Palliative Care (Scotland) Bill

ACT

Do you agree or disagree with the general principles of the Bill?
ACT believes that palliative care should be available to all who need it, including babies, children, young people and their families.

Do you believe there should be a specific duty on the provision of palliative care in the NHS (Scotland) Act 1978, over and above the general duty of “providing a comprehensive and integrated health service”?
There is concern that in legislating for this one particular type of care it will open a floodgate of requests for legislation for others.

Do you have any comments on the provisions concerning reporting and indicators contained in the Bill?
ACT recommends that further work is undertaken to establish robust high quality indicators specifically for children and young people’s palliative care.

Are you content with the definitions contained in the Bill, particularly that of “palliative care”?
We recognise the value of using an internationally recognised definition for palliative care and the WHO definition incorporates the principles which are relevant for children and young people. However ACT believes that for children and young people it would be more helpful to include the recognised definition for children and young people’s palliative care—such as the 2003 Royal College of Paediatrics and Child Health/ACT definition:

“Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.”

Do you have any comment on the costs identified in the Financial Memorandum?
The funding model for children and young people’s palliative care in Scotland requires further consideration. Existing costings reflect the provision of care rather than the true cost of a service needed to provide care. The funding needs to include the whole sector— as the provision of care comes from a wide range of paediatric specialities, as well as voluntary organisations and from adult services (especially in remote and rural settings) and this range of funding needs to be taken into account. In the recent development of a Children’s Palliative Care strategy in England, work was undertaken by the University of York to try to identify costings and this has relevance in Scotland, although it does not make specific consideration of the remote and rural issues. This information is available at http://www.york.ac.uk/inst/yhec/downloads/Final%20Report-may07v1.pdf.
Many children and young people with life-limiting conditions are not currently well supported within palliative care services and tend to receive piecemeal and crisis intervention rather than co-ordinated care. Over time, the provision of planned, high quality, palliative care to these patients could reduce hospital admissions and thereby counter some of the costs. There is also the possibility that when an effective multi-disciplinary team approach is established for the provision of community-based children and young people’s palliative care across Scotland, there may be extra funding required e.g. for housing; daily adaptations; equipment. Recognition needs to be given to the increasing population requiring palliative care. For example, there is an increasing population of young people with life-limiting conditions who are surviving longer, and a growing elderly population who will require palliative care.

To enable good standards of palliative care provision by non-specialist health and service providers there is a need for standardisation of policies, symptom management guidelines and extra hardware (e.g. syringe drivers). Additional funding will be needed to establish this effectively. There is also a need for an extensive skill-set / competency training programme for all likely to be involved with palliative care across statutory, voluntary and education settings. As more people are cared for within their home or local community, there will be a need for identified accessible pharmacies within communities to provide palliative care medications in the format and doses required. This may also have funding and training implications. There is a need for the provision of information in languages and formats that are appropriate to different ages and cognitive levels and those with disabilities.

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