

Introduction and background

Contemporary approaches to understanding dementia encourage us to think about how people can live well within our communities (Cantley et al., 2005; Behuniak, 2010; Williamson, 2012; Caine, 2014). People with dementia are increasingly finding a voice in debates around issues that affect them, with improved service user involvement and increased respect for 'experts by experience' (Dementia Alliance International, 2015). Salford Institute for Dementia (SIfD) at Salford University has addressed this need through creation of a group of people who have been termed Dementia Associates (DA); people living with dementia and their families and friends who meet together regularly and who work alongside institute staff on various projects. One observation made in a DA meeting identified the lack of events delivered *for* people with dementia *by* people with dementia. Therefore the DA with Salford University Institute for Dementia staff teamed up with community partners the Alzheimer's Society and social enterprise Social Adventures to co-produce an event for people affected by dementia. Peer feedback at the UK dementia congress in 2016 indicated that people wanted to know more (Luxmoore et al, 2016). Therefore, this paper reports the evaluation of planning and delivering this project and the resulting event: The Good Life festival. The aim of this paper is to share good practice and inspire others to create their own events of a similar nature.

Aims of the project

The project aimed to deliver an event that was co-produced and delivered by and for people affected by dementia.

Co-production is defined as '*a relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities*' (Joseph Rowntree Foundation, 2013, p1). Although this was an event rather than a service, this approach defined the principles of our intentions nicely.

Methods

A core planning group for the event was formed from the DA group and community partner contacts. The planning group consisted of two people diagnosed with dementia, three carers and three representatives from the partner organisations. Although one person with dementia and one carer left the group after 6 meetings, Lesley, Sam, Claire Emma, Pat and Beth continued as the core group throughout. Lesley, Sam and Pat will be referred to as volunteers. Pat is a carer. Lesley was diagnosed with Alzheimer's disease around three years ago and her husband, Sam, was at the time of the event her main carer; unfortunately he has since died (quotes from Sam in this article are written as he reported them at the time rather than in the past tense). Claire, Beth and Emma are referred to as professionals in this paper.

The small planning group ensured that meetings could remain person centred and a democratic approach was encouraged around defining the working process. As Realpe &

Wallace (2010) suggest, the role of professionals is changed in co-production to that of facilitators with shared power with service users as experts in their own circumstances. Therefore the professional staff took on most of the office based work because time and resources were available to them as part of their employment. They also became the facilitators of the group.

Planning meetings were held fortnightly over a six month period. Eventually the group chose an event theme of celebrating different ways people live well with dementia. The group members hoped to inspire others affected by dementia, especially those who were recently diagnosed, by delivering an event to showcase user-led initiatives that help people to live well. It was very important to the volunteers that this event should be different to other dementia related events they had attended, not just, as Lesley said, '*dishing out leaflets*'. The concept of 'The Good Life Festival' was born, with the tagline 'Dementia: our challenge, our adventure' to illustrate how people have reframed dementia as a challenge that could lead to new opportunities.

Promoting the event

Pairs teamed up to visit different services, for example the Memory Clinic, to advertise the event to new people and encourage inclusion. A publicity stunt included people affected by dementia cycling 80 miles on a stationary bike in the local shopping precinct (see figure 1). Those affected by dementia were able to connect with their peer groups, facilitating great interest within local dementia groups and members of the public. As Lesley said;

'The bike ride was great... We were changing people's perceptions... people think that you get your diagnosis one day and the next day you are ga ga... people see TV programmes with people with dementia and they see the worst, they see the wrong impression, they don't see the other side when people are living well. The cycling in the precinct did that, it got people's attention and showed how well we can be'.



Figure 1 Volunteer group member Pat takes part in the stationary cycle ‘From Salford to Southport’ to publicise the Good Life Festival.

The Good Life Festival event was administered by the SIfD and flyers provided contact details so that people could register their attendance so that numbers could be managed.

The Good Life Festival

On Saturday 12 March 2016 around 80 people were welcomed to the Old Fire Station at Salford University. The programme on the day featured a series of interactive workshops to promote dementia friendly initiatives as shown in figure 2.

Figure 2 The Good life festival programme

The Good Life Festival Dementia – Our Challenge, Our Adventure			
Start 10:30am	Living the Good Life with Dementia – Room 1 Natalie from the Salford Institute for Dementia will open the event. Joy from Dementia Havens will talk about her experiences of being diagnosed with young onset Alzheimer's Disease and the work she has done campaigning for people affected by dementia since.		
Finish 11:00am	Then choose a workshop:		
Start 11:15am	Keeping Active – Room 1 Lesley will talk about her experiences learning to swim with Marie from Dementia Friendly Swimming . Volunteers from Dancing with Dementia will give a dancing demonstration and a chance to join in!	Get Outdoors – Room 2 Join Jess and Hilary from Red Rose Forest to find out more about the Naturally Active programme, including nature walks, gentle bike rides and other nature themed activities that are great fun for all the family.	
Finish 12:00			
Start 12:00	Lunch – Room 1 Everyone joins together again for meat or vegetarian hot pot, served with red cabbage and bread. You are welcome to take your lunch into Room 2 if you need more space.		
Finish 1:00pm			
Start 1:00pm	“Take Care Son” – Room 1 Cartoonist Tony Husband will talk about the book that he wrote about his dad's experience of dementia. There will then be a chance to ask Tony to do some drawings live! Afternoon tea will be available afterwards.		
Finish 1:45pm	Then choose a workshop or tour:		
Start 2:00pm	A sense of Adventure – Room 1 Dementia Adventure support people to get outdoors and have adventure in their lives. Rachel will be joined by Tommy and Joyce who will talk about staying active and holidays with dementia.	Living well: friendship & work – Room 2 Mike and Kevin will talk about their experiences of working on the Open Doors programme after being diagnosed with dementia and how they live well with dementia.	Dementia Friendly Museum Tour Join Naomi for a free tour of the Victorian Gallery and other exhibitions at Salford Museum and Art Gallery.
Finish 2:45pm			
Start 2:45pm	Sing-a-long – Room 1 All join together again at the end of the day to sing our favourite songs with help from Clare, our Singing for the Brain leader, to close the day's celebrations.		
Finish 3:15pm			

Each session included people living with dementia talking about their personal experiences. This allowed attendees to connect with others in similar situations and to learn about how others have been through a process of coming to terms with a diagnosis and finding ways to continue to enjoy life. Efforts were made to make every aspect of the day dementia friendly. This included plenty of breaks for tea and home-made cake and a dedicated quiet room for anyone who needed a break from the activity. Wearing bright yellow sashes and hoodies, they were easy to identify and had time to talk to and support attendees (see figure 3)

Figure 3 Sam at the event.



A talk by cartoonist Tony Husband was one of the highlights of the day (see figure 4). He talked about his book “Take Care Son” which tells the story of his dad’s experience of dementia in a way that had everyone smiling but without glossing over or making light of the challenges his family faced. After his talk, attendees were invited to have their favourite memories turned into drawings to take home as a souvenir of the day.

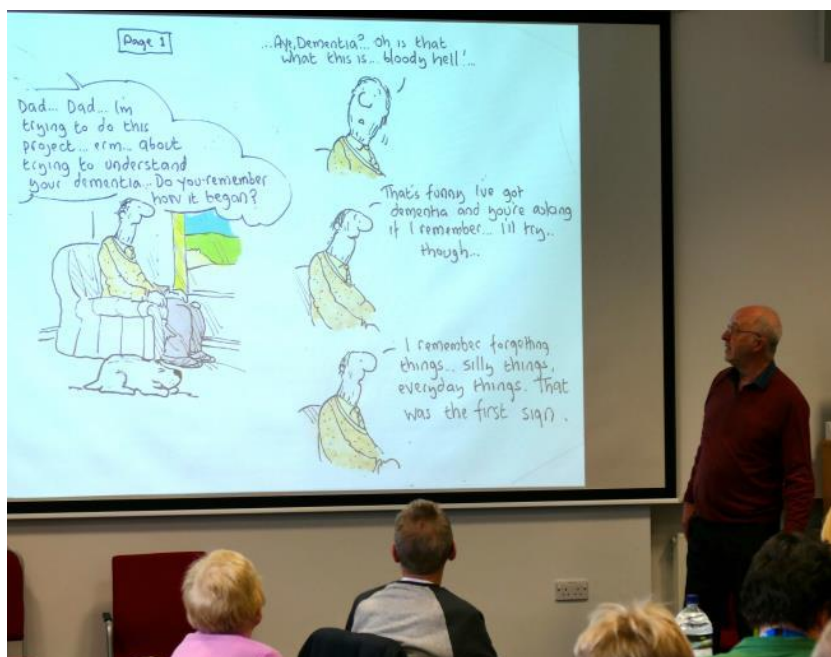


Figure 4 Cartoonist Tony Husband talked about his dad's experience of living with dementia.

Evaluation

The planning group and the event delivery were evaluated by both an evaluation tool and a post event debriefing and reflection (Lesley, Sam, Beth and Claire). Attendees were invited to complete a dementia friendly tool designed by the group and record a Yes, Not sure or No response to the questions:

- I have enjoyed the event today
- I have learned something new
- I feel more positive about living with dementia after today's event

There was also space to make comments, and although very little was written on the evaluation form on the day, a few people emailed later to offer this feedback.

In total, 35 responses were collected which can be seen in table 1.

Table 1 Evaluation responses

Statements	Yes (number)	%	No	Not sure	No answer
I have enjoyed the day	100% (35)		0	0	0
I have learnt something new	91% (32)		0	9% (3)	0
I feel more positive about living with dementia	77% (27)		0	14% (5)	9% (3)

Qualitative feedback from attendees indicated that the day was 'excellent' 'inspiring' 'well organised' with a 'fun and friendly atmosphere'. One person said:

'I think the biggest impact on me was that here were a host of ordinary people doing extraordinary things! I was proud to be part of the day, part of the bigger picture. The people with dementia facing challenges by making positive contributions to society, changing the way that the world reacts to the condition and really making a positive improvement. Absolutely amazing!'

One attendee offered more detailed feedback:

A chance meeting... in the Salford Precinct led us to The Good Life festival held on 12th March at the fire station in Salford. '... my husband has been diagnosed with Alzheimer's. It was a scary thing to think about. Having gone to the festival we have met lots of very inspiring people with dementia all getting on with their lives in a very positive way. The organization that went into the day was amazing the volunteers seemed to be everywhere, even helping being waiters and waitresses for the lovely meal supplied. We also had a visit from a quite famous cartoonist Tony Husband who spent a lot of time making cartoons of people he made one of my husband who was a builder so thank you for giving your time.

We were given some flyers and one was the Swinton Palais dance so on Monday we took ourselves off just as observers but we really enjoyed it. Also we were told about the swimming at the Worsley pool for Dementia and today we went along. A member of staff took my husband through all the facilities; he managed a 30 minute swim which he had not done for a few years. Without that Good Life Festival we would still be in the dark so a very big thank you to all the organizers and the volunteers who made the day special'.

A final debriefing meeting was held by the core planning group after the event and is presented below, first from a volunteer perspective followed by the professional perspective.

Volunteers: DA Lesley and Sam

We were satisfied with programme of the event of activities and the balance with the right number of people to maintain a family feeling. Having people affected by dementia talking openly about their experiences and supporting one another was effective;

'This was more hands on, it was people from the coalface, been there, done that, got the t-shirt, still on the learning curve, and helping people who have just started at the coal face. Hopefully that's what we've done' (Sam).

The tone of the event was set from the beginning of the day and caught peoples interest whereby a talk by a person with dementia *'set the tone'* as it showed *'look what I can do...she's got dementia and she's doing that?!'* you know, saying *I've been diagnosed and I'm still living life'*. (Sam)

Supporting those who were less able to get drinks, warning people about the cobbled path on their way in to the building and making sure that everyone got a friendly welcome were important as *'those little things made a difference, just to look after people'* (Sam)

The event publicity was successful in attracting people from outside their usual circles who were not accessing support services. We felt that providing transport for those who needed it helped to reach these audiences;

'Because people didn't have to worry about getting there, you are getting the people who might use it as a reason not to get out, they can't walk far or drive, it puts them off going out because it's an ordeal'(Lesley).

Professionals: Claire and Beth

Despite experience in delivering and facilitating dementia user involvement programmes, using a co-production approach to deliver an event was a new style of working which felt truly user led where the group had proper ownership of what we wanted to deliver and how we would work towards it. People living with dementia really listened and engaged with volunteers during promotional activities;

'The cycling stunt worked really well because it was a chance for the volunteers to really connect with the public. It really helped them to gain confidence to have people listen to them. It was a chance to challenge stigma in a very public place' (Claire).

Similar to Lesley and Sam, we were glad to see that the publicity of the event was successful in attracting people to the event who were not already accessing groups and services and making them aware of different things that were going on that they could access to help them to live well.

Evaluation of the planning group

Part way through the planning process, a decision was made to limit the size of the event. There wasn't a full consensus from the group at this point, which led to two members of the group withdrawing. From the professionals point of view this may have been avoided if they had agreement early on a *'clearer brief, more defined boundaries about what was within our budget from the start...to talk openly about people being mindful that some people with dementia may have additional needs or sometimes heightened sensitivities, and how we would prefer to work together. This might have helped prevent some of the challenges we had along the way...everybody who was involved was passionate about dementia, but was coming from a different perspective, we had to make sure that these strong opinions were managed and that decisions were always based on a group consensus'* (Claire).

We all learned from our involvement in the project, above all gaining an understanding as to the amount of work that was required to put on an event. The number and frequency (fortnightly) of meetings was about right. Lesley found that her dementia symptoms sometimes made it difficult for her to recall the progress and decisions that had been made by the team between meetings, *'if you'd said to me 'what did we do here today?' I didn't remember what we'd done, but having said that, I knew what we were doing and I knew the end result was the festival... it's not the number of meetings, it's retaining the information, people think I'm really good but I just bluff it half the time'*.

Although for the professionals *'...having a smaller group felt easier to manage, to make decisions and to give individuals with dementia the support they needed to contribute to the discussions* (Beth), the volunteers suggested that it would have benefitted from more participants to get a broader range of perspectives because *'sometimes you felt like you were in a box and you felt like you needed someone to come from outside the box, but the way it worked out I think we did OK, I think we took everything in'* (Lesley).

Both Lesley and Sam felt that the planning group achieved the aims that they set out to;

'I actually put it on my Facebook page and the amount of people that congratulated us was lovely...there was a bit of scepticism from some people who didn't think it was going to be as good as it was and they were surprised... I honestly do think though, for our first attempt, we couldn't have done better, I don't think so and I felt proud that we'd put it together because we'd been a team' (Lesley).

Transport for attendees who needed it was funded by Salford Alzheimer's society as part of their engagement remit. They also provided vouchers for speakers. SIfD funded food (approx. £400), sweatshirts (approx. £100) and costs for staff e.g. security, which were incurred as the event was on a Saturday. Although it would have been cheaper in the week, Saturday enabled relatives and friends who worked during the week to attend.

Discussion

The evaluation is overall positive. However, it could be that only those people with good things to say took the trouble to email feedback. Although 100% of the completed evaluation forms indicated they enjoyed the day, this could be positive bias; there were only 35 out of 80 returned. Nevertheless many lessons have been learned from the planning and delivery process of this event which are outlined in the recommendations section. The fact that 77% (n= 27) reported feeling more positive about living with dementia after the event demonstrates that this is achievable, though we have no information on whether or how this was sustained over time.

The success of the event perhaps lay partly in the existing good relationships between the parties concerned. One of the main challenges was to keep the spirit of co-production whilst also meeting what we saw as our obligation to ensure a duty of care. This potential conflict required a careful balance to be maintained between respecting each other as peers and the risk of paternalism. The DA group members are open about any impairment and able to make their needs known, in keeping with recognition of dementia as a disability (Alzheimer Europe, 2016). It was reasonable therefore for the facilitator role was filled by professionals with reference to the time, skills and resources available. Similarly, for example, Lesley, as a retired nurse drew on her professional skills and these were valuable assets in the co-production process.

The co-production process respected all contributions with the appropriate public acknowledgement (Swaffer, 2014) as authorship of this paper is shared. Although payment was not given, this was in keeping with previous agreements regarding how SIfD would work with the associates and how their work is recognised and rewarded.

One of the most rewarding aspects of the project has been to see the lasting legacy of the event, for example, learning that people who attended the event and have now gone on to attend new groups or services. Hearing from attendees that it was a success in terms of reaching out to new people was gratifying. A short film of the event and event blog can be seen at <https://www.youtube.com/watch?v=a-cG9XuhUwQ> and <http://blogs.salford.ac.uk/dementia/tag/good-life/>

Recommendations: Lessons learned

Volunteer (Lesley and Sam) recommendations:

Planning group

- More memory aids to refresh what has been decided or discussed at previous meetings.
- More planned consultation with other dementia groups and services to get ideas from wider perspectives and to make sure that the event is appealing to different tastes.
- Work with sheltered housing accommodation to put on group taxis to reach more people who are isolated.

Event

- Asking people to book their place in advance meant the group knew who to expect and could cater for individuals' needs accordingly.
- Setting up the venue the evening before, this took the pressure off on the day.
- Assign volunteers to serving drinks at tables for those who are less able.
- More choice of cutlery for those who were not able to use the plastic knives and forks provided.
- The clear signage was helpful and should be used again.
- Black on yellow text on signage and hoodies made signage easy to stand out and volunteers were easily identified by their yellow sashes.
- More music during the day would have been nice, for example background music during the lunch break.
- It was important not to make the event too long, as many people were tired by the end of the day.
- It would have been useful to organise a follow up letter to all attendees to make sure that people knew how to get involved with other resources/services advertised on the day.
- The venue worked well for the event; the environment was important and efforts were made to make sure that it was easy to move around the building and between rooms.
- If the space had been available, it would have been useful to have a private space for providing one to one support for attendees.
- Plan to contact people after the event to ask for evaluation feedback rather than on the day
- Asking people to indicate if they were happy to be photographed during the event when they registered was useful.
- Having a media strategy in place would have been useful, to know in advance how to share the outcomes of the event locally and beyond.

Conclusions

The success of the Good Life festival relied on a small co-facilitated group which operated on co-production principles but within an ethos of mutual support and duty of care. The aims of the festival were achieved as well as many lessons learned for informing events such as these

for the future. You can do it too; decide what you can commit to and stick to it within your skills and confidence.

One interested attendee who had requested a place, festival expert Dr. Gary Kerr (a researcher in social sciences at Salford University), remarked in his blog that ‘festival’ and ‘dementia’ were an oxymoron and that;

‘The festival was probably the most organised and well-thought-out festival event I have ever been to (as a festivals researcher, I’ve been to countless festival events), and this is to the credit of the organisers. They knew their audience well and they planned the festival around the needs of the audience’ (<http://www.garykerr.net/dementia-festival-a-beautiful-oxymoron/>)

Due to its success, The Good Life Festival Model has informed another event: The Dementia Awareness Festival in Salford in 2017.

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