

Supporting social connection for people living with dementia: lessons from the findings of the TRIO study

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Abstract

Purpose – *The purpose of this paper is to share the learning concerning how services and the paid carers working in them can support people living with dementia (PLWD) and their unpaid carers to overcome social isolation. This learning comes from the key findings from a Social Return on Investment (SROI) evaluation of a Shared Lives (SL) Day support service, known as TRIO.*

Design/methodology/approach – *SROI is a form of cost-benefit analysis that captures and monetises stakeholder outcomes. The SROI evaluation included a rapid evidence review, an interview study and a questionnaire study. The learning shared is drawn from the interview and questionnaire data that explored the reported outcomes relating to social connection, which included data related to participating in meaningful activities, confidence and independence.*

Findings – *PLWD who accessed the SL Day support service experienced better social connection, a sense of control over their activities (including their social activities) and community presence. A key foundation of these outcomes was the meaningful relationship that developed between the PLWD, their unpaid carer and the paid carer.*

Research limitations/implications – *This evaluation was a pilot study with a small, albeit representative sample size.*

Practical implications – *The learning suggests feasible and effective ways for paid carers to support the social connection of PLWD and their unpaid carers with their wider community.*

Originality/value – *There has been little exploration of how community-based short breaks (like SL Day support) can enhance social connection. The authors drew on a social relational model lens to illustrate how this service type had supported successful outcomes of community and social inclusion for PLWD.*

Keywords *Dementia, Respite, Short break, Integration, Person-centred, Shared lives, SROI*

Paper type *Research paper*

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Introduction

In the UK 1.6 million people are expected to be living with dementia by 2040 (Wittenberg *et al.*, 2019). To live well with dementia, social relationships are important. These connections help people living with dementia (PLWD) maintain a sense of autonomy and identity (Tochel *et al.*, 2019), and social interactions and activities can enhance the quality of life and reduce cognitive decline (Birt *et al.*, 2020).

Social isolation often accompanies a dementia diagnosis (Burgener *et al.*, 2015; Biggs *et al.*, 2019). PLWD may lose their confidence to participate in social activities because they fear doing something wrong (Rochira, 2018), feel embarrassed about their dementia symptoms (Shannon *et al.*, 2019) or are concerned about encountering stigma (O'Connor *et al.*, 2018; Birt *et al.*, 2020). For instance, Fletcher (2021) highlights that PLWD are frequently medicalised. Alongside the language and labels often used (Swaffer, 2014), this

can contribute to PLWD feeling stigmatised. Unfortunately, stigma about dementia remains prevalent as the wider public often lacks knowledge and understanding about dementia (Carers Trust, 2020; Herrmann *et al.*, 2018).

The symptoms of dementia can also create barriers to community participation. For instance, some PLWD finds functioning in social situations “exhausting” (Bartlett, 2014). Similarly, dementia symptoms (and others’ actions) may constrain the ability of PLWD to be agentic within social situations, i.e. to take control and make their own decisions (Featherstonhaugh *et al.*, 2013). When PLWD are excluded from social activities and everyday decision-making, their social citizenship is affected (Brannelly, 2011).

Unpaid carers supporting PLWD can also experience social isolation (Lee *et al.*, 2022). Some unpaid carers reduce their social activities because they are concerned about how the PLWD will be perceived in public situations (Werner *et al.*, 2012). Friends and other family members may also withdraw due to a lack of knowledge and stigma (Macdonald *et al.*, 2020).

The social isolation of PLWD and their unpaid carers can be conceptualised through the social-relational model. This model emphasises how both health conditions and the social response to these conditions can be disabling (Thomas, 2004; Shakespeare *et al.*, 2019). This model refers to the following:

- impairment effects: impacts of dementia;
- barriers to doing: environmental and social barriers; and
- barriers to being: stigmatising words or actions that impact on confidence and self-esteem (Cologon, 2016).

An implication of the social-relational model is that interventions that help mitigate the impacts of dementia and address barriers to both doing and being might reduce the social isolation of PLWD and their unpaid carers.

Short breaks are a common form of intervention for PLWD and their unpaid carers. A short break is any form of service or assistance that enables unpaid carers to have sufficient, regular periods away from their caring responsibilities (Shared Care Scotland, 2017). Traditional day and residential forms of short breaks may not support the varied needs and preferences of PLWD and their unpaid carers (Rochira, 2018; [author]), and it is possible that community-based short break options may better promote the social connection of PLWD and their unpaid carers.

TRIO Shared Lives (SL) day support is one type of community-based short break for PLWD and their unpaid carers. It operates in a semi-rural area of Wales and supports people living with mild-to-moderate dementia (called citizens by the service). In this short break, an SL carer (called a companion in the service) is matched with and supports a small number of citizens within their community. The companion uses their house as a resource and provides tailored and flexible support based on citizen’s mutual interests (Callaghan *et al.*, 2017). There is evidence that SL can help reduce social isolation, increase independence and improve well-being for older people (Brookes & Callaghan, 2013; Brookes *et al.*, 2016), but there is a paucity of research exploring this model for PLWD.

Study data collection and analysis

The learning shared in this paper is derived from a Social Return on Investment (SROI) evaluation of TRIO conducted between 2020 and 2022. SROI is a form of economic analysis that explores the costs and wider social benefits of interventions (Nicholls *et al.*, 2012). By comparing the costs of delivering an intervention with the social value generated, the method assesses whether an intervention represents good value for money. The evaluation

received ethical approval [Funding statement], and all participants provided informed consent.

Following the guidance on developing and evaluating complex interventions (MRC, 2000) and best practices in SROI development, the first phase of the SROI evaluation developed a logic model for TRIO describing its mechanisms and outcomes. This logic model was informed by a rapid evidence review of the SL literature and stakeholder interviews. Interviews were completed with one PLWD, six unpaid carers, five companions and one dementia support worker. Biographical narrative interviews were conducted with the unpaid carers and citizen (Wengraf, 2004, 2008), and semi-structured interviews were conducted with companions and the dementia support worker. Due to the Health Protection (Coronavirus Restrictions) (Wales) Regulations (Welsh Government, 2020), interviews were completed over the phone or online. Interviews were transcribed and analysed using framework analysis (Ritchie and Spencer, 1994). Framework analysis involves data familiarisation, identification of a thematic framework (we used our draft logic model for TRIO based on the rapid evidence review of the SL literature as the framework), indexing relevant text, charting indexed text and mapping and interpreting the data.

Based on the logic model and consultation with Project Advisory Group (PAG) members (who included a companion, an unpaid carer and a person living with memory problems), questionnaires were designed to quantify how much the logic model outcomes had been experienced by people currently engaging in TRIO. The citizen questionnaire included questions to quantify social connection and community presence, confidence, reduced social isolation and independence since being involved with TRIO. Each question used a Likert scale scored between one (strongly disagree) to five (strongly agree). Participant’s demographic information can be found in Table 1. Findings were sense checked with the PAG and through an online Knowledge Exchange event with short break stakeholders.

Findings

All the interviews conducted included content relating to enhanced social connection. The questionnaire responses from citizens indicated that TRIO had enabled them to experience greater social connection, participation in meaningful activities, improved confidence and independence (Table 2).

We detail below how TRIO provided support to enhance the social inclusion of PLWD and their unpaid carers. By providing person-centred support and relational care, TRIO was able to support the social connections of PLWD and unpaid carers. This foundation included a meaningful relationship that developed between citizens, unpaid carers and companions. This provided a launch pad for citizens to have social opportunities with their peers and maintain their community presence. It was also the basis on which unpaid carers could have a regular break from their caring role to attend to their own social needs. Using

Table 1 Demographic characteristics of participants

| <i>Interview study</i> | <i>Citizen</i> | <i>Unpaid carers</i> | <i>Companions</i> | <i>Dementia support worker</i> |
|----------------------------|---------------------------------|----------------------|-------------------|--------------------------------|
| <i>N (N female)</i> | 1 (1) | 6 (6) | 5 (5) | 1 (1) |
| % White | 100% | 100% | 100% | 100% |
| <i>Questionnaire study</i> | Citizens | | | |
| <i>N (N female)</i> | 7 (5) | | | |
| Mean age (range) | 86 (71–100) | | | |
| % White | 86% | | | |
| % English first language | 100% | | | |
| Duration of time with TRIO | Less than 6 months–over 6 years | | | |

Table 2 Citizen's questionnaire responses

| <i>Outcome quantified</i> | <i>To what extent do you agree or disagree with the following statements. Since TRIO</i> | <i>Total of ratings</i> | <i>Maximum rating possible</i> |
|---------------------------|--|-------------------------|--------------------------------|
| Meaningful activities | I am more able to do activities that are important to me | 32 | 35 |
| | I have become involved in activities | 30 | 30 |
| | Total | 62 | 65 |
| Confidence | I have more confidence in my ability to do things | 31 | 35 |
| | I have more confidence when meeting other people | 29 | 35 |
| | Total | 60 | 70 |
| Independence | I have more choice and control of my day | 32 | 35 |
| | I can make my own decisions as much as I want | 34 | 35 |
| | Total | 66 | 70 |
| Social connection | I have more opportunities to meet other people | 35 | 35 |
| | I feel more comfortable socialising | 30 | 35 |
| | I am more able to visit places that I want to | 34 | 35 |
| | I have been more involved in my community | 34 | 35 |
| | Total | 133 | 140 |

the social-relational model (Thomas, 2004) as a framework, we detail below how TRIO built on this foundation to provide support to enhance the social connection of PLWD and their unpaid carers.

Mitigating “impairment effects”

TRIO mitigated the impact of dementia symptoms by providing individualised and practical support.

Individualised support

Companions had leeway to address whatever aspects of dementia were causing a barrier to social activity and connection. Companions spoke of understanding that dementia could manifest in distinct ways:

They all have dementia, Alzheimer's, but they are all very unique in different ways. So, it kind of affects their mental and physical health in different ways (Companion 5).

For example, an unpaid carer identified that the companion supported their relative in social situations by helping them access quieter environments:

She didn't like going out to see other people. Social interaction has increased by 100% [...] [companion] has really helped [name] with confidence now and if somewhere is too busy, they won't go in, they'll find somewhere quieter (Unpaid carer 6).

The dementia support worker suggested that this individualised focus on overcoming the symptom challenges specific to the individual was distinct from other short break options:

It seems it's a tailor-made service for the clients and for the carers, and that's a big thing, rather than the person going to the day centre where they feel they've got to fit in the activities and the people there (Dementia Support Worker).

Practical support

Companions provided practical support as well as encouragement. Not all unpaid carers could accompany their relative out of the house, especially if their relative experienced additional health problems:

Tried once to take him to [place] on the bus, because we haven't got a car, and, oh, it was an absolute nightmare. I swore I'd never, ever do it again. He was just very unsteady on his feet, and I just kept thinking he was going to topple over. He kept leaning forward when he was walking. And my daughter said, 'No, mum, you don't do that again. You can't take him.' So really, I rely on them to take him out (Unpaid Carer 7).

This practical support was provided in such a way as to maximise the citizen's independence and sense of accomplishment:

So, it's just empowering her and making her feel good, how well she's done around the shop. Even though you've hung onto your trolley, and you've managed to get a few items off the shelf and that, it's just basically empowering them with all the strength that they have, really. [...] You're not there to care for them and they don't want to be cared for, either. It's about maintaining their independence and giving them autonomy in that because it's person-centred (Companion 3).

As one unpaid carer reported, companions were able to assist in navigating these barriers "seamlessly":

He was embarrassed about it (dementia) and even going out with TRIO even in a venue, he could no longer safely find his way to a toilet on his own and the carers made all of that very normal – er to take a bloke into a toilet and they never made a fuss, never made a big thing he never came home embarrassed about anything they were just they did it seamlessly (Unpaid carer 2).

Overcoming "barriers to doing"

The way TRIO provided the day support helped citizens and unpaid carers overcome barriers to being more socially connected.

Opportunities to socialise with peers

Companions supported up to three citizens in a session. These citizens shared interests and dispositions and were experiencing similar situations. Forming friendships with peers reportedly enhanced citizen's social confidence, and they were more willing to take part in social activities that could further expand their social connections:

Because they have dementia sometimes, they're aware of it and they'd rather say nothing than something at all, because they're scared, they might say the wrong thing, erm, but if there's a friend with them reassuring them, encouraging them to talk to the next person (Companion 2).

Providing choice and control

Another aspect of building social connection was supporting the citizen in exercising choice and control over their activities. With the support of their companions, citizens participated in community activities that were meaningful to them. These provided continuity with their life pre-dementia or valuable new experiences:

There would always be a choice about what do you fancy seeing, will we get some sweets, we'll go for a pub meal afterwards, and that was lovely because yet again that was normal, absolutely, normal (Unpaid carer 2).

It was also important that citizens could choose to leave a social situation at any time with their companion if they no longer felt comfortable:

You're giving them the confidence that if you need to escape, specifically people with dementia who have anxiety, knowing that if they want to escape – if they want to go home, they can go home, it's not a problem (Companion 4).

A companion recounted how one citizen had gradually gained confidence in social situations once she knew she had “escape” plan:

She was trying to think of an escape plan to not go as it would be a bigger circle of people and she would feel uncomfortable, and gradually, it disappeared, she would go to every party, she would get up and dance (Companion 4).

Providing unpaid carers with a break from their caring role

Companions provided unpaid carers with a break each week from their caring role. This enabled unpaid carers to take part in community activities themselves and to develop and maintain their own connections:

In those precious few respite hours, it could be something as simple as going to the supermarket or not keep on thinking what time is it, what time is it – or being able to meet someone for a coffee and just being able to “ah God [. . .] yeah great and relax” (Unpaid carer 2).

Unpaid carers referred to the trust that had developed between themselves, the companion and their relative over time which contributed to knowing that their relative was safe and happy. This enabled unpaid carers to experience time away from caring without experiencing guilt or anxiety:

I think, in the beginning, in the very, very beginning, the fear is that-. It's the unknown because you don't know what happens. That trust only comes with getting to know them. I know that when she's out with (name) she's safe, so it means that I can do something that I need to do for myself (Unpaid carer 4).

Addressing “barriers to being”

Fundamental in TRIO was the meaningful relationship that developed between citizens, unpaid carers and companions and through maintaining the community presence of citizens, companions recognised that they were helping to challenge the stigma about dementia.

Offering a meaningful relationship

In TRIO, PLWD were addressed as “citizens”, and SL carers were known as “companions” rather than “carers.” This was an important foundation for the relationship that developed:

They're not being medicalised all the time. You wouldn't want somebody taking them out and them saying, “Oh, there, there, you have to excuse her, she's got dementia.” Well, I wouldn't want that. That's not what-. I want her to feel-. Well, if there is any such a thing as normal, but I want her to feel as normal as she can and not be an outsider (Unpaid carer 4).

Unpaid carers valued how companions developed and maintained a relationship based on the person, not the diagnosis:

Mum was very in denial at first about her diagnosis. It was never questioned, it was never made a point of, well I'm here because you've got this condition, this is an illness that you've got, this is why I'm here so – it um, I think that's what worked, and I think that's why TRIO works in that respect (Unpaid carer 1).

Both unpaid carer interviews and the citizen interview described companions as being like extended family or a friend rather than a “paid carer”:

They had become part of the family, like an extended family and they knew the trials and tribulations and [. . .] you know, the good bits, the bad bits, the traumatic bits (Unpaid carer 2).

Well, she's more of a friend, we speak like friends so [. . .] it's really uplifting (Citizen).

The relationship that developed involved the citizen, unpaid carer and companion (as reported in [Author]). As companions built a personal relationship with the citizen (and unpaid carer), the citizen started to feel safe in the companion's company. This then formed a safe "base" from which to develop other social relationships.

Challenging stigma

Companions suggested that accompanying citizens to activities and amenities in the locality helped inform other community members and mitigate misunderstanding. They described having opportunities to "advocate" for citizens and for PLWD more broadly:

One of the ladies who I take out shopping, she bumped into people with a trolley, and she doesn't say sorry because she doesn't know that she's done wrong. [...] I'll apologise on their behalf, and I'll just say, "Oh, I'm really sorry. She doesn't mean it." They tend to get the gist from that, really. But I think it's a shame because had I not been there to support her it could become very, very difficult [...] I feel like I'm advocating on their behalf when I'm out with them (Companion 3).

Companions recognised that over time "welcoming spaces" in the community had been created. These were shops and cafes where staff recognised the companion and citizen because of their frequent visits. Companions reported that this may have contributed to better inclusivity for PLWD and enhanced staff understanding about dementia:

The staff there are really good, and they really understand the clientele, and they don't rush them when they try and pay and find the coins and stuff [café] they always facilitated us, they always put the tables together nothing was too much trouble and the staff got to know the citizens who we were supporting and they'd have a little chat with them and it would be so lovely (Companion 2).

Discussion

The illness-related and attitudinal barriers that PLWD and their unpaid carers face when seeking social connection within their local communities are well documented (Biggs *et al.*, 2019; Lee *et al.*, 2022). Short breaks that understand and address these barriers have the potential to reduce social isolation and challenge stigma.

The findings presented illustrate how TRIO, a community-based day service supported PLWD and their unpaid carers to enhance their social connection. By using the lens of the social-relational model (Thomas, 2004; Cologon, 2016), we identified how TRIO had addressed "barriers to being" such as stigmatising actions impacting on confidence and identity, supported PLWD to overcome socially imposed barriers such as limited community access "barriers to doing", and provided practical support where there were "impairment effects" of dementia, such as mobility problems and cognitive decline. A person-centred approach facilitated a meaningful relationship that developed between citizens, unpaid carers and companions, and this formed the foundation for enhancing social connection and community presence.

The approach we have evidenced in TRIO reflects many recommendations for supporting PLWD found in the literature. Seeing the PLWD as a social actor is central to person-centred support (Fazio *et al.*, 2018). The process of paid carers getting to know the PLWD (and their biography) underpins support that enables PLWD to exercise choice (Brannelly, 2011). Maintaining community presence and social activities sustains a sense of identity and contribute to living well following a dementia diagnosis (Daley *et al.*, 2013). Opportunities for PLWD to remain active in their community and interact with others, may maintain their social self and reinforce their agency. Furthermore, taking part in regular community activities highlights normalcy rather than exceptionalism and supports the integration of PLWD (Robertson *et al.*, 2020). Unpaid carers can support their own social

needs when they experience a break from caring, especially if they believe their loved one is with a trusted care worker (Van Aerschot, 2022).

Below we summarise the learning from the findings. These recommendations can help paid carers support the social connection of PLWD and their unpaid carers:

- Paid carers need to take time to get to know PLWD and their unpaid carer/s, and consistency of contact is advantageous (TRIO met weekly). The focus needs to be on understanding the PLWD and the unpaid carers, their interests and dispositions. From this basis, an understanding will be gained about the precise types of support needed.
- PLWD needs sensitive, tailored support to overcome the challenges that dementia symptoms create in social situations. Assistance needed may include encouragement, social support and, importantly, practical help to access social activities.
- Opportunities for peer support can be meaningful as PLWD can learn from others facing similar experiences. However, it is most valuable if people also share similar interests and enjoy the same types of things. This makes it more likely that friendships will develop.
- It is important that paid carers support PLWD to access their local community. This can be through practical assistance, social support and encouragement. There is also a place for advocating for the inclusion of PLWD in community activities.
- Paid carers should consider how they can provide unpaid carers with a break from their caring role so that they can address their own social needs. Unpaid carers need peace of mind to experience the most benefit from this break, and practitioners need to build a relationship of trust with unpaid carers to enable this.
- Paid carers have a key role in challenging the stigma about dementia. This can start by using language that does not differentiate PLWD as “others” and extends to sharing knowledge about dementia. Paid carers also challenge stigma when they empower PLWD to contribute to the local community and so foster better understanding and more dementia-inclusive communities.

Strengths and limitations

Our findings provide insight into how a community-based short break service enabled PLWD and their unpaid carers to maintain social connection and community presence. We drew on a social relational model as a lens to illuminate how TRIO provided multi-faceted personal and practical support that addressed the challenges that PLWD and their unpaid carers face. The lessons described come from findings from an SROI evaluation of TRIO. A key strength of this approach is the use of qualitative and quantitative methods to identify and measure outcomes important to a range of stakeholders involved with the service.

There are some limitations in the data on which this analysis was based. The sample of interview and questionnaire respondents was small, and we particularly note that only one citizen took part in an interview. In addition, the samples were relatively homogenous and consisted mainly of white female respondents. This means that there might be other people who need different types of support to overcome social isolation, particularly as PLWD have intersecting identities, for example, Lesbian, gay, bisexual and trans plus additional gender and sexual identities (LGBT)+ (Smith *et al.*, 2022), ethnicity (Duran-Kiraç *et al.*, 2022) and class (Rees Jones, 2017). Future research might focus on these diverse identities to understand how social isolation might be differently experienced and the support offered.

Conclusion

This study provides valuable insights from a short break SL service for PLWD and their unpaid carers. It suggests that this service supports PLWD and unpaid carers to continue to maintain social interaction by acknowledging and addressing the barriers identified in the social-relational model.

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