RCN Scotland response to the Health and Sport Committee inquiry into palliative care in Scotland - August 2015

The RCN, as a UK organisation, has been working with the Leadership Alliance for the Care of Dying People in England which reports directly to Baroness Neuberger following her recommendations in 'More Care Less Pathway[1]'. The Leadership Alliance response to the recommendations has produced an approach, One Chance to Get It Right[2], which we hope Scotland will learn from and build on, given the significant amount of clinical input – including from the RCN – that has informed this work.

Section A: Access to palliative care

Joined up care services

Those in need of palliative care should experience a service which is delivered in a timely and seamless manner, accessing care in a coordinated and compassionate way at the end of life.

Complex systems run differently by different care providers can lead to confusion in an already stressful situation for patients and their families. There is only one chance to get end of life care right. The implementation of health and social care integration should bring about a more seamless transition between services for those moving between medical care to palliative care and ensure individuals and their families experience a good death. The RCN's own Principles for Delivering the Integration of Care – whilst not specific to those with palliative care needs – set out the key elements of how we would hope this integrated world would work to improve care[3].

Our principles support the idea that there must be a single point where patients and their families can access the variety of services they will require in a joined up and holistic manner. Those services could include community nursing, AHPs, GPs, social work and third sector services, among others. Having a named professional can be hugely beneficial in coordinating care and being the link for families. However no individual professional can be available 24/7, 365 days a year. Local services need to ensure their systems take this into account so that patients and families are never left wondering who to call if they need help.

Particularly in health, an enabler to this type of joined up care is a managed clinical network. These networks of linked groups of health professionals and organisations from primary, secondary and tertiary care, work in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, ensuring equitable provision of high quality clinically effective services throughout Scotland.

Community capacity

Wherever possible, locally designed services must be able to meet the palliative care needs of those in their locality who chooseents andall.48t3(l)5(e)8(241 0 0 1 173y)2 173.66(.)]TJETBT1 0 0 1 30

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report before the recommendations of this inquiry are complete. We would hope that the outputs from this will influence the recommendations of this inquiry

Care home sector
In the future, the care home sector will also need to adapt to provide more palliative care for an ageing population. The RCN, along with other key stakeholders, joined with the Scottish Government and COSLA to form the Taskforce for the Future of Residential Care in Scotland[11]. Its report makes a series of recommendations including delivering 24 hour care for people with substantial care needs, the development of new accommodation that is more tailored to the care needs of residents/tenants and promoting better partnership working with volunteering and carers' roles to support people that live in care homes.

The taskforce was clear that care homes are an increasingly important setting for palliative and end of life care and support. In order to be able to provide high quality palliative and end of life care, care homes need to develop good internal resources and have well trained and well supported staff. This will need to include a review of registered nurse staffing for residents.

The staff in care homes, including health care assistants and support staff, are a critical element to this agenda and we need to be clear how any proposed changes would practically be implemented in this new landscape for the care home sector. The RCN will be carrying out further work on nursing services for the future of care homes over the coming 12 months. We will make our report available the next health and sport committee in the summer of 2016.

Public perception and understanding
The definition of the terms "end of life" is a key starting point for developing improvements to care. It will be important for practitioners, the dying person and their families/carers to understand clearly what is meant by "end of life care" within the context of any provision in Scotland. For example, in the recent guidance[12] on end of life care, issued by the Scottish Government, end of life is defined as caring for someone in the last days and hours of life, however, in the guidance produced for England[13] a patient is classed as being in end of life care if they are likely to die within the next 12 months. We need to clearly set out the expectations set around definitions, the timeframes involved and what good end of life care should look like. It will also be essential that the public understand the clear standards that will be applied to palliative care across all settings throughout Scotland.

We must acknowledge the impact that the headlines around the delivery of the Liverpool Care Pathway will have had on the public's perception of end of life care as we go forward. New approaches must clearly set out what patients and their families / carers should expect from health and care services at the end of life and ensure that all staff are trained appropriately to support a good death.

Section B: The initial conversations about palliative care

When to have the conversation?
The right time for individuals to initiate the conversation

Where complex decisions or particularly sensitive issues, such as nutrition and hydration of people at the very end of life, need to be discussed or explained to patients and the families then these difficult conversations should be carried out by a clinician who is competent to do so, such as a specialist nurse, GP, consultant or district nurse. The support and training available is variable across the professions and improvements are required in this area.

Families and carers should be involved, as often they are providing care and support for significant amounts of time, especially in the community. They are part of the dying process and unless there are very good reasons for them not be involved, such as safeguarding issues or the direct and specific wishes of the patient, they should be central to all palliative care conversations.

Supporting the conversations

We would urge the committee to consider including explicit references to advance care planning and starting early end of life care conversations