**National Institute for Health and Clinical Excellence**

**NICE Quality Standards Consultation – End of Life Care**

**Closing date: 5pm – 22 July 2011**

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| Organisation | Christian Medical Fellowship |
| Title (e.g. Dr, Mr, Ms, Prof) | Ms Philippa Taylor |
| Job title or role | Head of Public Policy |
| Address and post code | 6 Marshalsea Road, London, SE1 1HL |
| Telephone number | 020 7234 9660 |
| Email address | Philippa.taylor@cmf.org.uk |
| Are you happy to be named as a consultee to the Quality Standard on the NICE website? ☐ Yes | |

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Please provide comments on the draft quality standard on the form below. When feeding back, please note the draft quality statement number and indicate whether you are referring to the statement, measure or audience descriptor.

In order to guide your comments, please refer to the general points for consideration on the NICE website as well as the specific questions detailed within the quality standard.

Please add rows as necessary.

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| Question 1+2 | General Questions:<br><br>CMF welcomes this draft quality standard programme for end of life care for adults and the importance that NICE attaches to the care of dying adults. If implemented as it stands, these standards will provide a comprehensive and welcome contribution to improving the care of adults, family and carers, and to meeting their holistic needs at the end of life.<br><br>Caring for patients at the end of life involves meeting people as individuals, and there is no 'one size fits all', which can be a limitation of a 'tick box' type approach. Each person's journey towards the end of life is different, with some more concerned about relief from physical symptoms while for others it is a more emotionally distressing. Each person is also on a spiritual journey through which they interpret the meaning of their lives. For some this is religiously based while for others it is about personal worth, questions of meaning and purpose, close relationships and contribution to ideals they hold dear.<br><br>Unfortunately, there is an over-representation of difficult and tragic deaths in the discussion around end of life, while witnesses of 'good deaths' do not feel such a need to enter into this type of correspondence. This balance needs to be redressed so that people do not misunderstand and fear death, (and then, for example, place an over reliance on the use of advance directives). We are particularly wary about the use of advance refusals and care plans that offer premature withdrawal of nutrition, hydration, life-sustaining therapies and palliative treatments when as a society we now have |

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| | developed a wealth of resources to assist people in difficulty.<br><br>We have restricted our comments primarily to the spiritual needs of patients and to the personal care plans of patients. In our experience many patients approaching the very end of life (ie. last hours or days) are becoming drowsy and confused and are no longer able to discuss spiritual matters. Family members and carers often have need of spiritual support. We therefore suggest that it would also be beneficial to provide specific advice on how the spiritual needs of patients, families and carers might actually be met, and to ensure that it is then indeed met (and not for this simply to become a tick box exercise).<br><br>The standards do not address the broader question of whether nutrition and hydration are regarded as medical treatment or general care of patients in hospital - particularly the elderly, the disabled or confused patients. If it is medical treatment then the requirement is for adequate and appropriate food and liquid administration to be ordered and supervised by a health care professional, in a similar way to the administration of any drug regime. If it is general care there is a risk that it is regarded as the responsibility of the patient and their 'human rights' to take or refuse what is provided. This has lead to reports on elderly patients losing weight in hospital when presented with food which they have difficulty in cutting up or chewing, and drinks placed out of their reach - and at the end of the meal food and drink is removed without comment as it as regarded as the patient's choice not to eat or drink. |
| QS3 | DESCRIPTOR: The assessment could include questions such as ' Would you like a visit from the chaplain/ vicar/ priest/pastor/ rabbi/iman etc?' ‘Do you have a faith that helps you at times like this?’, Where do you get spiritual and emotional support?’ Questions aimed at understanding a patient’s basic world view (eg. atheist, theist, pantheist) will assist carers to provide appropriate support. It should be recognised also that some healthcare professionals, especially whose who have a personal faith, may well be competent to provide spiritual support themselves. The GMC, RCGP and MDU have all recently affirmed the appropriateness of a ‘tactful’ offer of prayer (see ‘GMC and MDU endorse 'tactful' |

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| | offers of prayer by GPs' - http://t.co/OpTQl06) If so these services should be arranged. |
| QS4 | Carers and family can be in need of as much, or even more, spiritual support than the patient<br><br>DESCRIPTOR: Carers and family could be asked if they would like a visit from the chaplain, vicar, rabbi or iman. Measures listed under QS3 above also appropriate. |
| QS5 | DEFINITIONS: include information/details about where and how to access spiritual support |
| QS6 | MEASURE: We question what is meant by 'local arrangements' to help people develop personal care plans, and who might take this role.<br><br>DEFINITIONS: There needs to be clarity on the differences between a care plan and advance directive/decision/refusal.<br><br>We note that in Scotland under the Adults with Incapacity (Scotland) Act 2000 as well as Continuing Power of Attorney for personal affairs, there is now the additional provision for a Welfare Attorney for welfare affairs. The latter has the legal right to be involved in all discussions on healthcare, medical treatment etc. Mention should also be made of the provision of a health and welfare lasting power of attorney under the Mental Capacity Act 2005.<br><br>We recommend LPA over advance directives – better to trust a person with your best interests at heart than a piece of paper which may be ambiguous or open to interpretation. In any event pressure should not be placed on patients to make formal advance directives or refusals and the anxieties underlying future undertreatment or overtreatment should be adequately addressed. |
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| QS 9 | Whilst for some patients, their spiritual framework consoles them and contributes to their resilience, others may require |

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| | additional support from spiritual advisors.<br><br>However many patients approaching the end of life are becoming drowsy and confused and are no longer able to discuss spiritual matters. At the same time, family members and carers often have need of spiritual support.<br><br>DESCRIPTOR: We recommend that family members and carers be specifically offered or invited to have access to that sort of support, and patient and family/carers should be offered to invite a spiritual leader to visit.<br><br>One important question not addressed in the standards is whether the health care professionals caring for the patient should be allowed to offer spiritual support/prayer for the patient and family themselves, or whether they should only offer to invite a suitable spiritual leader to provide that support. The GMC and MDU have endorsed the tactful offer of prayer by healthcare professionals (see above) and the GMC Guidelines on Personal Beliefs and Medical Practice the GMC guidance states, that although faith discussions would not normally be part of the patient doctor consultation, there were occasions when they were appropriate. The World Health Organisation's definition of health includes physical, mental, social and spiritual dimensions and part of practising whole-person medicine means addressing all issues that have a bearing on a person's health.<br><br>The GMC guidance recognises that 'all doctors have personal beliefs which affect their day-to-day practice' and that these principles apply to all doctors whatever their political, religious or moral beliefs. It emphasises that 'personal beliefs and values, and cultural and religious practices are central to the lives of doctors and patients' (p4); that 'patients' personal beliefs may be fundamental to their sense of well-being and could help them to cope with pain or other negative aspects of illness or treatment.' (p5) and that 'discussing personal beliefs may, when approached sensitively, help you to work in partnership with patients to address their particular treatment needs.' (p9)We would therefore like to underline the appropriateness in some circumstances of healthcare professionals providing spiritual care as part of whole person care. |
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| QS12 | DESCRIPTOR: to include the offer to patient and family/carers to invite a spiritual leader to visit. |

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| Omissions | One important omission we felt in the guidelines was a reference to the obligation to ensure that as part of end of life care patients are aware of and protected from exploitation and abuse. |
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| | A recent report by the Care and Social Services Inspectorate for Wales shows a 9% rise in the number of adult protection referrals in 2009-10. Around 5,000 cases of abuse are being investigated in Wales every year, the majority of those cases involving older people.<br><br>Elder abuse takes place in many different settings – for example, the older person's home, care homes, nursing homes and hospitals. It happens when an older person's human rights and dignity are violated. It can come through financial scams, physical attacks, sexual abuse, psychological abuse or neglect. The perpetrators are often in a position of trust and have control of the life of the older person. Elder abuse can also include actions that many people might not consider. For example, physical abuse can include inappropriate use of medication or force feeding, emotional abuse can include treating an older adult like a baby or otherwise injuring his or her dignity, and sexual abuse includes any sexual contact with a person who is incapable of consenting.<br><br>Furthermore, older adults are particularly vulnerable to less common forms of abuse, such as neglect and abandonment, violations of rights to privacy, community support and information, and financial abuse, which is the most prevalent form of abuse among older adults. Financial abuse is 'the illegal or improper use of an incapacitated or vulnerable adult or his resources for another's profit or advantage.' This type of exploitation can take many forms such as forgery, misappropriation of cash or assets, abuse of joint accounts, or abuse of power of attorney. Signs of financial exploitation may include disparity between income and assets, unexplained or sudden inability to pay bills, inaccurate or no knowledge of finances, fear or anxiety when discussing finances, or unprecedented transfer of assets to others. |
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**PLEASE NOTE:** The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion or the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.