We need to talk about Palliative Care

Royal College of Nursing Scotland

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-

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[1] More Care Less pathway - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

[2] One Chance to get it right https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

[3] RCN, Principles for Delivering the Integration of Care (2012) http://www.rcn.org.uk/__data/assets/pdf_file/0016/442132/RCN_in_Scotland_integration_principles.pdf

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 choose to die at home. It is particularly important that the resources required to deliver more palliative care in the community are taken into account by integration authorities when considering the practical implementation of any proposed changes to end of life care provision. Progress to shifting services into the community has been slow. A 2014 Audit Scotland review of Reshaping Care for Older People[4] found little evidence of progress in moving money to community-based services. Pressures on budgets are putting the sustainability of services at risk, as Audit Scotland highlighted in its overview of NHS finances published in October 2014[5]. Moving services to the community will increase the activity in these areas and, without sufficient funding, community capacity pressures will increase.

Early proposals around the future of the Scottish GP contract from 2017 suggest, if taken forward, these changes could have a significant impact on clinical responsibility and capacity with regard to palliative care in the community. This must also be taken into account as new approaches are developed. Planning a multi-disciplinary workforce of clinical decision makers to deliver truly responsive care 24/7 is required now. We welcome the Chief Nursing Officer's reviews of district nursing and advanced nursing practice as a support to this.

Training

All staff in health and social care need to have the basic skills and knowledge to deliver good palliative care. A fully trained generalist workforce would ensure that we could deploy specialist palliative care professionals when they are most needed, improving the sustainability of our health and care services. We need, however, to be clear about how this specialist support will be deployed across local and regional services in an increasing ageing population. Once we understand how we intend to develop this specialist support then we need to ensure that we are training enough specialists with senior clinical decision making authority, e.g. advanced nurse practitioners, to ensure the future sustainability of services[6].

In June 2015, Healthcare Improvement Scotland issued their standards for the care of older people in hospital. The standards are clear that "*areas such as palliative and end of life care…in hospitals can only be delivered when the*

[4] Audit Scotland – Reshaping Care For Older People - http://www.audit-scotland.gov.uk/docs/central/2014/nr_140206_reshaping_care.pdf
[5] Audit Scotland – NHS Financial Performance 2013/14 - http://www.audit-scotland.gov.uk/docs/health/2014/nr_141030_nhs_finances.pdf
[6] For further information on the potential of senior clinical decision makers in nursing, see: http://www.rcn.org.uk/__data/assets/pdf_file/0005/633470/SC0511-Nurse-Innovators-Report.pdf

team has safe staffing levels, supported by the appropriate skills mix for the patient population and the right attitude and approach to care."[7]

The RCN welcomes this focus on both the skills and numbers of staff required to provide quality palliative care. These standards, however, are limited to hospital settings. The same patient expectations must be set in the community if we are to ensure good palliative care is a central part of the 2020 vision implementation and reflected in the review of the National Care Standards[8].

In practical terms, the RCN has been developing two resources[9] to support nursing staff in providing good end of life care, one with a particular focus on the sensitive issues relating to nutrition and hydration[10], and the other on the wider issues of end of life care. Both resources are applicable in end of life care across the UK and have been informed by a review commissioned by the RCN and by the results of an RCN survey on end of life care.

Round the clock care

Our members have told us that, at the moment, when a patient enters the last days and hours of life, there is not equitable 24 hour, 7 day a week, access to the specialist palliative care assessments that they may require across all health boards in Scotland. Patients can require these assessments at weekends and out-of-hours and changes to specialist palliative care will require a whole system approach.

We need to focus on community services, as well as hospital services, looking at multi-professional models of care that maximise the potential of different professions to meet the needs of patients and improve patient outcomes out with core Monday to Friday day services.

The RCN is leading the Scottish Government's Primary Care Out-of-Hours review group work on models of care for 'Groups with Specific Needs' which includes those with palliative care needs. The outputs of the out-of-hours primary care review and the seven day care task force must clearly reflect a commitment to improved palliative care. The primary care review will 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

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[7] Care of older people in hospitals, Healthcare Improvement Scotland - http://www.healthcareimprovementscotland.org/his/idoc.ashx?docid=a196fdcc-4f87-49e2-9120-1476e10438f8&version=-1

[8] National Care Standards Review - http://www.gov.scot/Publications/2014/06/7325

[9] Getting it right every time. Fundamentals of nursing care at the end of life http://www.rcn.org.uk/__data/assets/pdf_file/0011/629858/End-of-Life_RCN.pdf

[10] RCN Nutrition and Hydration Guidance - www.rcneolnutritionhydration.org.uk & www.rcnendoflife.org.uk

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.

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[11] Residential Care Taskforce Report - http://www.gov.scot/Resource/0044/00444581.pdf

[12] Caring for people in the last days and hours of life – Guidance – http://www.scotland.gov.uk/Publications/2014/12/6639

[13] One Chance To Get It Right - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Section B: The initial conversations about palliative care

When to have the conversation?

The right time for individuals to initiate the conversation and the right time for professionals are not always the same time. Professionals require the skills and sensitivity to create the conditions for individuals and their families to feel comfortable to discuss their choices as soon as possible after diagnosis. The sooner people are able to discuss their wishes, fears and issues in an open and supportive way the better their outcomes.

Who should be involved in the conversation?

All health care staff should have basic palliative care skills at a generalist level to be able to have conversations about the care being provided. We must also support social care and third sector staff to discuss aspects of palliative care sensitively and with confidence.

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 within the inquiry report. Advanced care planning is crucial to ensuring that patients are making active choices about their end of life care while they are still able. Analysis of work carried out in NHS Shetland[14] has shown that patients with advanced care plans who were seen out of hours were cared for according to their plan without introducing alternatives which may have resulted in an inappropriate admission to hospital. Such early intervention can reduce the over or under treatment of the patient.

Recording and documenting the conversation

There are challenges in accurately recording and sharing information between everyone involved in delivering palliative care as there are many different systems in place for each professional group with IT systems that do not speak to each other. There should be a focus on developing shared access to

[14] NHS Shetland case study - http://www.jitscotland.org.uk/example-of-practice/247-community-nursing-service-model

the Key Information Summary of a patient's care plan, which must be accessible to anyone involved in the care of the patient. During the last days and hours of life, this shared record should remain with the patient to ensure the patient's wishes are met. Thorough audits of these records should be made to ensure reviews of significant events lead to ongoing improvements to practice.

Section C: Research into international comparisons of measurement of data

The RCN welcomes the commitment of the committee to undertake some focussed research into international comparisons of measurement of data in palliative and end of life care. Whilst we think that looking at international data is useful, there is a lot of evidence of good palliative care within the UK too. We would like to highlight the work of the James Lind Alliance and Marie Curie[15] which aimed to '*address the dearth of evidence in palliative and end of life care and help research funders to direct scarce resources to the unanswered questions around treatment, care and support most important to the 'end users' of research: patients, current and bereaved carers and families, clinicians, and health and social care practitioners, plus members of the community, such as volunteers with experience of end of life care*.'

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[15] James Lind Alliance - http://www.lindalliance.org/PalliativeCare.asp