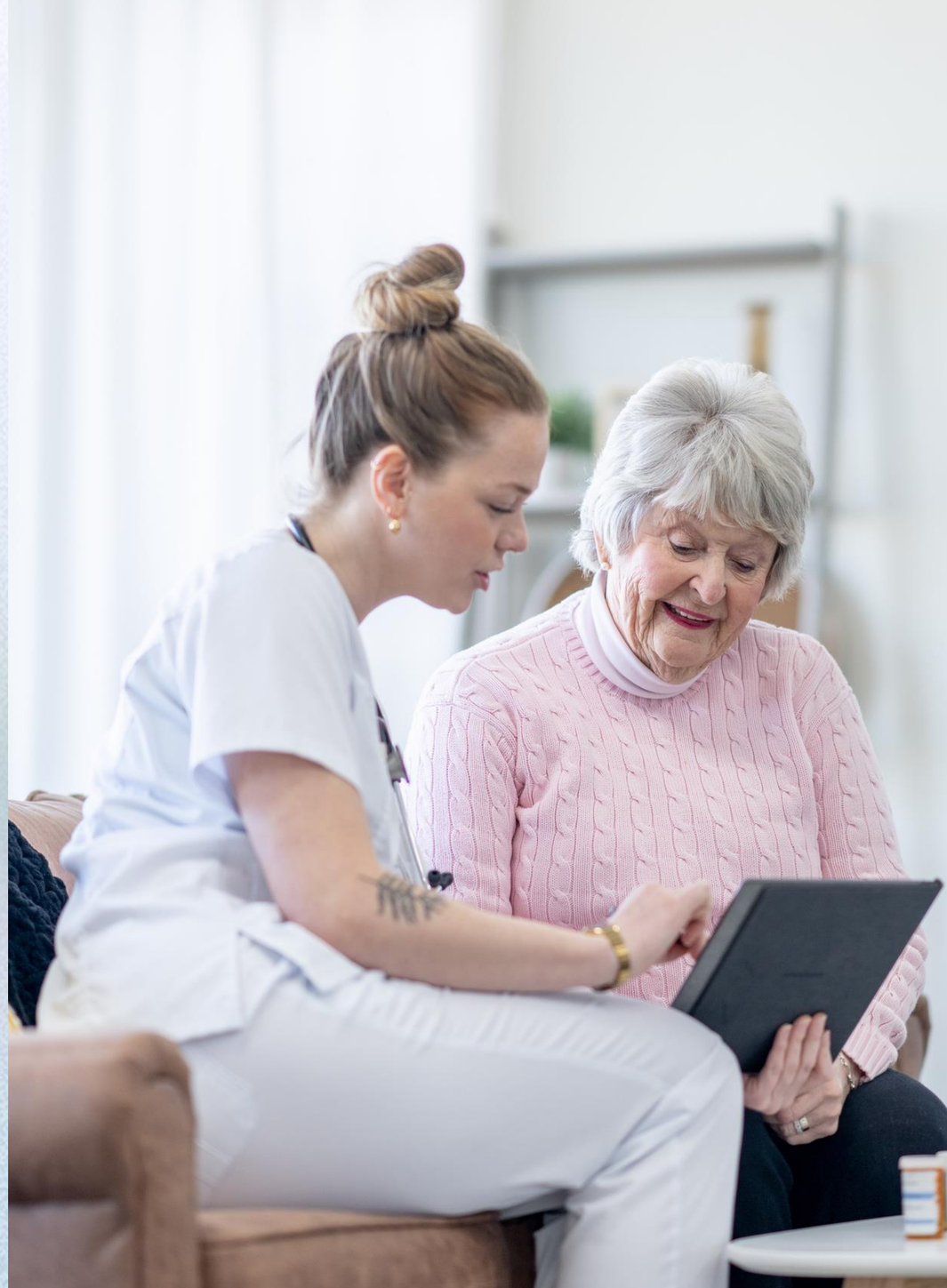
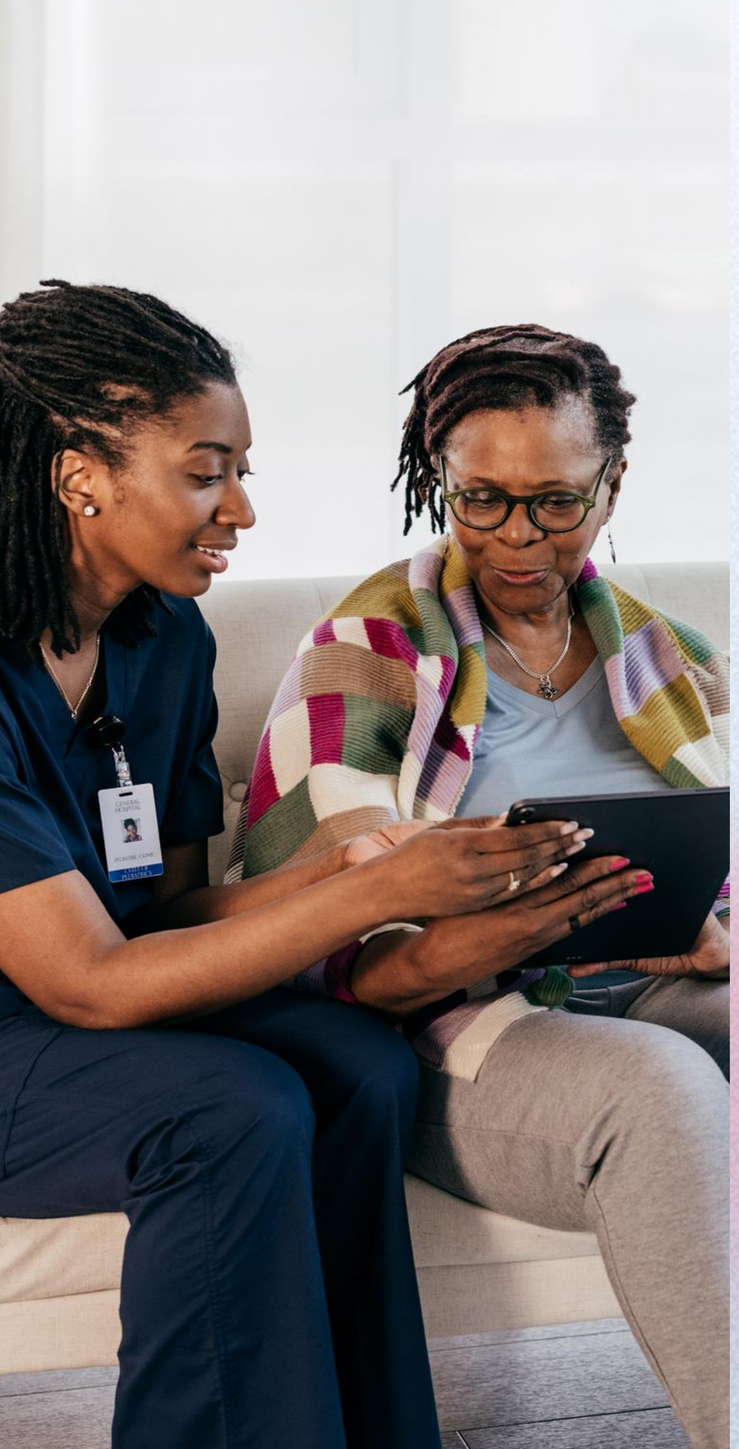
Spiritual Care in Dementia: A Building Block for a Palliative Approach

Integrating Research, Frontline Practice, and Spiritual Health Leadership





Why Dementia Requires a Palliative Approach

- Dementia is a progressive, life-limiting illness
- Palliative approaches support early integration of whole-person care
- Needs evolve over years – not only at the end of life
- If a palliative approach addresses the whole person, SPIRITUAL HEALTH CANNOT BE AN OPTIONAL ADD-ON

Practice Reflection: ***'The need for meaning often persists long after verbal communication has diminished.'***

The Spiritual Dimension of Dementia Care

1. **Spiritual needs are among the least systematically assessed and understood dimensions of care**

2. **Person-centred care includes meaning, purpose, identity, hope, belonging, and connection**

3. **Spiritual distress affects quality of life**

4. **Spiritual care may include religion, but it is not limited to religion**

Martins, Helga et al.“Spiritual Distress, Hopelessness, and Depression in Palliative Care: Simultaneous Concept Analysis”, Healthcare (Basel), 2024 May 7;12(10):960., part 3.1. doi: https://doi.org/10.3390/healthcare12100960

The Woven Ecosystem Framework

Resident-identity, meaning, dignity, and connection

Family-changing relationships, grief, decision-making and legacy

Spiritual Health is experienced across this interconnected experience of dementia care.

Care Team-compassion, resilience, and meaningful presence

Community & system-belonging, continuity, resources and access

What the Evidence Tells Us

Spiritual care can reduce distress and improve well-being

Gupta, Elena, and Pragnesh Patel, “Palliative Care in Dementia”, Annals of Palliative Medicine, Vol 13, No 4 (July 31, 2024) doi:// https://apm.amegroups.org/article/view/118859

It supports meaning-making, dignity and connection

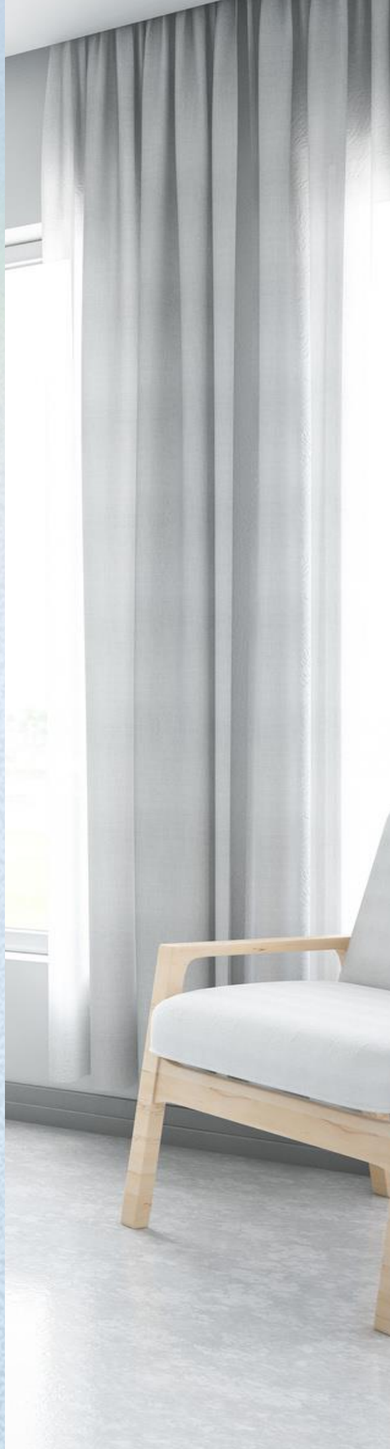
World Health Organization’s *International Classification of Functioning Disability and Health (ICF)* . (WHO, 2001). “Activity/participation” and “Environmental factors” chapters

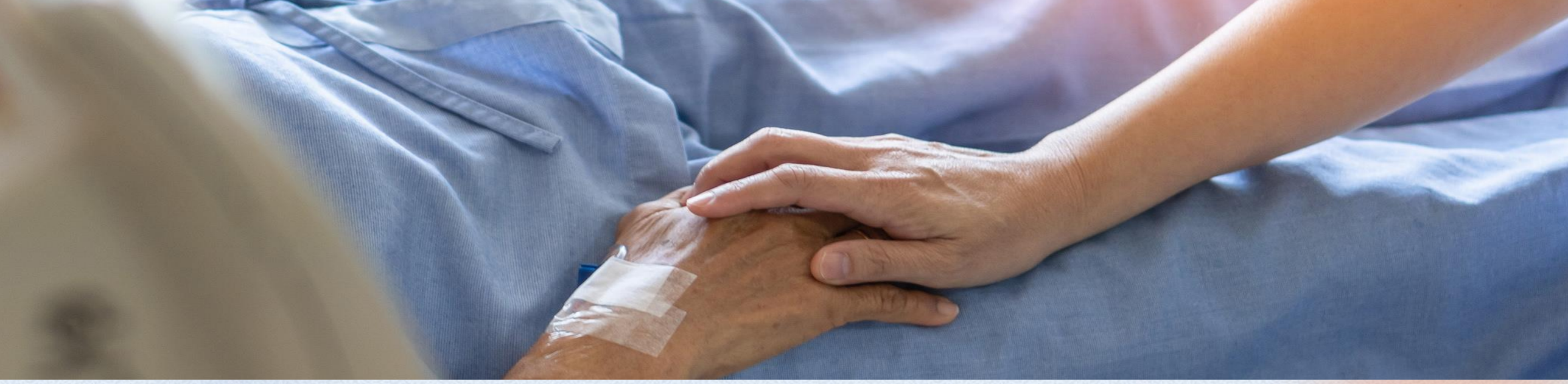
Benefits can extend to caregivers and care teams

Uzun, Ugur et al., *BMC Palliative Care. (2024)23:256. https://link.springer.com/article/10.1186/s12904-024-01589-y*.

In practice, music, ritual, prayer, familiar traditions and simple presence can create connection.

In practice, this can be very powerful!





Spiritual Needs Across the Dementia Journey

Early Stage:
Life review and spiritual conversations, validation

Middle Stage:
Familiar hymns, rituals, sacred texts, reminiscence

Late Stage:
Presence, touch, blessings, family support

The Caregiver Journey

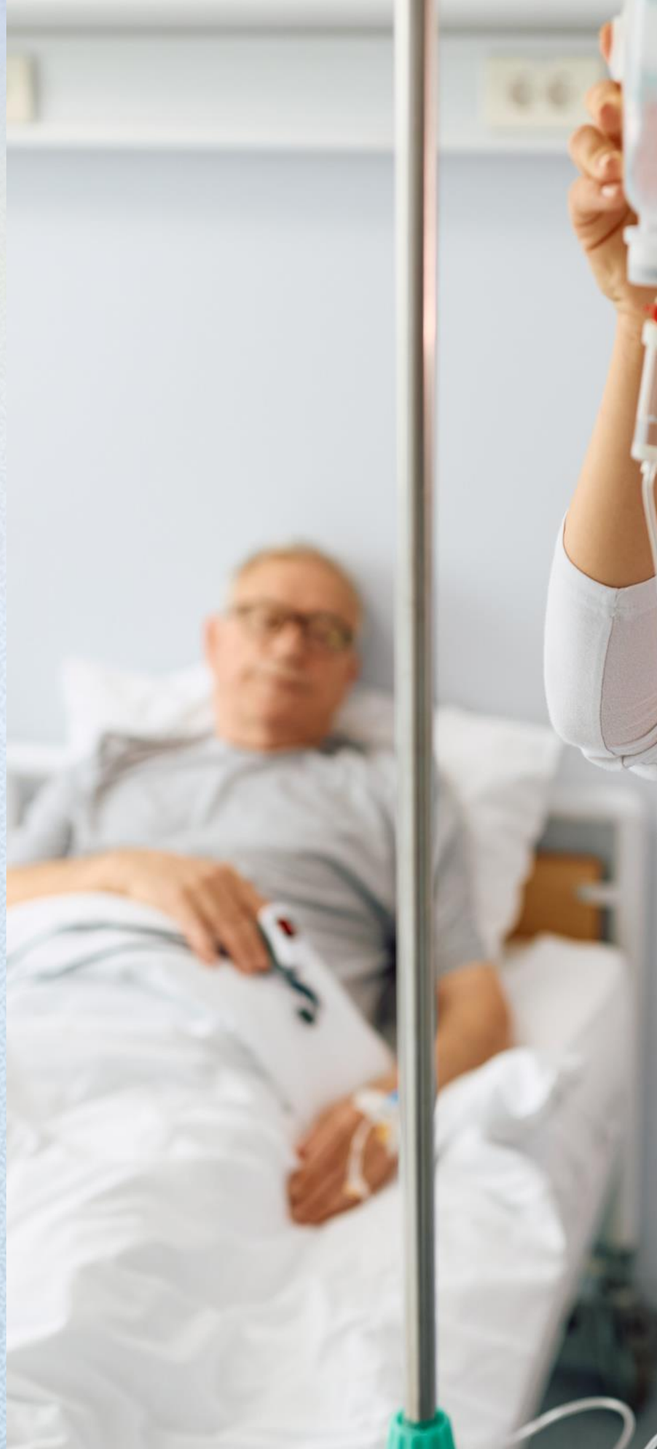
- Anticipatory grief
- Changing relationships and roles
- Complex decision-making
- Loss and bereavement

Spiritual care can accompany families throughout the dementia journey

Caregiver Meaning-Making

- Finding purpose within caregiving
- Reconciliation, forgiveness, and legacy
- Hope and resilience
- Shared meaning during decline and loss

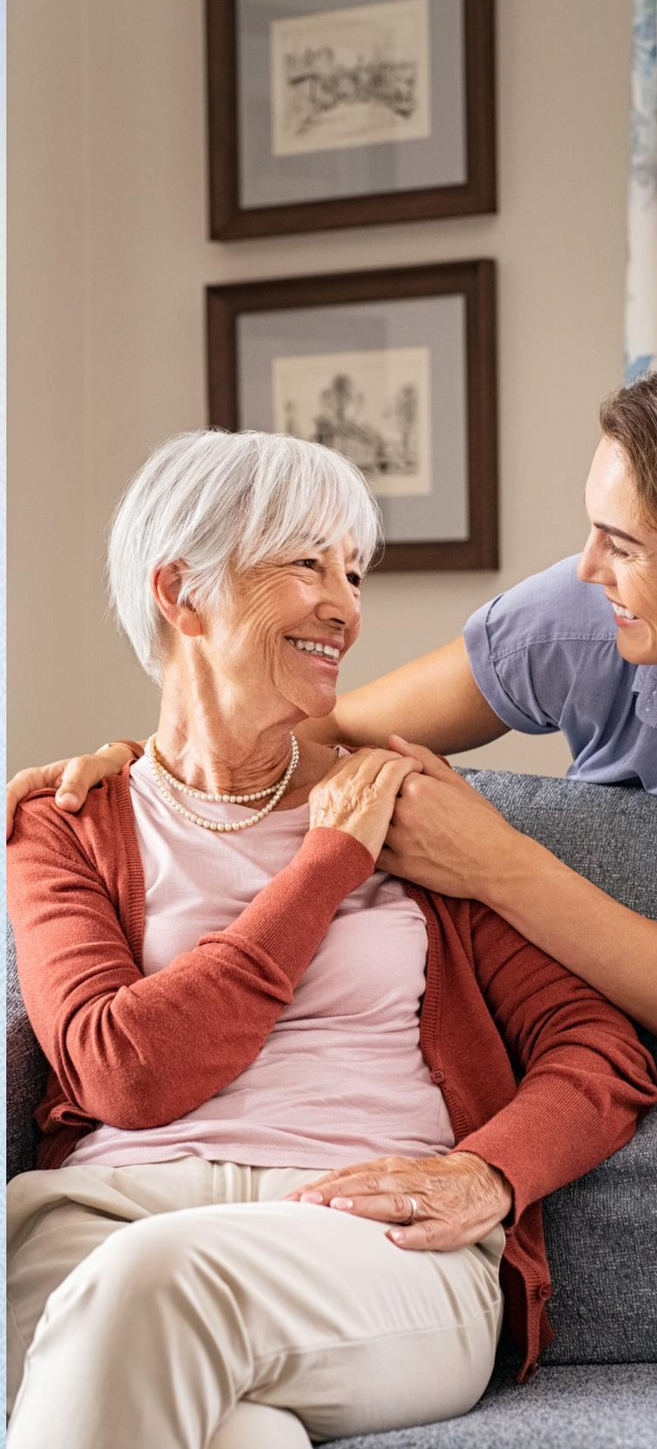
Supporting the caregiver is part of supporting the person with dementia



Why Spiritual Care Matters Across the Ecosystem

- **Resident:** Meaning and dignity
- **Family:** Grief support and connection
- **Staff:** Resilience and compassion

Spiritual care helps us never lose sight of personhood in dementia



Spiritual Care Is Part of Whole-Person Care

Spiritual care is for the whole care ecosystem – resident, family, caregivers, clinicians, and community.

It can support people through loss, bereavement, stress, transition, and questions of meaning.

Spiritual care may include religious beliefs and practices, meaning, purpose, identity, hope, belonging, and connection.

Dementia is a long-term illness; spiritual needs can change throughout the journey.

From Individual Practice to System Leadership

System Challenges:

- Inconsistent access to spiritual care
- Limited awareness of spiritual health
- Education and capacity gaps
- Good spiritual care cannot rest solely with individual practitioners

Organizations and systems must create environments where spiritual health is recognized, understood, and supported.

From Individual Practice to System Leadership

Predictor Identified	Strategic Impact
Early Physician-Family Communication	(OR 1.6) Satisfaction with communication within 8 weeks of admission is a primary driver. High-quality early dialogue is a more powerful predictor than any clinical palliative marker.
Resident's Personal History of Faith	(OR 19/15) Provision is driven by the resident's life story, not the physician's beliefs. This proves that spiritual care is a person-centered necessity, not a provider-driven preference.
Female Family Caregivers	(OR 2.7) Data shows female caregivers are more likely to facilitate spiritual care provision, highlighting a strategic need to better support and prompt male or non-traditional caregivers in expressing spiritual needs.
Standard Palliative Indicators	FAIL TO PREDICT. Being in a palliative care unit or having a comfort goal of care had no significant correlation with spiritual provision. Our clinical systems are blind to the spirit.

JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT, Volicer L; European Association for Palliative Care (EAPC). White paper defining optimal palliative ca
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Building capacity: Everyone Has a Role

- Spiritual Health practitioners
- Care Teams
- Organizational Leaders
- Capacity building strengthens rather than replaces the role of qualified spiritual health practitioners.

Everyone has a role — but not everyone has the same role.

Practical Applications

What can I do tomorrow?

1. **Ask a meaning-centred question**
2. **Use familiar music or ritual**
3. **Support life review**
4. **Create space for reflection**
5. **Support caregivers**

Building Spiritual Health Capacity in Manitoba

What would stronger integration look like?

- Spiritual health recognized as part of **whole-person palliative care**
- Spiritual needs considered **throughout the illness journey**, not only at end of life
- Qualified spiritual health practitioners integrated within **interdisciplinary care**
- Care teams equipped to **recognize spiritual needs, respond within their role, and refer when needed**
- Families and caregivers supported through **change, anticipatory grief, transitions and bereavement**
- Greater collaboration across **dementia, palliative and spiritual health care**

In dementia: *spiritual needs may be expressed verbally or non-verbally and remain relevant as cognition and communication change*

From Bedside Experience to System Change

Spiritual health practitioners have a unique view of what is happening “on the ground.” They hear the experiences of:
Residents • Families • Caregivers • Staff

That perspective can help organizations:

- Identify unmet spiritual needs
- Understand how care is actually being experienced
- Keep dignity and personhood at the centre of care
- Bring the experiences of residents, families and staff into organizational decision-making
- Advocate for compassionate, whole-person care

The Future of Spiritual Care in Dementia

- When memory fades, identity can still be honoured.
- When words disappear, connection remains possible.
- When cure is no longer possible, spiritual care affirms dignity, meaning, and belonging.

The End!

Thanks for Listening!

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