

Refresh of Liverpool's Joint Dementia Strategy

BAME Communities and Dementia

*Di Burbidge
Chinese Wellbeing
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The logo for Dementia Action Liverpool is a dark blue shape that is a square on the left and a semi-circle on the right. The text "Dementia Action Liverpool" is written in white, stacked vertically, within the square portion of the logo.

**Dementia
Action
Liverpool**

Introduction

Chinese Wellbeing (CW) was requested by DAL to co-ordinate the engagement with BAME groups in the city to inform the dementia refresh strategy. CW was one of the first to appoint a Dementia Champion in 2012 along with the Somali Elders which was funded by MerseyCare NHS. In 2016, CW was appointed the project lead for the BAME Dementia Champions service funded by the Liverpool CCG. Five Dementia Champions were appointed within African, Chinese, Somali, Arabic and Faith communities. The funding for this service was terminated by LCCG in December 2017 as part of a major budget cut which affected many third sector organisations.

Prior to commencing the refresh engagement, CW provided a report on the current position which included a summary of consultations held with local BAME communities dating back to 2012 and the outcomes from the Dementia Champions work to December 2017. The evidence and justification for the LCCG funding the development of a BAME Dementia Support Service remain valid today.

Demographic data

Figures from the 2011 Census indicate that 15.2% of the Liverpool population is from a minority ethnic group, i.e. non-white British, equating to almost 71,000 residents. This is slightly higher than the regional average (12.9%), but lower than England (20.2%). Between the 2001 and 2011 Census, the largest increase has been seen among the White Other group, followed by Black African and Indian. The change in numbers and age profile of these groups will impact on the need to provide culturally sensitive care for particular ethnic groups, with dementia likely to become a more significant problem as these populations age (Liverpool's Joint Strategic Needs Assessment (2013), Liverpool City Council).

The ONS 2011 Census identifies the **top 5 ethnic minority groups** in Liverpool as follows:

White Other	12,270
Black African	8,490
Chinese	7,980
White Irish	6,730
Arab	5,630

In the current strategy, Liverpool CCG undertook to update and improve its data relating to people from BAME groups diagnosed with dementia. This was to ultimately provide the evidence of the effectiveness of the Dementia Champions for evaluation purposes.

However, it would appear that no further work was done to improve the monitoring of information across GP practices.

The April 2017 data from practice registers are unreliable as 26.6% of people

diagnosed had no ethnicity stated. Of those where ethnicity was stated, 96% were White British/White Irish or other White, with only 4% stated as non-White ethnicity. It is unclear whether people were unwilling to state their ethnicity or practice staff did not record the information.

The approach

CW approached members of the Liverpool Dementia Action Alliance Diversity Sub Group to assist in the refresh consultations namely:

Mary Seacole House

Irish Community Care

Back to Life Liverpool

Each organisation provides a dementia support service albeit on a small scale due to limited resources and therefore has direct access to people living with dementia and their carers.

CW also invited the organisations previously involved in the BAME Dementia Champions to participate. However, since the termination of the LCCG funding it has been difficult for some to continue the work of the Dementia Champion role and there was some negativity to engaging with their respective communities once again on issues which have already been identified by local NHS commissioners through previous consultations.

The BAME Community Development Workers under the banner of Liverpool Community Development Service funded by MerseyCare NHS were also invited to participate. However, there is no one in the team currently providing support to people living with dementia and their carers.

Awareness of the dementia refresh was raised through our respective community networks and dementia support groups. Five workshops were held involving 122 attendees including people living with dementia and their carers from a number of diverse groups.

The questions for discussion at each engagement session were as follows:

What is working well now?

What needs to change or improve in current provision?

Where are the gaps? What else needs to be in place?

What are your top three priorities for the new strategy? What will really disappoint you if it is missing?

In order to accurately reflect the conversations and to ensure each community voice

is captured comments have been colour coded as follows under the key headings:

- **Green** = Irish Community Care- Irish and Irish Traveller Community (9 attendees)
- **Red** = Chinese Wellbeing- Chinese x 2 events (42 attendees)
- **Blue** = Mary Seacole House – South Asian Carers Network includes Arabic/Yemeni, Bengali, Indian, Pakistani, Algerian (8 attendees + 5 1-1 meetings)
- **Orange** = Back to Life Liverpool – African and African Caribbean (58 attendees)

Q1. WHAT IS WORKING WELL NOW?

The Group thought that good training for carers was imperative and that specific training for each type of dementia was helpful when caring for someone with dementia. The group stressed the need for specialised individualised care plans. Jenny states “I have a memory book of all her milestones in her life that I can read and show her, this has helped us form a close relationship and she feels safe to share stories with me good or bad.” The carers in the group felt building close trusting relationships with the families made their jobs easier and they were able to work better. It was felt that day centres in Liverpool provided an excellent service and helped people cope better. The majority of the group felt care in the home was better than care home.

Attendees at both events expressed appreciation on having the opportunity to attend the engagement event and the chance to express their views on the services needed to support the community in living well with dementia. They found the sessions to be informative and as they were delivered in Cantonese, attendees were able to fully understand the content and felt able to ask questions.

The dementia support services provided by Chinese Wellbeing were considered a lifeline by many attendees. It was important for them to receive information and advice about dementia first hand from Cantonese/Mandarin speakers which removes the language and cultural barriers experienced when accessing mainstream support services. For those living with dementia, the awareness raising and information provided through Tea House and the Network has helped to reduce the fear of dementia and has increased knowledge and understanding of how to maintain a healthy lifestyle.

“If it wasn’t for Tea House, we would not be able to recognise the early signs and symptoms of dementia”

The Chinese Dementia Support Network has been acknowledged as an essential peer support platform which keeps the Chinese community connected to other support groups such as SURF and DEEP. Carers have gained confidence in caring for their loved ones.

“The Dementia Champion has provided us with a lot of information about dementia and about the provision of dementia services in Liverpool. We also get advice on how to live well with dementia”

The carers' voucher scheme was recognised as hugely beneficial; however, some carers would like it to be more flexible.

Tea House and the Network provide the opportunity for carers and people living with dementia to get together and socialise in a culture and language specific environment with activities which provides stimulation and fun.

“I am so happy to meet new and old friends at Tea House. The activities and meals are culture and language specific which I cannot find with other organisations”

“The games and activities provided through the Network and Tea House are interesting and have brought me a lot of stimulation especially the cognitive exercises”

“My knowledge in relation to what is available is very limited. We get most out support from Mary Seacole House and if we need anything additional or specific we will be signposted through Mary Seacole House and supported to access the alternative support”.

“Attending the Umeed group as I can talk to other families who have similar experiences”

“I am responsible for all the caring responsibilities the only place I know to where to go for support is Mary Seacole House’s dementia support group”.

“I don’t think there is much support for BME communities dealing with dementia. I care for my mother-in-law and my husband didn’t think it was right to even talk about my mother in laws symptoms with the G.P but she was causing some dangerous situations at home and following this my husband let me speak to the worker at Mary Seacole House who then supported us to go to the G.P”

“I do not know of any support that I can access apart from the support group at Mary Seacole House”

“I only access Mary Seacole House and any support that I require I get through them”

More awareness of Dementia among the general public (multiple)

Less stigma of the condition than there was previously (multiple)

Sedgemoor House Day Centre as prices are affordable and facilities comfortable

Carer’s pathway is excellent support

Listening to family circumstances

Professionals more ready to listen when family members suspect Dementia

Swifter diagnosis and assessment of needs

Kindness and patience when dealing with the person with Dementia

Liverpool Memory singers

Additional Points

Working in partnership with other agencies

Networking and outreach among communities

Mary Seacole House

“A little book of friendship” by Alzheimer’s Society has been found to be very helpful

Communication with GP’s and pharmacists with families

Care line availability as a point of contact

More information is available now than previously could be obtained meaning patients seek help earlier

There is now a more open discussion about Dementia and its effects on patients and families

Dementia discussion groups for those affected by Dementia

Local authority supporting patients staying at home rather than a nursing home being the only option

Everton in the community

St Helen’s singing for the brain (multiple)

Give the person with Dementia responsibilities they can relate to

Treating each person as an individual

Dementia friendly churches

House of Memories support and training

There is a booklet available on dementia friendly toilets

Conferences such as: Dementia for design, Housing and Dementia Conference

Consultation events

List top 3 Priorities

- 1. Good education/training (although it was felt this was needed more of)
House of Memories used as an example**

2. Continuity of Care

3. Close Team Working – Home Instead was used as an example

1. People living with dementia and their carers valued the dementia support services provided by Chinese Wellbeing as they are accessible and culturally appropriate.

1. People accessing the support services at Mary Seacole House valued these services and many expressed the point that they do not know where else to go for information and advice.

1. More awareness of Dementia among the general public (multiple)

2. Less stigma of the condition than there was previously (multiple)

3. Sedgemoor House Day Centre as prices are affordable and facilities comfortable

Q2. WHAT NEEDS TO CHANGE OR IMPROVE IN CURRENT PROVISION?

The majority of group felt that GP's/medical staff had no experience or knowledge in treating dementia. More centres of excellence needed so that people know what they are dealing with. The group felt GP's did not know how or what to advise patient/carer.

They stressed the importance of a proper nutritious diet for both patient/carer. It was noted the importance of eating proper home cooked meals that reminded them of home i.e. Ireland. This was seen to be vital in supporting a person's care by providing home cooked food it helped the person connect culturally. For example cooking Irish Stew, Bacon and Cabbage, Soda Bread. The group felt there was a need for better communication between all MDT groups involved in patient care. More meetings, better link ups to services that could be accessed.

Many reported a feeling of being let down by their own GP's. They felt that there should be more training for GP's so that they had a better understanding of dementia and how it affects people. Carers would like to receive more information from their GP at the point of diagnosis.

One family felt they had been ignored by their GP when they raised initial concerns regarding the possibility of the onset of dementia. They felt that if the GP had been more responsive they would have been able to access support and treatment sooner which would have helped the family with their coping strategy.

"it has been hard for me to go through the process of getting a diagnosis and treatment even when an interpreter has been provided. I find it very difficult to be able to express my views and feelings"

The waiting time from the point of referral to the memory assessment clinic was

considered too long and was the cause of much anxiety and stress. One family has been waiting for 5 months. It was suggested that the GP should check on progress and feedback to those concerned.

Some confusion as to when to approach a mainstream organisation for advice and information. One person who rang the Age UK hotline for information was told to see their GP.

“being Chinese we wish that our children could look after us if we have dementia. However, they are fully occupied by their busy life and have no time to attend Tea House. If there were more newsletters and booklets about dementia in Chinese, we could take them home and our children would have the chance to understand how to support their parents with dementia and to understand lifestyle factors which help to prevent the disease”

Better signposting to appropriate services is required at the time of receiving a diagnosis. After a long period of time, one family was eventually referred to Chinese Wellbeing support services by a Care Navigator.

The threat to existing services has created an uncertainty about the future for Chinese people living with dementia and their carers in Liverpool.

“I am wondering why there is no stable funding to maintain the services of the Dementia Champion, Tea House and the Network. If the Liverpool City Council really knows the importance of the needs of Chinese and want to ensure there is equality in service provision”

“every year we are told that the services of the Dementia Champion, Tea House and Network might be suspended due to no funding. It brings me stress and worries about the future of the Chinese who have dementia”

“the staff of social and health sectors need more training on dementia”

Direct payments are difficult to access for people who speak little English. Opening a bank account and reporting expenditure to social services every 6 months is regarded as a barrier

A system in place where you can find out what is available. At the moment I do this through Mary Seacole House but if they were not there I would not know where to go and anything that I have seen or been told about does not meet the cultural needs of the person that I care for.

Information around diagnosis and support needs to be available in different languages and different formats.

Need to positively promote living well dementia.

Need more culturally appropriate support for BME families. There is a huge stigma around dementia diagnosis as there is a lack of understanding of the illness. In my culture there is no word for dementia and the closest explanation is that the person is going mad and then they are kept locked away. I care for my granddad and the family are they only ones that looks after him. There is a sense of shame attached so you don't talk about it. But this has got better since I have been accessing the support group at Mary Seacole House. Through this group there has been an increase awareness of dementia and how it affects families.

Information needs to be provided in appropriate languages for those whose English is not their first language. This is not necessarily in written format but audio because a lot of people from the older generation are unable to read or write in their own language.

Care worker who understand my culture and can speak the same language.

More information for families but also ways of making the person diagnosed understands what is happening to them.

Assessments and follow ups need to be more than once a year

Everything!

Priorities

Cultural stereotypes amongst professionals and practitioners or no recognition of cultural differences (multiple)

General lack of awareness regarding BAME cultural needs (multiple)

Assumption that patients from the BAME community will be looked after by their family or community so less help needed from social services/medical professionals (multiple)

Little awareness among families of legal impact of the condition and the need for documents such as Power of Attorney etc. (multiple)

Professionals can be too quick to dismiss family member's concerns which may have prevented crises later down the line if the concerns were taken seriously (multiple)

Lack of interpreting service resulting in lack of awareness (multiple)

Lack of diagnosis and support from practitioners resulting on misdiagnosis

Constantly having to chase agencies e.g. social services

Timescales – waiting weeks/months to access assistance

Older people without family support can deteriorate quickly as isolation is a major issue

Patient's economic situation influences choices and care received. This especially affects BAME communities as they tend to have less economic means

The social needs of the person are not always met even though the medical needs are

High turnover of carers needs to stop as it is detrimental to those being cared for

Leaving the person with Dementia out of the decision process when they are still able to make decisions for themselves

Additional points

Lack of communication between GP and the pharmacy

Lack of information in GP practices

Lack of communication between multiple agencies

Individual needs of the patient require assessment

Appointments not available with required doctor who understands patient's needs

Lack of consistency of care e.g. a different carer for every visit

Nursing care is not seen in a positive light – this needs to be changed

Community nurses need more of a link in with Dementia patients

Assessing capacity – it's not clear who needs to be informed and when

Lack of training for families to help them understand the condition and its effects

Need more Dementia friendly transport

Need more respect and dignity for people with Dementia

Confusion among some people about what Dementia is

NHS is good with emergencies but needs to be better at care for long term conditions like Dementia

Patients lose a lot of their human rights after their diagnosis as they are no longer looked on as a person

Larger providers overshadowing smaller community efforts. When these larger providers run out of funding what happens then?

People are disempowered from providing support in their own communities due to having to do risk assessments, health and safety etc.

Top 3 Priorities

1. Improved communication between everyone involved

2. Proper Food/Diet - that has cultural importance to the individual

3. Time it takes to put care package in place could be improved.

1. More regular sessions of language and culturally appropriate activity to help people living with dementia to maintain a healthy and active lifestyle and ensuring they stay connected and retain their cultural identity for as long as possible.

2. Carer voucher scheme could be extended to permit outings in order to help the person with dementia to have more involvement in community activities

3. Simplified process for Direct Payments.

1. To know what services and support is available and where I can find it.

2. Services and support to be culturally appropriate

3. Not to have to go to different places for support. A single point of access.

1. Cultural stereotypes amongst professionals and practitioners or no recognition of cultural differences (multiple)

2. General lack of awareness regarding BAME cultural needs (multiple)

3. Assumption that patients from the BAME community will be looked after by their family or community so less help needed from social services/medical professionals (multiple)

Q3. WHERE ARE THE GAPS? WHAT ELSE NEEDS TO BE IN PLACE?

The group felt there was a lack of education or knowledge on Dementia particularly with families. Training to be provided for families/friends as well as carer's making people aware of the training out there ie House of Memories.

"There needs to be more time for carer/nurse. They can be in and out and I am not sure what goes on or what they have done. It's not their fault. It's the restraints on them."

One carer stated that by having the right equipment at home it made it so much easier to care for the person such as wheelchairs, Zimmer frame, stair lift, ramps.

The group discussed more time being needed for nurses/carers, paid staff not being sure of what to do so carer ends up doing it all. It was felt that if carers were paid a better salary it would help people work better and reflect the work they do. The group felt fewer people should be coming in and out of homes to make things less hectic for the person living with dementia. The group thought that every carer/nurse

etc should know the background history of each person and suggested using a memory book.

Tea House and the Dementia Support Network are run monthly – families affected by dementia would like to see both sessions run weekly as they feel more support with social and health issues is required as the dementia journey progresses.

There is no dementia care home which can cater for the cultural and language needs of Chinese families.

“a friend of mine with dementia was put in to a care home. He thought his family had put him in prison. He refused to eat and drink and passed away within one week of being admitted”

“a nursing home seems to be a sad end for the Chinese living with dementia. It is better to have a nursing home which has the capability to deal with the cultural and language specific needs of Chinese people in Liverpool”

Language barriers exclude many from accessing mainstream services at the Carers Centre and Mossley Hill Hospital including the post diagnostic support programme. Many feel that the lack of language support creates an inequality in the care system for people from BAME communities.

“we feel isolated and ignored due to language and cultural barriers”

“The GP’s and nurses should have been more proactive in getting me diagnosed when I had concerns about dementia and also to get involved with my family sooner. This would have got me on the right track for me to be able to deal with my dementia”

Culturally appropriate care provider’s services taking into account language barriers, having the knowledge of the different cultures and how culture plays a big part in people’s lives.

With elderly people it is important that the carer can speak the same language because with dementia people revert back to their first language (same dialect if possible)

Leaflets and information provided in different languages. Not necessarily written as the older generation in the Asian communities may not be able to read in their language but audio information would be really beneficial. The same may apply to family members and carers.

There is huge focus on the shame attached to disclosing that a family member has dementia. This is due to the community perception of dementia and mental health overall. One of the participants stated that even accessing counselling services for

generic reasons can bring shame and people think the person is mad. This is what stops people from accessing services and asking for help. It is hard to tackle the issue of shame from the community. People struggle to trust people as they are scared that their communities will find out their issues.

More group activities to help such as memory boxes but they need to be culturally appropriate.

More awareness sessions so people from my community understand that having dementia does not mean you are 'crazy'.

People feel shameful to acknowledge dementia and mental health issues. This needs to change by raising the awareness of the illness. This has improved for me since I have been attending the support group at Mary Seacole House. (UMEED – meaning HOPE)

Carer's from the same religion (Muslim) who understands the religion and also speak the language.

Specific culturally appropriate day services but with language support for individuals with appropriate activities. My granddad would love to be go out but there is nowhere for me to take him where people speak his language (Arabic)

One to one support in the home.

Time out for carers.

More support from G.P's. I don't feel that they are supportive and don't listen. I feel that the GP assumed that due to our culture we don't want any additional support.

Priorities

Current cuts are affecting the quality of care. More funding is needed (multiple)

More training, respite (My Time and Local Solution) and support (including information on how to access benefits) should be available for carers and families (multiple)

Care plans need to be very personalised to cater for lifestyles and cultural differences (multiple)

Religious practices and spirituality should be respected in the care setting (multiple)

Education around Dementia should categorise it as a spectrum not as one size fits all (multiple)

Better training for professionals/careline in dealing with Dementia. Training needs to be proactive not reactive (multiple)

Advertise more widely for volunteers like Befrienders and professionalise volunteering (multiple)

GPS using social prescribing to refer people with dementia and carers to services available in the community including smaller, local organisations doing good work (multiple)

Treating people with respect patients, carers and care workers (multiple)

Increase the time carers have with the client to encourage more socialisation and include time for cooking preparation that isn't just a quick microwave meal (multiple)

Shared lives working to bring about greater awareness between families and care workers

Caring for the carer needs to be a top priority otherwise carers with not enough support end up burning out and then there is more burden on the Local Authority to look after the carer and the cared for

Carers input should be respected as carers are experts by experience

Better monitoring of care agencies for standards

Access to information for all before a crisis arises

Admiral Nurses – specialist dementia nurses as there aren't any at the moment e.g. like cancer nurses

There should be automatic follow ups with patients after diagnosis

After diagnosis there needs to be clear signposting for individuals to relevant services

Less red tape so that it is worth organisations whatever their size applying for funding

Additional Points

Lack of training for professionals on availability of support for BAME communities e.g. language barriers

BAME needs were not taken into consideration on the 2014 review

Access to service provision should be consistent, equal and fair

A central localised organisation for Dementia should be established which everyone affected can access

More staff needed and more recognition of the importance of nursing homes and

domiciliary care

More celebration of what a person CAN do rather than what they can't

There needs to be an increase in education about the prevention of Dementia

Community networking so that families do not feel so isolated

Pilot projects need to be sustainable as its no help if a project is good and then it is cancelled because it was a pilot

There is no education about Dementia in schools for young people. Some of these may be young carers themselves

There should be timed based objectives for various steps from when the patient is diagnosed to when they and their family are offered support

There needs to be a way to prepare people by getting them to learn the basics of Dementia before they are affected

Many people don't want to identify as having Dementia so sometimes not labelling an event as such may help get more people at events and getting access to information

Need to empower patients to take ownership

Dementia specific training should be given to all carers

Faith/non-faith community centres need to be more Dementia aware and become involved in the services provided for dementia sufferers

There needs to be recognition that grass roots community projects make a big difference

Services need to be more joined up to deliver a smoother journey for the user

There is a need for a directory of services like Health Watch

There is a lot of duplication of services and this is a waste of resources especially when there are funding cuts

The current care home structure is too rigid to adapt to the different needs of people with Dementia.

List top 3 Priorities

1. Better continuity of care needed
2. Better communication
3. Right equipment

1. Language specific information at the point of diagnosis
2. The Lifeline pendant is essential for those living alone – more assistance with the use of assistive technology.

2. Blue badges would be helpful for family carers when supporting their loved ones with outdoor activities, hospital appointments.

1. Culturally appropriate services for BME communities.
2. More support groups like the one at Mary Seacole House that are culturally appropriate.
3. Awareness of dementia and increasing the knowledge of people from BME communities around dementia and how it affects people and families.

1. Current cuts are affecting the quality of care. More funding is needed (x5)

2. More training, respite (My Time and Local Solution) and support (including information on how to access benefits) should be available for carers and families (x5)

3. Care plans need to be personalised to cater for lifestyles and cultural differences (x4)

**Q4. WHAT ARE YOUR TOP THREE PRIORITIES FOR THE NEW STRATEGY?
WHAT WILL REALLY DISAPPOINT YOU IF IT IS MISSING?**

1. Right training for carer, specific training for each type of dementia

2. Individual Care Plans which are person centred

3. More research needed into the different stages of dementia

1. Respite service should be more flexible and accessible to BAME communities.

2. A dementia care home/day services which can meet the needs of BAME communities.

3. Language specific pre and post diagnostic training/awareness programme for people living with dementia and family carers.

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1. Initiatives to raise the awareness of dementia in BME communities to reduce the stigma and shame

2. Day care support that is culturally appropriate

3. Care providers having care workers that from the same culture and speak the same language

1. Current cuts are affecting the quality of care. More funding is needed (multiple)

2. More training, respite (My Time and Local Solution) and support (including information on how to access benefits) should be available for carers and families (multiple)

3. Care plans need to be personalised to cater for lifestyles and cultural differences (multiple)

Still relevant today.....?

What people told us at a BME Strategy Development Event 2012: The BME Strategy Development Event was a one day conference where 120 older people from seven BME organisations met to brainstorm on the most effective ways of supporting older people around their dementia care needs within the community. The key findings and recommendations were:

Access to Services

From a total of 120 older people, 98 agreed that they have **difficulty accessing their GP** and Secondary Care services due mainly to **language problems, cultural barriers** and lack of **awareness**. They suggested **local community based services are more welcoming** and **accessible** due to the fact that they are nearer home and staff can communicate with them in their heart language.

Capacity Building

120 out of 120 agreed there was an urgent **need for trained BME dementia champions** and volunteers working in the **community**. Trained champions could also work effectively as interpreters because they also have both **cultural competency** and an appropriate **knowledge** base.

Information

50 out of 120 believed leaflets containing **information** on dementia should be available in **local languages**. Others believed **word of mouth** is more effective for older people within certain cultures due to **inability to read the written format** of their language.

Summary Notes

1. There is strong evidence to show by the growth and development of the BAME Dementia Support Network groups that the work of the Dementia Champions in raising awareness in their respective communities has increased knowledge and understanding and helped to reduce the myths and social stigma.
2. People valued the work of the Dementia Champions and value the current support services provided by the BAME organisations leading on the engagement.
3. The engagement has reinforced the view that there is a lack of culturally appropriate care which is truly person centred and that mainstream services remain inaccessible to BAME communities seeking support in living well with dementia.
4. The Dementia Champions have successfully raised awareness of dementia and subsequently community organisations are seeing an increased demand for their support services which is estimated to grow within Liverpool's ageing BAME population.

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