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Assistant Clerk to the Public Petitions Committee

PUBLIC PETITIONS COMMITTEE

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Dear Andrew

Scottish Partnership for Palliative Care (SPPC) Comment on **PETITION PE1499 ON CREATING SUITABLE RESPITE SERVICES FOR YOUNGER DISABLED ADULTS WITH LIFE-LIMITING CONDITIONS**

Thank you for giving SPPC the opportunity to comment on this petition and the discussion of the Public Petition Committee which took place on 26th November.

About the SPPC

The Scottish Partnership for Palliative Care (SPPC) is the umbrella body representing the major organisations involved in palliative care in Scotland. Our membership includes all 14 territorial health boards, all 14 of Scotland's voluntary hospices, 17 major national health charities, 7 professional associations and 1 local support organisation. The membership of the Partnership is detailed at www.palliativecarescotland.org.uk. Through a collaborative approach, the Partnership supports and contributes at national level to the development and strategic direction of palliative care in Scotland and the promotion of service improvement at local level. The Partnership's aims are to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis.

Due to the timescales for response this letter has not been through the SPPC's formal membership consultation process and so does not represent an agreed consensus of our membership.

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Comment on the Issues Raised in the Petition

As the petitioner stated in his presentation to the Committee in November, in some senses the problem of creating suitable respite services for younger disabled adults with life-limiting conditions is one which arises from welcome advances in medical sciences which has resulted in more children with life-limiting conditions living into adulthood.

Inadequate access to respite care is just one dimension of the many difficulties experienced by young people with life-limiting conditions as they move (transition) from children's to adult services. The recently published STEPP research project generated valuable learning and insights on these issues¹. Children's hospice services, including those provided by CHAS, offer the provision of holistic symptom management, emergency admissions, home care and short planned breaks. The purpose of a stay may also be the provision of a break for the child or young person and their parents, as well as end of life care and subsequently bereavement support for all of the family of the child or young person. Scotland's adult hospices are based on a very different model (in which the primary purpose of a stay will generally be to assess and deal with complex symptoms requiring a specialist intervention. Once these are resolved patients are generally discharged back into the community). Children's and adult hospices share many similarities and are based on a common philosophy however they are not equivalent institutions.

The need for age appropriate respite care also extends to adults who experience the onset and progression of disease at a young adult age, for example the many individuals with multiple sclerosis. The gap in services to which the petition refers pre-dates and is broader than the announced introduction of a Transition Policy in CHAS, one element of which is an upper age limit. The issue is not a new issue.

The issue of transition was highlighted as an unmet need in the Scottish Government's *Living and Dying Well* action plan in 2008. *Living and Dying Well: Reflecting on Progress* (SG March 2012) reported, regarding transition services, that "In many Boards this appeared to (be) a work in progress... A recurrent comment was the lack of equivalent adult services to transition to." The Scottish Transitions Forum has developed principles for transition which provide a valuable framework.

Although the petition emphasises the absence of suitable facilities, there are also barriers to accessing those facilities which do exist due to local authority funding policies, particularly since respite care for young people with high levels of need is relatively expensive (compared for example to typical costs for older people). The committee's discussion referenced Leuchie House, a voluntary sector provider of respite care for people with a range of long term conditions some of whom have high levels of need. Charging policies of local authorities may be a barrier to some young people accessing this service, despite the fact that the fees at Leuchie House are significantly subsidised by charitable fundraising and other grants.

A number of factors relating to Scotland's health and social care system combine to make this a complex problem to address (beyond the significant challenges of resources). Identifying these factors may help to provide pointers to solutions:-

1. The relatively small numbers of people affected in each local authority area may make dedicated local facilities difficult to finance and sustain. Any national solution is likely to require complex partnership across multiple NHS Boards and Local Authorities and there will be a need for a "lead broker", with the resources to carry out complex and potentially protracted work.
2. As has frequently been articulated, whilst the financial costs of respite care fall on Local Authorities (and also on individual members of the public and voluntary organisations), 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.
3. The range and complexity of needs of young adults living with severe disability and/or life-limiting disease makes a "one size fits all" solution inappropriate, and there is a need to develop a range of person centred options. Assessing the demand for services is therefore complex. There may be differences in preference as well as need (for example between getting respite at a dedicated centre vs. being supported to access a mainstream holiday facility, though this latter may not be feasible where support needs are high).
4. Whilst (at least until Self Directed Support becomes more widespread) responsibility for commissioning respite service lies with local authorities, some of these young adults may need quite high levels of clinical care as part of their respite.
5. There may be voluntary sector organisations who could be potential providers of new services, however the conditions for financial viability and sustainability need to be created for them to enter the market. A similar point could be made in terms of the independent sector.

These essentially practical complexities need to be overcome if the needs of growing numbers of young adults with life-limiting conditions are to be met.

With best wishes

Mark Hazelwood
Chief Executive
Scottish Partnership for Palliative Care

¹ http://www.togetherforshortlives.org.uk/professionals/projects/project_two