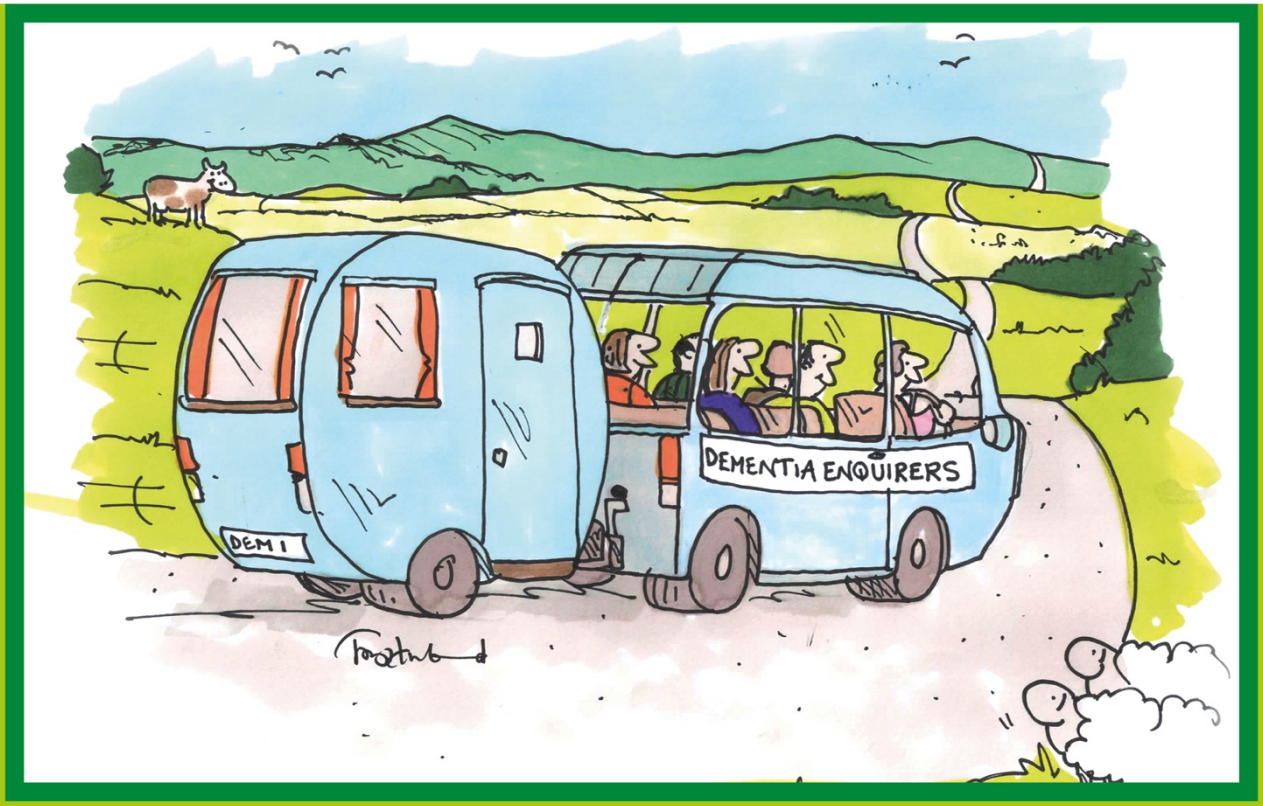
Beth Johnson Foundation

Dementia Enquirers Report



Does class, ethnicity or intellect affect the dementia pathway?

January 2021

Dementia Enquirers

COMMUNITY FUND

Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

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You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/beth-johnson-foundation-in-stoke-on-trent

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Dementia Advocacy Project

Beth Johnson Foundation

The Beth Johnson Foundation was one of the pioneers of advocacy starting in 1989 we offered citizen advocacy. In 1998 we established the dementia advocacy project which specialises in advocating for people with dementia.

We host a peer support and advocacy group for anyone over the age of 50 with a dementia diagnosis. We are a member of the DEEP network and this report is a review of our Dementia Enquirers research project that was led by people living with dementia. The group currently has 8 members who meet every month. They are supported by trained advocacy workers Betty Machin and Laura Higgins.

Dementia Enquirers Researchers

Gordon Vernon, David Stazaker, Masood Qureshi, John Tinsley, Betty Machin, Sue Naylor, Shelagh Robinson, Rita Toplass, Fred Dowding.

Research Question

Does class, intellect or ethnicity have a bearing on the dementia pathway?

We wanted to investigate our experiences of diagnosis and find out if our different life experiences, ethnicity, education, and class background had any bearing on our dementia pathway. We wanted to look at this because we are from a range of different backgrounds and we knew from our meetings that everyone had different experiences to share.

We found that class, intellect, and ethnicity all have a bearing on the dementia pathway. The impact of this can be both positive and negative.

Class –We see class as your employment and financial status. If someone has access to surplus money, they can use this to pay for hobbies and adjusting their lifestyles. We also found that being familiar with and having access to technology helped people to research their diagnosis. People might have more understanding of charities and how they could help as well as other support services. This information is not readily available at the time of diagnosis.

Intellect – We see intellect as your level of education and your ability to access or understand information. We also see intellect as common sense, not only an academic background. Intellect gives some people more confidence in speaking out to professionals, challenging opinions, and seeking further guidance.

Ethnicity – If English is a second language it can be difficult accessing understandable literature. Literature is often published only in English, making it easily misunderstood or inaccessible to many. In addition to linguistic barriers, there are cultural barriers which include a lack of understanding about dementia, for example: that a diagnosis is often influenced by someone's behaviour. The stigma of a dementia diagnosis appears to be emphasised when there is a lack of understanding, due to linguistic complications.

Our Methods

Initially we were asked to involve other members of DEEP organizations but members agreed that the project would be better managed by only including members of the Beth Johnson Foundation Peer support group. Currently members of the Peer support group consist of people who are considered to be of intellect, one member who is a Muslim and members from both working and middle class. We decided to do four things to investigate our experiences. We started with 1 – 1 interview between the 8 group members and advocacy staff. From these interviews we developed a long list of 13 questions. We then met as a group and discussed the questions deciding on 5 questions to use during filmed interviews between group members. Following these interviews, we met as a group and watched the films together. This led to further discussion about the themes we identified and led our findings and recommendations.

Interviews with staff to develop the initial 13 questions.

1. How were you told you had dementia?
2. Were you happy with the way you were told?
3. By whom were you told (Gender/ Ethnicity)?
4. After being told how did you yourself handle the diagnosis?
5. Did you tell family/ friends?
6. If you told family/friends how did it affect them? (For example, have you lost friends' do they treat you differently)
7. Do you think gender has a bearing on your dementia pathway?
8. Would you query if you felt your medication was not suiting you?
9. Have you other health issues such as depression?
10. Are you able to get about by public transport or do you drive or use taxis? (cost of taxis)
11. If you needed advice/ support in relation to your dementia from a health professional would you know how to contact?
12. How has your lifestyle changed if it as changed since your diagnosis of dementia? (prompts structure, routine, self-management)
13. Since your diagnosis of dementia what has been your biggest loss?

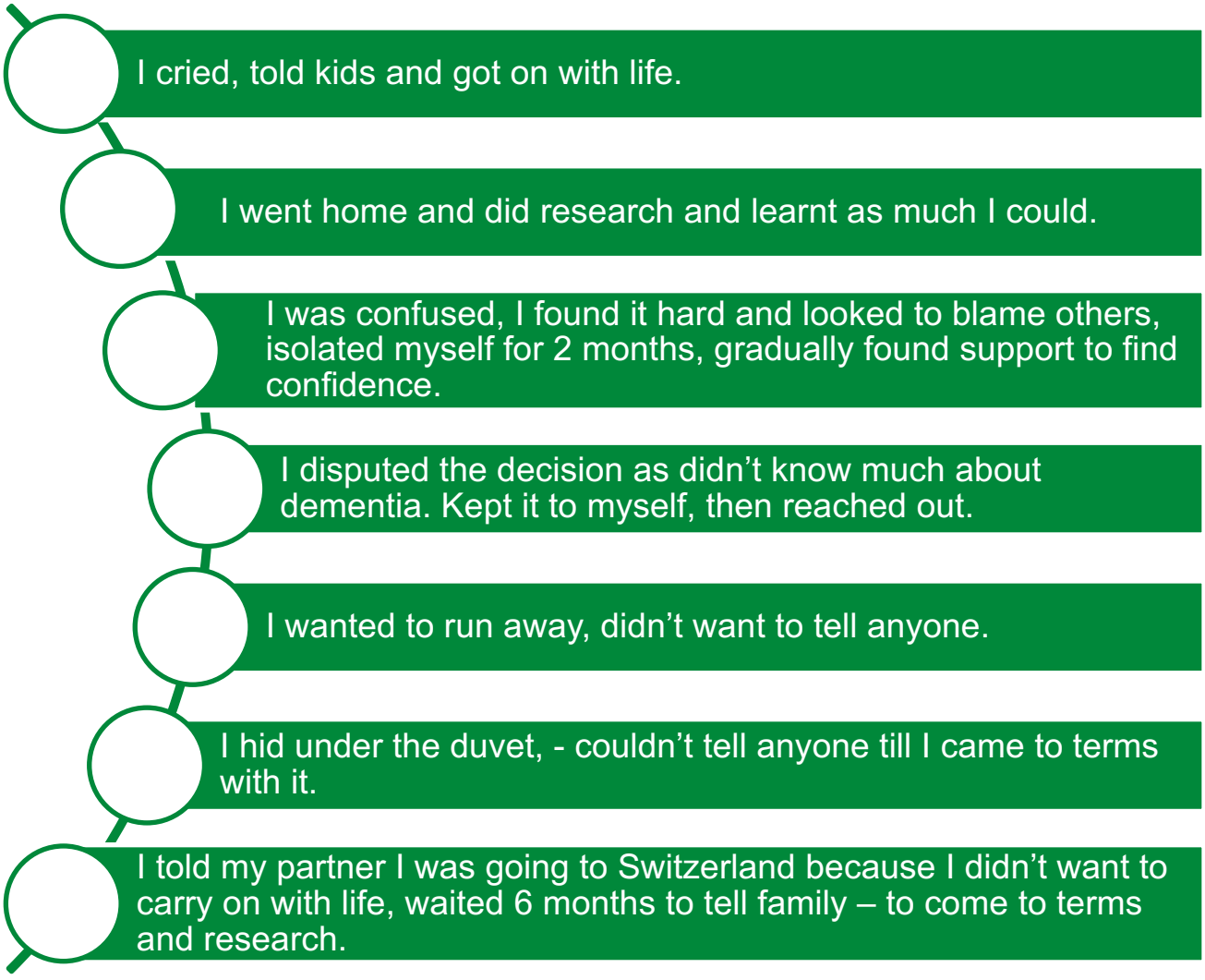
We held discussion groups to refine the questions and decided to focus on five questions:

1. What did you do when you were told?
2. When did you tell your family? How did they react and are reacting?
3. When did you tell friends and how did they react?
4. Where were you brought up and where did you live and work later in life?
5. How has your dementia impacted on your hobbies?

We participated in four filmed interviews to talk about our experiences and think more about the questions. The themes from these interviews were discussed as a group and focused on our experiences of education, community, and lifestyle. These interviews helped us to develop our findings and recommendations.

Diagnosis

We shared our experiences immediately following our diagnosis. Some main themes came from our discussions which included a period of self-isolation, pulling back from our support groups until eventually we reached out for more support. Often it takes some time to come to grips with a diagnosis - often leading to the feeling that it was a mistake.



Findings

Class

‘Money Matters’
‘It’s about living well with dementia, not getting by with dementia’

Conversations about class were related to money. We discussed the differences in lifestyles for people who were considered more affluent and those that considered themselves to be ‘working class’. Whilst you may not need a great deal of money, having some surplus income is especially important in helping people to maintain hobbies. We found that being able to travel to visit family and friends was more difficult if you had to be reliant on public transport. Public transport can also be challenging if it is inconsistent or when you have not used this before. If you have to stop working soon after diagnosis and your income is drastically changed, your quality of life can alter. Entering the benefits system can also be difficult for people either to navigate this or feeling uncomfortable claiming benefits after a lifetime in employment.

‘There was a stigma in asking for money, I felt ashamed’.

We all agreed that your financial situation can influence our mental, physical and dementia health. If you can maintain a similar lifestyle post diagnosis including hobbies and socialising this will make your life post diagnosis more manageable.

Another theme we found was around community and family life. Some people were raised in large families with a network of support and others led more isolated lives. People reported losing contact with friends who ‘fell away’ but others continued to maintain contact with friends. Finding ways to meet people with similar experiences was important to everyone.

Intellect

‘Does intellect sometimes come with finances?’

A better school, education and understanding of society.

Our discussions about intellect ranged from academic experiences to common sense. But the most common theme was the confidence to ask questions of professionals and push for answers to your concerns. We found that the skills needed to determine our own path following diagnosis were the ability to plan and adapt to the changes in our abilities.

‘It’s important to break problems down and work through them step by step’.

Whilst initially people with a higher level of education might be more confident in asking questions and researching their diagnosis, finding people to help put your plans into action, family members, friends or support organisations will always be helpful.

Ethnicity

We found there are cultural differences in how people from different ethnicities may understand and view dementia.

‘There is no word in my language for Dementia or Alzheimer’s.’

Following diagnosis one member explained how they never met anyone who they knew had dementia and initially he disputed the diagnosis. After some time, they reached out to an organization and asked them to come and explain to the family which had a very mixed response. Whilst family members, in this case, eventually accepted the diagnosis they do not seem to understand what this means day to day. Raising awareness of dementia and how it may affect different people is important across all cultures but especially so if a community has no word for dementia or if there are differences in the status of men and women.

We found that a diagnosis of dementia impacts most people’s confidence and, if family and community members do not understand what dementia is, it can be hard to get the support you need. Additionally, if literature is not available in a first language this could be hard to access if people from different cultures are not represented in support organizations due to a lack of understanding in the wider community.

Conclusion and Recommendations

We found that our understanding of class, intellect, and ethnicity all have a bearing on the dementia pathway. These impacts can be both positive and negative, for example: in some communities' dementia is often hidden or misunderstood. This means that it may be difficult to access information and support. Those people who are more affluent at the time of diagnosis may find that they can afford to continue previous hobbies and perhaps those with more academic education can more easily understand the consequences of the diagnosis. However, we also found that everyone's lifestyle changed after a diagnosis regardless of our understanding of class, ethnicity, and intellect. It was also clearly beneficial if people had access to technology and were able to research their diagnosis and access information and social connections using technology.

We recommend people consider the following:

'It's not only about memory'.
Awareness raising activities would make more people understand that dementia impacts people in different ways and that it is not only memory that is affected.

'Don't assume'.
Whilst some cultures may have very different levels of understanding about dementia this does not mean there is no understanding. Treating people as though they will or will not understand based on their ethnicity is unacceptable – just ask them what would help and work to raise awareness. An individualised response is needed, and assumptions should be avoided.

'Seeking support looks different for everyone'.
There is no one correct pathway after diagnosis. How someone approaches support and chooses to live with dementia is an individual choice but having enough information to make these choices is important.

'We are still part of our communities'.
Social contact is important and finding ways to maintain levels of contact both within your existing communities and creating new connections through hobbies or new activities is very helpful in creating a positive pathway experience.

People with dementia in the driving seat - reflections from BJF peer support group members involved in this project

All of the members agree that COVID has had a huge impact in relation to the methodology of the project. However, members have agreed that being in the driving 'seat' of the project was a huge boost to their confidence. One member said how good it felt to be listened to and know that what he was saying was being used in a purposeful manner in the project.

Other members have noted how they have had to use different strategies to engage with other members of the group relating to aspects of the project due to COVID and how this has increased their self – confidence in using different methods.

As in any type of groups there are members who are able to express themselves more readily than others. In the development of this project as members were in the driving seat they have facilitated those members who were not as confident ensuring that all members had an equal share of the participation of the project.