

## **SPPC Response to Consultation on Proposals for Carers Legislation**

### ***About the Scottish Partnership for Palliative Care***

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](http://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.

### ***The Carer's Assessment: carers support plan***

**Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?**

**Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?**

**Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children's services?**

**Question 4: Should we introduce two routes through to the Carer's Support Plan – at the carer's request and by the local authority making an offer?**

Yes to questions 1, 2, 3 and 4. It is important to reduce the present barriers to the identification of carers.

In respect of routes (q4) there would be a need for a reliable mechanism for the local authority to be made aware of the carer to whom they could then make an offer.

**Question 6: Should we introduce a duty for local authorities to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time, to be advised of the reasons?**

Yes – if someone is approaching the end of their life, the pressures on their carer can increase significantly very quickly, and therefore a timely Carer's Support Plan is important. A duty on LA's as outlined above may play a role in speeding up the process.

***Information and Advice***

The consultation states that "we will set out in statutory guidance the level and type of information and advice that is to be available' through LA services for providing information and advice on support for carers. Planning ahead for a person's decline and death is something that many carers should be directed to information and advice about, including anticipatory care planning, Power of Attorney, Advance Directives and DNACPR. (Information about all of this is available on the palliative care zone of the NHS Inform website:

<http://www.nhsinform.co.uk/palliativecare>).

***Support to carers (other than information and advice)***

**Question 11: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?**

Yes, this would provide greater consistency and greater clarity for carers about their entitlements.

**Question 13: Should we introduce a duty to provide short breaks?**

Yes.

***Stages and transitions***

**Question 14: Should we issue statutory guidance on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on *managing stages of caring*? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child's Plan through the stages of caring).**

Yes. Taking on the care of another person is often a gradual process, and initially carers may not immediately identify with being 'a carer'. However, as a person's health declines the caring role often becomes all-encompassing, yet carers may not feel that their own needs are legitimate. Guidance on 'managing stages of caring' is likely to reduce the ambiguity about the legitimacy of carer needs and about the role of the health care team in supporting carers, and therefore should be introduced.

## ***Carer Involvement***

**Question 16:** Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas out with the scope of integration?

Yes. We agree that carers have a unique and important role in the life of the person they care for, and that their views on the planning, shaping and delivery of services should always be recognised. Advance and anticipatory care planning towards the end of a person's life (or at any stage in their life) is best undertaken with the full involvement of carers.

## ***Planning and delivery***

**Question 20:** Should we introduce statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers strategies which must be kept under review and updated every three years?

**Question 21:** Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?

Access to a range of local services is important. This should include age and need appropriate respite care. For some groups with specialist needs it may be appropriate/necessary to offer services out with the area.

There is a need to consider how this statutory requirement to ensure provision can be adequately resourced, and resourced in a way which meets a diversity of individual and family needs.

It is important that carers are supported, and we highlight that this support should continue when they become bereaved carers. Carers of terminally ill people may see support and help suddenly withdrawn following the death of the person they are caring for leaving them isolated and vulnerable, as well as bereaved.

## ***Identification of Carers and Young Carers***

**Question 22:** Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?

**Question 23:** Should the Scottish Government ensure that good practice is widely spread amongst Health Boards about the proactive use of Registers of Carers within GP practices?

**Question 24:** Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?

As stated within the consultation document, it is important to ensure that carers are identified so that they can access benefits, help and support. A recent study showed that:

- Those in primary care, such as GPs and nurses, do not always identify those caring for people with life-threatening illnesses as carers and so do not signpost them to the support that could be available to them.
- Carers of terminally ill people may see support and help suddenly withdrawn following the death of the person they are caring for leaving them isolated and vulnerable, as well as bereaved.
- Many carers for those at the end of life are missing out on vital benefits, help and support as a result of not being identified or recognised as carers.

However, though we therefore agree that there is a need to continue with further policy and practice developments, we also agree is not necessarily helpful to make legislative provision for GPs or local authorities to maintain a Carers Register. Rather, the approaches suggested in questions 22 and 23 seem reasonable. Measures to gauge the effectiveness of these approaches should be put in place.

### ***Carer and Cared-for Person(s) in Different Local Authority Areas***

No comment.