



COMMUNITY
ACTION ON
DEMENTIA BRENT



NHS
Brent

Clinical Commissioning Group

Living with Dementia in today's community: Brent

Report prepared by Opinion Leader

September 2015

3	Executive Summary
4	Background
8	About the Research
11	Awareness and Understanding
15	Isolation and Loneliness
19	Cultural and Religious Issues
23	Balancing Risk
25	Maintaining Abilities
29	Best Practice in Brent
32	Improving Services
37	Conclusions
40	Recommendations for Brent
	Appendix:
44	• Case studies – filmed participants and community researchers
72	• International Horizon Scan – nine innovations
81	• Sample breakdown

Community Action on Dementia (CAD) Brent has the ambition to create a dementia-friendly community where those with dementia are empowered to live well. To do this, CAD has adopted a systems leadership approach to facilitate transformation of public services to address the complex social issue of dementia.

This report is the accumulation of the three strands comprising the first phase of research, which is to obtain an in-depth understanding what day-to-day life looks like for people with dementia. This firstly consists of a wide ranging scan of innovative international practise in building community support in mental health care and secondly local data mapping of dementia in Brent today. The third strand comprises of sixteen ethnographies undertaken by professional and community researchers, providing unique insights into the lives of people with dementia and those who care for them.

Thematic analysis revealed findings under seven themes which afford challenges and opportunities for CAD. These include: awareness and understanding; isolation and loneliness; cultural and religious issues; balancing risk; maintaining

abilities; best practice in Brent; and improving services.

The findings from the strands have been synthesised and six key actionable recommendations are prioritised. Each recommendation is supported by examples of innovative international best practise. These include:

1. Wide-reaching community dementia training to increase awareness and acceptance
2. Creation of a holistic care co-ordinator care role
3. Peer support service available to all at time of and after diagnosis
4. Creation of accessible information to help overcome stigma and cultural misunderstanding
5. Establishing a network by which statutory services and community groups work together to extend the care and support provided to people living with dementia
6. Use cultural hubs or faith communities to advocate and support people with dementia and facilitate education

This report acts to stimulate the project into the second phase – designing and prototyping new services to help those with dementia live better in Brent.

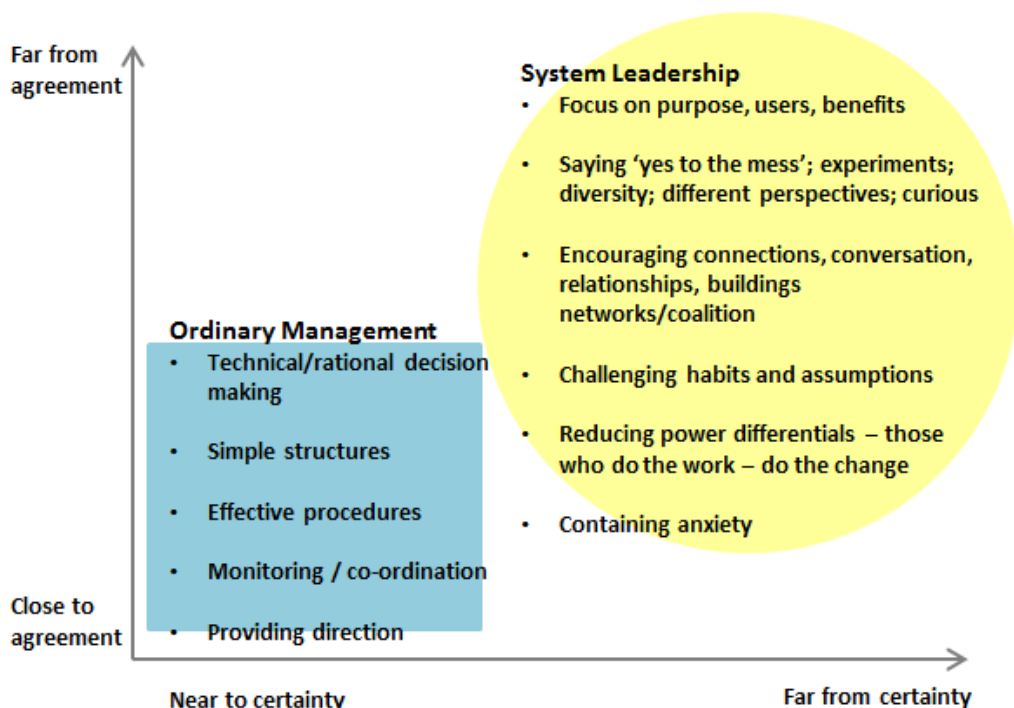
Why Systems Leadership to understand dementia?

In July 2014, Brent Health and Wellbeing Board re-defined its approach away from nationally mandated endorsements to a system leadership role. To do this Community Action on Dementia (CAD) Brent applied to join the national programme, 'Systems Leadership: Local Visions' which aims to promote and facilitate radically different methods to transform public service to address complex social issues, such as dementia.

The following diagram based on Ralph Stacey's work highlights when the different approaches are required: system leadership (see yellow circle) is applied to 'wicked' issues (complex and intractable challenges) such as dementia, and not simple technique problems (see blue box).

"The most common leadership failure stems from attempting to apply technical solutions to adaptive challenges" - Ronald Heifitz, HBR 2009 Immunity to change.

Technical problems v adaptive challenges



After Ralph Stacey

The team recognised that the path to a dementia-friendly Brent was not certain; nor was there broad agreement between people living with dementia, their families and carers or local stakeholders, as to the nature of the issues that needed to be addressed. Consequently the CAD Brent steering group sought to adopt a systems leadership approach which is committed to experimenting with new ideas, prototyping new products, connecting the system to more of itself and addressing power differentials by focussing on partnerships.

In order to give shape to this new approach, CAD borrowed from design-thinking and followed a process named the Radical Efficiency Project developed by the Innovation Unit (with NESTA). There are four phases to this work:

- 1.New perspectives on the challenge
- 2.New perspectives on the solution
- 3.Prototyping
- 4.Embedding and scaling

Please see diagram overleaf.

Overarching project aims

The overarching research goal of Brent's four phase journey is to ultimately build a dementia-friendly borough. It is clear that supporting people who are living with dementia is a challenge for public services, and public services alone will not meet the scale of this challenge or indeed deliver the improvements in people's well-being that are required.

CAD Brent therefore seeks to understand what needs to be done to galvanise a broader response, and how the ingredients can be put in place for those with dementia to live well.

The first phase

The first phase is about asking afresh the questions about what people with dementia's lives are really like, what are their aspirations, and the biggest challenges they face? It is about the authentic lived experience of communities – not about a consultation on existing services. It is about reconnecting with users and building a partnership with them. It is open-ended and all about gathering multiple sources of information that can help inform our understanding the locality.

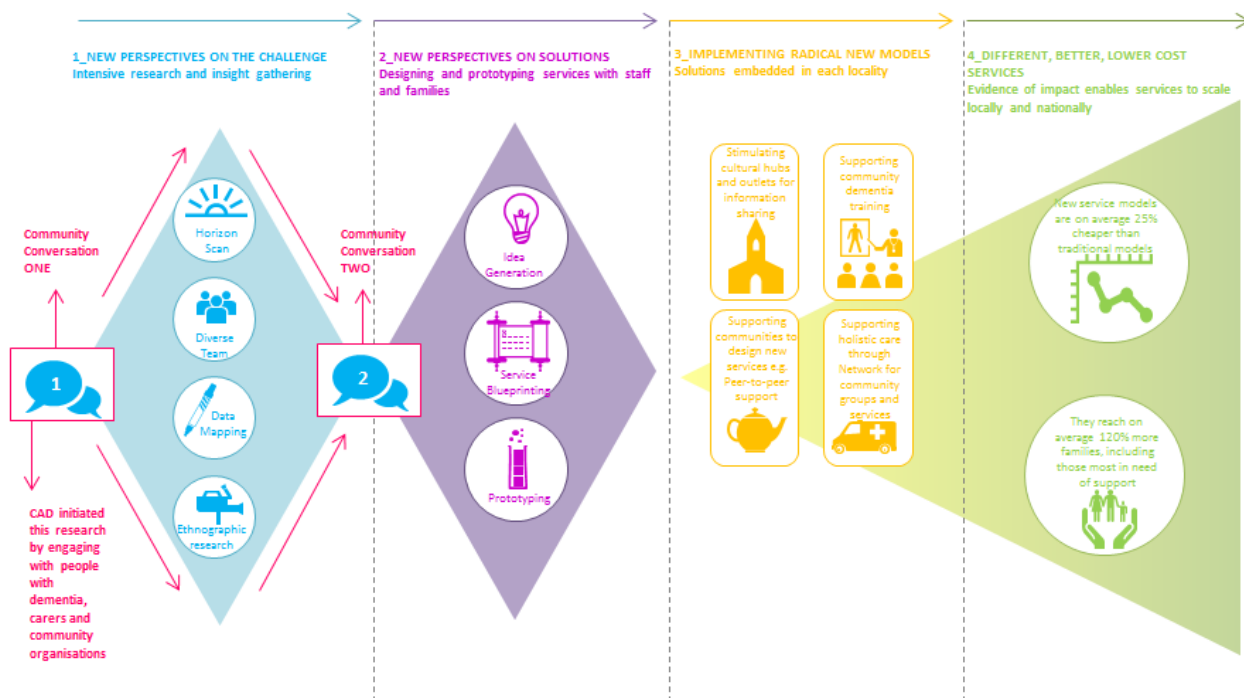
Aims for this research

The aims of this strand of the research are two fold:

- 1) To obtain an **in-depth understanding of the key issues and challenges faced on a day-to-day basis** for those with dementia living in Brent and to stimulate strategic thinking that will help those with dementia live better.
- 2) To obtain a **wide reaching understanding of international best practise** in community based dementia care to provide inspiration for co-produced new initiatives whilst determining key learnings.

Objectives for this research

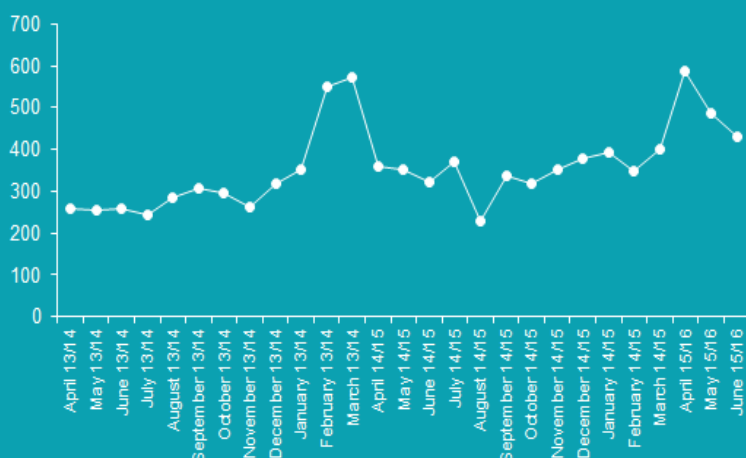
- Explore how the challenges experienced by those with dementia manifest themselves
- Produce insightful case studies based on the lives of real people
- Uncover opportunities to solve these challenges by juxtaposing perspectives and utilising existing resources
- Identify international innovative practice which have been successful in building community support for those with dementia, their families and friends.



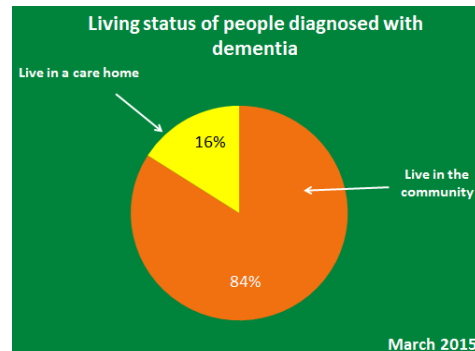
Dementia in Brent today

- 1,771 people living with dementia (March, 2015)
- £10,367,613 planned spend this year on residential care homes and nursing homes specialising in dementia
- £270,407 planned spend this year on extra care (supported living) housing specialising in dementia

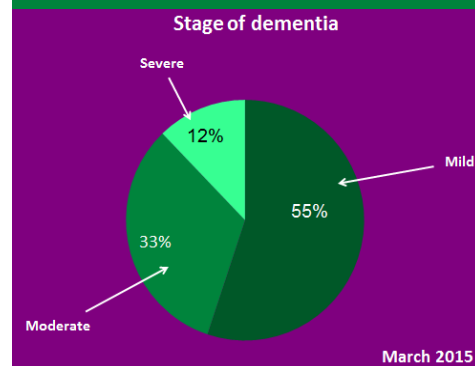
Number of patients aged 75+ admitted as an emergency for 72+ hours and identified as potentially having dementia



Figures for Ealing Hospitals NHS Trust included in data prior to October 2014 to allow for more accurate comparisons to be made with later data



March 2015



March 2015

Between 2002 – 2011, two-thirds of those diagnosed with dementia were female



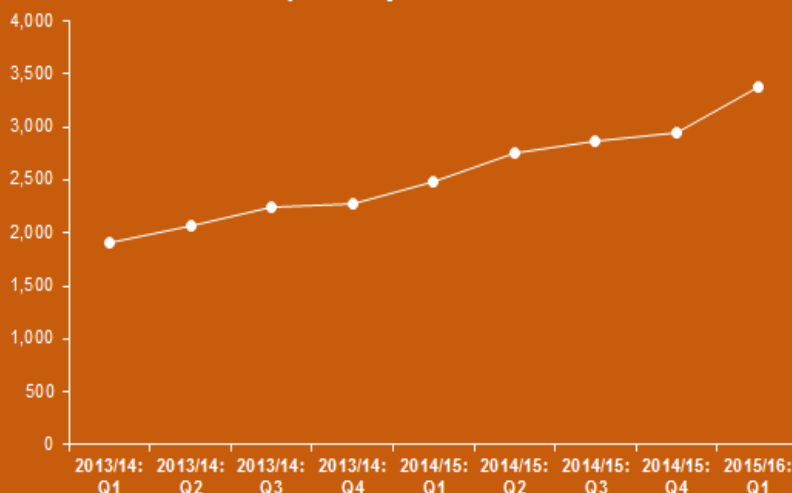
62%



38%

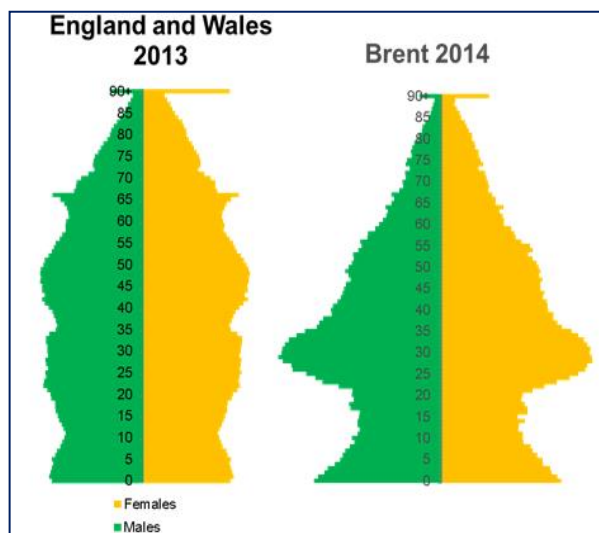
National Dementia Audit 2006 – 2011
Sample of 45 practices within Brent

Number of dementia related drug prescriptions per quarter by Brent CCG



Brent's Population

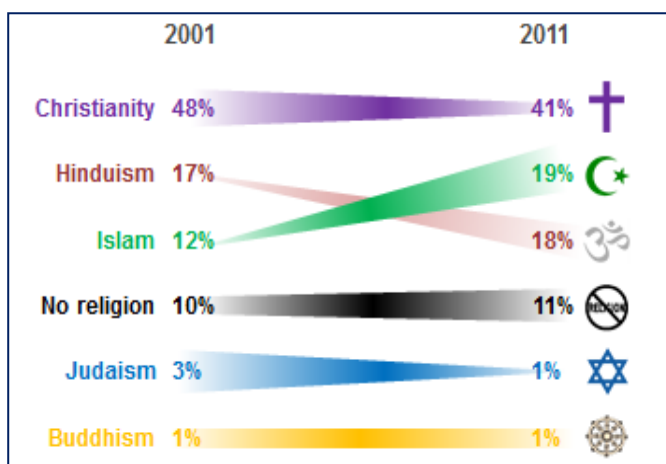
Compared to England and Wales Brent has a relatively young population although some key BAME groups are ageing.



while the BAME population is expected to increase, particularly amongst the Asian group.

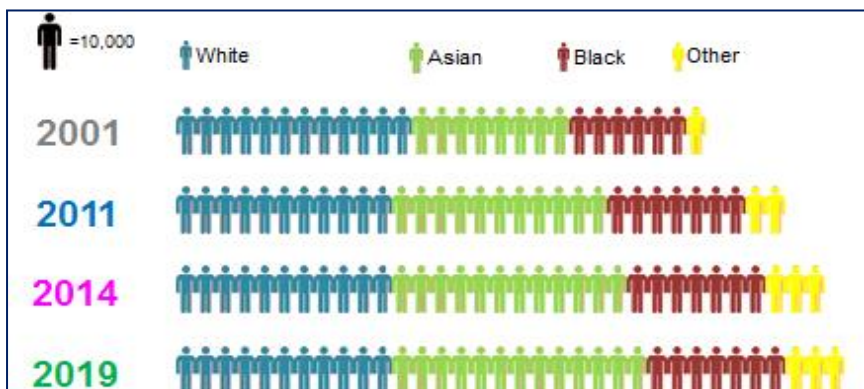
Religion in Brent

While there has been a decrease in the proportion of the population who state their religion as Christianity, it remains the most practised religious. A fifth (19%) of the population now follow Islam, an increase from 12% in 2001.



Ethnicity Change in Brent

Projections suggest that Brent's white population is set to decrease slightly,



Methodology

Six filmed ethnographies were carried out with participants with dementia in Brent by researchers at Opinion Leader. The ethnographies involved researchers following the participant and their carer for a day, observing and talking about their typical day to day activities.

The ethnographies were guided by the findings of an earlier community consultation which asked people with dementia, carers, community groups and professionals what was needed to live well with dementia. They were also informed by a review of research on health and well-being, access to services and support and community attitudes to dementia.

Simultaneously, ten community researchers were recruited and trained to carry out ethnographies with people with dementia in the community who may have been harder to reach due to cultural, language or religious issues.

The conversations with community researchers about their observations act to provide culturally appropriate insights possibly unattainable to an outsider.

The horizon scan accessed publicly available secondary research and followed a process of filtering to achieve nine inspirational case studies (for details please see overview in appendix).

The methods allowed the research to achieve the objectives by:

- Only through spending extended periods of time (one day) with participants with dementia and filming this could researchers create insightful stories representing people in real life settings.
- Only by observing participants were researchers able to see first-hand the challenges faced by participants, which they themselves may not have been aware of.
- Only by accessing the community through the perspective of those with dementia are we able to compare the experiences of participants and consequently identify good practice and highlight opportunities for improvement.

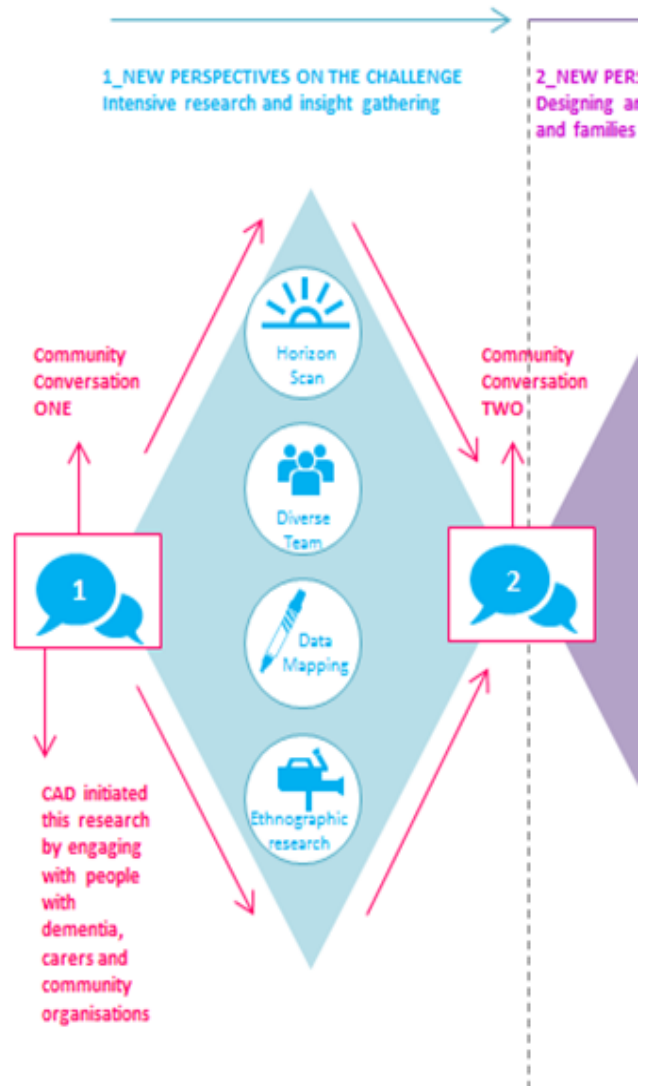
Where possible we have used verbatim quotes from people with dementia or carers. However where language or ability to articulate are issues, the researchers have been quoted on behalf of the person with dementia.

Advantages of ethnographic research

Ethnographic research allows an understanding of the issues facing people with dementia and their families/carers in their day to day lives. The combination of observation and co-discovery elements exposes the heart of what the issues are and what could be done to improve them.

The research takes place over an extended time period, in this case a whole day, allowing us to explore many facets of their life by accompanying them on their day to day activities. They are able to relax around the researchers over time which means that they are more likely to act in a natural way rather than in a way they think they should act.

Depending on the severity of the condition, people with dementia have a range of abilities to articulate their feelings, opinions and frustrations. Through first-hand observation we can understand these without the need for verbal explanations. We are also able to see how other people in the community interact with those with dementia and understand which behaviours they have difficulties with.



Understanding of the condition and its symptoms is lacking amongst those who have dementia, their friends, family and in the community as a whole. Dementia is stigmatised within society; the term dementia is associated with negative connotations which instil fear and can cause those with memory problems or their families to avoid talking about the condition. Negative assumptions about dementia prevent some participants and those close to them from learning about the condition or seeking help and support. However for those who do want to understand more and help raise public awareness of the condition, accessing open source information was difficult and time-consuming. With growth of understanding limited by a lack of information, the community in Brent was typically perceived to be uninformed and unengaged by participants, leaving them to feel that the condition is not well understood or accepted by society.

Denial

When first diagnosed with dementia, participants differed in their understanding of the condition and their willingness to accept their diagnosis. Some felt fear and dread but contrastingly for others, the diagnosis offered a sense of relief by providing the answer to their cognitive and behavioural changes.

Those who perceived the condition negatively often delayed seeking a diagnosis whilst their fears made it difficult for them to accept their diagnosis. Some resented the term dementia and described it as 'ugly', illustrating the barriers those with dementia face in accepting help or support.

"I've been recently diagnosed with dementia. It's only now that I'm beginning to adjust, because during the first period, I've been very defensive. I'm trying to, sort of, come to terms with it, and see how well I can help myself. I think it's difficult, it's difficult to accept, it's not been easy. " – Ken

On the other hand, those who wanted to understand their problems regard obtaining a diagnosis positively as it enables them to learn more about the condition and access help to manage their symptoms. This attitude typically encouraged participants to share their problems with others to access emotional support.

“Any kind of progressive illness that isn’t treatable is going to be really difficult for somebody to acknowledge, but it’s also probably a condition that you can live with for quite a long time without having to admit that you’ve got it. So it’s psychologically and emotionally difficult and people’s attitude to it, (the) fear. It’s really frightening, isn’t it? The sense of loss, that terrible sense of loss that you have.” – Project Officer

Lack of information

Participants with dementia became distressed when recounting the lack of information available to them after diagnosis. Diagnosis was referred to by many participants as a frightening experience, one in which information and guidance is crucial to encourage understanding and acceptance of the condition. However many participants felt there is a lack of locally accessible information about the condition, its’ causes, typical symptoms, what can be done to provide support and where this can be accessed.

“Nobody is explaining to me that there are people there to talk to, but when the time comes who do I turn to? Neither the G.P. nor the consultant or any organisation comes up and says, ‘We are there.’ Nobody is saying that you can go and do this to help with that. The consultant will tell you some things by using some very medical words which I cannot understand.” – Arun

The benefits of accessing objective information are clear to participants. It enables those with dementia and their families to grow their understanding of the condition and become aware of the services available to them, whether this be drugs to delay progression, behavioural management or counselling. However when receiving a diagnosis of dementia, many felt they were left alone; participants expressed that a basic level of information was not easy to access and left them feeling neglected, vulnerable, 'just a number'.

Some participants felt that the large amount of effort required to obtain information about the condition acts to reinforce the stigma surrounding it. They were often unsuccessful in their attempts to understand the neurological changes and the associated effects, what might happen to their behaviours or what their future may look like. They believe that this lack of understanding is driven by a lack of locally distributed, easy-to-read information and maintains the stigma surrounding the condition.

“There’s a stigma around the dementia, I think people don’t understand it, so they just think because it’s to do with your brain, then you’ve lost it, or you’re going cuckoo in the brain, and I’m trying to say to people it’s not. It’s the memory, you know? It’s just a mental health issue... Dementia doesn’t mean that you walk and eat out of the bin or sleep on the street - unless you get lost and you can’t find your way back, then you have a kip because you’re tired. I’m trying to say to people, ‘Look, it’s one of those things that-, one of those illnesses, one of those cognitive problems’. You have to get the full understanding to know how you can manage people.” – Dianne

An uninformed community

When reflecting on life in the community, participants typically expressed feeling that society does not cater for the changes to their behaviour resulting from dementia. Participants recognise that they often become confused, lost and tired when out and about. These symptoms affect their ability to carry out simple every-day activities, such as shopping, using transport or visiting friends. Being less able to take part in every-day activities greatly frustrates participants and has had detrimental personal effects. Some participants expressed feeling a loss in confidence in their self-efficacy and felt less able to execute ordinary tasks independently.

The diminished sense of self expressed by some participants contributes to the difficulty participants experience when wanting to explain to someone that they have dementia, especially if they become lost or confused and are in need of help.

“Stigma would cut down if people were understanding. If you’re going out on the street, and you saw somebody wandering away, then at least you know how to deal with a person, or to go over and talk to that person. Some people have ideas of their address you know, so that would be a big help. The brain hasn’t gone that bad. It will go for a minute, but you will eventually come back. Society has got to do everything to help.” – Dianne

This inability to communicate a need or difficulty is hindered further by low awareness of dementia at community level, as members of the public have low ability in recognising problematic symptoms or when to help somebody. Participants believed that lack of awareness results in little public support, thus leaving people with memory problems at times unable to function independently within society. Therefore stigma, combined with misinformation about dementia reduces the confidence of members of the public to provide help.

Feeling separated from the life you knew goes hand in hand with dementia. Changes in mental capacity can cause participants to not only regard themselves differently, but can also make their surrounding environments unrecognisable. Some participants have had significant sources of support to help them come to terms with the condition and accept what it means for their future, however others have had nobody to confide in, no outlet to help or support them in their darkest moments. Without the freedom to express themselves and to be understood on their own terms, some participants felt imprisoned by their surroundings, contributing to their withdrawal from society. For those with dementia to feel comfortable in themselves and their surroundings, it is clear that they need to be able to seek solace from those around them. People with dementia need to be able to express distress and sadness to others and receive help and emotional support, enabling them to remain an active part of society.

Expressing distress

The cognitive changes and alterations in behaviour that occur due to memory loss causes people with dementia to be frustrated with themselves, often questioning who they are now they have the condition. Negative emotions felt towards themselves often overpower the individual's willingness or ability to express their anxieties. Those who have the opportunity to talk frankly to somebody like a family member, friend, physician or even stranger and access their support expressed feeling a strong sense of emotional relief. They were very grateful towards that person for taking the time to listen illustrating its importance in acceptance. Contrastingly some people had nobody with whom they felt they could discuss their feelings about dementia, express their distress or rely on during the bad days.

“After he was diagnosed he didn’t believe the diagnosis; believing he was too young and carried on as usual.” – Mr. A

Without the freedom to express their thoughts and emotions, those with dementia often felt depressed and fearful of what the condition might mean for them, those close to them and the future. This negative outlook led some participants to hide the condition from those around them, and in doing so, withdraw themselves from society. This can create a negative feedback cycle whereby fear and self-doubt feed into loneliness and isolation, which in turn reinforce the fear and self-doubt.

“No, everyone has their own problems you see. I’ll keep it to myself because it shouldn’t be them (family) I should be telling really, because it wouldn’t make them happy. You know what I mean. I keep a lot of things to myself.” - Julie

Restricted choice

People with dementia typically felt reliant on family members or carers for simple day to day tasks which causes them to feel frustrated and depressed, consequently damping the desire of some to remain autonomous. Participants expressed wanting opportunities to be less reliant on family and friends, and have more control over their own freedom. However, those who have searched for such opportunities found little available to them in the way of local social groups, especially for participants with early-onset dementia.

“We went to a few day centres which were targeting older people - not really her thing. She loved going shopping and dancing (but the tea dances in Brent were way too tame for her). It would be much better to maintain the links that people already have in the community and help them to nurture their distinctive identities and personality.” – Project Officer

Not being able to access such support groups in Brent only acts to enhance participants feelings of isolation from society, resulting in them feeling alone and often embarrassed by their condition.

“Steven would like to go to a drop in facility – to talk to interesting people and keep connected to life, rather than suffer his social isolation at the Lansdowne.” – Community researcher about Steven

With little tailored support available, those who are able to access wider social groups are often discouraged by their own fears of becoming exhausted or confused. This causes some participants feel imprisoned in their own home, perfectly able but unwilling to access wider society.

“It is normal in a husband and wife, that the husband should be the breadwinner but it looks in my that I am not a breadwinner and that, sort of thing is what caused the ego in me to go down.” – Arun

The complexities of providing support

It is critical to understand that family and friends are not always best placed to act as the pillar of support in the participants lives. Close friends and family may have negative feelings towards the dementia because of preconceived ideas and expectations of the person with dementia. Similarly they may resent caring for somebody with whom they have a difficult relationship or whose ways of communicating or behaving are not easy to understand. Both of these factors can act to limit the abilities of friends and family to understand the present situation from the participants’ perspective. They may have little empathy for the feelings of the person with dementia and consequently can unintentionally limit their independence and autonomy.

On the other hand, the act of being supported is not an easy adjustment for those with dementia. Those who have confided in those close to them expressed feeling a threat to their identity and pride as their role within the family home can drastically change from one of leadership to one of dependency on others.

Admitting this shift in family dynamics has been difficult for some participants, causing them to feel a diminished sense of self within the family. Positively however, for others who had allowed themselves to be honest about these feelings found their families and friends to be highly valued sources of emotional support.

“Alison leaves notes to tell him when she is coming, but he does not remember to read them and worries where she is. He says how much he enjoys her company – he has little to do without her.” – Community researcher about Steven

Participants who do not have immediate family to rely on expressed being fearful and unwilling to divulge what the lived experience of dementia is really like. Some felt the worry and the distress they might cause others was inappropriate as everyone has their own problems to deal with, and do not need these compounding further. As such some participants chose to keep their thoughts hidden from others.

The complex intricacies in the perspectives of those with dementia and their family and friends, indicate that an independent source of support would be valued. Only this way can participants express their inhibitions freely without negative consequence on those close to them, whilst remaining able to interact with the world as they choose to.

“I think the upsetting part is that I want to tell them the truth, but then sometimes I can’t tell the truth because if I do tell them the truth then they will get more worried about it, and that is where I think that I am not honest enough. Although it might be a white lie or a black lie or whichever lie, a lie is a lie, and that I’m not honest to my family, that is something I feel bad.” – Filmed participant

Brent is a widely diverse borough consisting of many religious, ethnic and cultural groups where attitudes to dementia differ vastly. Perceptions and beliefs impact on the quality of participants lives. At the positive end of the spectrum participants have been able to access help and remain a valued and active part of society whereas at the opposing end, dementia can be regarded as an insanity which brings shame on the family, resulting in some people with dementia hidden from society. For some participants religious beliefs can act as a barrier to seeking support, instead tending to rely on faith and prayer for support. Regardless of one's understanding, places of worship are perceived to have a pivotal role in educating their congregations, reducing fear and stigma and in providing support so that all those who desire help are empowered to access it.

Cultural differences in attitude

Understanding of dementia can differ greatly depending on cultural, religious and educational factors. The condition can be highly stigmatised in some communities (particularly among people from African- Caribbean and Asian groups) which can prevent or delay people with dementia or their families accessing services and seeking support. Some participants described the embarrassment and shame bought onto the family by the condition; those with dementia have been labelled as 'crazy' causing families to hide them from society.

"People with dementia are particularly stigmatized in the West Indian community and labelled 'crazy'. People tend to sweep it under the carpet which narrows the world of the person with dementia." - Vincent

These cultural perceptions fostered a fear of dementia and negatively impact on the self-worth of those with memory problems, consequently several participants experience depression.

Conversely for other participants from BME communities, the stigma they perceive has ignited a desire to raise awareness about the causes of dementia, highlight the benefits of engaging with society to both improve understanding and encourage others to seek help.

“Do black people talk about dementia? Oh, do they? It’s the last thing on their minds. They only tell them that they’ve got some memory problems. Well, for crying out loud, if that is what’s going on then seek help. Seek help, and don’t hide it. I wish they wouldn’t. It’s so easy to hide, but if they don’t talk about it, how are societies going to understand about it? Some of them even hide it from their children.” – Dianne

Participants and their families stressed the importance of remaining involved in their community despite the neurological changes which the condition can bring. Not only does remaining connected socially help to reduce the emotional distress associated with memory, language and behaviour changes but also enables wider community involvement to support family members and participants.

To add weight to the need to remain connected with others, being with familiar people in familiar surroundings helps participants to regard themselves as the person they always have been: worthy of society and (apart from some allowance for their difficulties) not to be treated any differently.

“Anna does not like using the term Dementia, as for her it means that the illness is stamped on her. In Polish society people are not very understanding about Dementia and Alzheimer’s disease and unfortunately the community treat sufferers differently. Therefore people who live with dementia would like other people not to know about it. This is why she would rather join the groups which are not related to any illness and enjoy herself for as long as she can.” – Community researcher about Anna

Religious beliefs and the role of faith communities

For some participants, religious beliefs and practices are an opportunity for solace and calm in dark times and during bad-days. However, some participants expressed that accepting their dementia has caused them to question themselves and feel guilty at what the condition means for those around them. Some are unable to recall things they have said or done and worry about the emotional pain this causes and will continue cause to those around them as the disease progresses. Some participants express being fearful that others do not understand.

“Part of the reason he was not able to accept the diagnosis was the cultural stigma and his fear that others would not understand.” - Chhotu

“Look, why this, why me?’ I keep questioning it but I don’t get any answers, and there are no answers to it and that part is just very frustrating for me. .” - Arun

Religion plays a dominant role in some of the participant’s lives and has helped them to remain positive in times of darkness. There are important similarities and differences across various belief systems which can affect this, and are therefore important when considering support for those with dementia. Beliefs can be a barrier to accessing help if people accept the will of a higher power and rely only on that power to help them with their dementia believing they need do nothing to help themselves (such as seek medical help).

“The church has a role to play in promoting awareness and acceptance of dementia as a disease, which could reduce the stigma associated with it. The church could also help on a more practical level by encouraging people to befriend people with dementia.”- Vincent

Most participants highly value places of worship and their congregations as spaces which foster inclusivity, trust and honesty. They see them as pillars of strength in society, where anxieties and fears can be expressed in confidence and independent advice and support accessed.

“Talk to people. Get involved. Some of the faiths don’t want to get involved, they just want to do things for themselves, and you need to do more in the community. Get stuck in the community, hands on, and do what you have to do, because we need them. They need us. It would be good to know that they are there when we needed them, and not just in their own element, saying, ‘Oh, because you’re not a part of our congregation, we can’t help you.” – Dianne

Despite valuing places of worship some participants expressed feeling that dementia was ignored in their faith settings and opportunities to challenge stigma and raise awareness were lost.

“Cultural and religious communities are not an important source of support for her; she doesn’t feel like she can be open about her diagnosis.”- Community researcher about Debbie

If religious groups and communities were to publicly advocate support for those with dementia, participants believe this would promote open conversation and raise levels of understanding. In turn this would encourage religious groups to move away from ignoring the condition and proactively educate people about how to live well.

The behavioural and psychological changes that occur with dementia progression can put those with dementia at risk. The limitations of memory, cognition or judgement can make their environment or everyday situations difficult to negotiate, leaving them vulnerable. As such people with memory loss rely more on friends and family members for support. Simultaneously when requested by participants or otherwise alerted to their difficulties, family and friends feel increasingly responsible for the individual. This can cause them to restrict participants everyday activities, aiming to protect participants whilst reducing their own anxieties. However well intentioned, limiting independence can negatively impact the person with dementia, as a lack of freedom and reduced autonomy can increase the risk of depression. Participants with dementia acknowledge the concerns of their loved ones but want families to balance the risk, allowing the individual with dementia to remain as autonomous as possible whilst helping them to live well.

Becoming a burden

Some participants with dementia were aware of the cognitive changes taking place and want support to help them cope with their decreasing abilities - whether it be through family members, supported housing, carers or the health service. However participants acknowledge that decreases in their mental capacities come hand-in-hand with increases in their carers anxieties and stress about the condition. This effect makes some participants feel guilty about requesting and receiving help and support. This sense of guilt is heightened when participants had frightening experiences, such as becoming lost and confused when out and about. Not only did participants express feeling helpless and frustrated at themselves, but these experiences heighten their worry about the stress they cause to others. This complex situation caused some participants much sadness.

Stripping of freedom

To compensate for the stress and worry caused by the manifestations of dementia, families and friends have tried to support the individual by removing the objects or activities which cause anxieties.

Some participants do not feel trusted to be independent by their families, which in turn causes them to not trust themselves to carry out everyday tasks. Examples include family insisting on helping them wash due to worry that they may fall in the shower, cooking for them in case they burn themselves or start a fire, only allowing them out when accompanied or lastly, by taking control of their finances and belongings.

Participants were grateful for the help they are given but some participants couldn't help expressing frustration at their lack of autonomy and independence to make decisions for themselves.

"I think the idea of people being able to continue to live independently can be quite difficult sometimes for people to accept. They start thinking, 'No, this person can't be on their own, or be safe,' so that can be quite hard, I think, for people." – Project Officer

The experiences of many participants illustrate how family support, even with the best intentions can result in the person with dementia feeling undermined and over-protected. Too much help has left some participants feeling a lack of identity, unable to make choices and live independently - disempowered. This contributes further to the feelings of guilt participants express for the effect of the dementia on the lives of other people in their surrounding environment.

"In my family, they are much more protective than useful." – Ken

On the other hand however, some participants experienced a lower level of support as families and friends were not able or available to rely on. These participants were helped to live independently in supported accommodation or with formal carers visiting their home to provide support. While the wish for independent living was strong, some participants felt the need to restrict themselves from everyday tasks to prevent negative events from occurring, thus limiting their own ability to live well through fear and worry.

Retaining a sense of self and self worth is challenging when living with dementia. The neurological changes impact on skills built throughout life, forcing participants to change their perception of themselves and how they interact with the environment around them. This causes participants to question their sense of self often consequently causing them to lack trust in themselves when making decisions. Positively however, participants recognise that if they had the opportunity to remain an active contributor to society by sharing the knowledge and skills they have retained, they would feel more worthy, more confident and more valued. Some participants believe that sharing their skills would increase their happiness and the rate of brain deterioration may slow. It would also help to make them more active, encouraging them to continue to engage in society.

Losing control

Some participants felt their role in society and within the family had gradually become compromised. Several participants had not been able to maintain their role at work due to memory difficulties and bouts of confusion. Others were not trusted to look after their finances nor care for other family members as they had in the past.

Participants did acknowledge that as dementia progresses, everyday tasks can become more difficult. For instance simple tasks such as remembering how to wash, dress and eat breakfast in the morning increasingly require assistance.

Some participants were aware that they may not recognise their families in the future, nor recognise their house or themselves. Coping with these realisations has been a particularly difficult emotional process. Some participants with memory problems had turned to alcohol as a way of coping and in turn felt frustrated and increasingly worthless at their transition away from independence with condition progression.

"All these sorts of things, they are slowly and steadily, all these decisions have been taken away from me. If you can't make your own decisions, and these are only small decisions really, it feels bitter, you see? It feels bitter in the sense. I feel it puts that, sort of, restriction on me... Sometimes I just like to be on my own for a while, which I very rarely am because there is always somebody around me, most of the time." – Arun

The pull of independence

Whilst dementia may reduce a person's cognitive abilities, being able to continue to live as independently as possible is extremely important for participants. For them independence meant feeling a sense of self, a sense of purpose and feeling valuable within society. Remaining as independent as possible for as long as possible was clearly desired by all participants.

Participants can understand that some abilities deteriorate at a quicker pace than others, and therefore defining independence is therefore different for all participants, emphasising the needs for a range of outlets.

The feeling of accomplishment associated with completing a task for yourself by yourself is valued by all participants. This might be doing the shopping unaided, gardening or volunteering - whatever the participant can do and still enjoys.

"I would like to contribute something. Your wholeness is not only in what you get but what you feel you can share, so giving people something to do to slow down your rate of deterioration would be good." - Ken

“Since Anna’s husband’s death, she wants to deal with everyday tasks by herself and to be independent for as long as she can. She is noticing the changes but trying to cope with it in the best way she can... she keeps a diary where she puts all the appointments (and) she has a daily routine in the morning; the first thing she does is preparing her medication for the day by putting it on different plates. The plates indicate the different time of the day for the medication to be taken. She leaves them on the table, where she can notice if the medication was taken or not.” – Community researcher about Anna

When projecting to the future, being able to remain in their own home with professional help coming in as necessary is an important factor in retaining independence. Participants see this as a central tenet in protecting their well-being and sense of self when trying to manage the condition which is progressively changing their abilities.

“People say ‘if you have a problem with the house, you can move somewhere else...’ it creates the problem. Even if you take me from this place to the other place the dementia is still the same, you see. The place might be different, but that fear is still there. It’s not going away anywhere else. It’s just stuck like super glue. You can’t just get away from it.” – Arun

“It is my dying wish that I live in Brent because I have been living here. If I move up from here and start from scratch, I might not be able to even settle (and) that will go against me. 99% I might not be able to settle, because everybody I know of is here. How can you make a friendship within a short period of time. It is all in the darkness whether you can make it or you can not make it. If you can’t make it, then I can’t come back to Brent either.” – Arun

Enjoying the skills that remain

Participants expressed passions and dreams, dislikes and fears and as such still maintain abilities to share experiences and knowledge they have acquired over their lifetimes. Some symptoms of dementia mean that certain activities have risks attached to them, such as dog-walking, running or gardening. However as participants are restricted by family, friends and themselves they can lose confidence in a multitude of abilities and feel worthless.

Participants expressed desires to remain active in some of their passions and skills, excitedly describing the positive sense of purpose they would feel if they could share some abilities with other people.

Some participants had been lucky enough to find these opportunities and stressed the sheer importance the activity had in their life and the confidence it gave them to remain an active member of society. Maintaining existing links in participant's lives could provide an outlet to socialise and build their sense of self-worth outside of family circles. This would improve independence whilst helping to nurture their distinctive personalities.

However, participants who are able to go out in Brent can feel challenged by the lack of safe public spaces available to them to relax when feeling tired or confused. The fear of getting lost prevents some from leaving their homes as they would like to, thus risking greater social isolation. To combat this, participants expressed the need to have designated safe places where they would not be judged and instead, given any assistance they require.

"Okay, you've got diagnosed, but you're still independent. That's what it's all about, you're still independent, and you can say, 'At least I know I've got it, but I'm still valuable. I'm doing something.' I don't want anybody to kick me to the ground because, oh, I can't remember to do this, and I can't remember to do that, so I'm still grateful that I've got something that I can get up and go to." - Dianne

Currently services exist which have had a profound impact on participants lives. They have stimulated positive change and continue to act as pillars of strength and support. It is critical to recognise these services to understand how they have addressed participants' issues and un-met needs, and what role they play in society to help people with dementia live well. Best practise describes a person, service or process that has created a positive change to someone with dementias life. This might be by providing them with a sense of purpose, improving their feelings of self-worth or integrating them into the community. Peer support work is a crucial example of best practise, illustrating the benefits of expressing yourself, your anxieties and concerns after diagnosis. The Raunchy Rockers exemplifies the benefits of community groups to support people and help them manage their dementia, as does Dementia Cafes. These examples provide life-altering opportunities for participants through helping them to live well, a standard which should be available to all.

Case Study: Peer Support Programme

This case study is about a participant diagnosed with dementia at 47 who had the opportunity to access an Occupational Therapist (OT), starting her on the road out of her depression. Here she was given the choice to learn about vascular dementia in a safe environment and establish various behavioural management techniques which have greatly improved her quality of life, such as keeping a diary, various alarms and a dosette box for medication.

Due to the diagnosis she had been made redundant, which had lessened her sense of purpose and was contributing to her depression. The OT recognised that she needed to remain an active contributor to society to help her regain her sense of self-worth. With little available for younger people with dementia in Brent she was referred to Kensington & Chelsea and Westminster Memory Service. Here she had the opportunity to volunteer in their pioneering Dementia Peer Support Programme, whereby those who have received their diagnosis are able to express themselves freely, obtain advice from other people experiencing dementia alongside the professional opinion from nurses and psychologists.

Having the opportunity to help others with dementia come to terms with their diagnosis empowered this participant to show others that there is help available to remain as independent as possible and live well with dementia. Of equal importance here is this the empowerment this service has given this participant drive to break the stigma around dementia concerning age and ability. She wants to raise awareness that dementia does not only affect the older population as it can happen at any age. However life does not have to change with diagnosis as you are still the same person.

The positive impact of becoming a peer support worker has since stimulated this participant to seek other opportunities to advocate living well with dementia. She now advises Community Action on Dementia Brent on the realities of living with dementia and is active in the Memory Service's Young at Heart group, a group specifically for younger people.

Case Study: Raunchy Rockers Experience

This case study is about an Asian man with advancing dementia who has gradually become dependent on his family to help with daily activities. He has become increasingly withdrawn from society, fearful of his symptoms and the worry that they cause to his family.

However he does recognise that retaining a sense of independence is crucial for his well-being, enhancing his self-efficacy and sense of self-worth. As with most participants he wants to be able access society as well as spend time alone, but this is only possible if the community understands the condition and is there to offer support.

The Raunchy Rockers is a non-exclusive community group advocating that those with long term illness can live well and deserve to retain a sense of autonomy in their day to day life

“With the dementia friends, I can say what I want about my deepest fears, and I can say it in a safe place. It’s not going to help everything but it’s going to help reduce the fears, help other people understand a bit more”. - Arun

Since joining the group Arun has benefitted in a multitude of ways: he has the ability to express his greatest fears in confidence and he uses music and movement as therapy to help him in difficult times. The group enables him to trust others outside of his immediate home environment and be independent of his family, which has helped help him regain confidence in his self.

The group has given this participant a chance to access society through people who are trained dementia champions, knowledgeable of the condition and its behavioural symptoms, and value people equally. Raunchy Rockers has been a rich source of joy and contentment for this participant and he feels incredibly lucky to have found new friends who are so accepting of him and his dementia.

Case Study: Dementia Cafe

Participants who visit the dementia café highly value the opportunity it gives them and a family member to go somewhere outside the home to meet others like themselves. Both those with dementia and their carers are able to socialise on their own terms and relax in their surroundings. Participants expressed particularly enjoying the organised learning sessions whereby they have the opportunity to learn new skills or refresh old ones. The cafe gives participants confidence to maintain social abilities and by skill-building enables those with dementia to feel integrated into society.

“The café is great because people can relax there knowing that everyone has the same problems. It is very useful for people who are struggling to come to terms with the illness who often feel embarrassed and spend a lot of time trying to disguise their memory lapses. But it is much too far away for a lot of my clients and not easy to get to.” – Project Officer

Although participants desperately want to remain independent in the community, they experience many barriers in their own homes, their local environment, in social situations and when accessing health and social care services. Participants want services to be tailored to suit the needs of those who have memory problems and that the environment adapted to cater for common symptoms such as confusion, getting lost or other behavioural changes. People with dementia can be helped to remain independent though the provision of health and social care services. However thoughtless provision can cause emotional distress, create dependence and lead people with dementia and carers to avoid or withdraw from services because they are not meeting their needs. Tailored adaptations would enable participants to continue as independently as possible for as long as possible.

Holistic approach in care services

Participants who access professional care commonly experience a shortfall in the quality of service they receive. Many felt it only met their basic needs and did nothing to support carers and following diagnosis did not provide adequate support or information. Presently people with dementia can interact with up to five different services whilst still in their home. This for example may include a different morning and evening carer, meals on wheels, a project officer and a social worker. The lack of communication inherent within this fragmented approach is problematic.

People with dementia experience anxiety and distress when with unfamiliar people, particularly when these are the people providing the help for sensitive personal tasks. This lack of consistency can make people with dementia feel unsafe in their own home and untrusting of the service, both causing participants to become agitated and uncooperative making the job of the careworker more difficult.

Within the community there are numerous groups actively trying to improve the quality of life of people with dementia but these services are not well known or accessible to all. They are not accessible to people with memory problems due to a plethora of reasons: participants may forget when meetings happen, they may have no way of travelling without fear becoming lost on their way there or back. Such fears can have caused participants to withdraw from society with little wish to leave their home.

Those who do engage with community activities have a better sense of well-being. Arguably therefore, people who are not engaged with local community services have the most to gain; however no network exists between groups to support each other and encourage participants to take part. There is a need for better publicity and active outreach to people with dementia and their carers to encourage their participation. Carers expressed that if groups worked together they would be able to build on each other's momentum, and be in a stronger position to raise awareness without duplicating services and encourage an inclusive society for those with dementia.

“It is much too difficult to get social workers to recognise the care needs of clients with dementia. Just because people can physically wash, dress and cook and say that they are doing these things doesn’t mean that they are actually doing them or not really struggling to do them. Sometimes people are really not coping but there is not a lot of evidence of this. Phone assessments are not appropriate. And having to be prompted to change your clothes is just as much a need as having to be physically assisted to do it.” – Project Officer

Tailored emotional support

Participants expressed often feeling isolated and lonely due to their dementia. Neurological changes have altered their perception of the world and they can become confused and scared by what was once a simple task or a familiar place. Expressing these feelings can be hard for some as participants are fearful of what others may think about dementia, and worry about what it means for them and their families' future.

Some participants felt able to express their fears, hopes and dreams and emphasised the benefits of talking to someone who understands the condition. Simply having someone to talk to who will listen and not judge them is greatly desired by participants. Talking had helped participants come to terms with the diagnosis and for some it had provided a platform to help fight their depression. For others, it simply helped them make friends and feel included within society.

“The most important thing for Eileen is to be able to live and remain in her own home. Having a support system not only for the person living with memory loss, but also for carers and family is crucial, as this condition can cause great stress to all involved.” – Community Researcher about Eileen

“I don’t want to be a burden to my family if I become handicapped, because of behavioural problems. That frightens the life out of me, that is what I don’t want to have. I’m not angry as such, I sometimes become angry with my own self that I will become a nuisance if something does go wrong, and that is what worries me most. I want to know what the future holds for me. I’m looking for an answer but I can’t get the answer, nobody can give me an answer because there are no answers to it.” – Arun

“Something just to say – ‘If and when you get caught up in a situation, then we’re here - you can come and talk to us, but not pass you from pillar to post, and then you don’t know which direction to go. You can come and talk to us.’ A lot of people would love that.” - Dianne

Participants often expressed frustration at their loss of independence and reduced self-efficacy due to over-protective family care or cultural beliefs which restrict them from accessing outside help. To ease this tension, carers have highlighted the potential of a “dementia pathway” booklet. This would illuminate what a journey with dementia may look like, what the future may hold and advice on how to maintain independence, reduce problems, manage unusual behaviours and live well with dementia. They felt that an objectively written information booklet may help to manage expectations of participants and their families from the point of diagnosis, encouraging understanding of the condition and the support that is available.

User-led design

Participants often become dependent on their friends and family because services are not designed to cater for their needs, and they are therefore vulnerable to risk. This might be around the home, on public transport, when trying to access finances, telephone services, or in shops. Consequently tailoring services to meet the needs of those with dementia is critical for participants to remain independent and active within society.

People with dementia have problems using systems which everybody else takes for granted. For example, if they need to report problems like a broken boiler to energy companies they experience difficulty choosing options on automated telephone systems. The same problems occur when paying for goods with a credit card or getting cash from an ATM.

Memory problems mean that people with dementia may forget appointments or recall whether they made reservations such as for exercise classes. Automated systems are not designed for people with memory problems or sensory impairments and seriously disadvantage them.

In many cases missed hospital appointments cannot be rebooked without seeing the GP again, thus delaying help, causing stress and wasting resources.

“She wishes that the GP’s staff were more understanding and she did not have to wait two to three weeks for her appointments” – Community researcher about Anna

Participants often have problems remembering where they are going or how to get somewhere having left the house. Participants expressed particular frustration at transport and shops where it is easy to become distracted and confused. They would value some kind of system that reminds them to get off the bus or not to buy too many items in a particular shop. More importantly training in workplaces is needed to help service providers understand dementia better and increase their awareness of what is and what is not possible in a certain situations for those with memory issues.

“The memory service takes ages to do the assessments and get people diagnosed and not very sympathetic about missed appointments... this is something that really needs to change right across the health service. If a patient forgets an appointment, throws the letter away, does not have anyone to remind them etc. they get discharged from the service and referred back to the G.P. Can you imagine how difficult that makes life for people with memory problems and carers? It is very hard to even get your name on their systems as an alternative contact. And when you do they do not always use it.” – Project Officer

This research primarily sought to produce insightful in-depth stories of those living with dementia in Brent; to understand their challenges and to highlight opportunities which could solve these challenges and help those with dementia live better in Brent. Through the ethnographies produced by both the community researchers and the professional researchers, the key findings can be synthesised.

1. Unmet needs of those with dementia

Those with dementia have needs which are currently not being met by the services they access and the care they receive. Emotional support is typically lacking for participants in the study, some are depressed and fearful of the condition, yet are desperate to express their feelings to someone who understands and will not judge them.

Participants expressed frustration at their lack of independence as they have to rely on others for simple day-to-day tasks, reducing their sense of self-efficacy. This in turn has negative effects on participants' perceived ability to retain and share skills and abilities.

Participants with dementia want to be able to contribute to society in order to help them maintain a sense of purpose. However, opportunities to do so are perceived to be limited.

2. Challenges for living well with dementia

The neurological and behavioural changes associated with dementia cause participants to face challenges in almost every aspect of their daily lives. Understanding of dementia is low and stigma exists across UK society but particularly among some minority ethnic cultures or religions. This can mean that people with dementia or their families are reluctant to access services, which could help them live well with dementia.

The fear of becoming confused, getting lost or being a problem to their families or others caused some participants not to trust themselves. Instead they often limit their own autonomy while still able albeit needing some simple help. In a similar vein, some families have become over-protective which negatively impacts upon the sense of freedom and ability of the person with dementia to make choices. Striking a balance which protects the person with dementia whilst still nurturing their existing abilities is a challenge in a risk averse society. However on balance, not all participants are passive recipients of the condition as many are actively coping and negotiating ways to live better.

3. Opportunities to stimulate societal change

There are a wealth of opportunities available in Brent to help people with dementia live well within an inclusive supportive community. However there is considerable scope to enhance what already exists and how it is provided. Building upon existing initiatives which already add considerable value to participants lives is crucial. Key examples of this include peer support programmes, community groups such as the Raunchy Rockers, dementia cafes and initiatives offered by various faith groups and minority ethnic organisations.

Understanding the challenges faced by people with dementia when they are out and about enables us to identify aspects of service which would most benefit users if improved. There are examples of individual businesses ensuring people with dementia can still do the things they enjoy – such as barmen monitoring someone with dementia's spend and booking a taxi to ensure they get home safely.

Such initiatives are successful because they use a user-focussed approach . By considering the needs of people with dementia services can tailor their offerings and stimulate positive change in peoples' lives.

Understanding the challenges faced by people with dementia when out and about or within the health care system enables us to identify how the maximum benefit could be achieved by service improvements. There is a need for dementia awareness at community level to address fear and stigma, understand symptoms and to create social spaces where dementia is understood and accepted. Families would appreciate information about the condition, what to expect and how to support a person with dementia. Existing services need to be publicised and through a network, work collaboratively to support carers. Health and social care providers, business and service industries should consider how their systems disadvantage people with dementia and train staff to be dementia friendly.

Brent has a unique opportunity to create real change not only for those living with dementia and their friends and families, but for services to alter their processes in such a way that those with dementia are empowered to live as independently as possible for as long as possible.

NB: please see full Horizon Scan report 'International Examples of Community Action for Mental Health – A Case Study Approach'.

This unique insight into the lives of people with dementia and those who care for them provides evidence which should stimulate change. The community and professional researchers have accessed information which is difficult to obtain and not always sought. The research has uncovered the views of people affected by dementia about what is important to them, what challenges they face and how the family, community, faith groups, voluntary organisations and public services could make living with dementia easier.

Change can be costly, but the recommendations focus on those with the most impact often with very little cost due to the community emphasis. To stimulate change and stretch ideas the research includes the third research strand, the Horizon Scan identifying innovative international practise which has been successful in building community care for people with dementia and their families. By combining the ethnographic research with the horizon scan, we hope that our recommendations reflect the depth and breadth of insight required to galvanise Brent on its journey to becoming dementia friendly.

1. Facilitate community wide dementia awareness to enhance knowledge and understanding:

This is imperative to improve understanding of the condition and should be especially targeted at the public, businesses and services. Training for staff in public services, health and social care could be provided at differing levels depending on their role. Children and youth should also be targeted to eliminate stigma from the bottom up.

Examples of good practise in training and raising awareness include:

- Stoke Damerel Community College (see Appendix: Horizon Scan # 9)
- Clippers n' curls are good for the heart (see horizon scan case study)
- Dementia friendly Donegal (see Appendix: Horizon Scan # 8)

2. Create the role within the care system of 'holistic care co-ordinator':

The professional care received by those with dementia is fragmented and only adequate enough to meet their most basic needs.

NB: please see full Horizon Scan report 'International Examples of Community Action for Mental Health – A case study approach'.

For individuals to live well with dementia, they need access to a professional who can co-ordinate their care and ensure that their social, emotional and cultural needs are met. This person will liaise with and capture the expertise of local community organisations to ensure person centred, culturally appropriate care and support.

Examples of good practise in creating new services with a holistic approach to care management:

- Kerala Dementia Initiative (see Appendix: Horizon Scan # 1)

3. Peer support available to all at the time of and after diagnosis:

It is imperative that those who receive a diagnosis have the opportunity to come to terms with it. Through peer support people recently diagnosed with dementia meet others with the condition, express their emotional distress in a confidential environment and learn about their diagnosis from people who really understand dementia. Peer support provides a sense of purpose for those further along their journey.

Examples of good practise in encouraging understanding through engagement and building relationships:

- TimeSlips (see Appendix: Horizon Scan # 4)
- Stoke Damerel Community College (see Appendix: Horizon Scan # 9)

4. Create accessible information to help overcome stigma and cultural misunderstanding about dementia:

Creating an informed community will help to reduce fear associated with dementia and in turn, equip the public with skills, knowledge and confidence to support people with living with dementia. Information needs to reach out to the wider community and take account of culture, literacy, language and sensory impairments whilst utilising a range of media to convey the message.

NB: please see full Horizon Scan report 'International Examples of Community Action for Mental Health – A case study approach'.

Examples of good practise in enhancing community wide understanding of dementia to reduce stigma and encourage an inclusive society:

- Dementia Friendly Gurudwaras Project (see Appendix: Horizon Scan # 6)
- Dementia friendly Donegal (see Appendix: Horizon Scan # 8)

5. Establish a network by which statutory services and community groups work together to extend the care and support provided to people living with dementia:

Busy statutory providers are often unaware of what voluntary and community services, dementia friendly environments and businesses can do to enable those with dementia to live independently and comfortably for as long as possible. Fostering collaborative links between health services, community organisations, public and private services can lead would ensure a holistic approach to care.

Examples of good practise in integrating community and professional provision to enhance care for people with dementia:

- Together for a dementia friendly Bruges! (see Appendix: Horizon Scan # 3)
- Bus stop project (see Appendix: Horizon Scan # 5)

6. Use cultural hubs or faith communities to advocate and support people with dementia and facilitate education:

Cultural groups, community organisations and faith communities are best suited to support people with dementia and educate their respective constituencies. Commissioners should support existing groups to develop their capacity to promote understanding of dementia, encourage early diagnosis and help those with dementia remain active and independent.

Examples of good practise in promoting understanding and awareness and enabling people with dementia remain active in their own community:

- TimeSlips (see Appendix: Horizon Scan # 4)
- HEKLA (see Appendix: Horizon Scan # 7)



Appendix

1. Case studies – filmed participants and community researchers
2. Summary of the nine innovations from Horizon Scan report **‘International Examples of Community Action for Mental Health – A case study approach’**.
3. Sample breakdown

Case Study 1 - Vincent

Vincent is 78 and lives in a specialist home for people with dementia. He moved into the flat a year ago after his wife was unable to care for him anymore due to the impact on her health from caring for him full time. Vincent used to be an engineer and enjoyed going to the pub and watching and talking about cricket. Vincent is visited every day by one of his daughters who take him out to restaurants and shops. Vincent is a strong and fit man; however he is easily confused and finds conversation difficult.

Vincent likes being in the home which is modern and clean, and his flat is spacious and well equipped. He enjoys the activities which are put on in the home such as watching films, dancing and playing dominos. Donna, one of his daughters that provides care for him, feels that the home could do a much greater variety of activities which stimulate the residents both mentally and physically such as trips to see plays, walks and cooking and is frustrated that the well-appointed outside space is rarely used by residents.



Vincent used to enjoy gardening and growing vegetables and Donna thinks that being able to do this in the outside space would be great for the residents as it would help keep them active. He enjoys spending time with the other residents socialising and doing activities with them. Before he came to the home he used to go to a West Indian and African dementia society where he would have meals, play games and visit different places. He really enjoyed this service because he could connect with the others as they all came from the Caribbean like him and they served West Indian food and played West Indian music.

Vincent has lived in Brent all of his life and likes the area. He gets around by bus and whilst most of the time this is fine, occasionally the bus drivers do not take into account his condition by being impatient and setting off before he has settled.

Donna feels that shop staff should be more aware of dementia and better able to meet the needs of people with the condition. Consistency of care is important to people with dementia as they can become distressed if they are cared for by a range of people.

The pub that Vincent used to go to was very responsible to his condition. When he first became affected by the condition he would go to the pub and spend up to £500, buying everyone in the pub drinks. He also used to get lost after coming out of the pub. Once the pub became aware of his condition they had a tab set up for him which was carefully monitored, they made sure that he did not get drunk and would send him home in a taxi so that he did not get lost.

Donna believes that people with dementia are particularly stigmatised in the West Indian community and labelled 'crazy'. She said that people in her community tend to sweep it under the carpet rather than discussing it which she feels can narrow the world of the person with dementia. She feels that the church has a role to play in promoting awareness and acceptance of dementia as a disease which could reduce the stigma associated with it. The church could also help on a more practical level by encouraging people to befriend people with dementia.

Case Study 2 - Peter



Peter is 86 years of age and was born in Brixton, but he grew up in India and Africa before returning to London. He is passionate about travelling and languages, having been able to speak six in the past, reading books, and is fascinated by dogs as he likes their nature. Despite being confused often, Peter is an articulate witty man who knows London well; in the past he was Charlie Chaplin's chauffer and talks fondly of late nights exploring London with him.

Peter moved to his current residence in 1988 where he lives alone having been evicted from his last home in Brent. He enjoys his home and likes that his neighbours do not bother him however, after a deep rooted bed bug infestation, it is in a state of slight disrepair, including no curtains, a broken chair and TV.

Peter has various strands of support to help him manage his day-to-day life: a social worker who aligns the services he needs; a project officer, Margaret,

to help manage his appointments, his enjoyment and his house; Meals on Wheels to provide his daily lunch; and a carer every morning and evening to help him wash and dress. These services seem to fulfil his daily living needs but are not joined up as they do not communicate with each other, they leave notes around the flat but none have a complete overview of his life, where he goes, what he feels and what challenges he faces. Due to this, the services Peter accesses can be considered to be only adequate as he is not living particularly happily and the services do not fulfil him emotionally. Margaret suggests that Peter needs a co-ordinating person who would be a consistent person in his life as social services and floating supports help is limited – both have many clients over a certain time period, and can therefore only do so much.

Peter is aware that he has memory problems and is often confused but does not admit that he suffers from dementia, a word he later mentioned to dislike as he thought it an ugly word. He admits feeling lonely and tired often and becomes agitated more quickly than he used to.

Peter has a sister who he speaks to infrequently and a few friends whom he calls on the phone, however he doesn't like to moan or talk about himself, so he tends to keep his anxieties about his memory to himself - he is a proud man and does not want to burden anyone with worry. Peter likes to be sociable and as such, likes to be out and about as much as he can, however, when distracted he can become lost and confused and does not like to ask for help. On our way to visit his church via bus this became a reality, Peter became lost and angry with himself, he was embarrassed and we saw how a distraction leads to confusion which could potentially limit Peter's confidence and ability to go out independently. Margaret is aware of this and has helped him access a GPS tracker, a facility which will track his movements and automatically alert other people if he goes somewhere unusual.

Case Study 3 - Julie



Julie is 74 years of age and has lived in Brent since moving over from County Mayo, Ireland, at 19 years of age. Julie has three adult children, all of whom live close to her sheltered housing in Harlesden. Julie lives in a self-contained flat with many other Irish people, having moved there 7 years ago after having to leave her previous home due to flooding; she was left with nothing and in a state of homelessness and is very grateful for all the possessions she has been given. Julie spends her time listening to Capital Gold radio station, visiting the shops, seeing friends and will often stay out with her son James for days at a time.

James is unwell and consumes alcohol to cope with pain, Julie enjoys being around him and helps him financially. Julie is vibrant and nostalgic; she likes to focus on the positives of her past and speaks of memories with good humour often recounting her time working in a shirt factory in Ireland or of the dances that she used to attend.

Julie has not yet been diagnosed with dementia; she is aware that she has memory problems and has visited her GP for memory tests and a brain scan

Julie does not engage with the word dementia, she is aware and knowledgeable of Alzheimer's and becomes anxious when she thinks of people she has known with the condition. Julie recalls that she is often depressed, she feels very lonely despite having the community of Irish people living around her. When trying to find the source of this depression and anxiety, it seems that Julie does not want to engage in the future and in what her memory problems might change about her life at present.

Julie has excellent support from the sheltered housing scheme manager and from her floating project support worker, Margaret, who helps her remain as independent as possible, especially in the role of being out-and-about and in her finances. Julie is fearful of not being able to manage her finances and benefits; she is often embarrassed and does not like to ask for help.

Julie does not engage in the negative aspects of life, she appears saddened when speaking of them but will quickly change subject so as not to upset herself for too long. Julie takes some medication for her health but does not want to be reliant on medication if her mental state were to deteriorate, she also wants to try and remain living as independently as she can in the housing that she is in, and hopes that the support from the Housing Scheme and Margaret will help her be as independent as possible in the times ahead.

Case Study 4 - Ken

Ken is 70 and lives with his wife in the home he has lived in for 50 years. Ken has lived in Brent since moving from the Caribbean in the early 60s. Ken was diagnosed with dementia six months ago after he and his family noticed that his memory was getting worse. Ken is a very intelligent and articulate man and he has used his intelligence to try to cover up for the symptoms of his dementia. He is diabetic and has had two heart attacks as well as having difficulties with his mobility.

Before he retired Ken was a senior social work professional and continued to write articles on social work after he retired, as well as providing training for other social work professionals. Prior to the heart attacks, Ken had always been an active man and enjoyed sharing his knowledge and skills by coaching people in boxing and gymnastics and supplementary schooling.



Ken is in the early stages of dementia and experiences memory loss which leads him to repeat himself. He is finding it difficult to come to terms with the condition. He also finds it difficult to motivate himself to get on with his day and often does not get dressed until 11am. He finds it very difficult to change his mind-set from being a service provider to a service user. This means that he is unable to make the most of the services that he takes part in, such as the dementia café.

He finds it frustrating that he does not have the opportunity to share his skills and expertise with others due to having dementia and his other long term conditions. He sees his only opportunity for helping and teaching others is when he looks after his grandchildren.

Ken has become more isolated since having the condition. This is partly due to his sons being protective over him and discouraging him from going out and about.

He would like more opportunities to get involved with the community but feels that this has changed and that he doesn't belong anymore due to the demographic getting younger and the ethnic mix changing.

Case Study 5 - Dianne

Dianne was diagnosed with early onset vascular dementia two years ago when she was 47 years old. Dianne has lived in Brent for most of her life since moving over from Jamaica and wants to remain living independently in London, despite having no support from her family who live in Jamaica.

She is engaged in society, highly sociable and very vocal about her condition: she wants the people she meets in shops or

on the street to realise that dementia can affect anyone at any age, and advocates strongly that the level of awareness needs to change for the society to provide better support.

Dianne noticed that she was experiencing memory problems and breathlessness, and was quickly diagnosed by her GP. Dianne has a strong relationship with her GP that she values greatly but feels that the level of information available to her



about her condition was severely lacking; it was only after Dianne's partners' visit from Jamaica that she felt confident in her understanding of the condition. Dianne has accessed two services since being diagnosed, her Occupational Therapist whom she saw for the limited time of six months and the peer support service that she attends in Westminster. Here she has been able to incorporate various methods of behaviour management into her daily routine to help her remain independent such as exercise at her local gym, a diary to schedule her daily needs and commitments, and an alarm to remind her to take her blood pressure medication - the alarm can however make Dianne anxious as she often does not remember what it is meant to signify.

The peer support service has been fantastic for Dianne, she feels that it gives her a sense of autonomy and a reason to be within society. She is not only able to help other people with dementia come to terms with the condition but she recognises it to be of therapeutic value to herself, and strongly believes that a conversation around the condition needs to occur in society as it is the lack of understanding which is driving the stigma she feels from those in the

community towards her. Brent is a culturally diverse borough and Dianne believes that those of black ethnicity, like her, suffer due to the condition being linked to insanity and are therefore actively hidden from society. To prevent this, Dianne believes the church and faith communities should become the in-between space whereby those who are not confident enough or able to access services independently should be able to divulge personal worries and fears about dementia. Here the pastor could either help the family understand the condition better and encourage the person with dementia to obtain professional support.

Symptoms of tiredness and confusion are Dianne's biggest difficulties, especially when she is out and about as there are no public spaces available for her to relax and regain her awareness if needed. This lack of accommodation is starting to prevent Dianne from leaving the house unless she has a specific goal or destination as she is worried that although passers-by may help her if she became confused, they will not understand the best way to help. For Dianne, dementia awareness training in shops, her gym and on transport is the most important issue to be addressed as only then will she be able to remain an active member of society.

Case Study 6 - Arun



Arun is 71 years of age and has lived in Brent since 1971 having moved from Zanzibar with his family at the age of 21. He was a motor mechanic owning 6 or 7 cars until he became partially sighted and had to retire due to his medical condition.

Now Arun spends his days at the community centre or at the gym and is very fond of his now-retired guide dog and gardening. Arun describes himself as a Anglo-Asian and as an entirely devoted family man; he has dedicated his early retirement to bringing up his four now adult daughters – two of whom are presently suffering from serious illnesses.

Receiving a diagnosis was a relief for Arun as it explained his symptoms of memory loss and personality changes (in particular becoming more stubborn). Now Arun's wife assists him with almost every aspect of his life, he needs assistance when washing and dressing, with his finances and reminders to take his medication. Arun is an emotional man, he has had depression since becoming blind and since being diagnosed has not adjusted well to becoming dependant on his family. Arun feels guilty as he is unable to contribute to the household as he used to, expressing feeling useless and 'like a burden', enhancing his dampened sense of self-worth. He feels guilty and worried for the hurt and stress his dementia causes those close to him. He is greatly appreciative of his families care over him and doesn't know how he would cope without them, but feels frustrated at the lack of autonomy he has in some areas of his life. He feels that this has contributed to his extreme lack of confidence to make any decisions, only enhancing his dependence on others and exaggerating his own guilt.

Arun is still socially active, attending a community group named The Raunchy Rockers, where he has made some great friends which he calls (along with his wife) his 'pillars of support'. He values the group as it is a space where he has been able to meet like-minded people in an environment where there are no constraints on how you should act –it makes him feels lucky and positive. He feels liberated by the freedom to express himself to people in a safe environment, and enjoys the mix of people that attend. This group juxtaposes to his perception of how dementia is received within the community, he believes it is stigmatised due to a lack of understanding. This stigma has prevented him from accessing emotional support from his ethnic community as he is fearful of others perceptions of the condition.

Arun would love more opportunities to meet people like him, to be able to access emotional support from someone in an environment where he does not need to try and live up to others expectations of himself. He believes others would greatly benefit from having someone to talk, to help them cope with the condition and their changing selves.

Case Study 1 Chhotalal

Introduction

Chhotu had just turned 80 the day before I met with him; he was born in Jamnagar, a small town in Gujarat, India and later moved to Kenya. Chhotu was the second child with 5 brothers and 6 sisters. Chhotu is a practising Hindu and is able to speak English, Gujarat, Hindi and a bit of Swahili. He had studied Law at the 'Honourable Society of Lincoln's Inn' in London but decided to practise it in Kenya. He set up the first ever divorce law firm in Kenya and was responsible for making significant changes to divorce law in the country. Chhotu gave up his law practice and set up his own company, producing quality blankets.

In 1966 Chhotu moved to the UK and has lived in Wembley for the past 49 years. Chhotu was married and had four children with his wife, one son and three daughters. His wife passed away in 1997 and he now lives with his son and daughter in-law and their 2 sons

In the UK Chhotu was a director in 5 companies including 3 jewellers in London. Chhotu was very socially active, belonging to the Free Masons and the Lions Club. Chhotu collects stamps and says he currently has thousands of stamps in his collections.

Day to day life

Chhotu tends to spend more time at home now and rarely travels without his daughter in-law Nandini. He does not travel on buses however travels independently on the underground when he goes to Piccadilly Circus where he goes to sort out the family finances.



Other than personal care which Chhotu is able to manage himself, he is totally reliant on Nandini for all his other needs such as arranging and attending appointments, managing his medication and taking care of all his other day to day needs. Nandini says Chhotu would struggle to manage independently as the family have always done most things for him.

It is difficult to say whether Chhotu would struggle to cope independently due to his dementia or due to him having had everything done for him by his family. Chhotu still attends his clubs regularly and the family have made his friends aware of Chhotu's dementia. He says he is happy with the way he is treated by others at his clubs and hasn't really experienced any discrimination due to his dementia.

Chhotu participates in activities but becomes frustrated when he can't remember things and that makes himself withdraw from discussions and activities.

This was apparent when he was not able to remember details from his past and Nandini had to correct a lot of the information he provided. However he enjoyed conversing and was keen to share his experiences.

Dealing with dementia

Chhotu was diagnosed with vascular dementia and Alzheimer's around 12 months ago after his family noticed him constantly forgetting things. However he was not able to personally accept his diagnosis until a couple months ago after meeting others with the condition at the dementia café. Part of the reason he was not able to accept the diagnosis was cultural stigma and his fear that others would not understand.

What Chhotu feels he needs

Nandini stated the family have not had much experience accessing services and would not really know where to go for support. She stated they struggle to get appointments with his GP but get on ok with the specialists. Nandini feels there should be more support for carers including training or even a course on dementia which would help carers better understand the condition. Chhotu and Nandini thinks there should be more services like the Dementia Café and more awareness about dementia in general. I suggested to Nandini to get in touch with the Brent Carers Centre and contact Adult Social Services if the family struggled to cope in the future.

Dementia café

I went to visit Chhotu at the Dementia Café which he attends once weekly with his daughter in-law. The café were expecting to have a guest speaker however they failed to attend and I was given the opportunity to have an open discussion with all the attendees.

Everybody enjoyed attending the café and found it a good source for information and peer support. Other than attending the café nobody accessed other council services. All the attendees highlighted issues around services provided by supermarkets, banks and utility providers. The group said that staff at checkouts need to be more patient with people with dementia. Some carers expressed difficulties accessing the banks especially over the telephone. However one member commented that Lloyds Bank on the Wembley High Road provided extra support for people with dementia which the group felt was good practise. The entire group expressed difficulties accessing support and British Gas was mentioned. The main concern was the 'option' based telephone system and then going through all the security checks. They also expressed utter dissatisfaction with the dial-a-ride service offered in Brent and stated they are being prevented from using this service independently due to their dementia. The group felt that local businesses both big and small had a part to play in making Brent more dementia friendly.

Case Study 2

Harold

Introduction

Harold lives in Harrod Court, an extra care sheltered housing scheme in Brent. Harrod Court offers care packages agreed with the resident. Harold is on the maximum package and has five care visits a day as well as a falls sensor and a pendant for assistance. He is 83 years old and has been living in Harrod Court for several years and lived nearby in Brent before moving here. He was born in Jamaica and uses an electric wheelchair. Jeanette is the scheme manager for Harrod Court.

Day to day life

Harold said he liked to go to the shops. When asked if he had any difficulties in accessing the shops he focused on accessibility for the wheelchair.

He also attended events at Harrod Court. Jeanette later confirmed that he got involved in dominoes and Zumba. She also said he really enjoyed watching the fish. Harold is a Catholic and suggested that he went to the local Catholic Church on some occasions and members of the church visited him.

Jeanette said she was not aware that Harold ever went to church, nor that he had visits. She said that he did have visits from a friend and from family and was also friendly with Lincoln, another resident of Harrod Court from a Jamaican background.

He indicated that mealtimes were the most enjoyable time of his day. Food was brought to him and he needed help to eat. Harry mentioned that getting dressed was the worst part of the day. He didn't think that he had carers visit him every day to help with getting dressed, but his homecare agreement suggested he had two carers each day to help with this.



What Harold feels he needs

In terms of needs he would like to see met, Harry suggested he would like someone to accompany him on walks and take him on trips e.g. to see sports matches. I offered to walk with him but Harry said he was not in the mood today. Jeanette indicated that Harry did not normally sign up for trips out. Harry returned to the theme of going out as his hope for the future. He didn't have any specific recommendations for the Council commenting "at the moment I don't remember what I want the council to do."

Dealing with dementia

Harold was not aware that he had Dementia. He did not think he had ever been told that he had memory loss and became slightly agitated when asked questions about memory loss, saying things such as, "What memory loss? I don't know anything about that....". He did not have any specific medication or treatment for his dementia, nor had he been to any groups such as the Dementia Café. Harry was far more concerned about his mobility problems and how that impacted on his life.

Case Study 3

Anna

Introduction

Anna is a 79 year old lady, who has lived in Brent since 1947. She emigrated from Poland during the Second World War. She and her husband were both involved in the Polish community in the area. Anna enjoys living in Brent despite being a bit frightened to walk around at night.

She lives in the house with her daughter who supports her, although her daughter is away quite often due to her work arrangements. Anna has another daughter living within walking distance from her house, and she is always there to support her if she needs to. Anna's late husband had Alzheimer's disease. His illness had a massive impact on her own life as she was his main carer. In Polish culture it is the wife's and family's responsibility to care for the ill member of the family. Therefore Anna cared for her husband.

Day to day life

Due to the changes in Anna's health she has had to stop her weekly meetings recently with a group of friends she was playing games with. Although she used to do it for fun, now it turns out that she is taking it too seriously and she becomes very anxious, which leads to her heart palpitations. A few times Anna has left her belongings behind and walked away without realising it. Anna is still very active and attends all the events which are organised in the Polish community. At the last event she became frustrated as she could not understand part of the speech which was in Polish (her mother tongue).

Dealing with dementia

During her husband's illness she did receive some support from the social care, but it was not enough. Anna says the carers came talked and left, and at the end of the day she was the one who had to do everything for her husband. In time his illness progressed and it became very hard for her, sometimes he was leaving the house unnoticed at night and was wandering around in search of his childhood family home. It was a very difficult time for all involved. She turned to social services for help, requesting if they could take her husband to a care home for a week or two in order for her to have a rest. Unfortunately it was too expensive and she could not pay. Her husband did not like to go to a weekly Alzheimer's Group, as he could not bear seeing other people suffering from the disease and imagining what his life could look like in the future. Her husband passed away a few years ago in a hospice, where he was placed after his illness became very serious and neither Anna nor her family could care for him.

Since Anna's husband death, she wants to deal with everyday tasks by herself and to be independent for as long as she can, despite the fact that recently her own health worsened. She is noticing the changes but trying to cope with it in the best way she can. To deal with her forgetfulness she keeps a diary where she puts all the appointments and other arrangements on. She has a daily routine in the morning, the first thing she does is preparing her medication for the day by putting it on different plates. The plates indicate different time of the day for the medication to be taken. She leaves them on the table, where she can notice if the medication was taken or not.

What Anna feels she needs

She wishes that the GP's staff were more understanding and she did not have to wait two to three weeks for her appointments. Although she meets people on Sundays in the church which she is attending, she would not mind going to some places in Brent to meet up with the community. In her opinion there should be some events organised for older people. If Brent Council is organising those events she is not aware of them and suggests that, there should be better advertising.

Anna does not like using the term Dementia, as for her it means that the illness is stamped on someone. In her case it may also have an impact that in Polish society people are not very understanding about Dementia and Alzheimer's disease and unfortunately the community treat sufferers differently. Therefore people who live with Dementia would like other people not to know about it. This is also why she would rather join the groups, which are not related to any illness and enjoy herself as long as she can.

Case Study 4 Steven

Introduction

Steven is 65 and lives at Lansdowne Care Home, and goes home to his wife Alison most weekends. They live in a flat, so go out for short walks in the nearby park. Steven and Alison do not have children, their brothers live over 200 miles away and many friends have moved out of London, so if Alison cannot come, there are few visitors, just a neighbour who has a car that sometimes takes him out. Steven was an architect, played bass guitar, read two or three books a week and has travelled around the world with Alison when they were in their 40's, taking three years off of work. He likes to have a laugh and joke and talk one-to-one, Alison says he could have been a good actor. His interests are geography, history, travel and the Second World War, but he cannot concentrate enough to read now and finds writing too difficult.

Day to day life

He says his favourite activity is sleeping or talking to health professionals. The home put on various activities but everyone else is much older- which makes the pace and level of the activities unchallenging, so he chooses not to go often.

Alison retired a few months ago so has been able to take him to Tai Chi, which unfortunately closed, so he goes to a fitness class with Alison and one or two carers, who try to help him to do the movements. He says he enjoys it, though he rarely starts a movement before the group has started the next one.

He enjoyed Tai Chi because the movements are 'straightforward and simple' but Alison has yet to find another class. Going swimming at Willesden LC was suggested, where there are sessions in the afternoons suitable for Steven. They do not have a car, but Alison said she will look into dial-a-ride. She also thinks he will enjoy art.

The Home does not have a minibus and if they go anywhere the transport has to be able to take wheelchairs- not conducive for him to go along too, especially if they are going shopping- trips to Brent Cross are most usual and he hates shopping.

Alison takes him on the bus and tube- but he prefers taxis. He finds it difficult to get on buses easily without fuss.

Case Study 5. Bill

Dealing with dementia

Steven had encephalitis four years ago, which presents like and is first stage dementia, because his brain nerve cells are damaged and he will never talk and move fluently or at a normal pace again.

He moves and understands slowly, loses his vocabulary, is stiff, has poor balance and cannot go out alone. He cannot be independent; Alison says he wouldn't know when to cross the road. Steven says he takes a lot of pills- too many. Alison says that the sad thing is that he has been sitting in his chair too much for the past 4 years at Lansdowne, which has made him stiff and unused to walking. He has never had physio- as he is not 'bad enough'.

What Steven feels he needs

Steven would like to mix with able bodied people of various ages, but where and at what level? He is not capable of doing a University of the third age course, for example, in philosophy- they tend to be too advanced. He does not want to go to the dementia café at Ashford Place or be part of a dementia network.

Steven would like to go to a drop in facility- to talk to interesting people and keep him connected to life, rather than his social isolation at the Lansdowne. Alison wants him to be kept more active, to improve his stiffness and poor balance. Alison leaves notes to tell him when she is coming, but he does not remember to read them and worries where she is. He says how much he enjoys her company- he has little to do without her.

Introduction

Bill is from Jamaica, but has lived in London for 60 years and considers it his home. He used to work for London Transport as a ticket collector at St Johns Wood. Bill is a cheerful, lovely character who is willing to chat.

Day to day life

Day to day Bill likes to cook for himself and mainly cooks fish, although he couldn't name what fish exactly. He also likes his Jamaican food. He also likes to join in the activities & discussions they have at the house. He remembers to take medication for his blood pressure in the morning.

Dealing with dementia

A cleaner comes round once a week to help Bill. When talking about the potential to go to a centre to meet more people, Jim said that he was happy and was a 'loner'. He is content with going out to visit his family and friends .

Case Study 6

Eileen

Introduction

Eileen is 89 years old and has lived in Brent for many years; all of her neighbours and friends whom she knew have moved or passed away.

Her family are very important and close to her and they spend as much time with her as possible. She is aware that they have busy lives with work and other things so are not able to be with her all the time. She enjoys watching TV and likes to watch quiz programmes, deal or no deal, state opening of parliament and the Royal Family. Eileen wants a peaceful life and enjoys parks with gardens and a café where you can sit and relax.

Day to day life

Eileen's social life revolves around seeing her family, going to the local park and café with her carer and attending the dementia café. When she feels up to it she likes to go for short walks with her carer. Eileen used to attend her local parish church.

She goes to Ashford Place Dementia café one day a week where she likes to have a chat and a cup of tea with the staff and other members of the group. She uses mainly taxis for transport and uses a wheelchair to get about. Her shopping and business affairs are taken care of by her family and carer.

Dealing with dementia

Eileen's symptoms appear to be mainly short term memory loss; she has a relaxed and calm nature but will get anxious around strangers visiting.

Eileen thinks that being able to live and stay in her own home is what's most important to her health and wellbeing. She has a live in carer whom she is close to and gets on very well with. Having a carer gives Eileen and her family peace of mind, plus having company and someone to talk to gives her security and stimulation. She is also fortunate to have a supportive doctor if there are any concerns regarding her health.

What Eileen feels she needs

The most important thing for Eileen is for her to be able to live and remain in her own home. Having a support system not only for the person living with memory loss, but also for carers and family is crucial, as this condition can cause great stress to all involved. In terms of going out and using services, uneven pavements and insufficient drop kerbs are problems and make getting around more difficult, especially as she uses a wheelchair. Having a support system and social network is a must.

Case Study 7

Debbie

Introduction

Debbie has lived in Brent for 75 years; she describes herself as old, relaxed and lazy. She likes living in Brent as it suits her way of life and hasn't lived anywhere else. In her opinion Brent has changed since she was younger and has got dirtier and noisier. The best thing in her life so far has been her children.

Day to day life

On a day to day basis Debbie does nothing and enjoys that, she says it is her passion and dislikes being energetic. She does not go out or visit anybody and is happy that way, but if she does feel like going out then she needs transport because she is not going to walk. Her favourite part of the day is early morning, but she doesn't like midday as she gets bored.

Dealing with dementia

Debbie doesn't feel anything different or recognise any symptoms now that she is diagnosed. She takes medication for it but doesn't know what and isn't aware of it. She doesn't know how long she has had dementia and thinks that if her family and friends felt something in reaction to her condition they haven't said anything.

She gets help from carers and neighbours who, in her words, save her from doing things. However, cultural or religious communities are not important sources of support for her; she doesn't feel like she can be open about her diagnosis. Nobody has been unkind to her with regards to her diagnosis; she doesn't tell people and doesn't have to explain it to anyone. She has no idea what effect it would have if more people knew about dementia.

In terms of her social life, she feels it has remained the same since she has been diagnosed. However, Debbie used to be an outgoing person but being very proud and independent does not like to accept that she has dementia.

What Debbie feels she needs

Debbie doesn't think that anything will make any difference in her life, she just want to be left alone and has every intention of staying where she has always lived. She is not interested in other services and doesn't know about the services provided in Brent, but that isn't what's stopping her using them. She is not interested in things being done in terms of meeting people with dementia as she feels it would bore her.

Case Study 8 Julie

Introduction

Julie is 74 years old and lives in sheltered housing in Harlesden. She is Irish and came over to London from Mayo when she was 19 years old. Julie likes a glass of wine, listening to Capital Gold and loves dancing! Julie likes to feel happy, glamorous and she 'admires things'. She wants to feel this way as it's better than being depressed. Julie can feel depressed in the afternoons when there is nothing to do. Julie's daughter, Jan, lives in Tooting and has one daughter. Her son James lives in Kingsbury and also has a daughter.

Julie likes the flat where she lives and describes it as the best place she has ever had. 'It's my own place where I can come and go as I please'. She likes to become involved in things, but she occasionally has a cold or a sore knee which prevent her from joining others to go out.

Julie had a fractious marital relationship. She left her husband several times and stayed with her sister in Tooting. Her husband hit her and she had a breakdown as a result. She describes her husband as a 'good man who worked and provided for his family all his life'. Julie has experienced homelessness but she now lives in a place of her own and receives support to manage her bills and day to day living. Julie looked after her son James while he was very ill and they both were unable to manage bills and benefits. Today, Julie dislikes being told what to do



Day to day life

Julie has a fairly regular daily routine and likes to rise, wash and eat when she pleases. She eats when she is hungry and varies her meals between eating in and going out on occasions. Julie likes to think of people who helped her in the past. She enjoys good humour with other people and keeps in touch with Jan and James her children, going out regularly to meet her family. James can be unwell and uses alcohol to cope with pain. She enjoys lunch or coffee out and visits the bank and supermarket to get some shopping. She enjoys a meal from Burger King occasionally.

Julie loves a party and especially dancing! When she is not staying with her son, she will attend some functions and parties. Julie has a very strong sense of Irish identity and can relate easily to other Irish people who can offer help with matters of concern.

Dealing with dementia

Julie is aware her memory is getting poor and freely admits she can recall lots which happened many years ago while trying to remember what she has to do during her day.

Julie received support recently to get her flat painted and buy a new bed in time for Christmas. She found it very difficult to make decisions for herself and depended heavily on a floating support service and help from her Housing Manager to drive things to a conclusion. Julie feels at times she should be able to do more for herself, but experiences difficulty asking for help or remembering to do the things which matter most. Julie feels anything which goes wrong is her fault and she wants to fix herself without asking for help which she finds embarrassing. Agencies keep in close communication to ensure there are timely reminders and prompts in place.

Julie likes where she lives. She can come and go as she pleases without having to ask for permission to go out. She receives support from her Scheme Manager to ensure her rent is paid and matches her benefit entitlements. Her support officer meets regularly to discuss matters like getting her flat painted and dealing with other problems. The supporters are working hard to get access to additional help, but Julie is concerned that change will make things worse than they are today.

What Julie feels she needs

Julie is aware she can access services, but she is concerned about the diagnosis and its' impact on her life. Julie doesn't want to be moved to a place where she is locked up all the time. Julie is aware she will remain in Brent and would need to depend on the services they provide to help her remain safe and secure. She will only readily move if she feels safe and secure without a loss of her independence

Case Study 9

Mr. A

Introduction

Mr A is a 70 year old man who was born in Pakistan and is presently living in the Wembley area. He came to the UK in the 1970's to join his brother and then went back to Pakistan in the 1980's where he got married and returned a year later. He then bought his first home in Burnt Oak where he lived until 1992, when his first marriage ended in divorce. From this marriage he had two sons and one daughter, but he has not seen them since the separation.

After he returned to Pakistan, he worked as a teacher, which he said was one of the best things he did. He also remarried his second wife and had one daughter from this marriage before returning to the UK. Both his wife and daughter are now his main carers; along with his brother who provides support with translation as Mr A is only able to communicate in Urdu having lost most of his memory of English. Mr A has regular family contact with them all living locally, including the areas of Kilburn and Colindale. This integration results in overnight stays and being able to converse, when he wants, in Urdu. Mr A used to like playing Hockey and was an active member of a local Hockey club in the 1970's.

Day to day life

Most of Mr A's time is now spent at home with his wife and daughter, apart from the family social events, he remains on the second floor with 8 other people living on the ground floor and loft conversion of the standard 1930's house. He is able to access the community with support from his family who take him for walks to the park or to the top of his road and back and trips in the car to the local shops. He has no special interests or favourite things he likes doing now.

From observations by his family, Mr A has better days than others in regards to his mood and behaviour; mornings are usually the worse time of day for him, where he wants to be alone and isolated. Before Mr A was diagnosed he was attending the Pakistani community centre with his brother, but since 2012 his brother said that he started to with-draw and did not want to mix so ready with others, only his immediate family. He has shown no interest in wanting to pursue this activity again.

Mr A thinks the good thing about living in Brent is that most of the family live in the area and are able to provide support to him, when required. The bad thing is living in a crowded house with strangers and being confined to limited space.

Dealing with dementia

Mr A was diagnosed with dementia in 2012 at the age of 67 by the memory clinic after he began to forget things and was acting differently according to his family. He was still managing well, but previously his GP thought he was suffering from depression. After he was diagnosed he didn't believe the diagnosis; believing he was too young and carried on as usual. He then stopped taking his medication he had been prescribed for depression, which his family feel made the situation worse. Since then Mr A has moved to Brent to be closer to other family members, who provide the additional support required.

Mr A has a family history of dementia; his brother and sister were both diagnosed with dementia before passing away. At the time, Mr A was regularly involved in their care, resulting in the family having a better understanding of some of the behaviours from the condition.

About a year ago Mr A was prescribed medication by his doctor, after the family were struggling to manage his behaviour, which was challenging both physically and verbally. Without his medication he has erratic sleep patterns and has been known to search around the whole of the house during the early hours of the night, resulting in waking everyone up. Since taking the medication he has been more settled and less agitated; the down side is that it has made him drowsy.

What Mr A feels he needs

The rest of the family feel the situation for the future will get worse and are worried about how they will cope. One of the main positive differences would be having a larger home to live in, where Mr A can move around more freely without limitation, where he has more open space to walk around safely without family members having to devote their own time to take him out.

The main message that the family wanted to convey to the council, was to invest in suitably adapted housing for physical and disabled people, which would help with immediate family members living together.

Case Study 10

Bob

Introduction

Bob lives in a residential home with forty others in Brent. He has lived here for two years, and before this lived in Chislehurst in Kent. He enjoys living in Brent as there is always something on.

Bob doesn't have any family and all his friends are in the residential home. He enjoys playing dominoes and going on outings, especially to Southend-on-Sea. These activities are his favourite. Bob is positive about himself, but doesn't know the exact words.

Day to day Life

There is not a bad part of the day for Bob; he is happy where he is as there is always some activity going on planned by the warden. The best part is 11 to 4pm when there are games. In the morning he has breakfast, which he says is normal food. The carers feed and shower him every day.

He doesn't do much in Brent, but they go out as a group to the shopping centre or Southend-on-Sea. Bob never travels alone and has a carer, van and wheelchair with him. Bob says that he has no problems getting around despite using a wheelchair and there aren't any places that he no longer goes.

Dealing with dementia

Bob doesn't know anyone else with dementia and isn't sure how well he'd get along with them. He likes the idea of a dementia café but doesn't know if he would like to find out about these places, also saying that his network of friends would be restricted by his wheelchair use and he would need a carer to be there.

Dementia doesn't affect Bob at all as his carers are always there to help. He can't remember when he was diagnosed or how long exactly he has had dementia but thinks he got it whilst at the centre and that the GP told one of his carers, who then told him. He cannot remember what he was told about the disease though.

Being diagnosed makes no difference to him as everything is ok. The GP spoke to the carer after he was diagnosed about what they needed to do and help is always there.

Bob has no problem accessing services or getting appointments. It is for him easy to communicate with people and he doesn't use any health services to deal with his dementia as the carers give him his medication every day. Additionally, in an emergency, he just has to press a button attached to a necklace and carers come in very quick

Bob isn't aware of any services in Brent that provide help for people with dementia and doesn't think there is a stigma attached to the condition.

What Bob feels he needs

Bob is unsure about what needs to be done about dementia services but he doesn't know how he would explain the condition to someone he doesn't know and he thinks that if people knew more about dementia then they would know what to do in an emergency.

He can't think of what would make a positive difference as he is happy where he is and can't think of what message to say to the council.

Horizon Scan Case Study # 1 - Kerala

Dementia Friendly Initiative

Overview

- Large elderly population with few young people to provide care
- All health and social care workers trained to care for dementia
- Objective to train 100,000 volunteers in Kerala alone
- All medical colleges equipped with memory clinics for early diagnosis
- Standard care and treatment practices in care homes
- Telephone based helpline for info and support



Overview

- A collaborative initiative dedicated to preventing heart disease and stroke in the African American population
- Barbers and beauticians trained to deliver heart health messages and refer clients to clinics if appropriate
- Training in recognising symptoms of heart attacks and strokes – including on how to screen blood pressure
- Embraces the role of barbers and beauticians who are often seen as impartial and trustworthy

Minneapolis and
St. Paul, USA



Horizon Scan Case Study # 3 – Together for a dementia-friendly Bruges!

Overview

- All-inclusive community based long-term awareness programme to fight stigmatisation associated with the dementia
- Improvements to outdoor space to create more places to rest and relax
- Choir for people with dementia and their carers
- Police database to help find residents who wander – includes capturing info on last seen location, clothing, previous work address
- Trained dementia councillors for people with dementia and their carers
- Standardised training for shop keepers – ‘red handkerchief’ sign on front door



Creative Storytelling

Overview

- Aims to transform dementia care through creative improvisation and poetry, engagement methods which are not typically impeded by dementia
- Enables individuals or organisations to become specifically skilled in engaging with those who experience memory loss
- Allows people with dementia to express themselves freely and to connect with those around them on a level unconstrained by the condition and cultural norms
- Benefits both people with dementia and their carers who are given an alternative outlet by which to engage and communicate with the person with dementia



Overview

- A system specifically designed to calm the anxiety typically expressed by those with dementia in a care home setting
- Those with dementia are empowered to act on their desire to be elsewhere and leave the home, as the system ensures they are safely returned
- Collaboration between public transportation departments and local care associations
- Person with dementia can sit at the fake bus stop until they want to return to the care home, as no bus will visit the stop so there is no danger of the person wandering



Germany (&
across Europe)



Friendly Gurudwaras Project

Overview

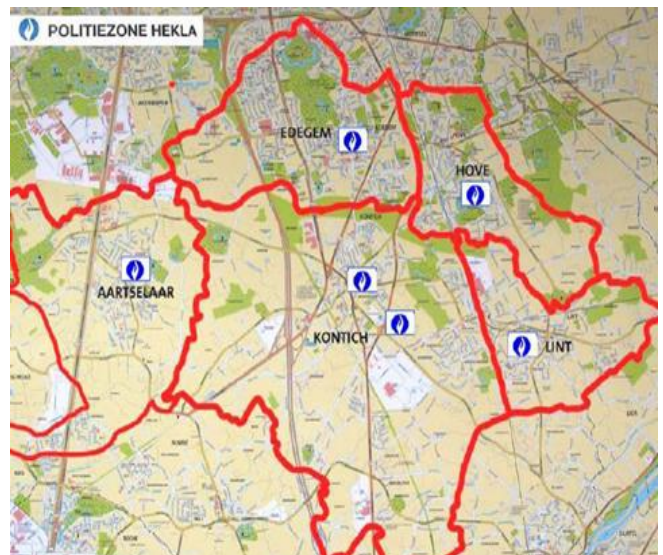
- An education project run in a Gurudwara (Sikh temple) by Sikh healthcare professionals aiming to raise awareness and reduce the stigma associated with dementia
- Several initiatives have been undertaken simultaneously: altering the physical environment; training key sevadars (volunteers); creating a community of 50 Dementia Friends from the congregation; physical and virtual information portals on dementia e.g. leaflets and podcasts; and a monthly memory café where people with dementia and their carers can meet and support one another
- Created toolkit for other gurudwaras – emphasises importance of engaging with people with dementia using different methods



Horizon Scan Case Study # 7 – HEKLA: The Missing Persons Project

Overview

- The healthcare sector has motivated the police force within five neighbouring areas to join together to form a united police force to search for a missing person, a typical behavioural symptom of Dementia
- Partner police forces sign up to a protocol to ensure key info including 'last point seen', and personal information are easily shared
- Persons with dementia can be returned home more quickly, reducing distress to the individual
- Carers get greater peace of mind knowing that the police are able to search over a wider area, more quickly, and become instantly informed about the missing person



Aware: Donegal

Overview

Five key projects:

- 'Be a sport for dementia' – encouraging people with dementia to continue to be active in sports clubs
- 'Ordinary Man, Extraordinary Memories' uses theatre to enhance understanding and awareness - works with schools
- 'You've got a friend in me' - aims to establish a network of Dementia Champions
- 'Hearth and Home' aims to stimulate support for people living with dementia within the community
- 'Faith, hope and charity' aims to support the clergy to provide pastoral care for their congregations through recognition of best practise
- Overall aim of project is to provide support to people with dementia and their carers, but also to increase awareness and maintain Donegal's status as dementia-friendly community

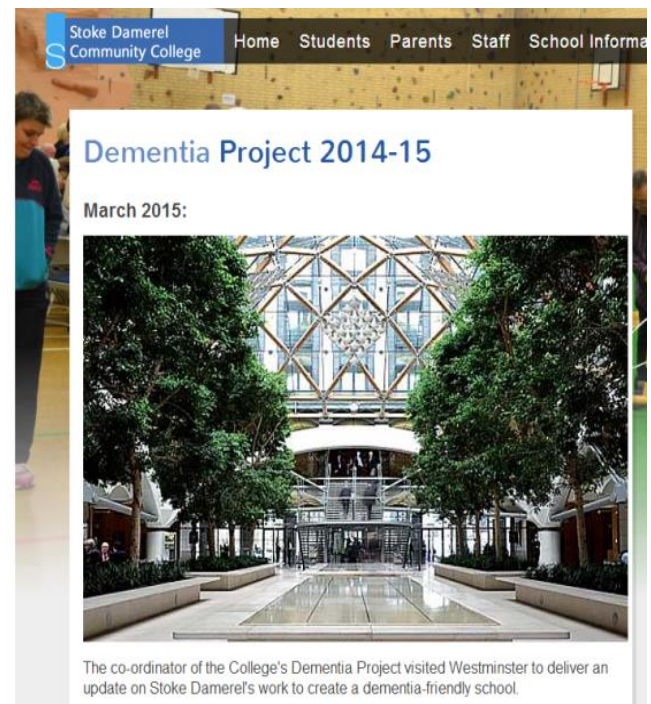


DEMENTIA AWARE DONEGAL



Overview

- Stoke Damerel are exploring ways in which to bring education about dementia into the school environment, using a whole curriculum approach
- Aims to break down stigma and stereotypes and instil understanding of the condition in the young of society, encouraging a dementia friendly community from the bottom-up
- Education around dementia is incorporated into 11 subjects, including sports where students play games with residents of a local care home where dementia and memory loss does not hinder participation, such as bowls and croquet
- Pupils present at conferences, and make short films to be used by the media displaying what it is like to live with dementia



Participant	Gender	Age	Ethnicity	Living status	Stage of dementia
1	M	82	Black-Caribbean	In community	Early / mild
2	M	80	White – British	In care-home	Moderate
3	M	65	White – British	In community	Early / mild
4	F	70	Black - Caribbean	In community	Moderate / late
5	M	80	Asian-Indian	In community	Early
6	F	87	White (Jewish)	In community	Early / mild
7	M	70	Asian- Pakistani	In community	Moderate / late
8	F	89	White – Irish	In community	Moderate
9	F	79	White – Eastern European	In community	Early
10	M	80	Black- Caribbean	In community	Early
11	F	74	White - Irish	In care-home	Early
12	M	77	Afro - Caribbean	In community	Early
13	F	49	Jamaican	In community	Early
14	M	86	White - British	In community	Moderate
15	M	78	Afro - Caribbean	In community	Moderate
16	M	71	Asian	In community	Moderate



COMMUNITY
ACTION ON
DEMENTIA BRENT



Brent

NHS

Brent

Clinical Commissioning Group