



Living with dementia in Blackburn with Darwen



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Background

It has been reported that nearly a third of suspected dementia cases among those 65 and older in Blackburn with Darwen (BwD) do not have a formal diagnosis. NHS figures shows that 1,575 people aged 65 and older living in BwD were estimated to have dementia in March 2023. 1,077 have had a diagnosis leaving 498 without a formal diagnosis.

The London School of Economics (LSE) has produced modelled projections for the Alzheimer's Society, showing how the number of older people (aged 65+) with dementia in each local authority. The cost of their care is likely to increase between now and 2030. For Blackburn with Darwen, they suggest that the total number of people with dementia will rise by almost 35%. The majority of this increase will be at the more severe end of the spectrum. This helps to account for the fact that care costs will rise even more steeply, by over 64%.

In this project, we wanted to understand the dementia care pathway in Blackburn with Darwen and how effectively it supports our residents and their carers.

Within our research reviewed the Blackburn with Darwen Local authority and Lancashire and South Cumbria's dementia strategies.

We found similar themes between the two strategies.

Blackburn with Darwen Dementia strategy

Blackburn with Darwen's ambition is to -

- Raise awareness of the factors which increase the risk of developing dementia.
- To have the best support offer which enables people living with dementia and their carers to live well as long as possible.
- For those at the later stages of their life to experience well planned and co-ordinated care and support in a timely manner.

Lancashire and South Cumbria focuses on 3 main areas.

- Preventing avoidable cases of dementia
- Improving peoples experience of being diagnosed and living with dementia
- Championing participation and innovation in research



Methodology

Healthwatch Blackburn with Darwen followed several lines of enquiry to explore the dementia pathway. We did this by -

- Focus groups
- South Asian residents online survey
- Engaging with a wide range of support services within Blackburn with Darwen

We carried out a series of focus groups with the aim of engaging with a wide cross-section of our community with respect of age and ethnicity. Overall, we spoke to **121** residents from the following groups -

Singing for the Brain - Alzheimer's society. The group consisted of 17 people aged between 65 - 84 White British

Dementia peer support group - Blackburn Carers Service Kingsway. 5 members of the group ages between 40 - 82 White British

Dementia Café - Blackburn Carers service Kingsway. The group consisted of 13 people ages between 89-82. 11 members white British and 2 South Asian.

Asian Carers Service - The group consisted of 8 members aged between 35 - 64 Blackburn carers service Kingsway 8 British Indian

Darwen dementia café @ Rushtons Café - Ran by the local PCSO and supported by the Age uk wayfinders - 4 members of the group ages between 75 and 87 (This was the second time this group had held so not many attend yet) White British

Kiran women's group - Bangor St Community centre - 20 members ages 60+ all South Asian heritage

Humraaz coffee morning - Unity House Blackburn - 18 members ages between 30 - 60 all South Asian heritage

Bastwell Ladies - Bangor Community Centre - Group consisted of 18 ladies from ages 42 - 68 - All South Asian heritage

Little Harwood community centre - 18 members aged between 37 - 72 South Asian heritage.

The residents online survey was shared via Facebook community group pages and contacts via email to engage with South Asian heritage residents.



Executive Summary and Recommendations

The aim of our engagement was to understand the dementia diagnosis and support system in Blackburn with Darwen. Key themes of areas for improvement in services came out through discussions with residents, face-to-face focus groups and our online survey. These key themes and recommendations are summarised below.

Education in the community

From our engagement it was clear that residents wanted better education around signs and symptoms of dementia in the community. Family members and carers explained how they would prefer more awareness of signs and symptoms of dementia. They believed this would enable them to be more aware of what symptoms to look out for and how to get a diagnosis. Residents said they felt they had to be “tech savvy” to find out information and nothing is displayed in poster or leaflet form anymore.

“I feel like information is out there but it’s not easy to find”

“It would be useful if there was an information stand like the Macmillan cancer research stand at the hospital all about dementia”

“I would like groups to be closer to my house, I don’t know where to find groups as I don’t use the internet. It would be good if posters could be put up in local newsagents, GPs, and chemists.

Recommendation

We found families and carers wanted to see more posters with the signs and symptoms of dementia within their communities like local shops, GPs, dentists, pharmacies, and community centres. Key simple visual posters like the ones pictured below.

Dementia UK have a free leaflet order form - you can order all different types of leaflets all containing useful information.

<https://www.dementiauk.org/information-leaflet-order-form/>



Asking the
same question
over and over again.
over and over again.
over and over again.
over and over again.
over and over again.

It's not called
getting old, it's
called getting ill.

If you or a loved one are experiencing memory loss, it could be a sign of dementia. Help and support is just a phone call or click away.
alzheimers.org.uk
0333 150 3456



NHS Health checks

The NHS health check is a free check-up of your overall health. The check is for people who are aged 40 to 74. It can determine whether you are at higher risk of getting certain health problems, such as heart disease, diabetes, kidney disease and strokes. During these check-ups you'll also discuss how to reduce your risk of these conditions and dementia. We found that the NHS health checks are not being accessed by most of our residents, particularly our South Asian communities.

Within our research, we attempted to discover how we could obtain an NHS health check without having to go through a doctor. NHS Health Checks can be booked through the Wellbeing Service (re:refresh) but we found the options for booking was very limited. You can only book an appointment one day of the month on a weekday, with only one or two times available on that day. This service is as such not accessible to the majority of our working population.

Recommendation

Promote the NHS health check throughout the borough and educate residents on the purpose of the Health Check. The Wellbeing service should aim to provide wider availability when booking a health check with the option of weekend sessions as well as pop up Health checks at community venues and events.

The NHS website has a link to a PR Health check toolkit which provides useful information - Key messages, Developing a local NHS health check campaign and FAQ's.

[NHS Health Check - Marketing](#)

Hospital care

We discovered the leading dementia nurse at East Lancashire Hospital (ELHT) has a vast amount of experience in hospital care with dementia patients. He is currently the only member of his team and is extremely strained in his workload. The means he uses to find out more about a patient's dementia diagnosis is time consuming - the information sits on a different Trust's system which cannot be accessed by ELHT. Staff dementia training is part of core mandatory training at ELHT which means all staff will undertake an E learning session.

Recommendation

After speaking to the lead dementia nurse, it was clear that the workload is too much for one person, this results in no dementia coverage when the lead dementia nurse is on an annual leave. We recommend that a business case is created to expand the workforce and enable a continuous dementia support in hospital setting. A view only access to LSCFT's Rio system should be explored by ELHT to ensure the dementia team can easily access information they need to examine the dementia diagnosis of the patient.

The Trust should also implement an interactive and practical dementia training session. We received feedback from residents about health care professionals

lacking an understanding of how to manage dementia patients so in person training may be more effective (delivered with residents with lived experience) to have a better understanding of the different types of dementia and techniques they could use whilst treating patients with dementia rather than an E learning course.



Promotion of services

Overall feedback from residents was uncertainty on where to go to find help after diagnosis. They felt after the memory assessment diagnosis they were left to navigate the system themselves. In looking into people's experiences of the pathway, it is clear that signposting is varied. The memory assessment refers people into the Alzheimer's Society, and it was reported that no referrals had come from any GPs in Blackburn with Darwen. The lead dementia nurse would signpost to local services such as the Way finder service by Age UK.

“Overall, across the whole of East Lancashire in the 2022/23 period we received 971 referrals to our service, 174 of those were for Blackburn with Darwen of which 67% came from the Memory Assessment Service, 22% were self-referrals, 7% from Secondary NHS Care, and 4% from other voluntary organisations, we did **not** receive any directly from GP's or Social Care in BwD.

Information provided by East Lancashire's Alzheimer's Society lead.

“I didn't know I could carry on using the dementia advisor [Alzheimer's Society] after my diagnosis”

Recommendations

To have a clear support system after diagnosis which is communicated to patients and carers, with GPs taking a lead on referrals for support.

Within our research we found out about Dementia Advisors. They are a dedicated team who provides vital 1:1 post diagnostic support to people diagnosed with any form of dementia and can assist people who are worried about their memory to help them through the diagnosis pathway.

Blackburn with Darwen Age UK have recently created two dementia support navigator posts funded by the National Lottery Community Fund. They are a way finder service to navigate the care system and offer free support and guidance.

These services are excellent for dementia support, unfortunately it seems that these services are not being promoted effectively.





Dementia groups and activities

From our perspective, the groups we currently have for dementia residents in BwD are not inclusive for all our residents. BwD have dementia cafes and singing groups which are excellent services, unfortunately we could not find groups to promote physical activity, wellbeing, groups for younger residents or residents from different religions or minority ethnic backgrounds living with dementia.

Recommendation

The wellbeing team should develop physical activity programmes which are inclusive for dementia patients. We recommend that there is also an offer available in the borough similar to The Beacon shed in Rossendale, which include outdoor activities such as gardening, nature walks and creative workshops. This could be linked to Lancashire Wildlife Trust's programme at Witton Park.

[Beacon Dementia and Wellbeing \(beaconrossendale.org.uk\)](http://beaconrossendale.org.uk)

The local dementia offer should be inclusive to our South Asian heritage Muslim communities and hold monthly memory groups for example looking into the history of South Asian countries such as India and Pakistan, explore the nations' music/food/language to help jog old memories but also widen this for different nationalities.

Everybody working together

We discovered that the dementia pathway does not appear very connected or collaborative. Each service provides a good standard of care but they do not seem to work together as a group of health professionals including communication about individuals.

Recommendation

Improve communication between services, better basic communication between services to ensure that key information is made available to everyone involved in the care and support of someone with dementia.

South Asian residents in Blackburn with Darwen dementia care access

We found the topic of dementia was still a taboo subject, with a lack of education and knowledge of the illness. This was clear when we conducted focus groups to ask questions about how they have found the care and support for residents living with dementia. The groups were often silent with not much discussion, translators were used for group discussions, but unfortunately due to lack of knowledge or experience, limited feedback was received on their opinions of services in BwD was

given. One lady from a focus group said “We need someone to tell us what to look out for”.

Recommendation

Health professionals and voluntary sector representatives should educate communities about dementia and what signs to be aware of. They should attend local gatherings, mosque events, schools, and community events and educational groups. We discovered that residents felt it was important for their doctor to play a crucial role in conversations with family and the individual. We believe it would be beneficial to educate younger generations around awareness of dementia so that they can keep an eye on their older family members and take a lead in initiating conversations with a GP when necessary.

Activities and groups to be created which are suitable for South Asian residents some suggestions from residents were cooking classes, pottery classes and dementia cafes in their local area.

Carers assessments

We wanted to find out who undertakes care assessments and how they are delivered. We tried to identify who undertook the carers assessments, Adult Social Care or The Carers service Blackburn with Darwen. It was reported from the Carers service “The system isn’t joined up and easy to navigate”. When we tried to find out information via the council website it takes you to a page where you sign up to become a member, this made it difficult to navigate and gain any information required. This appears to be an area that causes residents to feel anxious and uncertainty of what will happen next with the care and support they require. When we spoke with voluntary sector representatives who aid residents with such queries, it appears that they themselves are confused with the process.

Recommendations

There needs to be a more joined up offer for carers integrating the services together. A system should be established whereby care plans can be shared between different services enabling them to be updated with patients care plans and preventing the same questions being asked to the patient and carers. We identified the need to establish a clear pathway of what support is available and how to acquire it. An online information hub to be created, making it easier to locate information in one place. We found a carer hub in Birmingham which is funded and supported by the council, NHS and Childrens trust. By all of these important services working in partnership it enables information to be shared in one place.

[Carer Hub Support - Birmingham Carers Hub](#)



Example of Good Practice

Research into Rossendale's collaborative working

Figures from the NHS show 648 people aged 65 and older in Rossendale were estimated to have dementia in March 2023. Of them, 528 (81.5%) had a formal diagnosis - one of the highest rates of diagnosis in England. This led us to investigate the diagnosis pathway in Rossendale.

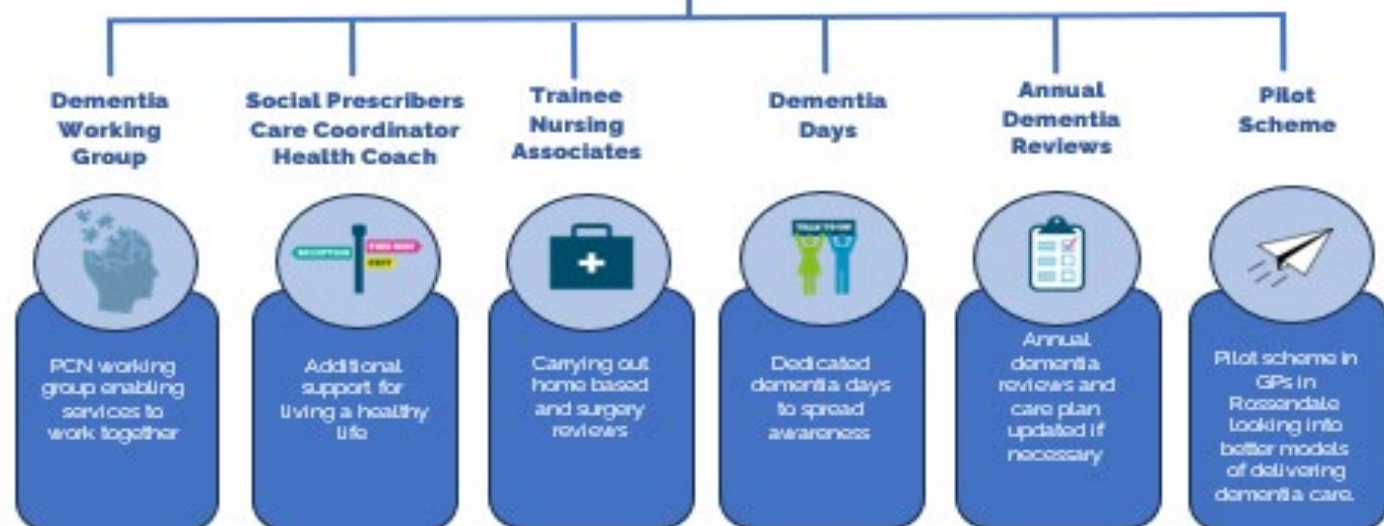
Rossendale have a pilot scheme in a GP practice looking at different models of delivering dementia care. Looking into these services it shows; Rossendale have a detailed wrap around services for residents living with dementia, this includes a personalised service at GP level, different activities within the voluntary sector and a Dementia wellbeing day each week at the hospice.

We included all the information in a graphic to demonstrate the effectiveness of the dementia pathway in Rossendale.

We used this information to explore what pathways exist in Blackburn with Darwen and to understand if there any current gaps in provision.



GP



Signposting to other Services in Rossendale



Beacon Dementia & Wellbeing

Services for people living with dementia and their carers



Beacon Shed

A unique dementia friendly community shed
A unique dementia friendly shed. Activities in this unique community shed include gardening, woodwork, making and mending, designing, DIY, nature walks and art sessions – all of which can be adapted to be dementia friendly.



CAST

A dementia lived experience & signposting group



Dementia friendly Rossendale Facebook group

Supporting Rossendale residents living with dementia and also their family & carers



Memory Matters

Free advice and support to help people living throughout East Lancashire with memory loss stay safe and independent in their own home



Rossendale Hospice

Dementia diagnosis day 8 patients that attend for a period of twelve weeks. We try to base activities around peoples interest and abilities. It also provides an opportunity to signpost people to other services or areas of support within the community.



Pre-diagnosis

Recognising the early signs of dementia can be difficult. People had often dismissed them or put their symptoms down to old age. We found residents wanted more awareness of dementia symptoms in the community. One area identified for improvement was to ensure that NHS health checks are taking place routinely and to use this tool as a key driver for awareness and early identification. Health checks are for people aged 40-74 every 5 years.

Within our research, we found that residents felt there was a stigma surrounding dementia and that was a barrier for them to go and receive a diagnosis.

From our focus groups and online survey, it has shown that Health checks are not taking place routinely or residents did not know about Health checks.

“Had a group session but didn’t know they did individual ones”

“Didn’t know it was available”

“No availability”

“Don’t know”

We contacted the lead contact of the Neighbourhoods; Wellbeing & Prevention team and they explained their service in more detail. They carry out a full check (which includes blood testing for glucose & cholesterol) and currently offer these in 3 locations once a month:

Albion Mill, Darwen Town Hall, and Care Network Hub

People can self-refer for health checks however, they also engage with residents through community events. This gives them an opportunity to carry out mini checks (BMI, Blood Pressure) whereby if the person is eligible for an NHS Health Check, they would offer them the opportunity to book one, using the QR code on the results card (attached) or by phoning the Wellbeing Hub Advisors to book it for them.

We asked the health and wellbeing team (re:refresh) how many Health checks have been carried out this financial year. From April - August 2023 a total of 9 NHS Health checks have been completed. The team explained that they have had staffing issues and unable to promote for that reason. The future plan is to carry out NHS Health Checks taking a targeted approach. They will link up with the Voluntary, Community and Faith Sector (VCFS) Partners/Groups to offer checks to those who may not access GPs for Health Checks and promote to the wider community.

Blackburn with Darwen
WELLBEING SERVICE

My Mini Health Check Results

Name: _____
Health & Wellbeing Coach: _____

Height	_____
Weight	_____
BMI	_____
Blood Pressure	_____
Resting heart rate	_____

NHS HEALTH CHECK

FOR MORE INFORMATION:
BwD Wellbeing Service
01254 682037
wellbeing@blackburn.gov.uk
www.refreshbwd.com

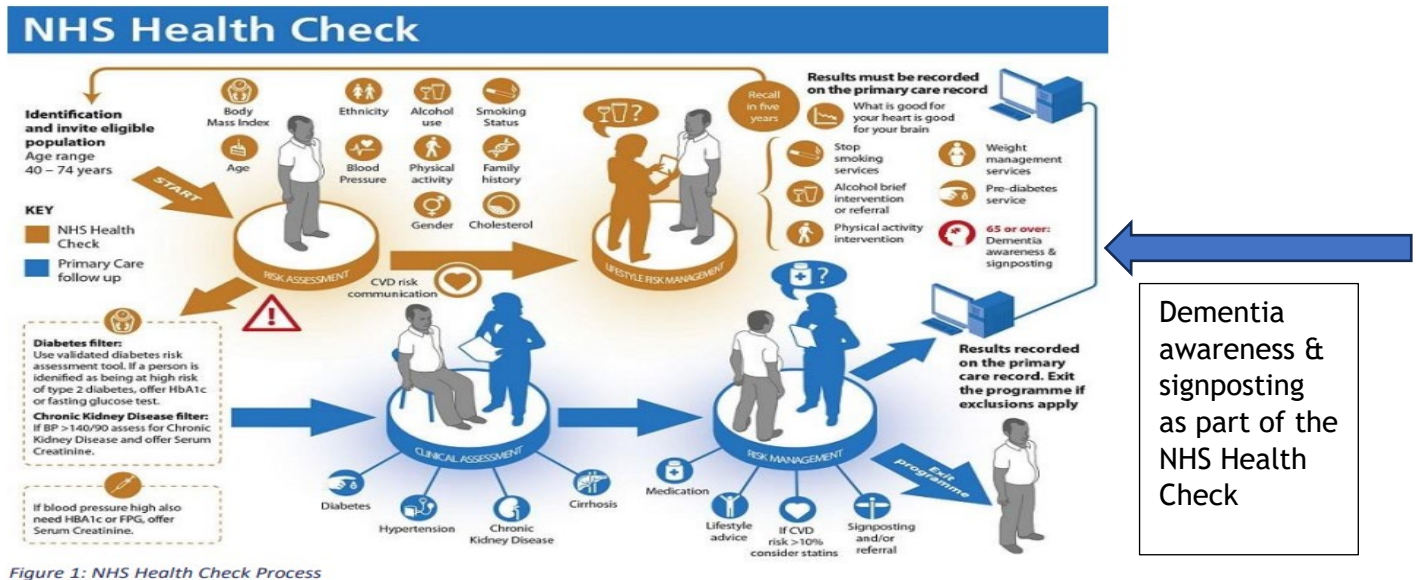
- Aged between 40 - 74 years
- Haven't had an NHS Health Check in the last 5 years
- No current diagnoses of, or be taking medication for any of the following:
 - Heart disease
 - High blood pressure
 - Atrial fibrillation
 - High cholesterol
 - Diabetes
 - Strokes or mini-strokes
 - Kidney disease
 - Dementia

SCAN ME

We also asked if they could provide us with figures of ethnicity backgrounds on Health Checks conducted last year to give us an insight into who is taking up the Health Checks. (Total checks completed in part year of delivery - 58)

Ethnicity	Percentage %
White - British	72%
Asian or Asian British _ Indian	11%
Asian / Asian British Pakistani	4%
Asian / Asian British Other background	3%
Chinese	1%
Not stated	8%

NHS Health Check Pathway



Within our focus groups, all the residents we spoke to went to their GP when they were concerned about the signs of dementia. This then led us to find out what the GP pathway consisted of.



Diagnosis

The role of a GP

We gathered feedback from some GPs across Blackburn with Darwen on what their role as a GP is within dementia care. Below are two responses from GP practices on what their referral pathway consists of.

We asked-

What is the referral pathway for a dementia patient?

Response 1-

“Patients who are seen by the GP with symptoms of dementia/memory issues are referred to the memory assessment service for further management.” Practice manager.

Response 2-

“At our Practice the GP’s, after conducting checks, refer any patients suspected with dementia to Secondary care. Patients with dementia diagnosis have annual dementia review carried out by Practice Nurses. Practice Nurses use the 6CIT risk code screening tool and arrange dementia bloods at the screening. They have a care plan in place which is augmented by the My advance Care plan which is completed by the patients before their reviews. Patients and their carers are also signposted to BwD wide services like Dementia connect from Alzheimer’s Society, Care Network hub, Age UK, and Carer Services as they provide both patients and their carers with a variety of resources.” Practice Manager.

Unfortunately, from our findings, it was evident that GP care is not consistent throughout the borough. Some GPs offer an excellent service, but several do not participate in any signposting to appropriate services or carry out annual reviews.

The main theme from our focus groups was that dementia patients were not having annual reviews, something which is recommended in NICE guidelines.

What residents said-



“My GP doesn’t seem interested in helping us, I’ve had to nag nag nag for a memory assessment twice!”

“My husband hasn’t seen his GP at all since he was diagnosed in 2018, I have never heard of annual reviews”

“When my husband goes for his MOT, they never ask about his dementia its focused on height, weight, bloods etc.”

“I’ve never had an annual review”

“I didn’t know it was something my GP should be doing”



Recommendation

GPs should all play an active role in dementia care for patients. Completing and reviewing annual care plans will create opportunities for GPs to ask simple and effective questions like the ones listed below:-

Have you got a LPA in place?

What are things which are important to you?

What are your up to date important contacts?

Do you have funeral arrangements in place?

[dementia-uk-advance-care-plan-template.pdf \(dementiauk.org\)](https://www.dementia-uk-advance-care-plan-template.pdf)

These conversations should then lead to signposting to support services such social prescribers, the Alzheimer's Society and Age UK way finder service so that patients have an ongoing support system in place. From the figures reported from the Alzheimer's Society, out of 174 referrals from Blackburn with Darwen last year, zero referrals came from GPs.

How could GP care be improved within dementia care?

A designated lead GP in dementia care within Blackburn with Darwen would help ensure that there is a focus on consistent care across all GP practices.

Longer appointment times

Having an easy to use appointment system and sending reminders to patients and their carers, with longer appointment times so patients do not feel the stress of a short time limit on their appointment.

Staff training

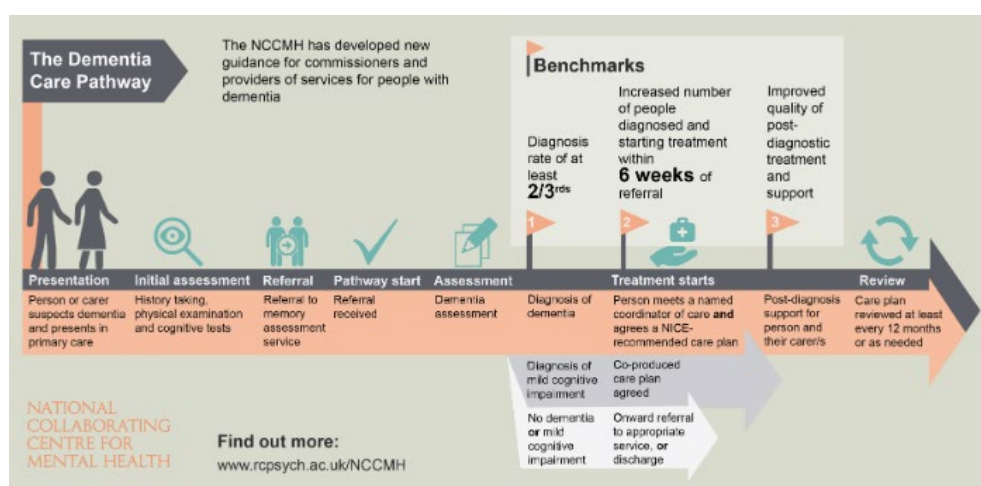
Regular staff awareness training to help them understand what information or support is needed for the patient.

Annual support

GPs coordinating annual reviews and reviewing care plans accordingly.

Signposting

Better signposting to support providers like the Dementia navigators and Dementia Advisors at Age UK and Alzheimer's Society.



Memory assessment service

We found the feedback we received from residents who have used the memory assessment was generally good. Residents liked the service and found it very helpful. We spoke with a member of the memory assessment team, and they gave us an overview of what the service consists of-

Their aim is to see patients within 6 weeks of referral. The main site is Gannow Lane located in Burnley, they also operate from other satellite sites around East Lancashire. They have a dedicated home visit nurse who can conduct an assessment at a home address. The admin team at the memory assessment felt that patients/carers call the memory assessment team weeks or months after they have been discharged from the memory assessment with common queries. They will ask questions about medication reviews or handrails etc. This demonstrates that patients/carers are uncertain where to seek assistance and advice after they have been discharged from the memory assessment team.

The memory assessment team signpost these patients/carers to the Dementia advisors from Alzheimer's Society.

Recommendation

We felt that the Memory assessment team provided a great service and collaborated with a variety of health professionals. An area of improvement would be to ensure that the patients/carers are aware of where to seek help or assistance after they had been discharged from the service.





Access to Services

Hospital care



When we spoke to the leading dementia nurse at East Lancashire Hospitals NHS Trust (ELHT), we discovered he had made a few areas of improvement. ELHT has recently had a new patient record system implemented and this has increased his referrals significantly. ELHT do not have the systems in place which they need to look into a patient's dementia diagnosis. The lead nurse has to contact another hospital trust (LSCFT) to provide him with information he needs regarding a patient's dementia diagnosis.

We asked our focus groups - Is there anything about your experiences of using health and social services you would like to tell us?

“People who work in the health service don't fully understand what it's like dealing with a loved one who suffer with dementia”

“Consultant in ophthalmology was quite rude on first assessment. He asked me if there were memory problems, completely ignoring the patient”

This highlights the need for appropriate training to all health care professionals who aid patients with dementia.

At ELHT they have an E-learning system for all staff to complete as part of their core mandatory training - this is a beginner's module. They are currently in the process of developing a tier 2 course which will give a more in-depth training around dementia.

Each year the trust undertake a PLACE assessment. Included in this assessment are questions designed to assess how well the healthcare setting already supports people with dementia, and what needs to improve. Without the right things in the environment it could contribute to people being and feeling less safe, more confused or anxious or less independent. Last year's PLACE results for the dementia results was 83.45% which is above national average of 80.60%. However, although it is above national average, ELHT have some work to do around delirium as they rank 153rd out of 156 hospitals for quality of delirium assessment.

The lead dementia nurse has recently set up a Dementia Champions group within the Trust, currently in its early stages, with the aim of creating a team of employees who can meet every month and hold discussions and training around dementia care. On discharge, dementia patients follow the same discharge pathway as other patients. The Age UK Way finder service is advised on discharge.

We asked the lead dementia nurse what the key issues are he sees with his patients. He reported the most common problems he encounters are:-

- Lack of support in the community including support not been inclusive for everyone
- Poor support from GPs
- He finds there is a lot of stigma around dementia and it isn't talked about enough
- Lack of information to recognise the signs and symptoms of dementia



Groups, activities, and respite

Residents' feedback regarding groups and activities was varied. Some residents were pleased with the handful they already use, but we found them to be lacking in variety.

“My husband really enjoys the group at Albion Mill, I worry as he has to get two buses to get there”

“I only come to this group. I don't get chance to come every time, but I find the meetings really useful. We can share experiences, learn, and gain knowledge from professionals”

“The names of the groups put my wife off attending. Dementia cafes and memory cafes hold more of a stigma around the diagnosis”

“I don't mind travelling to this group, there is nothing similar near where I live”

“I really enjoy this group; I love coming here. I wish they did it more than once a week”

“I have been a dementia advisor for 15 years for Alzheimer's society and I feel like there isn't enough activities within the borough and they are not inclusive of everyone. The respite services are poor and not enough is available. The term 'day care' holds a stigma with the patient “oh I am old now, I need day care” This then makes the patient feel undervalued.”

We have found that most of the groups are singing groups or cafes with no physical activities available. We spoke with the Wellbeing team to enquire about the services they provide for dementia residents of BwD, and unfortunately no physical activities exist. This led us to determine if there was any physical activity from another provider.

We came across a local business in Blackburn, they are in the process of setting up dedicated dementia sessions at their gym.

The dementia sessions will include:-

- physical sessions, group classes with our inhouse practitioners using the gym equipment
- Sessions with patients and carers/family members i.e., talks, board games, activities etc
- Counselling sessions
- Physiotherapy
- Benefit Advisor
- Café which includes light refreshments

The facilities will only be used for dementia patients on Mondays and Wednesdays 1.30pm - 4.30pm. The subscription cost is £48 per month per person which will cover 3 hours 2 days a week.

This service is great for keeping residents active, socialise and receive 1-1 support to keep them active and healthy but unfortunately it comes with a high cost. Find out more information by visiting their website.

[Mind2Muscle – Centre of Excellence](#)

While exploring what groups and cafes we have in Blackburn with Darwen, it is clear to observe that it is not inclusive of all our communities. There aren't any groups that would appeal to our South Asian communities and this feedback stood out from our survey.

What types of activities would benefit people living with dementia if they were available in your neighbourhood?

Survey feedback-

“Dementia groups for specific groups e.g., Pakistani dementia group and they could look into the history of Pakistan, explore the nations music/food/language to help jog old memories but have this for different nationalities as well eg India, Poland etc.”

“Free yoga and Pilates for women only”

“Going out meeting similar people”.

“Dementia services are limited for South Asian Community”

Dementia groups/cafés within Blackburn with Darwen -

- Blackburn with Darwen carers service - Dementia café and Dementia Peer support group
- Age UK - Memory Makers & Talk and tunes 50+ - Albion Mill, Darwen Town Hall & Morrisons Community Room in Blackburn
- Alzheimer's society - Singing for the brain @ Trinity Reformed church hall Brownhill
- Open door memory café - Revidge Fold, Shear Brow

Day care services ran by Age UK Blackburn with Darwen -

Three-day care provisions across the week are held at -

Accrington Road Community Centre, Greenfields Community Centre, and Little Harwood Community Centre.

Recommendation

There should be a varied range of activities for residents with dementia, other than singing groups and cafes. Promotion of physical activities as well as cognitive therapy should be encouraged. It would be beneficial if groups took place more frequently and were accessible for all. We would recommend that cafes and hubs avoid using the names “day care” and “dementia cafes” which are viewed as stigmatising by carers and residents with dementia.



Promotion of support services



Support for family members and carers

When carrying out this research we found the support for family and carers was often varied or support was minimal due to lack of funding. In our research, family members and carers wanted the skills to enable them to understand how to care for their loved one.

Alzheimer's Society

The Alzheimer's Society have 5 Dementia Advisers who cover all East Lancashire, with just one role being funded, the remaining roles are funded through charitable funds raised by Alzheimer's Society. They also deliver the CrISP programme and Singing for the brain from charitable funds in Blackburn with Darwen.

“It's a very emotional and confusing time, the Dementia Adviser helped me to focus on what is important and how to look at it. It's a brilliant service, lots of good information, just wish you could wave a magic wand!”

Carer of a person living with dementia

The Alzheimer's society have launched a Carer Information and Support Programme (CrISP). The programme is invaluable at equipping carers with the correct knowledge, strategies and community contacts which enables them to cope better.

The Carer Information and Support Programme aims to improve the knowledge, skills and understanding of those caring for a person with dementia, by providing effective support and up-to date, relevant and evidence-based information. The programme facilitates peer support and a shared learning experience led by trained Society staff and volunteers in a safe, accessible, appropriate environment. The provision of a structured programme for families and friends of people with dementia will: provide and improve access to good quality information, empower carers to access support services and financial benefits and entitlements, enable carers to plan for the future, help carers to feel better informed and less isolated, help carers to feel that they cope better within their caring role.

The positive feedback received from these programmes highlights the need for consistently delivering more programmes. The Alzheimer's society have delivered 2 CrISP programmes which is a 5-session programme. They have two trained Dementia Advisors who facilitate the programme within Pennie Lancashire. Alzheimer's society are seeking funding opportunities to enable the CrISP programme to be a consistent programme.

Here is feedback from carers who have attended the CrISP programme -

“Realising you can't make the problems go away, but you can put into practice certain suggestions and strategies”

“I don't feel so alone when dealing with situations, I have a good list of contacts and support now”

“I am more confident about handling any future deterioration in my partner's condition”

Recommendation

Alzheimer's Society to explore permanent funding opportunities for the CrISP programme so that it can be a consistent programme available for residents. From the feedback above it shows how much the programme supports families and carers throughout the dementia journey, enabling carers to learn coping techniques and other expertise.

Age UK Blackburn with Darwen Wayfinder Dementia Service

Age UK Blackburn with Darwen found they were receiving increased enquiries from residents living with dementia and their carers, from this they discovered there was limited support for people who had dementia in Blackburn with Darwen. Age UK Blackburn with Darwen successfully secured funding from the National Lottery Community fund to establish a Wayfinder dementia support service.

The wayfinders provide a local 'one stop shop' service for anyone living with dementia and their carers. The service supports people affected by the disease to navigate their way through living with memory loss and other symptoms. They have recruited two members of trained staff (Dementia support navigators). They support with benefits, entitlements, advice and information. They also signpost to local activities and support to help people remain as independent as possible for longer.

From launching the service in May 2023 - Sept 2023 they have received **85** referrals into their service. They went for a soft launch of the service as they didn't want a backlog of referrals resulting in making people wait too long. They went through Social



media, local press, their partners, the current service users and volunteers. Leaflets and posters were produced to promote and support the launch. They are now at the stage to carry out some further marketing, circulating posters and leaflets particularly in GPs and Pharmacies. They work closely with the lead dementia nurse at East Lancashire Hospital, upon discharge he will refer his patients to the way finder dementia service so they are able to seek any help or advice they may need. The navigators find it beneficial to have a close connection with the lead dementia nurse to investigate any outstanding queries patients may have.

Age UK Blackburn with Darwen Dementia service -

Contact number: 01254 266620

Email: Heretohelp@ageukbwd.org.uk

Recommendation

Similar to the Alzheimer's Society above, permanent funding for the Wayfinder Service would allow Age UK to provide a consistent offer for residents with dementia and their carers.

Support from Adult social care and Carers Service

We wanted to understand what support is provided both for individuals and carer. We found the support offer was beneficial for the individual through a range of care packages, but we found the support for the carer was lacking in areas.

We followed this up by getting in touch with Blackburn with Darwen Carers service and they gave us feedback on how they support carers. They help the carer and the person they care for get the right support and services in place and inform them of their options. They have an open-door policy so the carer can contact them as often as they need too. They provide peer support dementia groups once a month and this is an opportunity for carers to seek advice and tips on how to look after someone with dementia as well as their own mental health and wellbeing. BwD carers service also offer a respite service on a Monday afternoon for two hours, they would like to offer a lot more, but they are unable due to lack of funding and staffing.

We wanted to discover what respite offers are available for carers and it was revealed to us that carers can claim respite vouchers when they have undergone a needs assessment. The vouchers can be used for residential care or for somewhere they can go together for a break.

Blackburn with Darwen carers service can also provide personal grants to support carers take part in activities they enjoy.

Recommendation

We asked Blackburn with Darwen Carers Service if they felt any improvements could be implemented. A recommendation was suggested that carers should be

entitled to a sitting in service -a minimum of 6 hours per week. This would enable the carer to get jobs done or have some self-care sessions while the cared for can remain in their own home with familiar surroundings.

Blackburn with Darwen Adult Learning

We met with the dementia specialist tutor for BwD Adult Learning. She gave us an insight to the work they provide. They provide dementia friends training, deliver activities in dementia cafes, attend care home settings providing free training for the staff and activities for the residents. They adapt sessions so that everyone can take part in activities including supporting those who have a later diagnosis of Dementia.

They do not tend to get residents who have a new diagnosis of dementia, the learners are generally moderate or progressive in terms of their dementia journey.

The adult learning team have been tasked to provide dementia friends training to all Blackburn with Darwen council staff to enable BwD to become a dementia friendly council.

Lasting power of attorney

A lasting power of attorney (LPA) is a legal document that nominates one or more people (usually family or close friends) to make decisions on behalf of a person with dementia if they lose the mental capacity to make these decisions themselves. There are two types: • health and welfare • property and financial affairs. It is important to register both types of LPA as soon as possible to ensure that the wishes of the person with dementia are respected in the future, and that decisions are made in their best interests.

One of the residents said, “There wasn’t much information around LPA, and I would have appreciated the information sooner so I could have got things in place before my wife deteriorated.”

We found family members wanted more information about LPAs at an earlier stage than they were informed. The feedback from focus groups was that they were not aware there was two types of LPA.

Recommendation

Information appears to be easily accessible around LPAs. We found that awareness to family members and carers at the earliest stage is the most beneficial so they can organise LPAs in a timely manner.

The Alzheimer’s Society have a useful toolkit on their website, this includes all relevant information of what you would need to know including a short video.

[Lasting power of attorney for people with dementia | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/information-and-support/lpa/)

Dementia support from East Lancashire Hospice

East Lancashire hospice supports patients with a dementia diagnosis through access to different services. They feel that patients with a dementia diagnosis benefit from being supported in their own home. Support is initially offered from the Hospice at Home team and Creative support therapy. These services aim to:

- Support the person to achieve a longer and higher quality of life by offering coordinated care
- Support the person to continue to be able to carry out daily activities, continue with normal daily routines and independence
- Provide a familiar environment for the person, to retain memories, enabling them to feel safe
- Enable familiar faces to be around for the person which reduces anxiety/distress from both carers and loved ones.
- Provide additional respite to family of residents attending the Cast service

Creative Support Therapy

Patients with a dementia diagnosis attend group sessions, giving respite support to the carer, whilst supporting the patient to engage in therapies to aid interaction, such as Music therapy, trip down memory lane and art therapy.

They also have a group where couples attend together, allowing conversations to flow. The aim of the group is to reduce isolation and encourage social interaction.

The hospice are firm believers that patients with a dementia diagnosis should be supported in their own home with familiar surroundings and smells.

We asked about the referral process and learnt that any health professional can make a referral. Mainly GPs and district nurses refer into the service but residents can also self-refer in early onstage and so can carers.





Dementia care for South Asian Heritage residents in Blackburn with Darwen



From our research, people from ethnic minority communities may be more likely to develop dementia than those from other backgrounds. This is due to a higher risk of heart disease, stroke and diabetes. These are all risk factors for dementia. This information led us to investigate what support offer is available for South Asian heritage residents of Blackburn with Darwen and if the support offer is being taken up.

We know that statistically there is an expectation of a large increase in diagnosis rates for people from ethnic minority backgrounds. This has been backed up by the following report - https://www.alzheimers.org.uk/sites/default/files/2021-09/ethnic_minorities_increasing_access_to_diagnosis.pdf

When we attended several focus groups with South Asian communities. The group discussions were quiet with not much discussion or feedback. This appeared largely due to lack of knowledge of dementia in general. Most residents in the focus groups did not know anyone with a dementia diagnosis.

When we spoke to residents who have supported a family member with dementia it was explained that they care for him as a family. "We all take turns in taking him out or doing activities with him." When we asked if they take him to supported dementia activity classes she said, "We can't take him to groups as people will talk about us as a family".

We asked the groups what they already know about dementia and how to obtain a dementia diagnosis-

"People within the community don't see dementia as an illness it's a mental health problem"

“There is a stigma around the term dementia in the Muslim community”

“Don’t want to be labelled”

“We get embarrassed by things too easily”

“In our community it feels like you are punished for having a problem”

“Does a hit on the head cause dementia?”

These were extremely powerful messages from the group, we felt a lot of education must be provided in the community to enable residents to converse more openly about dementia and what it is.

The groups we attended were interested about learning more about dementia, what the signs and symptoms are and how to prevent getting dementia. This led us to ask what could be done to educate the community?

“Put posters up in common places where you wait, in the butchers, post office, community centres, behind toilet doors ensuring they are in a range of different languages like Urdu, Gujarati and English.

The groups suggested a video to be created which can be shared through Whats App contacts and social media. They felt that a video should explain how to recognise early signs and what the symptoms are. They suggested a person living with dementia to be included in the video as well as people from the community and maybe an Imam. We asked if they thought a health care professional should be included to deliver some of the key messages and they said they would prefer people to be featured who they can relate to and who are familiar to them.

The Alzheimer’s society shared their figures for referrals last year in Blackburn with Darwen.

Last year 2022/23 full year stats where 174 referrals in total were 91% White British and 7.6% Asian/Asian British.

As a result of these figures the Alzheimer’s society reached out to the underserved communities. Two of the Dementia Advisers are of South Asian heritage and speak various languages. They have a team objective to connect with underrepresented groups and have been doing more awareness raising. They have conducted a radio interview with AWAZ radio station, they attended a health event at a mosque and connected with a South Asian ladies’ group. However all these things are located in Pennine Lancashire not specific to Blackburn with Darwen.

In general, the learning from attending these events has increased referrals from this current year (April to end of July) in Blackburn with Darwen as they have received 57 referrals, 82% report a white origin and 18% report Asian/Asian British origin which shows an encouraging increase in reach within the Asian community compared to last year’s stats.

These figures show by connecting with communities and carrying out promotion work increases residents' awareness.

As we have found during this project, groups and activities are limited within the borough for residents from South Asian heritage backgrounds we asked:-

What types of activities/groups would benefit people living with dementia if they were available in your area?

“Cooking classes”

“Pottery classes”

“Looking back at old photos”

“Drop in cafes, somewhere where we can socialise and share stories. Every month do different activities, always include food and drink. That’s always an incentive for people to attend”

Recommendation

In the Greater Manchester area, Alzheimer’s Society received funding to provide specific support for South Asian communities to deliver dementia advice and support within the communities and have a whole team recruited for this named the Sahara team (Sahara means support in Urdu). It would be wonderful if we could have a similar service in BwD, we feel that by having dedicated dementia advisors in these communities it will enable the dementia advisors to engage with residents in mosques, community groups and anywhere where they feel comfortable.

We recommend dementia cafes be created in areas of Blackburn, which have a large population of South Asian residents amongst it. This will enable a familiar place to visit and meet people and families living similar lifestyles and creates an opportunity to share stories, activities and discuss coping methods between families and carers. This would also enable a hub for the Age UK way finder service and the dementia advisors from the Alzheimer’s society to attend these sessions and provide support and information.



We discovered an area of improvement was to educate children and young people about the signs and symptoms of dementia. This will enable more families to be able to discuss dementia without the stigma of having a dementia diagnosis and receive the care they require.

We found a useful resource on the Alzheimer’s society website for teachers, it includes 2 - 3 lesson plans, teaching young people about dementia and encouraging them to take action in their communities. By completing all lessons, young people will become Dementia Friends and each student can get their free badge and a poster for their class.

Language Barriers



It has been reported that the memory assessment team has recently received numerous referrals and they have experienced an increase in the need for translation services.

We asked in the focus groups - “Language barriers can be difficult when accessing healthcare, how can this be improved?”

“Translators who understand the needs of the patient”

“Translators need to understand the problems the patient has, if they are hard of hearing then they need to adapt to their needs”

“I’ve had a translator for my auntie who suffers from schizophrenia and speaks Punjabi, the translator didn’t speak the same dialect as my auntie, she couldn’t understand what he was saying. She would have understood English better!”

“I have recently taken my mother to a hospital appointment where my mother used a translator. The translator said to me after the appointment “Your mum has got dementia, she kept forgetting and needed me to repeat everything” to which I replied that she hasn’t “When she is nervous, she needs to be reassured regularly on what they are telling her to make sure she fully understands”

“It made me feel uneasy on how my mum had been spoken to/treated whilst she was in their care.”

Recommendation

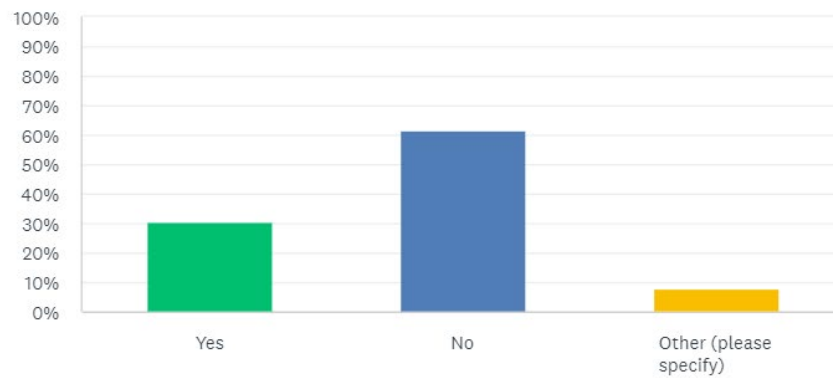
Patients should be able to access care services in a way that ensures their language and communication requirements do not prevent them receiving the same quality of healthcare as others. Ensuring translators are informed of patients’ needs is key. Organisations should also consider the use of interpreters with additional skills, knowledge or experience in relevant terminologies. Interpreters should ensure that they interpret for everyone in that appointment including the patient, parents or carers, any representative / chaperone and healthcare professionals.

Short survey around Dementia care for South Asian residents in Blackburn with Darwen

Short survey responses-

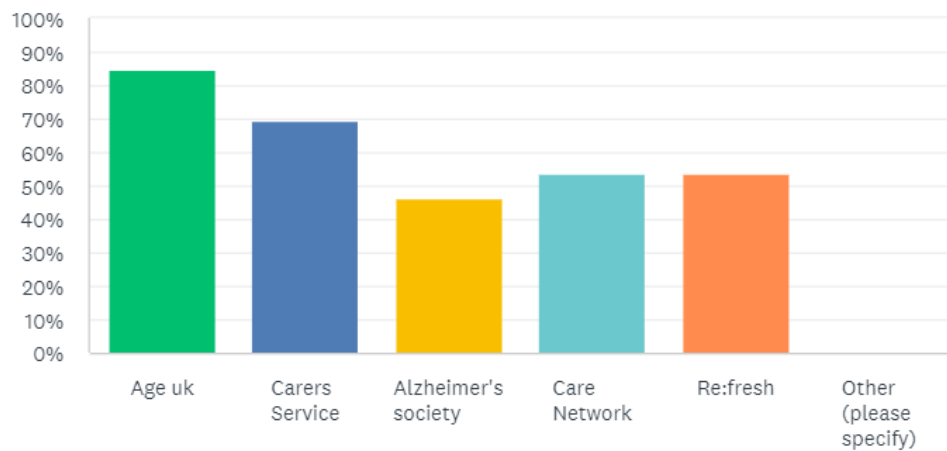
Do you have a family member with dementia?

Answered: 13 Skipped: 0



Please tick the boxes of the services you have heard of

Answered: 13 Skipped: 0



What types of activities would benefit people living with dementia if they were available in your neighbourhood?

Social

Support

Walking

Going out meeting similar people

Days out

Free yoga and Pilates for women only

Tea chat

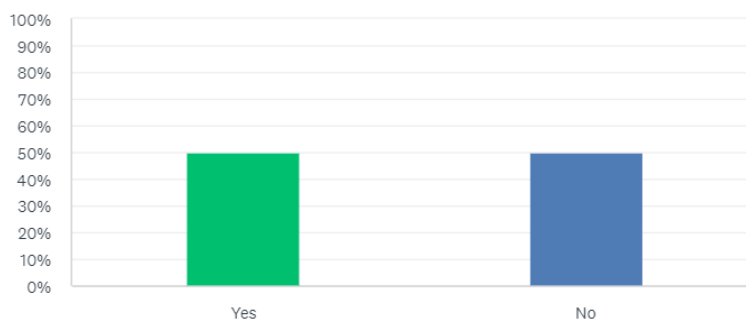
121 care

Dementia groups for specific groups e.g., Pakistani dementia group and they could look into the history of Pakistan, explore the nations music/food/language to help jog old memories but have this for different nationalities as well e.g., India, Poland etc

Music, groups

Do you feel there are barriers for individuals or families/carers in accessing support for dementia within your community?

Answered: 12 Skipped: 1



If yes, please tell us what you feel these barriers are

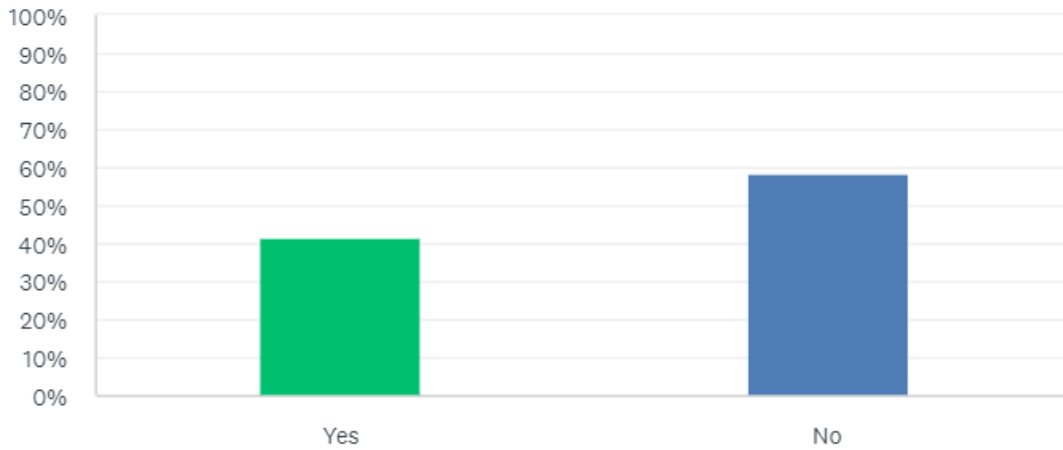
There isn't anything to help overcome dementia in our area

Lack of knowledge

Not talked about only at carers service

Language barriers, unable to leave the cared for

Do you and family members take up the annual NHS health check offered to 40-75 year olds via GPs and the Wellbeing Service?



If no, why not?

Did not know it was available

No availability

Don't know

Had a group session but not know about individual one