

Project Report



LIFE WITH DEMENTIA

Further Info & Tickets on Eventbrite: <https://bit.ly/2PwXK1p>
Tel: 0115 74 84220, E-mail: events@trentdementia.org.uk



**A FREE event designed and led
by People Living with Dementia
for People Living with Dementia**

Our Stories = Your Stories



★ Be part of Something New! ★



In 2018, Life with Dementia – ‘What Matters to Me’ was our first event designed and led by people living with Dementia in Nottingham. This report offers a summary of our process, the feedback we received and what we have learnt through this project.

Process

Life with Dementia - 'What Matters to Me'

Trent Dementia's empowerment project developed an innovative event which was developed and led by people living with dementia in Nottingham. We worked with a core group of people over 12 months who worked on every aspect of the event planning and then led the event with presentations and conversations about what they felt was important to share about their experience. We worked together to produce a successful event which was attended by 100 people, 28 of whom were living with a diagnosis, 23 were family or friends impacted by a dementia diagnosis and the remainder were professionals and volunteers from carer groups. The event development was funded by Trent Dementia and the event itself by a grant from Big Lottery - Awards for All.

This report offers a brief summary of our process, the feedback and what we have learned from supporting this event.

Process

The first stage of this process involved a small research project which sought to seek the views of people living with dementia about what was important to them in terms of sharing their experience. We asked people what, if any sort of event might aid them in sharing their experience and to what extent they might want to be involved. The result was the identification of a core group of people who, following diagnosis of dementia wanted to talk to others with similar experiences and share what they felt may be useful. We viewed the core group as a project team, we offered everyone involved an honorarium and expenses to ensure no undue expense and collaborated with them as they decided how they wanted to contribute. This required regular meetings, communications and updates as relationships developed. Once the group had decided to prepare several topics for conversation, detailing thoughts and experiences from diagnosis to preparing for the end of life, each person took the lead on a specific topic. The group members then considered what they needed in terms of resources, support and wider expertise. Core group members developed publicity, marketed the event and reviewed potential venues. The group considered deeply which organisations they wanted represented at the event and reviewed all the details, for example: signage, menus and room set up. Trent Dementia is a charity whose interests lie in education and empowerment. The

core audience for this event was people living with dementia, friends, family, carers and professionals.

Partnership

Alongside the event planning the development of DEEP¹ peer support groups was also viewed as important by the group. To this end, we applied and were successful in asking for support from Innovations in Dementia CIC² through their 'working together grants' which has enabled us to start hosting a DEEP Support Hub³ in Nottingham, offering support to independent DEEP groups as they develop. The team at Innovations in Dementia CIC⁴ and DEEP have been a crucial partner in offering guidance and support throughout this process. Their dedication to placing the voice of people living with dementia at the front of any conversation about the experience is well documented and aligns with the goals of Trent Dementias empowerment work.



Feedback

The feedback was overwhelmingly positive, and the group are now starting to expand and develop the next event as well as designing a DEEP Support Hub, funded in 2019 by Innovations in Dementia CIC's working together grant programme. We planned for 80 people in total, but

¹ <https://www.dementivoices.org.uk/>

² <http://www.innovationsindementia.org.uk/>

³ <https://www.trentdementia.org.uk/projects/life-with-dementia/>

increased this to 100, in response to enquiries by people living with dementia. We worked to ensure the audience was balanced in terms of professionals, family and gave priority to people living with dementia. There were 100 attendees including trustees and volunteers – 7 people who booked were unable to attend, but these people were replaced with people on our waiting list. Most bookings were made through Eventbrite. In addition, we offered phone and postal bookings to anyone who preferred this or was unable to access the internet. 28 people living with dementia attended, 23 family members attended, 49 Professionals (including volunteers, trustees and project team).

Feedback from the online and postal evaluation forms demonstrates the high value attendees placed on hearing the voice of people directly impacted by diagnosis, their concerns about inconsistent service provision nationally and appreciation of the atmosphere during the event. People said they felt welcome, enjoyed the range of discussions and meeting others with shared experience. Individually, members of the core group were pleased to have the opportunity to share their experiences in a way of their own devising. One said this was the first time they felt they had a voice since diagnosis and another said they felt ‘over the moon’ to be offering help to others at the start of their journey after diagnosis.

Feedback Summary

What did you like most about the day?

‘It was run by people with dementia. Very positive, welcoming, relaxed atmosphere. Plenty of volunteers and helpers’

People enjoyed the atmosphere and the way the event placed people living with dementia ‘front and centre’. They enjoyed talking to people with the same experiences and people commented on the enthusiasm and helpfulness of everyone involved. The opportunity to hear first-hand about positive and negative experiences since diagnosis was also appreciated as was the presence of an Admiral Nurse. People also stated they would attend another event, and several thanked the team for supporting an event led by people directly affected.

‘People with Dementia front & centre; break sessions for informal talk on topic; well organised & tone was spot on’

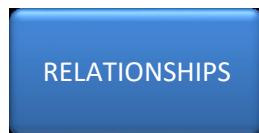
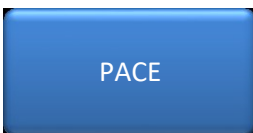
What did you like the least about the day?

‘It ending! It was a superb day. There was so much content. I would have liked opportunity to do a couple of sessions in the rooms but, I was enjoying the session I was in so much I didn’t want to leave’

Comments on Room Format

Whilst people reported enjoying conversations and engaging in some difficult conversations, the room format changed as the day progressed. Initially, the core group planned for a flow of people through the rooms, engaging in several conversations and were resistant to any timed slots for conversations. However, in practice, most room leaders choose to add privacy screens to the doors. On the day, a couple of delegates said they felt this was a barrier to entry and chose to remain in one room. This will be considered for any future event. The quiet room was used minimally, but, since a small number of people did choose to take time out in this room, it would be appropriate to offer this resource again.

Learning



1 Key Learning Points

Pace

We learnt that managing the pace in terms of the numerous tasks undertaken in planning an event was very important. The group met in person 6 times at the University and we also held some meetings via skype. A draft agenda was circulated the week prior to each meeting, and we provided support with transport, paid an honorarium to offset any additional costs as well as providing lunch and refreshment.

The group had a range of ideas they wanted to share. The initial programme could have easily covered 2 – 3 days of activity. Rather than 'policing' this activity, it was important to wait until the group came to decisions themselves whilst maintaining clarity over timings available. Ultimately, the day was still very full, but the group were very pleased with the outcome.

Managing tasks and workflow became easier when key logistical decisions had been agreed and each person became the lead for a specific topic. The group members worked individually on their presentations. Each person was linked to an additional supporter specific to their needs

and by request. The idea was that whilst leading the discussions, each person would have either a professional or volunteer present to contribute and help as requested.

Communication

The way we communicated information to the core group also required attention. For example, individual's wishes about how they would like to be contacted changed throughout the project. Monitoring this was challenging since we are supporting people whose condition may lead to changes in memory or ability to recall information. We have learnt to ask regularly each time we were going to share information what format each person wants this in. For example: phone, email, letter, in person or a combination of these. We have developed a system of full and summary minutes to share with the core group. Finally, we keep agendas to a minimum and will never invite anyone to join the meeting without first speaking with the group. We also share information in different formats, each member is provided with a folder containing relevant information. For example, previous minutes and directions to the meeting room are sent out prior to each meeting, with photos provided of the building and room to aid independent travel. We meet in and around the IMH at the University, but the room varies, and we found the use of photographs very helpful throughout this process.

Relationships

The core group meetings were very vocal and enthusiastic sessions, sometimes slightly hindered by the number of ideas people wanted to implement. The group needed time to get to know each other and develop a way of working together. This process requires an investment in time both during the meetings as well as gentle conversations outside of the group process both to encourage and build relationships. Managing expectations was also important throughout the process and was aided by consistent feedback to the group and planning the project timescale together.

Equality in Consultation

It became evident early in the core group process that people held a great deal of frustration following negative experiences with other organisations and individuals. In order to establish rapport with the group, these experiences needed to be aired to diffuse the negative emotions some people were experiencing. Whilst they were keen to be involved with the project, some members were aggressive in their approach to the team and it required sensitive work whilst maintaining boundaries in terms of acceptable behaviour. We need to think about ways to

establish ground rules as new members become involved in the project and we reiterated our desire for equality in consultation rather than professional's leading vs people with lived experience leading. This work was a productive process, but it is important to note the time required to ensure everyone has an opportunity to participate.

The core group were always consulted about all aspects of the event, leading on developing publicity, writing the programme and they negotiated with each other in terms of the content of the day. Core group members visited potential venues and reported back options before taking a decision about the preferred venue. This meant that each stage of event planning was consultative. For example, several posters were designed. We managed this by amalgamating aspects of everyone's work into three options before sending out for a vote. This was an effective approach and helped us work towards everyone having an equal contribution.

Conclusion

This project has afforded the opportunity for us to learn together what people living with dementia may find useful. We are expanding our core group membership and this group will be working together to develop our next event and offer support to people in Nottingham who wish to establish or engage with peer support groups. If you would like to know more about our work or be involved, please get in touch:

www.trentdementia.org.uk/contact



