

# Using touchscreen tablets with people with dementia

Touchscreen tablets like iPads can provide enjoyable and beneficial activities for people with dementia, but how can access to this technology be widened? **Erica Dove** and colleagues, who conducted a three-year project to find out, share their results

**W**e know that games on touchscreen tablets can provide an enjoyable activity for people with dementia as well as promoting social connections between them and those around them (Astell *et al* 2016). But we need to widen access to tablet technology so that more people with dementia can benefit.

“Let’s Connect” is a three-year project in Canada to do just that. To broaden access Let’s Connect is providing training to family carers, staff, and volunteers to support people with dementia to use tablets and play games on them. Here we share details of the programme, a joint project between the Oshawa Senior Community Centres and researchers at the University Health Network in Ontario, with a view to encouraging anyone else who is interested in adopting tablets for individuals or groups to give it a go.

## Step one: Training the trainer

The first step in Let’s Connect is a “train the trainer” session for staff and volunteers in the day services or long-term care homes taking part. Training sessions are held on-site and last around 90 minutes, including basic information about tablets (e.g. how to use them), game directions, and suggested scripts for presenting the games. Games have been selected for their dementia-friendly features (Joddrell & Astell 2017).

Among the games are familiar ones like bowling, jigsaws and word searches and less familiar ones like Bubble Explode, which we have found to have

lots of accessible features (Joddrell & Astell 2019). We tested lots of games to find the most suitable versions as part of the AcToDementia project and these can be found at [www.actodementia.com](http://www.actodementia.com). They can be played alone or with others.

Each trainee is given a tablet and walked through the selected games at their own pace. This is particularly helpful for those staff and volunteers who are less confident with tablets. Training manuals with photographs and large text are also provided, and we have created digital training tools (e.g. videos) to support remote sites wishing to start using tablets with their clients.

## Step two: Tablet groups

Step two is for the trained staff and volunteers to run a group activity at their day service or care home with support from the Let’s Connect team. In each location, Let’s Connect is a scheduled group offered as part of the regular activity programme. Each session lasts approximately 60 minutes and takes place twice a week for four weeks, over which time staff and volunteers gain experience supporting people with dementia to play the games.

A touchscreen tablet is given to each person, who can then choose whether to play alone or with others. At the first session, their game preferences are discussed and also if they need any physical aids to use the touchscreen, such as a stylus pen. Staff and volunteers are there to help if needed, for example in dealing with pop-up advertisements if these appear while the game is being

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played. Levels of help necessary can range from a little to a lot.

Support can also involve showing someone a correct game move, nudging them in the right direction, or giving reminders. We ask helpers to track attendance at sessions, which games were played and how much players enjoyed them. When the four weeks are up, people with dementia, staff and volunteers are asked for their feedback.

Feedback from people with dementia has highlighted their enjoyment in taking part. The most common reason they give is that it is a chance to learn new technology and try new things, for example:

*Keeps your mind working, gives you something to think about (participant, site 8).*

*I felt I was learning and doing things (participant, site 9).*



People with dementia also value the support provided by staff and volunteers, as well as the opportunity for social contact. For example:

*Well, it gave something for us to do together (participant, site 7).*

*...I didn't have any experience what to do, but someone was always there. I enjoy the assistance... it's encouraging (participant, site 8).*

Staff and volunteers also enjoy the "togetherness" of playing tablet games one-to-one with participants in a social setting, particularly important given the problem of social isolation for people with dementia (Kane & Cook 2013).

For example:

*I guess it's just connecting with the clients on a person level. It's an opportunity for staff to really get one-on-one engagements, which you don't always have the opportunity to do with [other] group programmes and things like that (staff member, site 10).*

*I think you get to know them and get to know their interests and what they like, and you just build relationships through playing the tablet (volunteer, site 9).*

Another key benefit is that playing tablet games changes perceptions and expectations of people with dementia. For example:

*It was just an eye opener. You know, you think people with Alzheimer's would not be interested in things like that (staff member, site 5).*

*I learned that people with dementia are probably able to do more than I thought they could (volunteer, site 5).*

As part of our research we are looking to see if these experiences are reducing stigma among the staff and volunteers, which is a common problem for people living with dementia (Benbow & Jolley 2012).

### Step three: At home

After four weeks at the day service or care home, Let's Connect transfers to people's own homes. Family carers are invited to a session to find out how their relative has been getting along with the tablet and are offered similar training to that given to staff and volunteers. Based on previous experience, we can give them information about their relatives' preferred games and the types of support they need.

Each carer is given a tablet kit, which also contains a manual and accessories,



**Above: A Let's Connect group session, and independent play with a stylus. The icons (below left) show the range of Let's Connect games**

with a record to keep track of tablet play at home such as how often it is used and which games are preferred. They are advised that they can find more games on the AcToDementia website.

Carers are encouraged to support their family member to play tablet games twice weekly for four weeks, sometimes alone, sometimes with the carer themselves, or perhaps another relative such as a grandchild. Once again, after four weeks we ask everyone for their feedback.

People with dementia report that they continue to enjoy playing the games at home and incorporate them into their daily lives, while additional benefits have been reported by family carers. First, they value seeing their relative engaged in a pleasant activity:

*My mother never puts [the tablet] down. She doesn't watch TV anymore. She's enjoying her game very much. She was playing until 10 o'clock last night (carer, site 8).*

*She'd sit down with the game and we'd actually have to suggest that she put it away,*

*because she's had too much screen time (carer, site 8).*

Another key benefit expressed by family caregivers is having a new and fun activity to do together with their loved one. For example:

*It was just the spending some time with Mom, seeing her enjoy herself... (carer, site 8).*

*It was an interaction between the two of us (carer, site 7).*

Finally, carers reported that their relative playing on the tablet gave them some free time, a significant factor when you consider the number of unpaid care hours they undertake (Brodaty & Donkin 2009). For example:

*That's one thing as a caregiver. When we're working 9am – 5pm or in my case 7am – 3pm... the day programme is a godsend. But the applications like the tablets have been very beneficial. You just can't find enough things for [family member with dementia] to do (carer, site 9).*

➤ He put his head down at 8:00 and was playing his game, and he didn't look up again until 9:15. And so, that gave me an hour of respite (carer, site 1).

### Sustaining Let's Connect

When Let's Connect finishes, staff and volunteers at each day service or care home are encouraged to continue running the tablet programme. To help them we give them training materials (e.g. tablet manual, help videos), our list of apps and links to the website, and our contact information. They are also given a tablet log to record the number of clients using the tablets as well as the games played.

Each site is asked to send us this information at the end of every month, so we can review progress. So far, Let's Connect has been adopted at 15 sites as a regular group activity and we are supporting new services further afield through our remote training materials.

### Future directions

The Let's Connect project is in its final year and continues to grow, our main goal being to spread the word about the benefits of tablets for people with dementia. We want to assist as many people as possible to implement tablet programmes in a wide variety of settings, including adult day services, people's own homes, and care homes. Everyone involved benefits from the enjoyment, shared learning, reduced stigma and social connection.

More information and resources relating to the project can be found on our website. Go to [www.oscc.ca](http://www.oscc.ca) and then type "Let's Connect" into the search bar. Enquiries from anyone wishing to adopt Let's Connect or access our training tools are welcomed. Contact the project coordinator at [erica.dove@uhn.ca](mailto:erica.dove@uhn.ca) ■

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# Successful psycho

Distress among family carers can become unmanageable if they are unable to cope with behaviours that arise from stress and distress in the person with dementia they care for, but a community-based psychosocial intervention for carers has led to much lower levels of caregiver distress, as **Juliette Nell**, **Susan Brown** and **Vicky Ladu** report

**B**ehaviours that challenge, such as agitation and aggression, are defined as expressions of distress arising from unmet health or psychosocial needs (Cohen-Mansfield 1986, James & Moniz-Cook 2018). They are common in all types of dementia. Previous literature has indicated that more than 90% of individuals with dementia are likely to experience these behaviours during the course of the condition (Ballard & Corbett 2013).

People with dementia report that the experience of behaviours that challenge is distressing for themselves (Kales *et al* 2015), while observing a relative displaying these behaviours may lead to considerable psychological distress for a carer (Barton *et al* 2014, Livingston *et al* 2014). The additional care burden can place a strain on relationships, and it is associated with negative outcomes such as the breakdown of home care and potentially a move into a care home (Barton *et al* 2014, Livingston *et al* 2014).

In the UK, two-thirds of people with dementia live in the community, in their own homes supported by family and friends (Luengo-Fernandez *et al* 2010). High rates of behaviours that challenge are observed in those who live at home (Moniz-Cook *et al* 2017) and studies have shown that caregivers report significantly higher levels of stress, depression and anxiety compared to non-caregivers of similar ages (Cuijpers 2005, Sörensen *et al* 2006).

When families do receive professional support, two-thirds indicate that health professionals fail to recognise the complexities of caring for someone where behaviour is an issue, which confirms the need for bespoke and specialised interventions (Moniz-Cook *et al* 2017).

As pressure has grown to reduce the use of antipsychotic medications, there has been increasing interest in non-pharmacological alternatives as a response to distress behaviours in

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dementia care. Psychosocial interventions tend to focus on resolving the unmet needs and involve formulating various causes for the behaviours to guide interventions (James & Jackman 2017). Findings from the international Delphi consensus indicate a preference for an escalating response to behaviours in Alzheimer's disease as they develop, commencing with the identification of underlying causes (Kales *et al* 2019). These psychosocial interventions are intended to reduce the frequency and intensity of behaviours.

### Understanding unmet needs

Various models can be applied to understand what unmet needs may be underlying distress behaviours. Kitwood (1997) famously identified six psychological needs to be mindful of when caring for individuals with dementia: love, comfort, identity, occupation, inclusion and attachment. His model focuses on the care recipient and how a carer can adapt to meet their needs.

Guidance from the National Institute for Health and Care Excellence (NICE 2018) states that carers should be offered a psychoeducation and skills training intervention, including education about dementia, support in the development of personalised strategies for distress behaviours with communication adaptations, and advice on how to maintain their own wellbeing as well as that of the person they care for.

A Cochrane review of interventions for behaviours that challenge found that the most effective programmes incorporated

# social intervention for carers

support for the caregiver as well as addressing the unmet needs in the care recipient (Moniz-Cook *et al* 2012). Carers who learned and implemented special strategies were more able to continue caring for their relative at home for a longer period (Hoe *et al* 2017).

## Formulation-led approach

Specialist care home services currently use the Newcastle Model formulation-led protocols in addressing behaviours that challenge (James 2011). The model is structured over a period of 12-weeks, during which health professionals support the implementation of care plans and bespoke training for care home staff based on best practice guidelines (James & Jackman 2017, NICE 2018).

Our service gives this support to staff in residential care and nursing homes across Sunderland and South Tyneside, reducing distress by helping them spot unmet needs and triggers for behaviours that challenge. We work with them to develop appropriate person-centred strategies and the approach has now been adapted by the Northumberland Behaviour Support Service to help family carers in their own homes. Sells and Howarth (2018) refer to this as the caregiver appraisal model.

The Northumberland team assisted our service when we received funding for a home care intervention in Sunderland in 2014, extended to South Tyneside in 2015. We were able to recruit professionals from a nursing and occupational therapy background to develop, lead and implement the new service. A broad range of complementary skills in our behaviour support team as a whole allowed us to deliver the service aims collectively.

We set out to evaluate our home care

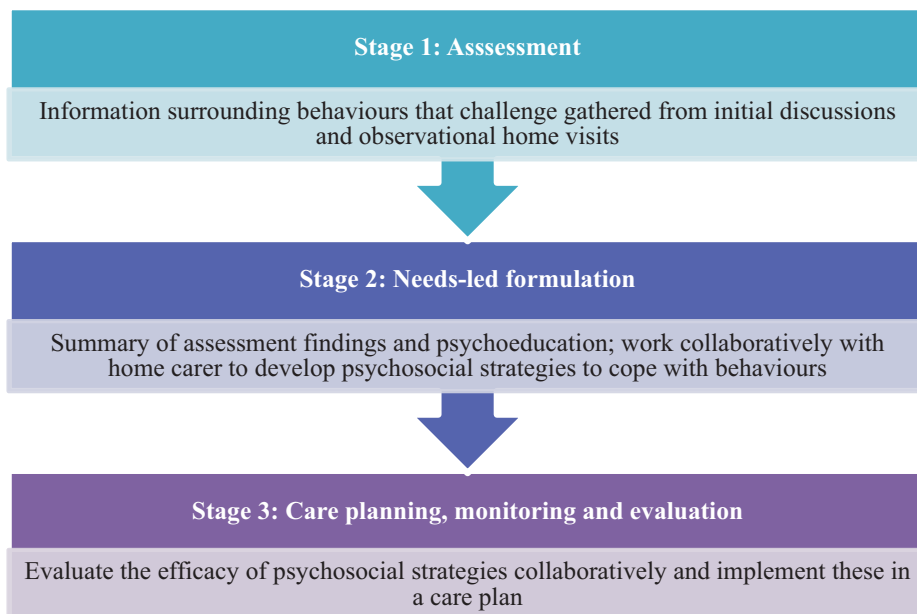


Figure 1: Home carer intervention process

service and its effectiveness in reducing distress among family carers. Based on the positive feedback from the care home-based intervention, it was hypothesised that caregiver distress levels would be significantly decreased.

## Methods

### Participants

In total, 34 family carers who completed our home carer intervention before 1 April 2016 were evaluated. In order to be referred to the service, it was necessary that the person with dementia for whom they were caring was being supported by the community mental health team and that their relatives had given informed consent to engage with the service. The majority of them lived in the Sunderland locality (85%), with the remainder being based in the South Tyneside locality (15%).

### Materials

The Neuropsychiatric Inventory (NPI) with Caregiver Distress Scale (Cummings 1997) measures 12 behaviours that are common in dementia such as agitation and disinhibition, in the context of their severity and frequency. Caregiver distress was measured on a 0 - 5 Likert scale in relation to each of these behaviours and scores were then added up to give an overall score out of 60 for the 12 behaviours as a whole ("pooled behaviours", see table 1 below). Higher scores are associated with increased carer distress and elevated symptoms in the individual with dementia.

### Procedure

A 12-session time frame for implementing the home carer intervention in clinical practice was agreed. The structure of the process was developed using a three-stage approach, which is displayed in the flow chart in figure 1 above.

Stage 1 refers to the assessment period in which a clinician met the carer and care recipient to identify presenting behaviours using the NPI and observe how the home carer typically responded. To ensure a person-centred approach, the assessor also found out about the cared-for person's life story since distress behaviours may relate to life events.

During this stage it was also important that the psychological needs of both ➤

Individual behaviours		Pooled behaviours	
Qualitative descriptor	Score	Qualitative descriptor	Score range
Not distressing	0	No distress - Minimal	0 - 12
Minimal	1	Minimal - Mild	13 - 24
Mild	2	Mild - Moderate	25 - 36
Moderate	3	Moderate - Severe	37 - 48
Severe	4	Severe - Extreme	49 - 60
Extremely distressing	5		

Table 1: Caregiver distress scores

➤ the carer and the care recipient were determined. Throughout the assessment process the clinician gathered this information, as well as information about the care recipient's neurological impairment, physical health, mental health, personality, their social environment and medication, for the purposes of the Newcastle Model caregiver appraisal. This is fundamental for formulation.

In stage 2, the clinician worked collaboratively with the home carer to identify the triggers for the behaviours, summarising the interplay between these and the thoughts and feelings of the person with dementia. From here it was possible to devise a formulation in which the clinician related the unmet needs of the cared-for person to Kitwood's framework of comfort, identity, occupation, inclusion, attachment and love.

Based on these findings, psychosocial interventions were suggested to avoid or curtail the behaviours. The final stage involved monitoring and evaluating these psychosocial strategies, before incorporating the more successful interventions into a care plan that the carer could continue to use. Following the home carer intervention, the NPI was completed again, taking around five minutes to administer.

## Results

Descriptive statistics for caregiver distress scores are shown in table 2 below. They indicate that distress scores decreased following the home care intervention. Before the intervention, the sample collectively fell within the minimal to mild category of distress, which decreased to no distress or minimal distress following the intervention. We were able to show that our data were statistically reliable.

Variation in caregiver distress is indicated by the large range in scores both before and after the intervention.

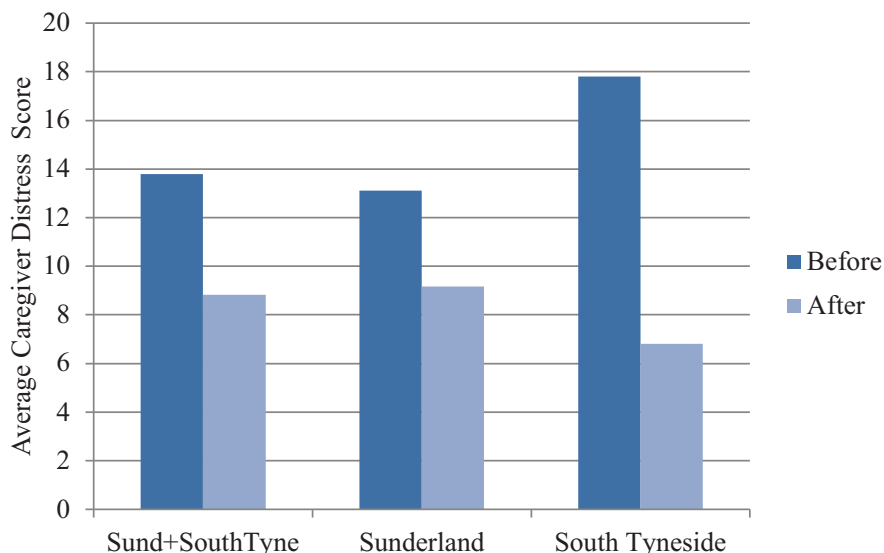


Figure 2: Average caregiver distress before and after intervention

The South Tyneside locality appeared to have higher levels of distress before the intervention; however, the average distress scores for both localities fell within the same qualitative descriptor (see figure 2 above).

In support of the statistical analysis, qualitative feedback from carers further strengthened the credibility of the intervention. They said that the most useful parts of the intervention were learning more about dementia and the specific diagnosis of their loved one, adding that the psychoeducation deepened their understanding and ability to identify unmet psychological needs. Carers also reported that the psychosocial strategies for responding to behaviours were extremely helpful.

## Discussion

The main aim of this evaluation was to assess whether our home carer intervention had a significant impact on the distress scores of carers who reside with a relative with dementia in their own home. Even so, carers did describe a variation in the severity of their loved

one's behaviours following the intervention; where some individuals showed improvements, others remained the same or showed a deterioration.

Since dementia is a progressive condition, these findings about behaviours are expected. The main outcome measure of this evaluation was caregiver distress scores, which were significantly lower after the home carer intervention. This indicates that, regardless of whether there were changes in the behaviours themselves, the change in the caregiver's perception of the behaviours and their ability to manage with appropriate strategies was fundamental in reducing their distress.

Previous literature has only provided limited evidence of the benefits of specialised interventions for home carers. This evaluation contributes to evidence of the necessity of psychosocial interventions to maintain the mental health of carers at home. It also highlights the utility of the NPI in assessing caregiver distress with a view to determining the need for directed interventions.

Our findings are in line with research demonstrating that the most effective psychosocial interventions involve working to meet the needs of the carer and the care recipient jointly (Hoe *et al* 2017, Moniz-Cook *et al* 2012) and mirror the success of the corresponding behaviour support service intervention in care homes. The findings support continuing development of the home carer service.

Our small sample size, however, makes it difficult to generalise these findings and they should be interpreted with caution. In addition, the majority of the sample were from Sunderland which

### Caregiver Distress Scores

	n		M	Min	Max
Sunderland and South Tyneside	34	Before	13.79	2.00	29.00
		After	8.82	0.00	23.00
Sunderland	29	Before	13.10	2.00	24.00
		After	9.17	0.00	23.00
South Tyneside	5	Before	17.80	6.00	29.00
		After	6.80	2.00	12.00

Table 2: Distress scores, showing number of participants (n), average scores (M) and range of scores before and after intervention

made it difficult to make comparisons between the two localities, probably because the South Tyneside locality is geographically smaller and perhaps because the service there was established at a later date. Given South Tyneside's higher average distress scores before the intervention, the effect of a larger sample size on the scores for the combined sample may have been greater than in our evaluation.

Future studies should have a larger sample size to produce more reliable results representative of the target population. Based on previous research it is likely that carer distress levels are in fact higher than we found (Cuijpers 2005, Sörensen *et al* 2006). Despite these limitations, we were still able to establish statistical significance which is very promising for future psychosocial interventions targeted at reducing the distress of home carers.

Some carers were unable to complete the home carer intervention so their data could not be included in our analysis. When accounting for the carers who dropped out, three common themes emerged. Firstly, some interventions came to an end if the individual with dementia was admitted to hospital or a care home. Secondly, some carers struggled to implement a psychosocial approach and instead preferred more practical interventions to support their loved one. Lastly, for some carers the 12-session intervention was too long and they opted instead for a shorter intervention with a greater focus on the psychoeducation component. For these reasons it was difficult to apply the suggested time frame in clinical practice and it became apparent that the structure of the intervention had to be adapted to the needs of the carer and the care recipient.

For carers requiring a shorter intervention, the behaviour support service developed carer awareness sessions offered in both localities to anyone who is referred. These sessions take place weekly over four weeks and the content is considerably different from that offered by voluntary agencies because it reflects a fundamental feature of our approach, namely needs-led formulation.

Sessions cover how carers should appraise their family member's behaviours and how to address any discord between the presenting behaviour and the carer's reaction. They are designed to be interactive and foster peer support among the carers attending. The behaviour support team hopes to widen accessibility in terms of session

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## Regardless of any change in behaviours, change in the caregiver's perception of the behaviours, and their ability to manage with appropriate strategies, was fundamental in reducing their distress

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location, transport availability and time flexibility.

A final thought arising from our evaluation: what if we had used the NPI to determine which individual behaviours contributed most to caregiver distress (Feast *et al* 2016)? We would have been able to see if psychosocial interventions to target the more severe behaviours were effective in improving overall caregiver wellbeing (Lautenschlager 2016).

If a rationale could be provided for identifying and addressing the more severe behaviours first, thereby promoting carer engagement with the intervention, it may be possible to build still further on these promising early results. ■

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