Guidelines for Supporting the Spiritual Care of Patients with Dementia in the Acute and Community Hospitals and Mental Health setting

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1. Introduction

This document is produced to help raise awareness of the importance of providing for the spiritual care for patients with dementia and their carers and to offer a way forward for enabling such care.

BACKGROUND INFORMATION

There is a tendency to assume that because a person is cognitively impaired and has difficulties communicating that they either do not have any spiritual needs or that they are incapable of responding to any kind of spiritual care intervention.

Professor John Swinton of Aberdeen’s Centre for Advanced Studies in Nursing, writes “Whilst outer appearances may well reflect chaos, forgetfulness and loss, there may well be hidden depths to the person that, if the key can only be found, may reveal new and healing perspectives on the situation.” He further suggests that “enabling people to function within the spiritual dimension is in fact a key which can unlock the person and reveal dimensions of personhood that appear lost until they are encountered in the stillness of that spiritual moment.” (Swinton in Jewell (Ed) 2011 p181)

Moreover, “Neglect of the spiritual dimension of care seriously impoverishes the quality of life for people just as surely as neglect of the physical dimension – though the latter may be more apparent.” (Shamy, Eileen, 1997, More than Body, Brain and Breath: A Guide to the Spiritual Dimension of Care for People with Alzheimer’s Disease, Jessica Kingsley, London p 55, Goodall in Jewell (Ed) 2011 p135)

Meeting the spiritual needs of people with dementia is not an optional extra but is crucial if the NHS is to fulfil its aims of holistic person-centred care.

2. Understanding Spiritual care and understanding dementia

There is a need amongst all staff groups to understand what spiritual care is and what it is not and also a need for staff to have a basic level of understanding of dementia and how it affects a person. These two
areas find common ground in endeavours which foster personhood. We cannot offer person centred care and therefore cannot meet spiritual need if we do not see the person behind the dementia. "Service users and their carers should expect procedures...to meet any particular needs and preferences relating to gender, personal appearance, communication, diet, race or culture, and religious and spiritual beliefs.” NSF Standard Two.

It is also important to realise that many patients coming into the care of the Health Board may not necessarily have a diagnosis of dementia but will have symptoms of memory loss, confusion, communication difficulty. Person centred Spiritual care will help to foster their well-being also.

2.1 Understanding Spiritual care: RCN definition

Spiritual Care
”That care which recognises and responds to the needs of the human spirit when faced with trauma, ill-health or sadness, and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires.”

Royal College of Nursing, Spirituality in Nursing Care Guide (NHS Education for Scotland, 2009)

Spiritual Care is not simply a matter of providing an opportunity for religious observance. We all have spiritual needs as we all have a need to feel valued and affirmed, be loved and love. We all have a need to hope in something whether in this life or beyond. We all have a need to have faith and trust in someone or something and we all need to know peace in our lives and have a sense of security and tranquillity. These are all essential human needs. They are all spiritual needs as they are to do with the inner realm of the human experience.

Attention to spiritual need requires a consideration of the person’s culture including their religious beliefs and experiences where present. But spiritual and religious needs are not necessarily the same.

A person’s spirituality is linked to their sense of identity. Therefore it is crucial that we see the person beyond the dementia and that requires more than addressing medical needs and engaging in therapeutic activity. Tools such as the This is Me document provide a mechanism for achieving this where it is used. Meeting the spiritual needs of older people as understood above is not an optional extra but is essential if the aims of holistic, person-centred care are to be met.
2.2 Understanding Dementia

Dementia is an umbrella term describing a syndrome caused by various diseases of the brain. The symptoms include gradual loss of memory, reasoning and communication skills, leading to progressive decline of the essential elements of mental functioning. There are several different types of dementia, including Alzheimer’s disease and vascular dementia. Dementia can also be associated with other diseases such as Parkinson’s disease. National Dementia Vision for Wales, Welsh Assembly Government

Individuals may develop psychological symptoms such as depression, and psychosis, and also display aggressive behaviour and tendencies to wandering at any stage of the illness. The different forms of dementia can affect people of working age as well as older adults and those with learning disabilities may be particularly at risk. Living with Dementia: A National Dementia Strategy UK Government

3. The Healthcare Environment & Dementia

The Royal College of Nursing recognises the need for a deliberate commitment within the Health Care setting for patients living with dementia. They identify 5 aspects of such care. (SPACE) Spiritual Care can make a valuable contribution to realising these aspects in good dementia care.

Make SPACE for good dementia care

The top five ingredients for supporting good dementia care

1. Staff who are skilled and have time to care
2. Partnership working with carers
3. Assessment and early identification of dementia
4. Care plans which are person centred and individualised
5. Environments that are dementia friendly

Dementia: Commitment to the Care of People with Dementia in Hospital Settings, RCN pg 2

Staff

National findings regarding both the need for staff training on dementia and the need for a greater realisation that spiritual care can provide the
key to fostering person centred care and reconnecting with the patients spiritual heritage.

The findings of the National Dementia Strategy and the National Dementia Action for Wales identify that there are marked deficits in the knowledge and skills of general hospital staff caring for patients with dementia.

Furthermore the "Education and training of healthcare staff on the issues involved in the provision of spiritual and religious care including the role of the chaplain / spiritual caregiver enhances the confidence and knowledge of care and can improve care for patients and their carers." (Standards for Spiritual Care services in the NHS in Wales 2010 document Standard 5)

Dementia care training for all staff who come into contact with patients is also a recommendation of the Older Peoples commissioner. Health Boards must find ways of delivering Dementia care training.

The Spiritual Care Department have identified 4 ways in which person centred spiritual care for patients living with dementia can be improved and are willing to work with other healthcare staff to achieve them.

**Recommendation 1**
All staff and volunteers who come into contact with patients with dementia receive basic awareness training including how to maintain a sense of personhood and well being including spiritual care. Chaplains are able to assist with such training. See Guidelines for person centred communication

**Recommendation 2**
Every ward/unit has a designated member of the care team to ensure that patients with dementia have the support and stimulation appropriate to their situation and ability. Funding should be made available for this work.

**Recommendation 3**
The routine implementation of the ‘This is Me’ document supported by the ‘Memories Are Made of This’ reminiscent book with all patients with memory/confusion issues. Spiritual Care Volunteers are available in some hospitals to assist with this.

**Recommendation 4**
A system of referral is created to assist in caring for the spiritual needs of dementia patients which may be identified in the ‘This is Me’ document.
It is very important that the patient’s religious affiliation is ascertained and documented at the earliest opportunity so that any dietary and
Spiritual care requirements can be implemented and the appropriate religious leader can be contacted if necessary, e.g. Imam, Minister, Priest, Rabbi etc (See Glossary of Terms and A Multi-Faith Resource for Healthcare Staff, NHS Education for Scotland) This base level screening for Spiritual Support is requested in nursing documentation but is largely not completed by front line staff.

**Recommendation 5**
Carers are actively supported to enable them to cope with the demands of caring for their loved ones so that such care does not have a detrimental impact on their own health and wellbeing. The hospitalisation of the carer presents significant challenges to the wellbeing of both parties.

**Partnership working with carers**
Carers are the link between the patients’s past and present. They can provide the information needed to offer person centred care and can assist with maintaining a sense of identity and connection with the present. The **This is Me** document is a tool which relatives and carers could complete both with and for the patient and also be involved in creating care plans which are tailored to the individual patient. Supporting such carers is an important role for the Spiritual Care Team. This is especially important for those carers who are looking after their loved ones at home. The Spiritual Care Department also holds an annual memorial service for relatives who have lost family members though dementia.

**The Environment**
This would include recreating an environment which those suffering from dementia associate with early experience of faith as it is an integral part of meeting their spiritual need. Thus a sacred space reminiscent of a ‘faith building’ establishes a connection with the patient that revitalises them as people. Creating a sense of holiness is important. Arranging a service in the dining room might seem acceptable but for the patient the dining room is somewhere where one eats not somewhere where one worships. Thus immediately confusing signals are being communicated and opportunities for reconnecting with their spiritual life made more difficult.
4. Implementing Spiritual Care

Spiritual care may be given by any member of the Multidisciplinary Care Team; however there are dedicated specialists in the Spiritual Care Department. Cwm Taf Health Board currently has 1 part-time chaplain designated for the spiritual care of patients with dementia and their carers. Spiritual care volunteers also assist in the delivery of person centred spiritual care. They have received additional training for this role.

Intervention from outside agencies, e.g. Leader of the patient’s faith community, may also be given, but must be agreed by the patient / next of kin (NOK) and monitored by the nursing staff to ensure that such intervention is not disrupt the patient’s well being.

Implementation will take the form of:

- Psychological, emotional and spiritual support giving personal value.
- Provision of information and other resources, including where appropriate, therapies and/or activities (such as music therapy, pet therapy and reminiscence) which will help to maintain the patient’s sense of well being.
- Short religious services on ward or in chapel / multi-faith room, to include well-known hymns, Lord’s Prayer, with patients being offered percussion instruments to assist in music making.
- Provision of a quiet space / hospital multi-faith chapel or prayer room for individual reflection, prayer and spiritual support for patients and carers.
- Routine ward visiting by Health Board chaplains and Spiritual Care Volunteers.
- Liaison with community resources and religious leaders when requested by staff, patients or carers.
- Support, encouragement and spiritual / pastoral care for the patient’s NOK.
- Organising visits and interaction from Choirs, schools, preferably in communal areas to give patients the stimulation of leaving the ward when possible, but also on dementia wards or units if it is difficult for patients to leave that environment.

The Spiritual Care Department offers care which will be:

- Accessible including out of hours religious care for end of life.
- Caring, sensitive and not time constrained.
- Patient focussed, with support for relatives / carers.
• Confidential, conforming to the Multidisciplinary Code of Confidentiality.
• Neutral, in religious representation and available to people of all faiths and none.
• Ethical, conforming to the Ethical Standards of the NHS.
• Honest, but sensitive in communication so that information shared is at a rate and level which will maintain or enhance a positive sense of well being.
• Non-judgemental, in not applying value judgements regarding the spirituality, religion, philosophy or lifestyle of the individual.
• Professional, conforming to the Codes and Standards of the spiritual care givers Professional Body.
• Consistent, conforming to the recommendations of the NICE Guidelines on Improving Care for Patients with Dementia.

• **Memories are Made of This** reminiscence book developed as an aid to patient enrichment by the Spiritual Care Department to be used to support the **This is Me** document
• Memory Box therapy for one to one care.

5. **Outcomes of Spiritual Care for patients**
Outcomes exhibited by patients relate to having a greater sense of well being.

It has been noted that during or after short “services” of hymn singing, prayer and a reading of a short familiar sacred text, patients often exhibit physical reactions such as smiling, foot tapping, clapping, arms raised, dancing. Similar responses follow the use of the memories are Made of This reminiscent book with patients.

Other responses can be:
- calmer presentation suggesting relief from anxiety and fear
- emotional feelings expressed
- memory refreshed through recalling words to hymns

Singing often has a unifying effect which can help the patient feel part of a ‘community’ again rather than being locked in isolation.

*“Music is no luxury to those lost in dementia but a necessity, and can have a power beyond anything else to restore them to themselves, and others at least for while.”* (Musicophilia Sacks, Oliver, 2007, Picador, London p347 in Jewell (Ed) 2011 p151.

Prayer can also have a calming effect on behaviour and memory may be stimulated by the Spiritual care giver and patients reciting familiar religious texts together.
6. **Guidelines for Person-Centred Communication**

1. Always introduce yourself by name and always use the patient’s preferred name.
2. Always ask the patient what they would like and how they would like to do it. Don’t assume that they are incapable of thinking and making choices. They may not always talk but they always feel.
3. Focus on what they can do and not what they can’t.
4. Avoid ‘no, you are wrong messages.’ E.g. no, this is your home now. Or No, your husband is dead.
5. Go with the story, don’t correct.
6. Use distraction if a patient starts to become agitated or distressed.
7. Approach in the line of vision so that they can see you coming.
8. Use memory prompts, cherished possessions, symbols to connect with happy/meaningful times.
10. Do not raise your voice unless the patient is hard of hearing and then it is always more helpful for the patient if they can see your face and read your lips.
11. Be patient in waiting for a response. It takes patients with dementia longer to process information.
12. Engage with the patient in their world rather that bring them into yours.
13. Smile and look into their eyes.

7. **References**

*NICE National Institute for Health and Care Excellence*

*CG42 Dementia: Supporting people with dementia and their carers in health and social care*

1.1 Principles of care for people with dementia

1.1.3
Health and social care staff should identify the specific needs of people with dementia and their carers arising from diversity, including gender, ethnicity, age (younger or older), religion and personal care. Care plans should record and address these needs.

1.1.9 Training and development of health and social care staff

1.1.9.2
Applying the principles of person-centred care when working with people with dementia and their carers; particular attention should be paid to
respect, dignity, learning about each person's life story, individualising activities, being sensitive to individuals' religious beliefs and spiritual and cultural identity, and understanding behaviour that challenges as a communication of unmet need.

All documents should comply with current approved practice and the author will need to references these within the document.

**This is Me** – A document initially developed by the Alzheimer’s Society but adapted by Cwm Taf Health Board forms an important aid in the delivery of person-centred care for those with dementia. Information needs to be gathered from relatives and carers as soon as possible after the patient is admitted to enable the best care. The document needs to be available for all staff, including chaplains, to refer to when offering care to the patient, and for the patient’s visitors to record feedback and journaling. Spiritual Care Volunteers may be available to help with the initial completion of this document if required.

**The source documents for these Guidelines are:**

1. *National Dementia Action Plan for Wales, Welsh Assembly Government*
2. *National Dementia Vision for Wales, Welsh Assembly Government*
3. *Living with Dementia: A National Dementia Strategy UK Government*
4. *Dementia: Commitment to the Care of People with Dementia in Hospital Settings, RCN*
7. *A Multi-Faith Resource for Healthcare Staff, NHS Education for Scotland)*
9. *NICE Guidelines on Improving Care for Patients with Dementia.*
Appendix A - Identifying a need for Spiritual Care

Criteria by which to identify the need for spiritual support:

1) Past or present connection with a Faith Community – see This is Me document, religious objects around the bedside, visits from faith leader.

2) Spiritual distress may be indicated during the early stages of dementia, or in more ‘lucid’ moments, by any of the following,
   - Abandonment e.g. “I feel abandoned, lost, alone…”
   - Agitation
   - Anger – directed at God, others or self “I’m no use to anyone, I hate being like this, I feel so useless”
   - Bitterness – “This is not fair…I don’t deserve this”
   - Despair – sensing negative future stretching ahead “What is the point of going on? What is the point of living? …”
   - Doubt – “I can’t believe in God anymore”
   - Fear
   - Fretfulness
   - Guilt / punishment – “I must have been very wicked, I’m being punished, I’ve wasted my life…”

3) A patient may need spiritual support if they appear to be searching for meaning:
   - Personal identity –“Who am I?” (loss or role, independence…)
   - Meaning and purpose of life (generally or within their current circumstances) – “What shall I do? What do I do now?” “I don’t know what’s happening”
   - Search for something greater than themselves (‘Higher Power’, ‘more than this’)

Criteria by which to identify the need for pastoral and emotional support from wider care team:

- Patient has few visitors
- Patient is weepy or agitated or confused and may present challenging behaviour because needs are not being met, or patient is unable to express their needs verbally, or because of fear, not understanding what is happening.
- Patient perceives carer / relatives don’t care or really understand
- Patient / carer is troubled and needs and ‘advocate’ to speak for them
- Patient is fearful about returning home or staying in hospital, or entering residential care
- Patient is grieving the loss of a relative, or home, or independence
- Relative is exhausted and needs encouragement to take a break from their loved one
- Patient or relative requires help with making funeral arrangements

Patients may simply need some “loving attention” from someone who has the time and sensitivity to listen or sit and hold their hand.

**Criteria by which to identify the need for religious support**

- **This is Me** document, or carer, relative, or visitor identifies patient has past or current membership of, or affiliation to, a religion and/or Faith Community.
- Patient, carer or relative or visitor asks for some religious rite e.g. Holy Communion, Prayer
- Patient has their own religious artefacts or material around bedside
- Patient or carer, relative or visitor becomes anxious about the patient’s fulfilment of religious obligations at certain times and occasions, e.g. Ramadan, Sabbath, Easter
- Patient or carer, relative, or visitor expresses desire for patient to visit the hospital chapel or multi-faith room
- Patient or carer, relative, or visitor requests devotional material for the patient e.g., Koran, Scriptures, rosary
- Patient or carer, relative or visitor asks about Kosher, Halal or other dietary needs, or personal care.
- Patient responds enthusiastically to chaplaincy provision of “religious service” on the ward e.g. hymns, prayers
Appendix B -