Rewilding Healthcare

BY CULTIVATING RELATIONAL SYSTEMS

TO REIMAGINE PALLIATIVE CARE WHEN PEOPLE ARE ALSO LIVING WITH COMPLEX MENTAL HEALTH CONDITIONS

the CHURCHILL fellowship

Marie Curie

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2024 Churchill Fellow

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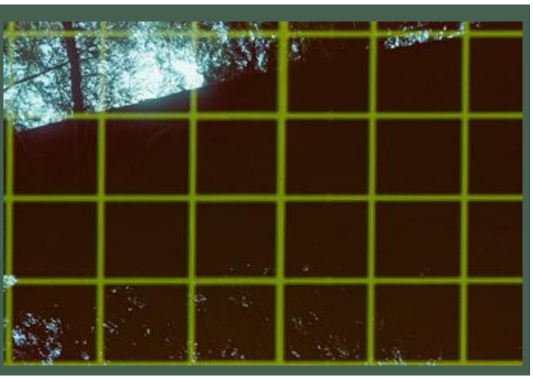

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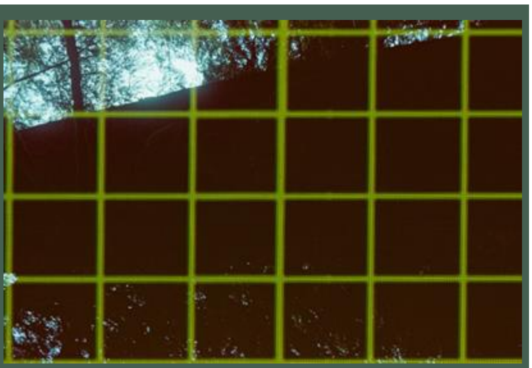

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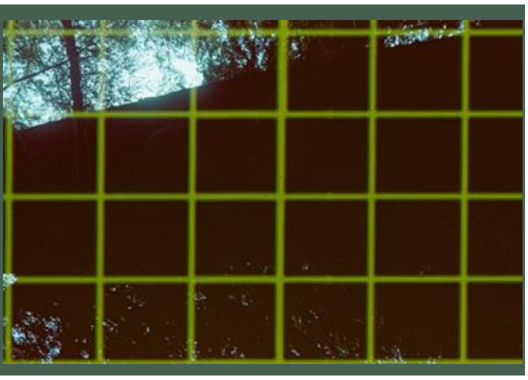
WHY READ THIS REPORT?



Do you shape, deliver, or influence health and social care?

Are you supporting someone who needs palliative care and who is also living with one or more complex mental health conditions?

Every day, multiple decisions throughout health and social care systems affect people with advanced incurable physical illness.

What happens when those people also live with complex mental health conditions that profoundly impact their experiences?

How do health and social care systems respond, and where do they fall short?

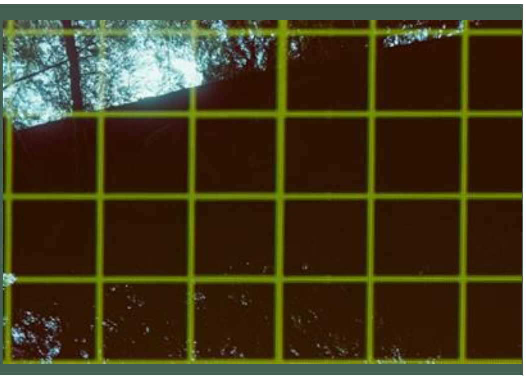
This report invites you to examine these realities and to consider how we can build a care ecosystem that meets complex needs while stewarding resources responsibly.

Are you ready to help rewild healthcare?

GET INVOLVED

Creating systematic solutions: inclusive palliative care & severe mental illness

TERMS AND DEFINITIONS USED IN THIS REPORT



CARE ECOSYSTEM describes the interconnected relational and structural elements (contexts, mechanisms, practices, and other conditions) that have to be navigated to enable people to experience coherent care.

COMMONS describes a philosophy of shared stewardship of resources (originating in “common land” before land enclosures, now used with respect to natural and social or political assets such as public health and social care systems). The commons describes a system built on mutual rights and responsibilities, managed collectively and communally.

COMPLEX MENTAL HEALTH CONDITIONS refers to serious mental, behavioural, or emotional disorders that significantly affect daily functioning and wellbeing. These conditions often require coordinated, long-term support across health and social care systems.

ECOLOGICAL RESILIANCE is the ability of a system to adapt to changing conditions by finding new balance points.

EXPERIENTIAL LEARNING (IN RELATIONAL SYSTEMS) is the process through which practitioners develop relational competence and contextual judgement through supported, experiential practice within structures that reward positive risk-taking and collaborative working (distinct from mandatory training or abstract knowledge-based education).

INTERSECTIONALITY describes how overlapping factors, such as social determinants of health, structural vulnerabilities, and aspects of identity combine to shape experiences of disadvantage.

PALLIATIVE CARE focuses on helping people live as well as possible when they have an advanced, incurable physical illness – and supporting those close to them. It is not only about care at the very end of life. Good palliative care looks after the whole person, addressing physical symptoms as well as psychological, social, and spiritual needs.

PARITY OF ESTEEM is used to describe the idea that care should be of equal quality when people are living with complex mental health conditions as for those without.

PART-SYSTEM EFFICIENCY describes the tendency for individual components, services, teams, or organisational units, to focus on doing the minimum necessary at the lowest cost and the highest speed. When policy, incentives, or performance measures concentrate on specific parts of the system rather than the system as a whole, this tendency intensifies. Each part becomes preoccupied with optimising its own processes, irrespective of whether those processes contribute to genuinely meeting people’s needs. The result is a narrowing of purpose: it becomes possible to deliver a service that is efficient on paper yet ineffective in reality, technically correct in process terms but experientially poor, uncoordinated, or even failing in its core purpose of delivering care.

In contrast, **WHOLE-SYSTEM EFFECTIVENESS** requires attention to whether the ecosystem collectively meets people's needs, regardless how the work is distributed. It depends on distributed responsibilities and resources that can travel with care recipients across boundaries and understanding success as the extent to which care is coherent and aligned with healthcare needs. Effectiveness is concerned whether the right goal is achieved. Whole-system effectiveness reorients attention to value, including reducing waste created when resources are expended without alleviating distress or meeting needs, and ensuring that what is done is not just fast or cheap, but meaningful.

RELATIONALITY describes "the capacity of a given environment of information exchange to create relationship."[1]

RELATIONSHIP is defined as the "shared understanding between people about meaningful use of resources, and willingness to change one another through genuine exchange."[1]

REWILDING is the intentional cultivation of a balanced care ecosystem in which structures serve relationship and ecological resilience can grow. It does not mean creating a wilderness by removing all order, but redesigning systems to make space for adaptive, relational practices that meet the real needs of people living with serious illness. New forms of order created and cultivated through rewilding healthcare will be characterised by structure serving relationship, that is, the structures are in the shadows with relationship and relationality positioned as first order goals through which other goals are achieved.

RISK is often used interchangeably in health and social care policy and practice. However, risk should be used to describe definable and predictable likelihoods of an event, outcome or consequence (either good or harmful). In contrast, **UNCERTAINTY** should be used to describe situations when it is unknown and unknowable exactly what will result in any given instance as a consequence of action or inaction. A relational approach to risk that distinguishes risk from uncertainty, asks "risk for whom?" and considers the harms of inaction alongside action, so that decisions balance duty of care with dignity of risk and focus on outcomes that meet people's needs.

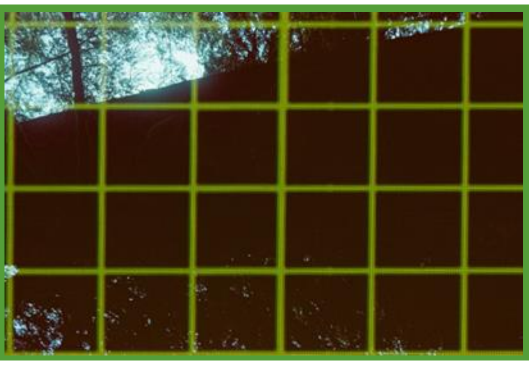
STEWARDSHIP is the responsible use of resources to create value, for example by avoiding waste where effort and expenditure fail to meet needs. Good stewardship requires relational decision-making for effective care.

STRUCTURAL VULNERABILITIES describe how the way that society is organised, including systems and practices intended to provide care, can unintentionally create harm.

FURTHER NOTES ON LANGUAGE

The terms "complex mental health conditions" and "advanced incurable physical illness" are used throughout this report. Both were chosen because these terms have been co-developed by myself, or by others, with people with lived experience – a process that started before my Fellowship and, given the evolutionary nature of language and meaning, one I expect to continue as we work together to develop shared language, meaning and practices.

EXECUTIVE SUMMARY



OVERVIEW

This Fellowship report asks a critical question: how can we reimagine palliative care so that systems meet the needs of people living with complex mental health conditions who are also diagnosed with advanced, incurable physical illnesses?

This is not a niche issue. Addressing it is essential for social justice and for responsible use of resources. In the United Kingdom, people with complex mental health conditions who require care for advanced physical illness often experience profound unmet needs. Significant resources are spent, yet their distress remains unresolved. This is not good them or for society.

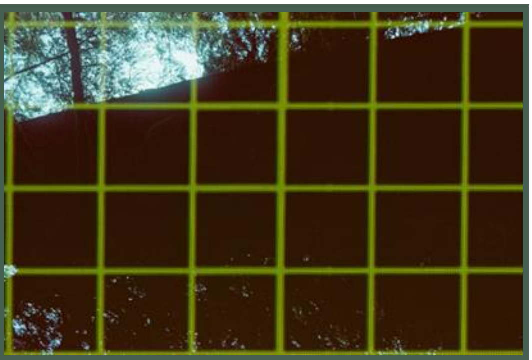
This report shares insights from visits to Canada, the United States of America, and Australia; learning that can inform improvements in the UK. These lessons are relevant to care for people living with complex mental health conditions including those classified as "severe and enduring non-organic mental and behavioural disorders" (ICD-11) but, because of the intersectionality commonly experienced, the lessons are also relevant more widely to improve inclusion and equity in care systems.

THESE ARE STRUCTURAL SYSTEM PROBLEMS, NOT PEOPLE PROBLEMS

"I don't fit the system"
"I know I have the difficult patient label"
"When they see mental illness on my notes, that's it"
"Thank you for thinking we are worth trying to make a difference"
"Not everyone thinks we deserve care"
"This might be everybody's secret story – a family member or friend with complex mental health conditions, the thing nobody wants to talk about."

These quotes come from conversations with people living with complex mental health conditions. Each story underscores hard truths: when healthcare fails those in the most difficult circumstances, it fails all of us. Getting care right for people with the least access to material or social resources, including the networks and support that help people navigate care (many of whom live with complex mental health conditions), has the power to improve care for everyone. Health and social care systems exist to deliver care to people. When mismatches between what people need and what systems provide occur, it is the system that must change. Structural change to rewild healthcare means intentionally redesigning so that structures genuinely serve relationship (see Terms and Definitions, p6), rather than dominating. It requires reshaping operational processes, governance frameworks, and decision-making pathways so they create the conditions for adaptive, relational practices to be cultivated and to grow. Therefore, rewilding healthcare systems is not about choosing between structure and humanity. Instead, structurally rewilded systems position relationship and relationality as first order goals, with structures intentionally in the background as a supportive scaffold. This enables responsible, context aware risk taking characterised by trust, respect, and shared judgement, broadening what the system understands as "good care" by drawing on community knowledge and lived experience.

MAJOR THEMES



EVERYBODY DIES. NOT EVERYONE GETS THE PALLIATIVE CARE THEY NEED.

WHEN PALLIATIVE CARE NEEDS ARE NOT MET EFFECTIVELY THE ECONOMIC AND SOCIAL IMPACT SPREADS ACROSS SOCIETY

The way we design and model interactions – between people and between people and structures within health and social care systems – shapes value, care outcomes, and the quality of experiences.

Relationship, defined as the “shared understanding between people about meaningful use of resources, and willingness to change one another through genuine exchange,”[1] offers a powerful mechanism for improving resource use, care outcomes, and satisfaction.

Rewilding healthcare to cultivate systems that put relationship at the heart of care isn’t about creating a “wilderness”. It is about creating a balanced ecosystem of care with space for relational practices, focused on what matters most to people, and meeting their needs. It is about embedding relational thinking into every decision point. Such an ecosystem would use community knowledge to enhance and diversify understanding of good care, placing accountability for responsible risk taking (because what is good is not necessarily what is “safe”) within relationships built on trust and respect. Rewilding healthcare offers an overarching way of thinking about care systems: intentionally cultivating balanced ecosystems where relationality guides practice and where people’s priorities shape decisions.

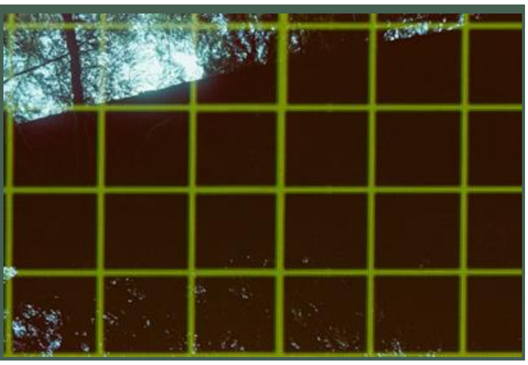
This approach prioritises the human aspects of healthcare and reframes structures as “relational containers”. Success is measured not by isolated efficiencies but by whole-system effectiveness, using the concept of relationality. Relationality describes “the capacity of a given environment of information exchange to create relationship.”[1]

DO NOT ASK WHEN TO USE RELATIONSHIP AND WHEN TO USE STRUCTURAL SOLUTIONS.
AT EVERY DECISION-POINT ASK, “HOW CAN WE BE MORE RELATIONAL?”

CREATING A RELATIONAL SYSTEM – COMMON PRINCIPLES

- Shared clarity and transparency
- Bringing together multiple perspectives through purposeful storytelling to influence decision-makers via co-production
- Rebalancing duty of care with dignity of risk through positive risk taking
- Prioritising meeting needs over criterion-led services
- Recognising and rewarding embedded, embodied, experience-based work
- Learning from positive deviances in current practices
- Focusing on meaningful progress
- Prioritising boundary-crossing relational solutions over structural “fixes” dependent on control to predict specific outcome

RELATIONAL DRIVERS OF SYSTEMIC CHANGE



Case analyses identified seven relational drivers of systemic change:

1. **Reframing risk through better decision-making** about what counts as risk, for whom, and how trade-offs between harms of inaction or exclusion and harms of action are weighed in positive risk taking to meet needs.
2. **Enabling “doing the right thing”** by strategically embedding relational work, coordination, and interdependence.
3. **Reimagining structures** as porous containers to allow preapproved boundary-crossing.
4. **Expanding workforce mix and mobility** to meet diverse needs.
5. **Co-designing special provisions** alongside mainstream integration.
6. **Using narrative evaluation and reward** relationship work to produce good outcomes and learn from new positive deviances.
7. **Addressing upstream structural vulnerabilities** to prevent systemic failure.

See place-based case examples within the main report for more details.

QUESTIONS FOR REFLECTION

When did we last reduce low value-added tasks to create space for change?

How are we engaged in positive risk taking?

Is work oriented to getting things right first time?

What would happen if we didn’t refer to choices as risks?

Is (near) real-time dialogue possible across settings?

What is being done to address whole-system effectiveness?

REPORT

CAN RELATIONSHIP DRIVE SYSTEMIC CHANGE FOR PEOPLE LIVING WITH COMPLEX MENTAL HEALTH CONDITIONS AND ADVANCED INCURABLE PHYSICAL ILLNESS?

AIMS

- **Learn from global innovations** that are transforming healthcare through relationship-centred approaches.
- **Apply this learning** to improve palliative care for people living with complex mental health conditions.
- **Adapt and transfer insights** to other situations involving structural vulnerability.
- **Advance social justice and responsible resource stewardship** within health and social care systems.

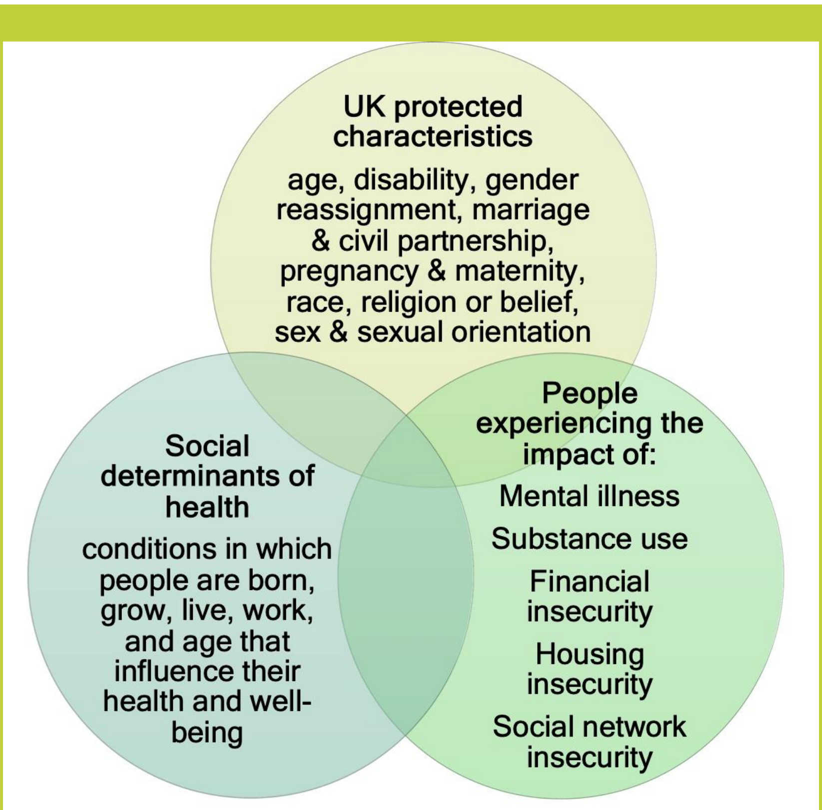
USEFUL CONCEPTS WHEN THINKING ABOUT INCLUSION AND EQUITY

PARITY OF ESTEEM

CARE SHOULD BE OF EQUAL QUALITY WHEN PEOPLE ARE LIVING WITH COMPLEX MENTAL HEALTH CONDITIONS AS FOR THOSE WITHOUT

Structural vulnerabilities describe how the way that society is organised, including systems and practices intended to provide care, can unintentionally create harm.

These vulnerabilities shape patterns of poor health and negative experiences. Examples include financial insecurity, unstable housing, lack of social support or advocacy, as well the impact of mental illness and substance use.



UK protected characteristics

age, disability, gender reassignment, marriage & civil partnership, pregnancy & maternity, race, religion or belief, sex & sexual orientation

Social determinants of health

conditions in which people are born, grow, live, work, and age that influence their health and well-being

People experiencing the impact of:

Mental illness

Substance use

Financial insecurity

Housing insecurity

Social network insecurity

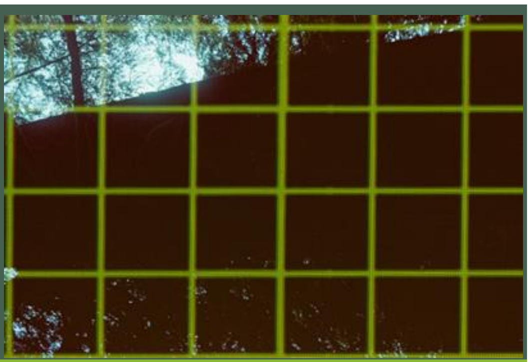
INTERSECTIONALITY: describes how overlapping factors – such as social determinants of health, structural vulnerabilities, and aspects of identity combine to shape experiences of disadvantage. These intersections can lead to adversity, including unwarranted differences in healthcare.

People living with complex mental health conditions often find themselves “at the bottom of the intersectionality pile”, facing exclusion through multiple mechanisms. For example, someone with a complex mental health condition who belongs to a minority group, lacks secure income, and lives in a community where mental illness is uncommon may experience amplified inequities in care, perpetuated by cultural, language, and social norms.

Separating physical and mental healthcare systems compounds intersectionality (of social determinants of health, personal characteristics, identity, and structural vulnerabilities) creating barriers for both people living with complex mental health conditions and those striving to provide safe, high-quality care. Including people with complex mental health conditions in palliative care is an opportunity to do right by them at the end of life. Beyond that, improving their experiences can teach us how to strengthen palliative care for other groups and reduce waste by avoiding high-intensity healthcare that does not match actual needs. At the heart of this is the need to reorient our healthcare system toward a relationship-centred way of delivering care.

POPULATION

Adults living with complex mental health conditions



Complex mental health conditions

+

Advanced incurable physical illness

On average death 20 yrs younger than those without severe mental illness

Two thirds of deaths are **amenable to palliative care** but people living with severe mental illness are half as likely to get the palliative care they need due to lack of integrated care and organisational boundaries.

Experiences of

- diagnostic overshadowing (assumptions about causes of illness)
- capacity being inappropriately questioned with assumptions about (death) literacy
- generalised stigma and bias

combine with

- challenges in self-advocating when unwell

to result in

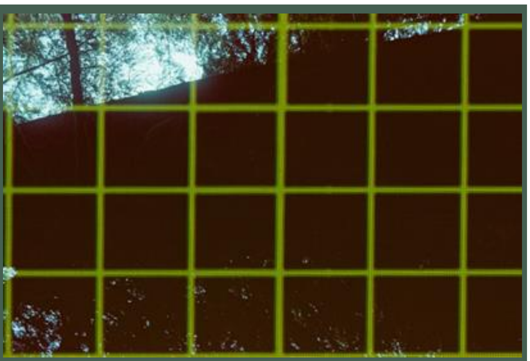
- high use of unplanned/crisis care and longer acute hospital admissions and higher in-hospital deaths
- exclusion from care decisions and opportunities to co-design better care

PEOPLE LIVING WITH COMPLEX MENTAL HEALTH CONDITIONS ARE HALF AS LIKELY TO ACCESS APPROPRIATE PALLIATIVE CARE. THEY ARE OFTEN EXCLUDED FROM CHOICES ABOUT THEIR CARE.

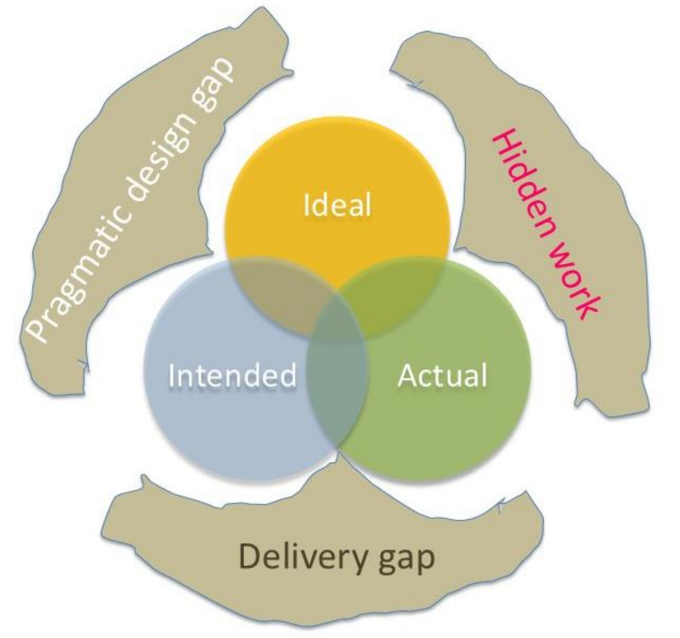
Seventy-five percent are admitted to an acute hospital at least once in their last year of life, and half die there. In the final 90 days, on average they spend four more days in hospital than those without complex mental health conditions. They are only half as likely to die in a hospice.[2-4]

Reliance on unplanned or crisis care leads to persistent distress and ineffective use of resources. When people remain in distress, they will keep seeking help wherever they can. Expending finite resources without meeting needs makes no sense. Getting healthcare right for those with the least, and in the most difficult circumstances, holds potential to improve care for all of us.

FROM SYSTEM GAPS TO SYSTEMIC CHANGE



With unlimited resources, designing an ideal healthcare system might be possible, but that is unrealistic. There will always be a pragmatic design gap between the ideal and what is intended, shaped by how resources are distributed and prioritised according to need regardless of the balance, or imbalance between structure and agency within a system. Relational approaches offer a better way for everyone to be engaged in an honest, clear, and transparent process about how these decisions are made, even though navigating the difference between needs and wants is challenging. However, if we want to improve healthcare through relationship, we should also focus our attention on two other gaps, within our collective ability to change:



1. **The delivery gap:** the difference between intended design (policy, or “what happens on paper”) and what actually happens in practice.
2. **The hidden work gap:** the space between expectation and experience. This gap is often filled by workarounds created by people within the system, usually unacknowledged or described as optional, such as “going the extra mile”. Hidden work mitigates structural failures and is almost always built on relationships.

I use the term “hidden” deliberately. Sometimes this work is overlooked by decision-makers; sometimes it is deliberately concealed because of mistrust and lack of relationship within care systems. This creates broken feedback loops: those doing the work do not share the impossibility of working to the design, and those making decisions cannot account for the realities and constraints of care. The result is an unhelpful fictional social contract where everyone is drawn into a pretence.

Using relationship as a mechanism for change in these gaps is about doing (and spending) differently, not necessarily more.

THE IMPORTANCE OF RELATIONSHIP AND RELATIONALITY FOR ECOLOGICAL RESILIENCE IN CARE SYSTEMS

Rather than asking *when* to use people-mediated solutions and *when* to use structural solutions, we should ask **how to think relationally about both**.

Ecological resilience is the ability of a system to adapt to changing conditions by finding new balance points. This is possible in a relational system, where relationship and relationality provide mechanisms for systemic change.

Rewilding healthcare is about creating an open, balanced ecosystem that meets people's needs while stewarding resources wisely. Rewilding healthcare to cultivate systems that put relationship at the heart of care isn't about choosing between structure and humanity or about creating a "wilderness" but demanding that structure serves relationship so that care becomes more inclusive, humane, and effective.

Ecologically rewilded systems do not remove order; they redesign it so that relational networks, diverse perspectives, and distributed decision making enhance flexibility. This is especially important in care involving serious illness and complex mental health conditions, where people's needs shift over time and cannot be met by rigid, linear processes.

In such ecosystems, trust-based relationships enable responsible risk taking, while rich feedback loops, including those drawn from community knowledge and lived experience, guide continuous recalibration. This dynamic interplay strengthens ecological resilience and supports systems that remain coherent while evolving in response to complexity.

What holds us back from making relationship the primary mechanism for care?

Misunderstandings about risk often create systemic bias toward structural solutions that can feel safe on paper but are disconnected from the realities of care.

A risk is a definable probability of harm. It is not the same as uncertainty. Nor does risk mean harm is inevitable, or that if harm occurs, the choices leading to it were always wrong. Yet risks are often approached with bias: inflating the likelihood of negative outcomes, overemphasising the risks of action over inaction, and giving physical harms more weight than psychological or social harms.

Institutional fears of losing control, privileging reputational risk above other risks, and failing to recognise that rules cannot replace trust (and can even erode it) are key drivers of unhelpful, non-relational thinking. This creates a false sense of control through rules that orientate people to focus their efforts on demonstrating that they tried to avoid harm, rather than efforts to achieve good. This problem is compounded when comfort through familiarity is confused with safety or quality, reinforcing normative practices without question.

A relational approach reframes responsibility and accountability as shared, within a social contract built on mutual understanding that healthcare decisions often happen in uncertainty. Positive risk-taking is essential if we want care that is not only safe but good.

Listening to Experience

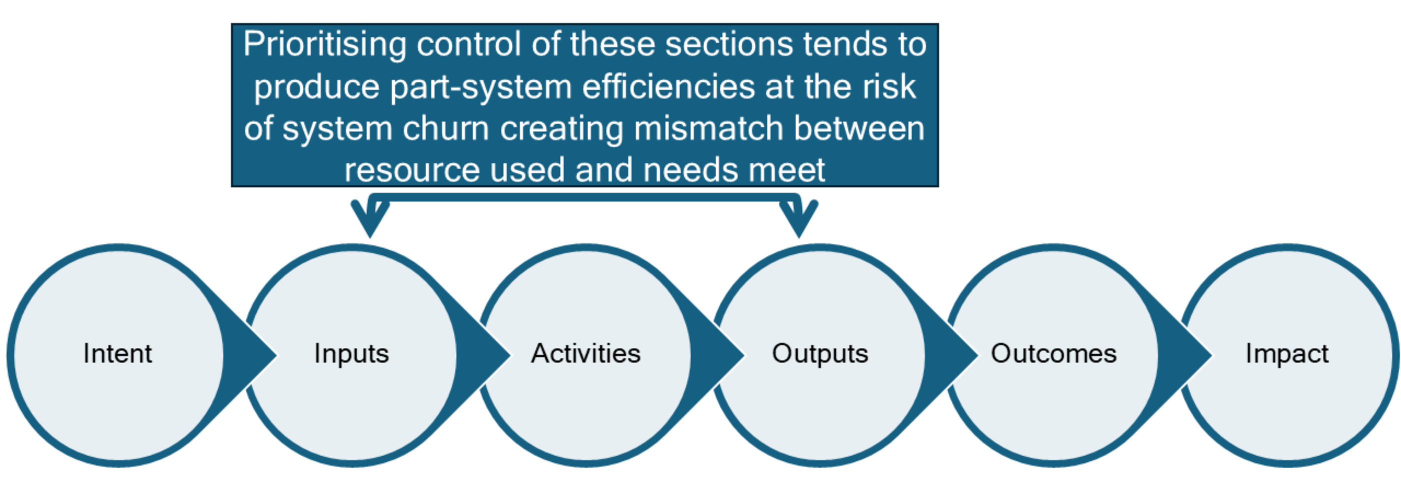
Before my Churchill Fellowship, I worked with different groups of people with lived and/or learned experience to explore what people with serious mental and/or physical illness want from a good healthcare system – their hopes, doubts, and fears. Together, we identified the need for relationship as the foundation for “collective social safety” – being safe with each other, whatever the situation.

Many people living with complex mental health conditions described themselves as “people whose needs don’t fit the system” and shared their awareness of being perceived as “difficult” because of this. They expressed surprise and gratitude for our interest, thanking us for believing they “deserved” good care.

I do not want to be part of a system that creates these experiences or leads anyone to feel undeserving of care. Yet, from my own experience as a practising doctor, I know what they mean, and I know this will be unsurprising to many working in any part of the healthcare system.

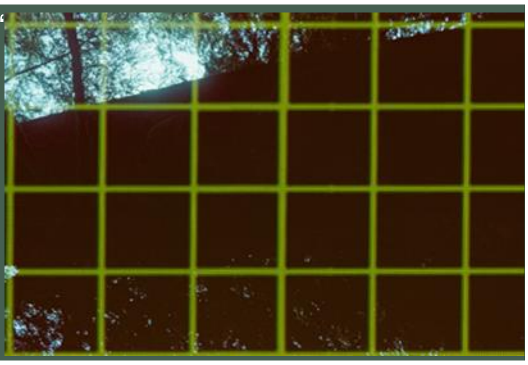
Failures in systems thinking: a mirage is created by part-system efficiencies often judged by speed or execution and exclusion of anything that doesn’t fit the rules.

This just creates system churn with mismatch of resource to needs and deviation from system purposes.



Prioritising control of these sections tends to produce part-system efficiencies at the risk of system churn creating mismatch between resource used and needs meet

UK CONTEXT



Closing the Gap in Care for People with Complex Mental Health Conditions

Historically, healthcare systems have failed to adequately address the physical health needs of people living with complex mental health conditions. This has been compounded by a focus on part-system efficiencies rather than whole-system effectiveness, and by insufficient attention to what matters most to people in need.

Examples of part-system efficiency rather than whole-system effectiveness often involve failures for care to be organised around the convenience of the intended beneficiaries, the health and social care workforce or even the system. Part-system efficiency describes a part of the system seeking its own efficiency, not that the whole system is partly efficient. Undue emphasis on “flow” is a common underlying factor, for example, automatically discharging people from hospital follow-up if they miss three appointments without any means to check if mitigating factors should have been considered, or if reasonable adjustments to support someone to attend were required. This efficiency saves time and permits reallocation of resource within the hospital outpatient departments in the short term but creates additional work for community services and/or emergency departments if a crisis occurs as a result. It also re-creates the work of a new referral and its associated processes when, as is inevitable with serious illness, the person returns through another route. Another example is the person whose needs are mismatched with the available services criteria. Such a person can find themselves “bouncing” around a system, being “processed” on multiple occasions by multiple services that deem their needs as too complex or not within remit without offering confirmed alternatives to help.

The Health and Care Act 2022[5] introduced a legal requirement to provide palliative care services in the UK. Parity of care demands that these services are accessible to people with complex mental health conditions.

The NHS 10-Year Plan, *Fit for the Future*,[6] prioritises community-based care through neighbourhood health centres. Integrating palliative care and mental healthcare – alongside other community services – is essential to improve care for people living with complex mental health conditions and advanced, incurable physical illness.

Reducing unplanned and crisis care, including unnecessary hospital admissions, will only be possible if this population is included in decisions about their care and offered options that meet their needs. This requires addressing unwarranted variation arising from intersectionality – social determinants of health, personal characteristics, identity, and structural vulnerabilities – while also allowing warranted variation to correct historical and current inequities beyond immediate healthcare needs.

FINDINGS: PLACE-BASED CASE EXAMPLES

Source: https://commons.wikimedia.org/wiki/File:World-map.svg

THE IMPORTANCE OF HERITAGE, IDENTITY AND PLACEMAKING IN STORYTELLING

Learning from global innovators: from troubles and trauma to stories with purpose

My Churchill Fellowship took me to the USA, Canada, and Australia to learn from global innovators transforming healthcare through relationship-centred approaches.

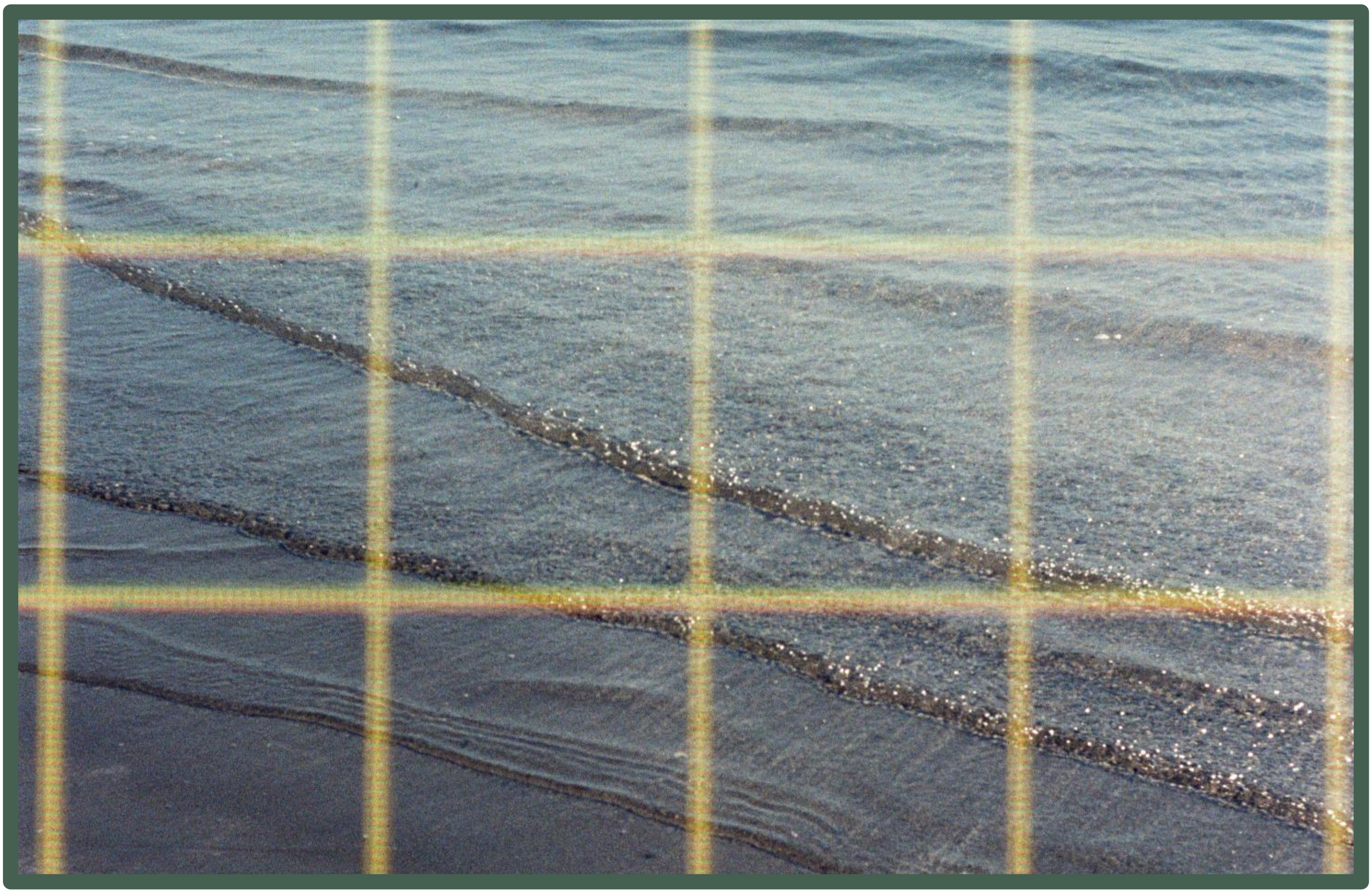
I did not set out to visit countries with a shared history of colonisation and suppression of Indigenous ways of life, including ecological approaches to living in balance with the natural world. Yet my learning was deeply enriched by how these histories shaped the stories of each place. I am grateful to all who shared their time and perspectives, whether identifying as “victims”, “perpetrators”, or both.

In every setting, I witnessed acknowledgement and respect for elders – past, present, and emerging. People involved in healthcare shared personal, family, and ancestral stories alongside their work. In doing so, they demonstrated that rewilding healthcare by cultivating relational systems means creating better ways to listen and tell stories with purpose – using relationship and relationality to support story-led change and (re)create a culture of “commons” in healthcare.

The “commons” describes a philosophy of shared resources that predates land enclosures: a system built on mutual rights and responsibilities, managed collectively and communally. At its heart is inclusivity – resources that everyone needs – and equity, achieved when all can use those resources in ways balanced by social contracts and sustained through knowing one another and contributing to their long-term maintenance. The concept of the commons applies as much to contemporary public institutions, health and social care, and natural assets as it once did to shared land.[7,8] Across all these fields, sustaining shared resources through mutual responsibility, reciprocity, and social norms that protect collective – rather than purely individual – interests remains essential.

A commons is often misunderstood as free for all “open access”, but ecologically and socially these systems operate very differently. Open access describes a space where anyone may use resources with no shared norms, boundaries, or reciprocal obligations, making it vulnerable to overuse and exploitation. By contrast, the inclusivity of a commons is based on recognising universal need while holding resources in trust for all who require them, rather than restricting access through enclosure or bureaucratic eligibility barriers. Crucially, commons-based stewardship is a system in which access, accountability, and responsibility are sustained through relational proximity and participation – people knowing one another, recognising shared stakes, and engaging in everyday practices of mutual visibility that deter misuse. This is what distinguishes a true commons from an unregulated open-access system in which power or privilege can freely distort the distribution of resources.

In both ecological rewilding and the rewilding of healthcare, the integrity of a healthy commons is maintained not by fixed structures or inflexible rules but by cultivating relational proximity: relationships that enable shared observation, local decision-making, and context-specific stewardship. Relational care ecosystems therefore depend on community, reciprocity, and shared stewardship of resources intended to serve everyone. The verb to common captures this: describing social practices – “commoning”[9] – that not only hold resources in common but self-govern for sustainability, with each set of commons assets anchored in a known and defined population who achieve commoning through relationship.



South Central Foundation

Nuka System of Care

ANCHORAGE

BUILDING RELATIONAL SYSTEMS THAT INTEGRATE PURPOSEFUL LISTENING AND STORYTELLING AS MECHANISMS FOR SURVIVAL AND CARE

South Central Foundation's Nuka System of Care, developed in partnership with Indigenous and Native American communities, is rooted in relational principles and designed to rebuild trust after deep historical discrimination and stigma. Workforce members are expected to spend up to 20% of their day on relational work, recognised as essential and delivering measurable benefit:

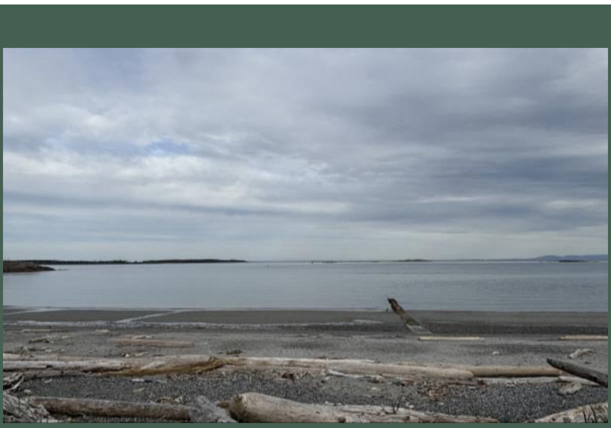
> *"We ask everyone to sincerely commit to our principles; if they do, they quickly see the power of relationship in practice. If they don't, then they don't stay." (Board member)*

Anchorage offers lessons from conditions where survival depends on community and reciprocal action. Shared identification of healthcare priorities led to upstream work to break "cycles of harm", addressed through storytelling groups that rebuild healthy relationships. Organisational data shows measurable impact: reduced healthcare needs and lower resource use across the system.

Focusing on the 20% of the population with high-intensity needs – including acute serious mental illness and end-of-life care – the Nuka System orients and rewards its workforce around four relational principles:

1. Outcome, not income: prioritise whole-system effectiveness and cost over part-system efficiency and budgets.
2. Person, not disease: address distress and needs wherever they appear in the system.
3. Population, not process: eliminate low-value tasks like complex referral criteria and triage, replacing them with relational handovers when complexity requires extra resources.
4. Service, not practice: deliver convenient care for those who need it, when they need it.

I witnessed how co-located healthcare support teams – case manager, care provider (family physician or advanced nurse practitioner), certified medical assistant, and behavioural health consultant – act as the coordinating hub for all other care. Results are striking: emergency visits and inpatient admissions reduced >40%, outpatient visits >30%, workforce and population satisfaction above 90%.

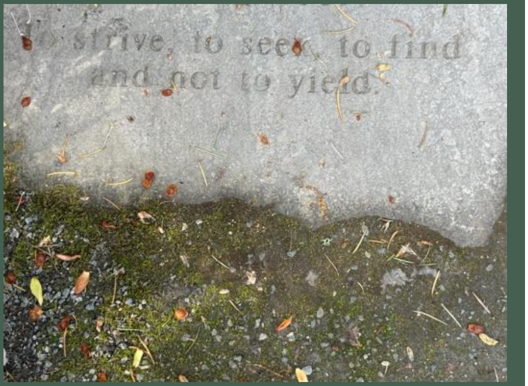


Palliative Approaches to Care in Aging and Community Health

University of Victoria

VICTORIA, BC

Beauty of Mending: Kintsugi and Beyond. Naoko



MOBILE WORKFORCE AND BOUNDARY-CROSSING: BUILDING BRIDGES

In Victoria, BC, I learned how researchers and mobile palliative care teams partner with charities supporting people who are homeless – many living with mental illness. To legitimise organisational and place-based boundary-crossing, the team:

- Challenges norms and restrictions that block care
- Works with whoever is close to the person – including shelter staff and chosen family
- Sets pre-approvals for health and social care workers to operate across traditional settings.

Over time, they identified where to focus permissions for flexible practice. Relaxing referral criteria has been impactful without overburdening the team, and purposeful listening to build trust is central. They now use a three-tiered list linking involvement to shared responsibilities:

1. Aware/in conversation – no immediate tasks; can seek help proactively or via someone else
2. Active care – team proactively seeks out and works with them
3. Stabilised but likely to need support – team checks in periodically with them and trusted contacts.

Building on trusted relationships is key. Community members such as support workers often hold strong ties that ease care transitions. These connections are carried forward through “warm handovers”, ensuring trusted individuals accompany people across health and social care – not as passive observers but as active partners defined by the person.

Key questions: Who is already working closely with people in need? How can we collaborate with them to strengthen care?

Palliative Education and Care for the Homeless

Princess Margaret Cancer Centre

Kensington Hospice

TORONTO

SPECIAL CASES AND BUSINESS AS USUAL: THE TWIN ARMS OF INCLUSION

In Toronto, hospital, hospice, and community teams I visited worked together to ensure that people with complex mental health needs requiring palliative care could access mainstream services, as well as care through “special case” provisions. While organisations within the health and social care system there recognised that tailored services can be important initially, the greater goal was systemic change, making mainstream care more inclusive by improving how accessible and adaptable to diverse needs the care offered was. Examples of their dual approach, combining some special provision with expectations that all care needs would be considered in mainstream services included:

Introducing universal distress assessments and interventions when someone attended hospital services or was admitted. This shifted assessment and intervention away from individual clinician judgment and normalised the importance of addressing distress for everyone.

In hospices, a gap between their inpatient admissions and the demographics of the surrounding community was identified. To address this, they:

- Set target inclusion quotas (e.g., 30% of beds for people living with structural vulnerabilities)
- Relaxed admission criteria, allowing flexibility for extended stays
- Embedded quota discussions into daily handovers and admissions meetings to maintain awareness.

To equip staff for this shift, hospices provided regular training and reflection sessions and created a peer support worker role – someone with lived experience of structural vulnerabilities, mental illness, or substance use. This role proved crucial for building understanding, negotiating challenges, and advocating for people who might otherwise lack family or social support.

Weill Cornell Medicine

NEW YORK CITY

COWORKING TO IMPROVE CULTURAL INTERPRETATION AND EXCHANGE

In New York, I saw the potential of healthcare professionals who were dual-trained, in psychiatry and palliative care, working within a hospital-based behavioural health and palliative care team. This team brought together a wide range of roles – chaplaincy, psychology, social work, language and cultural interpreters – alongside clinical expertise.

A culture of co-working and shared learning encouraged team members at Weill Cornell to approach care as a collective endeavour. By working together and drawing on each other’s perspectives, professionals reduced fear of the unfamiliar and extended their skills. This collaborative approach benefited everyone – especially the people receiving care.

Recent initiatives have included embedding mental health services directly into palliative care programmes, ensuring that patients with serious illnesses receive comprehensive support for both physical and psychological needs. The team has also developed collaborative care models that integrate psychiatric expertise into routine palliative care, improving access for patients with complex mental health conditions. In addition, they have introduced training programmes that weave psychotherapeutic concepts – such as psychological formulation and countertransference – into serious illness communication, equipping clinicians to navigate emotionally charged conversations with greater confidence and empathy.

What I Want to Say at Parties

So, what do you do?

I'm a chaplain at a hospital.
I visit people and see if they
need spiritual support or care,
maybe if they'd like to
pray together.

So… what do you *do*?

I'm a chaplain at a hospital,
I visit people and respond
if there's an emergency,
to provide spiritual and
emotional support to those
in crisis.

Okay but like, what do you do?

I'm a chaplain resident,
so two days a week I learn how
my compassion tears and heals
stronger, my eyes well up
at the growing pains,

and once a week I sleep
at the hospital, praying I
get through a REM cycle
before I am told that
someone has died,
or worse.

But what-
What do I do?

I hope that I'm the life vest
on the boat when the storm
story starts to creep across the
blackened sky, waves hissing at the
quaking hull.

I hope that I'm the Phone-a-Friend
on the game show you never wanted
to be on, all spinning wheels and
lights flashing in your eyes at
this cruel and sterile carnival.

I hope that I'm the prayer you forgot how to pray,
and the hymn you forgot how to sing,
offered so lightly you remember the
words and the tune only after I've left.

And I hope that I know how to be all of these things,
a life vest, a friend, a prayer and a hymn,
and to hold myself with a fraction of God's grace
when I fall short, and am only
me.

Jess Smith, Chaplain *(reproduced with permission)*

Heller School for Social Policy and Management Brandeis University

WALTHAM, MA

COORDINATING FOR RELATIONAL INTERDEPENDENCE

The Heller School researcher-founders of the Relational Coordination Collaborative have developed models that invert the usual dominance of structural over relational components in health and social care systems. Instead of relationships being invisible while structures dominate, their work shows it is possible to redesign systems so that structures serve relationships. This means recognising relational work as legitimate work and investing in rituals that make relationship-building an expected – and resourced – part of everyday practice.

I gained understanding of how their models are applied in practice. Job design should embed relational expectations and allocate time for them. Shared understanding of responsibilities and transparent, reciprocal accountability are mediated through chains of relationship – people knowing and trusting each other. Reducing barriers and making boundaries more permeable between teams and organisations is essential for this to succeed.

Structures and tools should support connection, not replace it. For example, communication platforms should enable dialogue – preferably in real time, or if asynchronous, still reciprocal – rather than creating delays and breakdowns between each transmission and response.

The Dartmouth Institute for Health Policy and Clinical Practice

Jack Byrne Center for Palliative and Hospice Care

HANOVER, NH

DISTINGUISHING WARRANTED FROM UNWARRANTED VARIATION

Policymakers understandably want assurance that relational care works, that it produces high-quality, safe, and effective outcomes. Rewilding healthcare to cultivate relational systems also means demonstrating that resources are stewarded well. Just as organisational models need to shift from control as a means of avoiding risk, evaluation must move beyond reliance on predictability as the sole measure of success.

The Dartmouth Institute works with health and social care organisations internationally to develop and apply relationally orientated measures of success. They have demonstrated locally within community, hospital and hospice care that relational care requires a different lens for evaluation, risk management, and accountability – one that values reality-based interventions prioritising boundary-crossing relational solutions over structural “fixes.” This includes:

- Influencing policy through relational co-production, focusing on meaningful progress rather than rigid predictions.
- Creating systems that support relationships, recognising the benefits of time and effort invested in meaningful connections.

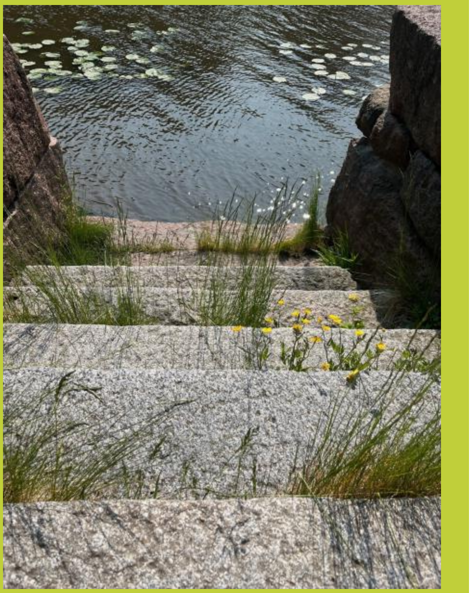
Key messages I gained from discussing and observing their work can be summarised as reduce, reward, recognise, and support:

- Reduce processes: remove or automate low-value tasks wherever possible. Service criteria and referral triage are prime targets for simplification – shifting from deferring to doing work.
- Reward doing what is right: train for competence and foster a culture where people act to meet basic human needs without waiting for permission.
- Recognise and support those who step up: value individuals who act because “if not them, then who?” and provide the backing they need.

European Association of Palliative Care Symposium: Future palliative care for patients with pre-existing complex mental health conditions

29TH MAY 2025

HELSINKI, FINLAND

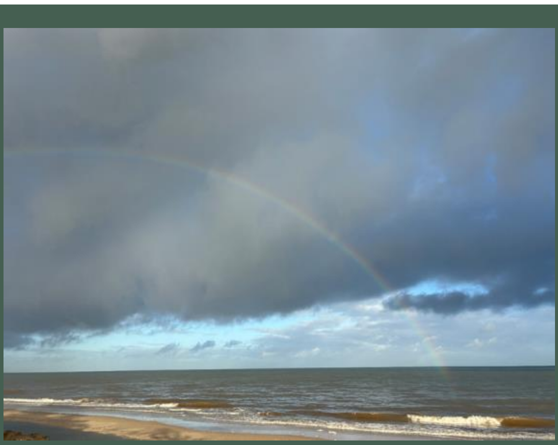


RESEARCH-DRIVEN CANCER CARE IMPROVEMENT FOR PEOPLE WITH COMPLEX MENTAL HEALTH CONDITIONS

Mid-way through my Churchill Fellowship travels, I co-chaired a symposium with Professor Mette Asbjoern Neergard to bring together evidence on palliative care for people living with complex mental health conditions. The symposium featured the latest work from the MENLOC group (Swansea, UK), the CASEMED group (Aarhus, Denmark), and the Marie Curie Palliative Care Research Department (London, UK). Across four contributions, we highlighted persistent inequalities and proposed relationship-centred approaches to guide palliative care redesign. Participants shared local challenges and successes to build a shared understanding of what optimal care requires.

The Danish CASEMED research group exemplifies how targeted research can drive meaningful improvements in healthcare. Through a multi-methods approach – including systematic reviews, interviews, and register-based studies – they have explored cancer and palliative care for patients with pre-existing complex mental health conditions. Their findings reveal persistent inequities in cancer care, such as higher mortality rates and reduced access to recommended treatments, even within universal healthcare systems. In response, CASEMED are developing a supportive cancer care model that empowers patients, relatives, and professionals to co-operate for better care. The model integrates early psychiatric assessment, caregiver engagement, continuity among healthcare professionals, and cross-sector collaboration through onco-psychiatric multidisciplinary team meetings. Co-designed with stakeholders and successfully piloted, it has proven feasible and effective in improving care coordination. The CASEMED model showcases how research can identify systemic barriers and translate findings into practical, scalable interventions, offering a route to enhancing equity and integration for vulnerable populations.

UK colleagues presented complementary work demonstrating substantial knowledge needs, fragmented support networks, and ongoing disparities in access for people with severe mental illness at the end of life. I concluded the symposium by outlining relationship-centred concepts from my ethnographic research and Churchill Fellowship, showing how such approaches can reshape systems, close gaps, and strengthen fairness in access to palliative care.

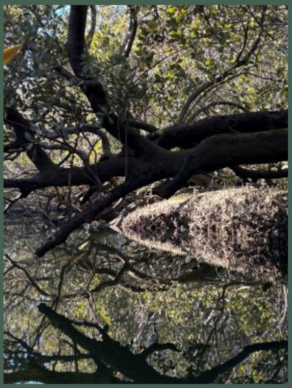


Research Centre for Palliative Care, Death and Dying

Flinders University

Modbury Hospital

ADELAIDE



LEARNING FROM POSITIVE DEVIANCE:
USING VIDEO-REFLEXIVE ETHNOGRAPHY FOR CHANGE

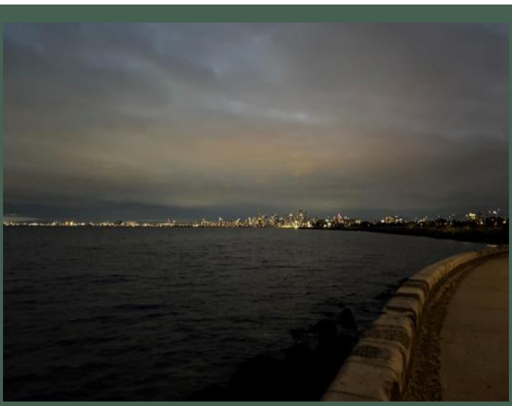
Video-reflexive ethnography (VRE) is built on four inclusive principles that orient researchers toward participatory, in-situ change as well as evidence building:

1. Exnovation – surfacing and critically examining everyday practices that are usually taken for granted.
2. Collaboration – engaging participants as co-researchers to reflect on and improve their own practices.
3. Reflexivity – encouraging participants to critically reflect on their actions, assumptions, and interactions through video footage.
4. Care – ensuring the research process is ethically sensitive, respectful, and supportive of participants' wellbeing and professional integrity.

This method reframes research as a tool for advocacy and activism, prompting questions such as: "*Are we asking the right questions?" and "When we listen to stories, are we doing so with shared purpose?"* Applied in healthcare, I was struck by research–practice partnerships in Adelaide that work upstream from immediate needs to ask: *What are the underlying causes and mechanisms of structural vulnerability?*

The multiple project collaborations I learned about are co-led by researchers at Flinders University with communities and health, social and voluntary organisations. These seek evidence not only to mitigate inequity but to reverse or modify its sources, learning from positive deviance – where people already work around formal systems to achieve good outcomes. Central to this approach is balancing duty of care with dignity of risk through positive risk taking. Relationship-based strategies build trust so that inclusive, shared positive-risk taking can occur – creating care that aims for more than just being "safe", and instead seeks new benefits.

Examples of their work that are having both local impact and global influence include developing better understanding of how people with palliative care needs think about safety in relation to how they think about home, how these concepts intersect with social and cultural identity including symbolic connections and, therefore, what is needed to practically co-create culturally-sensitive care.



University of Melbourne

St Vincent’s Hospital

MELBOURNE

TURNING PRACTICE-EMBEDDED UNDERSTANDINGS INTO EVIDENCE

PALLIATIVE NEXUS: INNOVATING EARLY PALLIATIVE CARE THROUGH CARE PLUS

This academic-clinical collaborative research group is dedicated to transforming palliative care delivery through evidence-based models. Their flagship initiative, Care Plus, responds to persistent barriers in early palliative care integration – such as delayed referrals and inequitable access – by embedding a structured, outpatient-focused pathway within routine cancer care.

Critical to the success of increasing palliative care use in Melbourne has been the development of research using co-owned intervention triggers to normalise referrals from different clinical fields to palliative care services. I saw how research and clinical teams work together to normalise palliative care, agreeing on intervention triggers and scripts to present palliative care positively, integrating it for everyone. This approach ensures that referrals are timely, consistent, and framed as a standard part of comprehensive care.

Developed using implementation science principles and co-designed with clinicians, patients, and carers, Care Plus standardises referral triggers, strengthens communication between oncology and palliative teams, and equips health services with practical tools for change.

The model prioritises symptom relief, psychosocial support, and continuity of care, delivered by multidisciplinary teams and adapted to local contexts.

Care Plus has demonstrated feasibility, acceptability, and measurable improvements in patient experience and care coordination. This work exemplifies how research can dismantle structural barriers and translate findings into scalable interventions. By integrating palliative care earlier and more equitably, Palliative Nexus offers a blueprint for improving quality of life and health system responsiveness for people with cancer and their families.

ThinkPlace

CANBERRA

LEARNING TO TELL A STORY FOR CHANGE

Transforming palliative care for people living with complex mental health conditions
During my time in Canberra, I spent two concentrated days working with Bill Bannear, a senior strategic designer at ThinkPlace, to develop the three-part strategy that follows. Bill's experience in systems thinking and social innovation, combined with ThinkPlace's grounding in human-centred design (HCD), provided the structure needed to translate my Fellowship learning into a coherent framework for action. We were also joined by Darren Menachemson, whose work at ThinkPlace focuses on complex system transformation, behavioural insight, and ethical design.

Together, we used human-centred design methods to map the patterns emerging from my Fellowship visits, clarify where system failures were relational rather than technical, and test how relational principles could be embedded in realistic, actionable ways. This collaboration led directly to the articulation of the **three-part strategy** that anchors the next section of this report:

1. **Change thinking**
2. **Shift local practice**
3. **Drive change through research**

Working with Bill and Darren ensured the strategy is grounded in relational insights while also being shaped for practical implementation within complex care systems. Most of the actions within it involve realistic alternative ways of working rather than additional or more expensive ways:

1. Change thinking
We must prioritise relationship and relationality. Systems should be designed as relational containers – spaces that enable people to know each other, share context, and collaborate effectively. This means:

- Rebalancing risk by embracing the dignity of choice alongside duty of care.
- Prioritising meeting needs over refining service criteria.
- Creating spaces for multi-perspective understanding, even without consensus.
- Bringing together people at risk of "othering" each other within the system.
- Recognising that small changes can make a big difference, starting with shared clarity and transparency.

2. Shift local practice
Apply collaborative, relationship-based approaches to improve inclusion and equity in existing work. Examples include:

- Protocols for building trust, warm handovers, and team mobility – working with whoever is already in relationship with people in need.
- Real-time dialogue tools and open referral systems.
- Workforce exchange programmes to build relationships across teams and services.
- Pre-set governance permissions to enable trans-organisational collaboration.

- Investing in rituals for connection, handover, and transition to sustain relational value.
- Projects should be co-designed with communities and practitioners, supported by policy environments that enable and reward relational working.

3. Drive change through research

Build an evidence base to:

- Establish ways to systematically create collective social safety – being safe with each other regardless of the situation.
- Evaluate success based on whether relationships produce good outcomes, even if different from predicted.
- Learn from positive deviance and real-world case studies.

Use this evidence to inform policy, guide investment, and scale effective models. Think not when, but how relationship and relationality can be embedded throughout systems – at every decision point.

"In terms of human understanding [in 1805], nobody yet knows what the wind actually is. So it's an invisible force. It's unknowable, unpredictable, and largely immeasurable. But as part of the national effort to conquer it, a key development at this time was Francis Beaufort's standardised wind force scale. A scale that relies not upon quantitative absolutes achieved with a mechanical measuring device, not actually about measuring the wind, but rather to use some extent subjective language to diagnose it according to visible clues. So in other words, it employs observational power and judgment. You describe the effect of the wind, not the wind itself, but the effect of the wind on everyday objects...where Beaufort used words, Turner uses paint…"

Quotation from 'An object of no small terror': Turner's Sublime Seas' Nicola Moorby, Curator of Historic British Art, 1790-1850 at Tate, Lecture on 27th January 2026, Courtauld Institute, London.

Image: J.M.W. Turner, *Bell Rock Lighthouse*, 1819, National Galleries of Scotland collection. National Galleries of Scotland.
[available at: https://www.nationalgalleries.org/art-and-artists/19251?artists%5B5582%5D=5582&search_set_offset=174&page=2]

A VISION FOR SYSTEMIC CHANGE

What would happen if institutions held back by a culture of transactional prediction learned to think relationally and were financially rewarded for doing so?[1]

Building a Movement for Relational Care

To create meaningful change, we need to build a movement that raises awareness and shifts thinking about this population – at system level, within organisations and institutions, and in the minds of individuals. Changing mental models is crucial to positive action.

The challenge with our current healthcare system is that it focuses on controlling inputs, activities, and outputs, rather than creating the right preconditions and permissions and attending to the wider ecosystems of life (e.g. social, public, civic, political, economic). A relational approach enables people to move between different groupings to deliver care. If institutions start to think relationally – rather than being constrained by a culture of transactional prediction – we can steward resources better, meet needs more effectively, learn from stories, ask the right questions, and build activities around collective social safety. This leads to better decision-making, positive risk-taking, inclusive choice, and care that is not just safe, but good – closing the feedback loop through mutual trust in a system that responds to feedback.

Put the Structures in the Shadows: Whole-System Thinking

In whole-system thinking, the system is the entire healthcare enterprise – both structures and people. Human factors are about optimising the interaction of people within the system. People are integral, not separate; we create and replicate how systems function. Part-system efficiency is not the same as whole-system effectiveness, yet this truth is often lost in healthcare policy.

Health and social care systems are hard to navigate – not just for patients and carers, but even for highly qualified professionals. In complex systems, safety comes from coherent relationships and mutual understanding.

Working with patients, carers, and professionals, we developed the concept of collective social safety: being safe with each other regardless of the situation. This reframes safety – not as risk-free (life is intrinsically risky) – but as relational. When thinking about risk in healthcare, common myths and flawed mental models often hold us back.

A good example of putting the structures in the shadows is how people can learn to work relationally. Experientially good care is learnt through good experiential learning based on principles, with genuine resourcing to allow relational working. While “education and training” are often proposed as solutions to systemic problems, they are frequently misunderstood as individual level fixes, presuming knowledge deficits, rather than recognising the realities of practice including delivery gaps and hidden work. This can reinforce concerns and create further disconnect rather than facilitating change. It is rare that a pure deficit of knowledge or lack of competence is the reason people do not work relationally. Meaningful learning, therefore, also needs to be understood as relational, experiential development that happens within systems designed to support positive risk taking, cross-boundary working, and needs-oriented care. Learning to work relationally can be a systemic change when organisations create the conditions, permissions, and rhythms that allow people to practise relational work within an ecosystem built on the principles of relationality.

PRACTICAL RECOMMENDATIONS

for transforming palliative care when people are living with complex mental health conditions

"Strong communities with good relational networks are healthier and safer and more economically effective. People, organisations and societies that are better at relationships are better at everything." (David Robinson)

1. Ask the Right Questions to Make the Right Decisions at Every Level of Healthcare Organisation:

- Do we need to work upstream, addressing causes – not just symptoms – even if this means going beyond healthcare to tackle structural vulnerabilities?
- How are we framing risk, and for whom? Which risks might we be biased toward or against? When should we talk about choices rather than risks?
- Are we engaging in positive risk-taking, offering inclusive choices and balancing duty of care with dignity of risk?
- Is care organised around user convenience?
- Can we do something differently to reduce high-intensity use, better meet needs, and release resources?
- How can we relieve distress in this situation? If we don't help, then who will?
- How can we learn from positive deviance and human workarounds that mitigate structural inadequacies?

2. Think of Systems as Relational Containers

- Accept that attempts to control outcomes through rigid rules can erode trust.
- Design integrated services with porous boundaries so people can move easily between them.
- Invest in relational job design and work rituals that prioritise relationship-building.
- Establish partnership models of care that include patients and their chosen care partners as legitimate team members, with clear, transparent responsibilities.
- Facilitate multi-perspective understanding by bringing together diverse stakeholders, including those with lived experience – even groups that have historically "othered" each other. Use facilitated storytelling to create shared common ground.

Relational systems require learning environments, spaces where people can practise new ways of working, reflect together, and develop confidence in positive risk-taking. This is not about mandatory training but about creating conditions for shared learning through real relationships and real work.

3. Make It Easy to Do the Right Thing

- Provide tech-enabled tools for near real-time dialogue.
- Simplify or automate low-value tasks, especially referral criteria and triage.
- Reward actions that meet needs, not just those that avoid harm.

- Support practitioners who act to meet basic human needs because “they can” or “if not them, then who?” – for example, by creating an organisational hardship fund for discretionary use.

Learning to work relationally happens most effectively when structures remove barriers, create permissions, and make relational work the path of least resistance. In this sense, learning is built into the system itself, supported by the environment rather than imposed upon individuals.

4. Increase Workforce Mobility and Skill Mix

- Implement transdisciplinary exchange programmes to reduce fear of unfamiliar situations.
- Create trans-organisational permissions and pre-approvals for collaborative work across boundaries.
- Expand roles and availability of chaplaincy, psychology, social work, interpreters, and peer support workers.
- Enable relationship handovers from those closest to the patient to support transitions between care settings.
- Formulate teams around a person in need and a shared understanding of purpose, with clear protocols for:
    - Introductory connections: accelerating trust at first contact.
    - Handover: passing context and trust from person to person.
    - Retirement: ensuring the value created continues beyond the team’s disbanding.

Workforce mobility, spending time in different teams, settings, and organisational spaces, functions as a form of experiential learning, enabling people to develop relational competence through immersion rather than instruction. This supports confidence, trust, and cross-boundary understanding far more effectively than isolated individual training.

5. Evaluate Success as Evidence That Relationships Produce Good Outcomes

- Know the population of need and use inclusion quotas to improve care for structurally vulnerable groups in mainstream services.
- Prioritise alleviating distress over rigid service criteria.
- Learn from positive deviance case studies.
- Link communities, healthcare decision-makers, practitioners, and researchers for longitudinal learning by building collective social safety – being safe with each other regardless of the situation – so trust is established, responsibilities are shared, and honest feedback improves care.

Learning is iterative: systems need to facilitate confidence in structural feedback loops that encourage people to share relational work enables, what it needs, and how it produces value.

Turning Recommendations into Action

These recommendations represent common themes to guide change in social systems such as healthcare. Each one offers a prompt to shift mental models of care – prioritising relationship and relationality in system design so that policies, practices, and resource flows create care that is not just safe, but good. This means attending to collective social safety, trust, relational glue, relational reach, and power dynamics.

WHERE DO WE GO FROM HERE?

CREATING A MOVEMENT FOR CHANGE

To transform palliative care for people with complex mental health conditions, we must change how we think, how we work, and how we learn. People living with complex mental health conditions represent a sentinel case for relationship-based redesign – a way to improve outcomes and experiences, steward resources wisely, and advance social justice. Relationship must be placed at the heart of health and social care systems.

This report invites policymakers, communities, and healthcare practitioners to join in creating a more inclusive, responsive, and relational future for palliative care.

What Will It Take?

- How do we make these models the norm?
- What would help you be part of a movement to influence policy and decision-makers – or to make practice-based changes locally?
- What research or evidence do you need?
- Are you already doing things the rest of us could learn from?

Part of the answer is simple: the more of us who try small changes, the more likely they will build into something bigger. Sharing successes and helping others do the same is key.

I am looking for partners – individuals or organisations – interested in applying these ideas in local or regional projects relevant to their context. I also welcome collaboration on inclusive research to build an evidence base for change.

If you are already doing good work to improve care for people living with complex mental health conditions who need palliative care, please share your learning and successes. Together, we can amplify what works and create systems that truly serve people.

A New Question for Every Decision Point

Don't ask *when* should we work relationally – ask *how* can we work relationally? This doesn't necessarily require more resources, but it does require rethinking investment and focusing on whole-system effectiveness from the perspective of those that healthcare is intended to benefit – not just part-system efficiencies that overemphasise speed and cost at the expense of meeting needs and creating value.

To achieve this, we need meaningful conversations about collective, distributed resources and responsibilities, striving for outcomes of trust and interdependence throughout the system, created through the mechanisms of relationship and relationality.

SUGGESTIONS FOR PRACTICE-BASED PROJECTS

1. **Warm Handover Protocols**
    - Enable trusted community members or chosen family to accompany people across care settings as legitimate partners.
2. **Simplify Referral and Triage**
    - Remove unnecessary steps or automate low-value tasks to make access easier.
3. **Distress Assessment for All**
    - Introduce universal distress screening in routine care to normalise support.
4. **Trust-Building Rituals**
    - Create small, repeatable practices (e.g., joint check-ins, shared reflection sessions) to strengthen relationships.
5. **Storytelling for Change**
    - Facilitate sessions where patients, carers, and staff share experiences to influence local decisions.
6. **Hardship Fund for Immediate Needs**
    - Provide a small discretionary fund for frontline staff to meet urgent basic needs without delay.
7. **Community Mapping**
    - Identify who already has trusted relationships with people in need and integrate them into care planning.
8. **Three-Tiered Care Lists**
    - Use a simple system to track people by level of engagement (aware, active care, stabilised but likely to need support).
9. **Inclusive Admission Criteria**
    - Relax rigid service criteria (e.g., prognosis limits) to allow flexibility for people with structural vulnerabilities.
10. **Peer Support Roles**
    - Recruit and train individuals with lived experience to act as advocates and connectors.
11. **Real-Time Dialogue Tools**
    - Introduce tech-enabled platforms for near real-time communication between teams.
12. **Relationship-Centred Job Design**
    - Allocate time in job plans for relational work (e.g., 15-20% of time for connection and coordination).

13. **Positive Risk-Taking Framework**
    - Develop local guidance that balances duty of care with dignity of risk through positive risk taking
14. **Workforce Exchange**
    - Pilot short-term staff exchanges between mental health, palliative care, and social care teams.
15. **Pre-Approved Boundary-Crossing**
    - Set up governance permissions for staff to work across organisational boundaries without repeated approvals.

GROWING THE EVIDENCE BASE

Proposed Research Questions

1. **Cultivating Innovation**
    - In a system that is highly siloed, risk-averse, and reimbursement-driven, what conditions help new models take root and flourish, so they become part of the ecosystem rather than isolated exceptions?
2. **Nurturing Change**
    - How can we observe and tend to signs of growth – capturing and sharing improvements as they emerge?
3. **Understanding Relational Outcomes**
    - How should we define and evaluate the health of relationships within care systems, and what indicators show they are thriving?
4. **Planting Ideas That Take Hold**
    - How can these concepts be introduced and cultivated so they resonate deeply with diverse stakeholders?
5. **Reframing Risk**
    - How can we rethink risk as part of a living system – acknowledging its presence while creating conditions for safe, adaptive growth? How can we best capture risks of unmet need, risks of inaction, and non-physical harms, and using narrative evaluation alongside conventional measures
6. **Coexisting with Risk**
    - What strategies allow us to live alongside risk constructively until new paradigms of shared responsibility and trust take root?
7. **Growing Willingness to Change**
    - Why is openness to change – fostered through genuine exchange – so vital for a healthy, adaptive system?

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WILL YOU JOIN A MOVEMENT FOR CHANGE?

Creating systematic solutions: inclusive palliative care & severe mental illness

“Our systems are hard to navigate for people who are very good at navigating things … people who are very resourceful find them hard. It’s genuinely confusing.”

“He’s not a cake, to be sliced into pieces for different services.”

”

“In every system it is always at the boundaries the problems occur.”

“We look out for each other here because the person I help today might be the person who stops me from freezing to death next winter when my car breaks down. People who need to survive will work together.”

“Co-survival is key. Problems are everyone’s.”

“Best care was when people took risks to try and respond… a human moment outside of the churning… synchronicity.”

“Safety is in coherent relationship, mutual understanding.”

”

“Inclusivity is about meaningful choice.”

“Swimming in the sea… there is a ritual that says you can walk into the ocean, dip four times and then leave all you need to let go of behind you as you walk backwards to the land.”

“The hospice is in the woods, bringing nature in, rocking chairs on wooden porches for each room, people here have lived lives entwined with the forest.”

“Small things can make a big difference… I’ve brought you an extra stool so we can sit together with people whatever their situation.”

Fieldnote quotations from the UK and during my Churchill Fellowship travels