuromuscular conditions can be genetic or acquired and, with few exceptions, there are currently no known effective treatments and currently no cures available.

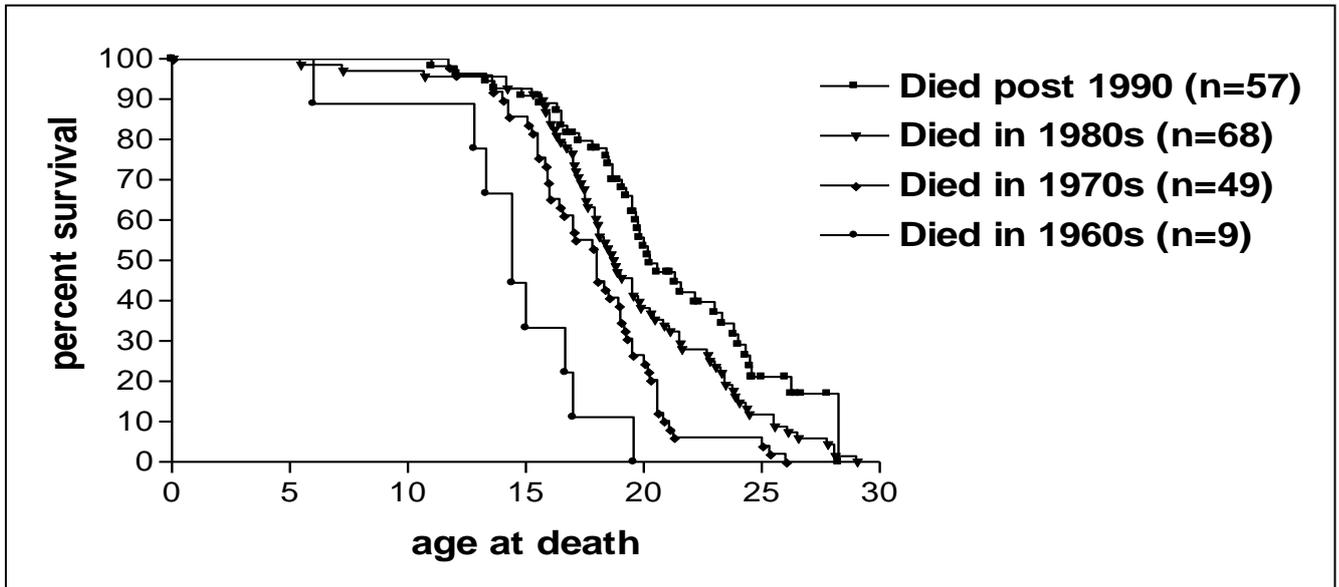
Clinical trials in some forms of muscular dystrophy are now underway. It is hoped that these may lead to the introduction of new treatments that can slow or arrest the progressive nature of these often devastating conditions and ultimately find cures.

Appendix 1

Duchenne muscular dystrophy survival

Duchenne Muscular Dystrophy Survival data 1960-1990

(Eagle et al Survival in Duchenne muscular dystrophy: improvements in life expectancy since 1967 and the impact of home nocturnal ventilation)



The authors reviewed the notes of 197 patients with Duchenne muscular dystrophy whose treatment was managed at the Newcastle muscle centre from 1967 to 2002, to determine whether survival has improved over the decades and whether the impact of nocturnal ventilation altered the pattern of survival.

Results:

1960s: Mean life expectancy: 14.4 years - No survivors beyond 19.29 years

1990s: Mean life expectancy: 19.5 years

Improvement is due to multi-disciplinary care, including access to respiratory support.

Acknowledgments

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Robert Watson, *'What About Us?'*

Duchenne Family Support Group

Muscular Dystrophy Campaign's Scottish Council

Action Duchenne

Children's Hospice Association Scotland

Health Board responses to Freedom of Information Requests

Scottish Muscle Network

Scottish Partnership for Palliative Care

References

Muscular Dystrophy Campaign, *Muscle disease: the impact. Incidence and Prevalence of Neuromuscular Conditions in the UK*, January 2010

A Partnership for Better Palliative and End of Life Care: Creating a New Relationship Between Independent Adult Hospices and NHS Boards in Scotland, July 2010

Cabinet Secretary for Health and Wellbeing response to Petition PE1499 on creating suitable respite services for younger disabled adults with life-limiting conditions, January 2014

Children's Hospice Association Scotland, *Annual Report and Accounts, 2012-13*

Convention of Scottish Local Authorities' response to Petition PE1499 on creating suitable respite services for younger disabled adults with life-limiting conditions, January 2014

Eagle et al *Survival in Duchenne muscular dystrophy: improvements in life expectancy since 1967 and the impact of home nocturnal ventilation* *Neuromuscular Disorders*, Volume 12, Issue 10, p. 926.

Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland, 2008

Scottish Partnership for Palliative Care response to Petition PE1499 on creating suitable respite services for younger disabled adults with life-limiting conditions, January 2014

Together for Short Lives & University of Leeds, *Life limiting and life threatening conditions in children and young people in the UK; national and regional prevalence in relation to socioeconomic status and ethnicity*, October 2011

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