**Workshop 1 – Pwd and caregivers – Dementia Café (Tuesday 23 November 2021)**

**Task 1. An activity/skill they like doing**

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| **Name** | ***Object* – what?** | **Why?** | **Where/When?** | **How? - learning** | **Today?** |
| [P23]  (female, carer) | *3 round chocolate cakes* | an activity she clearly loved and was proud of | **birthday and wedding cakes** she had decorated **for her daughter and son** | She learned cake decorating at **night school** | She felt that she now **had little time** to pursue this and instead made mince pies and Christmas puddings. |
| [P24]  (male, dementia participant) | **Refereeing** | x | He was a referee for football as well as rugby and he also liked playing cricket  He refereed mostly men’s matches at local leagues or for children’s matches | x | Now or before?  He mentioned refereeing in/for Eccles. |
| [P25]  (male, dementia participant) | he was a [RUGBY PLAYER] for Salford.  He also played the trumpet when he was in the army in the … brigade.  He also played in the rugby union.  He was a swimmer and swimming coach. | x | **swimming coach.** | x | x |
| [P26]  (male, former carer/dementia participant) | liked storytelling and dancing, | x | x | x | thought he could **teach dancing.** |
| [P27]  (male, former carer, now looks after [P26]) | *brought a pocket jointer and a piece to demonstrate pocket jointing.*  **enjoys doing joinery.** | Enjoy it | x | He had been an electrician | x |
| [P28]  (female, carer) | plays the piano and likes reading.  She also taught children swimming  was an international timekeeper | x | She also **taught children swimming**  was an international timekeeper | x | x |
| [P29]  (female, carer) | **Volunteering** | She loves being around people. | volunteers for **Age UK.**  She also **looks after her family and does the school run** for her grandchildren. | She used to work in social services with terminally ill people | volunteers for Age UK.  She also **looks after her family and does the school run for her grandchildren**. |
| [P32]  (male, former carer) | *a Manchester City book and a section of rugby shirts and the Manchester City* *football shirt he wore as a child.*  **cycles for leisure** | Beyond his love of sports, he spoke of his **efforts to stay fit,** including regular cycle rides.  He does like **to treat this as a more leisurely pursuit**, sometimes stopping for a pint on the return journey.  [P32] reminisced of a hands-on craft kit to construct a barrel organ which he completed in his youth and he still has now and **is very proud of**, very keen to bring it with him to the next engagement session. |  |  | [P32] and [P33] showed a particularly strong social bond and on occasions **connected outside of organised activities** |
| [P30]  (male, former carer) | *a music CD (musical theatre/ Westside Story) and a box set of conspiracy theory DVDs*  **ballroom dancing** | Listening to music (particularly singing) **calms** [P30] down and he also shares a love of ballroom dancing as a **pleasure.**  … conspiracy topics and historic news headlines can offer a basis of (constructive) discussion and debate. | He likes to share his joy of music by **lending CDs out to people.** |  |  |
| [P31]  (male, former carer) | *chose to share a novel (Magician, by Raymond E Feist)* | reflecting on his **joy of escapism reading** fantasy novels. |  |  | the experience of caring for his wife had taken a physical toll on his health. |
| [P33]  (male,former carer) | *Bring a snooker cue*  *His second object was a picture of him, his wife, and another family member taken during a cruise* | He enjoys **playing snooker**  one of his daughters works on a cruise for a long time and he and his wife enjoyed cruises. | he **enjoys camping – usually to be part of a beer festiva**l – but he **would like it for other activities too.** |  | was **part of a snooker team but due to Covid, he had to stop it.** It should start again very soon  – but due to covid-19, he got less external support with his wife so had not the possibility to find time to cycle. |
| [P34]  (male, carer) | brought one object – a notebook with some **stories** inside –  he would like **to try doing mosaics or related crafts** to put outside, in the garden. | He mentioned that he and his wife enjoy(ed) **travelling**  **Mosaics would bring color to the rooms** | he is part of a **writing club**  He finds time for him/writing **very early in the morning** when his wife is still asleep. |  | he has now **less time** for his activities due to his wife dementia. |
| [P35]  (female, dementia participant) | was very keen **to learn new languages –** French, but also Italian and Spanish.  She also really **enjoyed musicals** | She enjoyed travelling in France, Spain, Italy, etc.  **She seems still happy to listen to musicals** |  |  | Advanced dementia, very limited verbal communication. Not very interactive nor initiating activities anymore.  Very difficult to know for her husband if she enjoys or not an activity – so he offers activities they used to do (= continuity)  Walks are her only physical activities – initiated by his husband |
| [P36]  (female, carer) | She **brought an art canvas and some stick-on jewels** which were intended for her mother.  Pictures on her phone from what her mother did in the past couple of years |  |  |  |  |
| [P37]  (female, dementia participant) | Still enjoys **art canvas and some stick-on jewels with some support.**  She has various clubs to attend – **dancing for dementia, singing for dementia, armchair aerobics, dementia café.** | Before her dementia had progressed, she was a **keen** and talented illustrator | Papercraft wreaths, a model witch for Halloween and artwork using buttons.  Activities through organisations / **She has various clubs to attend** |  | Before her dementia had progressed, she was **a keen and talented illustrator** however she is **no longer able to do this.** |
| [P39]  (female, carer) | [P39] stated that [P38] **enjoyed walking**, to which he nodded along in agreement | They used to regularly go on long walks together, for the **enjoyment of the views and fresh air** |  |  |  |
| [P38]  (male, dementia participant) | He was previously a mechanic | and loved engineering prior to his diagnosis. |  |  | [P38]s **dementia has progressed too far** for this style of walking now |

**Other remarks/group comments:**

* Two participants offered comments that they had participated in co-design groups before and did not feel that results were effective or effectively communicated.
* They also voiced concern about services not being individualised enough, and we explained that this is why we wanted to do this project so that we could develop a service where we can tailor activities to the individual.
* The same participants also highlighted that being a carer was a day-by-day learning task, especially because all people and all dementia-related symptoms are different.
* They mentioned the difficulty to deal with the person they are caring for (but also with people around that might lack of understanding) and in consequence the difficulty to find time and support to access difficulties because it’s difficult to organise your day.
* They highlight the need to adjust and being flexible to take care of someone with dementia – it highlights the need to take into consideration carer’s needs and experiences to offer an efficient service and reduce the risk to face some resistance (i.e., carers irritated by prescriptive attitudes and being “educated” about dementia and how to act).
* The group mentioned dancing with dementia or something that tried but found it not very inclusive. They felt couples were not mixing and changing partners as they were meant to be. [P29] mentioned that it felt as if people with dementia had some sort of contagious disease.
* They also mentioned singing with dementia. They felt that this was very good and helped people with their memories.
* They highlighted the importance of their friendship, mentioning it’s the only good think that dementia offered them. They are very supportive friendships because with people that understand what they are living and the impact of being a carer…‘Dementia brought us together..’
* [P33] mentioned he had to stop working to take care of his wife (leisure vs. professional activity)
* What became strongly apparent in the ongoing discussion was how much engagement in social activity had been facilitated through the local group(s) including (pre-covid) organised trips such as pub lunches and memorable day trips, including Salford Quays and Blackpool.
* The environment was key in their experience for newcomers joining the group(s), whereby the act of ‘making a cuppa’ was critical to making them feel welcome and relaxed.
* He/they appreciate weekends away, walks – [P34] discussed with [P33] about the importance of accessible walks with clean paths to avoid falls and being accessible in a wheelchair – [P33]’s wife was in a wheelchair but he mentioned it was not a barrier to have access to activities outside of their home – it was really important for [P33] not staying inside and continue to have activities out of their home with his wife. We also discussed the importance of pubs and cafes “dementia-friendly/inclusive” features – e.g., not too noisy, not too dark, disabled toilets, etc.
* Art and Craft: This was seen as a really engaging activity, which can be enjoyed without prior skill. With the experience of previous classes, the group see this as being an activity that can be responsive, where activities and materials can be mixed. Additionally, this is seen as a social activity, participants opening up to chat and share laughter. One member of the group (carer) shared that they had been able to stop using anti-depressants through participating in painting.
* Walking: This is seen as a very accessible shared activity. Dog walking was discussed and whilst having a dog was seen as a barrier through additional responsibility, it was suggested that this is still possible through ‘others’ bringing their dogs along to the park for example.
* Holidays/package deals and Cruises: building on successful days out in the past, this came as a suggestion to tailor breaks for groups those with dementia and their carers.
* The conversation then moved on to activities they used to enjoy, however, both [P37] and [P38] dementia had progressed too far, so these were no longer possible: 1) Travel. All were keen globetrotters but now, we discussed how even local travel is difficult as there is distress if unknown routes are taken or if the routine is broken. 2) Squash, table tennis, curling, general sports. A couple of years ago [P38] and [P39] tried curling. However, it wasn’t a dementia-specific session and they found it unenjoyable due to the lack of understanding from the ‘normal’ (their word) people attending.

**Task 2: things I can help with/I’d like help with**

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| **Things I can help with…** | **Things I’d like help with…** |
| [P26] said he **could help with teaching or coaching ballroom dancing.**  **Being a volunteer - dancing** |  |
| [P26] said he like **to sit and talk about good memories** because he could bring up things you had never thought about.  **Being a volunteer – culture/history** | There was a suggestion that [P26] could talk to children or veterans **about the past and his experiences. [intergenerational activities - knowledge transfer]**  **Cf. narrative activities in some libraries in Sweden – mental heath, etc.** |
|  | [P26] would **like to go parachuting** because he had the training for it but never actually managed to do the jump**.[a volunteer partner with relevant expertise to do it – a databases of skills? + inclusive organisation/facilities]** |
| [P25] used to be a **swimming coach.**  **He didn't necessarily feel able to do this any longer** but spoke fondly of his time doing it. **[but ok earlier in the illness timeline]** | [P29] and [P23] said they **wanted to learn swimming** so they could join in. While they had taught to their children, they had never learned themselves and were afraid.  **[a volunteer partner with relevant expertise to do it – swimming]**  **+ inclusive organisation/facilities]** |
|  | [P24] said he wanted **to play rugby again**  **[a volunteer partner with relevant expertise to do it – playing a sport again]**  **+ inclusive organisation/facilities]** |
| [P24] also said **he wanted to referee** for the England team - he didn’t mind whether it was football rugby or cricket.  **Being a volunteer - sport** |  |
| The group determined that [P23] could help [P26] **learn making meat pies.**  **Being a volunteer - cooking** | [P26] **wanted help with making a meat pie or pudding** which [P23] could help him with  **[a volunteer partner with relevant expertise to do it – a database of skills?]** |
| Participants in the group felt that everybody helped each other | [P27] mentioned that **he liked doing social things as a group such as having a nice meal together or going to glassworks or similar excursions**. Another thing was a long weekend together in Southend. He said age UK had organised such in the past for them.  **Organisation/volunteers to offer more opportunities for social activities** |
| One participant said they would like to offer help **visiting people and talking to** them ([P29]?)  **Being a volunteer – visiting people** | [P24] said that he helped at home with the washing up. |
| [P28] said that she played the cornet and the piano | There was a suggestion to **make music together.** Go to sing together.  **Organising a band?** |
|  | [P23] said that she **would like to learn jewellery making.**  **Organisation/volunteers to offer more opportunities – arts and craft** |
| There was a suggestion that university **students could come and accompany a person from the group for a day to allow them to do something they could not do otherwise.**  **Education and advocacy about living with dementia** |  |
| There was an observation that in the past they had been put experiences when people took their loved ones with dementia shopping because they might walk the aisles and take things on the shelves. And with staff had queried why the shopper brought the person with dementia with them or why at this time. – a suggestion might be to **volunteer with shopping centres or supermarkets to raise awareness, help people understand, or support people with dementia and their carers in the task of shopping**. – Perhaps work with dementia friends to create such a volunteer and awareness campaign.  **Education and advocacy about living with dementia** |  |
| **[P34] might help one of his neighbours that is struggling with gardening,** **but it’s currently very difficult for him to find time due to caring for his wife.**  **Being a volunteer** |  |
|  | **[P34] would be happy to try mosaics – but probably on his own** (he tends to do things on his own or supported by his family/relatives) |
|  | [P34] is not very keen on short drives (but doesn’t care to drive longer distances), for **example from home to a meeting place, so some support for it might be useful** – including small buses to share with the other people involved in the activity.  **[a volunteer partner with relevant expertise to do it – transport]** |
|  | Isabelle asked if they **would appreciate walks in nature led by someone giving nature or historical details about the place** – he agreed he would appreciate it.  **[a volunteer partner with relevant expertise to do it – nature]** |
|  | Same for a **language exchange – meeting someone willing to improve their English by speaking with native speakers and offering another language** that [P35] was learning in return. He thinks that [P35] might have liked it when she was at an earlier stage of dementia.  **[a volunteer partner with relevant expertise to do it – language]** |
|  | **[P34] would enjoy more time in galleries and museums.** Going there with his wife doesn’t seem a problem but **he would be happy with support in planning (usually their relatives are doing it) – programme, tickets, transports, etc.**  **[a volunteer partner with relevant expertise to do it – planning activities]** |
| [P37]would **previously have been able to offer art and illustration skills**  **Being a volunteer – arts and craft** |  |
|  | **The main help that [P39] wanted was with transport.** She doesn’t drive and so getting [P38] to various venues is a real struggle, preventing participation. Taxis are too expensive, ring and ride to unpredictable, public transport is not an option and **charities don’t have enough volunteer drivers or services**  **[a volunteer partner with relevant expertise to do it – transport]** |
|  | **something for the carers as a bit of respite while the people with dementia were doing an activity – something in tandem.** [P36] and [P39] agreed that the activity was unimportant – it was the stimulation of any description that was important and just getting their loved ones out of the house.  **[a volunteer partner with relevant expertise to do it – human support during activities]** |