



Dementia in South West London – Responses and Actions Report on an Assessment Project in Wandsworth and Kingston

1 Introduction

This short evaluation report summarises the outcomes from a project commissioned by South West London and St Georges NHS Trust (the Trust) from the Dementia Services Development Centre (DSDC) based at the University of Stirling.

The project was set up to explore two questions

- What is the meaning of dementia in different communities and what are the responses to it?
- What are the implications for community resources and local services?

It was designed as a direct engagement with the Call to Action (C2A) and its theme of delivering better outcomes at lower cost. Equally importantly, the project was commissioned as a response to the Prime Minister's Dementia Challenge and in particular to the idea of "dementia-friendly communities".

The main focus for the project was a programme of workshops, structured conversations and discussions within the London Boroughs of Wandsworth and Kingston, which took place between September 2013 and April 2014.

This Report is also intended to provide the basis for a programme of dissemination within the Trust and with local stakeholders during 2014, using the Key Issues in Section 4 as a focus for exploring issues further.

2 Methodology

The project was designed and led by Professor June Andrews, Director of DSDC, and Mark Butler, a Visiting Fellow at DSDC. <http://dementia.stir.ac.uk/>

DSDC is currently undertaking a wider assessment of community responses to dementia and is actively involved in supporting and evaluating dementia change programmes across the UK. This broader background informed the design of the project.

At the outset the decision was taken to focus on a small number of relatively well-defined communities. This was to enable a deeper engagement with differences and similarities than would have been possible if a broader canvas had been used. In Wandsworth work centred on three faith communities, which could be described as Islamic, Black-majority church and Other Christian church. In Kingston the focus was on Korean, Tamil and Muslim communities.

The methodology used three parallel processes:

- a series of five workshops facilitated by DSDC and held in local community settings
- a series of community conversations held between individuals based in the local communities (who were briefed and supported by DSDC) and local community groups
- a desk-top research exercise on the context of Dementia and BAME communities

DSDC worked closely with members of the Wandsworth Community Empowerment Network (WCEN), and the Chair of the Happy Soul Festival in Kingston, to identify and involve suitable participants in the project. Community interviews in Wandsworth were undertaken by members of the WCEN on behalf of DSDC and the Trust, who also participated in the workshops.

Each workshop was facilitated by either June Andrews or Mark Butler with attendees including invited members of local communities, local third sector organisations, NHS professionals and representatives of the Trust including its Chair and Chief Executive. This report pulls together contemporaneous records of the conversations and the workshops.

Informed by initial desktop research the project team identified three themes and a number of questions which provided a framework for conducting the workshops and conversations:

Meaning and Understanding

- How well is dementia understood? Is there any difference from generation to generation?
- What is the natural response to dementia in the community?
- What does dementia mean to individuals, to families and to communities?
- How do people find out what dementia means in their communities?
- What resources are already in place which help people understand dementia ?
- What more could be done to increase knowledge and understanding?
- Is being “dementia-friendly” something which has meaning in the community?

Responses to Dementia

- What are the different reactions to a diagnosis of dementia?
- What are the challenges in responding to dementia in different communities at a time of austerity?
- Are there any barriers to early diagnosis ?
- Are the most effective responses to dementia clear and well-known in the community?
- What are people good at sorting out for themselves in response to dementia?
- What help do people feel they need?
- What are seen as the strengths of current community support on dementia?
- What could be developed further if more support were given? What would that look like?

Services and Capacity

- What is the range of views about current services in place to support people with dementia, their families and communities?
- What changes could be made to improve access to services?
- Is there more that can be done to support people with dementia in different communities?
- What more can communities do to support people with dementia?

- What could be done where to improve capacity and assets available on dementia within communities?
- What support and services should be developed in future?
- What are seen as the priorities on dementia by different communities?

3 Headlines

The following statements summarise the main conclusions

- The workshops where members of local communities engaged directly with those with dementia expertise were powerful in allowing open exchange on sensitive issues. This format, where different communities also came together to explore what dementia meant to them, allowed shared issues and differences to surface as a focus for greater understanding in those present. A lot of the conversation was practical and triggered by stories from within the communities. This allowed wider issues to surface naturally and to be explored without stigma or obstacle. Although only reaching a small number of people the value of such specific and bespoke sessions should not be underestimated as providing a platform for sustainable dialogue and co-production of responses and services between statutory services, third sector organisations and local communities.
- The central role of different types of knowledge formed a strong theme throughout the project. Some involved wanted to know about practical responses to dementia – what can be done. Others wrestled with the higher level theological implications for their own faiths. The need for commissioners and providers to understand the way dementia (and responses to it) is framed by faith and community became more and more apparent. Getting the different sorts of knowledge they felt they needed is seen as a huge challenge. But as one faith leader said the worst thing a leader can say is “I don’t know!”. The one overriding conclusion of this report is the importance of engaging directly with the different strands of this hunger for knowledge, through active conversation and open dialogue, where communities themselves wish to discuss the meaning and response to dementia. This extends to engaging with issues of theological training and facilitating interfaith dialogue which will be necessary to equip local community leaders for changing social responses to dementia. (Some of the knowledge issues are captured in Annex 1)
- Understanding of dementia is generally low and levels of denial are often high in BAME communities. But communities are dealing with difficult family and community issues all the time and responses to dementia need to be understood in that wider positive context. Knowledge is variable between communities depending on specific demographics within those communities and on levels of pre-existing insight around dementia. For example only now is dementia in older African and Afro-Caribbean people surfacing as an issue in local communities. Knowledge in those specific communities is, as a result, lower than in other BAME communities.
- “Professional” services (GPs, community and hospital services) are widely distrusted and access to them is poor. This places much more importance on the knowledge that is alive within the many “non-professional” networks that make up communities. In terms of

dementia people are keen to draw what they need to know towards them and develop greater understanding. The best means for doing this is likely to be different for different communities. Professionals and the organisations which employ them need to respect and work with this process of community self-education.

- At first people seem to want information around what dementia actually means in a technical, clinical sense - cause, prevention, facts. It is important for conversations and knowledge to grow and be supported around what dementia means in this technical sense, before any discussion about what communities themselves want to see happen as appropriate responses to dementia can really take place. The key lesson here is for statutory services and commissioners not to jump too quickly from conversations to detailed discussions about the design and provision of services, or worse still to start with questions about design and provision.
- One strong shared connection between the different communities in this project is that talk of “dementia” triggers reflection on the state of social connections and relationships in specific local communities and families, and the way they are changing – for example younger people’s responsibilities for older people; older family members joining younger members as they become established in the UK; the speed of change affecting the shape and make-up of communities as areas change their demographic and social status. (Some more detailed concerns are set out in Annex 2 for illustrative purposes)
- Dementia is referred to more openly now than in the recent past across all communities, but it tends to surface as part of broader discussions about essential stages and aspects of life, rather than being a subject which people see in isolation. So dementia is most likely to emerge in conversations about Healing and Coping; Ageing and family relationships; Death and dying. And also responses to dementia include the guilt and helplessness in responding to changes in people, such as former community leaders who move to the edges of communities as a result of their dementia
- Many of the well-publicised national initiatives and investments being made in dementia (Prime Minister’s Challenge, dementia- friendly communities, dementia friends etc.) are largely passing by local BAME communities. This is both a problem and an opportunity. It means that the statutory agencies and commissioners (if they are smart) will focus on working with the communities themselves to identify and develop assets which communities already have and want to develop in their own different ways. Services are likely to be more effective if they are consciously designed to complement local assets rather than importing standardised or nationally-validated models from outside. On the other hand careful and urgent consideration needs to be given as to why national resources and initiatives are not reaching where they are most needed. There are clear implications here for equality and access which need to be addressed.
- Communities expressed a clear view that some of the core assets they rely on are under threat from changes which the communities themselves see as beyond their influence – for example funding decisions affecting local organisations, physical meeting spaces and community services and resources. Places where people have traditionally come together physically to interact are reducing – so where do you go now for difficult conversations?

- Similar issues appear differently in different faith communities using different language and imagery. But what each shares is a common interest in what nurtures caring, coping and healing within their communities in a profound and powerful way. Equally communities express a palpable lack of confidence about whether they are doing the right things to alleviate problems around dementia effectively.
- One clear message from the work is that the best place to start making impact on the consequences and implications of dementia is often “elsewhere” – in promoting good food and cooking, social connection and shared activities, family, faith. Each of these elements on its own (and together) clearly counter the factors which fuel the negative symptoms of dementia disease (social isolation, hydration and nutrition, exercise, light etc.) and can directly improve the lives of people with dementia. This may be more effective in growing understanding and having impact on the footprint of dementia than relocating traditional clinical services (memory clinics etc.) within new settings within communities.
- Common issues which repeatedly came up in sessions included
 - *the importance of duty to care within families and the way it is being eroded in different ways in different communities;*
 - *the strong feeling of responsibility of the young and of women to provide care for older members of their family;*
 - *the impact of visible decline (and inappropriate behaviour) in respected elders on the whole community*
 - *the sense of separation from a true home where coping would be easier*
 - *the absence of trusted support services and people to provide care*
 - *the cultural barriers to using care homes*
 - *the insensitivity and inappropriateness of many statutory services*
 - *the reference to holy books for guidance on suffering and hardship*
 - *the inaccessibility and insensitivity of local GPs and their limited value in providing access to support*
 - *the importance of seeing dementia as part of transition towards a good death*
 - *the abiding and destructive stigma associated with dementia*
- If commissioners and providers start by looking at services and fail to listen to the rhythm of discussions in communities they will miss the critical role played by love, fellowship, hope, faith, belief and community - issues which give real support to people.

4 Commentary

The main issues raised in this project broadly support themes which have emerged from research¹, especially the importance of growing knowledge about dementia in communities and the key role of developing knowledge of communities in commissioners and providers of statutory and third sector services. But there are also a number of issues which are worth highlighting, especially around

¹ For example Lawrence, V., Samsi, K., Banerjee, S., Morgan, C. and Murray, J. (2010) 'Threat to valued elements of life: the experience of dementia across three ethnic groups', *Gerontologist*, <http://dx.doi.org.10.1093/geront/gnq073> and Seabrooke, V. and Milne, A. (2009) 'Early intervention in dementia care in an Asian community: lessons from a dementia collaborative project', *Quality in Ageing*, vol 10, no 4, pp 29–36.

knowledge, language, expectations and responses to dementia. There are real challenges here, especially for health and care professionals and commissioners.

Recent studies such as the Race Equality Foundation Report² have concluded that dementia is misunderstood and highly stigmatised in BAME communities suggesting this requires a single, culturally-appropriate dementia pathway from diagnosis to end-of-life. The picture that has emerged from this project however suggests a more nuanced picture requiring a more cautious, step-by-step approach, starting with a large unmet need for knowledge both within communities and within professional staff groups. Given the different responses to dementia in different communities, a single pathway, however convenient that may be for statutory and professional services to have in place, is unlikely to be the best way forward. The discipline needed by statutory professionals is not to jump to conclusions using professional frames of thinking and language, but to establish dialogue in plain language with communities and families within communities, with a genuine commitment to following-through into co-production of responses and solutions; to resist tokenism and imposition from outside the communities. This is a significant challenge for commissioners and arguably runs counter to the prevailing nationally-driven, top-down approach.

The way dementia is framed by statutory services is seen as creating problems. The ageing population is presented as a significant problem. Yet all religious faiths honour their elders and are positive about ageing. Professionals talk of “competence”, “risk management” and “treatment”. Faith has traditionally seen natural transition points in life which families and communities know, plan for and deal with in terms of living well and staying contented. It is hardly a revelation that professionals are seen as using an alien language, but it matters in this context as it makes knowing what services are available difficult for many communities to absorb and work with. This needs to be recognised as a fundamental barrier to improving access and equality.

There is a question about who decides what information about dementia is actually needed, when it is needed and in what form it is presented. The information needs for carers are different from more general community information on dementia. There was a strong feeling from the workshops that communities themselves need to take responsibility for training their own dementia leaders and for pressing for more relevant and interactive information from statutory and third sector sources. There was also a clear feeling that the specification of what information was needed should be co-produced with “experts”. The whole project revealed rich networks that already exist for social reasons. These seem fertile places for growing knowledge which would have credibility and relevance to local communities. The point that follows from this analysis is that it is not about adding to but about replacing some existing approaches to dementia awareness.

There were lots of ideas about places where people are speaking and connecting. The deficit that was felt is on being confident and informed about what dementia actually means to people and the positive practical responses which communities, families and individuals can take to it. There was a strong feeling sadly that this information was not currently forthcoming from health and care professionals, or was likely to be.

² Better Health Briefing Paper 30 - Black Asian and Ethnic Communities and Dementia – where are we now? David Truswell; November 2013

Some older members of BAME communities may not want to be involved with strangers, but they are hungry for practical information, such as on issues such as securing power of attorney, and for positive ideas about staying well and keeping well away from statutory services. The challenge for those with dementia expertise is how to share that practical expertise and help communities embed the knowledge they want in the ways they wish. The workshop suggested that the arts could play a role in bringing issues to life and overcoming stigma and barriers to understanding, in a way that would resonate with individual cultures.

Diagnosis was seen as being less pivotal for people in these communities than it might be assumed. Diagnosis is not seen as (or is in reality) the gateway to accessing support people need by these communities, partly because support is likely to be sought more from within families and respected sources of authority which exist elsewhere within the communities themselves. This suggests the pressing issue in terms of growing knowledge is about equipping those who are seen as sources of knowledge with what they need to know rather than forcing people towards more established sources of information and expertise outside the communities. The way information, reassurance and response from social rather than professional networks is sought is also changing rapidly as community demographics and dynamics change.

The workshops showed a variety of levels of knowledge about where services were currently available and how they could be accessed. People said they wanted more signposting as well as personal education and training. Both mattered to them.

Over the length of the project a number of specific question areas kept recurring:

- what are the early symptoms and what to do when they are apparent
- where to get a diagnosis and access to medication
- how to delay the symptoms
- what to expect in terms of stigma and how to deal with it
- how to deal with anxiety and difficult behaviour
- how to move towards acceptance?

In parallel the value of open discussion between faiths and communities also became more apparent as the conversations and workshops developed momentum, revealing a lot of existing awareness of what effective community responses to dementia might look like including:

- preparing well in advance (years ahead)
- promoting activities which counter the effects of dementia
- gathering together people who have experience of dementia
- providing games, music, activities outside the home for people with dementia
- the befriending of families by others.

One significant message brought out clearly by the project is the value of local conversations on dementia which do use professional or policy language. Such conversations are important in closing gaps of trust and confidence with statutory services but more importantly enable exchange between communities and networks. This raises a question about the most effective way of establishing effective dialogue and co-production between professionals, commissioners, providers and communities. For this project local agencies, based in the community areas, were used to facilitate elements of community conversation and connection. The experience of this project suggests they

may be of only limited value and could indeed become barriers themselves between mature dialogue between statutory services and local communities. This is in part because too many groups and interests lie beyond the scope and activities of these intermediaries. This can be further complicated where the agencies have a pre-set agenda around the way statutory services should operate. At the very least there should be caution about the use of such agencies by commissioners, providers and third sector organisations.

5 Key Issues for Commissioners

- Growing specific types of knowledge about dementia in BAME communities is a critical first step in increasing diagnosis and improving equality in service use and access. This applies both between “majority” and “minority” populations and between different BAME/minority populations.
- Knowledge development needs to be targeted to specific community audiences and needs, using non-professional language.
- Barriers between local populations and services in each area need to be understood and actively engaged with by commissioners. Barriers are likely to include overuse of professional language and reference points; lack of sensitivity and insight about community dynamics; perceptions about previous local service consultation and engagement; failure to understand or commit fully to co-production; lack of access to care support.
- The use of “apocalyptic” data, which emphasises the scale of “the problem” of dementia’s future growth, used to frame why dementia as a priority in public health terms, is off-putting to many local communities. It is likely that framing of dementia in terms of family and community responses to immediate challenges they face in their homes and communities will achieve more success. Bottom-up is more likely to be successful than Top-down.
- “Dementia friendly communities” may not be the most effective vehicle for engaging with issues of concern within local communities. However well-intentioned, DFC is seen by many as a vague national construction, remote from local communities, rather than something generated and owned by them. (It is to the credit of the Trust that they have been prepared to be guided by the conversations and by DSDC in terms of the pace and timing of the work and this has added value and depth to the work.)
- Provision of more services in local settings is unlikely to overcome the sense of disconnection between local communities and key gatekeepers such as local GPs unless there is investment in improving the sensitivity of local GPs and primary care services to local needs.

6 Key Issues for the Trust / Service Providers

- There is a clear appetite for more knowledge and information on dementia. This is an unmet need. Growing knowledge in communities about dementia is an essential first step to increasing access to and use of dementia services
- Training on dementia for all professional staff who have contact with the public is a prerequisite for improved outcomes. Training programmes need to increase awareness of different community sensitivities to dementia, the importance of using non-professional language at all points in any service or pathway, as well as increasing “technical” dementia knowledge.
- Local communities should be encouraged to help design and deliver training sessions for professional staff. Joint sessions built around conversations and exploration provide a powerful way of mutual engagement and can help develop long-term trust and reduce reliance on intermediaries.

- Training programmes should recognise the need for different levels of dementia awareness in front-line staff and community leaders depending on their roles. The effectiveness of such training needs to be subject to formal evaluation.
- Trusts need to invest more time and energy into growing their own effective and trusted means of engaging local communities in what they do. The use of unaccountable community-based intermediaries and agencies is not necessarily a cost-effective, desirable or sustainable way of reaching and developing dialogue with local people.

7 Next Steps

This Report is intended to provide a self-contained report on this project for the Trust.

There are however a number of suggested next steps which the Trust should consider taking the lead on so as to build on the work covered in this report.

These specific suggestions build on the strengths and traditions of the Trust.

The Trust championed the Recovery approach to mental health in the UK and opened the first Recovery College. There is now an opportunity for the Trust to develop a similar approach to dementia and to use the Recovery College - or a development out of the Recovery College - to assist people with dementia and their carers to understand the condition better and work to develop 'bottom up' approaches to dementia education.

The Trust has recently strengthened the leadership of older people and is in the process of considering strategic options which could include establishing the Trust as a learning centre for dementia reaching into local communities, with obvious reputational and practical benefits for the Trust as a whole.

Stakeholder events

The work of the project highlights a range of issues which are of mutual interest and priority for commissioners, local community leaders, third sector organisations and other providers. It would make sense for the Trust to host a series of events (in the two boroughs covered by the report but also others) which combined an exploration of these issues with a showcase of the Trust's services and plans for the future for local people with dementia.

Dementia Knowledge Development Programmes

Two flagship programmes suggest themselves which would provide both social and service impact.

- The Trust should develop a type of "community champions" programme built around dementia, designed to equip specific leaders within the area it serves. Online supporting material for communities, including video footage of the community champions, should be considered. This would in turn provide a sustainable community development platform which was seen to be co-produced with local communities, bringing wider benefits and opportunities on other service and health issues. The Recovery College and DSDC might be good partners for this work.
- The Trust should commission an audit of the dementia knowledge and community awareness needs of its professional staff, working closely with local communities and with specialist external expertise. The resulting insight and training packages could also be part of an offer to local providers, organisations and individuals as part of the Trust's development

of specialist skills for older frail people. This could have reputational value, reinforcing the role of the Trust as a source of expertise as well as a specific service provider, and also raise additional income.

Creative responses

- The Trust should support creative responses to the need for knowledge by promoting greater co-production with local communities. The sort of project worth developing would focus, with other community and public health partners, on innovative and proactive means of developing relevant information on dementia, in the language and form most appropriate to individual communities, whether in traditional form (such as leaflets) or using more modern social media and pop-up forms.
- The Trust could also host further conversations, which bring together local communities and dementia expertise with a greater focus on action planning for those local communities. DSDC would be pleased to be involved in any of this work.

Dementia and the Arts

- The Trust should take the lead in working through how the arts might support the growth in understanding and cultural sensitivity around dementia within the two specific boroughs covered in this report, working with local University colleagues, third sector partners and local artists. The way in which dementia is framed in different communities is clearly linked to cultural and faith reference points. This provides a potentially exciting route into establishing well-grounded culturally-sensitive networks of general value to the Trust and to commissioners. These would, if developed with conviction, allow engagement with health and well-being issues, such as dementia, in fresh and potentially creative ways at local level – a platform for building bottom-up rather than top-down.

These Next Steps are of course challenging but could provide a strong platform for moving forward on both strengthening dementia and community connection with wider benefits to the Trust and local people.

Professor June Andrews and Mark Butler from DSDC would like to thank everyone who has been involved in the project, especially members of the local communities, who gave so generously of their time and ideas.

Dementia Services Development Centre

May 2014

Annex 1 – Workshop – Knowledge Needs

These were identified by participants in the workshops as some immediate knowledge needs in Wandsworth and are listed as described

- Low level training on dementia for volunteers
- Training on practical support and advice
- Dementia training for hospital staff
- Dementia training for faith and community leaders
- Information on models of good practice
- Information for carers in culturally sensitive formats
- Information for communities on what to do if there is no family
- Information of assessment criteria and diagnosis
- Community awareness raising on the dangers of dementia and responses
- Information on the role and value of community assets and services
- Support for community conversations about dementia to reduce stigma and fear
- Training for “buddies” for the carers/ children of those suffering from dementia
- Training and awareness to faith communities to identify early symptoms and signs (early intervention)
- Advertising and distribution of information via social media as well as leaflets on how to detect early signs
- Where to go to talk in confidence
- More information about dementia in GP surgeries
- Information on social support such as outings in the summer and lunch clubs
- Education for young people to understand and support
- More awareness on how to look out for signs that you may be suffering from dementia
- How do we put community support in place to help dementia sufferers and their families until health and social care support is put in place

Annex 2 Workshop - Concerns

These were identified as some immediate concerns in Wandsworth in one workshop and are included as originally described for reference.

- Companies are looking for the cheapest contacts
- Care homes are now all run by big businesses
- GPs have been asking if patients would come in for a brain check
- People consider dementia as a mental health problem, so keep a lid on it until carers reach crisis point
- Distant relationships between family members which leads to care and advocacy services.
- Loss of trust as the GPs are making school boy errors
- Preventative services are being cut but when a sufferer reaches crisis point they only receive 2 hour visits and get charged for it. This is terrifying
- GP times and visits
- As a society this is a big national dilemma
- There is nowhere for people to go and socialise, we need more local spaces.
- Pick up and transportation services are also being cut
- The elderly are feeling trapped in their homes like prisoners
- No space within the home to accommodate family members and it's very difficult to get adaptations.
- The price of care is always rising
- Loneliness causes a rapid decline in someone's health and well-being
- Care system 'traps' you because the carer has to log in and out and you have to be there and not on the phone etc.
- Even the information services have had money taken away
- Islam – obligatory to look after parents but many don't know what to do so they just give money and walk away. Company and human contact is priceless
- Trying to sort out banks and direct debits can be difficult when passwords are forgotten and there is no power of attorney
- There needs to be more support from the voluntary sector
- Cuts are being made and paid carers are doing less and less hours
- Poor quality care homes
- Mistreated elderly patients
- What is the impact of dementia on the family system and how do you support people who are suffering from the psychological impact?
- Where are the places to learn about these issues?
- Where are the people who know about people in the community i.e. shopkeepers and pharmacies?
- In the context of London, communities that are in transit - how do we create communities of care
- Forgetfulness on its own is not necessarily dementia but is confused with it
- Many people carry a lot of secret fear because of their ignorance