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For all who work with people with dementia

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DementiAbility:
Enabling abilities – and success

Also inside this issue:

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- Online activities
- Analysis: prevalence of all cause young onset dementia

Online therapeutic activity programmes

for people living with dementia during Covid-19

When the pandemic broke out, people with dementia were frequently isolated and left without services on which they had depended. Care Visions Healthy Ageing and Alzheimer Scotland came up with a solution in the form of online therapeutic activities, as **Zara Quail** and colleagues explain.

When the pandemic struck, many people were required to self-isolate, which had significant consequences for people living with dementia and their carers, who had to stop attending group or participatory recreational activities and support or rehabilitation services (Wang *et al* 2020, Mok *et al* 2020).

Without outside interaction, people with dementia sometimes faced loss of previous skills, loss of social contact, loneliness and cognitive decline (eg, Rochford-Brennan & Keogh 2020, Read *et al* 2019). In recognition of the urgent need to provide ongoing therapeutic activities, Alzheimer Scotland and Care Visions Healthy Ageing teamed up at the start of 2021 to deliver an online therapeutic activity programme for people living with dementia and their carers.

Stimulating creative and cognitive therapeutic activities have been shown to benefit cognition, physical functioning and social interaction for people living with dementia.(eg, Cavalcanti Barroso *et al* 2020, Woods *et al* 2012) Participation in meaningful, personalised and recreational activities has been shown to increase positive emotions, improve activities of daily living, enhance quality of life, help with any behavioural issues, promote self-esteem and confidence and overall sense of wellbeing in a person with dementia. (eg, Lamont *et al* 2020, Roland & Chappell 2015) Meaningful activities have also been shown to engender positive attitudes towards carers, increase participatory engagement, create meaningful moments and support interpersonal connection, particularly as dementia progresses.(eg, Logsdon *et al* 2007, Keady *et al* 2020).

Key points

- The Covid-19 pandemic significantly disrupted continuity of care and services for people living with dementia and their carers.
- An online therapeutic activity programme offered interactive exercise, cognitive and creative activities.
- Initial barriers related to technology and online interaction were overcome with the help of carers and team members.
- High attendance and positive engagement were achieved through tailored content and smaller groups of three to five participants.
- By joining together, Care Visions' dementia therapists and Alzheimer Scotland support staff achieved the therapeutic intensity needed to ensure meaningful engagement for participants.

Collaboration

Alzheimer Scotland, as a national dementia charity, aims to make sure nobody faces dementia alone, and is committed to developing innovative practices. Collaborating with Care Visions on a new and ground-breaking programme was in line with their organisational vision to adapt, evolve and evaluate their high-quality therapeutic services.

After reviewing all in-person support and services, Alzheimer Scotland sought to find a way for these to continue by prioritising their digital strategy and adapting all pre-pandemic activities to online platforms. Within the first few months of the pandemic, staff across the organisation were upskilled and grew in confidence, delivering programmes of online activity.

At the start of the pandemic, Care Visions' therapists rapidly adapted their community-based therapeutic activity programmes with the aim of delivering meaningful and engaging programmes online through remote video calls. From setting up small film studios in their living rooms, to learning the techniques of video delivery and filming, therapists had to find even more creative ways to engage people through the screen.

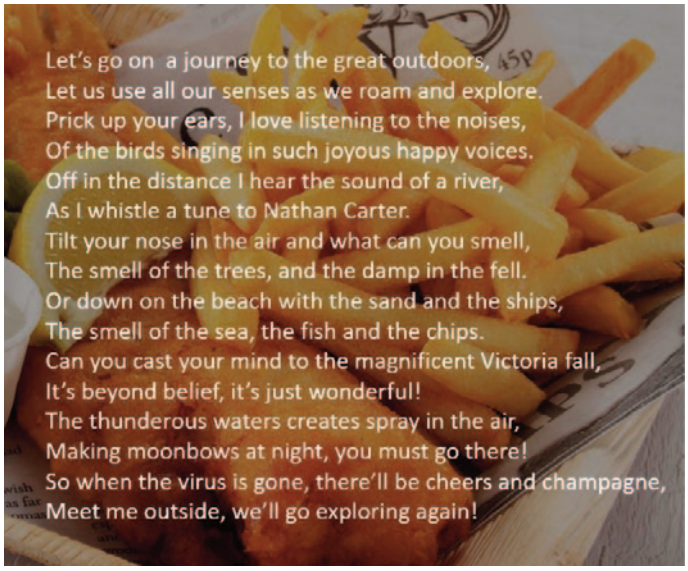
But the success of online delivery, though widely perceived, was not as clearly documented for people living with dementia, so Alzheimer Scotland wanted to learn from Care Visions' experienced team with a view to more confirmatory evidence of the benefit of this approach.

Therapeutic programme

Programme invitations were co-ordinated by Alzheimer Scotland with the support of their team, which included dementia advisors, community activity organisers, a practice team leader and localities lead. Eighteen participants situated in remote regions in Scotland signed up for the programme.

Detailed programme information leaflets, a digital

Dr Zara Quail is clinical scientific research lead, and at the time of writing Laura Bolton and Karina Massey were dementia therapists, all at Care Visions Healthy Ageing. Gillian Council is localities lead and Karen Black is dementia advisor at Alzheimer Scotland.



Above and following page: Two poems co-created by participants during the therapeutic activity programme

consent form and pre-programme questionnaires were circulated. The structured 6-week online programme was developed by Care Visions' therapists with the aim of facilitating meaningful engagement in activities and maximising participation in a digitally delivered format. Person-centred weekly session plans were completed in more detail once therapists had more information about each of the participants, which they gathered from an initial "meet-and-greet" and from participant questionnaires.

The 6-week programme consisted of two sessions of 45 minutes each per week attended by four or five people living with dementia and their carers, supported by one Alzheimer Scotland staff member per group. All sessions were delivered online using Microsoft Teams. The session structure generally allowed three activities per session, starting with a physical exercise to warm up and stimulate the mind and body, followed by a cognitively stimulating activity and ending with an interactive activity in the creative or artistic realm eg, music or poetry.

Pre-programme and weekly preparation by the dementia therapists included tailoring sessions to person-centred, identified needs, creating PowerPoint presentations for the visual content and preparing musical resources. While careful planning was important, spontaneity was a component of almost every session, for example prompting people to sing songs or give song requests, facilitated by an experienced music therapist. Among the wonderful works generated by the participatory sessions were poems co-created by everyone in each group.

Barriers and solutions

With the use of technology - new and even suspicious to some - come understandable barriers. For most participants, this was the first time they were meeting each other, which was a new experience compared to the familiar faces and acquaintances one might expect to meet in a local centre. Meeting strangers online for the first time can be intimidating, although meet and greet sessions helped to break the ice. In addition, the informal meetings that happened for a few minutes before and after sessions really helped to set the tone for the group and "soften" the digital experience.

Understanding and consent are important aspects of providing any programme, ensuring all participants are clear about the extent of their involvement and how information is collected and processed securely. Paperwork can sometimes be a barrier to participation, especially with remote delivery. Participants and their carers were asked to complete a consent form and pre-programme questionnaire online.

Issues that arose included complications downloading documents and reluctance in 50% of participants to complete the questionnaire. In response, Alzheimer Scotland staff gave support and encouragement to get the required consent forms completed and the pre-programme questionnaire was designated as optional to minimise barriers to joining.

Barriers related to the use of video technology included failure of the broadband network and lack of familiarity with aspects of online video such as muting and unmuting microphones and switching screen views. Staff provided invaluable remote support by helping participants in accessing and using the technology. When connection issues with video occurred, a telephone connection was offered, although this could result in difficulty hearing.

For participants with impaired vision, visual presentations might be difficult to see. Therapists overcame this through very clear verbal instructions and descriptions and ensuring any visual materials such as PowerPoints were clear and bright with contrasting colours. Screen sharing posed a challenge when a therapist needed to share presentations on screen because participants were then not visible on-screen. On these occasions therapists relied on audio input or the observations of a colleague on the interactions of participants.

Noise generation was a factor that affected the online group with up to 13 people on screen at a time, including participants, carers and staff. Noise generated, e.g., when carers provided assistance, could be both distracting and cause some anxiety. However, as participants became more aware of each other by taking turns, and familiar with muting microphones, noise generation improved.

Participation

It was particularly encouraging to see all 18 participants completing the 6-week programme. Ten or more of the 12 sessions were attended by 78% of participants. Factors that may have contributed to the 100% programme completion rate were the desire for social interaction and connection during times of isolation as well as encouragement and support by carers and Alzheimer Scotland staff.

Once technical barriers had been addressed, ease of accessibility online was a major factor in the high

attendance. Return to subsequent sessions may have been motivated by the noted improved mood and engagement in most participants following initial sessions. Continued involvement is also likely to have been prompted by session facilitation with general themes suited to all, and content tailored to personalised activities.

A relatively short-term commitment of six weeks also seemed to play a part in adherence. Among stated reasons for non-attendance at sessions were technical connection difficulties, health-related issues, and other commitments on session days. In terms of physical activity, it was heartening to see the initiative of participants limbering up and stretching in anticipation of exercise activities in later sessions.

Communication online

There were some concerns beforehand about how being online via video may compromise open communication, but we quickly found that participants were willing to share with everyone. Having a carer present helped to prompt sharing and conversation, and giving enough time was important for those with speech and language-finding difficulties.

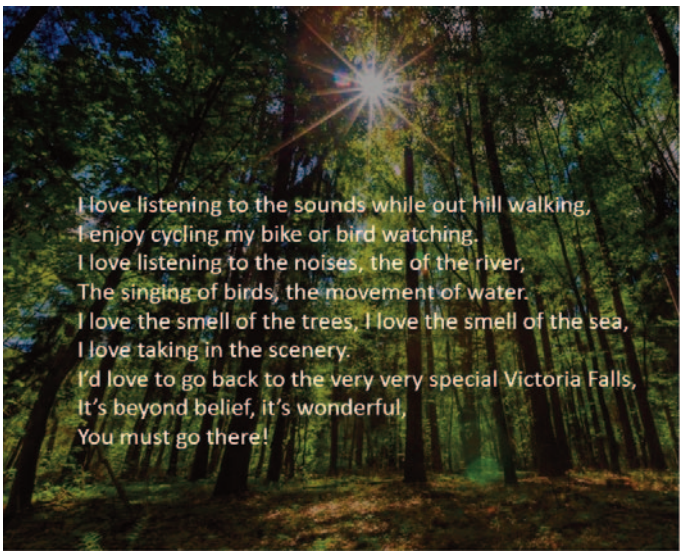
As the weeks progressed, participants became more independent and interacted quite naturally via online video. Positive social engagement increased over time, with more chatting before sessions and friendships being formed. Therapists worked to ensure inclusivity and utilised the knowledge they had gathered about participants to stimulate more engagement and interaction, noting that conversation was livelier when sparked by mutual interests.

Engagement and impact

Therapists measured engagement by qualitatively observing participants interacting through speech, movement, smiling, clapping, and leaning into the screen. In addition, they used an adapted version of the Menorah Park Engagement Scale to grade levels of engagement. (Camp *et al* 2004, Lee *et al* 2007). Constructive engagement was observed through active interaction in 96% of observations.

Reciprocal interaction and friendships between participants were also observed over time. The 6-item Philadelphia Geriatric Center Affect Rating Scale was used to observe affect, as in the visual facial and physical reactions within participants to gauge their mood.(Lawton et al 1996). The general affect reflected overall positive mood in 98% of session observations with "interest" in 54%, "pleasure" in 34% and "contentment" in 10% of noted observations.

Negative emotions of disinterest or sadness were noted in only 0.4% of observations. Overall, no extreme emotions were observed although it was suggested that it may be more difficult to engage participants with more advanced stage dementia who may become restless, anxious or distracted.



The therapeutic intensity of programmes may be expected to elicit both positive and negative emotions. Expressions such as sadness or anger needed to be supported sensitively, and it was helpful to have both therapeutic expertise as well as those who knew participants well to facilitate support for participants to feel safe enough to express their emotions. Supervision by Alzheimer Scotland staff on technical issues was invaluable, enabling therapists to focus on intensive therapeutic delivery.

Mutual learning

Alzheimer Scotland staff and carers said that they had gained knowledge and motivation from the dementia therapists and felt they had received informal training in demonstrating a structured group. Delivery of a group session, content and styles of managing the group structure online seemed to influence how staff adapted their own practice in other group work. They reported stronger engagement with other groups.

Dementia therapists gained more experience in achieving therapeutic rapport with online groups. Given the distance and lack of communication cues compared with face-to-face therapy, there was a need to make more adaptations and be more creative and animated for online delivery. Skills in how to help manage more difficult emotions online without the physical proximity to provide reassurance or comfort were enhanced.

Conclusions

Therapists expressed how moving it was to see how much the online sessions meant to people. Feedback from participants even included a poem written for the team, comments on how lovely it was to meet new people, make new friends, revisit old memories, see familiar faces each week and have a "normal time".

There was a need to set expectations about the end of the programme, with some participants feeling that a void would be left in the time previously dedicated to the sessions. Feedback from carers highlighted their enjoyment, noted improved mood of participants after

sessions and the benefits enjoyed by both participants and carers of socialising online.

Twelve sessions over a relatively short, fixed period of six weeks were advantageous for delivering an intensive programme. Thereafter, less frequent sessions or a booster programme every three months could help maintain the positive effects. Keeping to smaller groups of 3 to 4 participants with dementia was more effective for therapeutic intensity.

This first 6-week, small group programme enabled dementia therapists to identify and refine what works well to facilitate a good digital mode of delivery. It was noted that having separate, ideally one-to-one, online sessions for those at more advanced stages of dementia may be best.

Reception of the programme was overwhelmingly positive based on participation, engagement, observations and feedback. Despite potential barriers of technology and paperwork, Alzheimer Scotland staff provided invaluable support and encouragement. Benefits of mutual learning were observed and feedback from participants and carers in sessions suggested that such online programmes may have value in the future.

Alzheimer Scotland has since launched the Virtual Resource Centre on which Care Visions Healthy Ageing will have their on-demand dementia therapy videos hosted in the near future. You can visit the Alzheimer Scotland Virtual Resource Centre at http://vrc.alzscot.org/

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