Carers (Scotland) Bill

Leuchie House Short Break Care (Leuchie)

Leuchie is an independent charity set up in 2011 to provide short break respite care for people with long-term conditions. It is in a non-clinical environment, with a country house ambiance, but provides 24-hour expert nursing care for high dependency degenerative conditions such as MS, Huntingtons, Parkinson’s, stroke, MND and other long-term conditions. The service is palliative but not end of life. Leuchie guests come from 28 local authorities within Scotland, plus north of England, London and occasionally abroad.

Carers and family members can also stay at Leuchie for the whole or some of the respite period. We aim to be as flexible as possible and to make respite as challenge-free as possible for guests and their carers. Whilst staying at Leuchie, carers do not provide any care - Leuchie staff do everything, carers have a complete rest whilst enjoying the holiday experience with their loved one. Leuchie also offers a full physical and emotional assessment of guests and their carers, can provide training and support, counselling or refer back into the community teams.

The Leuchie response is structured around the experience gained over the last 12 years dealing with guests and their carers both as in independent charity dealing with various conditions and in past years when dealing with solely MS and their carers. It is also structured around questions posed by the Committee.

DO YOU SUPPORT THE BILL?

Leuchie supports many of its provisions and its ultimate aim to help the difficult journey as a carer especially the following points:

- Introduces a duty to support carers throughout the journey from the very beginning
- Replaces the current carers assessment with a new adult carer support plan and young carer statement for all young carers
- Is making local authorities accountable and responsible, especially in whether to have access to short break care
- Requires LAs to have a local carer strategy and to involve carers in determining that strategy for their local area

WHAT DO YOU FEEL WOULD BE THE BENEFITS OF THE PROVISIONS SET OUT IN THE BILL?

The main benefit we feel is the recognition of the gradual journey into full-time caring, accepting that many do not feel it is caring, "just looking after their loved one" and therefore not accessing support at an early stage. The replacement of the assessment with the ACSP makes the identification and self-realisation of their position easier, leading to preventative intervention before crisis. The ACSP will have documentation that will trigger reviews and
points when, especially in rapid degeneration, it becomes more rapid. Not just on time but condition determined.

The ability to have discussions with all parties around future planning and anticipatory care plans is most welcome - tackling the elephant in the room and taking recognition that both parties may have different points of view.

**HOW DO YOU FEEL THE BILL COULD BE AMENDED OR STRENGTHENED?**

As Leuchie deals with 28 local authorities and is very aware of the postcode lottery effect that brings and the inconsistency within each area, this is a major cause for concern. A carer in Scotland, no matter where they live, should have the assurance and confidence that the system is the same consistently throughout Scotland. We feel the Bill will not be successful if left as this, especially as budgetary constrictions increase with LAs. It will lead to different criteria and interpretation in each area, with varying revisions in each area.

There is already a recognition that Ministers could set out national criteria if local does not work. Why have two stages when we could just have a clear one from the beginning instead of missing momentum, causing confusion and uncertainty for carers which is the exact opposite that the Bill intends to do.

**IS THERE ANYTHING YOU WOULD ADD TO THE BILL?**

At the initial consultation with Shared Care Scotland we were very clear that the GP and Primary Care Team should be intrinsic in the assessment. They will know both the carers and cared for well, will see the situation arising and increasing for both parties and should be heavily involved.

It does indicate that an identification process has to happen for their strategy but the Community Health Teams will be those most qualified to make assessment and a realistic guess on the trajectory and prognosis for the future. They will know local support networks, family and friend support, family history but importantly they will know the people concerned which can only help in being person centred and outcome focussed.

A major issue is what happens when the caring stops. Carers give up their own life to care for their loved ones, save the country resources and then when their loved one dies they are left with no support and recognition. It is heartbreaking to see how there is nothing to help them adjust back into another life. They lose carer benefits, lose mobility allowance and have to find a job, after perhaps years of being out if the work place and no pension. A very poor thank you from Scotland.

**IS THERE ANYTHING YOU WOULD REMOVE FROM THE BILL ?**

No

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