

Insights from gardening groups for people living with dementia Research report and practical insights



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Further information:

See corresponding published academic article <u>'I can still swing a spade': a qualitative</u> <u>exploratory study of gardening groups for people with dementia</u> https://doi.org/10.1017/S0144686X23000892

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ABOUT THIS REPORT

Who it is for

This report is written for individuals and organisations involved in supporting and improving care for those living with dementia in the community.

Purpose

The report aims to provide readers with a deeper understanding of:

how group-based gardening initiatives can be used to benefit those living with dementia in the community.

It does this by presenting the findings of interviews with people living with dementia and their family who have attended gardening groups, and seven leaders of existing groups.

These individuals provide a wealth of insights into their experiences of gardening groups. These are reported under the following sections:

- About the groups
- Group benefits
- What works
- Challenges and solutions
- Navigating the pandemic
- Insights from leaders

BACKGROUND

Growing support for those living with dementia

Around two-thirds of the 900k older people with dementia in the UK live in their own home ¹². The responsibility of care at home will often place a large strain on family members and friends³. **There is a need for greater provision of community-based support for both people with dementia and those caring for them**. Research can support these aims by providing insights into what support may be beneficial and why.

"Long-term care systems must account for the significant emotional, financial and social impact of caregiving on families and relatives, while addressing the needs of people with dementia. This includes providing carers with access to education, skills training, respite and social support through affordable, evidence-based resources."

World Health Organisation ³

Recent research clearly demonstrates the need for a multi-faceted approach to support that aims to reduce negative psychological influences (such as loneliness and depression), increase more positive psychological resources (such as self-esteem and self-efficacy), while also benefitting physical health and creating a positive social environment ⁴.

There are likely to be multiple ways to provide valued support, and what people engage best with will depend on their individual likes, dislikes and experience of dementia. Here we look more closely at gardening initiatives as one promising and dynamic approach to support.

BACKGROUND

What we already know about gardening groups for people with dementia

One study asked carers what activities they thought the person with dementia would choose to do if the right support and information was available. Almost one in three people said they would want to do "community gardening/farming" Natural England ⁵

Despite much research showing that time spent in nature can be beneficial for both health and well-being⁶, much less is understood about the experiences of nature-based activities among people with dementia.

One review of several studies shows that using gardens and outdoor spaces within dementia care may be beneficial. It showed **potential to reduce agitation, as well as promote interaction and stimulation** ⁷. Research outside of care homes is more limited.

A handful of studies have examined the impact of structured horticultural activities (often led by horticultural therapists) as part of adult day-care services for people with dementia. Observers **noted increased engagement in activities, and positive emotions and well-being** among people attending these groups ^{8,9,10}.

Further research relating to a 6-week gardening programme where people with dementia are more autonomous—such as helping to design activities—also shows positive outcomes. Participants reported **positive impacts on their sense of identity, agency and community**^{11,12}.

RESEARCH DESIGN

Aims of the research

This research aimed to improve on the limited research around gardening groups as a tool to support people with dementia. We were interested in hearing about, 1) the practicalities of running this type of group, 2) how and why these groups can be beneficial, and 3) the challenges of running this kind of group (and possible solutions). The aim was to use these findings to support the design and implementation of similar gardening initiatives in the future.

Participants

Seven gardening groups took part, located in the South West, South East, East of England and London. From these groups, six group leaders, ten family members and three people with dementia shared their experiences of organising or attending groups.

The capacity of all participants with dementia was assessed prior to interview and only those with symptoms which would be classified as 'mild to moderate' were asked to take part to ensure that they were able to provide informed consent.

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All participants were living in the community at the time of the study, rather than care homes or residential settings.

RESEARCH DESIGN

Research methods

Semi-structured interviews were used, with the choice of doing these over a telephone/video call, or face-to-face at gardening group sites. People with dementia were also offered shorter recorded conversations, which happened whilst they were doing the gardening activities. This aimed to help capture in-the-moment experiences and reduce any pressures on memory recall.

Interviews with group leaders focused on practical aspects of running the groups, including strategies and activities which worked well, how they navigated the pandemic, and advice for future groups.

Conversations with people with dementia (sometimes accompanied by a family member) focused on their experiences of attending the groups and the impact of these on their lives.

Family members were asked if there was anything which helped or made it difficult for them and their loved ones to attend, about their own experiences of attending, how they felt they and their family member benefited, and why.

All data were transcribed, anonymised, and then analysed using qualitative methods to find any reoccurring patterns and themes which helped us understand these groups better.

Detailed methodology can be found in the published academic paper [https://doi.org/10.1017/S0144686X23000892]

Core elements of gardening groups

There were core elements that were found across groups:

Welcome and orientation

When attendees arrived they would be welcomed in. Group leaders might review what had happened previously, talk about seasonal changes in the green spaces and involve attendees in planning the day's activities, grounding attendees in time and place. In some groups, attendees took a walk around the garden, perhaps collecting materials for creative activities and taking a moment to appreciate the natural world around them.

Tea and cake

One or two planned breaks, usually with tea, cake or home-made treats, provided a familiar, enjoyable ritual, the chance to chat informally and build social connections.



Activities

Groups would then take part in gardening, creative, nature-based or other activities (see page 11).

Sharing and celebration

In all groups, attendees would chat about what they had done, within or after sessions. They might also create long-lasting reminders of activities, such as making memory books, creating videos or taking photographs, which could be shared with others. Gardening groups which were seasonal might hold end-of-year celebratory events, and some groups took part in open days or summer fairs to raise public awareness.

Links made with home

Attendees frequently took away produce and craft items, providing a joint focus of conversation with family, and sometimes continuing activities beyond sessions – for instance, being given recipes to cook ingredients they had grown.



6 [My mum] made me these little lavender balls [and] she was so proud.. and I've kept them in my house, and whenever she comes around she's like, Oh, I like these. ⁹ Family member

Activities

A range of activities were used in gardening groups which used the garden as their stimulus:

Gardening tasks

These included traditional gardening activities such as sowing, planting, digging, watering and harvesting, with adaptations to tasks so that everyone could take part.

Creative activities

In several of the groups, attendees and family members did creative activities, including painting, flower arranging, collage, clay tiles, leaf rubbing, felting or cyanotype photographs. They also used garden produce to cook seasonal recipes or press juice, or constructed items for use in the garden such as benches and arches, bird-boxes and bug hotels.

Other activities in garden settings

A range of other activities were carried out during sessions, including poetry and song, walking or sitting in the garden, games such as bowling or dominoes, and wildlife activities like bird and tree identification or pond-dipping. Some groups also did activities around a theme, such as school days or maps, benefited from museum outreach visits, or made visits to other gardens.

••They grew some sunflowers and then picked sunflowers and painted sunflowers [on a] tablecloth that had lots of giant sunflowers on it, and it seems that at any level you could belong and contribute.
Family member



Variations in group format

There were other aspects of groups that varied. This is likely influenced by differences in resources (funds, people and space), as well as the aims of the delivery organisation:

Who could attend

Some groups were open to people with formal diagnoses of dementia, while others were mixed groups of community attendees but aimed to be dementia-friendly. Some sessions were open to family members too, or were starting up intergenerational sessions, where older people and young children could garden together.

Length of attendance

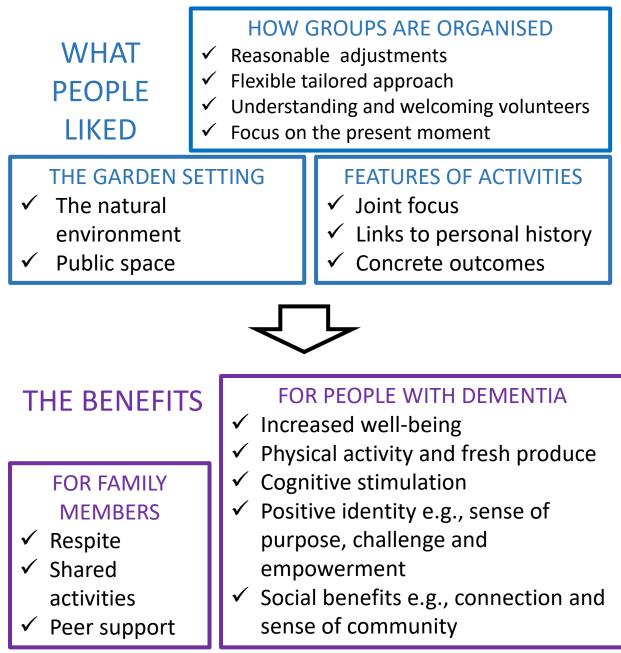
Some groups ran short courses bookable in advance, and others allowed drop-in attendance or online booking. Some were seasonal but others ran all year round due to the availability of heated facilities such as greenhouses or summerhouses for indoor activities.

Location

The sites where the gardening groups took place were both rural an urban, and ranged from a small privately-owned garden, to public spaces such as parks or woodland areas, allotment and community sites.

Overview

This overview and the following sections tell you more about **what people said they liked** about gardening groups and the **benefits they said they got from them.**



Benefits for people with dementia

Both family members and group leaders observed that attendees showed **increased engagement** with activities and social interactions during gardening sessions, and **positive emotions** which could persist for some time afterwards. Attending these groups provided space for **social connection**, and built feelings of **community**, through working together on joint tasks.

Some interviewees talked about how the groups helped support a sense of **purpose**, **challenge** and **empowerment**, with the opportunity to try out new activities or draw upon previously gained occupational and recreational skills. Other **wellbeing outcomes** reported were improved sleep and appetite, cognitive and sensory stimulation, physical exercise, availability of fresh fruit and vegetables, a regular routine and activities to look forward to, and sustaining a connection with nature.

G He literally walks through the door and he changes back to more like his old self.. and he's kind of tired for the rest of the afternoon but it's a good tired [because] he's done something. His brain has worked. He's seen people. He's talked.. He's just that totally different person.**9 Family member**

66 I don't really know how to explain it, it just makes my day. When I was diagnosed with Alzheimer's, I thought, 'What am I going to do now?' You feel in sort of a lost state, but since I joined.. it has been a new lease of life, I've got a sense of purpose [and] things that I enjoy, things that I used to do. Rather than just sitting at home and thinking, Oh, what am I going to do next? **?** Attendee



Benefits for family members

There were also important benefits for partners and family members arising from their involvement with gardening groups. These could include gaining **respite** from caring responsibilities, due to having the opportunity to take time out alone whilst their loved ones were cared for physically and emotionally, or through doing fun **shared activities** together within a supportive, inclusive environment. Some family members also benefited from **peer support**, gaining emotional support during difficult times, and learning from the experiences and knowledge of others. These benefits were described as supportive of families as a whole, given that the wellbeing of people with dementia and those caring for them is closely linked.

66 It's quite important that people understand this is for both the person with dementia and for the person who's trying to support them, as long as they can, because if we can support the carer, then the carer can support their person for longer.
99 Group Leader



• • It really is the only place I come to in the whole week where I can come here and I can just be me. I'm not having to worry about [my husband].. and it's the most enormous relief.. It's like literally a weight going off.. [And] I think for both of us, it says something that for both of us the two hours just goes like that, and I don't leave here feeling sort of mentally or physically or emotionally exhausted.. I go away feeling energised, actually. It gives you that extra sort of, we can manage. ??

WHAT WORKS

The garden setting

Gardening sessions in **outdoor, natural spaces** provided opportunities for encounters with wildlife, sensory stimulation, and being in a calm, relaxing environment. Many attendees had gardening or nature as a common interest, which brought them together socially and encouraged sharing of knowledge and skills. Groups which ran in **public spaces** such as parks or allotments also supported social connections with the wider community.



6 • Nature can be a really helpful tool because you can use it as distraction or it gives perspective or just focusing on breathing for a bit.. I think there are ways of using nature to, I guess, [bring someone] back into the space and make them feel comfortable.. [And] one of our members who lives in a care home said, 'For some of us this is the only chance we get to put our hands in the soil'. **? Group Leader**

WHAT WORKS

How groups are organised

The groups made a range of **dementia & disability-friendly adaptations** to materials, site and activities, taking a **flexible**, **tailored approach** to fit attendees' individual preferences and needs. These supported accessibility and feelings of physical safety for attendees and family members. Groups also relied on the regular support of **volunteers**, who assisted with everything from providing one-to-one support with tasks to providing befriending services and making home-made cakes. Interviewees talked about how caring, inclusive and welcoming the groups were, creating an 'atmosphere of acceptance' and lack of stigma, supported by an **understanding of dementia** and a **focus on the present moment**.

••We would sort of try and create a mindfulness around it.. the end result is the least important part of all this..So if you focus on the present moment. Are people engaged? Can you hear laughter? ****** Group Leader



WHAT WORKS

Features of activities

Practical gardening and creative tasks gave people living with dementia and their family members a **joint focus**, both during sessions and afterwards. Doing these activities together in pairs or small groups may help support social interactions and completion of physical tasks, removing pressure on motor skills and memory, and help build a sense of being part of a team. They can also help support a sense of personal identity, through doing **familiar tasks** which relate to previous roles their have had during their lives, and providing **concrete outcomes** which can be seen, touched and taken away, providing continuity with home.



Watering is something
you can see. You put the
water in and you see it
coming out the other end..
The first day he came.. he
had a walking stick and he
put his walking stick down
and picked up his watering
can. ?? Family member

The participants shared some challenges they encountered when running gardening groups, but also useful insights around how they might be overcome. These may be important to consider for new groups being set-up.

The site

The first challenge groups faced when initially setting up, was finding a suitable site or sites, and making adjustments to them where necessary. Group leaders noted that the perfect site rarely existed and were flexible in their approaches to using what was available in their areas, but these ideally might have existing features (or potential to add them) such as: level non-slip surfaces, a secure enclosed area, provision of toilet facilities, onsite parking and good public transport routes. Some groups ceased during winter, due to slippery surfaces, cold weather and reduced gardening activities, while others found alternative spaces and activities to run throughout the year.

C A lot of people mobility wise aren't so great, so of course if it's tipping it down with rain.. it might be a bit slippery and things like that.. I wish it was just all the time, but I understand that it's quite tricky.. they've only got.. it's like a summerhouse.. but I suppose they couldn't really have, like, 10 people in the winter. **99**Family member

Transport

For some groups, attendance was made more challenging by isolated rural locations, poor public transport or parking issues. Some of these difficulties were overcome through provision of transport by volunteer drivers or dementia-friendly taxi services, and some councils or dementia organisations covered these transport costs.

66We've really luckily got access to funding for taxis.. because transport is always a massive issue.. it's a 20minute drive.. but I would have to get two buses with a bit of a walk if I wanted to get there. **99 Group Leader**

Social barriers

Confidence was mentioned as a possible barrier to attendance, and family members in particular highlighted the importance of communicating safety measures and 'what to expect' to potential attendees. Some participants felt that male attendees might feel more reluctant to attend group activities, especially at female-dominated groups, and suggested that men-in-shed type activities could be more appealing for some. One group leader hoped to expand attendance to wider demographics, so that those who were less financially well-off, or lived alone, could be better supported to attend.

Group size

All groups had to consider what their ideal group size might be, given the space and funding available, and the number of volunteers they had for support. These decisions had to balance capacity against service provision, safety concerns and attendees' preferences, and might result in additional groups being run or having a waiting list.

Timing

Choosing the right time of day and day of week was often done by consulting with current attendees. One family member talked about the challenges of bringing their relative to their group when they worked full time, feeling that for some people, this barrier might prevent attendance.

I often think how many other people aren't taking their parents to this because they have to work. I mean, I'm quite lucky that I can say.. can I have a few hours off on a Monday.. I think there are other people who miss out on a lot because they can't take the time off work to take their parents to these wonderful things that are around.. If you're lucky enough to be able to get someone somewhere they're going to benefit. If you're not, they're probably going to stay at home.?? Family member

Funding

Funding came from a wide variety of sources. Depending on the region, this might come from Clinical Commissioning Groups or local councils - although not all councils were willing to fund gardening activities as they were not designated as 'day-care services'. Some groups were successful in obtaining grant funding, such as lottery money. Others were able to draw on crowd-funding for specific items, or draw upon local community resources such as business sponsors, corporate volunteer schemes, or local charitable organisations. However, funding in itself was a time-consuming activity, and could be a challenge for smaller groups with lower staff numbers and funded hours.

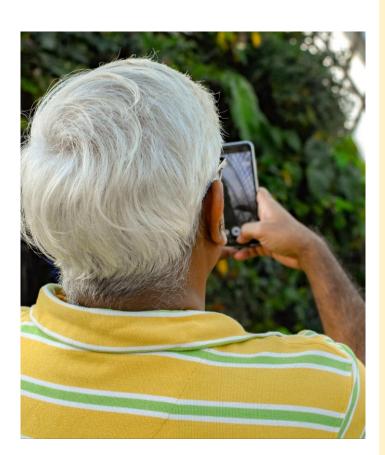
66 ...a paving and aggregate company.. They've been absolutely amazing and without that it would have been very different.. we always do loads with corporate volunteers at the gardening sites.. we've had skilled labour, unskilled labour, materials, money, discounts, and because it's [this region]'s first dementia allotment, that makes people want to get involved straight away, because it's a first.**99** Group leader

Other groups aimed to be 'as self-sufficient or self-sustaining as possible', to avoid relying on external funding.

⁶ [So] for example, [our dementia walking group] pay for their own refreshments [and] transport.⁹ Group Leader

Advertising and outreach

Some groups spread knowledge of their activities by having an online presence such as an official website or Facebook page, social media posts, live feeds, videos of activities, or inclusion in social prescribing databases. They might also engage with media such as regional radio, tv stations and newspapers, to build awareness of groups for potential attendees and help attract funding. One group leader advised new groups to:



6 Cocument every stage of the journey visually. We're going to make a diary book of photos of the whole development, so that participants can see, and [at events] we've had iPads with the photo kind of diary of the transformation, so people can see what's going on. **?? Group Leader**

Information on the groups might also be included in posters and flyers, newsletters and magazines, distributed locally or online. Some held open days, or became involved in wider community events and those run by dementia organisations. One group invited healthcare professionals to their garden site to see the benefits for attendees themselves, which might encourage referral or social prescribing, because they could 'promote it with passion' rather than just reading about it in a directory. Some groups also had attendees who acted as 'ambassadors':

6 6 There are certain personalities who naturally love talking about the group and.. just want to shout from the rooftops about how much it's helped them.. [and] if those people have that energy and passion for it then use that energy and passion and set up a community conversation or attend a community group meeting and just say, 'Can we come and talk to you about our group because we feel there are people there that might benefit?' [And] it's very much about the person with dementia being the ambassador, which has been such a lovely thing.. I think people really love hearing about their stories.**? 7 Group Leader**

All groups faced challenges during different stages of the Covid-19 pandemic. Sites needed to be maintained by group leaders and volunteers and attendees were at risk of inactivity and social isolation. Groups described a range of different strategies they used to stay connected and enable them to gradually restart inperson as restrictions lifted. These strategies may be of interest to any groups who experience interruptions in the future.

Staying connected

When groups were unable to meet physically, organisers aimed to provide cognitive and sensory stimulation, and maintain feelings of connectedness, through providing home or garden visits, newsletters and bulletins, phone calls, and online communications such as Zoom social calls, emails and WhatsApp chat groups. These communications were tailored to the local needs of attendees – for instance, sending printed newsletters for those offline or visiting people in public parks if they had no garden.



Activities

Several groups were able to fund activity packs containing everything needed for tasks, with clear dementia-friendly instructions on paper or video, and a wide range of activities from crafts to gardening; for example, sending seeds to plant in biodegradable pots and painting the resulting flowers. Some online activities, such as singing, also took place.

6 We made bird feeders. We made little mosaic tiles to make a pattern.. So although we physically hadn't seen them for a very, very, very long time.. when we saw them, it just felt like, 'We just saw you last week.. in the newsletter,' you know, it was brilliant.**?? Family member**



Getting restarted

Once groups could meet in-person again, they made a number of adjustments to ensure safety, with the benefit that many activities could take place outside. Some groups restarted with smaller groups sizes to allow adequate social distancing, sometimes with shorter length sessions or more frequent meetings. The groups aimed to clearly communicate these measures in order to support feelings of safety for all participants, including attendees, family members and volunteers.

There were some dementia-specific challenges when restarting groups, as some attendees and family members felt anxious about returning, had difficulties getting back into a routine, or with measures such as social distancing, frequent hand-washing or the wearing of masks, which might cause discomfort or inhibit communication.

66 We wore clear, plastic visors instead of masks, to kind of ease understanding what we're saying, [because] if we were wearing a mask and somebody's a bit hard of hearing, or got dementia, then the lip-reading aspect isn't available.⁹⁹ Family member

Not all bad

Despite these challenges, some positive outcomes were reported from having successfully traversed this difficult period, including feelings of pride and solidarity, having a greater diversification of services offered due to the adaptions groups had made to stay in touch, some future-proof pandemic-friendly garden designs, and deeper connections between everyone involved - from organisers and funders through to volunteers, attendees and family members.

66 I think a massive positive was how it diversified what we were offering,... Beforehand, if someone doesn't come to a group anymore, we'd almost say that's really sad but we can't do anything more for that person, whereas now we're able to say, 'Would you like an activity pack at home.. or would you like a phone call every now and again from a volunteer that knows you?' [And thinking about] people who were living in flats [who] couldn't go outside.. how do we keep those people connected to nature when their dementia is changing and their access needs are always changing.. we had to make it really inclusive and so I think that's been a real positive thing for us. It's almost like we've had to grow an extra limb and that was a really painful process but.. we've always got that now to use in other ways**?? Group Leader**

INSIGHTS FROM LEADERS

We asked groups for their recommendations for future leaders of groups like this, and here is what they said...

Consulting with the community

[I would advise] consulting with the community of people that are going to use your site.. get them involved every step of the way.. getting as many different kind of potential stakeholders involved, so getting family members that are going to be bringing their family along to be involved with the design. And keeping in contact with them so that they feel.. we are doing something for them.. [And asking] as many people as we could.. you know, what would you like to see? [This is] what we're working on, here's the updates, here's when it'll be open, please come and get involved.

Taster sessions are really good because you then can talk to people and say, 'You've come here because you've got dementia and you love nature or you have a connection to nature. What is your story? What day of the week would you like to meet? Do you have transport? Would you like to do more walking kind of things or would you rather have more activity-based things?' [So] involving people in the early days in terms of how to shape the group, and encouraging that co-production really early on [and then] they've actually contributed to what it is rather than us just deciding we're going to do it like this on this day of the week and there's no flexibility.

Growing slowly

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The groups do take a while to grow. It takes about a year to 18 months really to get a core group.. but I think things do just move at that pace and sometimes, no matter how much you're giving out posters and doing stuff, I think it can take time and it's not a negative thing.. I think actually that can be more sustainable and it can actually build really longstanding relationships.. I think that's something I wish I had been told earlier [that] it just takes time to kind of ripple out and for people to hear about it.

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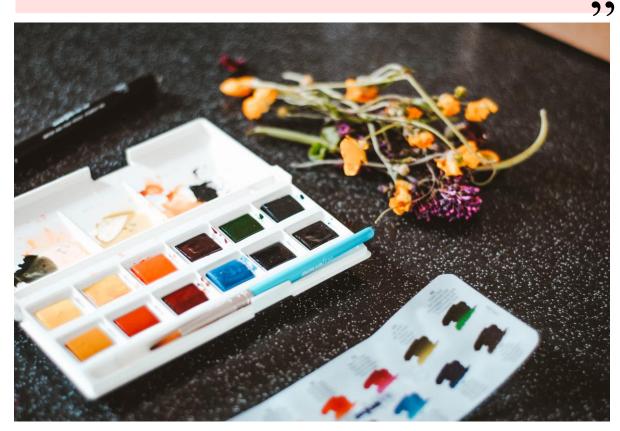
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INSIGHTS FROM LEADERS

Sharing a range of activities

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I think it is really important to think about all the activities related to gardening that you can offer as well and then ensure that people know about that, because sometimes, we'll have people saying to us, Oh, I didn't know it was like this. I thought we'd be outside in the garden all the time and I wouldn't be able to manage that. Whereas this is fine for me.



66

..and yeah, volunteers, volunteers, volunteers. Get the right people, look after them, train them, value their feedback, offer them the opportunity to make suggestions that you might well be able to incorporate. "

[Get] volunteers involved every step of the way.. give them a sense of pride in their contribution, aim for long term involvement.. Have lots of volunteer support sessions so [they] have as much social support as possible.

"

INSIGHTS FROM LEADERS

Story-telling

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I think it's really important if you can [to share what it is that you do], if you're already offering it and you want to develop it or you have any sort of sense of what impact it can have on people, so have stories. Storytelling is so important, because it makes it alive, [if] you can hear [somebody] speak, and what it is that they really love about it. Because I think that really helps getting funding as well. But it also helps inspire other people to join if they hear someone's voice saying, 'I didn't know what to expect, but I went along and we do gardening, and we do cooking, and I've made new friends and I've learned new things

If you don't ask you don't get

Ask local businesses for donations.. you'll be surprised what you can get.



"

CONCLUSIONS

- Community gardening groups are places where people living with dementia can experience connection with others, affirm their personal identity, and experience the unique well-being benefits of gardening and being in natural environments.
- These groups can provide respite and peer support for those in caring roles, potentially allowing care-recipients to live at home for longer.
- By providing positive examples of people with dementia being actively involved in community and creativity through gardening groups, it may help to challenge stigma as well as growing the case for funding this kind of initiative.
- Many participants expressed a wish that such community activities could be available for more people, across a wider geographical reach, so that 'everybody had that opportunity'.

** They're beautiful people doing a beautiful job, and I just wish they [could] have more of them.. because it's something that's very needed.?? Family member

•• Their kindness is fabulous and they have made me feel alive and they have made [my husband] feel alive.[?] Family member



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