Marie Curie Response

Consultation on the new National Health and Social Care Standards
22 January 2017

Introduction

1. Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our four volunteer led Helper services. We also provide nationwide support through our information and support service including our national helpline.

2. Last year we provided care for over 8,000 people living with a terminal illness, as well as their families and carers across Scotland.

3. Marie Curie's vision is for a better life for people and their families living with a terminal illness. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

4. At Marie Curie, we provide care and support across a variety of different settings, often in partnership with other healthcare providers. Marie Curie Hospices in Edinburgh and Glasgow are registered with Healthcare Improvement Scotland (HIS) as independent hospitals, regulated through self-assessment and both announced and unannounced inspections. The Marie Curie Nursing Service, providing care at home, is registered with the Care Inspectorate and is also regulated through self-assessment and inspections.

5. As such, we welcome the introduction of a single set of national standards relevant to all care settings and patient groups. We believe this approach is beneficial for organisations and services as it has the potential to simplify both care provision and regulatory structures, which should make the standards more useful and meaningful in practice.

6. However, we have concerns over regulatory and inspection processes and would like further clarification on how these will be undertaken in the future. We would not support a regulatory system that adds additional layers of assessment and inspection to already established procedures. We recommend a streamlined approach to regulation.

7. Monitoring performance against national standards can be challenging and often there can be a focus on providing specific pieces of written information to demonstrate compliance rather than a focus on practical and realistic care delivery. We recommend that the monitoring process needs to be developed alongside the standards. This should be accompanied by a statement to ensure that the effort of demonstrating compliance must not detract from the time, effort and energies invested by provider organisations in providing and managing care.

8. Marie Curie welcomes the human rights based approach to the standards and believes that they are aspirational and broadly reflect themes relevant to patients and service users. However, this broad approach makes it difficult to be able to ensure everyone's needs and outcomes are sufficiently represented. For example, the standards are, quite rightly, focused on increasing personal independence and confirming individuals' places in society. This is not always appropriate for everyone, such as some people approaching the end of life.

9. We recommend that there needs to be further consideration of the specific dynamics of engagement between service users and healthcare services to ensure providers are not held to account for inappropriate or unrealistic standards. For example, standard 1.35 "I can drink fresh water at all times" is a rather general and benign standard that should be applicable to all. However, this is not appropriate if a person, due to their condition, has no swallow reflex, is unconscious, or is fasting prior to general anaesthesia.

10. It is crucial that these standards are grounded in the principles of realistic medicine and that any inspection or regulatory frameworks are cognisant of the differences in providing specialist care, such as the palliative care provided by Marie Curie.

11. In previous consultations around the new National Health and Social Care Standards Marie Curie supported the introduction of specific standards or a statement around palliative care. This does not necessarily have to be a complicated document, but would ensure that care and support is realistic and practical for people living and dying with a terminal illness – and services are assessed with this in mind rather than against an inappropriate rigid framework.

12. We would also expect any specific standards and statements to link to and build on existing guidance, clinical standards and legislation. For example, any standard on palliative care must be cross-referenced with the Scottish Government's Strategic Framework for Action on Palliative and End of Life Care and clinical palliative care guidelines developed by NHSScotland.

13. Marie Curie supports the response to this consultation submitted by the Health and Social Care Alliance, which we are a member of. We support their suggestions and recommendations. In order to avoid duplication, we will focus our response to those areas of the consultation that specifically affect people living with a terminal illness.

To what extent do you think the Standards will be relevant and can be applied across all health, care and social work settings?

Neither agree nor disagree

14. We welcome the review of health and social care standards and the introduction of a single set of national standards relevant to all care settings and patient groups. We believe this approach is beneficial for organisations and services as it has the potential to simplify both care provision and regulatory structures, which should make the standards more useful and meaningful in practice.

15. The standards are very aspirational and assume that service users want and are able to participate fully in their care. This is not always the case for people living with a terminal illness and those at the end of life. These are people who often have very specific needs, requirements, aspirations and outcomes which are often different to general care and support. It is important that the people delivering their care are aware of this and can deliver appropriate and realistic care for them. We would recommend that this

is incorporated into the standards, or an additional palliative care appendix or specific standard is included to make sure the people get the care and support they need.

16. We understand that the first 4 standards are to be applied to every health and social care setting and standards 5-7 are to be applied to specific sectors. However, we believe that a number of the standard statements in sections 5-7 would be applicable to other services too. For example, Standard 7 relating to children and young people could easily also apply to very frail or elderly people, or other vulnerable people. We have concerns that by only including these standard statements in a specific children's standard, means they will not be embraced in other services. For example, statement 7.16 could easily apply to patients with advanced Dementia or Alzheimer's Disease. This statement could refer to power of attorney and anticipatory care planning which is vital in later life. Another example could be Statement 7.18 which could also be adapted to ensure people continued to be supported and cared for at the end of life. Our research tells us that people aged 70 and over in Scotland are missing out on palliative care as healthcare professionals can find it difficult to know when to introduce this approach in older people, particularly those with frailty.

To what extent do these Standards reflect the experience of people experiencing care and support?

Neither agree nor disagree

17. We believe that the expectations set out in the standards are fair and represent the type of care that people should receive, from any health and social care service regardless of the setting.

18. However, we share the Royal College of Nursing's concerns that there is not enough focus in the standards on safe and effective care. Following recent high profile coverage of adverse events and failings of care seen in Mid-Staffordshire, Lanarkshire, Vale of Leven and Aberdeen Royal Infirmary, ensuring safe and effective care is often the highest priority for people experiencing care. We believe that the standards should also reflect these concerns.

Standard 1: I experience high quality care and support that is right for me. To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

Neither agree nor disagree

Is there anything that is missing or should be added to this standard?

19. Statement 1.13. This statement should not be limited to needs and should also include spiritual care, an important consideration often missing from such standards. We suggest changing it to say "My emotional, psychological, physical and spiritual needs are assessed by a qualified professional at an early stage, regularly and when my needs or choices change." Sometimes people will change their mind about the care that they wish, or don't wish, to receive. This might have no relevance to their needs, but still should be respected by professionals and used to inform their care. We strongly recommend that anticipatory care planning (ACP) should be included in this standard. ACP is a process designed to support people living with a chronic long-term or terminal

illness to help plan for an expected change at some time in the future. It is a vital part of palliative care and should be included so patients know this is something they should expect to experience as part of their care. It is important that this is regularly reviewed with the person receiving care.

20. Statement 1.20. We support the statement in a broad general sense. However, we suggest that this should be revised to read “I fully participate, where possible, in developing and regularly reviewing my personal plan”. We agree that people should be fully involved and empowered to be involved in their care, have the right to change their mind and that this should be reviewed regularly. However, this should also take into account those people who have impaired capacity and are unable to fully participate in decisions around their own care. It is also important that when people are unable to participate in these decisions, plans are still regularly reviewed to ensure the person continues to receive the right care and support and the roles of carers is respected.

21. Statement 1.26. We suggest revision to “I am in the right place to experience the care and support I need and want, within the context of my own care”. Some people, particularly those with a terminal illness or those at the end of life, may have very complex, multiple conditions which means they may not have choice over where their care is delivered. It is important to acknowledge that while personal preference and choice is paramount, sometimes it is not possible to provide specialist care.

22. Statement 1.29. We suggest that this needs to be expanded to recognise that sometimes there are complexities in receiving medication in health and social care settings. For example, people with Parkinson’s will have a very structured timetable of medication. Often when they are admitted to hospital, their timetable will be disrupted and they may also be prescribed further medication depending on why they are admitted, creating complexities in medicine management. We suggest that this statement should be amended to say “If I need help with medication this is done safely and effectively, and takes into account both new and existing medication needs”.

23. Statement 1.30-1.35. While we recognise that the standards have been written using the principles of person centred care, we do not believe this is explicit enough in some sections. The eating and drinking part of standard one needs to reflect people’s preferences as well as the service’s convenience. We recommend addition of a statement that reads “I can have meals and snacks at an appropriate time, that is acceptable to me.”

24. Statement 1.35. We recommend that there needs to be further consideration of the specific dynamics of engagement between service users and healthcare services to ensure providers are not held to account for inappropriate or unrealistic standards. This general statement “I can drink fresh water at all times” may seem reasonable for all services. However, it is not always be applicable to everyone’s care. For example, it is not appropriate if a person, due to their condition, has no swallow reflex, is unconscious, or is fasting prior to general anaesthesia. We suggest that there should be recognition of these inherent differences in types of care, either through specialist standards or through flexibility and understanding in regulatory frameworks.

25. Statements 1.36-1.39. As with statement 1.26 above, these statements should be reframed to be within the context of someone’s care. These are quite rightly very

strongly focused on increasing personal independence and confirming individuals' places in society. However, they are not always applicable aspirations for people approaching the end of life.

Standard 2: I am at the heart of decisions about my care and support. To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

Neither agree nor disagree

Is there anything that is missing or should be added to this standard?

26. Statements 2.5-2.12. Anticipatory care planning (ACP) is a vital part of palliative care and in the care of people with long term conditions. It is a record that is developed over time through conversations, collaborative interactions and shared decision making. It is a record of the preferred actions, interventions and responses that care providers should make following a person's deterioration or a crisis in the person's care or support[1]. The ACP should be regularly reviewed and updated as someone's condition or personal circumstances change. The strongly believe that this should be included so patients know this is something they should expect to experience as part of their care.

27. The recent Scottish Government's health and social care delivery plan states that "all who would benefit from a Key Information Summary (KIS) will receive one". The KIS brings together important information to support those with complex care needs or long-term conditions, such as future care plans and end of life preferences. Any standard relating to anticipatory care planning should include the KIS.

28. As people's conditions become more complex it is also vital in some cases to discuss legal and practical issues as well as care and support preferences. We believe that this section should include a statement in recognition of these issues, including appointing a legal power of attorney independently, without coercion, and being able to be supported to document this.

Standard 3: I am confident in the people who support and care for me. To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

Agree

Is there anything that is missing or should be added to this standard?

29. Statements 3.1-3.4. While we agree with the statements outlined in this section, we do have some concerns that there is not enough focus in the standards on safe and effective care. We believe that there should be reference to professionalism and accountability in this standard.

30. Statement 3.5. We are supportive of this statement, however, we would recommend removing the caveat "if I do not know them" from the statement. We believe that staff should introduce who they are every time they provide care to someone. This would be beneficial for those people living with dementia and other conditions affecting their memory, but also for others as people can often see multiple health and social care professionals every day.

[1] http://www.gov.scot/Publications/2010/04/13104128/1

Standard 4: I am confident in the organisation providing my care and support. To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

Agree

Is there anything that is missing or should be added to this standard?

31. Statement 4.19. This statement should be revised to say "I am supported and cared for by people who have been appropriately recruited and trained to deliver the care that I need". This should include on-going training and support through continuing professional development and regular updates to maintain standards of care.

Standard 5: And if the organisation also provides the premises I use. To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

Agree

Is there anything that is missing or should be added to this standard?

32. Statement 5.9. There should be clarification on what is meant by a "service that is the right size for me". This could refer to the number of staff in a service, the size of the buildings or even the amount of other people that are supported.

33. Statement 5.19. We fully agree with this statement, however, we believe that timescales should be added, especially in the case of someone who is living with a terminal illness or those at the end of life. In these cases, time may be short and it is vital that aids and adaptations to people's homes or premises is fast tracked to enable people to live and die at home rather than hospital, if that is their wish and is achievable. 683 people died in hospital between the start of March 2015 and the end of September 2016. This is unacceptable. There needs to be a system in place to fast-track care and support for people living with a terminal illness.

34. Statement 5.25. As with previous statements, there should be an addition to this statement to recognise that this is not always applicable in the context of someone's care. We recommend that there needs to be further consideration of the specific dynamics of engagement between service users and healthcare services to ensure providers are not held to account for inappropriate or unrealistic standards.

Standard 6: And where my liberty is restricted by law. To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

Agree

Standard 7: And if I am a child or young person needing social work care and support. To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

Agree

Is there anything that is missing or should be added to this standard?

35. We believe that the majority of the standard statements in standard 7 would be applicable to other services and not just to children and young people. We would therefore recommend that this standard applies to all services. The majority of statements in this standard could easily apply to very frail or elderly people, or other vulnerable people. We have concerns that by only including these standard statements in a specific children's standard, means they may not be embraced in other services.

36. Statement 7.16, for example, could easily apply to patients with advanced Dementia or Alzheimer's Disease. This statement could refer to power of attorney and anticipatory care planning which is vital in later life, palliative and end of life care. We believe that reference to these aspects of care should be included in the standards – this could be included in Standard statement 1.13 or 2.5-2.12.

37. Statement 7.18 could also be adapted to ensure people continued to be supported and cared for at the end of life. Our research tells us that people aged 70 and over in Scotland are missing out on palliative care as healthcare professionals can find it difficult to know when to introduce this approach in older people, particularly those with frailty.

To what extent do you agree these new Standards will help support improvement in care services?

Neither agree nor disagree

38. On the whole, we agree that the standards set out what people should expect to experience from health, care and social work services. However, the standards alone will not necessarily drive improvements in care services. They need to be accompanied by a framework of mandatory education and training for all health and social care staff. We further believe that staff should be empowered to act upon these standards and challenge others' behaviour if necessary.

39. In a recent Unison Scotland report into social care, one in five social workers felt that they didn't receive adequate mandatory training and many feel that cutbacks, an intensifying workload and reduced hours are having a negative impact on the people they provide care for and causing increased stress in the workforce. 72.5 per cent of paid home care workers think this is set to get worse[2]. We are concerned that people working in health and social care are not supported enough to ensure that these standards improve the experiences of people's care.

40. Any framework to help support the implementation of these standards and improvements in care services should be developed alongside the standards.

Is there anything you think we need to be aware of in the implementation of the Standards that is not already covered?

41. We would also expect the new health and social care standards to link to existing guidance and legislation. We further recommend that any specific standards and statements to link to and build on existing clinical standards and guidance. For example,

[2] http://www.unison-scotland.org/library/WeCare_DoYou_UNISONCareWorkersSurvey_August2016.pdf

any standard on palliative care must be cross-referenced with the Strategic Framework for Action on Palliative and End of Life Care and clinical palliative care guidelines.

What should the new Standards be called?

42. National Health and Social Care Standards.

43. We believe this title will help to ensure people across all health and social care that they are standards they should be following. We also believe this makes it more clear for future inspections by Healthcare Improvement Scotland and the Care Inspectorate. These standards should be reflected in regulatory frameworks and any future clinical standards.

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Care and support through terminal illness