

# Macmillan Cancer Support

## Response to consultation on the NICE Draft Quality Standard for end of life care for adults

20 July 2011

### Introduction

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional, financial support and strongly advocate for better cancer care. We welcome the opportunity to comment on the draft quality standard for end of life care for adults.

### Key points

- We are pleased this draft quality standard recognises the importance of end of life care being available at all times, day or night
- We welcome the recognition of out-of-hours support across the draft quality statements, and the explicit reference of support for people “who experience an unexpected crisis at any time of day or night” in quality statement 13
- We also welcome the inclusion of quality statement 11 with its references to people nearing the end of life receiving care in their usual place of residence, including their home
- We believe quality statement 16 can be strengthened by reference to the importance of access to a community nurse
- We believe that quality statement 6 and 16 can be strengthened by specifically referring to advance care planning
- We believe quality statement 8 should include the provision of financial support
- We strongly recommend the inclusion of a glossary of key terms which are cited throughout the quality statements to provide clarity and consistency in interpretation
- We believe there needs to be a clearer explanation of how locality registers will be used as a mechanism for recording and meeting patient preferences within all quality statements
- We also believe there needs to be greater consistency in demonstrating the outcomes sought across all the quality statements.

End of life services are an integral part of the care delivered by any health or social care professional to those living with, and dying from, any advanced, progressive or incurable disease. 73% of people with cancer would choose to spend their last weeks and days of life at home if all their concerns about dying at home (such as access to pain relief, access to healthcare professionals, and support for their family and carers) were addressed, yet only 27% do<sup>1</sup>.

Macmillan Cancer Support has been campaigning for all people with cancer nearing the end of life to have access to 24/7 community nursing so that they are able to die at home if they wish to do so.

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<sup>1</sup> Statistic taken from Macmillan Feb 2010 online survey of 1,019 UK adults living with cancer. The Office for National Statistics showed that 27% of cancer deaths in 2009 occurred at home in England and Wales.

We welcome the use in the draft quality standard of the General Medical Council's definition of patients approaching the end of life – defined as being when people are likely to die within the next 12 months.

In the final version of this quality standard, it would be useful to understand how it relates to the Welsh Palliative Care Standards, which Macmillan Cancer Support responded to in January 2011.

### **Identification of people approaching the end of life – quality statement 1**

Predicting the end of life of a patient is difficult and some clinicians are often reluctant to discuss end of life issues with patients while they are still delivering active treatment. This can mitigate active end of life care planning and therefore prevent patient choice on place of care and death being met.

Through our work on end of life care we have identified good practice models for care at the end of life. The *Macmillan Specialist Palliative Care Service* offered at Midhurst appears to demonstrate the value of early assessment and intervention by dedicated palliative care services, which can lead to greater patient choice by providing as much treatment and support in the home/community setting as possible. Patients had fewer inpatient and A&E admissions, which can have considerable costs implications for the NHS and be a significant source of distress to patients and their families in the final days of life.

### **Access to services out-of-hours – quality statement 13**

We strongly support the inclusion of draft quality statement 13: Access to services - urgent care.

However, statement 13 could be strengthened to include reference to patients and/or carers having 'details of how to contact a named healthcare professional', and should include 'what to do outside of normal working hours'. The NICE Supportive and Palliative Care Guidance notes that a reduction in out-of-hours support is probably to blame for people not dying in their place of choice.<sup>2</sup> Most people would prefer to die at home and not in a hospital – between 56% and 74% according to different sources<sup>3</sup>. However, recent statistics show that only 27% of people diagnosed with cancer die at home<sup>4</sup>. We believe that the provision of out-of-hours support is essential to allow people to die at home.

Statement 13 also must ensure that urgent care is provided in all settings. Therefore, we propose that quality statement 13 could read as follows:

*People approaching the end of life who experience an unexpected crisis at any time of day or night, receive prompt, safe and effective urgent care appropriate to their needs in all settings. They are also offered details of how to contact a named healthcare professional, and what to do if they need urgent support out-of-hours.*

There could be reference to resources such as the *Out-of-Hours Toolkit*, which has been developed by Macmillan Cancer Support as a resource for health professionals involved in care during this period.

The Out-of-Hours Toolkit is a summary of extensive collaborative work and draws on the experiences of the Macmillan primary care community working together with service users and experts in the field of out-of-hours care. The toolkit brings together numerous good practice examples for particular facets of care for cancer and palliative care patients during the out-of-hours period.

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<sup>2</sup> NICE Supportive and Palliative Care Guidance, 2004.

<sup>3</sup> National Audit Office, *End of Life Care*, 2008.

<sup>4</sup> Taken from Macmillan Cancer Support online survey of 1,019 UK adults living with cancer, February 2010.

## Importance of 24/7 Community Nursing – quality statement 11 and 16

A multidisciplinary approach to end of life care in the community is essential to ensuring that people can live and die in their usual place of residence if they wish. Good coordination of care is also necessary to prevent the fragmentation of end of life care provision, inappropriate A&E admissions, and more patients dying in hospital rather than at home.

We are very pleased to see that statement 11 recognises the need to provide care and support in all settings, including at home. The availability of community nurses can help to ensure that patients receive high quality care in all settings, including their own home.<sup>5</sup>

Statement 16 should include a reference to the importance of 24/7 community nursing, as community nurses have a vital role to play in ensuring that people who wish to die at home can do so. Managing a patient's clinical, emotional and practical needs well in the final days can also reduce the need for unplanned hospital admissions.

Macmillan's campaign website, **End of life shouldn't mean end of choice**, has some excellent case studies on the difference community nursing can make to patients and their family. Poor care at the end of life can have a lasting impact on bereaved families and carers.

**CASE STUDY – Alison cared for her father, Ted, at home but when his condition deteriorated he was taken to hospital.**

**'One night he was in particular discomfort. I called the local palliative care nursing number to get some advice. They were nice but didn't really give me any help and I felt totally lost. I knew that if I called an ambulance he probably wouldn't be able to have his last few days at home. At the hospital after several hours in cubicles, he was transferred to his own room, where he spent his last two days. It's not what he wanted. He'd always wanted to live by the sea and at home he could see it. In those last few days that was something he wasn't able to do.'**

## Care planning – quality statement 6 and 16

It is very pleasing to see that care planning has been given recognition as a key process in providing end of life care. However, statement 6 makes reference to a personal care plan and statement 16 makes reference to a proactive holistic plan. There is a need for consistency in key terms to describe what is being offered to patients, and what it should include.

Patient wishes should be recorded in an advance care plan which informs both health and social care professionals about where a person wishes to be cared for in the final days of life. This discussion should also include their family/carer where appropriate, as it may help patients and families feel better prepared to make decisions. Therefore, we believe that both quality statement 6 and 16 should be amended to recommend that advance care planning should be offered to patients approaching the end of life.

Quality statement 6 and 16 should provide guidance on how the appropriate health and social care professionals involved in a patient's care can access the advance care plan. Evidence shows that if people are asked in advance about their preferred place of care at the very end of life, and this is

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<sup>5</sup> Macmillan Cancer Support. *Always There?* The impact of the End of Life Care Strategy on 24/7 Community Nursing in England, 2010.

documented, then professionals are more likely to be able to fulfil people's wishes.<sup>6</sup> Advance care planning interventions are also supported by the NICE Supportive and Palliative Care Guidance (#1.16 – #1.21).<sup>7</sup>

### **Financial support – quality statement 8**

We are particularly keen to see that patients continue to receive care and support based on a holistic assessment of their needs especially when approaching end of life.

We would strongly recommend the inclusion of a reference in statement 8 on providing information on financial support available to patients nearing the end of life. Signposting financial support is especially important given that the evidence from the 2010 National Cancer Patient Experience Survey showed only 50% of cancer patients who wanted financial information were given any<sup>8</sup>.

In addition to this, despite the “special rules” which enable people with a terminal illness who have six months to live to be automatically fast-tracked onto disability and incapacity benefits, Macmillan knows this support is not always accessed. Research undertaken by Macmillan in 2010 indicated that up to a third (36%) of terminally ill cancer patients will die without receiving either Disability Living Allowance or Attendance Allowance – benefits to which they are entitled.<sup>9</sup>

We are concerned that if explicit reference to providing information on financial support is not given in this quality statement, patients and their families could miss out on essential support.

### **Specialist palliative care – quality statement 14**

The statement should recognise that early identification of a patient entering into a palliative or end of life phase will help to facilitate discussion of that patient's needs and helps ensure advance care planning is in place to enable the patient's preferences to be met.

A recent evaluation of the *Macmillan Midhurst Specialist Palliative Care Service* showed that early referral to a specialist palliative care service is associated with patients spending fewer nights in a hospital setting and having fewer A&E attendances. It is also associated with fewer deaths occurring in a hospital setting.

### **Training and competence of staff – quality statement 7 and 19**

The term “competent generalist care” is used in quality statement 7 but there is minimal description about how those delivering care both in-hours and out-of hours can demonstrate that competence.

There is an opportunity in this quality standard to strengthen the obligation of providers of out-of-hours care to ensure specific training for healthcare professionals in interpersonal skills and symptom management of patients at the end of life. In appraisal systems measures of “everyday” performance should include appropriate knowledge, skills and attitudes in delivery of end of life care.

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<sup>6</sup> Abarshi E, Onwuteaka-Philipsen B, Donker G, Echteld M, Van den Block L, Deliens L. *General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands*. J Pain Symptom Manage 2009; 38(4): 568-77.

<sup>7</sup> NICE Supportive and Palliative Care Guidance, 2004.

<sup>8</sup> Department of Health. *National Cancer Patient Experience Survey*, 2010.

<sup>9</sup> *Cancer Patients Lose Out On Millions of Unclaimed Benefits*, taken from [http://www.macmillan.org.uk/Aboutus/News/Latest\\_News](http://www.macmillan.org.uk/Aboutus/News/Latest_News) Accessed 15 July 2011.

As 70% of the time in a week can be considered out-of-hours, statement 19 should require those healthcare professionals responding out-of-hours to demonstrate competence in all aspects of care – physical and psychological.

It is also very important to recognise in references to equity and diversity in all quality statements the needs of those with severe learning difficulties or psychiatric illness who are cared for in the community and for whom the provision of good end-of-life care can be challenging.

## **Overall comments – across all quality statements**

### **Consistency of language and definition of key terms**

We believe amendments need to be made to ensure that the language used in all quality statements gives clear guidance for commissioning/planning and to providers for delivering high-quality services for patients at the end of life.

For example, in quality statements 7, 10, 11, 12 and 13 it is not explicit what level of care is to be provided 'at all times' and 'day and night'. In contrast, statement 16, which references care provided in the final days of life, does not include a reference to 'at all times' or 'day and night', but refers to 'timely access'. Therefore it will be difficult to measure and monitor what level of care is being achieved consistently across all settings.

However, quality statement 11: access to services provides a definition for essential 24/7 care services to enable people to live and die in their place of choice. It includes:

- nursing services (defined as visiting, rapid response services and provision of one to one care at home, including overnight)
- medical and personal care services
- access to pharmacy services and access to equipment and adaptations.

It needs to be made clear that all statements which refer to services or care being offered 'day and night' and 'at all times', as a minimum, should be inclusive of the above definition.

Other phrases that require greater clarity include patient 'preferences', which is referenced throughout all the quality statements. This could be defined as, but not exclusive to, the physical, psychological, social, spiritual, religious, financial and information support needs of an individual and or their family/carer. Another example is the use of terms holistic care plans, personal care plans, care planning and terms such as adequate support. These may be very different from a patient's perspective than a professional's perspective.

Therefore, the quality standard needs an accompanying glossary of terms and definitions to provide a consistent understanding and clarity of what can and should be expected in end of life care.

### **Use of locality registers**

Many of the quality statements make reference to the use of locality registers. Ensuring the identification of all people who should be on a local end of life register can have an important impact on the outcomes and experiences of patients and their families and carers. Locality registers are also vitally important for out-of-hours service providers to substantiate and support decision making in emergency situations.

The recently released Palliative Care Funding Review made strong recommendations on the importance of locality registers, to allow early identification and assessment of patient need, and also for the development of the palliative care tariff.

Currently, the Department of Health's Quality Outcomes Framework (QOF) indicator set is focused on the maintenance of an end of life care register. The register identifies the patients nearing end of life and at regular multidisciplinary meetings, the team can ensure all aspects of a patient's care have been assessed and future care can be co-ordinated and planned proactively. To counteract the future risk of double counting of patients and any associated confusion, there should be a discussion in this quality standard of the link between the recommendation on the use of locality registers from the recently released Palliative Care Funding Review and the current GP registers for which the QOF indicator applies.

In addition, the Department of Health and the National End of Life Care Programme have recently released the final evaluation report of the feasibility and testing of electronic end of life care registers.

This evaluation included the commonly agreed core minimum dataset used by all pilot sites, which incorporates a number of items, some of which are set out below:

- Record creation and review dates
- Patient name and address
- Demographic information (date of birth, gender, ethnicity)
- Consent to share/add details to register
- Name of usual GP and details of practice
- Key worker details
- Carer details
- Hospice details (if applicable)
- Diagnosis and complications
- Secondary diagnoses (if applicable)
- Resuscitation status, and
- Preferred place of death.

There must be greater clarity given in all quality statements about the minimum data set required in a locality register for end of life patients. Locality registers are extremely important to effectively measure whether patients have been able to exercise choice at the end of life and therefore serve as a crucial success measure.

### **Consistency in the use of draft quality measure outcomes**

There is significant variation in the language used to describe the outcomes which accompany each of the draft quality measures, and some quality measures do not include a stated outcome at all. Clarity in the outcome sought and what success looks like is essential to achieving high quality end of life care.

It is not clear in the current draft how the outcomes will be measured or monitored and by whom, as they vary between each statement. Examples of inconsistency in outcomes include:

- Quality statement 6 'outcome: people approaching the end of life receive care that is aligned to their needs, preference and decisions'
- Quality statement 10 'outcome: people approaching the end of life receive care that is aligned to their preference (where appropriate)'
- Quality statement 11 'outcome: increase in proportion of people dying in the community'

Consistency in the outcomes sought would make it possible to see which areas providers and services are performing well and making progress, and where more effort or scrutiny may be required. We propose that there is a minimum set of defined outcomes for each quality standard: on advance care

planning, recording preference for care and choice on preferred place of death, and family and carer satisfaction. We recognise that additional outcomes may be required for specific quality statements.

### **Merging of quality statements**

In the event that NICE is seeking to reduce the number of Quality Standards, we would propose that the following statements are merged:

- Quality statement 3 and quality statement 6 could be merged, as both statements address the development of a plan which includes documenting patient preferences. As a result, we propose the quality statement could read as follows:

*People approaching the end of life are offered comprehensive and regular assessments, and are offered the opportunity to develop and review an advanced care plan, which sets out their needs, preferences and decisions in all aspects of current, and future, care and treatment.*

- Quality statement 7 and quality statement 8 could be merged, as both statements address meeting a range of patient preferences, including physical, psychological, social and practical needs. As a result, we propose the quality statement could read as follows:

*People approaching the end of life have access to personalised support of their physical, psychological, social, financial and practical needs, appropriate to their preferences.*

- Quality statement 15: access to service – transfers and transport. This quality statement could be incorporated into statement 13: access to service – urgent care. Quality statement 13 should be explicit that transport must include rapid discharge from hospital, to allow people to be moved to their preferred place of death, where appropriate.
- Quality statement 17 and quality statement 18 could be merged, as both statements address bereavement needs of families and carers. As a result, we propose the quality statement could read as follows:

*Carers and families who are bereaved are communicated with in a sensitive way and receive timely verification and certification of the death, as well as information that includes details of any coroner involvement. Carers, families and people closely affected by a death have access to bereavement support appropriate to their needs and preferences.*

- Quality statement 19 and quality statement 20 could be merged, as both statements address competency in skills and providing safe and effective care. As a result, we propose the quality statement could read as follows:

*Health and social care workers (including generalist and specialist service providers) have the necessary knowledge, skill and attitudes to provide safe and effective care for people approaching the end of life, and work as a multidisciplinary workforce team.*

For further information, please contact:

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