STITCH IT FOR DEMENTIA

CARER CRAFTIVISTS

Introduction

A game of snakes and ladders, a diamond, a set of keys, a mask, climbing roses on an archway ... What do these have in common?

Each image speaks to the experience of caring for a loved one with dementia. They were hand-stitched onto cloth as part of a textiles-based craftivist project that brought together carers, researchers and artists over a series of online workshops in 2021.

Craftivism links craft with activism - a 'gentle' form of protest, designed to bring about change in the world. The term was coined by sociologist Betsy Greer in 2001 and taken up by the Craftivist Collective. As they say, "If we want our world to be more beautiful, kind and just, then our activism should be beautiful, kind and just".

That is what these dementia carer craftivists seek—a better world for all those impacted in some way by dementia.

They didn't start off thinking of themselves as activists. Over the course of the workshops, these carer craftivists expressed the difficulties they had faced or are facing in their experiences of dementia care, from stigma and isolation to a lack of 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.

Through artist Michele Elliot's facilitation, and the support of the group, each craftivist found their own unique way of conveying their relationship with dementia. Their work enables us to become witness to some of what they have learnt from and with the people they have cared for, and, of course, from other carers.

In the following pages you will hear from each maker in their own words. We hope their wisdom brings you courage and inspiration.

Gaynor Macdonald: "The Ups and Downs of Dementia"

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 flip side, something that represented the lack of support, or peoples' 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. I thought that a game of snakes and ladders could embody those ups and downs.

My work starts with diagnosis and takes you through the six years until Charlie died. Stitching it at times seemed like a journey dealing with pure grief that perhaps I had only just begun working through. I couldn't have done this project if I hadn't felt I was in the hands of a very caring group of people who knew what it was like.

Also by Gaynor: "Being Strong" & "Dancing in the Rain"

Imelda Gilmore (with stitching support from Ruby Porter): "Mrs"

Though my work I wanted 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. For example, in the photo with our daughter his eyes look lost, as though he is searching for something he can't grab hold of, something out of reach. 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 I never would give up, are pictures like that.

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 carer. 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.

Sarah Wallace: “Arch of Roses”

My husband Bob built an arch 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. Campbeltown 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.

Also by Sarah: “Comforting Hands”

Penny Bingham: “A Gift of Grace”

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.

Najla Turk (with stitching support from Lucie Downer): Title?

My artwork is a representation of my journey as a carer—my journey of coping and building resilience and just finding the strength to get through this day by day. When I first became a carer, 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.

NOTE: For Lucy, 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 doesn't discount the other.

Manuel Tecson: "Unseen Unheard"

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.

Lynne Stone: “Here, holding life’s threads”

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 and 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 and 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.

Sophie Rhodes: “Absence and Presence”

I’ve responded to the work and words of the other craftivists in this project by reflecting on my intergenerational experience of having grandparents who lived with Alzheimer’s and Lewy Body Dementia. I translated adolescent memories, etched into my mind prior to my grandparents passing, onto natural wax papers. I have used images of Finland, where my grandparents are from, adapted family photographs, and handwritten letters from my grandmother. They each evoke moments described by my grandparents from their past, which were often shared with the most sharpness during their illness.

The textural collages act as a metaphor for the layers of their life, and the process of watching someone you love going into slow decline. There’s a mixture of grief and relief. Or, as my parents described it, a paradigm that can’t be understood totally, which takes years to make sense of. Some parts of living with loved ones with dementia I recall as quite a harrowing transformation, but the silver lining for me is remembering the times when my grandparents were cogent and lucid, and understanding that the person you knew was still there.

Michele Elliot: The banners

These two large scale banners share words and expressions that have been distilled from the Craftivist Carer 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 Stitch it for Dementia 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 Craftivist Carers relationships. Just two banners where we could easily have made another ten. Such are the messages that need to be shared.

Chloe Watfern: The research

Each work in this project is an embodiment of the knowledge of its maker. The process of making together, through many hours of discussion and deliberation, has also involved becoming researchers together—discovering point of commonality and patterns of meaning in the experience of caring for a loved one with dementia, and in the experience of craftivism. Life's threads.

As the lead researcher on this project, it has been a privilege to listen to and learn from a group of extraordinary advocates and makers. I understand my role, now, to be that of a translator—to help make sense of the deep insights that were shared during our workshops; to help articulate the significance of each person's work, and the stories folded into them. It has been wonderful to learn that, for many of the craftivists, this project has enabled them to tell their own story in new forums.

Many thanks to all of our sponsors and collaborators. I'd particularly like to thank my wonderful and nurturing team at the Consumer and Community Involvement and Knowledge Translation Strategic Platform of Maridulu Budyari Gumal SPHERE.

Dementia Reframed UTS UNIVERSITY OF TECHNOLOGY SYDNEY Maridulu Budyari Gumal Black Dog Institute

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We made it
...
Together
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Always loved,
never 'lost'
~extra turn
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Exhausted...
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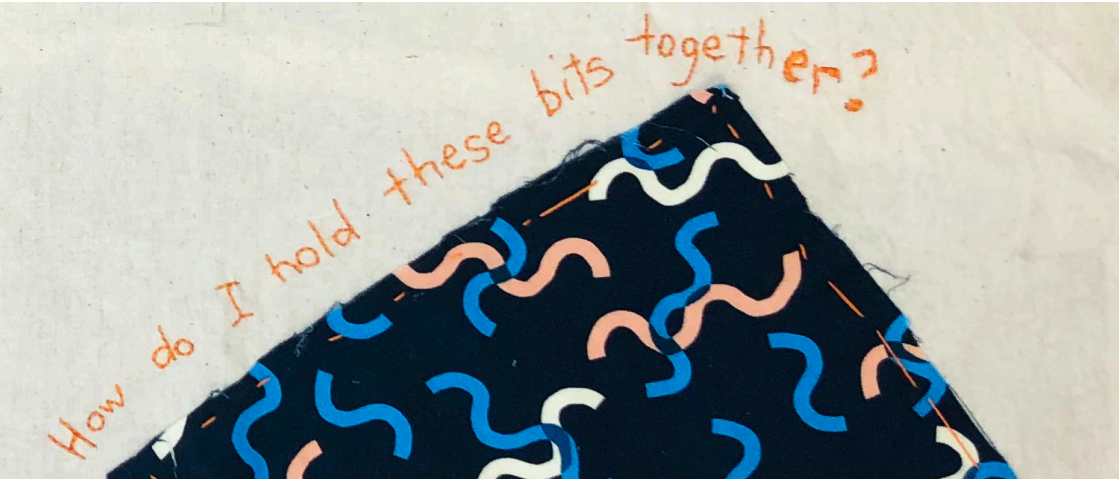
CARE IS a
reLaTioNShiP


How do I hold these bits together?