

A BREAK FROM THE PAST

Manifesto for the 2016 Scottish Parliamentary Election

There are already around two million people in Scotland who live with one or more long term condition and this number continues to grow.

There are nearly 790,000 unpaid adult and young carers in Scotland. By 2037 it is estimated this figure will be one million¹.

Short respite breaks are now widely regarded as essential to maintaining the health and wellbeing of people living with long term degenerative conditions and their carers. Yet over the last two years, **Scottish Government figures show the number of respite weeks delivered in 2013/2014 fell by 2,390 weeks compared with 2012/13, and fell by an additional 2,040-6,630 weeks in 2014/15** (lower and higher estimates)². There are also marked differences across the country in the availability of short breaks.

The integration of Scotland's health and social care services, the Carers' Bill, and the new Scottish welfare agency should help create the landscape for a better future for disabled people and their carers. We need to seize this opportunity to ensure this new landscape is fully in tune with the needs of the people it is there to support. And that the strategic direction and resources are in place to deliver a real break from the past.

We believe that everyone with a long term degenerative condition should have access to regular short respite breaks and that their carers should have regular breaks from caring.



Guests and staff outside Leuchie House national respite centre



A break for people with long term conditions

1. Short respite breaks make a significant difference to people living with long term conditions. They increase independence, boost confidence and self-esteem, have a tangible positive impact on wellbeing and ability to cope, and help to reduce isolation. Yet access is severely limited and often has to be fought for, causing unnecessary stress and anxiety.
 - **We call for people with long term conditions to have automatic access to short respite breaks and a choice of where to take them.**
 - **We support the national carers' organisations in their call for the introduction of a short breaks duty to establish short breaks as a vital statutory service¹.**
2. Preventative and anticipatory services such as physiotherapy and wheelchair assessments can do a great deal to help minimise some of the symptoms of long term conditions, to improve quality of life, and to reduce the need for, and cost of, reactive medical care. For example, we regularly see guests arrive at Leuchie House with painful sores and skin conditions which could easily have been prevented by adjustments to their wheelchair, or by advice on a change of sleeping position. However, there is very little support of this kind available to them in the community.
 - **We call for improved access across Scotland to more preventative and anticipatory services for people living with long term conditions.**
 - **We call for training for unpaid carers to help them play a part in providing preventative and anticipatory care.**
3. For people living with long term conditions, isolation is a significant issue. As their conditions progress and degeneration increases, isolation tends to increase too. There is an urgent and widespread need for more opportunities for support, socialisation and therapy to alleviate this. There are some excellent models of one-stop-shop support services in Scotland, such as Revive MS in Glasgow. This gives people with MS access to



Donald and Catriona's story

"My husband Donald suffered a severe stroke four years ago. Since then our daily routines have changed beyond all recognition and I have now become a full time carer. I do not for one minute begrudge looking after Donald, but I now know first-hand how stressful the physical and emotional demands of this role can be - and incredibly lonely. For people like myself, all we want is to get on with our lives as best as we can. To do that without getting to the stage where we are too worn out to continue caring, it is vital that we get a break safe in the knowledge that our partner is being well cared for. If it were not for Leuchie I'd be at my wits' end."



Donald and Catriona

counselling, complementary therapies, speech and language therapy, dietary advice and classes, as well as offering support for carers and allied health professionals. However, these services are rare and focused mainly on people with multiple sclerosis.

- **We call for support and therapy services to be available across Scotland to people living with all types of long term conditions, in order to improve their quality of life, offer ongoing advice and support, give access to therapies, and provide greater opportunities for socialisation.**
5. Getting access to adapted transport is a major problem for many people living with long term conditions. Without an adapted vehicle of their own and the ability for them or their carer to drive it, many people can become virtually house-bound. This causes practical issues such as difficulty attending medical appointments, and mental health issues including depression. If they live on their own, this can be particularly acute.
 - **We call for greater availability of affordable and accessible demand responsive transport for disabled people throughout Scotland.**
 6. The integration of Scotland's health and social care services is a welcome step towards a major transformation of health and social care delivery that will be focused directly on the needs of service users. However, as a recent Audit Scotland report³ has identified, both the rate of change and the lack of strategic leadership are real concerns, with the risk of preventing the new integrated service achieving its potential.
 - **We call for greater transparency on how the new integration authorities will achieve the scale and pace of change needed, and the strategic change management plans that will allow each authority to deliver integrated services.**

"Significant risks must be addressed if a major reform of health and social care is to fundamentally change how services are delivered, and improve outcomes for the people who use them."

Health & Social Care Integration:
Auditor General, Accounts Commission, Dec 2015



A break for unpaid carers

1. For the first time in Scotland's history, the Carers Bill enshrines in law essential new rights and entitlements for unpaid carers. Yet the new law will introduce local rather than national eligibility criteria for support, with each of Scotland's 32 local authorities tasked to produce a separate carers' strategy. Without a unified national approach, we are in danger of ending up with 32 different systems and huge variations across the country in the level and availability of support. Concerns are already apparent too about the availability of sufficient resources to enable the Bill to be fully implemented.
 - **We call for a simple, unified system for determining the criteria for support, with adequate resources to allow the Carers Bill to be fully implemented, backed by a clear procurement process.**
2. A welcome development of the Carers Bill and the associated debate is that it has highlighted the vital role short respite breaks play in alleviating the difficulties carers face and in improving their health and wellbeing. Under the new law, local authorities will have a duty to produce information for carers about short break services available to them. Yet the availability of respite provision for carers is in decline².
 - **We call for carers to have automatic access to short respite breaks for the people they care for and a choice of where to take them.**
 - **We support the national carer organisations in their call for local authorities to be properly resourced and accountable for delivering their Carers' Bill commitments including breaks from caring and free replacement care for eligible carers¹.**



Delmar & Rosemary's story

Carer Delmar and his wife Rosemary stayed at Leuchie House for the first time in February 2016. Having been seriously ill, Rosemary, who has MS, was low and withdrawn when they arrived. "Seeing the change in her over our 11 nights at Leuchie has been tremendous for me," Delmar told us at the end of their stay. Over the course of their break, we saw Rosemary brighten, engage and become full of smiles again. Able to have some time to himself while we cared for his wife, Delmar told us: "I can't remember when I last felt as relaxed and at ease with the world as I do at the moment."



Delmar and Rosemary

3. Unpaid carers can face considerable financial difficulties. Reduction in, or loss of, income, additional medical costs, the cost of specialist equipment and so on, can all be a real financial drain and lead to significant financial hardship.
 - **As a first step to improving the financial position of carers, we call for the Carers' Allowance to be raised to the same level as Jobseekers' Allowance on the establishment of the new Scottish welfare agency.**
4. Unpaid carers are usually family members who have taken on a caring role by default. They have little or no preparation for the role, or access to training on practical and preventative care. Most carers have to combine their caring responsibilities with their everyday commitments – family, work and so on. This can all have a considerable impact on their own health and wellbeing and lead to stress and anxiety.
 - **We call for carers to have access to regular health-checks, ongoing training and advice, and regular breaks from caring as part of their entitlement to support under the Carers Bill.**
5. At present in Scotland there is no one at the heart of government able to champion the rights of people with long term conditions, disabled people and unpaid carers. As a result their voices often go unheard and their needs are marginalised.
 - **We support The ALLIANCE in calling for a framework to champion the rights of people who live with long term conditions, disabled people and unpaid carers through the creation of the posts of a Scottish Minister and Commissioner for Long Term Conditions, Disability and Unpaid Carers, and the publication of a Carers Rights Charter⁴.**



About Leuchie House

Leuchie House national respite centre provides unique short breaks that enhance the lives of people affected by long term neurological, degenerative conditions, including multiple sclerosis, motor neurone disease, Huntington's disease, cerebral palsy and Parkinson's.

It is the only respite centre of its kind in Scotland, and one of only a few in the UK, providing over 6,100 respite days annually. On a daily basis we see the benefits of short respite breaks through the lived experiences of people whose lives are enhanced by respite care:

- For many carers the demands of a 24/7 caring role can leave them at breaking point. A short respite break is an opportunity for them to have time away from their caring responsibilities in the knowledge that the person they usually look after is receiving round-the-clock care.
- A short respite break enables a holiday experience to be combined with clinical and social interventions. This has a recognised therapeutic impact beyond the duration of the short break.
- During their stay at Leuchie, we are able to assess guests' and carers' physical, emotional and mental wellbeing needs. We can then make anticipatory and preventative referrals to their health practitioners when required, therefore avoiding the need for more formal or acute services. Last year, we made just under 700 anticipatory and preventative referrals.

“To find out that there was somewhere like Leuchie that could provide respite for myself and my wife was like having a weight lifted off our shoulders. For the first time we could have a break together with my medical care being provided and Barbara's needs being looked after too.”

John
full-time, unpaid carer

1. *Manifesto for Unpaid Carers in Scotland*: The National Carer Organisations, 2016
2. *Analysis of the Scottish Government's Respite Care Data 2015*: Shared Care Scotland, 2016
3. *Health and Social Care Integration*: Auditor General, Accounts Commission, December 2015
4. *2 Million Expert Voices - A Manifesto for Health and Social Care in Scotland*: The Alliance, February 2016

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