Carers (Scotland) Bill
Scottish Partnership for Palliative Care

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. 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.

SPPC’s views on the Bill are informed by the work of our members with people with life threatening or life limiting illness and their families.

SPPC’s response is structured around the key questions posed by the Committee in its call for views.

Do you support the Bill?

SPPC supports the intent of the Bill and many of its provisions. Death, dying and bereavement create particular issues for family carers. Demographic changes mean that the numbers of people dying are set to increase. People will increasingly die at an older age, following a lengthy but individually unpredictable period of decline. Carers trying to cope with these challenges will be older themselves and will often be living with more than one long term condition.

Specifically SPPC welcomes that the Bill:

- replaces the current carer’s assessment with a new adult carer support plan (ACSP) and provides a young carer statement (YCS) for all young carers;
- provides for the establishment of an information and advice service for carers in each local authority area which must include a short breaks services statement;
- introduces a duty to support carers whose needs cannot be met by general services in the community (including the information and advice service);
- requires local authorities, in determining which support to provide carers, to consider in particular whether the support should take the form of, or include, a break from caring;
- requires local authorities to prepare local carer strategies for their areas; and
What do you feel would be the benefits of the provisions set out in the Bill?

Research\(^1\) has identified 3 key barriers to carer identification towards the end of life:

1) The gradual process into caring, and the transition to, and identification with, the term ‘carer’.

2) The all-encompassing nature of caring for someone with advanced illness often resulted in carers prioritising the needs of the ill person at the expense of their own.

3) The legitimacy of carer needs and ambiguity of the role of primary care teams in meeting them.

The replacement of the carer’s assessment with the Adult Carer Support Plan (ACSP) has the potential to make identification of carers (and self identification by carers) easier and for this to happen earlier. The ACSP provides a lower threshold for the “legitimising” of carer needs (by both the carer themselves and health and social care professionals) than the current system.

The requirement that ACSPs include documentation of timescale/circumstances which would trigger a review is also welcome; demands often increase over time and towards the end of life circumstances and needs may change rapidly and require rapid and flexible responses.

SPPC welcomes the intention to include emergency, anticipatory, or future planning within regulations about information which the ACSP must provide (Policy Memorandum para 68).

How do you feel the Bill could be amended or strengthened?

Whether or not the Bill will actually lead to benefits which are detectable by carers and the people they care for will in large part come down to the quality and consistency of implementation. Much of the detail of implementation has been left either to future (as yet undrafted) regulations by Scottish Government and/or local decision by individual Local authorities.

MSPs are invited to consider whether better outcomes for carers and the people they care for might be achieved, and/or achieved more swiftly, if:

\(^1\) Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. Emma Carduff, Anne Finucane, Marilyn Kendall, Alison Jarvis, Nadine Harrison, Jane Greenacre, and Scott A Murray \url{http://www.biomedcentral.com/content/pdf/1471-2296-15-48.pdf}
1. Some areas covered by Scottish Government regulation might be included in the Bill itself and/or

2. Some areas left to local decision might be more centrally specified.

The most obvious and important example is around local eligibility criteria. The Bill proposes that local authorities will set local eligibility criteria which will “determine whether local authorities would be required to provide support to carers to meet carers needs”.

There is an extremely high likelihood that this will lead to different criteria in different locations, with an associated lack of clarity for carers. Locally set criteria are not consistent with a rights-based approach. There is also a risk that in current resource-scarce environment that criteria will be subject to ongoing revisions which restrict eligibility.

Whilst the Policy Memorandum associated with the Bill states that there should “be a Scotland-wide approach” what this might entail is not described in the Bill. Neither is it clear how such a Scotland-wide approach might be achieved in the absence of national specification. Neither does the Policy Memorandum commit Scottish Government to regulating in this area, stating only, in para 88).

“If the Scottish Ministers come to the view that the local eligibility criteria are not working in the intended way, then under the Bill’s provisions they could set out national eligibility criteria in regulations. Such national eligibility criteria would take the place of the existing local eligibility criteria.”

It would seem inevitable in the absence of a clear Scotland-wide approach that geographic variations will occur. These are likely to contribute to reinforcing health inequalities.

Eligibility criteria, whether determined locally or nationally should be fully informed by the views and experiences of relevant stakeholders.

Parental Care of Children with Life Limiting Conditions

The Bill ordinarily excludes parents as carers for the purposes of the Bill but the explanatory notes acknowledge that parents of disabled children are included within the intended scope of the Bill. SPPC believes that the Bill itself should explicitly state that parents of children with life limiting conditions meet the definition of carer for the purposes of the Bill. Such parents are providing significantly more care than would be considered normal parenting levels of care. Similarly siblings of children with life limiting conditions often assume carer roles within the family and we would wish to see this acknowledged too.

Responsibilities of Integration Authorities

The Bill places as duty on the ‘responsible’ local authority to prepare a carers’ plan. The Public Bodies (Joint Working) Act 2014 delegates functions and services relating to carers to the new integration authorities, and the Scottish
Government’s ‘Health and Social Care Functions Supporting Note’ specifies Carers Support Services as a function which local authorities must delegate.

Section 25(5)(b) of the Carers’ Bill seems to exclude any functions and services delegated to the integration authority from the Carers’ Bill from the duty to involve carers in carer services. Section 29(e) of the Carer’s Bill requires the local authority, in preparing its local carer strategy, to ‘have regard to’ any integration functions relevant to carers which are set out in the strategic plan prepared by an integration authority under s29 of the Public Bodies Act.

Perhaps the intention of these two clauses is to avoid duplication of duties (where there is an existing duty to involve service users under the terms of the Public Bodies Act). It would be helpful to clarify how the new provisions will work alongside the delegated functions under the Public Bodies Act. As it stands the Bill might cause confusion and even act as a barrier to providing integrated support for carers. Despite the integration of health and social care the Bill persists in allocating responsibilities to either local authorities or to health boards.

**Emergency Planning and Future Planning**

SPPC would like to see emergency and future planning specified as core content of the Adult Carer Support Plan in section 8(1) of the Bill. In referencing Emergency and Future Planning (whether in regulations or on the face of the Bill) wording should state “including planning for needs relating to death, dying and bereavement”. In Scotland there is a cultural reluctance on the part of professionals and the public to talk about and plan ahead for these issues, and for this reason there is particular value in explicit reference. Evidence shows that outcomes towards the end of life for people and their families are better when discussion and future planning takes place.

**Presumption of Eligibility**

SPPC believes that where a carer is caring for someone with palliative and end of life care needs there should be a presumption of eligibility.

**Is there anything that you would add to the Bill?**

**The Role of GPs and Primary Care**

The Bill is silent on the role of General Practitioners and primary care in the identification of carers. The Policy Memorandum does indicate (para 123) that local authorities must set out their plans for the identification of carers in their local carer strategy and that they must consult with NHS Boards before preparing their local carer strategies. However, given the centrally important role of primary care and GPs in the identification of carer’s there is an argument for stipulating more explicitly the need for their role to be considered in local carer strategies.
**Reporting**

SPPC would like the Bill, or perhaps more appropriately in associated regulations, to stipulate a requirement that responsible authorities report regularly against appropriate indicators relevant to the intended outcomes of the Bill.

**Is there anything that you would remove from the Bill?**

No.

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