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Relieving isolation and cultivating connection for carers and people living with dementia

Context before the pandemic

In March 2020, at the time lockdown began, I was, in addition to my teaching/counselling work, also working part-time at a local Edinburgh community centre where I'd been working for 6 years. My role there was in social and emotional support for carers and people living with dementia in the community. I ran a weekly dementia-friendly lunch club ('Lunch Breaks') and co-ordinated the centre's befriending programme for family caregivers (carers).

The centre was founded in the 1980s and operates from a converted church building that had been purchased by 3 other local churches to transform it into a community centre. The centre has a particular interest in supporting older people, including people living with dementia. The CEO at the time I started working there had a long-standing commitment to the Salvation Army, and the ethos of faith expressed in practical action to support people in need (of all faiths and none) was a major aspect of the centre's work. Administratively, the centre operates as a secular organisation and has a wide range of staff who may or may not have a faith of their own. In my own case, working in support for carers and people with dementia has the sense of 'a calling' for me, though part of me is hesitant to use the language of 'calling' to describe this.

The free-of-charge Lunch Breaks group began in 2014, supported by grant funding, and met every Friday at 1.00pm. We had a hot 3-course meal provided by the centre's chef, followed by a rolling programme of activities. Sometimes, I designed and led an activity myself, often based around interactive poetry or storytelling; or I might lead the group in 'shibashi tai chi' a modified set of tai chi moves that were gentle on the body and that the group delighted in doing. Some of the moves were graceful, such as 'the swan,' and others were playful, such as 'playing with waves' or 'painting a rainbow.' In one of our creative sessions, we made what the group called a 'friendship banner.'

Other times, we had guest facilitators. One local singer was a popular visitor, leading the group in 40s-80s pop music. She was a musical theatre graduate and had a warm and buoyant style. She would play through a set and also take requests, and shared snippets of information about the history of each song and how she first learned it from her grandmother.

We also had visitors from the National Galleries of Scotland, from their Dementia Friendly events series. They brought period objects to examine, vintage photographs, and fascinating hats, and led interactive sessions that engaged with participants flexibly and adaptively, whether through smiles, gestures, or conversations.

The Luminate Creative Ageing Festival brought us a performance of Magdalena Schamberger's 'Curious Shoes,' described as "a collaborative performance for people living with dementia, their loved ones and those who care for them. Curious Shoes provides an opportunity for somebody with dementia to share the experience of seeing a piece of high-quality theatre, without it being a stressful or worrying experience. It offers a chance to be creative, to be seen and to be heard."

There were also sessions based on physical activity. The centre was loaned a set of table tennis tables through a dementia-friendly project, and the group had fun with these. We formed a partnership with Celtic Football Club foundation, who sent us trained coaches periodically who brought, among other things, opportunities to try out boxing moves with boxing gloves, indoor golf, and dancing, as well as a range of table top games.

The camaraderie, mutual support and friendship in the Lunch Breaks group was marked. As facilitator, a ready listening ear was important, especially at times of difficulty, where focused listening could be so supportive. The creative activity focus really helped too. Many in the group spoke of how Lunch Breaks was the highlight of their week, helping them not to feel alone and bringing an opportunity for enjoyment.

When lockdown began towards the end of March 2020, we needed to close the building and the Lunch Breaks group could no longer meet.

The Isolation Times

All of us working at the centre needed to reach out to the individuals and groups we were working with to let them know about the centre's closure and to check on them. Those of us in the social and emotional support programmes also began to spend considerable time on the phone with the people we worked with, and this continued throughout lockdown.

In our befriending programme for carers, we had a team of volunteer befrienders. The first adaptation we made for befriending was to change over from in person to telephone befriending. We provided online training sessions for the volunteer befrienders for their new role as volunteer telephone befrienders, if they were happy to do this. If a volunteer wasn't in a position to do telephone befriending, then one of the staff team took on the role of telephone befriending of the carer, if the carer wished to have telephone befriending. Some preferred to put befriending on hold, until it was possible to meet in person again.

For the Lunch Breaks group, I took up a pattern of making telephone calls to each member of the group every Friday, the day that the group had been accustomed to meeting. I also created a weekly interactive newsletter called *The Isolation Times*.

The first issue noted that the newsletter 'is to help us all stay connected during these times when we need to stay at home.' Participants of the Lunch Breaks group all wished to have printed copies posted to them, rather than receiving them via email. All of us were working wholly from home, so my weekly pattern therefore became putting together the newsletter on Saturdays and Sundays, getting the envelopes addressed and ready for posting, then printing out and sending out the newsletters on Mondays. That way too, each group member had a chance to read the newsletter before we had our regular phone call each Friday. Group members sent suggestions for the newsletter as well as photos, poems or puzzles, so it became a focus of interaction which many said was a high point of their week to receive. I included aspects of my life in the newsletter, such as a photo of places and animals we saw in the Scottish Borders countryside, and I would include a short reflection of something that had caught my attention that week. This had the effect of encouraging the Lunch Breaks group to send material of their own, and seemed to grow over time into part of the group's identity.

In the background for me, there were health issues within my overseas (USA) family. My mother, who lives with dementia, moved into a care home in summer 2019. When the pandemic came in March 2020, the care home made it possible for me to have a Skype call with my mother every week, which still continues. This has enabled us to have greater contact than had been possible in the latter stages when she lived alone in her own home. By the autumn of 2020, my father had also developed multiple health issues and was in and out of hospital several times. I began to feel torn between supporting the members of the Lunch Breaks group with the newsletter and weekly phone calls, and the time and energy I needed to support my family in the way I wished. By December 2020, I made the decision to step back from my work at the centre with Lunch Breaks, and left my role there in February 2021. The production of *The Isolation Times* was taken on by another member of staff. The newsletter has continued weekly since its first issue, and continues to evolve. I learned recently that it no longer is called *The Isolation Times*, but has a new name to reflect new times.

Freedom, caring and dementia

My shift out of the support role with Lunch Breaks in February 2021 gave me more space and energy to focus on my family and, as time went on, my partner too, whose health worsened in autumn 2021. It also brought the opportunity to begin to build my private practice as a counsellor, and to undertake further development of my thesis research project on freedom and dementia.

I had taken up my PhD scholarship with the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh in December 2018. I have an interdisciplinary supervision team representing the disciplines of psychiatry, social science, and theology. I am a part-time student, due to complete in November 2024. My initial research project was focused on freedom and dementia, and was being developed to take place in specialist dementia units (residential medical care). I was intending to recruit research participants who were living with dementia in the specialist units. I also intended to interview family members, medical/care staff, and spiritual care staff. When the pandemic came, there was no longer any access to the specialist dementia units, and I needed to re-design my project for a community setting instead. At first, I aimed to recruit both people living with dementia, and carers; however, the ethics committee at that time were prepared to approve my study in relation to carers as participants, but not people living with dementia. Hence, my study has come to focus wholly on carers' ideas and experiences about freedom and caring in pandemic-affected dementia care. I am recruiting both unpaid (family) carers; and people who work in paid care roles (such as in care homes) with people living with dementia.

Liberation theology

The inspiration for focusing my study on freedom came from experience in dementia/caring, and ideas connected with liberation theology (Gutiérrez, 1971), which I first came across in the 1990s. In it broadest sense, liberation theology focuses on the imperative of practical social action towards liberation of the poor from systemic oppression both within and outside the church. In liberation theology/spirituality, salvation is not placed only in the realm of 'beyond life' but is also conceptualised as just, compassionate human relationships in the here and now.

Gustavo Gutiérrez (1988) writes :

> Sin is evident in oppressive structures… [It is] the root of a situation of injustice and exploitation… Sin demands a radical liberation, which in turn necessarily implies a political liberation… This radical liberation is the gift which Christ offers us. By his death and resurrection he redeems us from sin and all its consequences… This is the reason why any effort to build a just society is liberating. And it has an indirect but effective impact on the fundamental alienation [of sin]. It is a salvific work, although it is not all of salvation… Those who reduce the work of salvation are indeed those who limit it to the strictly "religious" sphere and are not aware of the universality of the process. It is those who think that the work of Christ touches the social order in which we live only indirectly or tangentially, and not in its roots and basic structure… It is those who refuse to see that the salvation of Christ is a radical liberation from all misery, all despoliation, all alienation (pp. 102-104).

I see parallels in this view with the social isolation and alienation that carers and people living with dementia often experience, a marginalisation that can only be overcome through compassionate, liberating community responding and action. John Swinton (2017) writes:

> The key, then, is to create places of belonging where people with dementia and those who offer care and support to them can find a place that is truly theirs and within which they can express the full experience of dementia – its pain, its affliction, and its lament as well as its joys and possibilities. If… dementia is as much a relational and spiritual condition as it is a neurological condition, then overcoming destructive modes of malignant social psychology and negative theological positioning will require particular forms of personal relationships that make welcoming, belonging and truly being in the moment with others a possibility… The ways in which people with dementia and their

> carers are framed and treated by society often function in precisely the opposite direction… (pp. 278-279).

When I was my support work role, carers spoke with me about the pressure and responsibility they felt to maintain social relationships and activities with and for the person with dementia they were caring for; while simultaneously losing their own social relationships and activities while facing ever-increasing financial and practical challenges. They felt abandoned themselves with no-one to help or support them in their caring. As I took up my thesis research, I wanted to ensure that I was hearing the voice of carers in relation to their own experiences and thoughts about freedom and caring in dementia.

Interviews with carers

To date in my research, I have interviewed 13 carers : 2 of them paid carers, and the remainder unpaid carers. Eight of the participants are women; and five of them are men. Both paid carers are women. I used a semi-structured interview format which includes open questions around freedom such as 'what does freedom mean to you, including in the context of caring?' and 'What helps you feel free?' My interviews are being conducted online using Teams. With informed consent, I audio record each interview using an encrypted digital recorder. These recordings form the core data for my research. The multi-stage, time-intensive transcription/analytic process has begun, and all interviews will be transcribed in full. Participants also agreed that the interviews could be transcribed and anonymised or pseudonymised for my thesis write-up, academic articles and presentations.

Themes in the data

At this stage of my iterative analyses, I have tentatively named some early themes arising from the qualitative interviews. For the purposes here I will share three of these here.

Freedom as relief from responsibility / availability of support

The first tentative theme is one I have called 'freedom as relief from responsibility/ availability of support,' which was notably absent and distressing for the carer. This unpaid carer explained that:

> Freedom for me is to relax and not have to listen out all the time for doors opening and closing, just doing what I want to do, just enjoying myself, which is hopefully going to happen eventually. It's taking time with social services getting in place. Even when I'm out I can't stop and relax, eh. I'm still thinking, I wonder if he's there. I check the GPS thing, because I've got my tracker on him, eh, and see if he's moved.

This theme of 'freedom as relief from responsibility/ availability of support' was also expressed by another unpaid carer, with the additional clear theme of systemic barriers -- systematic oppression even -- as being counter to freedom. This carer wrote to me the day after our recorded conversation, to add further reflections on her experience. She wrote:

> When Dad was discharged from hospital he was brought home with one large pack of incontinence pads but no further information on how more might be obtained. When none were forthcoming I then personally had to chase the GP who sent the district nurse out with some emergency supplies before we were eventually able to organise a regular supply. So no joined up thinking really between the hospital discharge system and the supposed personal care he was meant to receive once home, or how to go about getting it if like us it did not happen automatically as with us and with no information given as to how to go about obtaining it, albeit the hospital had had arranged for care staff visits to be in place on day of discharge. I then had to fight for further services such as physio etc. which they did not seem keen to offer initially - I think my Dad had effectively been "written off" by them all at this point. I was stressed beyond belief but what about all those other poor souls who did not have someone like me to advocate on their behalf?
>
> Next, and this is also relevant to knowing what your human rights are and what you should be entitled to receive, when the social services person came out to the house to see us after Dad got

> home, she asked me “what I needed?” How on earth was I expected to know “what I needed” since I had never been in this position before and did not know what to expect from anyone or any service which might be available. I feel therefore that everyone should automatically be given/offered what they are entitled to as regards practical support and services...I was very frustrated and eventually angry by all of this at the time, but I was so overwhelmed my caring role that I did not have the energy or bandwidth in my brain to deal with any extra hassle beyond that which I was at that point already experiencing and having to deal with. My experience was that only the basic minimum of support in any shape or form was offered by social services when Dad came home as the council seemed to not want to spend any cash if it could avoid doing so and which is why they asked what I needed instead of knowing what I/we would need and what I/we were entitled to receive and then automatically offering that.
>
> … Sadly my experience has led me to basically trust no-one in either the medical profession or hospital settings or indeed social services and that you really do need to get involved and/or do it yourself if you want it done properly. You can rely on no-one but yourself and since I have much more experience…in the ways of and in my dealings with those in the medical and hospital professions and in social services, I have found that it is pretty much always a struggle to get anywhere with any of them since they prefer dealing with those who are docile and unknowledgeable in these matters and who don’t ask for anything other than what they are begrudgingly given.
>
> The support of the various Carers groups and… the dementia charities etc., in one way or another are however invaluable.

The carer above talked about human rights, which in the UK are laid out in the Human Rights Act 1998 and the Equality Act 2010. A booklet produced for carers by the British Institute for Human Rights (BIHR) gives examples of possible violations of Article 8 of the Act, several of which apply in the case both of the examples I have included here from the carers I quoted above.

The BIHR (2012) notes that :

> If your local authority does not provide you with the proper support – for example, with adequate respite care and an appropriate carer’s assessment when you need it – this may seriously impact on your private and family life and could constitute a violation of your Article 8 rights.
>
> Examples include :
>
> - Poor health, as a result of not being able to access medical treatment or not being able to recover fully from medical treatment because of your caring responsibilities. You might also develop health issues as a result of the physical and mental consequences of caring.
>
> - Loneliness and isolation, because caring means you may have few opportunities to participate in social life.
>
> - Loss of privacy and family life, for example if a loved one or family member is moved into residential care against your wishes or theirs, or moved into a home far from where you live.
>
> Remember, it is important to keep social services (or any other public authority) informed about any difficulties you face in your caring role, as they have responsibilities under the Human Rights Act to protect rights.

Paradox of increased freedom in lockdown

The second tentative theme is one I have called ‘the paradox of increased freedom in lockdown.’

This unpaid carer said :

> Lockdown freed me in many ways as a carer…I used to have to use all kinds of devious means to make sure if my husband went to the pub that I was there to pick him up. I used to say to him, ‘I am

> always out at 3 so I can easily get you.' But I was always doing something at 3 that I had to interrupt. Or I had to talk with his friends about getting him home safely after the football.
>
> All that deviousness and difficulty stopped. And I said 'we're not allowed to go out!' [And] everybody was in the same boat. He didn't have to want to go to the pub because the pubs were shut. He didn't have to want to go to the football because there was no football.
>
> We did a lot of stuff with the family. We made loads of videos and cartoons and songs and everything for the grandchildren. I love doing creative things. We were able to develop all kinds of things to do together at home. Things that didn't cause me stress, and all that other stuff, I could just put that away, you know? So it was kind of upside-down for me, you know? The lockdown freed me from stress and freedom from lying awake all night thinking how I was going to keep him in the house/ safe.'

During the interview, she remembered a verse from a poem she had learned at school, and recited the following lines of it :

> Stone Walls do not a Prison make,
> Nor Iron bars a Cage;
> Minds innocent and quiet take
> That for an Hermitage.
> If I have freedom in my Love,
> And in my soul am free,
> Angels alone that soar above,
> Enjoy such Liberty.
> *(From 'To Althea, from Prison' by Richard Lovelace)*

She connected the poem with her feeling that freedom is not only an absence of constraint, but is also an attitude, a way of experiencing the world that considers freedom to be an internal response – a mind at peace -- regardless of those circumstances. This is also an orientation that is part of the teaching of mindfulness, and this participant had taken a mindfulness course at the start of lockdown, through a carer support organisation, and had continued to practice, having found it very helpful in reducing her distress.

Freedom as spiritual orientation/acceptance of suffering

This connects to the third theme from the interviews, which I have tentatively called 'freedom as spiritual orientation/acceptance of suffering,' and this emerged in one of the interviews with a paid carer. It will be apparent from the quotation that this paid carer practices Buddhism. She also wrote to me after our conversation, with further reflections. She wrote :

> One question I have been thinking about is how I manage to resist feeling my client's frustration, irritation and anger when he gets dressed.
>
> I think the answer is that I accept his suffering. I think when I was younger, I found it harder, if not impossible, to accept my clients' suffering. I would see it as something bad which needed eradicated. This would cause me to resist their suffering; rather than accepting that it might not be possible to fully eradicate or relieve their suffering, I would rail against it. This made my work with them unsustainable; I couldn't keep it up. It was too draining and discombobulating.
>
> Now I am older and I have been fortunate enough to do a lot of inner work - spiritual, therapeutic, self-development, whatever you want to call it - I am able to accept my client's suffering. I don't need to resist it.
>
> … I think this is why and how I am able to resist entering into his suffering with him…[N]ow that I have learned the skill of accepting suffering, I have greater freedom: I can choose to manage my emotions and energy in ways that serve me and my clients.
>
> If anyone wanted to go further and ask how I manage to accept clients' suffering, I would say it's because I feel much safer myself, I have increased understanding of systems (e.g. the healthcare

> system), I have a stronger sense of what is mine to influence and what is not mine to influence, and philosophically or spiritually I find a lot of relief in the idea that humans exist in samsara.
>
> Suffering is part of samsara. When I see things in this way, I am able to accept suffering. It's like when you walk, you don't say "Oh! why? Oh! why must I MOVE in order to WALK?" I am fed up of having to move when I walk!!! Why can't I walk without moving?!". It is absurd, and once you realise this, you accept the movement inherent in walking. I accept the suffering inherent in samsara. Of course, alongside this is the notion that beings can create nirvana in every moment through acts of love, compassion, wisdom, care etc. Care work probably gives me good opportunity to practice experiencing nirvana within samsara.

Liberation

Even at this early stage of my research, there are major themes emerging that relate to personal meanings of freedom, and there is much still to be heard and explored.

To me, themes in my data so far are relating to liberation theology, whose praxis operates at least three levels (Singer, 2018) :

1. Overcoming poverty (liberation from oppressive systems);
2. Hope in 'liberation from fatalism' (free will); and
3. Liberation from sin/communion with God.

In my interviews with carers, the initial themes I discussed above seem to me to connect with levels 1 and 2 :

1. In dementia/care, there is a pervasive presence of systemic barriers. Sporadic liberation from isolation comes only when there are systemic solutions and support available to help with caring.
2. There is also hope in liberation, conceptualised as 'freedom to choose,' which, in the two carer quotes I shared above, are illustrated by the ideas of practicing 'nirvana in samsara' and in the principle of 'Stone walls do not a prison make.' This idea was present for one unpaid carer who practices mindfulness; and one paid carer who practices Buddhism.

Hope, and freedom from systemic barriers and oppression through compassionate community action, are needed to relieve suffering and isolation in caring in dementia. One of many places in the Bible where the mission of liberation is recounted is in the Gospel according to Luke, chapter 4, verses 16-19 :

> **16** "And he came to Nazareth, where he had been brought up.
> And as was his custom, he went to the synagogue on the Sabbath day, and he stood up to read.
> **17** And the scroll of the prophet Isaiah was given to him.
> He unrolled the scroll and found the place where it was written,
> **18** "The Spirit of the Lord is upon me,
> because he has anointed me
> to proclaim good news to the poor.
> He has sent me to proclaim liberty to the captives
> and recovering of sight to the blind,
> to set at liberty those who are oppressed,
> **19** to proclaim the year of the Lord's favour."