

The Interface Lens

A conceptual tool for dementia care

Authors

Sharon Daltrey

Christopher Daltrey

Affiliation

Timeless Presents, UK - A social enterprise creating dementia-inclusive activities

Date

January 2026

Abstract

Much about how people living with dementia experience their lives remains poorly understood. Their behaviour often appears difficult to interpret or falls outside socially recognised norms, creating a gap between them and those responsible for their care. While specialist training and established models offer valuable insight, they do not reach the majority of family carers and frontline staff, and existing approaches are often solution-heavy and insufficiently transferable to support interaction in the moment of care.

This paper proposes an interface lens as a simple, transferable way of understanding how a person's inner experience meets the external world, and how this coordination may become strained or compromised in dementia. Used in this way, the interface lens offers carers a practical means of guiding interaction in the moment, to the benefit of both the person living with dementia and the carer.

The interface lens is presented as an additive, conceptual tool rather than a replacement for existing models or training and does not claim diagnostic or mechanistic authority. Its value lies in offering a way of noticing, adapting, and sustaining connection when other approaches fall short.

1. Introduction: When interaction doesn't make sense

The prevalent narrative surrounding the trajectory of symptoms and behaviours following a dementia diagnosis is one of gradual loss: most notably the loss of memory, accompanied by the loss of other abilities, for example paratonia. As a result, the presentation of people living with dementia is commonly described using deficit-based language.

‘Behaviours’ such as refusing to wash, wanting to go home, withdrawing from their surroundings, or becoming distressed and unpredictable are often reported in terms of what a person will not or can no longer do. Even where care is informed by person-centred approaches, including the important work arising from Tom Kitwood’s emphasis on personhood, there remains little shared understanding of how the person’s experience is expressed in these moments.

For family carers and professionals alike, everyday interaction can become a high-stakes and emotionally charged space. Care is usually well-intentioned and compassionate, yet the person living with dementia may still feel difficult to understand, leaving carers navigating moments that carry a real risk of distress or rupture. Over time, this can lead to repeated breakdowns in communication and the relational strain that accompanies them.

This raises a central question: when interaction becomes fragile and meaning is difficult to access, what is actually failing in these moments?

The perspective offered in this paper is informed by lived experience rather than formal clinical or academic training. I, Sharon Daltrey, am a family carer who supported a parent living with dementia over several years, and much of my understanding of interaction in dementia has emerged from navigating everyday moments of care without a shared explanatory framework.

In parallel, I am a co-founder of Timeless Presents with my husband Christopher Daltrey. Timeless Presents is a social enterprise that designs dementia-inclusive activities accompanied by guidance intended to support connection and engagement in later-stage dementia. Through this work, we have spent several years listening to family carers and professionals describe similar experiences of uncertainty, misinterpretation, and relational strain when interaction becomes difficult to understand.

This paper does not present empirical research, nor does it claim clinical authority. Instead, it offers a conceptual lens developed through sustained observation, reflection, and practice, intended to help carers and practitioners orient themselves when interaction feels fragile or confusing. The aim is not to replace existing models of dementia, but to complement them by offering a simple, transferable way of thinking about interaction in real time.

Furthermore, this paper is intended as an introduction to a conceptual lens. It proposes a way of understanding how the 'self' interacts with the outside world through a continuously operating interface composed of multiple overlapping senses and processes, with built-in redundancy. This lens is offered as a means of informing how interactions are interpreted in the moment of care, particularly where abilities are compromised. It is not intended to infer diagnosis or replace existing models, but to act as an additive perspective that offers an additional route for thinking about interaction and support in practice. This paper does not seek to synthesise or extend any previous work that is cited, but to offer a complementary, practice-oriented lens grounded in lived experience. All illustrative examples are drawn from publicly available material or anonymised lived experience and are used descriptively rather than diagnostically.

2. Limits of existing ways of understanding

Currently, there is no widely shared or accessible way of understanding the lived experience of people living with dementia. This is despite many years of study, thought, and research. This work builds on person-centred approaches to dementia care that emphasise dignity, agency, and relational context (Kitwood 1997 and Brooker 2007), while seeking to offer a practical lens for understanding interaction in the moment of care. While existing approaches have advanced understanding in important ways, they do not consistently provide carers with a usable framework for interpreting behaviour as it unfolds in everyday interactions.

Care frameworks often separate cognition, motor function, emotion, and behaviour into distinct descriptions, particularly in assessment and documentation. While these classifications can be useful, they do not necessarily support understanding or response in the moment of care. As a result, many people providing hands-on care remain uncertain about the difficulties the person living with dementia is facing, or how best to respond to them. For carers, interactions can feel unpredictable and sometimes frightening, or distant and isolating, disrupting the ordinary patterns through which people usually connect with one another.

Current thinking frequently circles ideas of personhood and person-led care, accompanied by a wide range of descriptive terms, strategies, and guidance. While these approaches are valuable, they are often difficult to recall or apply in the moments of interaction that matter most. Additionally, specialist dementia training does not reach the majority of those who could benefit from it, particularly family carers. Meanwhile, people living with dementia continue to wait for connection of some kind, even as those around them struggle to understand how to reach them.

3. Introducing the interface lens

The conceptual interface, when functioning optimally, can be understood as an emergent, overlapping coordination layer. It can be thought of as a perpetually running operation composed of multiple senses and processes, alongside different forms of memory, all operating with built-in redundancy. There is no suggestion that this interface represents a discrete structure or mechanism of any sort. The term ‘interface’ is used here in a conceptual sense, drawing loosely on its broader use to describe points of interaction rather than discrete mechanisms (e.g. Norman). This paper proposes that, in dementia, this interface becomes progressively disrupted and unreliable, offering a way of understanding how different behaviours might emerge but also how those behaviours may be supported.

The interface lens describes how a person’s inner experience interacts with the external world, and how this interaction can become compromised when communication falters in either direction. Most people have experienced being greeted warmly by someone who clearly knows them well, while they themselves struggle to remember who the person is. The usual response is to carry on the conversation as well as possible without alerting the other person you don’t remember them until such time the context of the conversation finally rescues the memory, or alternatively they admit defeat. The ease with which a human can handle such a complex interaction is a clue to how those living with dementia continue to function and express themselves.

There are many theories describing how people gather information and use it to understand and interpret the world beyond the self. These theories largely sit within discrete disciplines and rarely speak to one another, despite all referring to processes occurring within a single human organism.

A composite description of an interface may offer a way to bring these perspectives together into a more integrated, cross-disciplinary understanding. Understanding such an interface can therefore help to clarify how disruptions in its functioning may influence behaviour, as seen in dementia. Even where a person’s sense of self is

compromised, incoming information continues to be received and interpreted, often resulting in responses that appear inconsistent or difficult to predict.

Even the most well-known and feared symptom of dementia, memory, can be understood through this lens. Memories can, and do, surface unexpectedly, suggesting that they are not always lost, but instead may be inaccessible until a particular combination of external context and internal state surfaces the memory through the interface. This reframing offers a way of making sense of a common phenomenon that is often observed but poorly explained in everyday care.

Similarly, in some cases, individuals may appear outwardly coherent or socially engaged while significant internal difficulty remains unexpressed, until the limits of this compensation are reached. This can be understood as an uneven compromise of the interface, in which familiar social conventions continue to be enacted even as other aspects of self, including memory, are increasingly strained. Borrowing the descriptive term “masking” from autism literature, this form of compensation appears to be largely instinctive and automatic, drawing on deeply established patterns of social interaction rather than conscious or strategic effort. In dementia, this automatic continuation of social behaviour may persist until changing conditions expose the underlying strain on the interface. From the outside, this can appear as sudden confusion or deterioration; through the interface lens, it can instead be understood as a system that has been compensating until it can no longer do so. The fracture lies not in meaning, intent, or even memory, but in the failure of the interface through which meaning is expressed and received.

A striking example of this can be seen in the documentary *A Road Trip to Remember*, in which Chris Hemsworth travels with his father, Craig, who has Alzheimer’s disease, in an attempt to reconnect through shared memories.

In one scene, Chris and his father meet with an old friend, Spencer. They converse easily, interact warmly, and climb into a vehicle they once used to catch wild cattle in the outback, touching the levers and engaging with the machinery. The exchange is fluid and convivial, and all three appear to be sharing a genuine moment of connection. Later, all three sit down together and Chris asks his father what he remembers about Spencer. Craig hesitates briefly, then begins speaking about Spencer as though he were someone else entirely, even asking Spencer whether he knows the person Chris is referring to.

Through the interface lens, this moment can be understood as the point at which an interaction that had been supported by context, familiarity, emotional tone, and sensory cues is suddenly required to rely on explicit memory recall. With the interface already compromised, Craig continues to respond to the cues available to him rather than to the memory itself, maintaining participation in the only way possible. The result is not

withdrawal, but a response that reveals the gap between his inner experience and the outward demands placed upon him.

Prior to the question, the connection between father and son was real, emerging from presence, shared environment, and intent rather than factual recall. After the question, the strain on the interface becomes visible. What appears from the outside as a sudden failure can instead be understood as the moment when an interface is asked to do something it can no longer reliably support.

By contrast, the dementia compromised interface may be supported through channels that place less demand on explicit recall. One such example is music. In people living with dementia, the ability to engage with music or singing often remains accessible even when language or factual memory is unreliable. This perspective is consistent with work on embodied forms of selfhood in dementia, which suggests that engagement and expression can persist beyond verbal or cognitive decline (Kontos, 2004) Through the interface lens, music can be understood as providing shared timing, emotional resonance, and embodied participation, allowing connection to be maintained without requiring verbal explanation or recall. Rather than testing the interface, music appears to scaffold it, offering an alternative route for interaction when other channels are strained. Research on music and dementia similarly suggests that musical engagement can support connection and participation without reliance on verbal recall (McDermott et al., 2014)

4. Behaviour as information, not opposition

In dementia care, behaviours that disrupt routines or cause distress are often approached with the aim of restoring calm. This focus is understandable and frequently necessary, particularly in situations involving risk, fatigue, or limited support. However, when calm becomes the primary indicator of success, behaviour may be treated as something to be managed rather than understood. Outward calm, while often welcome, does not necessarily indicate comfort, understanding, or engagement, and may obscure the person's underlying experience at the point where interaction has become difficult.

We do not live calmly for a lifetime, nor do we expect to. Human beings respond continuously to circumstances and surroundings, and the need to react, adapt, and express internal states does not disappear with a diagnosis of dementia. When calm becomes the dominant reference point, behaviours that fall outside this expectation can be labelled as challenging simply because they do not conform, increasing the likelihood of misunderstanding and escalation. Viewed instead through the lens of a strained or compromised interface, such behaviours can be understood as responses

shaped by difficulty in transmitting or receiving meaning. This reframing offers carers a way to assess what may be happening in the moment, rather than reacting solely to the behaviour itself.

5. Illustrative interaction examples

Wendy Mitchell, writing from her own experience of living with dementia, describes the condition not only as a change in memory, but as a profound shift in how a person relates to their senses, emotions, communication, and environment. She emphasises that small changes in context can make a significant difference, and that without explanation or shared understanding, these differences often remain unseen. Viewed through the interface lens, such accounts suggest that difficulties in interaction arise not from a loss of intent or engagement, but from a disrupted process through which sensory and emotional information is integrated and understood.

Mitchell has also written about how writing provided a means of connection and expression when other forms of communication were more difficult. She describes being able to access and organise her thoughts through the keyboard, even as spoken interaction or real-time processing became more challenging. Viewed through the interface lens, this suggests not a preservation of ability in general, but uneven access to different channels of expression. Where one pathway remained available, others were compromised, highlighting the importance of recognising and supporting alternative routes through which meaning can still be conveyed.

Another well-known pattern in dementia is repetition, often described as looping information or asking the same question many times. When new memories cannot be reliably formed, continuity of context from one moment to the next may be lost, resulting in repeated arrival into the present without orientation. Viewed through the interface lens, this behaviour might be understood as an ongoing attempt to establish meaning and safety in the absence of retained context. The same question may therefore be asked repeatedly, because it is being asked for the first time, each time.

The underlying concerns are often likely to be simple and human: Am I safe? Where am I going? Who am I with? While this can be exhausting and frustrating for carers, understanding repetition as a response to interface strain rather than wilful behaviour makes it easier to respond to the need being expressed, rather than to the repetition itself.

One individual regularly narrated an aspect of his working life when a passenger in a car, returning repeatedly to his former role as a driving instructor. These accounts were offered without prompting and often repeated in similar form throughout the journey.

Rather than representing confusion or fixation, this narration, viewed through the interface lens, appeared to function as a way of establishing situational coherence and framing context, serving as a form of introduction to an unrecognised driver.

Taken together, these examples illustrate how behaviours commonly described as problematic or puzzling in dementia can be reinterpreted as meaningful responses shaped by strain within the interface. Similar patterns may be observed across a range of situations, including resistance to care, withdrawal, agitation, or a persistent desire to return “home,” where the behaviour itself reflects an attempt to restore coherence, safety, or familiarity in the face of disrupted processing. The interface lens does not seek to explain every behaviour in dementia, but it offers a way to approach interaction with greater curiosity and responsiveness, particularly in moments where meaning appears difficult to access.

6. Implications for care and everyday interaction

The implications of adopting the lens of a strained or failing interface are twofold.

First, this lens inherently confers dignity and consideration on the person living with dementia. It begins from the assumption that connection and communication are still being sought, even where they are difficult to access or express. As a result, behaviours are approached not as opposition or decline, but as signals arising from misalignment or strain within the interface. This orientation naturally encourages responses and adaptations that aim to reduce escalation and distress, rather than correct or contain behaviour. This aligns with existing understandings of behaviour in dementia as communicative rather than oppositional (e.g. Alzheimer’s Society; NICE)

Second, the interface lens offers carers a practical and accessible way of making sense of interaction in the moment. By asking themselves, “Where might the interface be strained or failing?”, carers are prompted to listen and observe more carefully, attending to factors such as:

- sensory load
- emotional tone
- timing
- familiarity

- channel availability (speech, touch, music, movement)

For example, a commonly observed behaviour in people living with dementia is the repeated wish to “go home”. This can be difficult to respond to, particularly when the person is already at home or when their current location cannot be changed. In practice, this is often addressed through reassurance or distraction.

Viewed through the interface lens, the carer can instead consider what may be prompting the wish. This might include unmet physical needs such as hunger, thirst, discomfort, or fatigue; emotional states such as sadness or uncertainty; sensory overload; or the absence of familiar routines or cues associated with safety and belonging. Each consideration may suggest a different adjustment that can be made to reduce strain and provide comfort.

Over time, this approach supports the development of confidence and judgement, particularly for those providing care without access to formal training. For family carers, who rarely receive specialist guidance, the lens can help sustain connection by enabling them to meet their loved one in the present moment, with recognition of their agency, intent, and humanity.

7. Scope, limits, and transferability

As a conceptual lens, the idea of a failing interface is offered as a way of unifying the many processes through which a person interacts with the external world into a single, integrative layer. Within dementia, this interface may become increasingly compromised and inconsistent, affecting how sensory, emotional, cognitive, and social information is received, processed, and expressed.

This lens does not attempt to explain the diagnosis or causation of any form of dementia, nor does it make claims of cure or improvement in the underlying condition. It does not replace the need for specialist knowledge, appropriate training, or adequate support for carers. Instead, it offers a practical and accessible way of orienting to interaction, intended to support carers in navigating moments of uncertainty as they arise. Future work could explore how this lens might be operationalised or evaluated in practice.

Finally, recognising that all people rely on a continuously operating interface through which inner experience meets the external world, and that this coordination may become compromised under certain conditions, raises the possibility that this conceptual lens could have relevance beyond dementia. Exploration of any wider application lies outside the scope of this paper and would necessarily depend on context-specific expertise. Further consideration and examination in other settings would therefore be welcome.

8. Conclusion: Re-orienting care in moments that matter

For people living with dementia, an urgent and ongoing need is for those caring for them to better understand how connection and interaction can still be supported, how dignity may be maintained, and how care can remain genuinely person led. The interface lens proposed here offers a practical, transferable way of thinking about interaction that is additive to existing concepts and approaches. Rather than prescribing solutions, it offers an invitation to notice strain, adapt responses, and preserve connection in the present moment. In doing so, it invites carers and practitioners to meet the person in front of them not through what has been lost, but through what remains possible in the moment.

AI use statement

The authors used AI-assisted tools to support drafting, editing, and clarification of language during the preparation of this paper. The conceptual framework, examples, and conclusions are grounded in lived experience and were developed by the authors.

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