



**Strathcarron Hospice's Living Right Up To The End:
The impact and experience of compassionate neighbours on social
networks**

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Executive Non-Technical Summary

Background and rationale

- Compassionate neighbours and people with long term conditions are matched by Strathcarron hospice.
- This report summarises an evaluation of the service, from the perspective of the compassionate neighbour, the person with the long term condition and informal carer.

Methods

- Two focus groups (with a total of 14 compassionate neighbours) and interviews with five people with long term conditions and two informal carers, were conducted between January and June 2020.

Findings

- Compassionate neighbours had a positive impact on increasing social contact and reducing loneliness.
- While compassionate neighbours tended to have busy and varied social lives, the support networks of people with long term conditions seemed to consist of mostly family, very close friends and health professionals.
- The range and type of contact between compassionate neighbour and person with long term condition appeared to be tailored to shared interests; the matching process works well.
- New connections beyond the one-to-one relationship had not developed, so more extended and dense social networks had not materialised.

Conclusion

- Despite the small sample size, the data clearly demonstrate that the programme is enjoyed by both compassionate neighbours and people with long term conditions.
- 'Living Right to the End' successfully meets the needs of community members who are lonely.
- Increasing the reach and impact of compassionate neighbours could be enhanced by encouraging the development of wider and denser networks, beyond the one-to-one relationship.

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1. Introduction

In 2018 Strathcarron hospice was awarded a grant to enhance the skills of community volunteers (Compassionate Neighbours) to support people living with long term conditions (LTC) and their carers in Falkirk West and Falkirk Central *live right up to the end*.

The grant supports a range of activities in developing the role of community volunteers with the end point being to:

- Signpost people with LTC to community resources.
- Provide social, emotional and practical support to people with a LTC, and their informal carer(s).
- Facilitate open conversations about planning for the later stages of their life, including anticipatory care planning.
- Build the confidence of people with LTCs and their informal carers to connect with and participate in community activities in a meaningful way.

The aim of *Living Right* is to engage compassionate neighbours to address recognised areas of need, specifically around providing support, including reducing loneliness, to people with LTCs.

This report summarises an evaluation of that goal.

2. Background: Volunteering and compassionate neighbours

Volunteering in palliative care has a growing evidence base. An initial focus of this evidence was on describing volunteering,^{1,2} where the role was defined as providing psychosocial, spiritual and instrumental support to patients, supplementing formal and informal carers.¹

Volunteers have a key role in supporting people with life-limiting and long term conditions (LTCs) redressing experiences of loneliness, and has been used to good effect in a range of health conditions.³⁻⁵ The organic development of new relationships with non-healthcare professionals is compromised by the disabling socio-material world. Consequently, people with LTCs, and their informal carers, are likely to have reduced social networks with few opportunities for expanding their interpersonal relationships.⁶

Loneliness exacerbates carers' physical and mental health,⁷ and predicts low quality of life.⁸ Loneliness is more pronounced in rural areas,⁹ and carers of people with life-limiting conditions are recognised to be at particular risk,¹⁰ and those with greater caregiver burden experience more loneliness.¹¹

Volunteers can play an important role in combating loneliness, and make a significant contribution to UK hospices, enabling the delivery and quality of a range of services. Hospices value volunteers for their support in the provision of a de-medicalised, holistic approach to care.^{12,13} This holistic approach includes the concept of 'being there', which is understood as a more relational, responsive and flexible approach to care than that provided by more 'task-oriented' approaches to clinical care.¹⁴ This is valued by recipients of befriending volunteers in palliative care who appreciate that someone 'cares about them' in a way that is manifested through meaningful social interactions, reciprocity and practical advice, and that is not necessarily linked to the performance of particular tasks.¹⁵ Volunteers themselves report the many benefits that volunteering brings them, including the extra meaning it gives to their lives, and the opportunities it provides for personal development.¹⁶

Outcome studies have reported varied impacts from volunteers. Systematic reviews identify the benefits of volunteers for carers and patients, including greater care satisfaction and increased longevity.^{17,18} Other studies have demonstrated positive impacts on the need for undertaking goal-based activities, and emotional/relational engagement.¹⁹ Assessment of volunteer engagement on health related quality of life demonstrates some positive trends despite not reaching a level of statistical significance.²⁰ At present, studies on volunteering have tended to lack critical appraisal, including examining possible adverse effects.¹⁷

Compassionate neighbours is a sub-set of compassionate communities and health promoting palliative care,^{21,22} which seeks to increase dying at home by mobilising the support from community groups and social networks.²³ This is part of a wider agenda to normalise death and dying, and to redress the current medicalisation of severe illness, placing informal networks centrally and the professional networks in a more peripheral position. Community development groups have called for a greater role for communities in playing active roles in the lives of people with advanced illness.²⁴

Compassionate neighbours often includes befriending and addresses loneliness in people with life-limiting or chronic conditions. Indeed, compassionate communities is founded upon the idea that people should be perceived holistically, which includes relationally,²³ in the context of their families, friends, neighbourhoods and volunteers.

Sufficient evidence has been produced to allow a meta-ethnography to be conducted, which concluded that community engagement in end of life care was established, including influencing place of death and reducing carer fatigue and isolation.²⁵

3. Methodology

3.1 Design

This evaluation employed a qualitative interview methodology, alongside social network analysis to report the impact of the 'Living Right' compassionate neighbours project.

Social network analysis (SNA) is a methodology which foregrounds the exploration of relationships and networks, to enhance understandings of communities.²⁶

3.2 Evaluation questions

1. What impact do the compassionate neighbours have on people with long term conditions and their carer's relationships and social networks?
2. Do compassionate neighbours provide social, emotional and practical support to people with a LTC, and their informal carer?
3. Do patterns and opportunities for support change after introducing a compassionate neighbour?
4. What do compassionate neighbours contribute to the person with the LTC's social circle?
5. What are the views and experiences of compassionate neighbours on providing the service?

3.3 Sample and recruitment

The sample sought to include (i) people with LTCs, (ii) compassionate neighbours and (iii) informal carers. The sample did not seek to be representative, but to be strategic and theoretical in examining issues and concerns raised in prior rounds of data collection. Inclusion criteria were focused on:

1. People with a LTC, an informal carer or a compassionate neighbour engaged in one-to-one compassionate neighbour pairing.
2. Informal carer was defined widely and pragmatically – allowing people to identify themselves as someone who shares closely in the illness experience; they did not have to be kin.
3. Informal carers could participate three months post bereavement if the person they cared for had died.
4. The compassionate neighbour relationship must have endured beyond six contacts.
5. Participants must have capacity to consent to the study; people living with dementia were not excluded if they were judged to have capacity to consent to the study.
6. The focus group sample comprised people who have varied experiences – including those who have had several different experiences of being a compassionate neighbour.

Strathcarron approached 29 people, of whom six agreed to be approached by the research team. Five people with long term conditions consented to participate.

The study information sheet was provided to people with long term conditions/carers at a routine check-in meeting with them, occurring after six contacts with the compassionate neighbour. Focus groups were advertised to all compassionate neighbours with two dates offered. Compassionate neighbours could attend the focus group on whichever date suited them. Forty-nine compassionate neighbours were informed of the focus groups; 15 agreed to participate, of whom 14 attended.

Recruitment commenced in December 2019 and moved slowly. Initial rounds of recruitment identified fewer eligible participants than expected, including several people with substantial cognitive

impairment. Recruitment continued through the first half of 2020. However, with the study occurring during the initial wave of COVID-19 and related restrictions, data collection was curtailed, and the sample was smaller than originally intended.

3.4 Data collection methods

3.4.1 People with LTC and informal carers

Interviews with people with LTC and informal carers were conducted by a female researcher with a PhD in social network analysis. They were invited to participate in two interviews, though consenting to the first did not compel them to undertake both interviews.

- Interview one explored the person's experience of the compassionate neighbour relationship. Questions focused on the matching process, what activities they undertook together, feedback on the relationship, the benefits and limitations of the relationships, suggestions about adaptations to strengthen the compassionate neighbour project.
- Interview two focused on the person's social network, to understand what individuals and organisations provided them with different types of support (e.g., emotional, informational) and whether those individuals or organisations were connected. A target was used to create a visual representation of a person's support network, whereby the participant's name was placed in the centre of the target and they were asked to place those who supported them on the target depending on how close they felt to these supporting actors (i.e., those who were very close were placed closer to the centre of the target). The interview was then used to tease out the interconnections and qualitative nature of the tie.

A pilot interview was conducted to ensure that this social network analysis data collection method would capture the information needed to answer the research questions. The pilot process confirmed the appropriateness of the questions, and no modifications were required.

3.4.2 Compassionate neighbours

Two focus groups were conducted at the hospice with the compassionate neighbours, by female researchers with PhDs in qualitative methods. Compassionate neighbours could choose which of the focus groups to attend. Questions sought to elicit feedback on their role as compassionate neighbours, what worked well or less well, the impact on them, and any reflections on adaptations to the programme.

3.4.3 Data processing

All interviews and focus groups were audio-recorded and then transcribed. Transcripts were not returned to participants for checking. None of the interviewers had any prior relationship with the interviewees.

3.5 Analysis

Inductive thematic analysis proceeded through a five-stage process of thematic analysis. Step one involved familiarisation with the data set. Step two involved identifying a thematic framework. Step three involved indexing the data with reference to the thematic framework. In Step four, responses were synthesised from across respondents into refined themes. Step five focused on data interpretation and finalisation of key themes. Qualitative data were coded and analysed in the software package NVivo V.12 by two researchers with extensive post-doctoral research expertise in qualitative methods.

Social network analysis examines the structure and composition of people's social networks.²⁶ Each social network commences with the person living with LTC, and then maps out the people who support them and the connections (ties) between each person in the network. This data is visualised (in a diagram called a sociogram), where the immediate people supporting the person living with LTC and how they are connected can be viewed as a network with a range of characteristics. Visualisations of these sociograms represent understandings of how integrated compassionate neighbours are in the social networks of respondents.

3.6 Ethics and governance

University of Stirling ethics approval was gained on 24/11/2019, reference: GUEP739.

Project steering meetings in 2020 were convened to include user involvement. Their role was to provide ongoing feedback on the project methods, findings and utility from the perspective of 'experts by experience'.

4. Findings

Two focus groups were conducted with six compassionate neighbours attending the first and eight different compassionate neighbours attending the second.

Five initial qualitative interviews were conducted with seven people (three individual interviews and two dyadic interviews). Subsequently six people engaged in a second interview to complete the social network analysis exercise.

The data are presented in three main sections:

- getting connected,
- wider social connectedness,
- strengths and potential enhancements.

4.1 Getting connected

4.1.1 The matching process

Overall, the matching process had gone well.

M Initially the pairing – I think [staff member from Strathcarron]’s got a gift or a talent for matching people, and it very, very rarely goes wrong [...] I think she puts a lot of work and a lot of thought into it before she pairs people up.

E Yeah, because as I said, me initial one, I thought ‘Oh right, this is no quite what I imagined’ and actually, it couldn’t have worked out any better [...] So there’s just, there’s so much, so much common ground between us. (Focus group 2).

Focus group participants did note however that there had been some false-starts:

M There was one man that I was visiting and I kept trying and trying but we had nothing in common. I tried and tried to make conversation but he just wasn’t interested. Sometimes his wife would be in the room and I’d be talking to them both about, whatever, but she was interested, she’d turn round and he was sitting looking at the wall and it wasn’t anything to do with a condition but he was just not interested at all (Focus group 1).

Having interests in common was an important feature which was sometimes achieved, but not always:

We have an awful lot in common and that was a good thing. (interviewee 2, person with LTC)

I feel [compassionate neighbour] is not my type of person because he doesn’t ever mention sport. (interviewee 3, person with LTC)

All parties felt that the matching process for current connections had worked well, with some taking time to develop, and others appearing an immediate good fit:

E She just said right away 'Oh you can see right away whether they are going to match or not'. H [from Strathcarron] came out when I met [person with a LTC] for the first time, and again it was like – oh yeah – you could, you could just tell (Focus group 2).

[Compassionate neighbour] has been coming for 2 ½ years now, maybe 3, but it has now developed into [compassionate neighbour] is a friend. Not just like somebody that comes and sits and chats. We know about her family and she knows about ours and [J - Wife] looks forward to her visits and she is a nice person. It really works well. (interviewee 4, person with LTC)

Many respondents indicated the connection was easy to develop and led to reflections on how to negotiate and label the relationship.

4.1.2 Negotiating and labelling the new relationship

Labelling the relationship was varied, with some referring to the role as 'befriender' and others opting for a less formal label of 'friend'. The term 'compassionate neighbour' was not one drawn upon spontaneously, though it was recognised as the term adopted by Strathcarron Hospice.

Despite drawing on the term 'friend' the roles and relationships undertaken were not always consistent with conventional understandings of friendship. The compassionate neighbours drew on ideas and activities which positioned them as pseudo-professionals rather than peers.

V This lady did have dementia, not badly, but she, she did – you could miss it if you didn't know the signs of it I think, she was very good at covering it up (Focus group 2)

Some explained their boundaries in terms of past work identities, invoking ideas of 'disclosure' which are at odds with concepts of friendship:

V It's probably my background, that you didn't disclose too much about yourself when you were actually at work, because it wasn't about that – you didn't want people to be intrusive. You were very selective, and perhaps I'm maybe a bit more selective

[...]

I Yeah, you're adding value, you're adding a value

D I think you're kind of assessing that when you go in, the initial meeting as you said, the pairing's O.K, then you're reviewing it, so after three months, if it wasn't going well for either of you, you have to be open and honest and be able to say that. But once you've kind of assessed what's, what's needing done, what's good in the relationship, you're probably looking for opportunities to build on that (Focus group 2)

A quasi-professional position was also drawn upon by compassionate neighbours in their appraisal of what was within and beyond their remit:

M She talks a lot about her family when we're out, and I'm very careful never to give an opinion – I think we're there as a listening ear – rather than a decision maker for them. (Focus group 2)

Compassionate neighbours were attentive to the potential stigma that can come from this different kind of relationship:

D He introduced me as his friend, which was quite nice – I'd only been in a couple of times – and people who knew him were saying 'J, who is this?' 'Oh this is my friend.' So it was quite nice – 'I'm getting my friend a coffee' it was just a nice.

V I think that's really lovely, because, yes, [name] calls me her friend, not a Befriender, but maybe it's important to them that it doesn't separate them from everybody else (Focus group 2)

Thus, despite the surface description of the relationship as 'friends' this was not evident in how everyone spoke of the interactions or their own perception of the relationship. For people with a long term condition, the relationship was described more in unproblematised terms:

I would say that she is a friend already, I think so because you can discuss anything, I would say that I could treat her as a friend and likewise, she could treat me as a friend. (Interviewee 2, person with LTC)

4.1.3 Setting the agenda

The content and frequency of meeting appeared to be mutually negotiated to suit both parties. This was more difficult when the person with the LTC had communication problems, and the compassionate neighbour would take it upon themselves to fill the gaps by talking

Informal carer: [The Compassionate Neighbour] is very chatty and very friendly and it doesn't seem an obstacle that [person with LTC] can't really speak in return.

Person with LTC: No

Informal carer: No he's very natural (Interviewee 3).

Other times, family members were involved in negotiating contact on behalf of the person with the LTC:

Interviewer: Who decides how often you meet up?

Response: We can decide. If I wanted to go and see the lady I visit, I can do so. I'll send a text to her daughter and say I'm going to pop in and see her mum today and they're really grateful. (Focus group 1).

Activities include staying in the home of the person with the LTC chatting, outings to garden centres and trips to local attractions. Some interviewees described attending group social activities such as bowling or church events. Many reported having a lot in common to talk about, including pets, sports and other hobbies.

Negotiating some aspects of the new relationship had included payment for refreshments when on outings and reciprocity via other means.

4.1.4 Understanding the role and responsibilities of the compassionate neighbour

Asking favours or for practical assistance was described as appropriate by some, but not by others:

I can't think of anything that I would really have asked her to do for me but I made a vow to myself that I wouldn't do that because I felt that that's not what she is here for she is here to give me a bit of company and a chat and that's really all I would expect. (Interviewee 2, Person with LTC)

Compassionate neighbours spoke of the role they have in managing medical emergencies, including an awareness of where key contact names and numbers were stored, or being primed to perform CPR. Managing acute deterioration led to discussion of advance/anticipatory care plans and whether the person's choices were clearly documented:

V *She was quite clear that if she did have an event nobody was to call an ambulance, however, what she hasn't told me and I haven't been able to address it actually, is – does she carry that form with her? Because if she doesn't – we have a real problem (Focus group 2).*

The quote above reflects the tension in recognising the importance of discussions about anticipatory/advance planning, but not feeling that they could or should address such matters, even regarding decisions which had been clearly articulated but not necessarily clearly documented. Similarly, compassionate neighbours did not instigate conversations about death or dying:

E *My first lady obviously had a very life limiting illness, and she did speak to me about death. Now it maybe that she maybe didn't want to speak to her family about that [...]*

V *Although we get on really well, and we call ourselves friends – I'm not sure I want to broach that – uncomfortable broaching that subject with her. I would rather somebody did it here, or the family did it. They may well have had that conversation, I don't know [...] if death came into the conversation I wouldn't be uncomfortable with that, because it happens so often – but I wouldn't bring it up – I would want her to bring that up. Because it sounds quite negative*

E *Yes that's right (Focus group 2).*

Despite compassionate neighbours knowing that all the people they were matched with had a long term condition which was life-limiting, they did not feel they had the confidence, skill or permission to talk about death:

M *I think you need a certain amount of confidence to do it. You know, to be able to – well to deal with the death – if they talk about death. Not to, you know, evade (Focus group 2)*

Other Compassionate Neighbours had taken on a role in supporting the person's finances:

8 She'd no family here, he had family and his family were trying to get their money and I got so involved, taking on the Guarantor of the Public and the Royal Bank (Focus group 1)

Financial discussions were beyond the scope of expectations set for compassionate neighbours, but this exceptional circumstance involved the compassionate neighbour being in regular discussions with the Hospice team, including the social worker.

When people with LTCs were asked who they spoke to about advance or anticipatory care choices no-one mentioned the compassionate neighbour. Most referred to adult children or professionals such as social workers or lawyers. Wider health issues were also mostly discussed with family, and general practitioners. However health was seen as an appropriate topic for discussion between compassionate neighbours and people with long term conditions, though not necessarily for their own needs:

Interviewer: Who would you turn to, when discussing your health?

Person with LTC: Probably [daughter].

Interviewer: [daughter]?

Person with LTC: I think so. Well, obviously I would need to tell [befriender] – I, probably the two of them...I would say the two of them.

Interviewer: And, and when you say you would need to tell [befriender], what do you mean by that?

Person with LTC: Because, if I didn't tell [befriender], she would be quite hurt (Interviewee 3)

4.2 Wider social connectedness

4.2.1 Support networks of people with LTC

Sociograms were constructed from accounts of who people with LTC said supported them, and if those people were connected. Figure 1 shows the support networks, with the person with LTC in the middle (yellow) and the people who they say support them in their network.

Two of the networks are more family-centred (green), while the other two have more variety in terms of the people they nominated, including friends (grey), compassionate neighbours (red) and health professionals (blue).

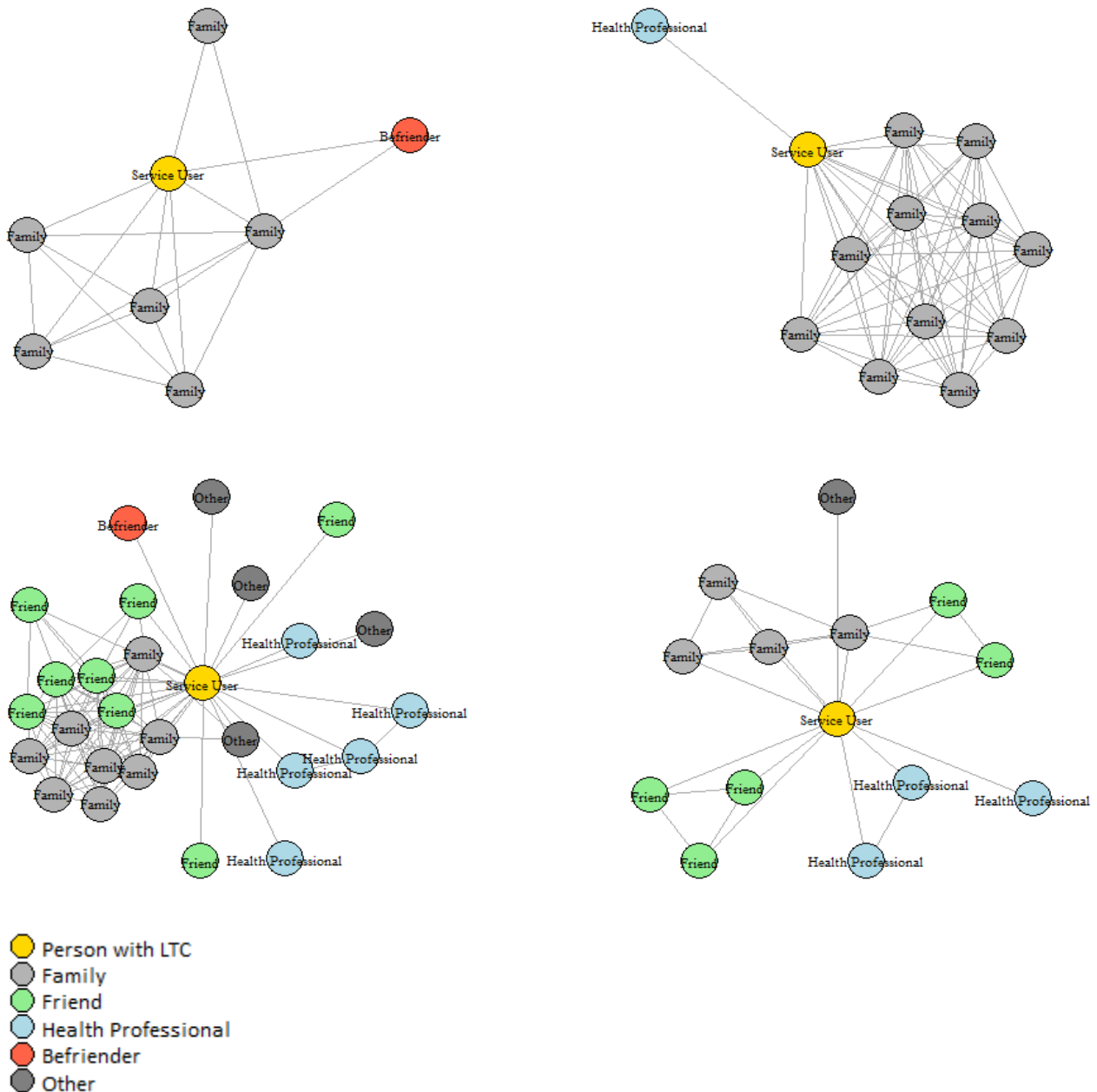
Only two of the people with LTC nominated their compassionate neighbour for support. Due to the small number of people who completed the social network exercise, and the different relationships described, it is hard to make firm conclusions of why this may be.

The people with LTC who did not nominate their compassionate neighbour suggested their compassionate neighbour had not immediately come to mind when thinking about support, or that although they would not approach them in the first instance, they may approach them for different

types of support in the future. The two people whose networks contained compassionate neighbours had different experiences, one suggesting they just socialised with them, while the other relied on the compassionate neighbour for several types of support.

Data from interviews and focus groups suggested that compassionate neighbours had a large effect on those who felt socially isolated by creating a meaningful friendship with the person, enabling people with LTC to make new connections and establishing connections with the person's family.

Figure 1: social support networks of people with long term conditions



4.2.2 Prior and enduring connections

Many Compassionate Neighbours appeared to be quite busy people:

*He does a lot of volunteering, he works in the garden, he works at the depot going around sorting books which is quite overwhelming and he is a befriender.
(interviewee 3, person with LTC)*

E I find it fits in with my lifestyle, because I still do supply teaching and I've got a very, a very busy, just a very busy life in general, so actually it's, it's, it's just it does, it fits in – you just know that your there for between an hour, maybe two hours, it just depends on how the day goes, yeah, but it fits in (Focus group 2)

People with LTCs were typically socially isolated with minimal enduring social networks. Use of the hospice day service along with disease-specific support networks were mentioned as offering social contact and outings, but notably almost all social engagements involved activities focused on health and symptoms, rather than generated by hobbies and interests. Many people with LTCs reflected on the ebbing away of social engagements, except for continued contact with relatives on whom they were keen not to be overly reliant:

I feel as if [my daughter] should be home with the girls, and [her husband], rather than, you know, staying here, and just running about mad with me (interviewee 1, person with LTC)

Reduction in social networks had occurred partly due to their own ill-health, or due to caregiving roles for their spouse. The following participant had been active in volunteering with a national organisation, but had relinquished this due to her husband's health:

Just before [person with LTC] was diagnosed I was on the point of becoming a befriender [...] but I had to step back because I knew I was going to care for [person with LTC] and I can't just say "oh tomorrow I'll come and see you" because [person with LTC] could go somewhere. (interviewee 3, informal carer)

Focus group participants reflected on how isolated and lonely the person they saw was:

*5 That lady that I go to visit that has dementia, every week when I walk out the door she'll say "would you mind coming back because I like you". It would break your heart, she just says it. She doesn't have a life, she sits on her sofa every single day watching television. Her daughter's at work so she sees nobody, it's sad to watch.
(Focus group 1)*

This was strongly echoed in the data from people with life-limiting conditions, whose social networks had contracted dramatically with few friends, and reduced contact due to the friends' busy schedule or difficulties in visiting:

It was a horrible period I went through, because all of a sudden, [name] wasn't coming in anymore, who.... I got quite friendly with and then the District Nurses weren't coming in so it was a case of...you know....all of a sudden you realised that you were on your own [...] it really is isolated up here. (Interviewee 1, person with LTC)

I used to have a lot of friends but I don't now. [...] Just losing touch with people [...] I don't really socialise much at all. (Interviewee 2, person with LTC)

4.2.3 Relationship between the compassionate neighbour and person with LTC

As noted in section 4.1.1 the matching process had largely worked very well and so the relationship between compassionate neighbour and person with long term condition was amiable and positive for most people.

Arrangements varied considerably from daily contact, to scheduled fortnightly visits and those with more flexible arrangements. Several people with LTC or their informal carers reported that if the scheme stopped tomorrow they would be 'heartbroken' whereas others said their relationship with the befriender would endure:

She is one of the kindest, persons I have ever met [...] To be quite honest, I'm getting now that I, I rely on her (interviewee 1, person with LTC)

It's possibly not got to that point yet but I would miss her if she wasn't coming (interviewee 2, person with LTC)

People spoke about looking forward to the contact and 'waiting by the door' in anticipation of seeing the compassionate neighbour.

We've got such a good relationship you know we understand each other, nothing is a problem for her you know she's just, she's just a wee angel. [...] I could phone her at any time and it's not a problem you know like if maybe I'm feeling a bit down, eh I know that anything I need she would do it for me. (Interviewee 5, person with LTC)

As noted above in 4.1.2, people would refer to each other as 'friends' as a marker of the closeness of the relationship.

I would say that she is a friend already, I think so because you can discuss anything, I would say that I could treat her as a friend and likewise, she could treat me as a friend. (interviewee 2, person with LTC)

Others had positive relationships but not at the level of friendship:

I wouldn't discuss personal things with her. She would do a favour for me. We both have the same Doctor so if my prescription's ready for renewal, [befriender] would take it along and pop it in. These sort of things she would be very good at and it wouldn't be a problem to her. (interviewee 3, person with LTC)

4.2.4 Compassionate Neighbours' connections with the person with the LTC's family

For people with long term conditions with a partner, the compassionate neighbour was a positive force of providing company so they could engage in other tasks or as respite.

Other speakers specifically drew on the idea of the compassionate neighbour being a friend to them too:

[Compassionate neighbour] is a friend, she is one of [J - Wife]'s friends and I treat her as a friend of mine. We are just friends and that's it. I don't treat her as someone that's having to come along. Like if you are paying someone to come then, you are paying them to come and do it and they are there because it's their job, because you are giving them money to do it. [...] If it comes a time and she said for whatever reason she couldn't do it, we would feel that as a loss. [...] But I'm pleased to know her as a friend, someone supporting me. (interviewee 4, informal carer)

[My husband is] well impressed with [befriender], they get on awful well [...] He's grateful to her because it's really has made a difference for me. (interviewee 5, person with LTC)

A compassionate neighbour reflected on the death of someone they had previously been matched with. Describing the recognition of closeness to the person with the long term condition and family was signalled by how quickly they were informed of the death:

M *I got a 'phone call within fifteen minutes of her death, to say that she'd passed away. So that's quite meaningful. (Focus group 2)*

4.2.5 Forging new connections

Some of the activities pairs engaged in had resulted in new connections:

M *If there's something special on at the church, like a Flower Festival or Christmas Festival or that – she just loves to come along, and they come into the, you know the hall for their tea, and of course they'll all come through 'Your friends are in' so I'll go through and chat to them but everybody comes and chats to her and she just loves coming along to it. And I think I was, what was I at a night out somewhere with her, and her husband took the two of us to that, so she quite likes to include me in her social life when she can (Focus group 2)*

Few of these were durable though, and appeared to require ongoing support of the compassionate neighbour to enable the person to attend. The new connections did not flourish or continue without the compassionate neighbour's ongoing involvement:

The next thing I knew I was enrolled in the Age Concern Club, which, the first time I went I felt quiteisolated....[...]...but, gradually... the second time I went, it was as if I'd been there for, for ages. I never met such a nice crowd of old ladies, as the saying goes, and I do not know what I could do without [befriender] coming and taking me out. (Interviewee 1, person with LTC)

4.3 Strengths and potential enhancements to the programme

4.3.1 Strengths

There was considerable amount of data extolling the benefits of the compassionate neighbour scheme. The positive impact was described as people 'lighting up' when they saw each other and describing the other in terms such as 'angel'.

F You sit and have conversation with them for about an hour, an hour and a half, two hours whatever time it is, that's two hours of brightness in your day along with theirs, so I feel that whatever we give to them they give us it back. (Focus group 1)

A I like sort of chatting to people and having a wee blether sometimes uh huh. It's good for her too, cause she doesn't see many people during the day (Focus group 2)

I think I'd be broken hearted if somebody said to me 'Well, you've had her for 'X' amount of weeks, it's gonna stop (interviewee 1, person with LTC)

One compassionate neighbour readily indicated that they gain more from the relationship than the person they are matched with:

M I'm not a needy person, but I think I get a lot more out of it than the person I'm befriending. I think, for me, that I've got the time and you're giving that time to somebody. I like driving, the chap I've got now we're an ideal match because he just loves sitting in the car and we go over the hills over Stirling (Focus group 2)

Prior to Lockdown in March 2020, many of the pairs were meeting weekly or fortnightly. Shifts had been made to accommodate telephone calls after that time, or offered to drop provisions at their door.

The relationship was also seen as positive for others. One interviewee indicated that the compassionate neighbour was a safety net if her daughter was unavailable:

[My daughter] knows that [compassionate neighbour] is always around... if maybe I, get into a panic or something – [compassionate neighbour] would come in before [my daughter] could get here. (interviewee 1, person with LTC)

Disabled interviewees spoke of the additional confidence the compassionate neighbour brought to experimenting with leaving the house.

The opportunity to meet with other compassionate neighbours was very welcomed, particularly as an informal learning space to hear about others' experiences as a way of preparing for deterioration in the person with the LTC or their death:

E The coffee morning get-togethers are really good because you hear about other peoples' experiences, because you go along and you think you're doing fine with your one, but it is different, it's good to hear different peoples' experiences of different ages, of different health issues, and kind of different things that have cropped up. [...] The more you hear about different situations, the better you are, I

think, at dealing with things that crop up. And you hear about the different scenarios that could happen. (focus group 2)

The training was also roundly appreciated, particularly Sage and Thyme.

V *My understanding is there aren't enough befrienders – I was asked if I would see somebody else and I just said 'No' at the time because I wanted to concentrate on the person that I was actually seeing, and I felt I would be sacrificing something in that, but I think there is a great need for more Befrienders and I'm trying to persuade friends that it's a good thing (focus group 2)*

M *I don't think I would ever have gone out to try and find somebody myself. The idea of compassionate neighbours is absolutely fantastic but I don't know that I would go and chap somebody's door that lives up the street, that's living on their own, to ask if there's anything I can do to help [...] Working within the structure of Strathcarron it's really good, and you've got the guidelines as to "You don't do this" and "You don't do that" and some of them are ..."Well, maybe" and I think it's great having [Strathcarron staff] that we can phone and say "I've come across this, and I'm a bit concerned. What do you think?" and you'll talk it through with them and I think that's really good (focus group 1)*

4.3.2 Enhancements

Very few improvements were generated through discussion. One focus group participant was keen to have more insight into the scope of the scheme, with an interest in learning how many people were involved in being compassionate neighbours, and how many contacts occur.

One speaker reflected on the limitations of the current model of being constructed around hospice networks and contacts. The interviewees in this sample all had prior connections with the hospice. For example, their spouse or other relative had been cared for by the hospice team. Consequently, while adopting the nomenclature of compassionate neighbours, the neighbourhood element of the connection was secondary to the connection with Strathcarron:

D *I don't know how you access the people who are maybe lonely but are not in contact with **anybody**, but it's a good start, and something to build on*

E *Yeah*

A *I think there's a lot of people out there falling through the net that we don't know about (Focus group 2)*

Speakers recognised that the relationship may well endure beyond the initial scope of 12 months they had anticipated being matched with the other person for. This was seen as both a strength (longevity of a personal relationship) as well as a concern that this reduced the number of people who could benefit from a compassionate neighbour.

5. Discussion

Participants in this study were very positive about the impact of compassionate neighbours in increasing social contact, combatting the loneliness associated with living with a life limiting condition in the community.^{20 27} While compassionate neighbours reported having busy social lives, people with LTCs reported narrow social networks, and were experiencing loneliness and isolation.²⁸ Social relationships and networks are important in bereavement support,²⁹ and hence the relationships established in this project have current benefits for the person with a long term condition, and future dividends for their informal carers.

The range and type of contact appeared to be well tailored to individuals' likes and interests. The importance of the one-to-one relationship was considerable, especially if the person with a LTC had very few supportive contacts out of their family or health professionals. Use of the term *friend* to describe the relationship reflects the high status which they attributed to their compassionate neighbour, and vice versa. The word *friend* also points to success, that a new non-professional and somewhat reciprocal relationship had developed²³, despite the professionalised vocabulary of some compassionate neighbours using terms such as 'disclosure'.

Compassionate neighbours were demonstrably providing social support, addressing a recognised deficit in the traditional clinically focused service model.³⁰ Emotional support was evident in some pairings through the discussion of family issues and health concerns. However, limited evidence was available from these interviews about practical support beyond transport to outings, though interviewees did refer to being able to ask for help with some tasks despite not often doing so. The findings echo other studies of volunteering in palliative care in providing social contact² and facilitating leaving the house for short outings.¹⁹

New connections beyond the 1:1 relationship had not developed, rendering some fragility to the arrangement. A study of social networks of people using palliative care services had identified that the number and density of social ties can be strengthened over time,⁶ pointing to the potential for community compassionate neighbour initiatives to have greater reach. This potential for extending the scope of new relationships has also been shown in community facilitation approaches.³¹

Compassionate neighbours were overwhelmingly positive about their role.³² They spoke highly of the training and support provided by Strathcarron and the enjoyment they gained from meeting other compassionate neighbours. There is a paucity of literature summarising successful strategies in recruiting, training and retaining volunteers in palliative care.¹⁸ Where studies on training volunteers have been conducted, they tend to focus on inpatient rather than community settings.³³ The approach adopted in the Living Right project is therefore laudable, having developed its own protocols and approaches. With an anticipated increased demand for volunteers (driven by demographic trends in longevity and chronic conditions, alongside later retirement ages and the increased likelihood of grandparents caring for grandchildren), there is a need for palliative care services to think strategically about recruiting and retaining volunteers.¹³

5.1 Limitations

Recruitment was slow and fewer people with long term conditions meeting the inclusion criteria than was initially estimated. Data collection was further complicated and truncated by COVID-19. Some interviews had been planned to occur face-to-face but had to be conducted over the phone.

Meetings between compassionate neighbours and people with long term conditions also ceased, in line with government guidelines to *stay at home* and maintain physical distance.

A discussion took place between University of Stirling and Strathcarron Hospice in late summer 2020 to determine the best course of action, regarding data collection. With recruitment having exhausted existing compassionate neighbour relationships, and no further matches occurring, the decision was taken to cease data collection. Consequently, the number of interviews is lower than had been planned and analysis changed to accommodate the reduced amount of data. Full statistical social network analysis was not possible to perform, and the grounded theory sampling approach of theoretical sampling was exchanged for a pragmatic opportunity sample.

Nevertheless, adequate data was collected to achieve a position of sufficiency and saturation whereby similar themes, topics and experiences were evident across interviews and focus groups.

5.2 Conclusions and implications

The programme is enjoyed by both compassionate neighbours and people with LTCs. It clearly addresses a need among users of the approach in tackling loneliness.

Compassionate neighbours were typically very busy, but their existing social networks had not been routinely used to connect the person with the LTC to other groups and individuals. Volunteer busyness may act as a threat to the longevity of the relationship, since satisfaction with and withdrawing from volunteering is linked with a high number of other commitments.³⁴ Hence explicitly linking people with LTCs with compassionate neighbours' existing social networks may both enhance the number and type of social connections while reducing potential for volunteer withdrawals.

Strathcarron may wish to consider providing more support in building infrastructure to expand the social network of people with LTCs, to reduce reliance on the one-to-one relationship. The benefits of adopting a more systemic approach to building networks is in the potential for those new relationships to be self-sustaining, and additive to the compassionate neighbour's role.

People with long term conditions who participated in this study had a relationship with Strathcarron prior to the compassionate neighbour programme, often by virtue of a spouse having received clinical care through the palliative care team in recent years. Although the sample size was small, it points to the potential for growing the scheme to include local community members with long term conditions not known to Strathcarron.

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