Back to the fundamentals: Reintegrating dignity and spirituality within person-centred care

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A Quote

• “I would probably rather tell you about my sex life than about my spiritual life. And I’m fairly sure that you would be more scandalised to find a bible at the bottom of my briefcase than a copy of the karma sutra.”

• (Allen 1991 pg 52)
Objectives

• Demonstrate that these altruistic and humanistic aspects of the person are central to the delivery of care

• Highlight that dignity and spirituality are central to identity – an individual’s own sense of purpose, values and beliefs

• Reinforce that these concepts are fundamental aspects of caring and compassionate care, integral to the concept of holistic practice and person-centred care
Recent Reports
Debate in context 2017: Adult inpatient Survey

“Since 2009, the percentage of respondents who said they were ‘always’ treated with respect and dignity in hospital has increased, 82% in 2017 compared with 78% in 2009. Trend analysis indicates that there has been an underlying behavioural change since 2009, where results were below expected limits, and has risen above expected limits since 2015.”

A turning point in my career

Peter, 72 years old, was known by his family and friends to like a short or two. He was admitted to hospital with an acute episode of chest pain. A diagnosis of angina was made since ECGs showed no evidence of recent infarct.

It came to light later that Peter was a practising Roman Catholic who found meaning and purpose in his beliefs. Peter had only been in hospital overnight and he had not seen his wife because she had taken herself off to their daughters ‘down south’ after an argument. Nevertheless she was informed by Peter of his admission into hospital and she was intending to visit as soon as possible. In the afternoon on the following day Peter was due to be discharged when he developed sudden severe central chest pain, collapsing with a cardiac arrest – resuscitation was initiated. During the resuscitation Peter’s wife arrived on the ward. Unfortunately she did not see Peter before he died.

After Peter’s death his wife asked if the Catholic priest had been. Inspection of the nursing notes showed that nothing in relation to religion had been entered.
Medical Model?

TRAUMA NURSING CARE MANIKIN, Clinical Training Model, medical model, anatomical model
Frequently used terms

• Individualized care
• Holistic care
• Spiritual care
• Dignity in care
• Person-centred care
• Relationship/family centred care
• Compassionate care
• Integrated care
• Evidenced based care
“Putting the patient first
The patients must be the first priority in all of what the NHS does. Within available resources, they must receive effective services for caring, compassionate committed staff, working within a common culture, and they must be protected from avoidable harm and any deprivation of their basic rights p85”
Standard representation of holistic care
Something there?

Hardy writes:

“It is therefore of interest that in recent years a considerable body of evidence has been accumulating in both the physical and social sciences suggesting that our spiritual nature is real and not illusory. Or many of the people I have spoken with during my research put it ‘there is something’. [he goes on to say]

... that spiritual awareness is a necessary part of our biology, whatever our religious belief or lack of them.”

2006 pp xi –xii
Introduction to the Dignity Government Initiatives

- Dignity in Care Campaign aims to **stimulate a national debate** around dignity in care and create a care system where there is zero tolerance of abuse and disrespect of older people. *(Launched in November 2006)*

- It is led by **Government in partnership with many organizations**.

- Lays out the **national expectations** of what a care service that respects dignity should value.

- Introduced **Dignity Champions** Scheme.

- Focuses on ten **Dignity Challenges**.
# 10 Dignity Do’s

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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<tbody>
<tr>
<td>Abuse</td>
<td>Have a zero tolerance of all forms of abuse.</td>
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<tr>
<td>Respect</td>
<td>Support people with same respect you would want for yourself or a member of your family.</td>
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<tr>
<td>Privacy</td>
<td>Respect people’s right to privacy.</td>
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<tr>
<td>Autonomy</td>
<td>Maintain the maximum possible level of independence, choice and control.</td>
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<tr>
<td>Person-centered Care</td>
<td>Treat each person as an individual by offering a personalised service.</td>
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<tr>
<td>Self-esteem</td>
<td>Assist people to maintain confidence and a positive self-esteem.</td>
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<tr>
<td>Loneliness &amp; Isolation</td>
<td>Act to alleviate people’s loneliness and isolation.</td>
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<tr>
<td>Communication</td>
<td>Listen and support people to express their needs and wants.</td>
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<tr>
<td>Complaints</td>
<td>Ensure people feel able to complain without fear of retribution.</td>
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<tr>
<td>Care Partners</td>
<td>Engage with family members and carers as care partners.</td>
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Model of Dignity – Adapted from Dignity and Older Europeans (2004)
Abraham Harold Maslow (April 1, 1908 - June 8, 1970) was a psychologist who studied positive human qualities and the lives of exemplary people. In 1954, Maslow created the Hierarchy of Human Needs and expressed his theories in his book, Motivation and Personality.

**Self-Actualization** - A person’s motivation to reach his or her full potential. As shown in Maslow’s Hierarchy of Needs, a person’s basic needs must be met before self-actualization can be achieved.
Fenton’s and Mitchell’s definition (2002 p 21)

Dignity is a state of physical, emotional and spiritual comfort, with each individual valued for his or her uniqueness and his or her individuality celebrated. Dignity is promoted when individuals are enabled to do the best within their capabilities, exercise control, make choices and feel involved in the decision-making that underpins their care.

Spiritual and dignity preserving nursing care

SPIRITUALITY

Social

Physical

Psychological
Question 2

- What is your understanding of the word spirituality?

https://www.menti.com
Responses from a recent public lecture

What is your Understanding of the Word Spirituality
Patients’ perceptions

“Well that’s what I thought when I got this letter you know. Well I thought well again we’re back to religion!”
(A older lady receiving Palliative Care)

“Spirituality I think it is personal, it depends on what the individual believes for example my mother believes spirituality to be psychic, ghosts and people coming back from the dead. Where as I think it to be what religion you believe in your own aspects towards god or however it is that you worship.”
(A young lady receiving medical care in an Acute Trust)
Ghosts and Ghouls
Nurses perceptions

“I think it’s different to every person, to me spirituality is what makes me feel what makes me! The emotional side, the essence of living! It makes somebody feel whole. It’s the sparkle. Yeah it’s just Je ne sais quoi! I don’t know?”

Senior Nurse working in Palliative Care
“I certainly don’t see spirituality as belonging to a religion; I don’t see it as that. And I think that probably because I don’t have a practising faith at the moment. Working at the hospice and seeing people die and it just makes me doubt the existence of a forgiving merciful God. So I can’t see it doesn’t fit comfortably spirituality and religion to me. The chaplain and I have lots of interesting conversations and discussions, which he always wins. Because he’s got lots of information and experience from the religious point of view! So you come away from these conversations feeling very dissatisfied. So it’s certainly not there! It sort of experiences I think to me, things that things that you know I find meaningful, think awe the wow factor!”
“My current understanding is that it’s three-fold! The meaning purpose aspect which is most often talked about is only part of spirituality and I would say that equally at least relationships and I still struggle to find the right word a sense of transcendence awe, wonder, mystery are also important parts of spirituality and spiritual care.”
Definition of Spirituality

Spirituality is universal, deeply personal and individual; it goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all of humanity.
A couple of useful guides
Distinguishing Religion and Spirituality
Adapted from (Koenig et al 2001 p 18)

Religion

- Community Focused
- Observable measurable, objective
- Formal orthodox, organized
- Behavior orientated, outward practices
- Authoritarian in terms of behavior
- Doctrine separating good from evil

Spiritual

- Individualistic
- Less visible and measurable, more subjective
- Less formal, orthodox, less systematic
- Emotionally orientated, inward directed
- Not authoritarian, little accountability
- Unifying, not doctrine oriented

“It seems that, as human beings, we are persistently driven by goals beyond mere material satisfaction to seek deeper level of meaning and fulfilment.”
Sheldrake (2014) 4 typologies (Types of spirituality)

- Ascetical
- The mystical
- The prophetical
- The practical

Spirituality
Sheldrake (2014) 4 typologies (Types of spirituality)

- **Ascetical:** liberation from material preoccupations and a deepened moral behaviour (p14. Discipline and non religious practice of meditation, mindfulness (p168)

- **Mystical:** a quest for an immediate consciousness of, or sense of a deep connection with, God or the ultimate depths of existence... way of ‘knowing’ that transcends purely rational analysis (p15)

- **Practical:** promotes the everyday world as the main context for following a spiritual path (pp15-16)

- **Prophetic:** while equally focused on the everyday world, goes beyond the practical service of our fellow humans in favour of social critique and commitment to social justice as a spiritual task. (p16) Finally the critical-prophetic ‘type’ is arguably detectable in some discussions of spirituality in relation to renewed vision of human care in the health professions...(p168).
After a robust and dynamic discussion with several rounds of voting, agreement was reached on the following definition of spirituality:

“Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.”
In summary - so what is spirituality?

**Existentialism:** the way individuals derive and find meaning, purpose and fulfilment in life.

**Relationship:** the relationships that are significant to an individual’s sense of identity, health and wellbeing – these could be relationships with family, friends, the environment, community and creatures.

**Transcendence:** a sense of something greater and beyond self this could be God, deity, supreme being or Higher Power. It could also be aspects of life that enable the individual to transcend themselves or situations.

**Connection:** the sense of connection individuals have within themselves, with others, the environment and for some God or higher Power.

**Religiosity:** for some people their spirituality and worldview is based upon adherence to a specific religious teaching, doctrine and practice. These inform and influence belief, attitudes, values and behaviours.

RCN (2010) Spirituality is about:

- Hope and strength
- Trust
- Meaning and purpose
- Forgiveness
- Belief and faith in self, others and for some this includes a belief in a deity/higher power
- Peoples values
- Love and relationships
- Morality
- Creativity and self expression
For me spirituality is absent when:

• It devalues, diminishes the identity of the person, leading to a violation of their dignity

• Leads to an intentional destruction of human life, communities, societies, environments, natural world

• Ideologies that are divisive, oppressive, disempowering, promoting propaganda that lacks sensitivity and respect for equality diversity and fundamentally upholding of human rights
Extract from the award-winning short film:

What do you see?

- Film produced by Amanda Waring based on the poem ‘Crabbit Old Women’ by Phylis McCormack.

- [https://www.youtube.com/watch?v=MTcopj6dYWQ](https://www.youtube.com/watch?v=MTcopj6dYWQ)

“We get treatment in the hospital and care in the hospice”
Treatment

Scientific
Proficient
Technical Competence
Detached
Robotic
Cold
Care or more precisely caring

Warm
Time
Presence
Valued
Accepted
Recognise the person
Hard and Soft Nurse

**Hard**
- Proficient
- Technical Competence
- Detached
- Robotic
- Cold

**Soft**
- Warm
- Time
- Presence
- Valued
- Accepted
- Recognise the person
Fundamental aspects of Patient dignity

- Need for information
- Communication
- How we address individuals - courtesy
- Choice and decision making
- Respect
- Treated with decency
- Participation in care delivery
- Autonomy and independence
- Confidentiality
- Privacy
- Attitudes

Dignity conserving care
Dignity Domains

- Autonomy
- Privacy
- Social Inclusion
- Communication
- Personal Hygiene
- End of Life Care
- Eating and Drinking
- Pain
- Safety
Dignity in Care Indicator Tool

<table>
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<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>Q20. Have staff enquired about your religious and spiritual beliefs?</td>
<td>Yes, sometimes, No, Don't know/ Can't remember</td>
</tr>
<tr>
<td>Q21. Have you been given sufficient support to practice your religious or spiritual beliefs?</td>
<td>I do not want or need to practice my religious or spiritual beliefs whilst in hospital, Yes, always, Yes, to some extent, No, Don't know / Can't remember</td>
</tr>
<tr>
<td>Q22. How clean were the ward bathrooms and toilets that you used?</td>
<td>Very clean, Fairly clean</td>
</tr>
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If YES, what was the cause of this noise? [ ] Yes, minimal disturbance, [ ] No
Conclusion

• Continue in our drive to re-establish and safeguard, our core values and principles of caring

• Spirituality and dignity remind us to focus our attention on the individual – the person, not the medical condition or treatment

• Institutions and organisations and indeed wider society must value the contribution of our health and social care workforce

• There must be a open, honest and transparent culture where integrity, honesty and sensitivity flourish
The EPICC Journey: Overview of the Project and Outputs

Professor Wilfred McSherry
Countries represented

- United Kingdom: England, Scotland, Wales, (Northern Ireland)
- Croatia
- Czech Republic
- Norway
- Netherlands
- Poland
- Turkey
- Ireland
- Malta
- Denmark
- Germany/Austria
- Belgium
- Ukraine
- Greece
- Spain (mainland + Gran Canaria)
- Portugal
- Lithuania
- Sweden
- China
- Malaysia
- Thailand
- Palestine
- New Zealand

Enhancing Nurses’ and Midwives’ Competence in Providing Spiritual Care through Innovative Education and Compassionate Care
What have we developed

- Established the EPICC Network (Launch 1 & 2 July Cardiff)
- Developed a Gold Standard Matrix for Spiritual Care Education and Adoption Toolkit
- Developed a Website and online repository
### Spiritual Care Education Standard

**Core Spiritual Care Competencies for Undergraduate Nursing/Midwifery Students**

#### Preamble

This EPCC Spiritual Care Education Standard describes the spiritual care competencies expected of undergraduate nursing and midwifery students. For every competency, the learning outcomes are described in aspects of knowledge, skills, and attitudes. These competencies are based on studies on spiritual care competencies, which were discussed and agreed upon during the EPCC Teaching and Learning Events 1 and 2. It should be considered that these competencies are practiced within a compassionate relationship and founded in a person-centred and reflective attitude of openness, presence, and trust, which is fundamental for nursing and midwifery as a whole.

**Spirituality**

EPCC has adopted the European Association for Palliative Care (EAPC) definition of spirituality and an adapted version of its definition of spiritual care (to reflect well-being as well as illness), which were derived from international consensus work in palliative care.

Spirituality: “The dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.”

The spiritual field is multidimensional:

1. Existential challenges (e.g., questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).
2. Value-based considerations and attitudes (e.g., what is most important for each person, such as relations to oneself, family, friends, work, aspects of nature, art and culture, ethics and morals, and life itself).
3. Religious considerations and foundations (e.g., faith, beliefs and practices, the relationship with God or the ultimate).

**Spiritual care**

Care which recognizes and responds to the human spirit when faced with life-changing events (such as birth, trauma, illness, loss) or sadness, and can include the need for meaning, for self-worth, to express oneself, for faith support, for hope for rites of passage or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationships and moves in whatever direction need requires (adapted from ).

**Cultural context**

The content and application of the EPCC Spiritual Care Education Standard should be considered within the cultural context and the language of the country in which it is used.

**Terminology**

Throughout the EPCC Spiritual Care Education Standard, the term ‘person and individual’ is used. These terms refer to the ‘patient,’ ‘client,’ ‘service user,’ ‘pregnant woman,’ ‘carer,’ ‘family member,’ ‘relative,’ ‘care recipient’ and so on, depending on the country in which the Standard is used, along with the local context.

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<table>
<thead>
<tr>
<th><strong>COMPETENCIES</strong></th>
<th><strong>KNOWLEDGE (COGNITIVE)</strong></th>
<th><strong>SKILLS (FUNCTIONAL)</strong></th>
<th><strong>ATTITUDE (BEHAVIOURAL)</strong></th>
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<tbody>
<tr>
<td><strong>INTRANPERSONAL SPIRITUALITY</strong>&lt;br&gt;Is aware of the importance of spirituality on health and well-being.</td>
<td>- Understands the concept of spirituality. &lt;br&gt;- Can explain the impact of spirituality on a person’s health and well-being across the lifespan for oneself and others.</td>
<td>- Reflects meaningfully upon one’s own values and beliefs and recognises that these may be different from other persons. &lt;br&gt;- Takes care of oneself.</td>
<td>- Willing to explore one’s own and individuals’ personal, religious and spiritual beliefs. &lt;br&gt;- Is open and respectful to persons’ diverse expressions of spirituality.</td>
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<td><strong>INTERPERSONAL SPIRITUALITY</strong>&lt;br&gt;Engages with persons’ spirituality, acknowledging their unique spiritual and cultural worldviews, beliefs and practices.</td>
<td>- Understands the ways that persons’ express their spirituality. &lt;br&gt;- Is aware of different world/religious views and how these may impact upon persons’ responses to key life events.</td>
<td>- Recognises the uniqueness of persons’ spirituality. &lt;br&gt;- Interacts with, and responds sensitively to the person’s spirituality.</td>
<td>- Is trustworthy, approachable and respectful of persons’ expressions of spirituality and different world/religious views.</td>
</tr>
<tr>
<td><strong>SPIRITUAL CARE: ASSESSMENT AND PLANNING</strong>&lt;br&gt;Assesses spiritual needs and resources using appropriate formal or informal approaches, and plans spiritual care, maintaining confidentiality and obtaining informed consent.</td>
<td>- Understands the concept of spiritual care. &lt;br&gt;- Is aware of different approaches to spiritual assessment.</td>
<td>- Conducts and documents a spiritual assessment to identify spiritual needs and resources. &lt;br&gt;- Collaborates with other professionals.</td>
<td>- Is open, approachable and non-judgemental. &lt;br&gt;- Has a willingness to deal with emotions.</td>
</tr>
<tr>
<td><strong>SPIRITUAL CARE: INTERVENTION AND EVALUATION</strong>&lt;br&gt;Responds to spiritual needs and resources within a caring, compassionate relationship.</td>
<td>- Understands the concept of compassion and presence and its importance in spiritual care. &lt;br&gt;- Knows how to respond appropriately to identified spiritual needs and resources.</td>
<td>- Recognises personal limitations in spiritual care giving and refers to others as appropriate. &lt;br&gt;- Evaluates and documents personal, professional, and organisational aspects of spiritual care giving, and reassess appropriately.</td>
<td>- Shows compassion and presence. &lt;br&gt;- Shows willingness to collaborate with and refer to others (professional/non-professional). &lt;br&gt;- Is welcoming and accepting and shows empathy, openness, professional humility and trustworthiness in seeking additional spiritual support.</td>
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