**INDIVIDUAL INTERVIEW 13**

**WITH P15**

**9th July 2021**

Audio File Name: The interview started on teams but latest connection would not allow us to conduct the interview on teams. We switched to zoom and tried to record through teams however this did not work fully. Therefore we are recording our notes after the interview.

**KEY:**

**INTERVIEWER 1: = Interviewer (Interviewer in bold)**

***INTERVIEWER 2: = Secondary Interviewer (Interviewer in bold italics)***

P15: = Participant – Carer

The carers husband is a PLWD and should have been present, however was unable to attend.

This interview was with [P15] alone because [HER HUSBAND] was visiting one of his state groups and his routine is very important to him.

[P15] mentioned that [HER HUSBAND] had been diagnosed 10 years ago and there had been a lot of change over the last 10 years, that he is now [IN HIS 70s] and that he is still young at heart.

At the beginning when he was diagnosed there was nothing for people with early stages of dementia once diagnosed. She mentioned that the memory café was not appropriate, because it was mostly for more people with more advanced dementia. [P15] mentioned that [HER HUSBAND] needed to find acceptance. It was very difficult to face with people with advanced dementia. At the beginning he felt a sense of shame being diagnosed with dementia. Because dementia is associated with the stigma associated with mental illness even though dementia is a neurological disease. She mentioned that support was very patchy. Early on several groups they approached for [HER HUSBAND] to join were not welcoming to people with dementia. For example there was a new men’s group in the area who were not accepting people with dementia at the time.

[P15] mentioned that it took them five years to find suitable support. One of the groups was the DEEP group which she felt was more inclusive in its groups. Another support group was the Salford group for dementia studies, a research group which also works with people with the lived experience of dementia. Dementia UK was also helpful as well as Alzheimer’s Society outreach programme. Thanks found a veterans group that did arts-based activities and coffee mornings and that we are well coming to [HER HUSBAND] and others with dementia. [HER HUSBAND] enjoyed being part of research programmes and sharing is experience.

Activities [HER HUSBAND] is able to pursue through these groups or otherwise in charge included:

* singing for the brain and other music sessions
* through the Alzheimer’s society outreach program talking about meaningful things at the clinical care groups
* A connection to Manchester United groups
* dog walking
* a walking group, but this didn’t last long because they always take to the same walk and he got bored
* Social activities such as having a drink with friends
* Cycling. When he could no longer cycle on the road [P15] got him an exercise bike which he used until last year.
* When dog walking was not an option because their beloved dog died and [HER HUSBAND]’s walking skills were not as before, [P15] found an alternative by buying a chicken: [HER HUSBAND] truly enjoy being around them and taking care of them.
* [P15] also mentioned that he likes to help her as well as in the groups for example with washing up picking berries in the garden and other tasks. This sometimes takes patience to break down the tasks to allow him to do them.

[P15] mentioned that people with dementia often have many good years to live. [HER HUSBAND] had eight years before he started to withdraw. The cope with the lockdown was very difficult because everything shut down. There was only one initiative which helped them to get through lockdown and which was only closed for about three weeks [name of support group? Social care group…?] [P15] said that his language and physical skills badly deteriorated during and because of the lockdown and the lack of social physical engagement during this time.

One group that has been particularly important for [HER HUSBAND] and [P15] still attends is Willows Dementia Hub. [P15] mentioned that they offer very varied and creative activities of various kinds including for example a Hawaiian birthday party, baking, arts-based activities, et cetera.

Also mentioned that they were involved in a mapping exercise of dementia services in Greater Manchester already for the second time. But much has changed because of the Covid pandemic. They have also been involved in the development of the Better Moments App. However she felt that advice given by the dementia care expert group had not been fully taken into account. And that she was unsure how the data that are being collected through the app was being used. She felt that the app had developed from something to facilitate access to services to something else but she was not entirely sure what.

Key points made during the interview included:

* There needs to be more consistency of services delivery (longevity but also from a geographical point of view – disparities in GM)
* Single points of contact for people newly diagnosed are necessary to support them to find the appropriate resources and support.
* There needs to be better social care services and training for staff – what examples they experienced help through a particular member of staff who allowed people to talk about their negative experiences and emotions with dementia whereas another member of staff that replaced them once they left took a different approach with tea and biscuits rather than allowing people to speak out and voice their emotions. The immediate consequence was they decided to not attend this group anymore as it was not supportive and even
* There need to be more appropriate and tailored offers to the large variety of needs (gender, age and generation, kind of dementia, stage of dementia). Not enough offer for people with early-onset dementia and/or newly diagnosed
* Facilities and groups need to be more dementia friendly but they don’t have to be dementia specific.
* The fact that services and groups are often dementia labelled or organised in mental health facilities can be a barrier to access (stigma, sense of shame).
* There need to be opportunities for people to be feeling valued so being able to help in whatever little way they can.
* There is a need to ensure participants that their contributions are taken into account and valued