

# GUIDELINES FOR SPIRITUAL CARE IN PALLIATIVE CARE



## 1. GENERAL PRINCIPLES

- ➤ Palliative care aims to deal holistically with physical, social, psychological and spiritual needs.¹
- ➤ Those approaching the end of life and the bereaved should be offered spiritual and religious support appropriate to their assessed needs and preferences.<sup>2</sup>
- Every individual has a spiritual dimension, relating to the meaning of life for them, which may or may not be expressed in terms of a faith or belief system.<sup>3</sup>
- ➤ There is not one agreed definition of spirituality, although this lack of definition may be a strength leading us to be more concerned with its meaning for the individual, and further searches for one definition is not advocated.<sup>4,5</sup>
- Spiritual care and religious care are different and very individual although the differences are not always clearly understood. They should neither be artificially separated nor assumed to be interchangeable. Spiritual care is not necessarily religious but religious care at its best should always be spiritual.<sup>3</sup>
- ➤ The diagnosis of life threatening illness has a profound effect on people and on their family and friends. It often provokes questions relating to identity and self worth as patients seek to find an ultimate meaning to their lives.<sup>7</sup>
- ➤ It has been shown that spiritual support by religious communities or the medical system is significantly associated with increased patient quality of life (p=0.0003). Near-death quality of life increases by 28% for patients receiving pastoral care or spiritual support from the medical team.<sup>8</sup>
- ➤ It is widely accepted that good communication and the ability not to impose one's own beliefs is essential in order to address spiritual issues.<sup>9</sup>
- ➤ It is agreed that it is the responsibility of every worker to identify and respond to spiritual need, albeit at different levels.<sup>5, 6</sup>
- ➤ Awareness raising procedures and specific simple educational programmes, have been shown to improve the documentation of spiritual and religious needs and the care given.<sup>10</sup>
- ➤ There is evidence of a widespread need for training, and educational intervention has been shown to provide significant benefits in terms of improving nurses' confidence, reducing hopelessness, providing better job satisfaction and increasing spiritual wellbeing. <sup>5,11,12</sup>
- ➤ The emerging literature suggests that narrative or storytelling approaches, using generic, open, assessment questions, are favoured over 'tools'. Where

- a narrative approach is a challenge for staff, simple assessment tools promoting open questions may be a necessary supportive alternative.<sup>5</sup>
- Integration of spirituality at work, and the spiritual support of staff, may buffer the emotional stress and risk of burnout for healthcare providers dealing daily with the sorrow of terminal illness, and enable them to continue to provide spiritual support.<sup>5,13</sup>
- Additional resources including web-links and local training courses are outlined in Figure 1

## 2. GUIDELINES

- > Specialist palliative care services should encourage the process of spiritual caring, which requires constant reflection, assessment and review. [Level 4]
- ➤ All specialist palliative care professionals should be aware of spiritual issues for patients and families and be able and feel confident to respond in a flexible, non-imposing and non-judgmental manner. This will include support in living with unanswered questions without necessarily requiring onward referral.<sup>5,7</sup> [Level 4]
- Accurate and timely evaluation of spiritual issues should be facilitated through a form of individual, preferably narrative, assessment, based on recognition that spiritual needs are likely to change with time and circumstances.<sup>5,7</sup> [Level 4]
- Assessment of spiritual needs does not have to be structured, nor require the use of an assessment tool, but would need to include care elements such as
  - 1. Exploring how people make sense of what happens to them
  - 2. Identifying sources of strength they can draw on
  - 3. Exploring whether these are felt to be helpful to them at this point in their life. <sup>5,7</sup> [Level 4]
- Spiritual care should provide support to make sense of difficult life events. This may be achieved through exploration of spiritual and existential issues, fostering of realistic hope and promotion of wellbeing.<sup>7</sup> [Level 4]

### 3. STANDARDS

- 1. Every patient record should demonstrate documentation of an initial spiritual needs and preferences assessment.<sup>2,7</sup> [Grade D]
- 2. Every patient record should demonstrate a record of the patient's faith tradition (religious affiliation or belief system) or its absence. [Grade D]
- 3. Where there is a faith tradition, the significance to the patient should be recorded. [Grade D]
- 4. Every patient record should demonstrate evidence of ongoing spiritual assessment and support where indicated.<sup>2,7</sup> [Grade D]
- 5. Where the patient has a documented faith tradition, the patient record should demonstrate evidence of ongoing religious assessment and support where indicated.<sup>5,7</sup> [Grade D]

- 6. All specialist palliative care staff should be able to demonstrate evidence of training in spiritual awareness as part of their continued professional development.<sup>5,7</sup> [Grade D]
- 7. All specialist palliative care services should have access to suitably qualified, authorised and appointed spiritual care givers. [Grade D]
- 8. All specialist palliative care services should have access to a current directory of local spiritual care resources (religious and other). [Grade D]
- 9. Each local specialist palliative care services should have a nominated person to be responsible for liaising with local faith leaders and other spiritual resources.<sup>7</sup> [Grade D]
- 10. Each local specialist palliative care services should have specialist palliative care inpatient and day facilities with dedicated and accessible multifaith quiet space and equipment.<sup>7</sup> [Grade D]
- 11. Each local specialist palliative care services should have specialist palliative care services whose policies and procedures reflect recognition of the spiritual needs, support, and education of their own staff members. <sup>5,7</sup> [Grade D]
- 12. There should be an agreed Network Spiritual Care Policy. 5,14 [Grade D]

# Figure 1 Additional Resources for Training in Spiritual Care

## **Useful Web links**

1. Religious Needs Website www.queenscourt.org.uk/spirit

A religious needs resource developed by Cheshire & Merseyside Network Spiritual Care Subgroup.

## 2. Cheshire & Merseyside Network Spiritual Care Policy

www.mccn.nhs.uk/userfiles/documents/MCCN%20Spiritual%20Care%20Polic v

# **Training Courses Available**

# 3. e-ELCA (End of Life Care for All) e-elearning

www.e-lfh.org.uk/projects/e-elca/register

Registration page for e-learning package developed by e-lfh (e-learning for healthcare)

4. 'Opening the Spiritual Gate' www.openingthespiritualgate.net

Website containing information about the Network face to face and elearning training course

### 4. REFERENCES

- 1. World Health Organisation. WHO Definition of Palliative Care 2002 http://www.who.int/cancer/palliative/definition/en/# [Last accessed 10/05/14]
- National Institute for Health and Care Excellence. Quality Standard for End of Life Care for Adults. London: Department of Health. QS13, 2011 modified 2013.
- 3. The Scottish Government. Spiritual Care and Chaplaincy. Edinburgh: NHS Scotland 2009.
- 4. Gordon T, Mitchell D. A competency model for the assessment and delivery of spiritual care in the NHS in Scotland. *Palliat Med* 2004; **18(7)**: 646-651.
- 5. Holloway M, Adamson S, McSherry W, Swinton J. Spiritual Care at the End of Life: a systematic review of the literature. London: Department of Health 2011.
- 6. Mount, B. Healing, quality of life, and the need for a paradigm shift in health care. *J Palliat Care*. 2013; **29(1)**: 45-48.
- 7. National Institute for Clinical Excellence. *Improving Supportive and Palliative Care for Adults with Cancer*. London: Department of Health. 2004.
- 8. Balboni TA, Paulk ME, Balboni MJ, et al. Provisions of Spiritual Care to Patients with Advanced Cancer: Associations with Medical Care and Quality of Life Near Death. *J Clin Oncol* 2010; **28:** 445-452.
- 9. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a metastudy of qualitative research. *Palliat Med.* 2010: **24(8)**: 753-769.
- 10. Drijfhout M, Baldry C. Spiritual Care: making it happen. *Eur J Pall Care*. 2007; **14(5)**: 191-193.
- 11. Morita T, Murata H, Kishi E, Miyashita M; Yamaguchi T; Uchitomi Y. Meaninglessness in Terminally III Cancer Patients: A Randomised Controlled Study. *J Pain Sympt Manage* 2009; **37**: 649-658.
- 12. Wasner M, Longaker C, Fegg MJ, Borasio GD. Effects of spiritual care training for palliative care professionals *Palliat Med* 2005;**19**: 99-104.
- 13. Holland JM, Neimeyer RA. Reducing the risk of burnout in end-of-life care settings: The role of daily spiritual experiences and training. *Palliat Support Care*. 2005:**3**: 173-181.
- 14. MCCN Spiritual Care Group. *Merseyside & Cheshire Cancer Network Spiritual Care Policy*. Liverpool. Updated June 2012 www.mccn.nhs.uk/fileuploads/File/MCCN%20Spiritual%20Care%20Policy %20Guidelines%20and%20Standards%202012%20amended.pdf [Last accessed 10th May 2014]

### **GUIDELINE DEVELOPMENT GROUP**

## **Lead Contributor**

**Dr Karen Groves:** Consultant in Palliative Medicine, West Lancs, Southport & Formby Palliative Care Services, Southport & Ormskirk Hospital NHS Trust & Queenscourt Hospice, Southport.

### **Contributors**

**Dr A Whitmarsh:** Consultant in Palliative Medicine Blackpool, Fylde & Wyre Hospital NHS Trust.

Dr C Watt: Consultant in Palliative Medicine, St John's Hospice, Lancaster

Dr K Gaunt: Specialty Registrar in Palliative Medicine, Mersey Deanery

Dr E Taylor: Specialty Registrar in Palliative Medicine, Mersey Deanery

Mrs C Baldry: Director of Nursing & Education, Queenscourt Hospice, Southport

**Mrs D Valentine-Gray:** Clinical Nurse Specialist in Palliative Care, Liverpool Womens Hospital NHS Trust

Mrs A Black: Clinical Nurse Specialist in Palliative Care, Royal Liverpool and Broadgreen University Hospitals NHS Trust

**Mr P Saltmarsh** Assistant Directorate Manager in Palliative Care, Royal Liverpool and Broadgreen University Hospitals NHS Trust

Ms A van der Woude: Aintree Palliative Care Service, Aintree University Hospital NHS Trust

Mr G Ellams: Quality Assurance Officer, Halton Haven Hospice, Halton

## **Invited Expert**

Professor DJ Davies: Centre for Death & Life Studies, Durham University

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