Understanding Trust in Integrated Care through the Lived Experiences of Motor Neurone Disease (MND)

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Focus on trust

SETTING THE SCENE – WHY AND HOW DID WE DO THIS AND WITH WHOM?

WHY DOES TRUST MATTER TO THOSE WITH LIVED EXPERIENCE OF MND?

WHAT IS THE THEORY BEHIND TRUST AND WHAT DID WE LEARN TOGETHER?

HOW IS TRUST EXPERIENCED THROUGH LIVED EXPERIENCE OF MND?

DISCUSS THE IMPORTANCE OF TRUST AS A FOUNDATION OF INTEGRATED CARE

‘Trust arrives on a tortoise and leaves on a horse’ (Dutch proverb)

McKee M, van Schalkwyk MC, Greenley R, Permanand G. Placing trust at the heart of health policy and systems. Int J Health Policy Manag. 2024;13:8410. doi:10.34172/ijhpm.2024.8410

Why, How and with Whom?

Trust is central to how care is received and delivered. How does it shape people's care experiences?

We explored the literature to identify the core elements of trust and gathered different perspectives.

We collected personal stories through the MND Australia Lived Experience Network and the Kerry Specialist Palliative Care Unit in Ireland, and through research and clinical work

About motor neurone disease

Neuroprogressive condition affecting adults of all ages.

There is no known cure

Average life expectancy is 2-3 years and can be rapidly progressing

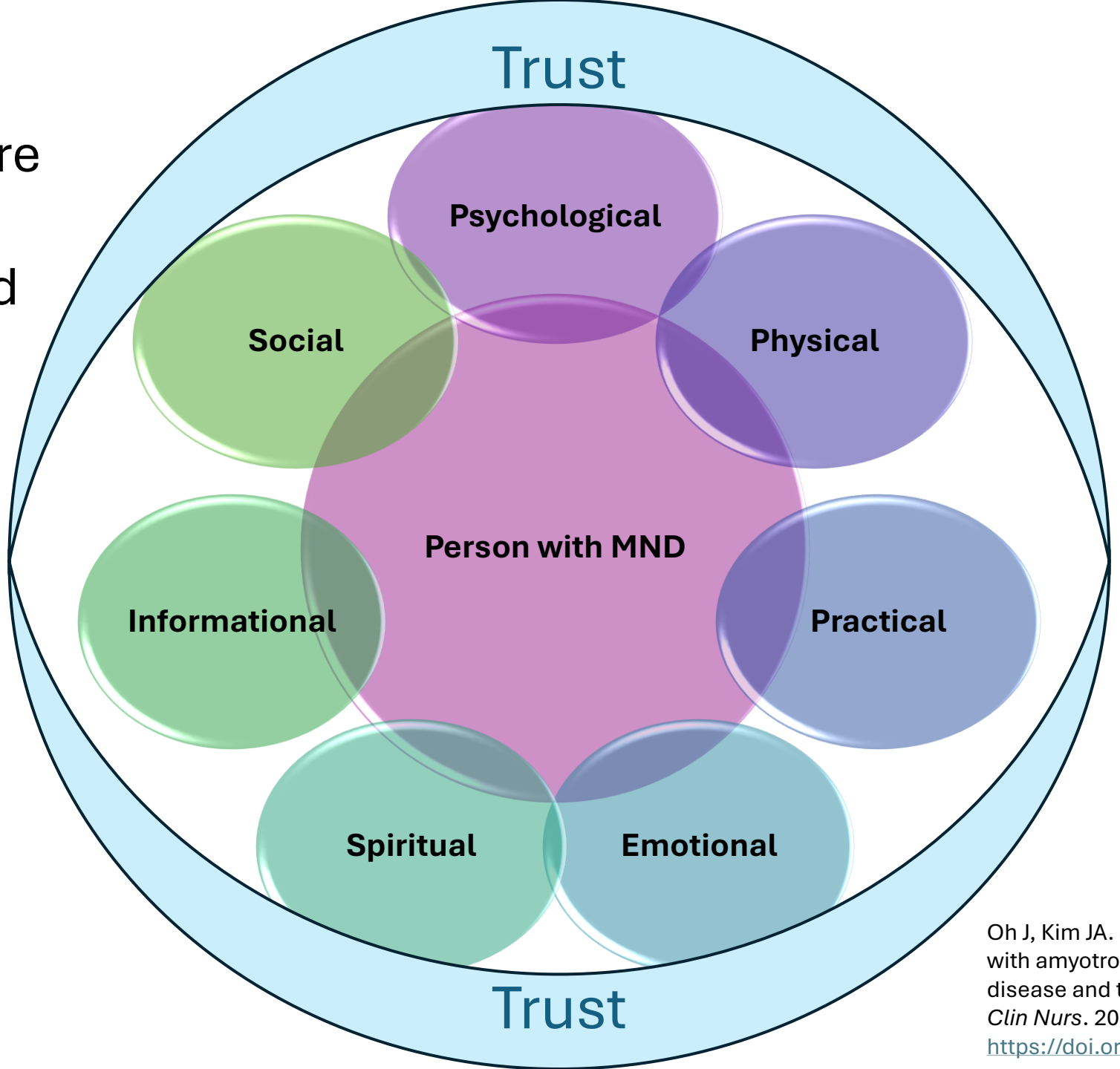
Varied presentation which can affect physical function, cognitive function, communication, breathing, eating & swallowing

Impacts whole families

Demand for services, care and support increases with the progression of the disease

Access to a MND specialist multidisciplinary team is the gold standard model of care

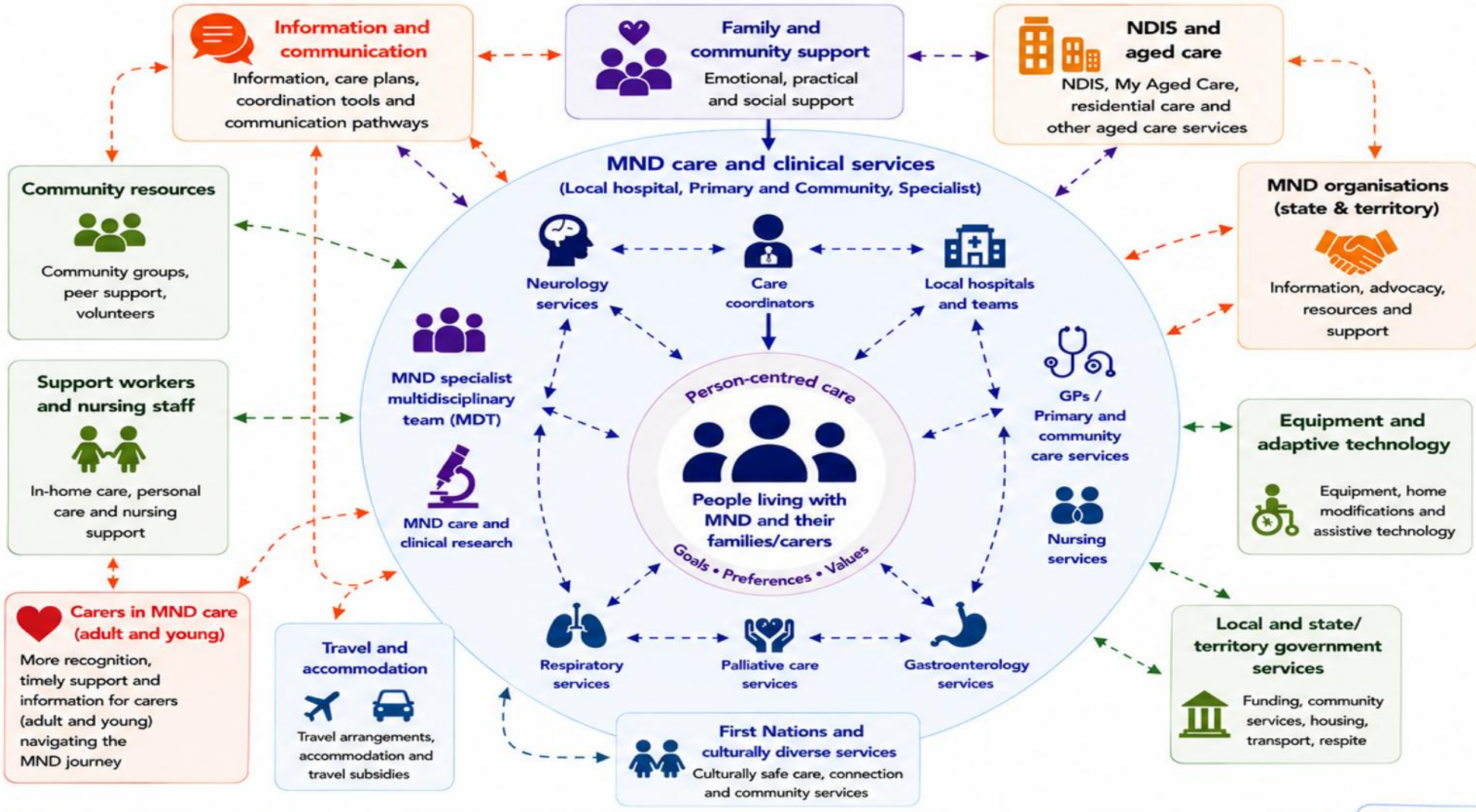
MND Specific Supportive Care Needs for Individuals and Families



Oh J, Kim JA. Supportive care needs of patients with amyotrophic lateral sclerosis/motor neuron disease and their caregivers: A scoping review. *J Clin Nurs*. 2017; 26: 4129–4152. https://doi.org/10.1111/jocn.13945

The complexity of MND care: Many services, systems and moving parts

People living with and impacted by MND are at the centre of a complex, fragmented system



Types of complexity

Multiple services
Many providers across health, community, disability and aged care

Geographic and access
Rurality, travel, transport and accommodation challenges

Funding and systems
Different eligibility, funding streams and policies

Information and communication
Fragmented information, variable systems and unclear pathways

Changing needs over time
Needs evolve from diagnosis to end of life

Impact of complexity

- Harder to navigate the system
- Duplication and delays
- Care gaps and inconsistent experiences
- Variable access and outcomes
- Increased burden on people and families

Care journey: Needs and services change over time

Diagnosis	Early stage	Ongoing care	Advanced care planning	End of life care and bereavement
Timely information and connection	Assessment, planning and education	Coordinated support as needs change	Future planning and risk management	Compassionate, coordinated and continuous support

Key

- Many services and systems involved
- Direct coordination from care coordinator to person (advocacy, navigation, support)
- Connections between services, systems and supports (often complex, fragmented and bidirectional)

Why does trust matter?

Introduce Keith Malpress and Gillian Lewis

Theory of trust

Trust is the willing acceptance of vulnerability.

Rousseau et al.(1998)

Rousseau et al.(1998) identified risk and interdependence as the necessary conditions for trust.

Integrated care does not require trust by accident. It creates the conditions that make trust necessary.

Rousseau, Sitkin, Burt & Camerer (1998)

Understanding trust in care relationships

What do we mean by trust?

- *Trust is the belief that individuals and institutions will act appropriately, perform competently and responsibly, and consider the interests of the trustors in their actions*
- *Trust is often the difference between care that feels clinically correct and care that feels genuinely safe, collaborative, and person-shaped.*

Why does trust matter ?

- *People may forget specific conversations or clinical details, but they rarely forget whether they felt safe, heard, and respected.*
- *Trust is not an optional extra; it shapes how people experience every interaction, decision, and relationship*

Mistrust is not the opposite of trust

Mistrust is a distinct construct shaped by structural, historical and social inequities, rather than simply the absence of trust.

You cannot fix mistrust by being trustworthy. It has different roots.

Pelizzari et al. (2026); Griffith, Bergner, Fair & Wilkins (2021); Souvatzi et al. (2024)

Trust has levels

Interpersonal, organisational and system trust behave differently and are not substitutes.

Trust in a person does not transfer to a system, and system trust does not compensate for a poor relationship.

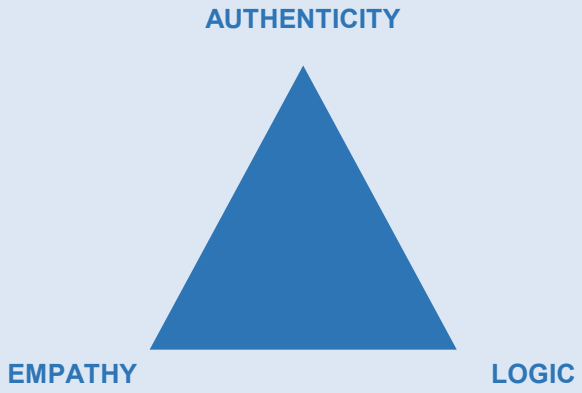
Meyer, Brown, Calnan, Ward et al. (2024); Rousseau et al. (1998)

Models of Trust – developed independently

Frei & Morriss (2020); Moore & Khan (2022); Vanhaecht et al. (2024)

The Trust Triangle

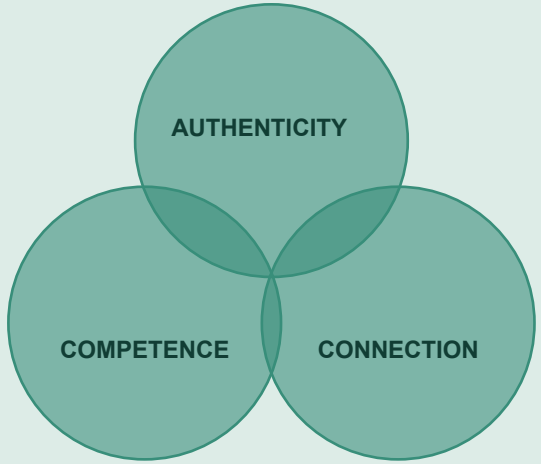
Frei & Morriss, 2020



Trust wobbles when one of the three gives way. Most breakdowns can be traced to a single failing side.

The Trust Trifecta

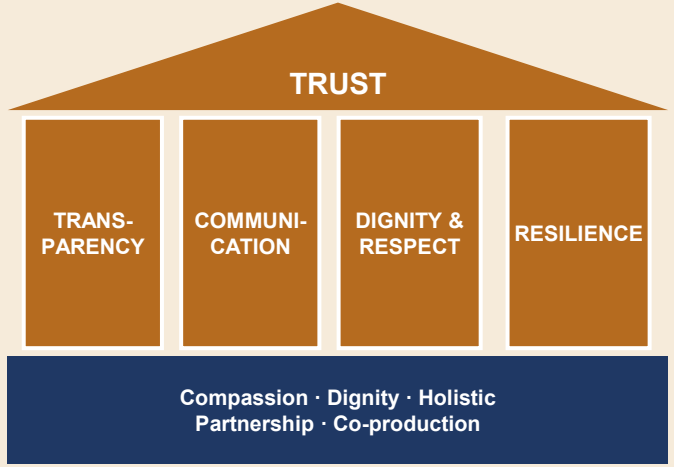
Moore & Khan, 2022



Adapted from the Trust Triangle and from Brené Brown's work. Substitutes competence for logic and connection for empathy.

The House of Trust

Vanhaecht et al., 2024



Trust as something co-created over time, resting on structures rather than on individuals.

The building blocks of trust – 5 core constructs

2 x FOUNDATIONAL CONSTRUCTS

Vulnerability
Being open, honest and willing to take relational risks

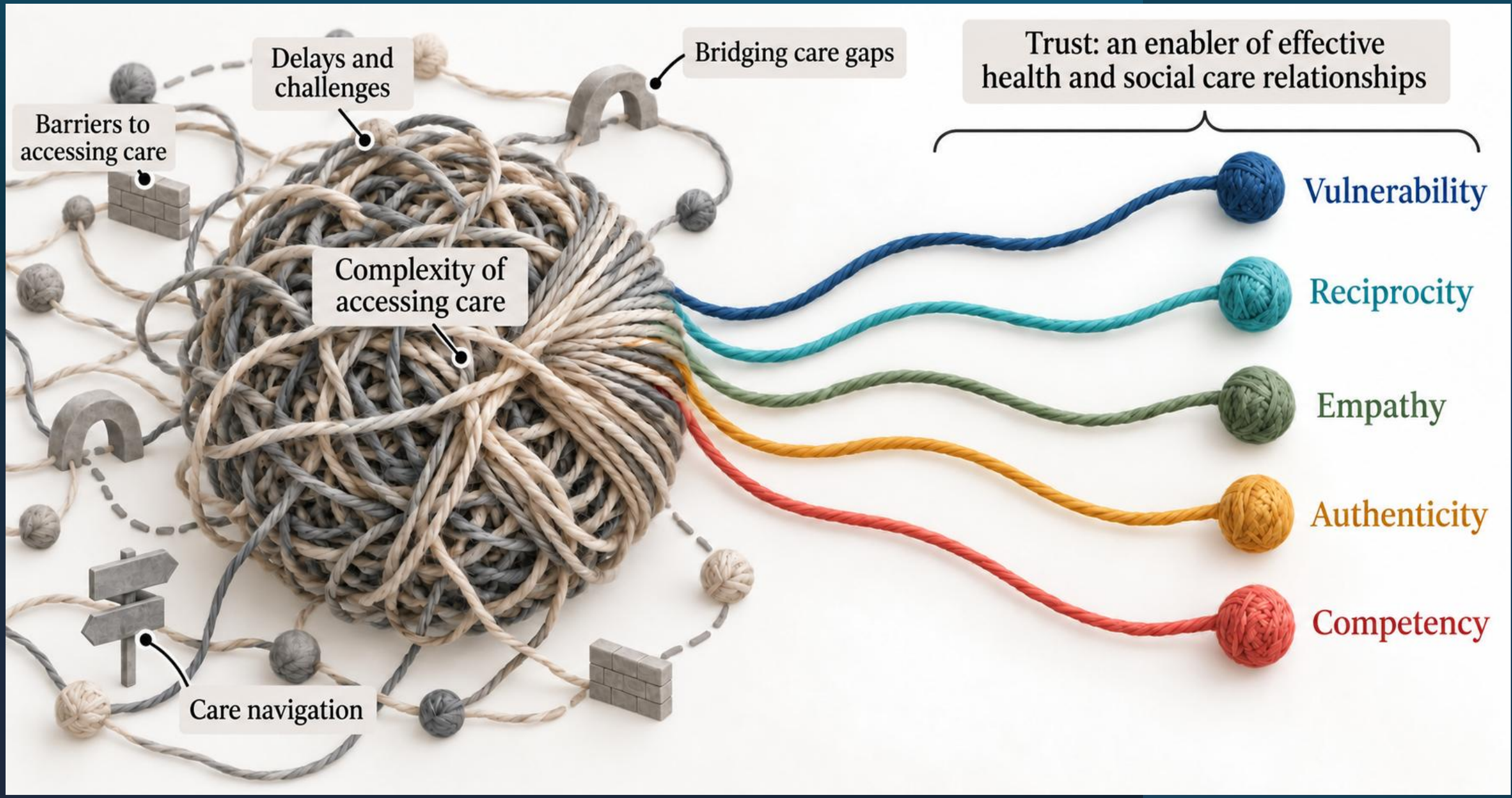
Reciprocity
Mutual exchange, cooperation and collective benefit

3 x TRUST DRIVERS

The three trust drivers are mutually reinforcing, and their relative importance may vary depending on care context, culture and personal experience.

Core values that support trust building

- Compassion and Kindness
- Dignity and Respect
- Holistic
- Partnership
- Coproduction


Delays and challenges
Bridging care gaps
Barriers to accessing care
Complexity of accessing care
Care navigation
Trust: an enabler of effective health and social care relationships
Vulnerability
Reciprocity
Empathy
Authenticity
Competency

What we did

- Understanding lived experience is central to studying trust
- A co-produced perspective project involving people living with MND and clinician-researchers in Ireland and Australia.
- Contributors recruited through the MND Australia National Lived Experience Network and an Irish specialist palliative care service.
- A topic guide distributed to generate discussions. Experiences of trust shared through discussions, written reflections and iterative feedback — in whatever form and depth each person chose.
- Reflections collaboratively reviewed and organised into thematic areas. All perspectives were included.
- Contributors chose whether to be named as authors or to remain anonymous.

How is trust experienced: Lived experience of trust in MND care

Over to Gillian and Keith

Importance of trust as a foundation of integrated care

'Finally, in Hands I Can Trust'

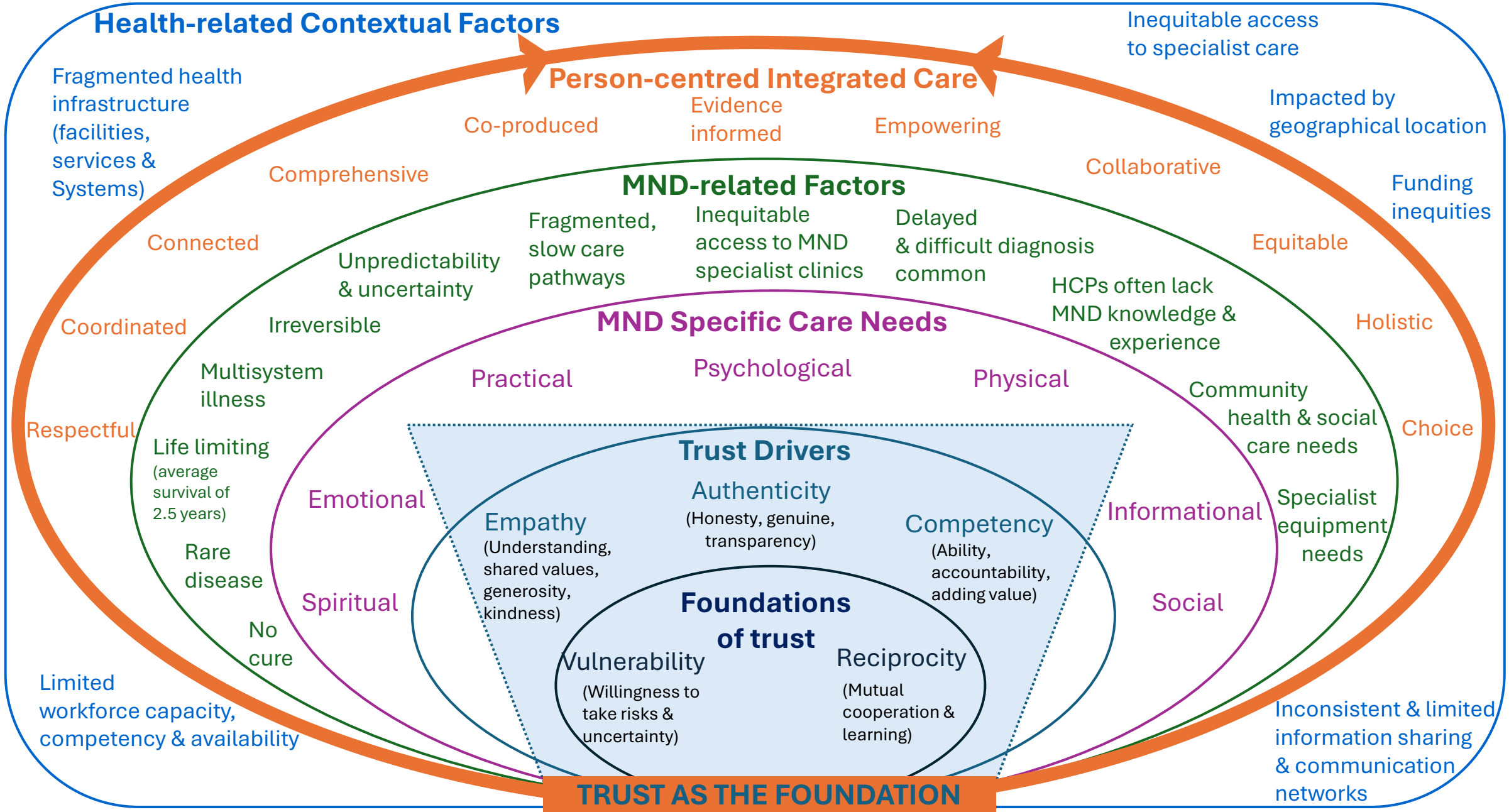
'Trust is both a responsibility and a privilege'

'Who Takes Responsibility for Trust?'

- There was an important relationship to build, and **Everybody** was sure that **Somebody** would do it.
- **Anybody** could have taken the time to listen, communicate openly and build trust—but **Nobody** did.
- **Somebody** became frustrated because building trust was **Everybody's** responsibility.
- **Everybody** thought **Anybody** could repair trust when things went wrong, but **Nobody** recognised that **Everybody** had a role to play.
- In the end, **Everybody** blamed **Somebody** when trust was weakened, and **Nobody** did what **Anybody** could have done: taken the first step to listen, respond and rebuild it.

Key message: Trust is everyone's responsibility—but it needs to be made visible, practised consistently and supported by the system.

Healthcare **2025**, *13*(16), 1994; https://doi.org/10.3390/healthcare13161994



Reference: Lisiecka, D.; Dyson, N.; Malpress, K.; Smith, A.; McNeice, E.; Shack, P.; Hutchinson, K. 'Finally, in Hands I Can Trust': Perspectives on Trust in Motor Neurone Disease Care. Healthcare **2025**, 13, 1994. https://doi.org/10.3390/healthcare13161994

What does this mean for professionals?

'Trust is both a responsibility and a privilege — and a meaningful marker of healthcare success.'

1. **Start with the person**
   Know the person, not only the condition /illness.

2. **Recognise every touchpoint**
   Every interaction can **Build trust** ↑ or **Erode trust** ↓
   The cumulative experience shapes the person's trust in both professionals **and the wider system**.

3. **Provide a TRUST ANCHOR -** *A consistent person across the care journey*

- knows the person and family
- maintains relational continuity
- supports navigation and transitions
- remains present as services and needs change

4. **Protect trust through transitions**
   Never withdraw care without a planned transition.
   Continuity, communication and a clear handover matter - particularly when time is limited.

Questions