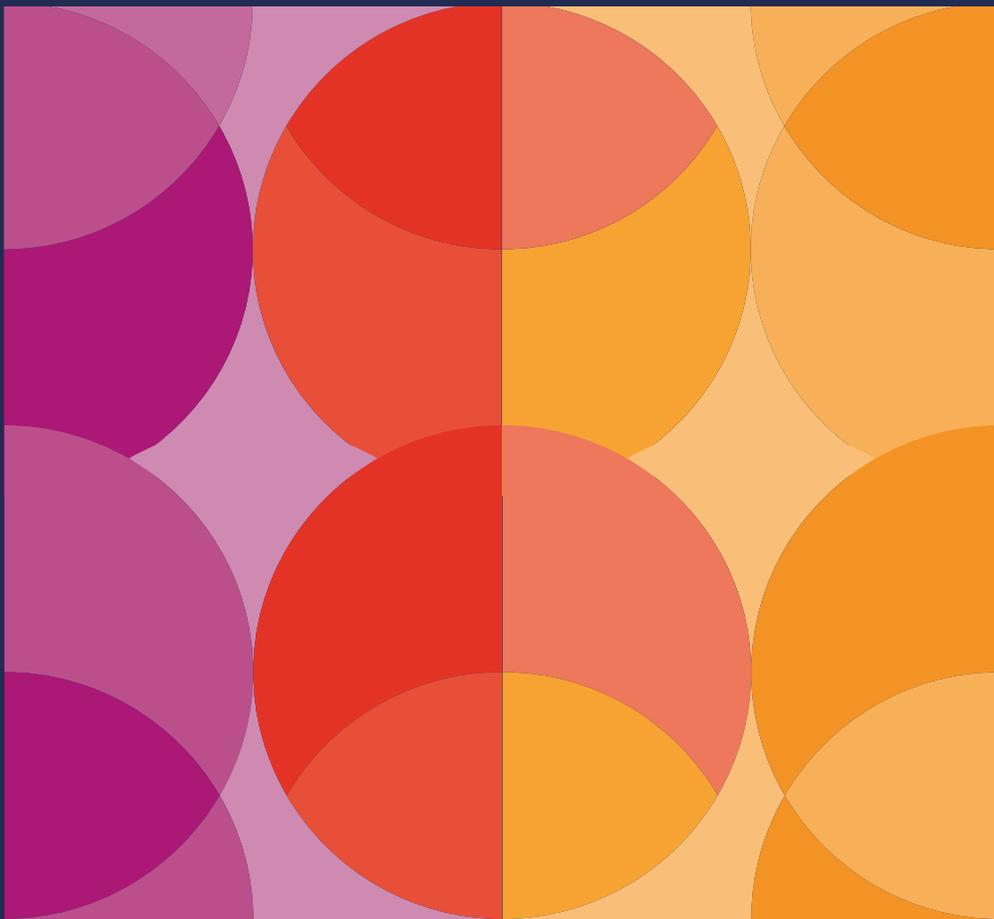




All about you

A retrospective review

April 2021



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retrospective review
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Summary

From late 2018 Cotman Housing ran a project named All About You. Funded by Sport England and delivered in partnership with AgeUK, it aimed to support carers of people with dementia to be more physically active. Over half a million people in the UK care for someone with dementia and most are not doing physical activity or sport.

The project was due to run to September 2021 but unfortunately, due to low participant numbers and the Covid-19 pandemic, it ended early.

Cotman appointed HACT to evaluate the project when it first started. Whilst the project ended early and did not generate the amount of data anticipated for evaluation, HACT has written this retrospective review based on engagement with Cotman staff through the project.

The project confirmed that there are many carers who need support but are not receiving it. Although the number of participants was low, this does not reflect a lack of interest on the part of carers. Many were receptive, indeed keen, to be more physically active. The everyday realities of caring for someone with dementia negated this desire.

Our key findings were that:

- Whether they wanted to or not, **many carers just did not feel able to take time out for themselves to exercise.** Supporting them to do this is a necessary first step, before physical activity can even be considered.
- Any future project promoting physical activity amongst carers should consider it a two-step process. **Support the carer to take breaks from their caring duties first, and then work on getting them to use that time for physical activity.**
- **Support needs to be bespoke,** to match the specific needs and capacity carers have.
- **Projects like All About You have to be resourced effectively.** It takes time to engage with carers.
- **Similarly, projects need longer lead-in times.** Allowing a period of time for engagement and promotion prior to the project starting would increase the chances of success.
- **Be prepared to be inventive.** Cotman had planned innovations, such as sending trainers into participants' homes, that could have increased participation.

Carers are a group who need all the help they can get. It is unfortunate this project did not work as hoped, but Cotman's experience adds to a body of evidence and will hopefully support other organisations to deliver effective services to carers.

1 Introduction

Cotman Housing is a housing association based in East Anglia. Part of the Places for People group, it has over 3,300 homes across Norfolk, Suffolk, Essex and Cambridge. In late 2018 it launched a project named All About You based primarily in Norwich and its surroundings. Its purpose was to support carers of people living with dementia to take part in sport and physical activity. The project was delivered in partnership with AgeUK and funded by Sport England.

The project was due to run until September 2021, however in July 2020 Cotman took the decision to terminate the project early, at the end of August. Throughout its operation, the project struggled to engage the number of people anticipated, however it was the Covid-19 pandemic that ultimately necessitated this decision. Like all housing associations, lockdown meant that Cotman could no longer deliver services in person, which has been a challenge for all projects. All About You also had the additional issue of the target group being largely comprised of those who were advised to shield.

Lockdown and shielding made running the project unfeasible, and All About You was therefore paused. However, as it became clear that the pandemic would continue into at least Spring 2021, the decision was taken to end All About You early. The project found it difficult to engage people even before the pandemic, and the time available between the point when it might be able to restart and the end date of September 2021 would not be long enough to reboot it effectively.

At the outset, HACT was engaged to evaluate All About You. The evaluation was originally intended to measure the success of the project by tracking its impact on participants through quantitative surveys and qualitative interviews. However, for the above reasons, the evaluation originally envisaged was not possible. Nonetheless, Cotman asked HACT to write this retrospective report, which summarises the issues encountered with the project and what can be learned. The information in this report has been compiled from the ongoing conversations HACT had with Cotman throughout the project, and interviews with key staff upon the ending of All About You, as well as engagement with staff, volunteers and Cotman documents that HACT had been undertaking throughout the project, prior to the Covid-19 pandemic.

HACT commends Cotman's commitment to good practice in research. It is easy to welcome evaluation when something has worked well, however reflecting on where something has not worked as planned is a vital exercise, and just as important to growing our knowledge base.

This report has been written with this in mind. The aim is that documenting Cotman's experiences with All About You will support both Cotman's internal learning, and also any other organisations looking to run a similar project in the future.

2 All About You in practice

Target audience

The target audience for All About You was carers of people with dementia. Any project addressing this target audience is a valuable one; carers of people with dementia are a sizeable but underserved group. NHS England estimates that in England there are around 540,000 carers of people with dementia, and that one in three people will care for a person with dementia in their lifetime.¹ For carers in general, 63.5% say they have had no or not enough support.² Clearly, there are likely to be significant numbers of people in Cotman's area of operation who are caring for someone with dementia, and not receiving the support they need or want.

Evidence also suggests that physical activity in carers is an area worth focussing on. Research shows that carers do not feel able to focus on their own health and wellbeing. NHS Digital found that only half of carers say they look after themselves while under a fifth say they can spend their time doing things they value or enjoy.³ Specifically in carers of people with dementia, Dementia Carers Count conducted a survey that found only 27% have time to pamper themselves or do a sporting or craft activity.⁴ Clearly,

as it is combined in that statistic with other activities, the figure for physical activity is lower.

Therefore, there is certainly a need for projects that support dementia carers to do physical activity. Cotman responded to this need through its project.

Delivery

All About You was designed to offer support to both carers and the person being cared for, by providing a varied programme of activities in which both could participate, either together or separately. Cotman developed partnerships with local leisure centres to offer participants memberships, to allow them to take advantage of the facilities and classes. Age UK Norwich also recruited and trained volunteers to offer ongoing support and encouragement to carers. The role of volunteers was central to the operating model, as by spending time with the person being cared for, they allowed the carer the time and space to do physical activity.

However, as noted, All About You was a project that struggled throughout its operation to get the desired participant numbers. The following pages explore some of the issues Cotman encountered during delivery.

1 <https://www.england.nhs.uk/mental-health/dementia/#:~:text=However%2C%20for%20some%20dementia%20can,with%20dementia%20in%20their%20lifetime.>

2 <https://www.dementiastatistics.org/statistics/impact-on-carers/>

3 https://files.digital.nhs.uk/88/F04948/PSS_SACE_Report_2018-19.pdf

4 <https://dementiacarers.org.uk/for-dementia-professionals/carers-consultation-results/>

Generating engagement

Despite planning, the project struggled with engagement. The number of participants that sign up was lower than anticipated throughout the project's operation. The original target was to have 30 people signed up to the project by Year Three, however only 13 signed up, with four regularly active.

The project struggled to overcome the issue of carers not feeling able to take time for themselves. Carers simply do not feel willing and able to take the time to do physical activity. There is both a practical and an emotional cause to this. Practically, carers are often physically exhausted. Being a carer can be physically demanding and can leave carers with very little energy. It is very difficult to convince them that the small amount of personal time they have should be spent doing physical activity, as opposed to resting.

Cotman also found that there is an emotional element to carers' unwillingness to take time out to do physical activity. Many carers feel they can't take time for themselves because the person who they care for needs them. They might even feel selfish for doing so. These feelings can be especially acute in cases involving couples that used to do activities together; carers might feel guilt at doing the same activities alone.

Finally, in terms of difficulty engaging carers, Cotman found that a major issue is that some

carers need far more than just some support to do physical activity. There are some who are really struggling and finding the time to do physical activity is far down their list of priorities, or perhaps not on it at all.

From HACT's interviews with Cotman staff, it seems that Cotman tried just about everything it could to generate engagement. Staff formed relationships with many dementia organisations in the area, and regularly visited dementia support groups to promote the project. This tells us what major barriers there are to engaging carers, which is a vital piece of learning for any future attempts to engage them in projects.

Resourcing

The amount of resources allocated to the project also limited its success. Only one Cotman staff member working 20 hours per week was allocated to the project. While much was achieved with the time available, it nonetheless restricted how much could be done. A particular issue was the number of existing local groups and meetings that were already available. Although the existence of these groups is positive, it proved challenging to engage and visit them all to promote the project, whilst also doing the practical tasks of delivering and managing the project within the time available. More time, and therefore more scope to engage these groups, might have helped deliver higher participant numbers. Being able to do this more concertedly would have helped promote the

project to a wider pool of people, as well as increased engagement with groups to convert potential interest into participation.

Volunteers

Limited resources also meant the project relied on volunteers, many of whom were enthusiastic and built an excellent rapport with participants. However, using volunteers restricted the pool of participants that could engage with the project as only those who have needs that can be met by a volunteer could be involved.

For example, the project could not engage any cases where an individual has personal care needs, as this is beyond volunteers' competencies. Carers of people with dementia are already hard to engage, for the reasons noted above, so reducing the potential pool of participants to only those with lower-level needs by using volunteers was a major challenge.

Lead-in time

There was limited lead-in time for the project. Cotman had to begin work almost immediately upon being awarded the project, as this was the timeframe desired by Sport England. This meant less time to organise things like promotion, marketing and networking that are key to the successful delivery of any project. As a result, the KPIs set by Cotman were challenging from the outset.

Covid-19

Whilst the project faced significant challenges from the outset, the major blow came from the Covid-19 pandemic. When lockdown was imposed in March 2020 all leisure centres were forced to close. Compounding this, many of the target audience were advised by the government and NHS to shield themselves. This meant that, even if Cotman had found a solution to the issue of leisure centres being closed, continuing the project would have been extremely difficult. Some of the volunteers were also told to shield themselves, adding to the difficulties.

One adaptation made by many housing associations during the early months of the pandemic was to shift services to remote delivery. However, given both the target audience and the nature of the project, this was not a viable option.

Covid-19 also prevented Cotman from bringing instructors into participants' homes, something that Cotman had investigated prior to the pandemic. The idea had received an excellent response, and Cotman felt that it would have boosted participation in the project. However, the pandemic prevented the implementation of this new mode of delivery for the project. Since the mixing of households was forbidden under lockdown rules, and many of the project's target audience were highly vulnerable, it was clearly not appropriate to have someone regularly entering the participants' homes.

Partnership working

Partnership working was both a strength and challenge of Cotman's approach. Cotman recognised it lacked specialist knowledge of the dementia landscape in and around Norwich, and as such needed to develop partnerships with organisations that did.

The relationship with AgeUK was a positive experience. AgeUK lead the Dementia Action Alliance in Norwich, which was a useful resource for Cotman. The Alliance is made up of organisations in Norwich that work with people with dementia, and therefore were able to help with access to potential participants. However, a conference planned with Dementia Action Alliance Norwich in July was cancelled due to Covid-19. Cotman had hoped the conference would help build relationships with other organisations that could connect them with potential participants. Its cancellation meant Cotman was not able to forge those relationships.

In other ways, partnership working challenging. Despite the Alliance, Cotman found that work on dementia is disjointed. There are many organisations of various sizes working with people with dementia, carers, or both. Neither is there a joined-up approach between those offering support, nor is there a holistic approach to what and how support is provided. This made it hard to link All About You with the other groups and projects that could have made it most effective.

Impact

The lower than anticipated participant numbers obviously limited the impact of All About You. However, it should be noted that in cases where it worked, it did work very well. Those participants who took up the offers available to them made great use of them and will miss the project and the opportunity it gave them to do physical activity. It is unfortunate that there were not more participants on whom to collect survey data, as anecdotal feedback from staff and volunteers is very positive. Had it been possible to generate enough survey data, it seems likely this would have shown a positive impact for the project.

In particular, staff noted how valued the project had been by couples that had taken part. For a couple where one has dementia, doing physical activity together can have a huge emotional benefit. For example, swimming proved particularly popular, offering a chance for two people to be a couple again, rather than patient and carer, even for an hour a week.

Those who took part also benefitted from forging new relationships. This includes volunteers, who feedback that they found it an enriching experience. In many ways, these new relationships are the major positive legacy for the project. Even if the physical activity element is not maintained, for people with dementia and their carers, a new relationship is in itself a positive outcome.

3 Learning from All About You

Whilst All About You may not have gone as Cotman had hoped, there is nonetheless a huge amount to learn from the experience. This is the case both for Cotman internally, but also for other organisations wanting to undertake a similar project.

The first, and perhaps most important lesson, is that this is a group that really does need support. Carers are somewhat forgotten, and Cotman found how few other services there were available for this group. Whilst it can be a challenging group with which to work, it really is vital that this work is done, as the impact can be huge. Carers getting time to look after their own physical and mental health is of the utmost importance, for both themselves and their ability to be effective care-givers.

In terms of practical learning about delivering such a project, the main conclusion from Cotman's efforts is that this is a group who need a very bespoke service. Many carers do not feel they have the time to focus on themselves, and even if they do, they are unlikely to want to get in a car or on public transport to travel to a leisure centre. A delivery model more likely to be successful would be to have trainers going into homes. When Cotman proposed this prior to the pandemic, the response was positive. Having such a project go into carers' homes would remove the biggest barrier to engagement, which is travel. Also, as noted, carers are often

very used to services and support coming into the home, so this may feel like a less daunting way of engaging with physical activity than, for example, visiting a leisure centre.

That said, even this model may run up against the barrier Cotman found of carers simply not feeling able to take time for themselves. The feeling that it is selfish to do so poses a significant emotional and psychological barrier. Any project wanting to get carers physically active therefore needs to give serious thought to tackling this. It may be that physical activity has to be a second step. The first step being to work with carers to help them understand that they can, and must, take time for themselves, and support them to do so. Only once this is achieved can physical activity even become a viable ambition. One way to make this easier would be to catch people at the start of their journey as a carer. Cotman found these were the people with the most enthusiasm. They are not as set in patterns and behaviours as a long-term carer might be, offering the possibility of ingraining healthy behaviours around physical activity.

Importantly, all of this needs to be resourced appropriately. The resources for All About You certainly limited what could be achieved. There may need to be some acknowledgement that this is simply not a group who can be supported on limited resources. To work, it would need a full-time member of staff, and the funds to send

trainers into carers' homes, or to provide respite care for them so they can have time to do physical activity. This would need significant resourcing from funders. However, this is a group that needs support so it is worth doing. There is a case for bidding organisations to be more ambitious about asking for funding to be able to provide a service that would be more effective.

Challenging funders more around what is realistically deliverable is another learning. With hindsight, Cotman could have challenged Sport England more on the budget available and perhaps been more conservative with KPIs. It is also important to remember that there is nothing wrong with being hard-nosed when it comes to assessing whether funding on offer is enough to deliver a quality service. If the funding on offer seems too low, Cotman should not be shy about saying so and declining to bid.

Finally, Cotman's experience demonstrated the importance of contacts and being really linked into local networks of organisations providing support and services for carers and people with dementia. All About You did not have any lead-in time, and this is something that any similar project should certainly change.

A project of this type is far more likely to be successful if there is a planned sustained period of engagement, marketing and networking far in advance of the project actually launching.

Conclusions

All About You may not have worked as hoped. However, for those who did take up the support on offer it was an extremely valuable project. Whilst the participant numbers may not have been as high as hoped, this does not diminish the benefits experienced by those who did get involved.

Ultimately, while there were challenges from the outset, it was Covid-19 that forced the premature end of the project. It is very possible that the combination of Cotman's plan to offer trainers in participants' homes and a soft-relaunch of the project through the planned July Dementia Action Alliance Norwich event may have worked to increase engagement. However, the pandemic and lockdown rendered this moot.

That being said, learning from projects that do not work can be just as valuable as from those that do. There is a huge amount for Cotman to learn from All About You, in terms of engaging carers, and more broadly in how to run successful projects. Further, there is a lot to be learned from All About You for any other organisation that wants to support carers of people with dementia.

This is why it is so important to be self-reflective when projects wrap-up, whether they have worked or not.



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