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Craftivism as Inquiry: Holding Life's Threads

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Abstract

In this article, we share insights regarding an arts-based research project where carers of people with dementia conveyed their experiences in cloth. Carers face high rates of mental ill health and burnout, while forming a largely undervalued and unrecognised workforce. Through this project, carers' knowledge was valued and amplified using an innovative methodology – craftivism. During a series of five workshops in 2021, a small group of carers, researchers and artists gathered online to develop an exhibition of craftivist textile works. They evoked the complexity of their makers' journeys supporting loved ones at the end of life, finding joy and meaning despite grief and isolation. Making and crafting, together, we built community and highlighted the importance of the relationships at the heart of care: holding life's threads. This article contributes to a growing literature surrounding arts-based methods in qualitative research, advocacy, and community life, while providing another platform to share and celebrate the stories of all those involved in the project.

Keywords

craftivism, dementia, care, carers, qualitative methodology, arts-based research

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Craftivism as Inquiry: Holding Life's Threads

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In this article, we share insights regarding an arts-based research project where carers of people with dementia conveyed their experiences in cloth. Carers face high rates of mental ill health and burnout, while forming a largely undervalued and unrecognised workforce. Through this project, carers' knowledge was valued and amplified using an innovative methodology – craftivism. During a series of five workshops in 2021, a small group of carers, researchers and artists gathered online to develop an exhibition of craftivist textile works. They evoked the complexity of their makers' journeys supporting loved ones at the end of life, finding joy and meaning despite grief and isolation. Making and crafting, together, we built community and highlighted the importance of the relationships at the heart of care: holding life's threads. This article contributes to a growing literature surrounding arts-based methods in qualitative research, advocacy, and community life, while providing another platform to share and celebrate the stories of all those involved in the project.

Keywords: craftivism, dementia, care, carers, qualitative methodology, arts-based research

Prelude: Life's Thread

Here I am, holding life's threads. It's not where I thought I was going to be. My husband was diagnosed with primary progressive aphasia. Over the years, he has lost the ability to read, write, speak, or really communicate much at all. So, my relationship with him has changed dramatically. I'm now the keeper of all

connections. I'm the one who holds it all together. Then there's the managing of self, the anguish, the loss of self. It's not all about me, but it's me as the thread holder. In my work, I have used the Japanese Boro technique of patching together many layers of material—you prevent the fabric from fraying by overlapping it with another piece of fabric. I've incorporated some photographs. As I started to put the piece together, I noticed the photographs of my husband became smaller. He's not actually in the last photograph, it's me on my own because that's where I'm at. In a way, this work is very complicated. My son says I have no spare space in it. I don't think he's grasping that that's what life is like: there is no spare space. (Lynne Stone, see Figure 1)

Figure 1

Here, Holding Life's Threads



Figure 2

It's ok I'm here



Here I am, holding life's threads. I've never cared for a loved one with dementia, but I've learnt, slowly, stitch by stitch, conversation by conversation, about what it is like to be in a relationship with someone who is changing. I've learnt this from a group of extraordinary advocates and makers whose threads I now hold, gently, in a loose weave. Together, we have discovered points of commonality and patterns of meaning in complex experiences. Together, we have made a body of work that helps tell stories that are hard to articulate, in a way that seems to touch people.

Sitting in an exhibition of our work at an inner-city university, I stitched over a handprint on a piece of calico, alongside a small group of other people, also making. I was thinking about touch and what it means to hold something precious but ineffable like a relationship. I wasn't sure if the handprint was my own. Many people had traced their hands onto the cloth at an earlier exhibition of our work in a small church hall in a country town not far from Sydney. After I had traced mine, a woman came over and traced hers, one finger overlapping slightly, near my wrist. Then, I had been thinking about N, who was grappling with her diagnosis of early-onset Alzheimer's. "Hold my hand at the end," I had heard her say. (Chloe Watfern)

Introduction

In 2021, as COVID flared up around us, a small group of carers, researchers and artists gathered online to share stories of caring for a loved one with dementia, and to devise textile artworks that would somehow do those stories justice. The project was inspired by craftivism – a "gentle" form of protest designed to bring about positive change in the world, through craft. As a qualitative inquiry into the lived experience of carers, the project sought to understand, and amplify, the core messages, experiences, and wisdom that our participants wanted others to know about the dementia journey. In this text, we have co-authored an account of the process of inquiring together; an account that includes intertwined stories of care and creativity, through the lens of craftivism.

During our research, each carer craftivist expressed the difficulties they had faced or are facing in their experiences of dementia care, from stigma and discrimination to limited support or insight from health professionals, the care sector, and society-at-large—all issues that are calling for recognition and change. And yet they also held onto joy.

Their slowly evolving craft-making embraced the complexity of their experience—navigating relationships and roles, trying to hold all the threads together—sometimes creatively with lots of colour, sometimes tangled, knotted, frustrating and despairing, often exhausting, always a work in progress. Each craftivist found their own unique way of conveying their relationship with dementia. Their work enables us to witness some of what they learnt from and with the people they have cared for and from other carers. Here, we describe the many ways that craftivism became a mode of inquiry and advocacy, illuminating the threads of each work and how they came into being.

Background

Craftivism

From guerrilla knitting to cross-stitched protest signs, public interventions that could be called craftivist have had a long and colourful history: resisting oppression and discrimination through acts of making. The term, craftivism was coined by the sociologist, crafter, and activist Betsy Greer, who wrote: “the very essence of craftivism lies in creating something that gets people to ask questions; we invite others to join a conversation about the social and political intent of our creations” (2014, p. 12). Sarah Corbett (2019) of the Craftivist Collective asserts, “if we want our world to be more beautiful, kind and just, then our activism should be beautiful, kind and just” (introduction, epigraph). While textiles have often been a part of craftivist projects, all kinds of making can be understood to operate in this way. The artist Ann Hamilton wrote it best: “every act of making matters. *How* we make matters... Make something to change your mind—acts that amplify” (2009, p. 71, original italics)

The process of making can be a form of nourishment for those involved. The reparative powers of crafting have been documented by a growing literature: repetitive, mindful processes like knitting, weaving, stitching, and lacemaking seem to improve wellbeing and help us reach a sense of “flow” (Csikszentmihalyi, 1997; Demecs, 2019; Kenning, 2015; Maidment & Macfarlane, 2011; Wellesley-Smith, 2021). Beyond personal growth, craftivism is more explicitly focused on the connective, communicative, and political potential of making (Youngson, 2019). For example, Sarah Corbett described herself as a “burnt-out activist” who, in 2007, began to hand-stitch mini protest banners that she left in public spaces using cable ties (Corbett & Housley, 2011). Engaging in craftivism might have helped Corbett reckon with her burnout and channel her activism into a mode that helped improve her wellbeing. But perhaps more importantly, it also offered another avenue to change others’ minds. Through acts of making that were beautiful, kind, and just, Corbett hoped to “leave seeds in people’s minds rather than telling them what do” (2019, p. 346).

At another level, researchers and makers have begun to explore craftwork as a mode of coproducing knowledge with participants (Demecs, 2019; Shercliff & Holroyd, 2020). Craftivism offers a novel way to conceptualise, and engage in, art-based knowledge translation—a field of research and practice that draws on varied art forms to catalyse dialogue, raise awareness, and enhance engagement with health(care) and related research (Boydell et al., 2012a & 2012b; Parsons & Boydell, 2012, Parsons et al., 2017; Watern et al., 2023). Our research has shown that arts-based methods inspire affective responses, reduce stigma, and impact overall mental health and wellbeing. They are particularly effective at targeting wider audiences as they are accessible to the public, and do not require specific expertise. Consequently, individuals representing different ages, genders, backgrounds, and cultures find resonance with these art forms, which amplify understanding of the messages expressed (Hall et al., 2019; Lafrenière & Cox, 2012; Scott et al., 2013).

Carer Craftivists

While many arts-based research projects have focused on the lived experience of dementia (e.g., Kontos & Naglie, 2006; Moss & O’Neill, 2019), fewer have worked specifically with carers (Pienaar & Reynolds, 2015). Care-ers constitute a huge, unpaid, and often devalued or unrecognised workforce in Australia, and globally (Deloitte Access Economics, 2020). Family carers of people with dementia can make a big difference to the quality of life of their loved ones, but struggle with isolation, grief, and limited support (Bunn et al., 2012; Chan et al., 2013; Farina et al., 2017; Williamson et al., 2022). All too often, we focus on fixing

problems in individuals, rather than understanding dementia as a social experience that can be navigated with dignity and compassion, when people are supported by their communities.

In calling upon forms of labour typically associated with the domestic sphere, craftivism is often aligned with feminist movements that seek to elevate and interrogate the role of this kind of labour in society. Gentle, slow, often beautiful, raising questions, leaving seeds, acts that amplify—conceptualizations of craftivism, outlined above, informed our qualitative inquiry into the lived experiences of carers of people with dementia. This inquiry was aligned with narrative traditions, embodying a curiosity about how people live and what makes up their experience. Blix and colleagues described a relational ontology of narrative inquiry in which “experiences are continuously interactive... peoples’ lives are composed and re-composed in relation with others who are also living storied lives” (2023, pp. 2-3). This emphasis on relational engagement with storied lives made sense in the context of an inquiry about care and dementia, which we understood to be fundamentally experienced in relationships. As a person undergoes cognitive decline, their experience—and those of others around them—is shaped by the types of support, care, and empathy they receive (Macdonald & Mears, 2019).

How might we make sense of the experience of care? How might stitching into cloth help us understand and give voice to relationships and roles that are deeply complex, embedded as they are in complex lives? Mitchell wrote about the many ways that we can make sense through textiles, highlighting the deep relationship between knowing and making, between words and textiles: “text and textile share common association through the Latin *texere*, to weave. These fragile references suggest for textiles a kind of speaking and for language a form of making” (2012, p. 325).

Making (Research) Together

In this text, we contribute novel insights into the links between care, craftivism, and qualitative research, as we expand upon our use of craftivism in participatory narrative inquiry. Unlike more conventional publications of research findings, we evoke intertwined stories of research creation and lived experience, showing how these were weaved through the process of making together.

We understand each craftivist’s work to be an embodiment of their knowledge. The process of making, together, over many hours of discussion and deliberation, involved us all becoming researchers together—identifying patterns of meaning in the experience of caring for a loved one with dementia and in the experience of craftivism. Each workshop was also recorded and transcribed verbatim, and Chloe and Michele shared fieldnotes following each session. In this article, we draw from those transcripts and fieldnotes to develop an account of the process of developing this body of work. Working with the transcripts in NVivo—software that helps to manage qualitative data—Chloe used an inductive or bottom-up coding process to identify underlying and repeated patterns of meaning (i.e., themes; Braun & Clarke, 2006, 2020) in the accounts offered by all those involved in the workshops. Here, we try as much as possible to be “experience near,” using thick description to help evoke what it was like to become craftivists, together (Geertz, 1973). We use a multivocal representation, incorporating first person singular and plural—the “I” and the “we.” Similarly, the crafting was both an individual and collective endeavour, with each unique work sitting within a broader narrative of shared experience.

Origin Story

In May and June of 2021, Chloe Watfern and Michele Elliot facilitated five online workshops with a group of seven carers. Michele is an artist with a longstanding practice working with textiles. She is also an educator, a community worker, and an artist-in-residence with a translational health research centre in Sydney, Australia - the Knowledge Translation Strategic (KT) Strategic Platform of Maridulu Budyari Gumal SPHERE (Sydney Partnership for Health, Education, Research, and Enterpriser). Chloe is an artist, writer, and lead researcher on this craftivism project. As a research associate of the SPHERE KT Strategic Platform, Chloe had worked closely with Michele on a previous art-based project (The HIVE, see Watfern et al., 2021). In 2019, Michele created a textile work evoking the words of family and health professionals involved in palliative care (see

Figure 3). The title of Michele's piece, "Today is a gift," came from a conversation with a carer and dementia advocate, Imelda Gilmore, whose beautiful words floated in white muslin. Chloe, Michele, and their broader KT team aimed to extend the artistic collaboration with Imelda Gilmore, while inviting other carers to coproduce a creative project.

Figure 3

Today is a gift

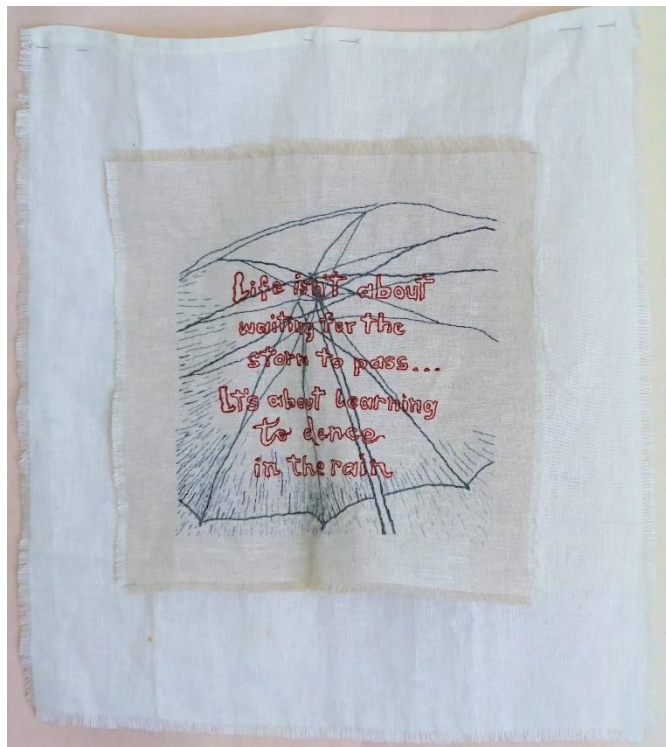


Chloe was introduced to Gaynor Macdonald through SPHERE's Age and Ageing Clinical Academic Group. Gaynor cared for her husband Charlie over the six years that he lived with dementia. With her colleague, Jane Mears, she established Dementia Reframed, an organisation focused on improving information for the community about living with dementia and supporting carers on their journeys. Gaynor immediately warmed to the idea of becoming a craftivist, encouraging us to make our project dementia-care specific. Gaynor was so enthusiastic that she began to hand-stitch by herself before our group workshops even began (see

Figure).

Figure 4

Dancing in the Rain



Ethics and “Participants”

We refined the scope of our project through conversations with carers, like Gaynor and Imelda, as well as with geriatricians, care-er peak body representatives, and other dementia care experts. With a protocol in place, we received ethics approval from the relevant university human research ethics committee in March 2021 (UNSW HC180607) and began to formally recruit participants through the health research centre’s networks. Gaynor and Imelda signed their consent forms but sat in an interesting grey area between participant and investigator. This was a dichotomy that we wanted to dissolve, inviting every participant to become researchers and craftivists with us. We particularly wanted to value the creative outputs that would be produced by the group as a form of research, led by the participants. The messy reality of recruitment and building relationships with craftivist co-researchers was complicated by the strict protocols required by our ethics committee. We could devote a whole article to the conundrums and grey areas posed by university ethics in coproduced creative research. For now, suffice it to say that through a process of snowball recruitment and ongoing dialogue, we formed a group of carers who were passionate, articulate, and keen to explore textiles as a way of telling their stories. Of the seven carers who joined us, only one was a man, caring for his mother. He was one of three people actively caring for a loved one at the time of the workshops. For those three, it was challenging to join the workshops. Some arrived late, others could not make it to all. As we will discuss later in this article, the time required to participate might have been a barrier, but we discovered wonderful solutions to ensure that each person could participate on their own terms.

The Workshops

Each participant was mailed a pack of materials before the first workshop (see Figure). To keep the project cohesive, we focused on working with needle, thread, and cloth, rather than exploring too many diverse genres or mediums. We were aware that focusing on textiles might have deterred people who did not want to work in this form. We were also aware of the possible gender bias towards this kind of craftwork, associated as it is with a certain kind of femininity. Here, we navigated a tension between aesthetic unity and inclusive opportunities for self-expression, perhaps teetering more towards the former than the latter. But we also knew that material constraints and focus can provide an opportunity for expansive and deep communication that might be lost otherwise.

Figure 5
Materials Package



Evocative Objects and Complexity

After initial introductions, Michele began the first session with a simple task of finding an object close at hand that embodied or was somehow related to an aspect of care, caring, or relationship to their special person. The group members were given five minutes to decide on an object, so as not to labour too long or hard. The idea was to begin to find meaning in something of the everyday. Once each person had found an object, they were encouraged to make a contour or outline drawing or to simply trace around it. This spontaneous activity can be a helpful entry point into the creative process. It is not intended to be analytical or overthought. Michele understood her role to be supporting people in exploring and “not knowing”:

When we started, Michele asked us to choose an object that might symbolise our experience of caring. I found that really challenging. How was I going to choose a symbol of my relationship with my husband, Charlie? Then I thought perhaps I would choose something that evoked a funny story from our time with dementia or, on the flipside, something that represented the lack of support or people’s attitudes. But every meaningful object seemed too particular to express

the complexity of dementia care. I wanted to find a way of telling a big story that was tough and wonderful, hard, and easy, exhilarating, and exhausting, because the experience of care was gruelling, absolutely gruelling, and constant. But that was not the relationship I had with Charlie. That's the tension I suppose. (Gaynor Macdonald)

As each person shared their objects, they too spoke about the complexity of the caring experience, and of their relationships—the difficulties of making that visible, of expressing that complexity:

I think because of the complexity, it can be an amalgam of all that—the stigma, the isolation, all of that. The gaining of patience and tolerance and humility. It's very complex and I see the potential for any combination of that to come through. (Penny Bingham)

For Imelda, some of this could be embodied in a box of medals (see Figure). She told us that, about a year before her husband Graham died, she found out he was eligible for a service medal for his time in the reserve army. She managed to organise it so that he was presented with his medal while he was still alive. Now, it has been passed down to their eldest son. To honour Graham like that was very special for Imelda. When she began to draw the box of medals, she realised that she liked the way the box was rough, and her drawing was not perfect; it was not square. And then she thought, “What are some words? What am I doing here?” So, she wrote, quietly, from her side of the screen: “Something you have given to others will be remembered by others, even when you can't remember.” She explained to the group, as she shared what she had made:

That's an extraordinarily emotional experience, that little box of medals and the pencil and paper to express that. I think that's an incredible gift that you're giving us, allowing us to just express what it is we were doing here and then on our journey. (Imelda Gilmore)

Figure 6

Imelda's Work in Progress



Eventually, Gaynor alighted upon a game of snakes and ladders as the form that would give voice to the complexities of her experience of dementia care— “the ups and downs of living with dementia” (see Figure). Over 48 squares, it takes us from Charlie’s diagnosis, through six years of grief, hope, exhaustion, and exhilaration, until his last days.

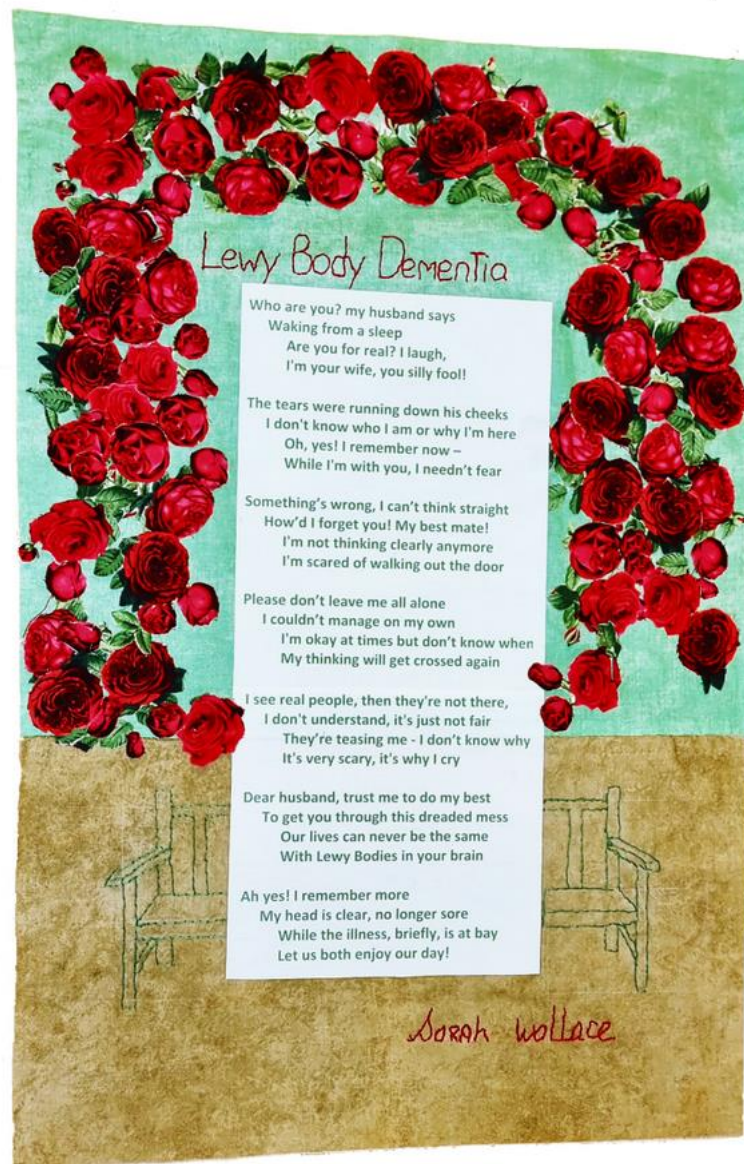
Figure 7

The ups and downs of living with dementia



Meanwhile, Chloe has not forgotten all the evocative objects that these carers had worked on before they joined the craftivist group. She has not forgotten Penny, who showed us a quilt she used to hand-stitch while she was sitting with her husband, Fred. She has not forgotten Sarah, who made thousands of tiny mice in all kinds of colours while her husband was sick, which she sold for \$2 each at a community centre for men to promote their wellbeing. She has not forgotten Imelda, who used to sit on Graham’s bed and knit blankets. When he was buried, she put the last one she made, an extremely heavy 12-ply blanket, in the casket with him to keep him warm.

Figure 8
Arch of Roses



This arch was built by my husband Bob many years ago. We had yellow roses around it, but in 2016, when he was diagnosed with dementia, we changed the roses and decided to have bold, rich, red. Every year they've grown thicker and thicker, they're higher, and this year they've finally joined up over the arch. All that I went through with my husband, and the pain that he went through, with Lewy Body Dementia, was horrific. But when I look at these roses, they are my saving grace. That's what love is: growing roses together. I made up a lot of poems when Bob was going through the stages. I wrote a poem everywhere my husband went. Campbelltown Hospital, Braeside, Liverpool Hospital and in Hammond Care's Linden Cottage. I'm not saying they're the best poems, but they did help make sense of what happened. The poem in the middle of this work was the very first poem I wrote when my husband woke up one morning and asked me who I was. He didn't know who he was either. (Sarah Wallace)

Stitching and Talking: Being Together Apart

We approached the workshops with an open and flexible structure, enabling us to adjust and respond to the way the workshop space unfolded. We had planned to use the sessions for making together: stitching, talking, and developing the work collaboratively. We knew that making together can provide a powerful avenue for conversations that might not happen otherwise. Working on shared tasks, conversations evolve in the doing. But in the online space of Zoom, things transpired slightly differently. Because we were not together, the workshop time was more often devoted to sharing what had been made in between sessions. Zoom created a kind of structure to proceedings, as each person took the “stage” or the “mic,” which does not tend to happen during an in-person making session. Nevertheless, a collective camaraderie developed within the group, as people bounced ideas off one another and picked up the threads of others’ stories:

- Lynne: My relationship is only one part of it. There’s the managing of self, the anguish.
- Penny: The loss of self, Lynne!
- Lynne: Yes! The loss of self and the anguish of being looked at with hatred and loathing. I guess I’m more focused on “how do I hold all the threads together?” That’s where I am, in that space, if that helps anyone else.

This clearly resonated. Later, Imelda would find a piece of cloth covered in squiggly lines. She cut it, then placed it on a piece of calico and began to stitch. Above, she wrote, “How do I hold all these bits together?” (see Figure).

Figure 9
Mrs



Through my work, I wanted to be able to express a story, which is really a circle. I wanted to honour my beautiful young husband who had young onset Alzheimer's disease. I cared for Graham through his journey. He died five years ago. I wanted to honour Graham's precious presence. Through my work, I wanted to express the pain of relationship change, yet the love that upholds it. I wanted to express the isolation, hard work, challenge, frustration, and aloneness of being a care-er. The symbols I have chosen sit more or less within a circular movement. No two days are the same, often no two hours are the same. It's a constantly moving picture because it's life. (Imelda Gilmore)

Imelda alighted upon the idea of an artistic scribe. She found that she did not have the time to keep going with the slow process of stitching and wondered if we could pair her with someone who would be willing to help. Luckily, our group included wonderful people willing to put up their hands. Ruby, a nurse-in-training and an intern with our Strategic Platform, agreed to be Imelda's artistic scribe. Imelda guided Ruby, explaining how each section of her composition needed to evoke a different kind of feeling: "I don't want my stitching to be nice and neat and tidy because its fraught with anxiety and it's messy. That's the way my dementia life is."

The part with the medals, she continued, should be beautifully, ritually stitched. Around the photograph of her husband and daughter, she wanted the stitching to be sad, an expressive sadness, not necessarily something negative: "[Like] it's foggy. It's a miserable rainy day."

For Najla too, her hands full, caring for her husband, Riad, it was too difficult to make time for stitching. Yet, the process of devising an image to be stitched by her artistic scribe, medical student Lucie, proved transformational. At our first workshop, Najla arrived late, in tears. It had been a hard day. Her husband had been screaming. She was overwhelmed, anxious, and uncertain about the project, even though she had been looking forward to joining us for days. But by the end of our workshop series, supported by the experienced carers in our group, Najla appeared a different person. She explained proudly that she had realised that she is a diamond and that she could use the diamond form to represent her experience (see This artwork is a representation of my journey as a care-er—my journey of coping and building resilience and just finding the strength to get through this day by day. When I first became a care-er, I felt uncertain, confused, helpless and extremely vulnerable, not to mention fearful of cultural stigma and social isolation. But through meeting Gaynor, and her support and nurturing—our conversations—I came to realise that I can accept the journey, I can go deep beneath the surface. I can also let go and just be in the present. I chose to represent my journey through a diamond because I want to reflect light. I choose to see the light of the journey ahead. I choose to lead. I choose to encourage people to follow my lead. I choose to see the diamond in my husband. And even though he's progressing, and the dementia is much worse than it was twelve months ago, now I'm seeing the joy in every part of the journey. (Najla Turk)

Figure 10). For Lucie, working on Najla's project led to a kind of healing. She had a lot of guilt associated with her grandparents' dementia. Working on the stitching helped her to see that you can have guilt, but you can also have beautiful moments, and one does not discount the other. These exchanges, the sharing of knowledge and skills and time, are part of what made this project successful and so special for all involved. Stitching and talking, making together, even though we were apart, we created a space where the experience of caring for someone with dementia was valued and understood. For those of us in the group who had not experienced dementia first-hand, like Chloe and Michele, it was humbling to learn from these extraordinary advocates and witness their relationships grow.

This artwork is a representation of my journey as a care-er—my journey of coping and building resilience and just finding the strength to get through this day by day. When I first became a care-er, I felt uncertain, confused, helpless and extremely vulnerable, not to mention fearful of cultural stigma and social isolation. But through meeting Gaynor, and her support and nurturing—our conversations—I came to realise that I can accept the journey, I can go deep beneath the surface. I can also let go and just be in the present. I chose to represent my journey through a diamond because I want to reflect light. I choose to see the light of the journey ahead. I choose to lead. I choose to encourage people to follow my lead. I choose to see the diamond in my husband. And even though he’s progressing, and the dementia is much worse than it was twelve months ago, now I’m seeing the joy in every part of the journey. (Najla Turk)

Figure 10
Diamond



Not Lost? Difficult Emotional Terrain

To express their experiences with dementia in stitch, each participant revisited parts of their lives with their care partners: moments of change, last words, goodbyes, profound love, frustration, lost hats and keys, and maybe a deeper kind of loss, although this last word was debated among the group. Certainly, each participant moved through difficult emotional terrain as they grappled with how dementia had affected them personally. In Lynne’s words, the project gave her “permission and opportunity to actually explore how I feel about what’s going on and to capture something of my inner life.” This is an inner life inextricably linked to her husband’s, as they move together through his dementia.

For many, like Lynne, photos became part of the way that they chose to convey their stories. For example, in our second workshop, Imelda shared a photo of her husband with their

daughter. She drew our attention to the expressions in their eyes. Her daughter, so angry with the disease that was taking her father away, even as he sat there beside her, looking into the distance:

It's as if he's looking for what's just not there anymore... a lot of people don't take pictures, once the person who has dementia loses their intelligent look. But some of the most precious pictures, the ones that I would never give up, are pictures like that. The person is still there... and that precious presence is wonderful.

In this same workshop, Gaynor shared her frustration with people always talking about losing a person with dementia. She insisted "you only lose a person when you walk away from them." She remembered all the people in her community who turned away from her and her husband after his diagnosis, perhaps not wanting to face the loss that they took for granted. Sarah stepped into the conversation:

Sarah: There *is* loss involved in the experience of dementia. You lose communication, you lose touch, they look lost. As a care-er, you can't get away from that.

Gaynor: That's true, but only if you think about it negatively. We *can* learn communication skills to hold people in connection.

As a trainer and consultant, Gaynor affirmed the many ways that people can be supported to change alongside their loved ones with dementia. She affirmed an approach to dementia that focuses on strengths, on support, on knowledge, rather than all that is and can be lost as a person progresses through their disease:

I had to consciously reject and resist the way in which people would try to encourage me to think after Charlie's diagnosis. And I'll go on rejecting them because I didn't want to be plunged into a black hole, and I don't want to see other people forced into that black hole: it was horrible.

Through her stitching, Gaynor worked through their six-year journey—all the emotions and memories—deciding what she wanted to make public: "Stitching it, at times, seemed like a journey dealing with grief that perhaps I have only just begun working through."

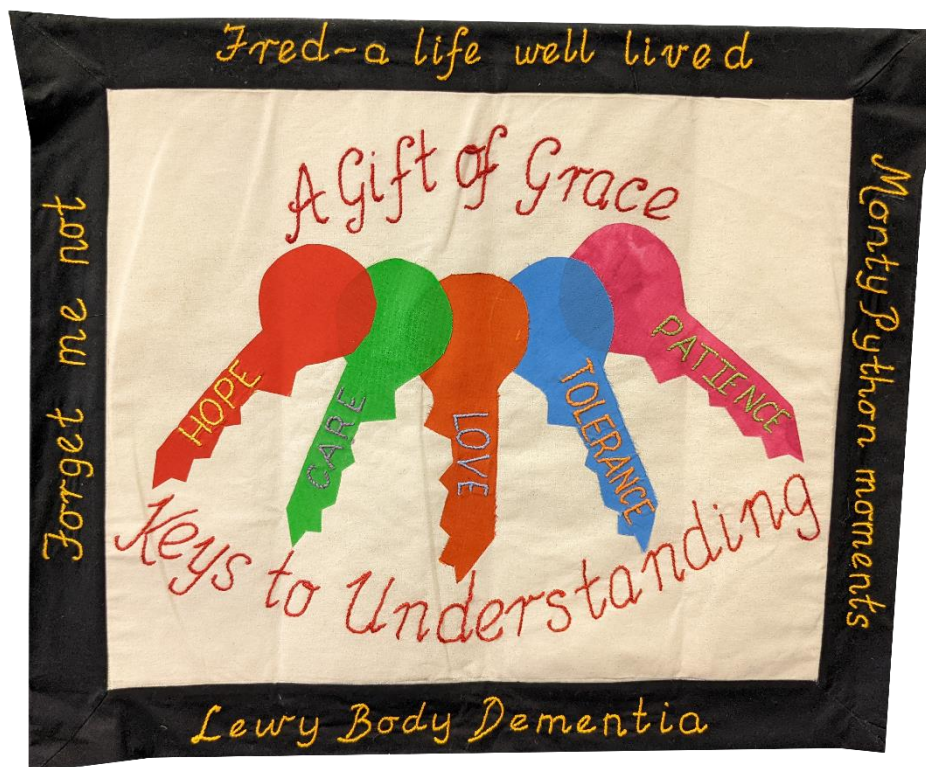
Some of the photos are very intimate and personal, like the photo on square 47 of Figure 7, the last of the two of them together: "Although I am a dementia care counsellor and care trainer, there is something about my own experience I find very hard to talk about. So that's been important."

Working through the difficult emotional terrain as a group, knowing that other people knew what it was like, made a huge difference for all participants. It was the strength of the group that enabled this difficult emotional terrain to be expressed in all kinds of beautiful, vulnerable, and evocative ways.

I was catapulted into the world of dementia in 2013 when my husband was diagnosed. It was something I knew nothing about. During his illness, Fred was obsessed with keys. We were constantly reorganising keys, looking for keys, losing keys. I decided that would be my theme for this work—keys to

understanding. The arc across the top, “A Gift of Grace,” is the title of a memoir I’m writing. When my husband was diagnosed, the doctor answered my question “what can we do?” with one word, “nothing.” I was angry about that. It wasn’t good enough. But in some ways, he did me a favour. It took me on a trajectory of learning, of acquiring knowledge. I learnt about dementia, and all its challenges. I also learnt about patience, tolerance, love, care, and hope. (Penny Bingham)

Figure 21
A Gift of Grace



A Stage

This project has been, in part, an exercise in public storytelling. We wanted to amplify and value the knowledge of carers—to share that knowledge with people for whom it might make a difference. Part of our workshops were devoted to discussing this: who should know, who should see, who should hear about all that we were addressing through the project? This was very hard to pin down. There are so many arenas crying out for change when it comes to dementia, from the aged care system to the attitudes and skills of medical and allied health professionals, to society-at-large, where dementia is still widely stigmatised. Everyone had stories of feeling unseen and unheard, of their knowledge and labour not being valued. Everyone had stories of being avoided or unsupported as they navigated their care partner’s diagnosis.

I hadn't lived with my Mum for maybe 30 years until I began looking after her full time at the start of 2019. The relationship of coming back with my mum has evolved, as it normally would. I realized that I didn't really know who she was. What I gained from caring for her is an insight into a world of uncertainty, and a lot of anxiety. It has been pretty raw for me. My mantra is surrender, give over to the evolving dementia.

But I think as carers we've all felt unheard and unseen, and as human beings, it's all we want really, don't we? Is to be seen, to be heard.... And in a way that being unheard and being unseen ties in with the mask, which I want to be faceless, although it's definitely got a voice. This is where it starts, where the voice of carers who do not have a stage yet come through. (Manuel Tecson)

Figure 12
Unseen Unheard



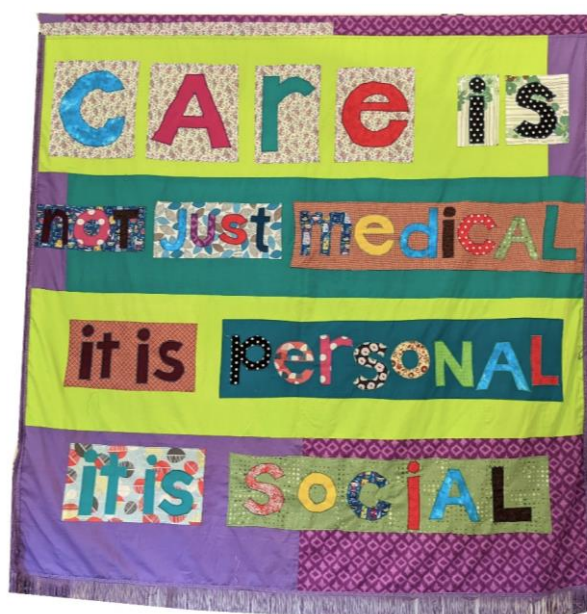
Part of the stage-building that this project embarked on involved inviting more people who were affected in some way by dementia to contribute their own stories and responses—a slow building of community and empathy for all those living with dementia. At an exhibition hosted by Gaynor's organisation Dementia Reframed, in a church hall in a country town south of Sydney, we shared tea and scones and stories of care, of love, and of change. A woman living with early-onset Alzheimer's disease joined us, accompanied by her husband and carer. She revealed how empowered she felt to continue to live her life to the fullest, surrounded by kind, supportive, and empathetic people like the ones she had just met. Her husband told us:

I feel like I belong, I am in a place I can learn and grow as this dementia journey rolls on. I think that the more people that can join the journey, spread the word and help those that care, helps everyone live life to its fullest.

Someone put on a song and Najla and her husband Riad began to dance, her diamond hanging behind them, moving with the breeze. Riad, too, has been making. His paintings rested on bookshelves on the other side of the room, charting his journey with dementia—the lines becoming looser, more abstract, as his disease has progressed. They were no less beautiful.

Later, a small group of us would sit on a stage together in the Great Hall of the University of Technology in Sydney, in the heart of the city, during a public event focused on the intersections between art and health. Our audience was wide-ranging: academics, artists, doctors, executives, carers, and people with lived experience of all kinds of illness, including of dementia. At one point, Manuel's mask was blown up big on the screen behind us—seen, heard. At one point, Najla pulled out a glittering piece of faceted glass she had bought at a bargain shop the day before. Riad smiled from the front row. Their relationship, a diamond, shining for all to see, at least in that moment.

Figure 33
The Banners



These two large scale banners share words and expressions that have been distilled from our workshop transcripts. It was a challenge to represent the many hours of conversations and reflections that took place over this time, as so much of their discussions call out to be heard and shared beyond the project. In translating the words to a large-scale banner, I drew on the traditional banners of the Women's Suffrage movement and the enthusiastic revival of textile practices for storytelling and raising awareness of social issues, in this case, those faced by carers of people living with dementia. The materials come from the project itself and from donated and recycled fabrics. The bright colours and pattern arrangements echo the rich and layered experiences of the carer craftivists' relationships. Just two banners where we could easily have made another ten. Such are the messages that need to be shared. (Michele Elliot)

Conclusion

How can we care better? How can we value the role that carers play, and support them to live well with their loved ones up until the very end? This project has begun to answer those questions gently, slowly, stitch by stitch, conversation by conversation. In this article, we have shared how, through the process of making together, we explored and expressed the complex relationships at the heart of the experience of dementia—as the person living with a diagnosis change and as the people who care for them respond as best as they can. Holding life's threads.

Too often, research is done “on” people, even “for” people, rather than “with” them. We looked to traditions of arts-based research and knowledge translation (Boydell et al., 2012) for examples of visual, literary, and performative approaches to collaboration with research participants in the creation of knowledge. We also learnt from a lineage of craftivist change-makers who have operated outside of academic institutions, rethinking the value of traditionally domestic forms of labour, like needlework, while starting conversations about important social issues (Corbett, 2019; Greer, 2014). Participatory textiles have begun to be acknowledged as a valid and empowering research methodology, yet they have not yet been widely applied in qualitative health research (Shercliff & Holroyd, 2020). This article has helped articulate and model a way of doing craftivist research that values and amplifies the knowledge of carers – a group who are disproportionately undervalued, under supported, and isolated. Our approach could readily be applied to research with other groups, or concerning other issues, that deserve social support and awareness-raising.

Letting craftivism guide our inquiry, we told our stories through evocative objects that were made to be seen and to plant seeds in the minds of others. We created an emergent space for knowledge to be shared and for all those involved, and all those who witnessed their work, to support each other using their own unique gifts. We contributed to the ongoing task of building communities that value the wisdom and work of carers. We showed the power of making, together, to enact small changes that amplify.

Our work is ongoing. In September 2023 an exhibition, “Care is a Relationship,” opened at the University of New South Wales Library Gallery. New communities were invited to add their own marks and stories to a collective artwork that complements and expands upon the body of work we created back in 2021. From our positions, inside and outside of academic institutions, we are bringing care and craft to the halls of knowledge. We have found that craftivism is a powerful frame for doing research with and for those that knowledge is meant to serve.

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Dr. Gaynor Macdonald was an anthropologist, an independent certified trainer/consultant with Positive Approach to Care, and ran Dementia Reframed, a community-based team of dementia carers who share creative and supportive information to carers and others living with the impacts of dementia. She died unexpectedly in July 2022. We feel her loss deeply.

Michele Elliot is an artist, educator and community facilitator based in the Illawarra region of New South Wales. She is one of several artists-in-residences with SPHERE.

Lynne Stone is a former school principal who has been supporting her husband and facilitating his communication since his diagnosis of primary progressive aphasia in 2015.

Imelda Gilmore is a dementia advocate, a voluntary role she has fulfilled since caring for her husband who had young onset Alzheimer's disease and died aged 68 in 2016.

Sarah Wallace cared for her husband Bob after he was diagnosed with Lewy Body Dementia. She had the skills to care for her husband, having worked in the UK and Australian health systems, but she could not have imagined the nightmare of dealing with the Australian aged care system. She has recently published a book about the experience, *Behind Closed Doors: One Family's Journey Through the Australian Aged Care System*.

Manuel Tecson is a chef, a son, and carer for Monica who was diagnosed with Alzheimer's disease in 2016.

Najla Turk is a published author, seasoned educator, diversity consultant and dementia advocate. Since her husband's diagnosis of early onset dementia, Najla has been committed to supporting carers as well as raising awareness about the fast-spreading disease to help reduce the stigma amongst culturally and linguistically diverse communities.

Penny Bingham is an advocate for people living with dementia and their care-ers. When her husband was diagnosed with Lewy body dementia in 2013, she enrolled in the University of Tasmania's Bachelor of Dementia Care and subsequently became an educator for Dementia Australia. She is actively involved in a range of community-based dementia programs in NE Victoria.

Jane Mears is an Associate Professor in social policy. She has worked as an academic, a teacher, community activist and advocate for the past 40 years. She works on collaborative engaged action research projects with communities and government in the areas of women and caring, aged care and violence against older women.

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