Who cares about care?

An artistic inquiry into the everyday realities of unpaid dementia caregivers

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‘There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.’ [1]

Rosalynn Carter

[1] Rosalynn Carter, Rosalynn Carter Institute for Caregiving

Artistic Statement

Caregiving can be a painful, loving, and deeply draining experience at the same time. Witnessing a family member care for an ageing person living with dementia for almost a decade led my interdisciplinary practice to focus on the community of care. As a designer, seeing how dementia slowly entered and reorganised everyday life, I kept returning to one question:

> *How might design offer support within such a complex and emotionally difficult situation?*

When I began this research in September 2025, my intention was to design something that could make life easier for older people living with dementia (PLWD) and therefore ease the lives of their caregivers too. At that stage, I imagined the outcome might be a product, service, or practical tool. However, as the research developed, my attention shifted towards the people around them. I began to realise that one of the most overlooked pillars within the community of care is the unpaid caregiver.

My research therefore focuses on understanding the community of care from the perspective of unpaid caregivers. I wanted to explore their lived experience:

> *what they carry?*
> *what they lose?*
> *what support they receive?*
> *what remains missing?*

Through this, the project began to ask a different question:

> *How can design approach the needs of unpaid caregivers, not as secondary figures in the care system, but as central participants whose wellbeing directly shapes the quality and sustainability of care itself?*

This project does not position caregiving only as a burden. The research revealed care as an experience shaped by love, loyalty, intimacy, and commitment. However, these forms of connection exist alongside exhaustion, uncertainty, grief, isolation, and the gradual loss of time for oneself.

Unpaid caregivers often occupy a difficult and contradictory position. They are central to care, yet their labour is frequently unsupported and underrecognised. The gap between lived experience and public understanding also became central to the project. Caregivers' labour could become visible only when something went wrong, while the ongoing rhythm of responsibility, worry, love, exhaustion, uncertainty, and loss remained difficult to articulate or recognise.

This leads to the central research question:

> ***To what extent can a research-led artistic outcome help address the invisibility of unpaid dementia caregivers by creating a deeper understanding of their everyday lives among people without caregiving experience?***

Context

There are currently 982,000 people living with dementia in the UK, a figure projected to rise to 1.4 million by 2040. Dementia and Alzheimer's disease were also the leading registered cause of death in England and Wales in 2024[2]. These figures reinforce the urgency of the subject, but they do not fully reveal the everyday labour that takes place around dementia, often inside private homes.

Kate Washington's *Already Toast*[3] frames unpaid caregiving as an all consuming role shaped by burnout, lack of support, and structural failure. This closely connects to what emerged in my interviews, where caregivers repeatedly described the emotional and practical weight of care, as well as the absence of sufficient support around them.

The Care Manifesto by The Care Collective[4] also positions care as a social and political issue, rather than only a private family responsibility. This perspective is important to my research because it suggests that caregiving should not be understood only as something that happens inside families, but as something shaped by wider systems, values, and social structures.

Within dementia specific care, Anne Basting's *Creative Care*[5] offers a more relational and creative approach, shifting attention away from purely clinical models and towards connection, imagination, and lived experience. This has helped me think about how creative practice might engage with dementia care beyond problem solving alone.

Qualitative studies of dementia caregiving also identify recurring experiences such as exhaustion, sadness, frustration, social isolation, and the difficulty of understanding dementia as it changes family relationships. These sources help position my own research where similar patterns appeared repeatedly:

> *being thrown into the situation without knowing what to expect*
> *emotional weight*
> *isolation*
> *repetition*
> *feeling of being overlooked within the wider care system*

Dementia is often discussed through the symptoms, independence, and support needs of the person living with the condition. However, its effects extend beyond one individual. Dementia care is sustained through a wider community of family members, friends, neighbours, health professionals, charities, and unpaid caregivers. Within this community, unpaid caregivers may gradually take on responsibility for practical tasks, emotional support, decision-making, appointments, domestic labour, and the everyday uncertainties of decline. Over time, this can reshape their relationships, routines, work, health, and sense of self.

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[2] Alzheimer's Research UK, *Dementia Statistics Hub*; Office for National Statistics, *Deaths Registered in England and Wales: 2024* (9 October 2025).
[3] Kate Washington, *Already Toast: Caregiving and Burnout in America* (New York: Beacon Press, 2021).
[4] The Care Collective, *The Care Manifesto: The Politics of Interdependence* (London: Verso, 2020).
[5] Anne Basting, *Creative Care: A Revolutionary Approach to Dementia Care* (New York: HarperOne, 2020).

In *Caring Democracy*, Joan Tronto[6] frames care not only as an act of love, obligation, or family duty, but as a social and political practice shaped by how responsibility, time, resources, and attention are distributed across society. This perspective is important to this project because it makes visible how much care is expected to take place privately, within homes and families When unpaid care is treated as something natural or inevitable, the labour involved can become taken for granted. The constant vigilance, emotional pressure, difficult decisions, and changing identity of the caregiver may remain unseen, even by people close to them. *What I Wish People Knew About Dementia*[7] also reinforced the importance of accessible knowledge and lived experience in challenging narrow public understandings of dementia.

Over one year at the RCA, my body of work has explored caregiving as a painful, loving, and deeply draining experience, situated within an interconnected society. Through interviews, moving image, performance, and product design, I have aimed to understand unpaid caregivers' needs and lived situations more deeply. The work first seeks to make these realities more visible to people without caregiving experience, and gradually open wider conversations around caregiving as a growing social challenge, including with those who shape care systems and policy.

Body of Work

During my research, I created six distinct projects, each exploring a different aspect of my research question through a different method of making. While interviews formed the foundation of all outcomes, my work also drew on ideas and theories from literature, podcasts, and socially engaged art practices.

1. Who cares about care?

Understanding caregiving requires paying attention to its contradictions. It can be loving and painful, meaningful and deeply draining, private and socially consequential at the same time. To explore these realities, I conducted qualitative, free flowing interviews with ten unpaid dementia caregivers and six people who had witnessed dementia care within their own families. The caregivers were based across Iran, the United Kingdom, India, Jamaica, Canada, South Korea, and Sweden. All interviewees had cared for a parent living with dementia. I also engaged with 45 publicly shared caregiver stories from Alzheimer's Society. Participants were anonymised and the interviews invited them to speak about why they became caregivers, the duration and realities of care, the support they received, what remained missing, and what they wished others understood.

Figure 1 presents a system map extracted from interviews and case studies. As the map shows, different feelings, difficulties, challenges, and structural gaps are deeply interlinked. It is very difficult to consider any one aspect in isolation.

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[6] Joan C. Tronto, *Caring Democracy: Markets, Equality, and Justice* (New York: New York University Press, 2013).
[7] Wendy Mitchell, *What I Wish People Knew About Dementia: From Someone Who Knows* (London: Bloomsbury Publishing, 2022).

Rather than seeking one universal account of caregiving, this research attended to both the differences and recurring patterns within these stories. Caregivers spoke about guilt, exhaustion, anxiety, loneliness, lack of preparation, changing family roles, and difficulty maintaining a life beyond care. They identified needs for practical information, emotional support, connection with others in similar situations, and greater public awareness. Yet one concern appeared repeatedly beneath these different experiences:

> *People without direct caregiving experience often did not understand what caregivers were living through.*

The interviews made it clear that my project should not claim to address or resolve the structural pressures of unpaid caregiving. Instead, it asks whether a research-led artistic outcome can respond to one aspect of the issue, namely, *the invisibility of caregivers' everyday lives.*

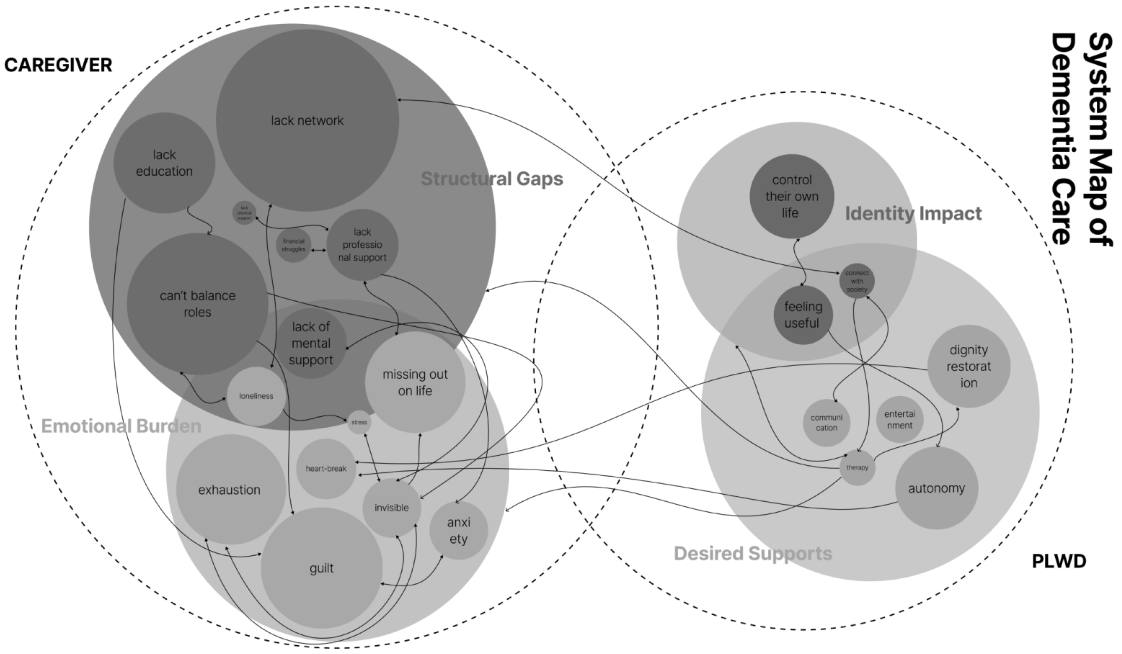

Figure 1 System Map of Dementia Care, Zahra Baqer 2025

2. Invisible

Invisible is a moving image work, developed in response to the most recurrent feeling I identified through my interviews and case studies, namely, *feeling unseen*. The film follows a woman balancing caregiving alongside motherhood, a newborn child, and the responsibilities of running a business. She gradually fades beneath the weight of these overlapping roles. Through layered sound, the work reflects the constant thoughts, emotional pressure, and invisible responsibilities that shape her everyday life.

The work was successful in communicating with people who had personal experience of caregiving or had already read about the project. However, when shown to a general audience, it was often understood more broadly as a reflection on unpaid labour or the

everyday pressures of motherhood. The connection to unpaid dementia caregiving was not always clear. This response led me to consider the need for more direct context, as many audiences remain distant from the specific realities of unpaid dementia caregiving.

3. Out of Sync

Out of Sync is a three channel spatial film that explores the emotional realities of unpaid dementia caregiving. Through fragmented moving images, layered voices, and sound, the work aimed to translate experiences of emotional strain, and invisible labour into an immersive audiovisual encounter. Built from caregiver interviews and lived experiences, the film invites audiences to pause within a condition that is often unseen.

The visual structure presents three dimensions of one imagined caregiver. A woman in her forties who is a working mother and a daughter caring for a parent living with dementia.

The left screen shows her dementia care duties.	The central screen represents the limited moments she has for herself, including selfcare and “me time”.	The right screen shows the other demands of her life, including work, housekeeping, and childcare.

This relationship between fragmented imagery and a wider voice-led narrative was informed by Chris Marker’s *La Jetée*[8]. Rather than explaining every part of the story directly, the film uses fragments, sound, and memory to create an emotional understanding of the character’s life.

The audio was developed from material across all of my interviews and case studies. Three voice actors tell three composite narratives, each shaped from all the caregiver stories that were analysed through my research. Although the narratives emerge from different individual experiences, they are edited into one cohesive conversation. Without a clear opening or ending, the audience enters a collective flow of caregiving stories, in which one voice may appear to continue, answer, or deepen another.

This approach was also informed by Suzanne Lacy’s *Stories of Women, Work and Uncertain Futures*[9]. I was particularly inspired by her use of one woman reading another woman’s story, which creates distance from individual autobiography while allowing testimony to become collective and public. Similarly, the audio in *Out of Sync* does not present one caregiver as representative of all others. Instead, it brings together recurring experiences across many lives while protecting the anonymity of participants.

[8] Marker, *La Jetée* (Argos Films, 1962).
[9] Suzanne Lacy, *Stories of Women, Work and Uncertain Futures* (2024-25), multimedia installation, Manchester International Festival.

The musical score was developed collaboratively with Sofia Kiviniemi, a composer from the Royal College of Music. Through several meetings, I shared excerpts from the interviews and collected stories with her, and she developed music in response to their emotional atmosphere. The music became an important part of the spatial environment, supporting the tension between repetition, care, exhaustion, and moments of quiet.

The work was presented at Orleans Gallery, CUT THE STEM Gallery, and in several individual evaluation viewings. Audience members with personal experience of dementia caregiving often recognised themselves or relatives in the film. Here is an example of a feedback I received following the screening:

> *"The exhaustion felt by the caregiver and the constant need to be alert and attentive. The lack of personal time was also very well captured and presented. You almost felt exhausted after watching the film which helped empathise with the caregiver."*

A family member of a care giver also said:

> *"I'm not sure if it's inaccurate but my perception before watching the film was that the love you have for the person you are caring for can help drive you through the difficult times. However, the film presented a very mechanical experience, perhaps on purpose to demonstrate that despite the love you have for the person you're caring for, the pressure and intensity of the experience can start to wear you down and the feeling of not being seen creates a sense of isolation."*

This feedback suggests that the work could communicate with people who have some awareness of dementia, but do not fully understand the everyday realities of a caregiver's life.

Specific scenes also activated personal memories. One audience member reflected that the apple peeling scene reminded them of their grandfather, who no longer knew what a knife was or how to peel and cut fruit independently. Another said that the sea scene reminded them of the days when they cared for their mother and went to the beach to reconnect to themselves. The music was also frequently described as moving, meaningful, and well aligned with the film.

However, feedback also showed a limitation in how the work communicated with audiences without direct experience of dementia care. Some viewers described it as a poetic and emotionally strong short film, but felt that it did not fully represent the specific realities of their life as a caregiver. Others suggested that nothing should be removed, but that additional context could help audiences unfamiliar with dementia caregiving understand the situation more clearly. One viewer felt that the work might be particularly effective for friends and family members of caregivers, who may have some knowledge of dementia but do not yet understand the caregiver's inner world.

This feedback informed the development of my next project, leading me to consider how more direct context could sit alongside emotional and poetic representation.

4. 36 Hours

36 Hours is a work-in-progress performance, planned for presentation at the RCA Graduation Show in July 2026. It developed from a poetic text I wrote in response to Arthur Schnitzler's *Sterben*[10], caregiver stories gathered through my research, and a commissioned written reflection on Schnitzler's novel by Zohre Baqer[11].

The title draws on Nancy L. Mace and Peter V. Rabins' *The 36-Hour Day*[12]. The phrase reflects the feeling that dementia caregiving can extend beyond the limits of an ordinary day. Responsibility does not necessarily end after a practical task is completed; it can continue through worry, anticipation, emotional vigilance, and the need to remain available. Bringing these literary and research materials together, I wrote *36 Hours* as a composite text rather than the story of one individual caregiver.

For the performance, I am collaborating with Hanna Horobynska, a composer, and Yuko Arai, a choreographer. Both collaborators were introduced to the text and to my previous moving image work. In response, they are developing music and choreography that engage with the narrative and with each other. During the ten minute performance, I will read the text while *Invisible is* projected on a screen behind the performer.

Through voice, movement, music, and projected moving image, the performance aims to translate aspects of the caregiver's emotional journey for an audience without direct experience of dementia care. Rather than attempting to represent every reality of caregiving, *36 Hours* creates a shared space in which the overlapping pressures of love, responsibility, exhaustion, waiting, and loss can be encountered.

5. A Cool Glass

A Cool Glass is a speculative ritual and object concept developed during the IED Summer School 2026 under the supervision of Charlotte Jarvis. Set in a future where formal care systems have become inaccessible and unpaid care has returned almost entirely to the home, the project imagines a five minute ritual that allows caregivers to pause before returning to their responsibilities. Using a soft sensory vessel, cooled water, and responsive sound generated from the caregiver's emotional state, the ritual creates a small threshold between being consumed by care and returning to oneself. The work is currently in the early stages of making its first prototype.

6. Chiron

Chiron emerged during a two day hackathon at London Business School. My pitch, informed by recurring issues in my caregiver interviews and case studies, led to the formation of an interdisciplinary team of five including myself as concept designer, a software and UX designer, and three business and finance students from London Business School.

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[10] Arthur Schnitzler, *Sterben* (1912).
[11] Zohre Baqer, *'Reflection on Arthur Schnitzler's Sterben'* (unpublished commissioned response, 2026).
[12] Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day* (New York: Grand Central Publishing, 2012).

The project responded to needs that appeared repeatedly across my research, namely, lack of accessible knowledge, lack of time, loneliness, invisibility, exhaustion, and the unpredictability of dementia care. The team developed an early prototype and business proposition for an AI enabled care companion. A reliable, easy access library and conversational tool for unpaid caregivers of parents or older relatives living with dementia.

The proposed platform combines voice based interaction, expert informed guidance, peer connection, and AI initiated matching. It aims to support caregivers at moments of uncertainty, helping them access relevant information, feel less alone, and identify when professional support may be needed. While my earlier outcomes focused on making caregivers' emotional realities visible, *Chiron* began to explore how those research findings could also inform a more practical form of support.

Although our business plan did not progress to the final stage of that hackathon, the experience was an important learning opportunity. It showed me that developing and launching a tool of this kind may need to follow alternative routes to a conventional profit and loss business model, such as grant funding, public health partnerships, research funding, charitable support, or other forms of mission-led investment. This became my main learning from the experience. A care tool designed for a vulnerable audience must prioritise trust, accessibility, and long term social value, rather than being shaped only by commercial return.

Reflections

Reflecting on this project, I now understand dementia not as a single clinical condition, but as an interwoven community of care shaped by emotional, social, cultural, and economic conditions.

The central learning from this research is that public understanding of dementia and unpaid caregiving is often limited. Therefore, in artistic outcomes with an awareness raising intention, it is important to consider framing, context, and accessibility carefully and in detail. Otherwise, this labour can remain unrecognised by people who have not entered a caregiving role. My aim was therefore to create conditions in which caregivers' everyday experiences could be heard, recognised, and discussed more widely.

The outcomes developed through this research each refined this aim. *Invisible* showed that, without enough context, a work based on dementia caregiving can be read more generally as a story about motherhood or unpaid labour. *Out of Sync created* emotional recognition for audience members with lived experience, but its poetic and fragmented form did not automatically communicate the specific realities of dementia care to viewers with little prior knowledge. This complicated my original assumption that emotional representation alone could create understanding. I learned that, for an artistic work with an awareness based intention, framing, context, and accessibility are not secondary additions. They are part of the responsibility of the work itself.

This learning continues through the later outcomes. *36 Hours* tests whether performance can bring more direct narrative context into conversation with poetry, sound, and movement.

A Cool Glass moves towards a speculative ritual that acknowledges the caregiver's need to return to themselves before returning to care. *Chiron* translated recurring research needs, including lack of time, accessible knowledge, and loneliness, into a practical digital care proposition.

The collective nature of the research was one of its main strengths. First hand interviews with diverse unpaid dementia caregivers and people who had witnessed dementia care in their families created a rich but situated body of material within this research scope. Collaboration also expanded the work beyond my own perspective. Working with other artists, caregivers, and Dr. Melissa Pineda[13] (a dementia educator) helped me expand my perspective and test how testimony could be translated through different methods.

A significant limitation of the research was the composition of my direct participant group. The caregivers I interviewed were adult children caring for parents; I did not interview spouses, despite spouses being another major group within dementia care. Kate Washington's *Already Toast*, written from her experience of caring for her husband, made this absence clearer. Spousal caregiving may involve different histories of intimacy, partnership, shared identity, and loss that my research did not fully address.

Looking forward, I see this research developing through exhibitions, moving images, and socially engaged research partnerships. Wellcome Collection's *The Coming of Age*[14] demonstrates how ageing can be explored through art, science, popular culture, personal testimony, and questions of care, value, and social responsibility. I would like to develop future work with dementia and caregiver organisations, creating moving images and participatory outcomes with caregivers rather than only about them. My practice is therefore moving towards social research through filmmaking. Listening, gathering stories, creating collective narratives, and testing how artistic work can make hidden experiences more visible without claiming to solve them.

[13] https://www.instagram.com/dementia_hacks_and_hope/
[14] Wellcome Collection, *The Coming of Age* (exhibition, London, 26 March–29 November 2026).

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