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‘... this is my home and my neighbourhood with my very good and not so good memories’: the story of autobiographical place-making and a recent life with dementia

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Abstract

As part of the wider Neighbourhoods and Dementia Study, co-researchers from the Open Doors Research Group (based in Salford, UK) produced a series of three films with the title ‘The Changing Face of our Neighbourhood.’ These films were subsequently placed on ‘YouTube’ and document co-researchers’ storied experiences of Salford and the industrial, economic and social changes that have occurred over the inquiry group’s lifetime. Drawn directly from this autobiographical and socio-generational work, this article focuses on the experience of lead

author Lesley Calvert, who was diagnosed with dementia in 2013 and has been a member of the Open Doors Research Group since 2014. Lesley grew up and worked as a district nurse for almost 40 years, remaining close to her place of birth in Salford all her life. In this article, Lesley draws upon her autobiographical narrative which she shares in the three films to describe the intersections between biography, place-making, belonging and dementia. The article concludes with the importance of democratising the research space and why academic researchers need to create opportunities for personal stories to be told, heard and acted upon.

Author Note

As a person living with dementia, Lesley Calvert's wish was to be known by her given name rather than being protected by anonymity. The necessary external ethical approval processes have been granted to enable this to happen.

Introduction

The Economic and Social Research Council / National Institute for Health Research-funded Neighbourhoods and Dementia mixed methods study [referred to in this article as the Neighbourhoods study] is a five-year programme of work (2014-2019) that is led by The University of Manchester and has eight independent, but inter-linked work programmes (see: <https://sites.manchester.ac.uk/neighbourhoods-and-dementia>). The Neighbourhoods study is mainly focused on the individual and in particular, how people living with dementia go about their everyday lives in the neighbourhoods in which they live, or places with which they have a special connection (Keady & the Neighbourhoods and Dementia Research Team, 2014). In keeping with

the study's interest in the personal and in socio-geographical location, this article presents an autobiographical narrative of one person living with dementia, Lesley Calvert, and her experience of place-making and belonging to the city of Salford in Greater Manchester, UK.

Lesley's story is taken from work programme 1 of the Neighbourhoods study which is facilitated by Caroline Swarbrick in the authorship. The primary aim of work programme 1 (known as 'Member Involvement') is 'to support people living with dementia to feel enabled and empowered to develop and facilitate their own research agenda on topics connected to the neighbourhood' (Swarbrick, & Open Doors, 2018). The purpose is thus to facilitate neighbourhood-level research which is planned, designed, conducted and disseminated by people living with dementia (Keady & the Neighbourhoods and Dementia Research Team, 2014; Swarbrick, Open Doors, Scottish Dementia Working Group, EDUCATE, Davis, & Keady, 2016; Swarbrick & Open Doors, 2018). The work programme includes the participation and co-investigator status of a number of activist groups of people living with dementia and their care partners, including the Open Doors Research Group (Swarbrick & Open Doors, 2018).

The Open Doors Research Group is a sub-group of Open Doors, a peer support group for people living with dementia that is located in Salford, Greater Manchester (UK) and supported by Greater Manchester Mental Health NHS Foundation Trust (Howorth, Keady, Riley, & Drummond, 2012). Open Doors is facilitated by Cathy Riley in the authorship and was established in 2009, with the Open Doors Research Group set up five years later (by Cathy Riley and Caroline Swarbrick). The vision was to undertake research in dementia studies supported by academic

organisations, including Lancaster University and The University of Manchester (Howorth et al., 2012). The Open Doors Research Group currently has 45 members which comprise of people living with dementia (with and without capacity) and their care partners, plus group facilitators (Howorth et al., 2012; Swarbrick, & Open Doors, 2018). All members of the Open Doors Research Group, including the facilitators, are collaboratively referred to as 'co-researchers'.

Lesley Calvert has been a member of the Open Doors Research Group since its inception. Lesley's story is shared to help promote further connections between the notions of place-making (Milligan, 2009; Pierce, Martin, & Murphy, 2011; Rowles, & Bernard, 2013) and belonging (May, 2013; May, & Muir, 2015). The story also brings in the notion of social class into the public narrative of living with dementia.

Background

Since the start of this century there has been a steadily increasing interest in exploring the everyday lives of people with dementia (Hallberg, 2003) including their connections to neighbourhood spaces and places (Milligan & Thomas, 2016; Phinney, Kelson, & Baumbusch, 2016). This interest has mainly, but not exclusively, been driven by three major policy and service developments.

- 1) The global reframing of dementia as a public health priority (Alzheimer's Disease International, 2012) with the recognition that people living with dementia are themselves agents of social change, such as through the formation of self-representative activist groups and peer support networks (Bartlett, 2014; Willis, Semple, & de Waal, 2018)

- 2) The enshrinement of human rights for people living with dementia under the World Health Organisation's global plan for dementia (World Health Organisation, 2017), a change underpinned by the use of empowering and person-centred language to describe personal experience, such as through the narrative of 'living well with dementia' (Martyr et al., 2018)
- 3) The world-wide adoption of the dementia-friendly community movement to positively shape the everyday lives of people with dementia (Alzheimer's Disease International, 2015) and to enhance social (Bartlett & Brannelly, 2018) and relational (Kontos, Miller, & Kontos, 2017) citizenship.

On this third policy and service development point, whilst the language and definition about what may constitute a dementia-friendly community is open to debate and challenge (Duggan, Blackman, Martyr, & Van Schaik, 2008) and many diverse models are seen to exist (Alzheimer's Disease International, 2015), Crampton, Dean and Eley (2012) identified four key dimensions of a dementia-friendly community, namely: people, places, networks and resources. These authors position people living with dementia the centre of each of these four dimensions in order to maintain inclusivity and opportunities for transformative actions. At its heart, therefore, a dementia-friendly community empowers people living with dementia to have high aspirations and, in the words of the Alzheimer's Society (2013), to feel 'confident, knowing they can contribute and participate in activities that are meaningful to them' (p.41).

The literature reveals that this confidence can be achieved in many different ways and with many different outcomes for people living with dementia, such as by enhancing personal well-being and resilience through peer support and neighbourhood friendship groups (Clarke, Keyes, Wilkinson, & Alexjuk, 2013; Ward, Howorth, Wilkinson, Campbell, & Keady, 2012). Moreover, dementia-friendly communities continue to attach a real significance to breaking down social stigma and replacing negative societal stereotypes with positive individual representations about what people living with dementia can achieve when offered support, opportunity, independence and self-belief (Alzheimer's Disease International, 2015; Alzheimer's Society, 2013). This momentum for societal change has predominantly been achieved through public awareness campaigns, such as that seen in the 'dementia friends' initiative (see: <https://www.alz.co.uk/dementia-friendly-communities/dementia-friends>), with public education about dementia becoming a key building block to instigating - and sustaining - change at local, regional and national levels (Alzheimer's Disease International, 2015).

Moving the lived experience of dementia from the private space of the home into the public domain of everyday life, such as in the local services offered by cafes, shops and civic amenities, produces significant opportunities for social action and social connectedness for those living with a dementia. As seen in both the environmental and cultural gerontology literature, one way of understanding this drive for greater social connectedness in local neighbourhoods is by focussing on constructs such as place-making (Milligan, 2009; Pierce, Martin, & Murphy, 2011; Rowles & Bernard, 2013) and belonging (May, 2013; May & Muir, 2015).

In this article, and drawing on these layers as context, one of the Open Doors Research Group members, Lesley Calvert, has written an autobiographical narrative and illustrated it with a number of carefully chosen photographs to show and tell the meaning of (her) neighbourhood place-making and sense of belonging as experienced over her lifetime. However, before this story is shared, we will outline the study design and methods.

Study design

Methods of study

Lesley's story is part of a wider project which we eventually named 'The Changing Face of our Neighbourhoods'. The three 30-minute films that comprise the project were finalised by co-researchers in early 2018 and are free to access at: https://www.youtube.com/watch?v=SlKs-Ac1_eo&list=PLxqVG-8W1ALfRZ8P9FA_R941OqiZ8Riyj [accessed on 30 January 2019]. The films took us three years to plan, develop, finalise and disseminate through the cycles of action and reflection (Heron, 1995). The inspiration to develop 'The Changing Face of our Neighbourhoods' suite of films was brought about via planning meetings in 2015 when it transpired that the majority of co-researchers had either grown up or had a deep-rooted historical connection to Salford. As such, we wanted to document our collective memories of a 'traditional working class' neighbourhood experience in Salford and to undertake heritage research to supplement our individual and collective stories. This, then, became our research question. Project planning meetings during 2016 further refined and developed our areas of interest with visual materials to support the storytelling provided personally and through the 'Memories Matter' reminiscence collection at Salford Museum and Art

Gallery (for additional information see: <https://www.salfordcommunityleisure.co.uk/culture/reminiscence>;

accessed on 30 January 2019). As a group, we were in agreement that we wanted the films to follow an interview-style format, whereby we asked each other questions on a one-to-one basis on camera. During the final planning meeting, we designed the topic schedule and made sure everyone had a copy to take home prior to filming to enable anyone to rehearse their answers if they wished.

Working alongside a local film producer (Beena Khetani in the authorship), we were keen to have the opportunity to be involved in the filming process as well as be 'on camera.' In preparation, we were invited to a workshop run by Beena which introduced us to the world of film making and production. We also had the opportunity to try out the filming equipment as well as see ourselves on-screen. Filming took place over the course of two days at a community resource centre in Salford in April 2017, the same location where we held our monthly meetings. For those being filmed (which included Lesley Calvert), the chair used by the 'interviewee' was positioned in front of a blank green screen. The green screen was used to enable photographs and images pertinent to the story (chosen by us) to be superimposed behind the speaker on the finished film. In addition to having the opportunity to be involved with operating the filming equipment and asking questions to those being 'interviewed', we were also involved in the film editing process. Footage was transcribed by Caroline Swarbrick.

As will be shared shortly, Lesley's autobiographical narrative and some of our supporting photographs were taken directly from the film-making process together with transcribed text from the supportive interviews

about her neighbourhood memories of Salford. Lesley had the final say on what appears in the shared narrative in this article.

Ethical Approval

Ethical approval for the study was obtained from Yorkshire and The Humber-Leeds West Research Ethics Committee (ref: 16/YH/0507) and the project complies with the Mental Capacity Act (Department of Health, 2005). In the overall study, we followed the British Psychological Society (2008) guidance for including people who may not have capacity to consent.

Findings

About me

My name is Lesley Calvert and I was diagnosed with Alzheimer's disease in September 2013. For 39 years I was a district nurse in the city of Salford in the UK. Since I was diagnosed with Alzheimer's disease my aim is to live my life to the full and to 'spread the word' that it is possible to live well with dementia with a little help and support. Due to my professional background I have always had an interest in research, so when I was asked if I wanted to join the Open Doors Research Group I jumped at the chance. The first picture I would like to share is me working with my friends in the Open Doors Research Group putting together the resources for our neighbourhoods study. The photograph was taken in Salford museum alongside other co-researchers and some of the pictures I found from that time have been included in this article. I am the person in the middle of the photograph leaning on the map.

Photograph1. Open Doors Research Group (*courtesy of Beena Khetani*).

Insert photograph 1 here

My Childhood

The memories of my childhood are still very vivid, more than I can say about my recent memories! The neighbourhood where I grew up was street upon street of terraced houses (see photograph 2), like the ones that were painted by the Salford artist L.S. Lowry and depicted everyday working class life and factories. Those paintings are now worth a lot of money. I live in the city of Salford, which is now part of Greater Manchester, although to people who were born here, we still like to say we are Salfordians not Mancunians!

Photograph 2. Street of terraced houses.

Insert photograph 2 here

When I was growing up, there were five of us who lived in a two-up, two-down terraced house. There was no central heating, just a cold tap. Hot water was obtained by boiling the tin bucket on the gas hob. Baths were taken in front of the fire in a tin bath: cleanest first, dirtiest last. To keep us all warm in bed we went to the jumble sales at the church hall on a Friday night and my mum would buy old fur coats or old army coats. Nobody bothered about having second-hand clothes. It was the 'norm' but they really did keep us warm. We slept three in a bed, my brother at the bottom and me and my sister at the top.

Everybody knew all their neighbours, young or old. Friendships lasted. Nobody ever locked their doors during the day. This was probably

because nobody had much to steal. You knew all the children in the area as you were within walking distance of the school you went to. You knew the adults as well because they would usually attend the local churches, which were the hub of the community or work in the shops on Regent Road in Salford. This is a far cry from today's neighbourhood where people just 'come and go'. You just start to get to know - and like - your neighbours, and then they move out usually within three years. I don't know why that is, but a lot of people rent houses around Salford and maybe it is to do with that.

If you look at photograph 3, I'm the little one in the photo and we have just got ready for the Whit Walks. Everybody who attended church of any denomination would walk on Whit Friday, Whit Sunday or Whit Monday. After the walk we would go around to our family and friends to show off our new clothes and they would give us money.

Photograph 3. Whit Walks.

Insert photograph 3 here

This next photograph I would like to share from my childhood is one from a birthday party. This photo (numbered 4) was taken inside the house of our friends and I am the little one at the front licking the spoon. The older girls are dressed in their best clothes.

Photograph 4. Birthday party.

Insert photograph 4 here

School and Shopping

When I was younger, the main shopping area in Salford was Regent Road which is shown in photograph 5; a picture taken in the 1950s. On Regent Road you could buy anything from a toilet and cistern to clothes and food. There was a public house on every corner. My great aunt and uncle had the 'Spread Eagle' public house on Regent Road. Unfortunately, my great uncle was killed by an out-of-control lorry on Regent Road and his wife had both her legs amputated. There was also a Woolworths [large department store, now out of business in the UK] on Regent Road, a British Home Stores [large department store, now out of business in the UK] and a large supermarket, which sold almost everything: that was called 'The Queens'. At the bottom of Regent Road, near to Regent Road School which I attended, was the abattoir where the cattle and pigs would be slaughtered. The smell of raw meat was terrible and we would hold our noses when passing going to school.

Photograph 5. Regent Road in 1950s (*courtesy of Salford Museum and Art Gallery*)

Insert photograph 5 here

I remember that one day, after the cows had been taken off the cattle trucks on Cross Lane, they should have gone down Liverpool Street, which ran parallel to Regent Road to the slaughter house. But the cows hadn't been milked and they came stampeding down our street. We were all out playing and, as nobody locked their doors, we were thrown into the nearest house. Our sideboard was splattered with milk but we all were safe from the stampeding cows.

Growing Up

When we had our houses compulsory purchased they said they ‘*were not fit for human habitation*’ and were to be pulled down. Also, all the shops on Regent Road were pulled down as well, which meant the people working in the shops were put out of work. One of these people was my mum who worked at the Spa dry cleaners. Money was tight but things became harder for us all after she lost her job. This was when our friendly neighbourhoods were broken up. We didn't live far from the Salford docks where all the food and machinery would come in by large ships. After they knocked down all the houses and shops they built a motorway to the docks (see photograph 6). Then, when the motorway was finished, lo and behold they decided to shut the docks. This is now known as Salford Quays where the BBC and ITV television studios are situated and also where the long-standing and popular soap opera ‘Coronation Street’ is set.

Photograph 6. Regent Road in 1970s (*courtesy of Salford Museum and Art Gallery*)

Insert photograph 6 here

Regent Road is now just a dual carriageway into Manchester (see photograph 7). It is always gridlocked. People who had never been brought up in the area, or were too young, would never believe how it has changed.

Photograph 7. Regent Road in 2000s (*courtesy of Salford Museum and Art Gallery*)

Insert photograph 7 here

There are a few large shops there now, but nothing like it used to be. People were moved to places as far as 12-15 miles away or put into high rise flats in Salford precinct. However, the neighbourhood was broken as in the high rise flats you never saw your neighbours.

We only moved two miles away to a place called Weaste, where my mum and dad purchased another house. The reason we moved there was my dad still worked in Trafford Park and he couldn't drive so went to work on his bike over the locks on the Manchester ship canal to the Carborundum. The house we moved into was similar to the one we left except it had three bedrooms and an upstairs bathroom. This was luxury as we didn't have to go out in the middle of the night to use the toilet.

My Life Now

I have stayed in this street in Weaste, getting married and buying the house next-door-but-one to the house I grew up in. For a long time we had a very similar neighbourhood to the one I left, everyone caring and helping each other. There were plenty of shops where you could get whatever you wanted still within walking distance. This changed in the 1970s when people had more money to spend and could afford to buy a car, driving to the big supermarkets to get whatever they needed - modern living and everything under one roof. Now there are only two houses in my street that are owner occupied. You don't know your neighbours as they only stay while they get a house in a better area. There are a few neighbours I know and I wish they would stay, but I know they are all looking for a better area they can call home. However,

to me, this is my home and my neighbourhood with my very good and not so good memories.

Discussion

Our article has presented an autobiographical narrative of one of our members' (Lesley Calvert) neighbourhood memories and stories about growing up and living in the city of Salford, Greater Manchester, UK. Whilst it is a life that has incorporated a diagnosis of dementia in recent years, it is not a life that should be defined by it, as Lesley herself is keen to point out. This is especially seen in the shared autobiographical narrative when Lesley proudly affirms her identity as a 'Salfordian' with the fierce rejection of all other cultural markers that could undermine her sense of self. Indeed, the self-identity statement is also a sharp reminder that for those of us living with dementia it is, first and foremost, to be a person. We note that this simple - but profound - analogy was first applied to the dementia field by the late Professor Tom Kitwood in his classic text *'Dementia Reconsidered: the person comes first'* (Kitwood, 1997). It is why, in that book, Kitwood saw biographical approaches to care practices and life story work as a cornerstone that builds a connection between those of us who live with dementia and those of us who live without it. Without a deeper appreciation of the PERSON with dementia - as Kitwood (1997) so memorably phrased it - care practices in these organisations would simply skim the surface of our authentic and relational knowledge and deliver sub-optimal and non person-centred care (see also: Brooker & Latham, 2015).

Whilst this assertion continues to hold meaning for those of us who live in supportive care environments, we acknowledge that Lesley lives on her own at home and in a community to which she has expressed a

sense of belonging, despite a revolving door of neighbours and a general feeling that her neighbourhood has been 'run down' through central and local government underfunding and societal changes caused by the decade-old austerity agenda in the UK (Stuckler, 2017). Arguably, the biographical knowledge and investment in memories that supports Lesley at home - and underpins her personhood - exists in her long-standing association with familiar neighbourhood spaces, places and people in Salford, including the friendships that have been built (by all of us) in recent years through the wider Open Doors Network. This cumulative and reciprocal exchange instils a sense of belonging and selfhood for Lesley that she is able to exert through, and in, our article by the telling of her story and her editorship about *what* is shared and *how* it is shared.

Drawing on the this point, from the autobiographical information that we have shared, much can be learnt. For instance, Lesley's use of the subjective headings '*About Me*'; '*My Childhood*'; '*School and Shopping*'; '*Growing Up*'; and '*My Life Now*' are displayed in a chronological order of life-stages that does not feature the word 'dementia' in any form. This absent narrative and chronological life story ordering is not unique and is reminiscent of other autobiographical narratives shared by people living with dementia (see for example: Keady, Williams, & Hughes-Roberts, 2007; Kindell, Wilkinson, Sage, & Keady, 2018). Indeed, it probably reveals how those of us living with dementia are continuing with our day-to-day lives by absorbing the bad days with the good days that come with the lived experience rather than living a life defined by and shaped by a diagnosis (Hutchings et al., 2010; Rockwood, Fay, Hamilton, Ross, & Moorhouse, 2014).

The sub-heading titles and contents also describe the sensory world, neighbourhood experiences and times of Lesley's (ongoing) autobiographical narrative. To develop our point further, Lesley's chronologically ordered and written accounts of *'My Childhood'* taken together with the photographs shared in this article, vividly illustrate the street upon street of back-to-back terraced housing that was a familiar landscape in Salford and which was a traditional feature of Lesley's everyday life at that moment in time. Such everyday experiences for Lesley included: having an outside toilet; only one cold tap in the house; accessing hot water by boiling the tin bucket on the gas hob; having limited rooms inside the home; and dressing in second-hand clothing to keep warm at nights.

Reading this story from a first-world 21st century perspective, Lesley's childhood and growing up contains sub-plots of: poverty, social deprivation, pollution, inadequate housing, gender inequality and the constant threat to home finances due to the precarious nature of factory, shop and dock work. On the other hand, these more heart-rending narratives are counter-balanced by Lesley's stories of: friendships, local schooling, family, the role and importance of the church within the community, upholding long-standing traditions and social routines, community trust and a sense of belonging to a set of people within an identified and boundaried neighbourhood. As Hydén (2018) would argue, these stories also contain evidence of generational connections and solidarity that uphold the person's narrative sense of self and identity.

This autobiographical narrative also clearly locates Lesley's attachment to home and how home changed and evolved over her lifetime. This

importance of home to creating a sense of belonging is not unique and was also seen in the work by Ward et al. (2018) where people with dementia in their walking interviews connected their 'home' to a fixed place within their self-identified neighbourhood. For people living with dementia, being able to understand and project this 'fixed' connection of home to themselves and to others was crucial to safely wayfind and to navigate and negotiate around local landscapes ... and to subsequently return 'home'. However, informed by Lesley's suggestion, this analysis sets up an intriguing question. If the fixed marker of 'home' becomes fluid through the advancement of dementia and the cognitive capacity to assimilate the 'here and now' as an ordered construct, then how likely is it that the search for belonging becomes rooted in a relational connection to time and an associated biographical connection to home? As seen in photographs 2 and 5 in our article, if you live with a more advanced dementia and went searching for your back-to-back terraced home in Salford - which is now a busy dual carriageway - then you are highly likely to be labelled as 'confused', a 'risk' and 'disorientated in time and place' by others once your purpose becomes known. Even though, for you personally, the search makes complete and perfect sense. Arguably, this place-attachment disruption warrants additional exploration to further theorise the lived experience of dementia.

Finally, to move the field forwards, it is important to develop participatory social research methods which are inclusive to all people living with dementia, including those who may not have capacity (Keady, Hydén, Johnson, & Swarbrick, 2018). It is important that all aspects of creativity are embraced in order to enable and empower individuals to participate in ways that do not necessarily involve the spoken word (Bellass et al., 2018). For example, 'The Changing Face of Our Neighbourhoods' also

supported those in our group who were unable to communicate verbally to choose music and photographs for inclusion in the films. This, in turn, facilitated our own personal involvement that was both biographically meaningful, inclusive and an authentic representation of our individual lived experiences.

Conclusion

Lesley Calvert's story brings social class into the story of dementia studies that has been absent from the debate for too long. Salford was an area in England in the mid-19th century that Frederic Engels studied and, together with Karl Marx, eventually composed the communist manifesto to as a rejection of the industrial conditions, poverty and worker exploitation that was experienced first-hand in local factories and neighbourhood communities (Engels, 1845). These observations and resultant communist manifesto literally polarised and changed the world order in the decades that followed, up to, and including, the present day. Lesley's experience of a working class childhood in a working class area of the north of England is also one laced with rich artistic, community and cultural heritage that, to a significant extent, changed in the years to come in the community regeneration programmes that were commissioned to ostensibly make life better for the resident population. As Lesley makes clear in our article, and in her testimony, we cannot change where we are born or where we live whilst growing up or, it must be said, influence some of the political and economic decisions that are seemingly taken in our best interests, but we can use these experiences to forge a new pathway of understanding that embraces a life with dementia that is drawn from biography, belonging, place-making and a connected sense of self and identity. Without an enhanced understanding of these constructs and intersections, we are at risk of

simply repeating the patterns of the past and seeing those of us who are living with dementia only in the 'here and now' and as the clinical sum total of a cognitive score. As we have shown, human life is so much more than that.

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Author Biographies

Lesley Calvert is an active member of the Open Doors Service and Research Group. She has given numerous national presentations relating to her involvement as a 'co-researcher'. Lesley lives with a diagnosis of young onset dementia

John Keady leads the Dementia and Ageing Research Team at The University of Manchester and was founding and co-editor of *Dementia: the international journal of social research and practice* between 2002-2018.

Beena Khetani is the Director of Chronicle Films and Sonder Radio. She has a background in film and television and has produced numerous life story films for people living with dementia.

Cathy Riley is the Open Doors Service Manager, based at Greater Manchester Mental Health NHS Foundation Trust. Cathy was one of the founders of Open Doors, which was set up in 2009 as a post diagnostic support service. Cathy has been instrumental in the Service's growth and development to support people living with dementia and care partners across Salford, UK.

The **Open Doors Research Group** was established as a subgroup of the Open Doors Service in 2014. Referred to as 'co-researchers', all members of the Research Group are affected by dementia, either with the lived experience, as a care partner or family member. The group was set up to develop its own research agenda and undertake a small-scale research project.

Caroline Swarbrick is a Senior Lecturer based in the Centre for Ageing Research at Lancaster University. She is passionate about the involvement of people living with dementia as co-researchers and using creative methods to support people who may not have capacity.

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