

PRESENTERS: SOUL CARERS NETWORK



CAROL SCROOBY
Soul Carer

- **Profession / Current Role** : Soul Carer, Grief Counsellor and Mentor
- **Organisations and Affiliations** : Soul Carers Network, Abundant Life Palliative Care and Maryland Palliative Hospice Centre, PALPRAC Connect member
- **Highlight:** Being included in a MDT ensuring that the dying patient and their loved ones' wishes and spiritual needs are met, so they may die 'in character'.
- **Personal** : Music as medicine – as self-care I sing in a harmony group. I use my singing or play appropriate music as part of my soul caring offering.



RAFAELA PEERUTIN
Soul Carer

- **Profession / Current Role** : Soul Carer/End of Life Doula, Grief & Bereavement Counsellor, Speech Therapist, Death Educator and Mentor
- **Organisations and Affiliations** : Certified member of MISS Foundation USA (Dr Joanne Cacciatore), Abundant Life Palliative Care, Maryland Palliative Hospice Centre and PALPRAC Connect member
- **Highlight:** witnessing an extremely conflicted family come together at the dying patient's death bed.
- **Personal** : Strong interest in wildlife conservation including time with the Global White Lion Protection Trust.

HOW DO WE “MIND THE GAP”? REFLECTIONS ON THE ROLE OF SOUL CARERS IN A HOME, A MEDICAL PRACTICE, AND A STATE HOSPITAL

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<https://www.soulcarersnetwork.co.za/>



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METHODOLOGY

- May-June 2025 interviewed 12 people.
- 5 family members, 5 private palliative care doctors and 1 state hospital nursing sister were selected using convenience sampling.
- Transcripts were analysed using top-down coding based on the QOL questionnaire and bottom-up according to the text.
- Reporting on 2 family members, 2 doctors and 1 RN
- Reporting in the order of the richness of the data with the number of mentions in brackets.



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2. Emotional Support

- Support the doctor and medical team (7)
- Mediate difficult conversations (3)
- Provide guided support of death process (2)
- Spend time with the patient and family (2)
- Listen & engage non-verbally (1)
- Provide calm & compassionate presence (1)
- Bereavement Support (1)

1. Spiritual Support

- Enquire about spiritual matters (17)
- Facilitate conversations about spiritual matters (12)
- Provide spiritual care that is often neglected (7)
- Support dignified & peaceful death (7)
- More spiritual care training and work experience for doctors (6)
- Don't always have expertise to deal with spiritual matters (4)

3. Social Support

- Facilitate teamwork (16)
- Identify Soul Carer (2)
- Consider patient & family (2)
- Act as an anchor (1)
- Encourage family members and friends to say goodbye (1)



4. Physical Support

5. Practical Support

- Provide advance care plan (1)
- Demystify dying process (1)

Financial & Regulatory Barriers

- Medical Aids don't cover Spiritual Care (8)
- Accreditation needed for an HSPCA number (4)
- National Policy Framework and Strategy for Palliative Care [NPFSPC 2017-2022] (3)

VALUE OF SOUL CARER TO
PRIVATE MEDICAL
PRACTICE

“...it’s often a spiritual answer and a spiritual perspective that helps to add light to what is seemingly a complex medical and social problem...”

Medical Practice, Doctor D

2. Emotional Support

- Support the doctor and medical team (5)
- Mediate difficult conversations (3)
- Compassionate presence (3)
- Spend time with the patient and family (2)
- Provide calm & compassionate presence (1)
- Provide consistent contact (1)
- Focus on & monitor well-being (1)
- Listen and engage non-verbally (1)

1. Spiritual Support

- Support dignified & peaceful death (7)
- Facilitate conversations about spiritual matters (5)
- Some clergy are not that familiar with palliative care (1)

3. Social Support

- Arrange and keep vigil (1)



4. Physical Support

5. Practical Support

Financial & Regulatory Barriers

- Use of volunteers as no funding available (2)
- No category for soul carer [or related term in hospital] (1)
- National Policy Framework and Strategy for Palliative Care [NPFSPC 2017-2022] (1)

VALUE OF SOUL CARER TO
STATE HOSPITAL

“...standing in the gap for the family and not having that pressure to die alone...”

RN, State Hospital

2. Emotional Support

- Spend time with the patient and family (6)
- Focus on & monitor well-being (6)
- Provide guided support of death process (4)
- Provide calm & compassionate presence (3)
- Listen and engage non-verbally (3)
- Mediate difficult conversations (1)

1. Spiritual Support

- Facilitate conversations about spiritual matters (11)
- Support dignified & peaceful death (6)
- Make sense of Death (2)
- Acknowledge the inevitability of death (2)

3. Social Support

- Facilitate teamwork (6)
- Act as the anchor (2)
- Encourage family members and friends to say goodbye (2)
- Consider patient & family (1)



4. Physical Support

- Bring physical comfort (6)
- Notice physical changes (5)

5. Practical Support

- Demystify death (7)
- Create calm environment (1)

**Financial & Regulatory
Barriers**

VALUE OF SOUL CARER TO
FAMILIES

“...the soul carer was the kind of glue that held everybody together in that space and gave us all a sense of purpose as a team...”

Patient 1 family

SUMMARY

- **DOCTOR** Private medical practice valued soul carers for their spiritual support and socio-emotional support
- **STATE HOSPITAL** valued soul carers primarily for emotional and spiritual support
- **FAMILY** felt soul carers supported them emotionally and socially



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Q&A

HOW DO SOUL CARERS “MIND THE GAP”?



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ROLE OF SOUL CARER/ END OF LIFE DOULA

Soul Carers are non-medical, trained companions known around the world by different names including spiritual carers, death doulas or end-of-life companions amongst others

We 'mind the gap' in palliative care, working alongside and supporting all medical and health professionals by providing support to the patient and also by supporting family members and friends in the patients' circle of care.

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