The Dementia Interface Lens

A different approach to connection

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Summary

This book introduces a different way of thinking about dementia through the idea of a strained or compromised interface, the bridge between inner experience and outward communication. It aims to help carers feel more confident responding in the moment, even when they don't have answers.

Through lived examples, familiar stories, and practical design principles, it shows how connection can still emerge even when memory and language falter. It explains why people with dementia may sometimes mask their uncertainty, how behaviour often communicates meaning, and why carers need practical experience (praxis), not just theory.

The book also reveals how Timeless Presents designs tools that honour adulthood, support dignity, and create the conditions for connection in advanced dementia.

Ultimately, it invites families, carers, designers, and practitioners to see differently, listen differently, and build environments where humanity remains non-negotiable.

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Foreword

The lady in front of me had been described as “non verbal”, but I could see her lips moving. So I made eye contact and asked, “Are you trying to tell me something?” She said yes. Not with words, not with a nod, but with her eyes. There was something she wanted to share, so I leaned closer, and she whispered, ever so softly, “Why have you come here?”

By the usual understanding of dementia, she was in very late stage. She was not expected to have memories left, or language left, or anything left to say. And yet here she was, asking why I, a stranger, had come to the place where she lived.

The awareness required to form that question, and the intention behind it, made me question whether the current narrative about dementia can really be the whole truth.

Anyone who has cared for or worked alongside someone with dementia will recognise moments like this. Moments when a person reaches out, when something aligns, when humanity breaks through the assumptions placed upon them. There are also moments of frustration, when someone cannot make themselves understood. We believe these moments are not mysterious. They are signals. These moments can suggest that a person is still trying to communicate through whatever channels remain available.

This way of noticing grew from moments like these, many of which I experienced with my father during his journey with Alzheimer's. I wanted to understand how they happen and, more importantly, how people might be supported to create the conditions for them to happen again.

The designs and guidance we create through Timeless Presents are one way of doing that. They are intended to make these moments more accessible, not rare or dependent on luck or instinct, but grounded in an understanding that can be learned and deepened over time.

Much of what is now understood about dementia, including preserved abilities, emotional memory, relational awareness, and disengagement, is already established in academic and clinical circles. But this knowledge rarely reaches the people who need it most in a usable form. Families, support workers, and hands-on carers are often working with outdated models of decline, while newer ideas such as person-led care may be introduced without explanation or practical support for how to live them. The result is a gap. Not just in information, but in understanding, confidence, and possibility.

This book exists to explore that gap. It is an attempt to translate what is known into something people can actually use, grounded in lived experience and in the belief that humanity remains, even when so much else appears to be lost.

Chapter 1 – A Moment to Remember

The care home where my dad lived had a small caravan parked in the garden that residents could use freely. During a visit with Dad, late in his dementia journey, my husband and I decided to have a look inside. It was good to be with him in a private space again, unobserved and free to interact with each other.

Among the curated contents of the caravan was a soft red ball. It immediately caught his eye. I assumed it was because it resembled a cricket ball. He had played for many years.

We started throwing it to each other, gently at first. It soon became clear that his ball-handling skills, honed by decades of playing sport, were still there. To our astonishment, and his, his muscle memory seemed to take over, as if he were back on a cricket pitch. He caught and threw the ball faster than we could, with spin and force. It escalated. We spent an hour or so throwing the ball with increasing difficulty, bouncing it off surfaces and seeing what it could do in the confined space. We chatted about nothing in particular, in the way families do. We laughed and enjoyed each other's company. It was an unexpectedly rich and fulfilling hour, and one I still remember in detail.

During that time, we could see his confidence grow. With the validation that he was doing brilliantly, he appeared to relax. The tension we had often sensed in him seemed to ease. On the way home, my husband and I talked about what had happened, carrying the warmth of that connection with us.

Something as simple as a red ball had ignited a whole interaction because we were open to participating. For most of us, most of the time, connection rests on memory, the shared stories and reference points that shape our relationships. That is why we can feel so lost when those memories become inaccessible.

Yet this simple, familiar object showed us something important. Connection does not vanish with memory. With the right conditions, it can shift. It was a vivid reminder that dignity and joy live in presence, and that finding ways to experience presence still matters, for everyone.

Chapter 2 – The Interface: A Lens for Dementia

Like most people, I cannot access all of my memories on demand, but nobody asks me to do so to prove that I am still human. Yet for people living with dementia, the absence of recall is often treated as evidence of depletion, as though memory alone defines personhood. We challenge that assumption.

Over time, we have come to think of disrupted memory retrieval as a strained or compromised interface. This is our way of describing what happens when dementia affects the bridge between inner experience and outward communication. From lived experience, it would seem that many capacities, skills, and emotional responses may still exist, even though access to them can become unreliable. Seen this way, the interface that usually carries those qualities into the world, and helps translate the outside world back into understanding, can produce inconsistent results when it is disrupted.

Consider this: how is it that something like a memory can appear to return, when it has seemed to be no longer accessible? Anyone who has cared for someone with dementia can recall moments when this happens. We experienced it ourselves. Over time, it became clear that creating the right conditions for connection to emerge was something we could sometimes influence, rather than something we had to wait to happen by chance.

This perspective matters because it shifts the focus. That dementia is not simply a loss of memory or a loss of self, an emptying out of humanity. Instead, it can be understood as a disruption in the channel through which connection usually flows in both directions. When the interface becomes strained, recall may be slow, unreliable, or absent, and families can feel as though the relationship itself has vanished.

Yet with the right conditions and understanding, different forms of connection may sometimes become possible. Connection does not have to disappear. It can emerge differently, through presence, music, gesture, and shared activity. Familiarity plays a crucial role here. When something feels recognisable, it can support connection without placing pressure on recall or diminishing the person in any way.

This way of thinking emerged through our own lived experience and practice, as we tried to make sense of interactions that did not fit existing explanations. Naming it has helped us notice patterns, test our assumptions, and share what we have learned with others. We believe the implications are too important to keep to ourselves or to gatekeep. Anyone can take this lens and begin to use it by paying closer attention to where an interaction feels strained, asking where an interface might be failing, and adjusting conditions or expectations to better support connection.

Chapter 3 – Masking, Meaning, and the Social Brain

This understanding, that dementia involves a strained or compromised interface, has fundamentally changed how we perceive interactions with those who are experiencing it.

Crucially, it also allows us to recognise that while memory recall may be compromised, many aspects of personhood remain remarkably robust. One of these is the ability to read social cues and participate in social interactions. As social beings, we are hard wired to fit into whatever situation we find ourselves in. We have a lifetime of experience doing just that.

Most of us have experienced the moment of meeting someone who clearly remembers us, while we do not remember them. Without thinking, we extend the conversation in careful, non-specific terms, buying ourselves time for the memory to surface. It is an instinctive social response when personal memory is not there.

In dementia, these instinctive responses can lead to misunderstandings about a person’s internal world. With access to social cues and whatever contextual information surrounds them, people with dementia can often mask uncertainty to excellent effect, while the conditions allow.

A striking example of this can be seen in the Chris Hemsworth documentary A Road Trip to Remember, in which he takes his father, Craig, who has Alzheimer’s, on a journey to try to resurface memories.

In one scene, Chris and his father meet with an old friend, Spencer. They chat easily, interact warmly, climb into a car they once used to catch wild cattle in the outback, touch the levers, and reminisce about the machinery. The exchange is fluid and genial, and they appear to be getting on like a house on fire. Later, when the three sit down together, Chris asks his father what he remembers about Spencer. Craig hesitates briefly, then begins talking about Spencer as though he were someone else entirely. He even asks Spencer whether he knows the person Chris is referring to.

In the documentary, this is presented as a moment of confusion interrupting clarity, something sudden and unpredictable. But viewed through the interface lens, it can be understood differently.

With his interface compromised, Craig was still able to rely on various cues to remain engaged. What he could see, what felt familiar, what was being said, and the emotional tone of the interaction all supported his participation. He appeared to be maintaining the interaction by drawing on available cues, even where recall was uncertain. When asked to perform an act of memory recall that his interface could no longer reliably support, he continued responding to the cues available to him, answering the question in a way that might have worked under other circumstances, except that Spencer was sitting in front of him. The moment revealed the gap between his inner experience and the outward demands placed upon him.

The ease with which he does this is striking, but it should not be surprising. Most of us do it without conscious effort or awareness. Those who do not, such as some people on the autism spectrum, may expend significant energy to achieve the same effect. Masking in both instances is not a flaw. It is a deeply human adaptation to surviving socially.

Before the question was asked, the connection between father and son was real. It emerged from presence, shared environment, and intent rather than factual recall. After the question, the limits of Craig’s interface became visible. His confidence dropped as he moved into this part of the conversation, not because something suddenly changed, but because the interface was being asked to do something it could no longer reliably manage.

Viewed through a compromised interface lens, nothing sudden happened at all. The moment simply exposed the limits of the interface. When we recognise this, we can stop waiting for connection to arrive by chance and start paying closer attention to the conditions that allow it to emerge, and those that cause it to collapse.

Chapter 4 – Behaviour as Communication - Listening Differently

From our own observations, and from reading many other examples, we have come to question what is meant when we say that memories are “lost” in dementia. We have all had conversations where someone remembers something we do not, at least not at first. With time, context, or prompting, that memory may surface and become accessible again. This reminds us that memory is not a fixed or permanent thing, but something that is often dependent on conditions. Understanding this can help explain why people with advanced dementia might say or do things that seem, from the outside, incomprehensible.

One example comes from a LinkedIn post written by a doctor who advocates for dementia awareness. She described a friend whose mother, who had dementia, loved to eat out, but they had stopped doing so because she would suddenly stand up in restaurants and make throwing motions, leaving her daughter, and other diners uncomfortable and unsure how to respond. When the doctor accompanied them on a visit, the behaviour appeared again. She simply asked the mother what she was doing. The reply was immediate. She was feeding the chickens. As a child, she had to feed the chickens before she was allowed to eat herself.

With that understanding, the behaviour becomes illuminated. What appeared to be a ‘forgotten’ memory was finding expression through action rather than words. The familiarity of the setting and the preparation for a meal had summoned it. Physically reliving the moment was how her body chose to communicate it. From the outside it looked bizarre, even troubling, but with this additional context it becomes entirely understandable.

How many so-called behaviours are really memories surfacing in a form the person can no longer articulate? How do we honour communication that arrives this way, through movement, repetition, or gesture rather than words? We may not always know the meaning, but staying open to the possibility that behaviour is a form of communication can only help. It asks us to listen differently, because existing models do not always translate into something people can use in the moment, and because behaviour often carries meaning long after language becomes unreliable.

Viewed through the interface lens, the carer can pause and consider what might be placing strain on that bridge between inner experience and outward expression. This may include unmet physical needs such as hunger, thirst, discomfort, or fatigue. It may involve emotional states such as sadness, anxiety, or uncertainty. Sensory overload, unfamiliar environments, or the absence of routines and cues associated with safety and belonging can also play a role. Each of these possibilities points not to correction, but to adjustment. A small change in conditions can sometimes reduce strain and allow communication, or comfort, to emerge in a different way.

Once we begin listening differently, the next question becomes how we respond. Not in theory, but in practice.

Chapter 5 – Praxis

Care is often described through frameworks and philosophies, person-centred, person-led, relationship-based. These ideas matter. They give direction and shared language. But understanding a philosophy is not the same as being able to live it, especially in the moment-to-moment reality of dementia care. There is often a gap between what we understand and what we can actually do.

That gap is where something often overlooked becomes important. Between understanding and doing lies something you might hear described as praxis: the kind of knowing that can only be learned by doing.

A simple way to think about this kind of learning is through swimming. You can read a clear and accurate description of how to swim, but that knowledge alone does not prepare you for being in the water. It does not tell you how the water will feel, how your body will respond, or how to adjust when things don't go as expected. Those things can only be learned through experience, by noticing, trying, and adapting.

Dementia care is similar. Ideas like person-led care remain abstract until a carer has some way of feeling what they mean in practice. Being able to stay in the moment, especially when the person’s communication is unclear or non-verbal, requires more than good intentions. It requires attunement, confidence, and something to orient around in the moment.

This kind of learning is not a replacement for specialist training, just as learning to float does not make someone a professional swimmer. But without some lived experience, training has little to build on. Learning this way provides a foundation. It supports confidence, attention, and a sense of “I can work with this”, which makes deeper learning possible.

Through our own work, we have seen that shared activity can offer a gentle way into this kind of embodied understanding. When something feels familiar and open-ended, it can slow interaction down and help carers notice responses, rhythms, and preferences as they emerge. Over time, philosophy begins to feel less abstract. It becomes something that can be recognised and lived, rather than remembered or performed.
In advanced dementia, where verbal

communication may be limited, this kind of practice can matter a great deal. If behaviour can be a form of communication, then learning how to meet it requires more than explanation. It requires experience. Not perfect responses, but the space to notice, adjust, and remain in the moment with them.

A Note on Aggression and Escalation

At times, this mismatch between inner experience and outward expression can present as anger, raised voices, or behaviour that feels aggressive. These moments can be unsettling, and it is important to recognise that the safety of everyone involved must always come first.

When someone living with dementia expresses themselves in this way, it may reflect frustration, confusion, discomfort, or a sense of being overwhelmed. The cause is not always clear, and may be different each time, or shaped by several influences at once.

In these moments, it can help to remember that what is being expressed is not necessarily directed at you, even if it feels personal. The person may not be able to process what is being said, explain what they are experiencing, or regulate their response in the way they once could. It can also help to recognise how strong the instinct to correct, explain, or resolve what is happening can be. Where it is safe to do so, gently setting aside that need and allowing the moment to settle can reduce pressure for both of you.

Reducing confrontation and avoiding unnecessary correction can sometimes help reduce escalation. Taking a step back, softening the interaction, or allowing the moment to pass may be more supportive than trying to reason in that moment.

It is important to recognise that responding differently in these situations can feel unfamiliar and may take practice. It can also be emotionally demanding, so it is important not to be too hard on yourself. Support is available, and you do not have to manage these moments alone.

This does not mean accepting unsafe behaviour, but recognising that these moments are often best understood as expressions of strain within the interface, rather than intentional acts. When the pressure within the situation is reduced, the person may regain a greater sense of ease.

Chapter 6 – Making the Principles Tangible

Our own approach to addressing this gap, long before we knew how to articulate it, was largely instinctive, shaped by our own experiences and the gaps we had lived through. Over time, those instincts were tested, challenged, and refined, eventually forming the thinking that now sits within the pages of this book. Once we were able to name it, it felt important to share it.

At the heart of this work is a simple but difficult question: how do you connect with someone when memory is unreliable, language is fragile, and behaviour becomes the primary form of communication? Every tool we have made has been one response to that question. But there will be other responses and ways of working with the compromised interface lens, and we welcome that. The lens itself does not belong to us. It belongs wherever it helps people see differently.

From the beginning of this journey, one image has stayed with me. The search for a place where my dad could live when he was no longer safe at home was a grim exercise. We saw lounges and sitting rooms ringed with people, sitting and staring vacantly into the mid distance, as though this were some kind of gold standard. As though decline should be quiet and unobtrusive. As though life was already over, and what remained was simply waiting. They are still there, and they still haunt me.

This is why the interface matters. When we assume that outward stillness or difficulty means absence, we stop looking, stop listening, and stop offering ways in. But when we understand behaviour as effort, and the interface as strained rather than empty, different possibilities emerge. Shared activity, familiar rhythms, and simple points of focus can make embodied listening possible. They give people something to follow with, allowing person-led care to move from aspiration into lived experience.

We are sharing this way of seeing because the implications are too important to keep to ourselves. If connection is still possible, even in advanced dementia, then it becomes a responsibility to notice the conditions that support it, and to challenge those that quietly deny it.

In the end, nothing in this book matters more than this: humanity is not negotiable. A diagnosis may change how someone communicates, but it does not diminish who they are. Our responsibility is to recognise the person who remains, and to meet them with presence, patience, and dignity, even when the circumstances are difficult.

Conclusion

This book is offered in the hope that what we have described will feel recognisable. Not as a theory to be learned, but as something many people already sense, often without having language for it. Our intention has been to give shape and name to experiences that carers and families frequently encounter, but are rarely encouraged to trust. We will not always understand what we are seeing, and we will not always get it right. What matters is the willingness to keep noticing, adjusting, and staying in relationship. Listening differently does not always mean doing more. Sometimes it means releasing effort that was never helping in the first place.

You do not need specialist training or formal permission to begin listening differently. The ability to notice effort, respond with curiosity, and create the conditions for connection is human. It grows through attention and experience. Training can deepen it, and expertise can support it, but the first step does not belong to institutions. It belongs to everyday encounters, and to the willingness to stay present.

This is an invitation to families, carers, designers, practitioners, and communities to take what resonates, adapt it, challenge it, and build on it. To work with us if that feels useful, or to take the ideas elsewhere if that is what the moment calls for. This work is bigger than any one organisation. It will take many hands, many cultures, and many forms.

What matters is that we keep moving toward a world where humanity in dementia is non-negotiable, and where connection remains possible, even when memory and language falter. If this book helps even one person see differently, listen differently, or act with greater confidence and care, then it has already begun to do its work.

Alongside this book, we are co-founders of Timeless Presents, a UK-based social enterprise creating dementia-inclusive activities designed to support insight, engagement, and connection in later-stage care. Our products are grounded in the same thinking described in this book and are used by families, care homes, hospitals, and health services to create conditions where connection can still emerge, without relying on memory, instruction, or correction.

For readers who are interested in seeing how these ideas translate into practical tools, you can find more information about our work at:

www.timelesspresents.com

For those who want to explore further

The ideas in this book grew out of a longer piece of work that explores the interface lens in more depth, and situates it within wider thinking about dementia, communication, and meaning.

That paper is written in a more academic style, and is intended for readers who want to engage with the underlying concepts in greater detail, or who are working in research, education, or policy contexts.

It is not required reading for understanding or using the ideas in this book, but it may be of interest to some.

You can access it here:
https://www.timelesspresents.com/the-interface-lens-for-dementia

This book was written by the authors, drawing on lived experience, professional practice, and original thinking. Artificial intelligence tools were used at points as a supportive aid for structuring, clarifying language, and refining drafts. All ideas, interpretations, and conclusions are the authors' own, and responsibility for the final content rests entirely with them.