Health and Sport Committee
Preventative Agenda: Neurological Conditions
Submission from Leuchie House

Introduction

We welcome the opportunity to respond to the Scottish Parliament’s Health and Sport Committee’s evidence session on neurological conditions as part of the ongoing inquiry into the Preventative Agenda. We believe this is an important piece of work as the Scottish Government continues its development of a national strategy for the care of people with neurological conditions.

About Leuchie House

Leuchie House is Scotland’s only dedicated respite centre and specialises in offering caring respite breaks for people with long term neurological and physical conditions. Included in every Leuchie break is person-centred 24 hour care, specialist physiotherapy sessions along with a number of other important services such as wheelchair assessments and pressure mapping delivered by our unique ‘Leuchie MOT’.

In 2017 Leuchie welcomed guests from 26 local authority areas across Scotland which equated to 6,354 respite days. During 2017 we also carried out 821 anticipatory and preventative interventions, allowing us to address potential problems before they became an issue, providing immediate support while guests were at Leuchie, and making referrals to community health professionals for ongoing care. These guests had a wide range of long term conditions including multiple sclerosis, Parkinson’s, cerebral palsy, motor neurone disease, spinal injuries and the effects of stroke.

We work for and support people at all stages of more than 35 different conditions and our expert nursing and care team is experienced at supporting a wide variety of care needs, from low to very high dependency, predominantly the latter.

In summary we believe:

1. There remains inadequate provision of ongoing rehabilitation and support in Scotland for those dealing with the aftermath of acute events such as brain or spinal injuries, or for those who have received a diagnosis of a degenerative neurological condition. Addressing and improving service delivery in these areas will go a long way to avoiding preventable health complications.
2. Respite centres such as Leuchie House can play an important role in supporting both the physical and mental health of those suffering neurological conditions and their carers. To this end we believe respite care should be funded appropriately.
3. There is insufficient regard paid to the health of the unpaid carers looking after people with neurological conditions and to how a preventative approach could be developed to support this group.
4. Integration authorities remain in their infancy and during this transition period there are many people with neurological conditions who are being let down and falling through cracks in the system.

5. There needs to be a greater focus placed on building relationships between integration authorities and third sector organisations, together with a move away from an unintentional bias to prioritising resources to acute and primary care services. Improved relationships would create more opportunities for third sector bodies such as Leuchie House to share best practice and learning with integration authorities, particularly on preventative programmes.

6. Without robust statistics it is difficult to properly plan for the delivery of services for people with neurological conditions. We eagerly await the results of the Scottish Government’s National Advisory Committee on Neurological Conditions (NACNC) examination of the current provision of neurological care and support available from the NHS, integration authorities and local authorities.

1. To what extent do you believe the Scottish Government’s approach and the approach by integration authorities and NHS Boards towards neurological conditions are preventative?

The Scottish Parliament and Scottish Government have for many years taken action to tackle Scotland’s damaging relationship with tobacco and alcohol which we believe will be vital in terms of advancing the prevention agenda. The government is also in the process of addressing issues around obesity and healthy weight, work which we very much welcome as crucial in addressing Scotland’s significant public health challenge.

However, there are some important distinctions with regard to discussing prevention in a neurological conditions context given the fact that many neurological conditions and head or spinal trauma cannot be prevented. Therefore, we believe there is a balance to be struck between discussing prevention of the conditions themselves with prevention of further conditions/complications as a result of inadequate treatment and support around the primary condition.

Nevertheless, in the short to medium term, it has been the experience of Leuchie House that there remains inadequate provision of ongoing rehabilitation and support in Scotland, for those dealing with the aftermath of acute events such as brain or spinal injuries, or for those who have received a diagnosis of a degenerative neurological condition.

This lack of ongoing rehabilitation and insufficient provision of important services such as physiotherapy, wheelchair assessments, nutritional advice, pressure mapping and emotional support means that many people across Scotland are missing out on support. This puts them at greater risk of developing further illness which may put an unnecessary burden on primary and acute care.

We are also concerned that there appears to be very little provision of community based rehabilitation across Scotland and that many people are not provided with important services which could greatly enhance their quality of life.
At Leuchie we regularly support our guests with the ‘Leuchie MOT’ which was recently awarded a special commendation in the 2018 Knowledge Exchange Awards. This is a personalised care service which looks at all aspects of a guest’s life, ranging from diet, through to wheelchair suitability (where appropriate) and an analysis of their current medication. These are all services which we believe should be delivered as standard in the community but for a wide variety of reasons are often not – meaning that a number of preventable further health issues such as postural deteriorations and the development of pressure ulcers could be prevented.

Therefore, we believe it may be prudent for a more appropriate funding mechanism to be developed, either centrally or locally, to adequately resource centres offering respite care to those with neurological conditions or who have suffered head or spinal trauma.

This would allow at minimum, on an annual basis, those with neurological conditions the opportunity to discuss and remedy any healthcare related issues they may have and so greatly reduce the need for readmission to acute care or contact with primary care. Delivering care in a respite setting may also provide opportunity for key health tests such as smears or bowel cancer screening, which in our experience are often overlooked for those suffering from a neurological condition, and thus reduce the burden on primary care.

At Leuchie we have already begun to look at how we can deliver our ‘Leuchie MOT’ service in the community. We would welcome the opportunity to tell the committee more about how third sector organisations can help deliver important health and social care services in the community supporting the work of integration authorities and the prevention agenda.

A greater focus on prevention would also have a positive impact upon the army of unpaid carers in Scotland, who currently have to deal with the stress and worry of additional, sometimes unnecessary hospital admissions, GP visits and additional caring responsibilities. Our experience is that these can impact upon work and social commitments and can in turn negatively contribute to the loneliness and social isolation of carers – an issue which is currently occupying the focus of the Scottish Government. Without the commitment of those carers, quite simply the health system could not function. This is why we believe there needs to be a fundamental rethink as to how Scotland’s respite system is funded to ensure that carers feel appropriately supported and able to enjoy a life apart from their caring responsibilities.

Indeed, many carers who support loved ones with conditions such as Parkinson’s can conceivably undertake their caring responsibilities for many years under challenging circumstances which may include disturbed sleep, dealing with continence issues and witnessing profound mental health issues in their loved ones which can be extremely distressing. We would welcome the committee looking at how a preventative approach can better support carers, especially those seeking to re-join or continue in the workforce once their caring responsibilities have ended.

2. Is the approach adequate or is more action needed?
Whilst the integration of health and social care remains in its infancy, urgent action is required to ensure that people with neurological conditions who require support now are not let down before authorities are up to speed.

We believe that a greater focus must be placed upon preventative activities which are often delivered by a range of agencies, or the third sector. This includes ending the bias that remains within integration authorities to prioritise resources to acute and primary care services to the detriment of the social care sector. This is exacerbated and driven by the fact that key national targets and performance indicators focus on hospitals as opposed to other care settings, as well as the fact that many integration authorities are under-resourced which limits their ability to focus on a preventative agenda. It is our view that greater value needs to be placed on the role that the social care sector can have on delivering a preventative agenda and that value should be reflected in more appropriate funding. A huge part of this work will be changing cultures and increasing knowledge about the level of expertise and experience that third sector organisations can bring to the table.

As well as changing cultures, action is also required to change structures and one important step forward would be to look at how the delivery of neurological services could be included within the remit of integration authorities.

We also believe there is much work to be done to improve the relationship between integration authorities and the third sector, paying particular regard to the huge resource implications for third sector bodies in their attempts to engage and build enduring relationships with 31 individual and distinct integration authorities and the myriad number of individuals involved.

3. Are the services for neurological conditions being measured and evaluated in terms of cost and benefit?

It is our belief that it is difficult to measure and evaluate the impact of services for those with neurological conditions until we have a system of gathering reliable data on those with these conditions, where they live and what resources exist in those areas. We eagerly await the results of the Scottish Government’s National Advisory Committee on Neurological Conditions (NACNC) work in this area.

We also consider that greater resources need to be deployed to facilities such as Leuchie House, which in many circumstances provide the only specialist care and support that those with neurological conditions may be getting. Organisations such as Leuchie which operate in the third sector develop a number of preventative programmes which are anecdotally evidenced by guests to be successful but often find it difficult to have these programmes adequately resourced, especially at a time when budgets are strained. We would therefore welcome any proposals which look to strengthen opportunities where third sector organisations can share expertise and best practice with integration authorities.

We are also concerned that the work undertaken by the Sue Ryder charity in their Rewrite the Future report highlighted that a number of health boards (9 out of 14) had no three-year neurological service plan in place as part of the National Clinical
Standards. Therefore, without proper planning of services for neurological conditions, it is difficult to measure and evaluate in terms of cost and benefit.

We believe it is only possible to undertake a cost/benefit analysis when the Scottish Government has completed its work on a refreshed set of clinical standards and when the outcome of the work being undertaken by NACNC is known.

We look forward to seeing the results of the committee’s inquiry and will be more than happy to provide any further assistance to the committee to aid this important work.

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