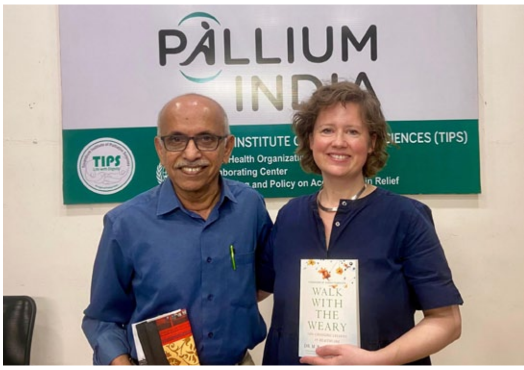
Dialogues About Dying

The 6Rs of Culturally Responsive Conversations in Palliative & End-of-Life Care

Arabella Tresilian, Churchill Fellow 2024

A healthcare mediator explores conversations about death and dying in India, South Africa and Peru, and develops a communication framework to build trust and prevent conflict in culturally diverse palliative and end-of-life care settings.



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All photographs have been taken and are shared with individuals' informed consent.

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About the author

I am Arabella Tresilian, a UK-based accredited mediator, registered with the Civil Mediation Council and the International Mediation Institute. I specialise in supporting families and professionals navigating complex decisions about medical treatment and care planning, particularly where vulnerability, disability or end-of-life issues are present. My work frequently involves disputes arising in residential and community settings, including cases concerning mental capacity, life-sustaining treatment and culturally sensitive care.

Through my mediation practice, I have observed that many conflicts in end-of-life care arise not from disagreement about clinical facts, but from unrecognised cultural, relational and structural dynamics. This Fellowship builds on my professional experience by exploring how culturally responsive dialogue can prevent escalation, strengthen trust and improve shared decision-making at life's end.

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Acknowledgements

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I also wish to thank **Marie Curie**, partner funder to this Fellowship, whose advisory support and expertise in palliative and end-of-life care helped ensure that the insights from this international research remain grounded in the practical realities of care in the United Kingdom.

My thanks also go to the **Medical Mediation Foundation (UK)** for its support of the research, particularly through conversations and guidance relating to research into mediation practice and healthcare.

This research was made possible through the generosity of several organisations that facilitated introductions, field visits and professional exchanges during my travels. In India, I am deeply grateful to **Pallium India** for enabling meetings and conversations with healthcare professionals, practitioners and community members working in palliative care. In South Africa, I thank **Conflict Dynamics** for coordinating interviews and sharing insights from mediation practice in healthcare contexts. In **Peru**, I benefited greatly from connections through **Mediators Beyond Borders International** and the Global Peace Summit in Lima, and from the warm welcome of the team at **Sacred Valley Health (Ayni Wasi)** who facilitated my field visits in the Cusco region.

I am also grateful to the many healthcare professionals, mediators and researchers around the world who contributed reflections through the **international questionnaire on conflict in healthcare**, which helped inform the research questions and analysis within this study.

I would like to thank the following individuals who generously offered guidance, introductions, professional insight or personal encouragement during the Fellowship:

- **Sarah Barclay** – Founder and Director, Medical Mediation Foundation, United Kingdom
- **Margaret Doyle** – Mediator and Researcher, University of Essex, United Kingdom
- **Luis Oré** – Mediators Beyond Borders International, Peru
- **Smriti Rana** – Strategic Partnerships Lead, Pallium India, India
- **Graham Saunders** – Director, GAS Design Ltd, United Kingdom (graphic design support and personal encouragement throughout the Fellowship)
- **Felicity Steadman** – Director, Conflict Dynamics, South Africa

Finally, I wish to express my sincere gratitude to all those who supported this work through conversations, introductions, encouragement and practical assistance along the way. I am especially grateful to the many interview participants who shared their time, experience and wisdom so generously.

The individuals who contributed interviews to this study are acknowledged in the following section.

About my travels, host organisations and interviews

This study draws on 27 qualitative interviews conducted with healthcare professionals, mediators, community health practitioners, legal experts, community leaders, indigenous community members, traditional healers, and individuals with lived experience of caring for family members at the end of life.

Interviews were carried out between February and October 2025 across three countries – India (Feb/Mar), South Africa (Jun/Jul) and Peru (Sep/Oct) – as part of my Churchill Fellowship study *Dialogues About Dying: Preventing Conflict and Supporting Culturally Responsive Conversations in Palliative and End-of-Life Care.*

Field visits were conducted in person in India and Peru, and remotely via Zoom in South Africa. Interviews were arranged through professional networks and local host organisations. The Fellowship research was supported by coordinating partners including:

- **Pallium India** (https://palliumindia.org), India – a pioneering organisation working to improve access to palliative care across India through clinical services, training, policy advocacy, and community engagement, with a strong commitment to compassionate, patient-centred care, provided via homecare, community and in-patient services.
- **Conflict Dynamics** (https://conflictdynamics.co.za), South Africa – a leading conflict resolution organisation providing mediation, dialogue facilitation, and training to support constructive engagement across communities, organisations, and public institutions.
- **Mediators Beyond Borders International**, Global Peace Summit, Lima (https://mediatorsbeyondborders.org) – MBBI is a global network of mediators and peacebuilders working to build mediation capacity and strengthen dialogue processes worldwide, promoting peaceful responses to conflict in communities and institutions.
- **Sacred Valley Health (Ayni Wasi)** (https://www.sacredvalleyhealth.org), Peru – a community health organisation based in Ollantaytambo (Cusco region), serving remote Quechua-speaking communities in the Sacred Valley, working to expand access to culturally responsive healthcare through local health workers, training, and partnerships with regional health systems.

In addition to my formal interviews, many informal conversations with practitioners, community members and families during field visits in India and Peru significantly enriched my understanding of local practices and perspectives surrounding serious illness, dying and caregiving.

For the purposes of the report, interviewees are not individually identified in the main text, and quotations are attributed only by country, in order to preserve anonymity and respect the open reflections that were shared. Interview participants are listed below with their roles and organisational affiliations at the time of interview.

India – interviewees

Interviews with healthcare professionals, legal researchers, palliative care specialists and community practitioners working in health, policy and hospice care – kindly facilitated by Pallium India.

1. **Udit** – Hotel Owner, Delhi, India
2. **Dr Dhvani Mehta** (and team) – Co-Founder and Lead (Health), Vidhi Centre for Legal Policy, New Delhi, India
3. **Dr Parth Sharma** – Community Physician and Public Health Researcher; Founder and Editor, Nivarana, Delhi, India
4. **Anamika Pandey** – Deputy Director, Psychosocial Counselling; and **Jyotisna Rajpal**, Field Support Team Leader – CanSupport, New Delhi, India
5. **Dr Roop Gursahani** – Consultant Neurologist, P. D. Hinduja National Hospital & Medical Research Centre, Mumbai, India
6. **Dr Smriti Khanna** – Palliative Care Consultant, P. D. Hinduja National Hospital & Medical Research Centre, Mumbai, India
7. **Dr Leena V. Gangolli** – Director, Sukoon Nilaya Palliative Care Centre, King George V Memorial Trust, Mumbai, India; **Dr Eric Borges** – Chairman, King George V Memorial Trust, Mumbai, India; **Mrs Vandana Uberoi** – Honorary Secretary, King George V Memorial Trust, Mumbai, India
8. **Dr Sangeetha Suresh** – Paediatric Palliative Care Lead, Pallium India, Thiruvananthapuram, Kerala, India
9. **Dr M. R. Rajagopal** – Founder, Pallium India, Thiruvananthapuram, Kerala, India.

In Thiruvananthapuram, Kerala, I was also fortunate enough to accompany several of Pallium India's palliative care teams to home visits and community clinics, to meet patients, families and communities, and learn about Pallium's inspirational approach to making palliative care accessible in the community.

Dr Dhvani Mehta, Vidhi Centre for Legal Policy, Delhi

Dr Parth Sharma MD, Delhi

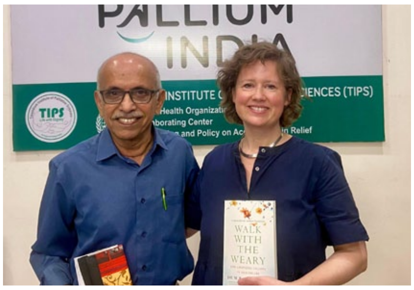
Ms Anamika Pandey and the CanSupport team, Delhi

Dr Smriti Khanna and **Dr Roop Gursahani**, P. D. Hinduja National Hospital, Mumbai

Dr Leena V. Gangolli, **Dr Eric Borges** (Chairman), **Mrs Vandana Uberoi** (Hon. Secretary), King George V Memorial Trust, Mumbai

Dr Leena V. Gangolli, Director, and the team at Sukoon Nilaya Palliative Care Centre (KGVM Trust), Mumbai

Dr Sangeetha Suresh, Pallium India, Thiruvananthapuram



Dr M. R. Rajagopal, Founder, Pallium India, Thiruvananthapuram

Pallium homecare visits with **Snr Nurse Nazeeba** and **Palliative Care Assistant Chandran**, Thiruvananthapuram

South Africa – interviewees

Interviews with mediators, social workers, faith leaders and paediatric palliative care specialists working in conflict resolution and healthcare – kindly supported by Conflict Dynamics, South Africa.

1. **Bishop Peter Lee** – Bishop Emeritus, Anglican Diocese of Christ the King, Johannesburg, South Africa
2. **Angela du Plessis** – Mediator and Social Worker, Conflict Dynamics, South Africa
3. **Naëtt Atkinson** – Mediator, Conflict Dynamics, South Africa
4. **Barbara Booyens** – Mediator and Hospice Counsellor, Mediator Consulting, South Africa
5. **Dr Samantha Govender** – Paediatrician and Paediatric Palliative Care Specialist, General Justice Gizenga Mpanza Regional Hospital; Chairperson, PatchSA, KwaZulu-Natal, South Africa
6. **Nomonde Keswa** – Mediator and Former Social Worker, Conflict Dynamics, South Africa.

Perhaps from an over-abundance of caution towards protecting personal privacy, I didn't ask my South African interviewees if I could take screenshots of our Zoom calls – I now wish I had done so!

Peru – interviewees

Interviews with community health workers, mediators, traditional healers, healthcare professionals and indigenous community leaders, including discussions at the Mediators Beyond Borders International *Global Peace Summit in Lima and field visits kindly facilitated by* Sacred Valley Health (Ayni Wasi) *in the Sacred Valley region of Cusco.*

1. **Carla and Paulina** – Delegates, Mediators Beyond Borders International Global Peace Summit
2. **Félix** – President, Peruvian Network of Environmental Vigilance Committees; Delegate, Mediators Beyond Borders International Global Peace Summit, Lima, Peru
3. **Adolfo del Álamo** – Traditional Herbalist, Ollantaytambo, Cusco Region, Peru
4. **Lida del Álamo** – Community Health Worker, Sacred Valley Health (Ayni Wasi), Ollantaytambo, Cusco Region, Peru
5. **Community Weaver (Chinchero)** – Community Member, Chinchero, Cusco Region, Peru
6. **Sofía** – Community Health Promoter and Quechua Translator, Sacred Valley Health (Ayni Wasi)
7. **Benedicta** – Community Health Promoter, Sacred Valley Health (Ayni Wasi), Peru
8. **César** – Community President, Chaullacocha Community, Cusco Region, Peru
9. **Lindsay –** Coordinator, Sacred Valley Health (Ayni Wasi)
10. **Silvia Rosa Martínez Jiménez** – Executive Director, Sacred Valley Health (Ayni Wasi)
11. **Community Resident ('María')** – Community Member, Cusco, Peru
12. **Dr José Percy Amado-Tineo** – Emergency Care Physician, Hospital Nacional Edgardo Rebagliati Martins, Lima, Peru.

Mediators Beyond Borders International
International Peace Summit, Lima, Peru

Carla and Paulina (Bolivia),
Delegates, MBBI Summit, Lima

Félix, Presidente, Peruvian Network of Environmental Vigilance Committees, Lima

Adolfo del Álamo, Traditional Herbalist, Ollantaytambo

Lida del Álamo, Community Health Worker, Sacred Valley Health (Ayni Wasi), Ollantaytambo

Community member and weaver, Chinchero

Sofía and Benedicta, Community Health Promoters, Sacred Valley Health (Ayni Wasi)

César, Community President, Chaullacocha Community, Cusco)

Lindsay, Coordinator, Sacred Valley Health (Ayni Wasi), Ollantaytambo

Silvia Rosa Martínez Jiménez, Executive Director, Sacred Valley Health (Ayni Wasi)

Dr José Percy Amado-Tineo, Emergency Care Physician, Hospital Nacional Edgardo Rebagliati Martins, Lima, Peru

I am immensely grateful to all those who generously shared their time, knowledge and personal reflections, and whose insights have shaped and enriched this Fellowship study.

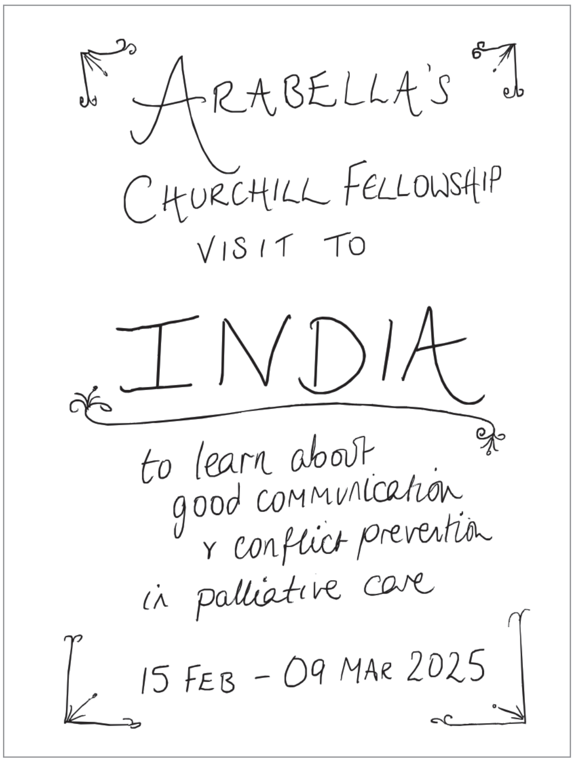
Thank you *(English)* – **Gracias** *(Spanish)* – **Anchata añay** *(Quechua)*

My visual diaries of my travels to India and Peru

The interviews I was able to conduct cover a crucial part of my Fellowship, yet they don't convey the expansiveness of my 'extracurricular' experience of travelling to India and Peru. The following links take you to my visual diaries of those trips – both photographic and sketch-based. It is hard to express the beauty of the extraordinary sights I saw and the unbelievable kindness of the people I met – but these diaries give a hint.

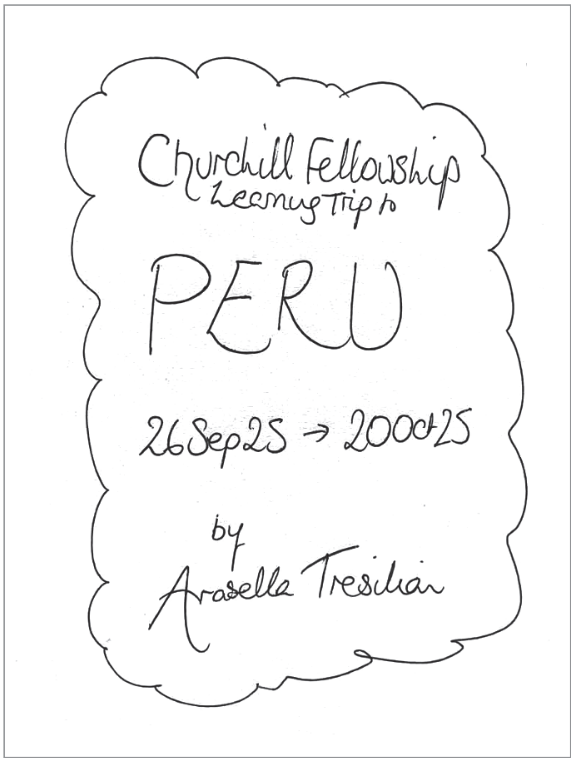
India 2025 – Photo Diary by Arabella Tresilian – Churchill Fellowship

Peru 2025 – Photo Diary by Arabella Tresilian – Churchill Fellowship



ARABELLA'S
CHURCHILL FELLOWSHIP
VISIT TO
INDIA
to learn about
good communication
y conflict prevention
in palliative care
15 FEB – 09 MAR 2025

India 2025 – A Pictorial Diary of my Churchill Fellowship visit – by Arabella Tresilian



Churchill Fellowship
Learning Trip to
PERU
26Sep25 → 20Oct25
by
Arabella Tresilian

Peru 2025 – A Pictorial Diary of my Churchill Fellowship visit – by Arabella Tresilian

Diary extract: Visit To Chaullacocha, Andean Community, Peru 12 Oct 2025


Gathering medicinal herbs in the Andean, Quechua-speaking communities, Peru

Today was one of the most extraordinary days of my life. With Lindsay and Sofia from Ayni Wasi, Alyscia from New York, and our driver, Juvenil, I travelled high into the Quechua-speaking mountain communities at 4,200m, where Ayni Wasi has trained many local health promoters.

We spent the morning in the home of Benedicta, sharing a coca leaf ceremony and talking about life, death, and healing in the highlands. Sofia and Benedicta took us on a walk beyond the house, and gathered over twenty medicinal herbs, explaining their uses.

Later, we were served fresh trout, potatoes and onions beside the mountain lake at the Chaullacocha community centre*, and I interviewed both the community president – on his work as a local mediator – and Ayni Wasi's team back in Ollantaytambo.'*

My project: Dialogues about Dying

My original project objective

Dialogues about dying: tools for preventing conflict in palliative care

Helping prevent and resolve disagreements about the care and treatment of critically ill people

I am a medical mediator who practises independently and with the UK's Medical Mediation Foundation. In my work, I support families and healthcare professionals by facilitating conversations that promote mutual decision-making about the care and treatment of unwell individuals. Conflicts in health and social care can be devastating for patients, families, and professionals, especially when they involve life-limiting conditions.

I have been awarded a Churchill Fellowship to learn from experts overseas. My project, titled 'Dialogues about Dying', focuses on researching innovative communication protocols to prevent and resolve conflicts in palliative and end-of-life care. My goal is to reduce the need for legal proceedings in resolving disagreements about the care and treatment of critically ill adults or children.

I plan to learn from palliative care professionals and mediators in South Africa, India, and Peru about how death and dying are discussed with families and how conflicts are prevented or de-escalated. Additionally, I hope to gain insights into various cultural, religious, and spiritual perspectives on dying to help professionals become more culturally informed and inclusive.

Arabella Tresilian – The Churchill Fellowship

UK context

Conflict at the end of life can be devastating for patients, families and professionals. In the United Kingdom, disagreements about treatment limitation, withdrawal of life-sustaining interventions, discharge planning or decision-making authority sometimes escalate to formal complaints, mediation or legal proceedings. These conflicts are often framed as disagreements about 'best interests' or clinical judgment. In my professional experience as a medical mediator, many disputes also involve unrecognised cultural expectations, differing norms about family roles and spiritual meaning-making, or uncertainty about who holds decision-making authority.

The UK provides universal healthcare through the NHS, with a legal and ethical framework governing capacity, consent and best interests (Mental Capacity Act 2005). While these structures provide clarity, they do not always prevent relational breakdown, including in hospital wards, care homes, hospices and community palliative care teams – where clinical realities, family dynamics and cultural expectations intersect.

A growing body of UK research highlights that high-quality conversations are central to effective end-of-life care. The National Institute for Health and Care Research (NIHR) emphasises that communication about prognosis, treatment options and personal priorities significantly shapes care outcomes, while also noting that access to such conversations is not equal across populations (NIHR, 2023). Inequities in access to palliative and end-of-life services persist, particularly for ethnically diverse and socio-economically disadvantaged communities, contributing to disparities in experience and outcomes (NIHR, 2023).

These disparities reflect wider structural inequalities in UK healthcare. The NHS Race and Health Observatory has identified persistent ethnic health inequalities across the life course, including barriers linked to structural and interpersonal racism (NHS Race and Health Observatory, 2023). Public discourse has also highlighted concerns about inequitable treatment experiences within the NHS, including high-profile commentary on differential care affecting patients from ethnically diverse backgrounds (The Guardian, 2025).

Medical disputes at the end of life have, in some cases, reached national prominence. The case of Archie Battersbee, involving contested withdrawal of life-sustaining treatment, illustrates how clinical decision-making, legal frameworks and deeply held family beliefs can intersect in highly public and polarised ways (Sage Journals, 2023). While such cases are exceptional, they bring into focus the relational and cultural tensions that may also operate more quietly in everyday practice.

Underlying these challenges is a broader question about meaning: what constitutes a ‘good death’? Emerging scholarship questions whether dominant global frameworks for the ‘good death’ reflect culturally specific assumptions rooted in high-income Western contexts. Zaman (2025) argues that prevailing global narratives of the good death may embed particular moral and cultural assumptions, potentially marginalising alternative understandings shaped by collective decision-making, spiritual continuity and relational obligations in non-Western settings (Zaman, 2025). Similarly, Borgstrom and Sallnow (2023) caution that the concept of a ‘good death’ can become prescriptive or exclusionary if treated as a universal ideal, rather than a culturally contingent and socially situated construct (Borgstrom and Sallnow, 2023).

In this UK context – characterised by legal clarity, persistent inequities, unequal access to high-quality conversations and contested cultural assumptions – culturally responsive dialogue emerges as a core component of equitable, person-centred end-of-life care.

Disparities in Palliative Care: Access, Trust, and Workforce

- **Financial inequity:** 46% of Black working-age people in the UK die in poverty, significantly limiting access to essential end-of-life support. (Marie Curie, 2024)
- **Awareness gap:** 22% of minoritised communities have never heard of ‘palliative care’, compared to only 4% of the White population. (King’s College London / YouGov, 2024)
- **Trust deficit:** 30% of people from ethnic minority backgrounds lack trust in healthcare professionals to provide high-quality end-of-life care. (The BMJ, 2025)
- **Workforce representation:** Only 20% of palliative consultants are from minoritised backgrounds, compared to 41% across other NHS specialties. (The BMJ, 2025/26)

What is health and care mediation?

Health and care mediation is a structured process in which an independent mediator facilitates dialogue between patients, families and healthcare professionals when disagreements arise about treatment, care or decision-making. The aim is to create a safe space for participants to be heard, to better understand each other's perspectives, and to explore collaborative ways forward, often avoiding the need for adversarial legal proceedings. The development of this field has been advanced by the work of the Medical Mediation Foundation (MMF), founded in 2010 by Sarah Barclay, whose research and practice initiatives have explored how mediation can improve communication and conflict resolution in healthcare settings. Academic research by Dr Jaime Lindsey has also examined the role mediation can play in resolving medical treatment disputes and supporting participation and procedural fairness for those involved. Health and care mediation is increasingly relevant in complex decision-making contexts, including disputes that may otherwise come before the Court of Protection. I practise as a health and care mediator and am an associate mediator with the Medical Mediation Foundation. It is my hope that this report will be of interest not only to practitioners working in palliative and end-of-life care (PEOLC) and members of the public, but also to mediators interested in, or practising within, the growing field of health and care mediation.

What I wanted to learn

I wanted to use the opportunity of my Churchill Fellowship to explore how culturally responsive dialogue can prevent and de-escalate conflict in palliative and end-of-life care, in both in-patient and community settings.

As a UK health and care mediator, I frequently support families and professionals in highly emotive disagreements about treatment and care planning for critically ill adults and children.

My Fellowship set out to examine whether earlier, more culturally informed communication practices in end-of-life care settings could reduce relational breakdown and avoid unnecessary litigation.

Through international fieldwork in India (in person), South Africa (virtually) and Peru (in-person), I studied how palliative care professionals and mediators discuss death and dying with families, how they navigate cultural and spiritual differences, and how conflict is prevented or repaired in resource-constrained and culturally diverse contexts.

Rationale for Fellowship destinations: India, South Africa (virtual) and Peru

I was originally inspired to explore contexts outside my own UK, Western-centric sphere for two reasons.

1. I had noted that a significant proportion of the disputes I worked on as a healthcare mediator seemed to arise – from my observer's perspective – from ineffective intercultural discourse between professionals and families from culturally different backgrounds. It felt like there was a wider death lexicon missing, and a need for a broader understanding in healthcare of 'non-Western', or 'global south', or 'global majority' principles and concepts around death and dying.
2. I was inspired by the article in the BMJ, Controversy: A good death- tyranny or useful concept? By Libby Sallnow and Erica Borgstrom – BMJ Supportive & Palliative Care, in which the authors, two leading voices in end-of-life studies, explored the 'disconnect between the principles described in "a good death" and the lived realities for people living in the global south, or those suffering discrimination or marginalisation in the global north.'

I selected India, South Africa and Peru as Fellowship destinations because I wanted to learn from three non-Western contexts in which palliative and end-of-life care is practised within high religious and cultural diversity, and where healthcare professionals must routinely navigate differing assumptions about family authority, spiritual meaning, suffering, and the language used to speak about dying. My purpose was not to identify a single 'best model', but to observe how conversations are shaped when shared norms cannot be assumed – and to bring that learning back to the UK as a contribution to more culturally responsive, person-centred dialogue.

Contexts that differ from the UK: universal healthcare and the dynamics of dispute

A crucial difference between the UK and each of these settings is the structure of healthcare funding. The NHS is free at the point of access, and while resources are not unlimited, the moral and practical landscape of end-of-life care is not usually shaped by direct payment at the bedside. In India, South Africa and Peru, there is no single universal system in the same sense; access to treatment and support may depend on geography, insurance, public/private pathways, or ability to pay. As a result, end-of-life disputes in these contexts may centre more explicitly on scarcity, affordability, and availability, alongside the relational and cultural dimensions that also exist in the UK.

My Fellowship aim, however, was not to identify solutions to the substantive resource issues that shape end-of-life care in these countries, nor to draw simplistic comparisons. My interest was sociological and linguistic: to learn how healthcare professionals and mediators navigate the *language of dying* – how they speak about hope, suffering, responsibility, decision-making, and the approach of death – when culture, faith, and family structure vary widely and when trust cannot be assumed. The learning I brought back is therefore primarily relational: transferable principles for dialogue that can strengthen understanding, reduce escalation, and support more culturally responsive, person-centred care in UK residential and community settings.

Limitations of my learning approach

This Fellowship report is best understood as a practice-informed, qualitative inquiry. The three-country design privileged depth of relational learning over breadth or representativeness. South Africa was explored virtually rather than through in-person observation. Within each country, interviews were concentrated in specific regions and professional networks, and the views shared reflect those who were willing and able to participate. These limitations do not diminish the value of the learning, but they do shape the claims that can be made: the 6Rs framework is offered as a practical contribution to dialogue, not as a definitive map of end-of-life care across cultures.

Purpose of this report

This report shares my learning from the Fellowship, as synthesised into the 6 actionable themes I saw arising in my interviews, which I have called the 6Rs framework. I hope that this report and my ongoing dissemination of my learning contributes to ongoing discussion about how relational practice can optimise end-of-life care. It is intended to inform healthcare professionals, mediators, policy-makers and educators, and to offer practical guidance that can be applied within everyday clinical conversations in residential and community settings.

The Fellowship did not seek to compare healthcare systems or evaluate models of service delivery. Rather, its purpose was to examine how conversations about dying unfold across culturally and spiritually diverse contexts, and what relational disciplines might be transferable to the UK. At its core, this report is concerned with the language of dying – how meaning, authority, suffering and hope are spoken about when shared assumptions cannot be taken for granted.

The questions I wanted to answer

1. What communication practices prevent or reduce conflict in end-of-life decision-making?
2. How do healthcare professionals in culturally diverse settings surface and navigate differences in family roles, authority, spirituality and expectations?
3. What can UK residential and community care settings learn from international approaches to relational dialogue at life's end?
4. How might structured communication reduce the need for formal complaints, mediation or court proceedings?

Key findings

- Many end-of-life conflicts do not arise primarily from clinical disagreement, but from unrecognised relational, cultural and structural dynamics.
- Escalation often follows moments where families feel unseen, unheard, or excluded from decision-making processes.
- In diverse international contexts, healthcare professionals who proactively name roles, acknowledge spiritual meaning and revisit conversations are able to reduce relational distress.
- Cultural responsiveness is not about specialist knowledge of every tradition; it is about structured curiosity, clarity and relational humility.
- From these insights, a practical framework emerged: **The 6Rs of Culturally Responsive Conversations in Palliative & End-of-Life Care: Recognise, Respect, Reflect, Relate, Revisit, Restore.**
- The 6Rs offer a structured conversational approach that can be applied in everyday clinical encounters across hospice, care home, hospital and community settings.

Implications for practice

1. Embed relational and culturally responsive communication training within hospital (ICU, PICU, HDU and general wards), hospice, care home and community palliative teams.
2. Introduce structured prompts (e.g. aligned with the 6Rs) into advance care planning (ACP) and serious illness conversations.
3. Normalise early clarification of decision-making roles, expectations and constraints in in-patient and community settings.
4. Recognise conflict as a systemic signal rather than a personal failure.
5. Incorporate mediation-informed approaches into end-of-life care pathways to prevent escalation.
6. Revisit conversations over time rather than treating them as one-off decision points.
7. Prioritise dignity restoration and relational repair – even where agreement is partial.

The 6Rs Framework

The 6Rs did not emerge from a single country, nor from a single interview, but from noticing what skilled practitioners did, repeatedly, when cultural difference was present:

- They **recognised** context before asserting expertise.
- They **respected** values without assuming agreement.
- They **reflected** meaning and emotion before moving to decision.
- They **related** as human beings, not only as professionals.
- They **revisited** conversations over time rather than treating them as one-off events.
- They sought, where possible, to **restore** dignity even when consensus could not be achieved.

These practices were visible across settings shaped by different religions, resources and histories. The contrasts sharpened the insight: while substantive disputes about resources, prognosis or treatment may vary across systems, the relational architecture of escalation often follows similar patterns.

The 6Rs therefore represent a synthesis of my sociological observation and mediation-informed practice – a structured approach to dialogue that can be translated into the UK context without importing the substantive constraints of other health systems.

The following section sets out the 6Rs framework in detail.

A note on the term ‘families’

Throughout this report I refer to the role of ‘families’ or ‘family caregivers’ in conversations about palliative and end-of-life care. I recognise, however, that this term can unintentionally suggest a stable or unified support structure, which does not reflect the complexity of many people’s lives. As Dr Kate Woodthorpe, Co-Director of the Centre for Death and Society (University of Bath) observed in an online talk (11 March 2026), discussions in end-of-life care can sometimes assume the presence of a ‘mythical family’. In reality, family relationships may be fragmented or strained, shaped by estrangement, geographical distance, financial constraints, or differing expectations of reciprocity and care. Some people approaching the end of life may have little or no contact with relatives, while others are supported primarily by friends, neighbours, or members of their community. For this reason, the terms ‘informal carers’ or ‘unpaid carers’ are often a more accurate description of those involved in supporting patients and participating in important conversations about care, preferences, and decision-making. In this report, I continue to use the word ‘families’ for readability, while recognising that the people who accompany someone at the end of life may extend far beyond traditional family structures.

Glossary of key terms and abbreviations

- **Advance Care Planning (ACP)**: A voluntary process in which individuals discuss and record their preferences for future care and treatment, in case they become unable to make or communicate decisions.
- **Best interests**: Under the Mental Capacity Act 2005, a decision-making principle requiring that any decision made on behalf of a person who lacks capacity must aim to promote their welfare and rights by considering their past and present wishes, feelings, beliefs and values, alongside the views of those involved in their care.
- **CPR – Cardiopulmonary Resuscitation**: An emergency procedure used to attempt to restore breathing and circulation following cardiac or respiratory arrest.
- **Culturally responsive care**: An approach to care that recognises and works with patients' and families' cultural, relational, spiritual and social contexts as integral to care.
- **EoL/EoLC/End-of-life care:** Care provided in the final phase of life, when death is expected in the foreseeable future. It prioritises comfort, symptom management, dignity and support aligned with the person's values and wishes.
- **ICU – Intensive Care Unit**: A hospital unit providing specialist care for critically ill patients requiring close monitoring and advanced medical support.
- **Palliative care (also PEOLC: Palliative & end-of-life care)**: An approach that improves quality of life for people facing life-threatening illness and those close to them through the prevention and relief of suffering. It addresses physical, psychosocial and spiritual needs and may be provided alongside curative or life-prolonging treatment.
- **Relational distress**: Emotional or interpersonal strain arising from miscommunication, unclear roles, unacknowledged expectations or unresolved conflict in care settings.
- **Shared decision-making**: A collaborative process in which healthcare professionals, patients and often families work together to make healthcare decisions, integrating clinical evidence with patient values and preferences.
- **The 6Rs Framework:** A structured conversational model developed through this Fellowship to support culturally responsive dialogue in end-of-life care: Recognise, Respect, Reflect, Relate, Revisit and Restore.

The 6Rs of Culturally Responsive Conversations in Palliative and End-of-Life Care (PEOLC)

A framework to support effective dialogue, developed via my Churchill Fellowship fieldwork in India, Peru and (virtually) South Africa

by Arabella Tresilian 2026

Overview

The **6Rs of Culturally Responsive Conversations in Palliative and End-of-Life Care (PEOLC)** offers a structured framework for healthcare professionals, mediators and care teams working with patients and families from diverse cultural and spiritual backgrounds.

The framework emerged from observing how experienced practitioners navigate difference in real time – particularly where assumptions about autonomy, family authority, spirituality, and the meaning of a 'good death' cannot be taken for granted. Across varied contexts, certain relational disciplines consistently reduced escalation and strengthened trust. The 6Rs synthesise those practices into a coherent, transferable model.

The framework is not a checklist of cultural traits, nor an attempt to provide exhaustive knowledge of specific religious or ethnic traditions. Instead, it offers a disciplined approach to dialogue – one that foregrounds curiosity, humility and relational continuity. It is designed for application in residential and community settings, where conversations about dying unfold over time and often involve multiple voices.

Each 'R' represents a relational forward step within conversation – while presented sequentially for clarity, in practice they overlap and recur. We can summarise these steps as follows:

1. **Recognise:** Acknowledge that every person's experience of illness, dying and decision-making is culturally shaped. This includes recognising the influence of family structures, faith traditions, migration histories, socio-economic context and prior experiences of healthcare. Recognition begins with resisting assumptions and asking open, exploratory questions – for example: *"How are decisions usually made in your family?"* or *"How do people close to you talk about serious illness?"*
2. **Respect:** Demonstrate respect for cultural, spiritual and familial traditions, even where they differ from biomedical norms. Respect is conveyed not only through words but through pacing, tone, body language and the willingness to pause. It may include seeking permission before initiating sensitive discussions, acknowledging spiritual frameworks, and validating relational obligations.
3. **Reflect:** Attend to one's own professional and cultural lens. Reflection involves awareness of personal assumptions, emotional responses and institutional norms that may shape the interaction. It may be modelled explicitly – for example: *"Please help me understand what matters most to you here."* Reflection protects against inadvertent dominance and fosters humility.
4. **Relate:** Prioritise relational connection before information exchange, as trust is often the precondition for meaningful decision-making. Relating may involve shared storytelling, careful listening, recognition of grief and the use of metaphors or rituals that hold meaning for the patient or family. It affirms shared humanity alongside professional responsibility.
5. **Revisit:** Recognise that end-of-life communication is rarely a single event. As conditions evolve, conversations require revisiting – checking understanding, clarifying uncertainty, and allowing time for meaning to settle. Revisiting reduces the pressure for premature resolution and supports continuity of care.
6. **Restore:** Where conflict, distress or misunderstanding has occurred, attend intentionally to repair. Restoration may involve acknowledging harm, clarifying miscommunication, supporting reconciliation within families, or allowing space for grief and truth to coexist. Even where agreement is partial, dignity and even trust can be restored.

Together, the 6Rs provide a practical architecture for culturally responsive dialogue. They do not eliminate substantive disagreement, nor do they resolve structural inequities. Their purpose is relational: to create conversational conditions in which difference can be acknowledged without escalation, and in which dignity and relationships remain central at life's end.

R1: **Recognise** – Recognise context before asserting expertise

‘Recognise’ refers to the practice of identifying what is materially shaping an end-of-life conversation before moving into recommendations, planning or persuasion. Across interviews in India, South Africa and Peru, distress and escalation were described less as the product of irreconcilable difference, and more as the result of misrecognition: key realities remaining unspoken, misunderstood or treated as irrelevant.

‘Recognise’ therefore extends beyond clinical recognition of deterioration. It includes attending to culturally patterned silence; family decision hierarchies; spiritual or cosmological interpretations of illness; fear of blame or legal exposure; economic constraint as moral pressure; and the practical burdens of care. When these contextual drivers are not acknowledged, conversations can narrow prematurely to technical decisions, becoming rushed, defensive or traumatic.

‘Recognise’ is also ethically practical, creating a shared map of what is present in the room – relationally, culturally and structurally – allowing subsequent movements of Respect, Reflect, Relate, Revisit and Restore to rest on stable ground. Therefore, to ‘Recognise’ is to take context seriously, not as background detail, but as central to the conversation itself.

The patient's wife goes out to work in the day. She is also a full-time caregiver.

His home is not wheelchair accessible. So he stays at home. It's been 3 years. Pallium will provide help.

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1.1) Recognise what is ‘unsayable’, and build safe entry points

Across all three settings, difficulty naming death did not necessarily indicate denial or lack of awareness; it often reflected cultural norms about speech, protection and moral responsibility. In India, reluctance to name death was attributed to cultural prohibition: *“We don’t talk about death… to do so is a sin… if you talk about it, then you bring it forward”* (India). In South Africa, a related but distinct dynamic emerged: sensitivity about disclosing *“sensitive issues to strangers”*, with information given *“only as much as they think you need”* (South Africa). In Peru, interviewees described both intuitive communal preparation in some contexts and non-planning in others, suggesting that awareness of mortality may exist without taking the form of ‘advance care planning’. In these instances, silence can be recognised as meaningful rather than oppositional, and of approaching end-of-life dialogue with cultural humility.

- Identify whether death and decline are culturally difficult to name before assuming avoidance or lack of understanding.
- Use permission-giving language and indirect entry points (e.g., ‘worries’, ‘what might happen’, ‘if things change’) before introducing explicit death talk.
- Check preferences for directness or gentler framing, and clarify any family norms about what is said – and to whom.
- **Prompt:** *‘How do people in your family or community usually talk about serious illness or dying?’*

1.2) Recognise hidden decision architecture (who decides, who is deferred to, who is excluded)

Across settings, tensions around end-of-life decisions were often shaped less by disagreement about treatment than by unspoken family structures – who holds authority, whose voice carries weight, and whose labour of care remains unseen. Interviewees described strain emerging not because ‘major decisions’ were disputed, but because long-standing family dynamics were imperceptibly shaping the process: “*There is… the situation in the family… tensions… from years ago*” (South Africa). One clinician reported how parents of a seriously ill child in hospital might say *“Doc, our elders say we must take the baby back home to do the prayer there, or he will die”* (South Africa). In India, the absence of a formally prescribed surrogate hierarchy meant that families and healthcare professionals frequently had to improvise around authority: “*We don’t have anything that prescribes who the decision maker would be*” (India). A related example concerned resuscitation decisions: “*90%… said, ‘No, please don’t do that [CPR] to me.’*” Yet relatives later responded with surprise, “*No, I had no idea [that my relative wouldn’t want CPR]*” (India). Here the risk of conflict lay not in ideological disagreement but in a failure of recognition – assumed wishes substituting for expressed ones. Recognising this hidden decision architecture – moral, relational and logistical – allows healthcare professionals to surface these dynamics before they destabilise care planning.

- Map decision-making early – identify who is recognised as an authority (elder, spouse, parent, clinician) and who is practically carrying day-to-day care.
- Avoid assuming that legal ‘next of kin’ structures match the family’s moral or relational model of authority.
- Notice patterns of exclusion – for example, when information defaults to fathers or senior men while mothers or daughters provide most of the care.
- Where families are geographically dispersed, recognise that migration, travel and time zones can generate conflict even when values align.
- **Prompt:** *‘Who should be involved in decisions, and how should we reach agreement?’*

1.3) Recognise structural fear and defensive pathways (law, blame, institutional workarounds)

Across settings, healthcare professionals and families described how structural pressures – legal uncertainty, fear of complaint or blame, and system constraints – can shape how end-of-life decisions are communicated. In India, end-of-life 'resolution' sometimes occurred through discharge against medical advice (DAMA), resulting in abrupt withdrawal of care: "The patient is discharged against medical advice… everything is withdrawn abruptly… extubated in an ambulance" (India). Interviewees also highlighted how legal guidance intended to support healthcare professionals could prove difficult to operationalise: "After the Court laid down these guidelines… doctors… found these guidelines unimplementable" (India). In Peru, structural pressures were visible in a different way – weak primary care pathways meant that many patients arrived late and in crisis: "*Muchas veces las enfermedades llegan en etapas avanzadas… llegan… a urgencias.*" ["Many times illnesses arrive in advanced stages… they arrive… to emergency"] (Peru). In such contexts, time is short, trust is thin, and the appearance of 'choice' may mask limited practical options. Recognising these structural dynamics – and naming them carefully – can help prevent families interpreting institutional constraints as indifference or concealment.

- Acknowledge the system pressures that may shape care decisions – legal uncertainty, fear of complaint or blame, bed pressures, and uneven palliative care provision.
- If you are a professional – recognise how liability anxiety can tighten language and shorten conversations; if you are a family caregiver – recognise that staff may be communicating within institutional constraints and ask for a clear pathway and review plan.
- Identify when the care setting itself (e.g., emergency admission versus planned review) may compress time for discussion and increase the risk of misunderstanding.
- **Prompt:** *'Here is what we can and cannot offer today; here is what we can do next.'*

1.4) Recognise economic constraint as moral pressure (not merely 'practicalities')

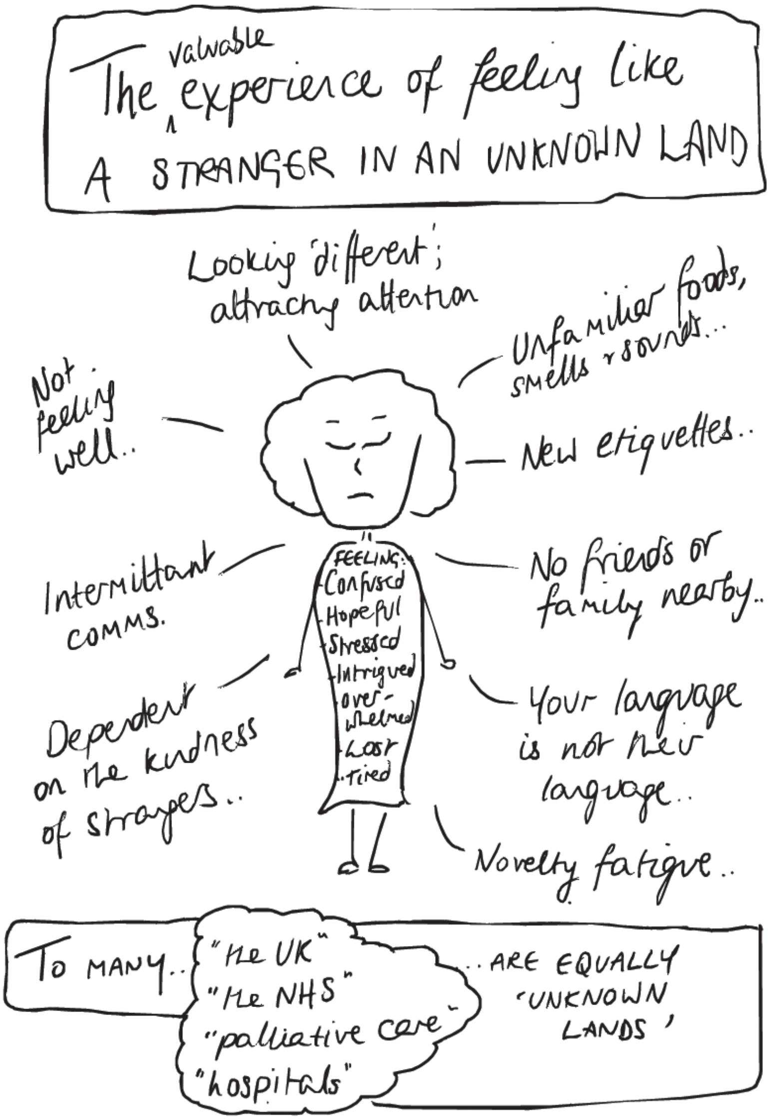
Economic realities were frequently described as shaping end-of-life decisions not simply as practical limitations but as moral obligations. In Peru, families spoke of profound sacrifice in attempts to prolong life: "*Podemos vender nuestras casas y posesiones solo para mantener vivos a nuestros seres queridos un poco más.*" ["We can sell our homes and possessions just to keep our loved ones alive a bit longer"] (Peru). In India, interviewees described a similar moral economy in which financial capacity became intertwined with duty: *"If I withdraw [life-sustaining treatment], it will be seen as I didn't take care of my parents… If you can afford it, you do as much as you can"* (India). In such contexts, continuing treatment may be interpreted as proof of love, while limiting treatment risks being read as abandonment or neglect. Some healthcare professionals described beginning conversations through practical discussions about ICU costs or family burden before shifting toward questions of dignity, presence and care priorities. Recognising economic constraint therefore involves understanding how affordability, duty and honour can become tightly linked within family decision-making.

- Ask neutrally about costs, travel, work commitments, childcare, equipment and the affordability of home care.
- Avoid using moralising language about 'doing everything' – recognise that continued treatment may be experienced as filial duty or social proof of care.
- Frame alternatives as legitimate forms of care rather than as 'giving up'.
- Offer practical pathways – for example transfer, home support, or step-down care – that reduce burden while maintaining dignity.
- **Prompt:** *'Are finances or practical burdens affecting what feels possible?'*

1.5) Recognise plural meaning-systems and the trust implications

Families may hold multiple explanatory frameworks simultaneously – biomedical, spiritual, ancestral or traditional healing – each shaping how illness and treatment are interpreted. When healthcare professionals overlook these meaning-systems, trust can fracture quickly. In South Africa, spiritual interpretation of illness sometimes led families to disengage from clinical teams: "The family thought [the child patient] had been bewitched. So they didn't want to speak to the doctors anymore" (South Africa). In Peru, interviewees described how abrupt prognostic communication could push families toward alternative care systems: "*A veces los médicos son muy duros… le dicen a la familia de forma muy abrupta que su familiar va a morir.*" ["Sometimes doctors are very harsh… they tell the family very abruptly that their relative is going to die"] (Peru). Language inequities also played a role. One interviewee explained: *"Ser indígena, hablar quechua o ser mujer son condiciones de vulnerabilidad... los médicos no les hablan de la misma manera."* ["Being indigenous, speaking Quechua, or being a woman are conditions of vulnerability… doctors don't speak to them the same way"] (Peru). These dynamics highlight that recognition is not simply about cultural sensitivity but about maintaining relational trust and communication safety.

- Explore whether families are holding multiple explanatory frameworks – medical, spiritual, ancestral or traditional healing.
- Avoid dismissing spiritual or traditional interpretations – recognise them as meaning-making systems that influence trust and engagement.
- Treat language access as part of clinical safety and dignity – use interpreters, community health workers or visual explanations where needed.
- Invite families to state beliefs or practices they want respected and ensure these are documented in care planning.
- **Prompt:** *'Are there spiritual or cultural practices we should honour as we plan care?'*



R2: **Respect** – Respect values, beliefs and relational obligations

If ‘Recognise’ concerns conscious perception, ‘Respect’ concerns conscious response. Once belief systems, decision hierarchies, linguistic differences and moral pressures have been made visible, the question becomes: *how should we stand in relation to them?*

Across India, South Africa and Peru, practitioners demonstrated that respect is not a soft interpersonal virtue but a structural and linguistic practice. It shapes whether biomedical authority is experienced as collaborative or coercive, and whether families feel accompanied or overruled.

‘Respect’ in culturally responsive end-of-life care requires practical accommodation without romanticisation, and humility without abdication of professional responsibility. It is enacted through seemingly small but consequential choices: who is invited into the room; how prognosis and comfort care are framed; whether permission is sought before initiating sensitive discussions; how silence is held; and how spiritual or economic realities are acknowledged without judgment.

Importantly, ‘Respect’ does not require agreement, but rather a commitment to taking values, beliefs and relational obligations as morally meaningful, even when they differ from clinical norms. Where this commitment is absent, trust erodes quickly. Where it is present, disagreement can remain contained within relationship.

2.1) Respect belief systems without dismissal

Belief systems – religious, spiritual or cosmological – often shape how illness, suffering and dying are understood. Respecting these frameworks does not require healthcare professionals to share them, but it does require recognising their influence on meaning and decision-making. In India, healthcare professionals described families who believed that *“enduring more pain towards the end of your life means it’s good karma”* and that *“talking about death… is considered to be inauspicious”* (India). In such contexts, conversations about symptom relief may be misinterpreted as moral compromise unless spiritual meaning is first acknowledged. In Peru, interviewees described death as part of an ongoing relationship with life: *“la muerte… es un estado con el que convivimos”* [“death is a state we live alongside”] (Peru). In South Africa, spiritual authority may be located with elders, pastors or traditional healers, whose presence can be central to trust and decision-making (South Africa). Respecting these frameworks broadens engagement and allows care discussions to proceed without undermining spiritual integrity.

- Ask explicitly about religious, spiritual or cosmological beliefs that may influence care decisions.
- Prioritise understanding before challenging or correcting belief frameworks.
- Explain how palliative care can align with – rather than threaten – spiritual or moral commitments.
- Where appropriate, make space for prayer, spiritual presence or ritual alongside clinical care.
- **Prompt:** *‘Are there beliefs about illness or death that are important for us to understand as we talk today?’*

2.2) Respect decision hierarchies and relational authority

Family decision-making structures often reflect relational authority rather than purely individual choice. Respecting these hierarchies means recognising how legitimacy is established within a family or community. In India, healthcare professionals described highly collective decision processes: *"very collective… you can be talking to 20 family members sometimes"* (India). In South Africa, authority may rest with a recognised family elder: *"there's always a patriarch or a matriarch… That [child's] mom can't make the decision – it has to be someone else"* (South Africa). At the same time, legal developments in advance care planning in India allow individuals to designate their own decision-maker: *"you can nominate anyone you want"* (India). Respect therefore involves navigating both collective legitimacy and individual autonomy. When relational authority is ignored, families may experience decisions as illegitimate; when individual voices are overlooked, patients risk being silenced.

- Map formal and informal authority within the family early in the conversation.
- Invite elders or designated spokespersons where culturally appropriate.
- Document agreed decision pathways to reduce later misunderstanding or conflict.
- Remain attentive to gender and generational dynamics influencing who speaks and who remains silent.
- **Prompt:** *'Who needs to be involved for this decision to feel right and legitimate for your family?'*

2.3) Respect the distinction between cure and care

Families may interpret the redirection of treatment to 'comfort care' as abandonment unless the distinction between curing and caring is made explicit. In India, healthcare professionals described how comfort-focused care can be perceived *"as a substitution for waiting"*, creating *"a sense of abandonment"*. (India). Economic and moral pressures may intensify this perception. In such contexts, stopping treatment may be interpreted as a failure of duty rather than a compassionate shift in goals. Respect therefore requires careful language that maintains moral dignity while clarifying that care continues even when cure is no longer possible. When healthcare professionals describe palliative care in concrete terms – comfort, symptom relief, accompaniment and follow-up – families are better able to see it as active care rather than withdrawal.

- Clearly separate stopping treatment from stopping care.
- Describe comfort-focused care in practical terms – symptom control, emotional support and ongoing presence.
- Reassure families that healthcare professionals will remain involved and available for review.
- Avoid language that frames treatment redirection as 'giving up'.
- **Prompt:** *'Stopping this treatment does not mean we stop caring – our focus shifts to comfort, symptom relief and being alongside you.'*

2.4) Respect language, identity and place

Language, identity and place can shape whether care feels respectful, safe and comprehensible. In Peru, interviewees described layered vulnerability through the phrase *"ser indígena, hablar quechua, ser mujer"* ["to be Indigenous, to speak Quechua, to be a woman"] (Peru). Communication improved when healthcare professionals adapted their approach – one interviewee noted how trust increased when a doctor explained care in Quechua and *"took time"* (Peru). Place also carried symbolic meaning. In both Peru and South Africa, dying at home was often associated with dignity and relational presence: *"It would be better to be at home, surrounded by family and at peace"* (Peru). For some families, home is not simply a logistical setting but a space of spiritual continuity. When language barriers or culturally unfamiliar settings dominate the encounter, families may experience care as distant or alienating. Respect therefore involves attending to how communication access, identity and physical setting shape the experience of care.

- Offer interpretation or language support proactively where needed.
- Slow explanations and minimise medical jargon.
- Ask where the person feels most at peace receiving care.
- Recognise that home may hold spiritual or relational significance beyond logistics.
- **Prompt:** *'Which language feels most comfortable for this conversation?'*

2.5) Respect structural and economic realities

Economic and structural pressures often shape end-of-life decisions alongside clinical considerations. In some contexts, families described the profound financial sacrifices required to pursue treatment. In India, one interviewee noted: *“They might have to sell their land or sell their homes to get the treatment”* (India). In Peru, the economic burden of dying was captured succinctly: *“La muerte cuesta.”* [“Death is expensive”] (Peru). Although care within the UK’s NHS is largely free at the point of use, families may still face significant indirect pressures – loss of income when relatives stop working to provide care, travel costs, housing constraints or the practical demands of supporting someone at home. When such realities remain unspoken, clinical recommendations may appear detached from the family’s circumstances. Recognising these pressures can help ensure that care plans are both medically appropriate and practically sustainable, preserving dignity while acknowledging the constraints families may be navigating.

- Name financial and logistical pressures openly when discussing care options.
- Consider practical feasibility alongside clinical appropriateness.
- Notice moral sensibilities about continuing or limiting treatment.
- Explore realistic alternatives when home care or escalation may create unsustainable strain.
- **Prompt:** *‘Are there financial or practical limits we should factor into this plan so it is workable for you?’*

R3: **Reflect** – Reflect meaning and emotion before moving to decision

If ‘Recognise’ concerns perception and ‘Respect’ concerns stance, ‘Reflect’ concerns pausing, and is the interruption of urgency. In end-of-life care, urgency can be pervasive, arising from clinical deterioration, institutional timelines, resource constraints and emotional shock. Without reflection, these pressures compress conversation into speed and certainty. ‘Reflect’ creates breathing space between stimulus and response.

Across India, South Africa and Peru, practitioners described how trajectories of care shifted when reflective space was either absent or deliberately created. Where it was absent, conversations narrowed, authority hardened and positions polarised. Where it was present, hidden motives surfaced – love, guilt, honour, fear – and hierarchies became visible.

‘Reflect’ invites professionals to examine their own cultural lenses and institutional habits, and to name uncertainty without loss of credibility, making visible the assumptions that can otherwise operate unchecked.

3.1) Reflect before escalation of medical intervention

Escalation in serious illness can occur through momentum rather than deliberation. Reflection creates space to examine uncertainty before invasive or irreversible interventions are initiated. In India, healthcare professionals described how diagnostic ambiguity within teams could drive escalation: *“There are some doctors who feel this was an acute exacerbation… and others saying, no, this is the first sign of decompensation”* (India). Without a pause, treatment may proceed despite unresolved clinical interpretation. Reflection can also reveal misalignment between patients and families. One doctor described asking patients directly about resuscitation: *“If… taken to the hospital, would you want to be resuscitated?”* Many patients responded, *“No, please don’t do that to me,”* while relatives later said, *“No, I had no idea”* (India). In South Africa, another interviewee reflected on how treatment boundaries can shift: *“After a first round of chemotherapy, the patient initially said, ‘That’s it, no more!’ but later he went on to accept every single treatment that was offered”* (South Africa). These examples illustrate how reflective pause can surface uncertainty, values and limits *before* escalation becomes difficult to reverse.

- Build deliberate pauses before initiating invasive or irreversible interventions.
- Clarify expected outcomes and review points before commencing treatment.
- Ask what benefit is hoped for – and what will count as success.
- Encourage healthcare professionals and families to articulate uncertainty openly.
- **Prompt:** *‘Before we proceed, can we pause and clarify what we are hoping this intervention will achieve – and how we will review it?’*

3.2) Reflect on emotional drivers and generational authority

Decisions near the end of life are often shaped as much by emotional bonds and family dynamics as by clinical reasoning. Reflection involves recognising how love, duty, grief and generational authority can influence decision-making. One Indian daughter described disagreement within her family: *"My father wanted to continue [with our mother's life-sustaining treatment]… whereas me and my sister both agreed that we should remove it."* She reflected that *"these decisions are also purely emotional… not just religious"* (India). In South Africa, a family member later recognised how emotional attachment to a loved one had prolonged treatment, and therefore lifespan: *"We prolonged our mum's stay… not for her sake, but for our sake"* (South Africa). Another interviewee captured the central reflective question: *"Whose need are we dealing with?"* (South Africa). Such accounts illustrate how treatment choices may reflect intergenerational authority, guilt, responsibility or fear of regret. Creating space to reflect on these drivers can help families distinguish between honouring a loved one's wishes and responding to their own emotional pressures.

- Ask gently about the emotions influencing the decision.
- Notice generational or gender-based authority patterns shaping the conversation.
- Distinguish between perceived moral duty and likely medical benefit.
- Normalise mixed feelings – love, exhaustion, guilt and uncertainty.
- **Prompt:** *'It sounds like this decision carries a lot of emotion – shall we talk about what feels most difficult or pressing to you right now?'*

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3.3) Reflect on professional authority and 'pedestal culture'

Clinical authority can unintentionally suppress dialogue when patients or families feel unable to question professional judgment. Reflection therefore involves examining how deference, dependence and professional hierarchy shape conversations. In South Africa, one interviewee observed that patients may hesitate to challenge healthcare professionals because they rely on their expertise: *"We almost can't refute what they [oncologists] are saying… because we are so needy of their services"* (South Africa). Another described how professional cultures can deflect responsibility when outcomes are poor: *"What is perceived as failure gets dumped on somebody other than the man with the scalpel"* (South Africa). In India, similar patterns of deference were reported, with families saying to doctors, *"You tell us what you think is best"* (India). These dynamics can silence uncertainty or dissent within both families and clinical teams. Reflective practice therefore includes recognising how authority is exercised – and ensuring that conversation remains open, transparent and shared.

- Invite questions explicitly and normalise second opinions.
- State uncertainty transparently where it exists.
- Encourage respectful challenge without defensiveness.
- Notice when deference may be suppressing discussion.
- **Prompt:** *'If at any point you want to question or challenge what we're saying, that is entirely appropriate – please do.'*

3.4) Reflect on structural and informational gaps

Decisions at the end of life are sometimes shaped less by values than by gaps in information, communication or system design. Reflection involves examining whether families are acting on clear understanding or responding to confusion, fatigue or bureaucratic barriers. In Peru, interviewees described families who "*took their family member home 'temporarily' and just never returned… meaning the patient died at home without palliative care, without any medical support"* (Peru). The question remained whether this represented an informed decision, or resignation in the absence of hoped-for support. Another healthcare worker described navigating hospital systems as *"jumping through hoops… and in the end: 'there is no answer'"* (Peru). In India, healthcare professionals noted the absence of designated facilitators to manage conflict or complex decision-making: *"there is no allocation of that responsibility to a specific trained person"* (India). When explanations are unclear or systems fragmented, families may withdraw from care pathways without fully knowing the options available. Reflective practice therefore includes checking comprehension and recognising when structural silence – rather than deliberate choice – is shaping outcomes.

- Check understanding using plain language before proceeding with decisions.
- Clarify what is known, uncertain or still evolving.
- Address language barriers early through interpretation or visual explanation.
- Explore whether withdrawal from care reflects informed choice or accumulated frustration.
- **Prompt:** *'Can you tell me in your own words what you understand about the situation so far?'*

3.5) Reflect using culturally resonant narratives

Reflection may become more accessible when framed through familiar stories and shared experiences rather than abstract ethical principles. One clinician in India described opening his conversations with families by sharing a widely recognised scenario: *"I saw someone treated in the ICU for three months… lakhs worth of bills… but he didn't survive"* (India). By beginning with a story many families had already witnessed, he could move gradually from practical concerns toward questions of presence, dignity and suffering – first acknowledging cost of ongoing treatment, then exploring whether being at home with family (rather than in the costly ICU) might better reflect the person's wishes for end of life. This approach scaffolded reflection within culturally recognisable experience rather than importing unfamiliar language about 'autonomy'. Economic narratives can also shape reflection elsewhere. In Peru, interviewees described families who might *"sell houses… just to keep their loved ones alive a bit longer"* (Peru). In South Africa, healthcare professionals noted how treatment decisions were sometimes guided by what families had seen happen to others, rather than by formal advance planning. Using culturally resonant narratives can therefore help people reflect on goals of care through experiences that already carry meaning.

- Use familiar community stories or shared experiences to open reflective conversation.
- Begin with practical realities – cost, presence, family burden – before abstract ethical concepts.
- Link financial, relational and dignity concerns in the discussion.
- Frame advance care planning through examples that families recognise.
- **Prompt:** *'Many families have seen long ICU stays that did not change the outcome – how does that experience shape what feels right to you now?'*

Ceremony: Offering to Pachamama for the MBBI Summit. We were each able to receive a blessing & make an offering of coca leaves, which were later cast ceremonially in the sea.

R4: Relate – Relate as human beings experiencing human life side by side

If ‘Recognise’ clarifies context, ‘Respect’ affects tone, and ‘Reflect’ regulates pace, ‘Relate’ concerns the quality of human presence within the encounter.

Across interviews in India, South Africa and Peru, families’ enduring memories were rarely defined solely by what was decided. They were shaped by whether they felt accompanied, included and treated as persons rather than as cases. The manner of the conversation – its tone, attentiveness and relational steadiness – often carried as much weight as its content.

‘Relate’ refers to the practical foundation of trust, comprehension and shared decision-making. In contexts marked by taboo around death, high deference to healthcare professionals, language barriers or fractured family relationships, relational presence becomes ethically significant. Without it, even accurate information may be experienced as abandonment or coercion.

To ‘Relate’ is to remain professionally grounded while allowing space for shared humanity. It affirms that decisions about dying unfold not only in legal and clinical frameworks, but within dynamics of attachment, memory and meaning.

4.1) Relate by building continuity and familiarity

Trust in end-of-life conversations usually develops gradually rather than through a single decisive discussion. Relationship-building therefore depends on continuity – repeated contact, familiar faces and reliable points of access. In India, healthcare professionals described relational work as iterative: *"it takes multiple visits. Sometimes it doesn't happen in one conversation,"* and often involves *"just also giving them that space"* (India). Community-based palliative models further strengthen this continuity by embedding care within neighbourhood networks: *"They train volunteers who are your neighbours… so palliative care isn't automatically associated with a hospital but is culturally present"* (India). Similar relational dynamics appear elsewhere. In Peru, communication was described as most effective when healthcare professionals created time and space for dialogue: *"La comunicación es fundamental… dentro de la comunicación hay dos cosas: el tiempo y el espacio."* ["Communication is fundamental… within communication there are two key things: time and space"] (Peru). Continuity allows families to return to difficult questions, absorb information gradually and rebuild confidence slowly.

- Plan for repeated contact – even brief follow-up – rather than relying on a single 'big conversation'.
- Keep key faces consistent where possible (named clinician, nurse or volunteer).
- Establish a clear route for contact and follow-up so families know who to call.
- Expect that information will need to be repeated as understanding evolves.
- **Prompt:** *'You don't have to remember all the information today – we'll come back to this, and I'll stay involved.'*

4.2) Relate by including the wider circle

End-of-life decisions rarely occur within a simple clinician–patient dyad. Many interviewees described care as relationally embedded within wider family, community and spiritual networks. Inclusion can therefore stabilise trust and reduce suspicion that decisions are being made in isolation. In South Africa, collaborative team processes were described as essential: *“it’s not one person’s decision… we all make that decision… then we go to the medical officer or the nursing staff, and we bring them into the team”* (South Africa). In Peru, families associated dignity with being allowed to remain present at the bedside: *“al final… la familia dice que se va agradecida porque nos han dejado estar con ellos.”* [“In the end the family says they are grateful because we allowed them to be with their relative”] (Peru). Community perspectives echoed the same ethos of accompaniment: *“se trata de visitarlo… de darle abrazos, de acompañarlo hasta su última morada… un día es por él, y un día es por nosotros.”* [“It’s about visiting… embracing… accompanying to the last resting place… one day for him, and one day for us”] (Peru). Relational inclusion therefore functions as a form of conflict prevention – acknowledging that people experience illness, grief and decision-making collectively rather than individually.

- Ask early who should be involved in key conversations – elders, siblings, spiritual leaders or community supporters.
- Offer practical ways to include absent relatives – phone calls, video links, shared updates or summaries.
- Protect opportunities for family-only time at the bedside when possible.
- **Prompt:** *‘Who would you like with you for these conversations – and who would you like us to update?’*

4.3) Relate through plain language, listening time, and dialogue

Interviewees repeatedly described communication not as the transmission of information but as a relational process requiring time, clarity and genuine listening. In Peru, healthcare professionals emphasised that dialogue must begin early and remain understandable: *"Lo principal… comunicación desde el inicio… decirle lo que tiene… no solamente con términos técnicos… y darle un tiempo también para que hable."* ["The main thing is communication from the start – telling the person what they have, not only in technical terms – and giving them time to speak"] (Peru). The relational value lies not only in explanation but in allowing families space to respond. In India, relational listening was described as foundational to difficult conversations. As one interviewee explained: *"Unless I spend that half an hour to listen to that story, I will not get there anywhere"* (India). In South Africa, similar concerns were raised about how poorly delivered news can fracture trust: *"We were absolutely amazed at how medical students were given absolutely no guidance in those softer skills… It's quite astonishingly badly skilled, the way some break bad news"* (South Africa). These accounts highlight that communication failures often arise not from disagreement about treatment but from the absence of dialogue, time and emotional attunement.

- Use everyday language as standard, treating clarity as a form of relational care-taking.
- Pause deliberately and allow silence so families can articulate their thoughts.
- Allocate explicit time for questions rather than only delivering information.
- Offer explanations in short segments and gently check understanding.
- Where language barriers exist, involve interpreters or community communicators and allow additional time.
- **Prompt:** *'I'll explain this without medical terms, and then I would really value hearing what you're thinking.'*

4.4) Relate through embodied presence

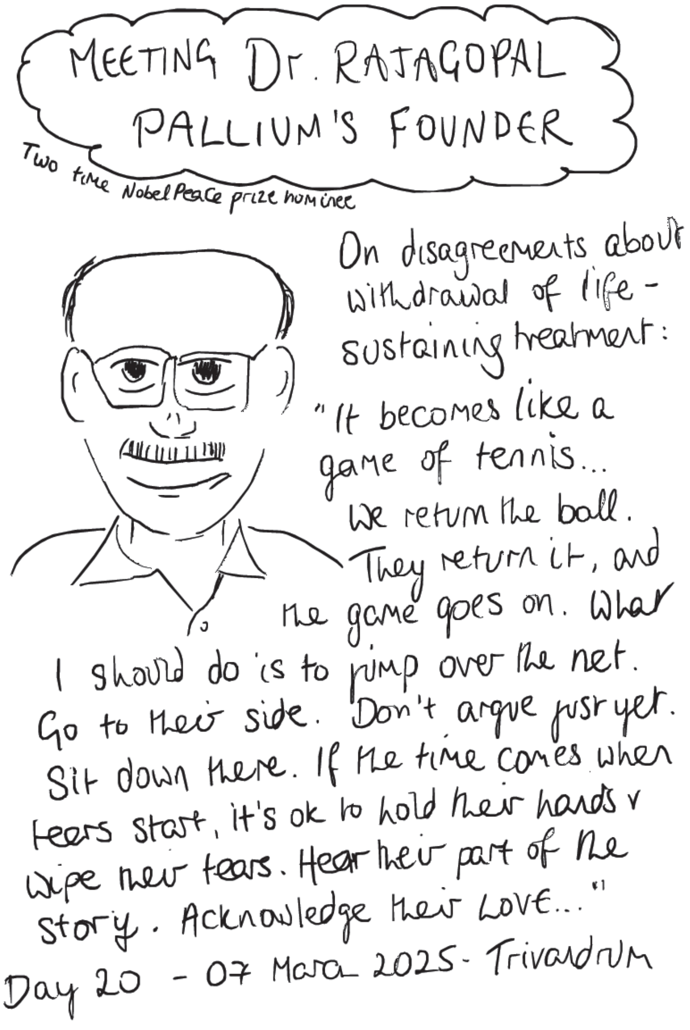
Relational connection is often conveyed less through words than through physical presence, posture and proximity. In India, one clinician described how conversation changes when it happens within the patient's own environment: *"because I work in the community, I'm sitting in their home, I'm sitting on their bed and talking to them"* (India). The setting itself softens hierarchy and can make difficult or taboo topics more discussable. In South Africa, the importance of presence at the end of life was expressed in simple acts of companionship: *"[The child patient] should not be dying alone… it was a nurse that sat there and held his hand and whispered sweet nothings"* (South Africa). Such gestures do not alter the clinical trajectory but shape the experience of dying. Similar principles appear in other relational practices described by interviewees, where listening, touch and companionship communicated dignity, attention and solidarity when words may be insufficient.

- Sit down and reduce visible hierarchy – meet families at chair or eye level with an unhurried posture.
- Where possible, use familiar environments such as home visits to support difficult conversations.
- Allow space for silence, staying a little longer rather than rushing the exit.
- Ensure someone – clinician, nurse or volunteer – is present during key moments if family cannot be there.
- **Prompt:** *'May I sit with you for a moment? There's no rush.'*

4.5) Relate through story, metaphor, and personhood

Relational care often emerges through narrative rather than clinical explanation. Interviewees described how stories, metaphors and everyday memories allow families to speak about dying without being forced into technical or abstract language. In South Africa, one practitioner recalled accompanying a patient through imaginative metaphor: *"We would talk and pretend-dance through the room… [The patient said,] 'Promise me… you will always leave a window in the sky open to escape through'"* (South Africa). Such language meets the person where they are emotionally able to engage. In Peru, relational presence was framed as communal accompaniment. Indian interviewees similarly emphasised the relational dimension of conversation, noting that meaningful dialogue begins by entering the family's world rather than imposing clinical categories: *"What I should do is to jump over the net, go to their side… sit down there… hold their hands"* (India). These accounts illustrate that relating involves recognising the person beyond their illness – their identity, relationships and the language through which they make sense of life and death.

- Invite families to share a short story about the person – what they value, what brings comfort, what matters most.
- When families speak through metaphor or imagery, respond within that language rather than overlaying clinical terminology.
- Name aspects of the person's identity beyond illness – roles, relationships, daily joys.
- Where appropriate, support legacy-making such as photographs, messages or meaningful moments.
- Recognise communal practices of visiting, touch and accompaniment as forms of care.
- **Prompt:** *'Tell me a little about them – what would they want us to know about who they are?'*



On disagreements about withdrawal of life-sustaining treatment:

"It becomes like a game of tennis… We return the ball. They return it, and the game goes on. What I should do is to jump over the net. Go to their side. Don't argue just yet. Sit down there. If the time comes when tears start, it's ok to hold their hands & wipe their tears. Hear their part of the story. Acknowledge their love…"

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R5: **Revisit** – Revisit conversations over time rather than treating them as one-off events

If 'Reflect' introduces pause, 'Revisit' institutionalises it. 'Revisit' assumes that understanding and acceptance develop over time, and that end-of-life decisions rarely resolve within a single conversation.

Across interviews in India, South Africa and Peru, practitioners described how deliberate return points altered the trajectory of care decision-making. Where conversations were treated as one-off events, decisions were sometimes made under shock, or positions hardened in response to fear and uncertainty. Where revisiting was built into practice, premature closure was avoided and escalation reduced.

'Revisit' addresses two common potential harms: decisions made too quickly under emotional strain, and prolonged conflict sustained by ambiguity, inertia or unclear pathways. It reframes dialogue as iterative rather than definitive.

Importantly, 'Revisit' is most effective as a designed practice involving setting clear review structures, naming when conversations will be returned to, documenting shared understanding and explicitly inviting further questions. In doing so, it communicates continuity – and reduces the pressure for families or professionals to defend positions prematurely.

5.1) Revisit by returning to explanation after shock

Initial conversations about serious deterioration or dying are often heard through shock. Interviewees described how immediate reactions may not reflect a family's considered position but rather their emotional response to the moment. In South Africa, one family member recalled reacting defensively when asked about treatment limitation: *"I freaked out… 'So you want me to decide to kill my mother?'"* Reflecting later, she explained how a fuller conversation might have changed the response: *"If the doctors had sat me down and gave me a background… maybe I would have given a different response"* (South Africa). Indian healthcare professionals similarly emphasised that understanding develops gradually through repeated conversations. As one interviewee noted, acceptance may unfold unevenly: *"It might not be in the linear way… it may go haywire"* (India). Revisiting explanations after the initial shock therefore becomes an ethical practice of care – allowing families to hear the information again, ask questions and re-engage with the decision-making process once the emotional intensity of the first moment has passed.

- Assume the first conversation may be filtered through shock – plan a second meeting by default.
- If a family reacts strongly, return with calmer framing rather than treating the response as final.
- Re-explain using different language – focusing on what the body is doing and what care remains possible.
- Offer private space and sufficient time rather than making decisions in communal spaces or hurried encounters.
- Invite families to bring written questions to the next meeting so concerns can be addressed fully.
- **Prompt:** *'That was a lot to take in – can we meet again tomorrow so I can explain it more slowly and answer your questions?'*

5.2) Revisit by designing review points into decisions

End-of-life decisions often evolve gradually rather than through a single definitive conversation. Interviewees described the value of structuring care around review points that allow families and healthcare professionals to reassess together. In India, healthcare professionals emphasised that acceptance unfolds over time: *"it takes multiple visits. Sometimes it doesn't happen in one conversation"* (India). Time-limited trials were frequently used to create space between hope and realism, allowing treatment to proceed temporarily while preserving the possibility of reassessment. As one practitioner explained, *"time limited trial… five to seven days"* followed by review can help resolve uncertainty without locking families into an irreversible course (India). In Peru, healthcare professionals similarly highlighted the importance of revisiting conversations as the situation evolves: *"cuando vemos que… probablemente va a fallecer… es mejor decirlo."* ["When we see that the person will probably die, it is better to say it"] (Peru). Such clarity enables families to prepare without forcing immediate acceptance. In South Africa, the same principle was described as a process rather than a moment: *"It is a process. It doesn't happen in 24–48 hours… sometimes… a whole week or two weeks"* (South Africa). Revisiting therefore functions as a structured practice – pacing decisions, clarifying goals, and allowing meaning and understanding to develop over time.

- Use of time-limited trials (hours or days) when prognosis or response is uncertain.
- Agree and document the review point clearly – including date, time and who will be present.
- Distinguish a trial from escalation – trials remain reversible; escalation may not.
- Define in advance what improvement would justify continuation and what would prompt reconsideration.
- **Prompt:** *'I propose we try this for a short period and then meet again at a set time to review what we are seeing together'*

5.3) Revisit by setting compassionate timeframes

Compassionate timeframes help balance emotional preparation with clinical clarity. Interviewees described how families often need time to gather relatives, perform rituals or emotionally prepare, yet uncertainty can prolong suffering if decisions remain open-ended. In India, healthcare professionals sometimes used incremental steps to avoid forcing families into an overwhelming global decision. As one practitioner described, recounting a discussion with the family of a critically ill patient, to whom he said: *“Let’s agree on one thing right now… we will not intubate”* (India). This narrowing of the decision horizon allows families to move forward gradually while preserving dignity and agency. In South Africa, teams paired preparation time with a clear endpoint: *“We say [to the family] ‘Come Friday… at 10am the baby is going to be withdrawn…’, so they have a time frame”* (South Africa). Such clarity enables families to organise visits, say goodbye and prepare spiritually or emotionally. In Peru, interviewees stressed that compassionate revisiting must include honest conversations about the limits of cure: *“el médico sea honesto… lo mejor es llévatelo a tu casa, dale una mejor vida.”* [“Let the doctor be honest [and tell the family], ‘The best thing is to take him home and give him a better life’”] (Peru). Revisiting therefore involves pacing decisions while helping families understand when the goal of care has shifted.

- When a clinical boundary is necessary, explain the timeframe clearly and the reason for it.
- Pair any timeframe with support – who will be present and how the family can use the time.
- Use defined time windows to enable travel, farewells, rituals or inclusion of key people.
- Avoid open-ended postponement that prolongs uncertainty or suffering.
- Confirm in advance what will happen at the review point rather than leaving expectations unclear.
- **Prompt:** *‘Let’s set a clear time to review this, so you have space to prepare and we don’t leave you in uncertainty.’*

UK legal context

In the UK, decisions about withholding or withdrawing life-sustaining treatment are guided by established legal and ethical frameworks. For adults who lack decision-making capacity, the Mental Capacity Act 2005 requires healthcare professionals to act in the person’s best interests, taking into account clinical evidence, the person’s values and wishes, and the views of those close to them. In paediatric care, decisions are similarly framed around the child’s best interests, and are usually made collaboratively between parents and clinical teams.

Where disagreement arises about treatment decisions, a range of mechanisms may assist in resolving the dispute, including mediation, second opinions and consultation with Clinical Ethics Committees. These processes can help clarify information, explore options and support shared decision-making. If agreement cannot be reached, or if the situation requires urgent legal determination, the matter may be referred to the courts (typically the Court of Protection for adults lacking capacity and the High Court, Family Division for children), which have ultimate authority to determine what course of treatment is lawful and in the patient’s best interests.

5.4) Revisit by checking goals and meaning as circumstances change

Goals of care rarely remain static during serious illness. Interviewees described how understanding, expectations and priorities often shift as families absorb new information and witness changes in the patient's condition. Revisiting goals allows these evolving meanings to be acknowledged rather than forcing families to remain aligned with an earlier decision. In Peru, healthcare professionals cautioned that unexamined optimism can create later conflict: *"A veces por querer dar esperanzas… se crea una falsa expectativa."* ["Sometimes, in trying to give hope… a false expectation is created"] (Peru). Revisiting therefore helps ensure that hope is held responsibly as circumstances change. Indian practitioners described a similar process of gradual recalibration, often beginning with familiar experiences such as prolonged ICU treatment and its consequences. One clinician explained that decisions often become clearer when families revisit what it will mean to choose to let their dying relative leave ICU: *"First thing, it will save you money… then I bring in the emotions afterwards… [telling them] your relative can be with you [at home]"* (India). In South Africa, reflective reconsideration sometimes occurred only in hindsight, when a family member reflected on their insistence that a parent's treatment in ICU should be continued at any cost: *"With the benefit of hindsight… maybe I would have given a different response… If the doctors had sat me down and gave me a background…"* (South Africa). These accounts illustrate how revisiting conversations enables families and professionals to adjust goals gradually as meaning and reality become clearer.

- At each review, restate the shared goal of care (cure, stabilisation or comfort) and confirm it still fits the situation.
- Ask what has changed since the last conversation – symptoms, fears, family perspectives or practical constraints.
- Normalise shifts in preference as understanding develops.
- Revisit what "doing everything" means, distinguishing helpful treatment from burdensome intervention.
- Return repeatedly to the patient's values and priorities rather than assuming they remain unchanged.
- **Prompt:** *'Last time we spoke, the goal was ___. Has anything changed for you since then, or should we adjust what we're aiming for?'*

5.5) Revisit by supporting questions, dissent and inclusion of differing views

Revisiting conversations creates space for questions, disagreement and evolving perspectives that might otherwise remain unspoken. Interviewees noted that deference to healthcare professionals, family hierarchy or emotional shock can suppress dissent until conflict emerges. In India, one practitioner described deliberately pacing decisions so families could return with questions: *"I wouldn't want a decision on that day… [I'd want the parents to] come back the day after tomorrow with all their questions"* (India). In South Africa, a family member reflected on how a loved one's treatment preferences shifted over time as hope persisted: *"It taught me a lesson… when there's hope, when the heart is still ticking, people just go on in desperate hope"* (South Africa). The account illustrates how patients and families may revisit decisions repeatedly as circumstances and emotions change. In Peru, interviewees emphasised the importance of ensuring families truly understand the situation rather than assuming agreement: *"El médico debería de preguntar si entienden que esa enfermedad no tiene cura."* ["The doctor should ask if the family understands that the illness has no cure"] (Peru). Revisiting conversations therefore functions as a safeguard – allowing questions, dissent and additional voices to be included before decisions become entrenched.

- Invite questions explicitly at every review, including doubts, second thoughts or worries about regret.
- Encourage families to name disagreement early and agree how differing views will be addressed.
- Identify who needs to be present in future conversations to avoid later 'surprise stakeholders'.
- Provide a named contact who can maintain continuity between meetings.
- Where available, offer facilitated dialogue or mediation to support alignment between families and clinical teams.
- **Prompt:** *'Before we finish, what questions are you holding back – and who else should hear this explanation next time?'*

R6: **Restore** – Restore dignity even when consensus could not be achieved

If the earlier Rs shape how conversations unfold before death, 'Restore' concerns what those conversations make possible after it. 'Restore' shifts attention from clinical outcome to relational and communal repair.

End-of-life dialogue does not conclude when a treatment decision is reached, nor even when life ends. Its consequences are carried forward in the condition of the bereaved – whether grief is fractured and traumatised, or held within shared meaning and dignity.

Across interviews in India, South Africa and Peru, restoration was described not as a single act but as a constellation of practices: attentive symptom relief; honest preparation; practical protection of families from avoidable harm; acknowledgement of loss; space for ritual; opportunities for reconciliation; and the ongoing presence of community. Where truth had been spoken with care and relationships preserved, families were more likely to describe peace, even in sorrow.

'Restore' does not imply that death is made acceptable, nor that conflict can always be resolved. It recognises, however, that how we speak before death shapes how loss is borne after it. To 'Restore' is to treat dignity, reconciliation and relational continuity as integral to care – not as optional extras.

6.1) Restore by protecting dignity through comfort and practical care

Restoration often begins with the relief of suffering and the preservation of dignity through attentive, practical care. Interviewees repeatedly described how small clinical actions can repair distress, rebuild trust and stabilise families. In India, one practitioner recalled noticing a blocked catheter in a patient who was visibly distressed: *"He is rolling in bed… I see the catheter is blocked. I take it out; the urine just gushes out… Next day he was able to sleep"* (India). The intervention was simple, but its effect was profound – restoring comfort, dignity and faith in care. In Peru, families emphasised the importance of dying in familiar surroundings when possible: *"La mayoría de las familias… traen al paciente a casa… intentar darle una mejor calidad de vida."* ["Most families bring the patient home, trying to give them a better quality of life"] (Peru). South African interviewees similarly framed dignity in relational terms, emphasising the human presence that accompanies comfort care: *"Life is more than a heartbeat… something that involves relationships, something that involves holding a hand"* (South Africa). Together, these accounts illustrate that restoration is not only philosophical or spiritual – it is enacted through symptom control, physical relief, presence and practical support that enable families to experience the final phase of life with steadiness rather than chaos.

- Prioritise symptom relief as a dignity intervention – pain, breathlessness, agitation and other preventable distress should be addressed promptly.
- Treat 'basic comfort work' (positioning, catheter care, hydration, reassurance) as clinically significant rather than ancillary.
- Where possible, support continuity of comfort care at home or in the person's preferred place of care.
- Provide clear instructions for whom to contact if symptoms escalate, particularly outside normal hours.
- Where resources are constrained, acknowledge limits openly and work with families to find workable solutions.
- **Prompt:** *'Our priority now is comfort and dignity – let's make sure symptoms are controlled and that you know exactly who to contact if anything changes.'*

6.2) Restore by preventing abandonment and abrupt endings

Restoration is undermined when the end of life is experienced as sudden withdrawal, abandonment or procedural improvisation. Interviewees described how systems under legal or institutional pressure can produce abrupt transitions that fracture trust and distress families. Such experiences leave families feeling that care has stopped rather than changed. In Peru, interviewees linked later anger to earlier over-reassurance: *"Generalmente… mienten a los familiares y dicen que sí los van a curar."* ["Usually they lie to families and say they will be cured"] and *"A veces por querer dar esperanzas… se crea una falsa expectativa en el paciente y el familiar."* ["Sometimes, wanting to offer hope creates false expectations in the patient and family"] (Peru). South African interviewees similarly emphasised that restoration depends on preparation and accompaniment rather than sudden rupture: *"We don't hide the fact that grieving is part of life. We deal with grieving"* (South Africa). Preventing abandonment therefore requires open communication, continuity of care and careful planning so that the transition from treatment to comfort remains supported and humane.

- State explicitly that care continues even when life-prolonging treatments are limited or stopped.
- Plan transitions in advance – including discharge, home support and escalation limits – to avoid sudden endings.
- When withdrawal of treatment is discussed, explain the process, comfort measures and who will be present.
- Create safeguards against last-minute decisions driven by institutional pressure or uncertainty.
- Where guidelines feel unclear, acknowledge this and establish a transparent, documented plan with the family.
- **Prompt:** *'Even if treatment options change, we will not stop caring – we will plan this together so nothing happens abruptly or without comfort.'*

6.3) Restore by enabling farewell, presence, and not 'dying alone'

Restoration at the end of life is frequently expressed through presence, farewell, and the assurance that a person does not die alone. In South Africa, accompaniment is central to dignity, with a strong cultural and moral emphasis that *"a person should not be dying alone"* (South Africa), and with rituals of collective presence – from bedside companionship to extended mourning – helping families process loss and sustain connection. In Peru, restoration is closely tied to permission and proximity, where families express gratitude for being allowed to remain with their loved one: *"la familia dice que se va agradecida porque nos han dejado estar con ellos"* ["the family says they leave grateful because they were allowed to be with them"] (Peru). In India, restoration is framed through relational closeness, meaning, and preparation for death, with an emphasis on connection and reassurance: *"Loved ones, come around… keep speaking to them… tell them that you love them"* (India). These accounts highlight that restoration is not only about symptom control, but about enabling presence, facilitating meaningful goodbye, and protecting the relational fabric at the moment of death. Where systems fail to support this – through restricted visiting, rushed discharge, or lack of planning – families may experience enduring distress; where it is enabled, grief is more often accompanied by a sense of peace rather than regret.

- Ask early who needs to be present, and plan around travel, work, childcare or visiting constraints.
- Create protected time and space for farewell conversations – minimise interruptions where possible.
- Where appropriate, support transfer home or to a familiar setting if this enables presence and aligns with the person's wishes.
- Encourage memory-making if families desire it – photos, music, prayers or meaningful objects.
- If relatives cannot be present, ensure someone remains with the person so they do not die alone.
- **Prompt:** *'Who needs to be here to say goodbye, and what do we need to put in place so you can be with them in the way that matters to you?'*

6.4) Restore by making space for ritual, spiritual continuity and practical mourning needs

Restoration at the end of life often occurs through ritual and communal practices that help families integrate loss and reaffirm belonging. Interviewees described mourning not only as a private emotional process but as a structured social and spiritual transition. In Peru, wake-to-burial practices were described as collective acts of restoration: *"velan toda la noche… al día siguiente… los hombres van a cavar la tumba… luego se sirve mote y carne de alpaca."* ["They keep vigil all night… the next day the men dig the grave… then mote and alpaca meat are served"] and *"al día siguiente la familia lava la ropa del difunto… lo bueno se guarda… lo roto se quema."* ["The next day the family washes the deceased's clothes… the good items are kept… the torn ones are burned"] (Peru). These rituals restore spiritual order and social cohesion. South African interviewees described similar communal containment, where neighbours and relatives remain present during mourning: *"people will come and go… they'll sit in silence with her… for a week or so"* (South Africa). In India, palliative practitioners emphasised that a peaceful death involves addressing the full spectrum of "total pain" – physical, psychological, social and spiritual – so that a person *"dies peacefully, without pain… without any psychological… social… spiritual discomfort"* (India). Recognising ritual, belief and practical mourning needs therefore supports both dignity in dying and healthier communal healing after death.

- Ask what rituals, prayers or practices matter before and after death, and explore what can be safely supported.
- Where hospital policies limit rituals, help families plan culturally meaningful practices at home or within community settings.
- Offer practical guidance about next steps after death – documentation, contacts and available support.
- Anticipate that mourning can carry financial or logistical burdens and signpost community or charitable resources.
- Treat ritual and mourning practices as part of dignified care, while maintaining appropriate safety boundaries.
- **Prompt:** *'Are there rituals, prayers, or ways your family marks dying and death that you would like us to honour here or help you plan at home?'*

6.5) Restore by strengthening community support and reducing moral and financial injury

Restoration extends beyond the bedside into the social and economic conditions that shape families' ability to care and grieve. Interviewees described how financial strain, caregiver exhaustion and weak community support can deepen moral distress after death. In India, healthcare professionals sometimes framed advance planning as a way of protecting families from unnecessary suffering and financial harm: *"First thing, it will save you money… Second thing, your relatives can be with you… Third thing, you won't have to suffer… unnecessary intervention"* (India). Community-based palliative networks were also described as restorative infrastructure: *"They train volunteers who are your neighbours…"* (India), embedding care within familiar relationships rather than relying solely on hospitals. In Peru, community reciprocity helped distribute the emotional and financial burden of death: *"despedirse es costoso… muchas veces se hace a través de ayni."* ["Farewells are costly… often done through *ayni*"]

(Peru. Ayni is Quechua for ‘mutuality’, ‘reciprocity’ or ‘goodwill’.) South African interviewees similarly emphasised the protective power of communal presence: *“The village will deal with it… it takes a village to cope with somebody dying and being buried”* (South Africa). Strengthening these relational and community supports can reduce isolation, prevent moral injury and allow bereavement to unfold within a network of care rather than abandonment.

- Raise financial and practical pressures early – including travel, caregiving time and potential costs – as part of honest care planning.
- Use advance planning to reduce crisis escalation and protect families from financial risk.
- Where possible, link families with community-embedded support such as volunteers, neighbours or trusted intermediaries.
- Recognise caregiver fatigue and offer respite, guidance or referral as a restorative intervention.
- Where institutional trust is fragile, work with culturally legitimate bridges such as faith leaders, community promoters or voluntary networks.
- **Prompt:** *‘Let’s talk about what is realistically sustainable for you – financially and practically – so we can build a plan that protects your family as well as your loved one.’*

Conclusion: The 6Rs in Practice

The 6Rs – **Recognise, Respect, Reflect, Relate, Revisit and Restore** – emerged from the observation that many conflicts in end-of-life care are not caused by medical disagreement alone, but by breakdowns in understanding, trust and communication. Through my interviews and field observations in India, South Africa and Peru, this Fellowship explored how healthcare professionals, families and communities navigate conversations about dying when culture, belief, authority and uncertainty intersect.

Across these diverse settings, a consistent pattern appeared, in which distress and escalation tended to arise when contextual realities remained unrecognised, when belief systems were dismissed, when decisions were rushed, or when families felt excluded from the process. Conversely, where professionals took time to understand the relational landscape – who holds authority, what meaning is attached to illness and death, what fears or practical pressures shape decisions – conversations became more constructive, and care more humane.

The 6Rs therefore offer a relational framework for communication, rather than a cultural checklist. They provide a structured way of approaching complex conversations with humility, curiosity and practical attentiveness. We are invited to:

- **Recognise** the unseen drivers shaping decisions – cultural norms, economic pressures, family hierarchies, spiritual beliefs and systemic constraints.
- **Respect** these realities without abandoning clinical clarity.
- **Reflect** before escalation, creating space for emotional, ethical and professional deliberation.
- **Relate** through presence, dialogue and inclusion of the wider circle around the patient.
- **Revisit** decisions over time, recognising that understanding and acceptance develop gradually.
- **Restore** dignity, meaning and communal support as life draws to a close and families move into bereavement.

Taken together, these practices encourage healthcare professionals and teams to shift from single conversations toward relational processes, and from information delivery toward shared understanding.

The UK health system already operates within strong ethical and legal frameworks governing end-of-life decision-making. However, law alone cannot ensure that care is experienced as compassionate, culturally sensitive or trustworthy. For ethnically diverse and seldom-heard communities in particular, misunderstandings about authority, spirituality, autonomy or the meaning of a 'good death' can deepen existing inequities in access to palliative care.

The 6Rs do not attempt to resolve every cultural difference. Instead, they offer a practical method for working respectfully within difference – widening whose perspectives are heard, and slowing conversations enough for meaning to emerge.

In this sense, the framework supports a broader shift toward relational literacy in healthcare: recognising that good clinical decisions depend not only on evidence and law, but also on the quality of the human dialogue through which those decisions are reached.

If adopted within training, clinical governance and everyday practice, the 6Rs may help reduce avoidable escalation, complaints and legal disputes. More importantly, they offer a way to strengthen trust between professionals and families, and to support care that honours dignity, connection and cultural meaning at one of the most vulnerable moments of life.

Recommendations

The following suggestions arise from the findings of this Fellowship and may support the development of culturally competent, person-centred end-of-life care across ethnically diverse and seldom-heard communities:

- **Strengthen structured relational training within existing programmes:** hospice, hospital, care home and community palliative teams may benefit from incorporating structured approaches to culturally responsive dialogue – such as the 6Rs – into existing communication skills training. Protected time and leadership endorsement could support earlier recognition of relational risk and greater clinician confidence when working across diversity.
- **Normalise early clarification of decision-making roles:** advance care planning and serious illness conversations might routinely include explicit discussion of who is involved in decisions, how agreement is reached, and how UK legal frameworks operate. Modest adjustments to documentation and conversation prompts may reduce misunderstanding, particularly for families unfamiliar with NHS processes or statutory decision-making structures.
- **Treat emerging conflict as a systemic signal:** rather than attributing tension to individual 'difficult behaviour', organisations could approach conflict as a potential indicator of unaddressed cultural, relational or structural dynamics. Clear pathways for early facilitated conversation may help prevent adversarial escalation and strengthen trust, especially within historically underserved communities.
- **Integrate mediation-informed approaches earlier in complex cases:** introducing mediation principles – structured listening, neutrality, restoration and procedural clarity – at earlier stages of complex end-of-life discussions may prevent entrenchment. Defined referral options and awareness across integrated care systems could support more proportionate and relationally grounded responses.
- **Attend intentionally to dignity and relational repair:** even where consensus cannot be achieved, services may wish to consider how conversations conclude. Explicit acknowledgement of distress, clarification of misunderstandings and attention to relational repair can reduce moral distress for professionals and support healthier bereavement experiences for families.

Taken together, these measures may contribute to reducing inequity in end-of-life care by strengthening trust, widening participation in decision-making, and ensuring that diverse cultural meanings are recognised rather than marginalised.

Next steps

The next phase of this work will focus on the **dissemination, translation, and practical application of the 6Rs framework** in palliative and end-of-life care (PEOLC). The intention is to ensure that the insights from this Fellowship contribute to real-world improvements in communication, trust-building, and conflict prevention in culturally diverse care settings.

Potential areas of development include:

- Present the **6Rs framework** at conferences, hospice networks, and professional forums to encourage dialogue and uptake among practitioners.
- Publish **practitioner-focused articles and commentary** to stimulate informed discussion about culturally responsive communication in end-of-life care.
- Offer **workshops and training sessions** on the 6Rs framework for healthcare professionals, volunteers, families, mediators and community organisations.
- Develop and pilot **accessible tools and learning resources** to support professionals, families, and volunteers in navigating difficult conversations about dying.
- Partner with healthcare providers, hospices, and community organisations to **pilot the 6Rs framework in practice**, with particular attention to **equity, cultural responsiveness, and inclusion**.
- Collaborate with researchers and practitioners in the **Bath and Bristol area**, where there is a strong hub of interest in palliative and end-of-life studies.
- Continue to **share the 6Rs framework internationally** through training, mediation practice and collaborative projects with organisations working to improve dialogue and equity in palliative and end-of-life care.

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It is my hope that the reflections gathered in this study may contribute, in some small way, to strengthening dialogue between professionals, patients and families facing some of life's hardest moments. Conversations about dying are never easy, yet they can become windows to understanding, dignity and connection when approached with cultural humility, compassion and care.

This report is offered in gratitude to all those who work – often unseen and with great dedication – to make healthcare more humane, more equitable and more accessible in our diverse and interconnected world.