collaborative NEWCASTLE

Search Newcastle

Supporting older people in Newcastle

"Dementia, Navigating the Maze" Conference Report

6th September 2022

Contents

Introduction

The "Dementia, Navigating the Maze" conference was organised by Search Newcastle, drawing on their skills of engaging communities and reaching people who often don't have their voices heard. Search brought together a range of people who live with dementia, their carers and family members to meet with professionals and key organisations who offer dementia services and support across the city to discuss what is important to them and how their support needs should be met.
On the 6th September 2022, 89 people were present at the conference in the Moncur Suite at St James Park of which 39 were people either living with Dementia or Carers. Many professionals on the day also shared their personal experience of supporting family members who live with dementia.

The conference was funded by the CCG (Clinical Commissioning Group) now the ICB (Integrated Care Board) as part of Search's Post Diagnostic Support Service. The conference was facilitated by the Chief Officer and Chairperson from Search, with Speakers from the CCG, Newcastle City Council, The Alzheimer's Society, Northumbria and Newcastle Universities. The local BBC news reporters were present and the conference featured on the local BBC news that evening and the following morning, highlighting the experiences of 2 carers who were interviewed. Search Trustees and staff with support from some key staff members of Alzheimer's Society welcomed everyone to the conference, registered their arrival and guided them to their seats for lunch.

The conference opening address was given by Councillor Kilgour who set the scene locally, this was followed by some fascinating speakers whose presentations whetted the appetite for the interesting round table discussions. This gave those living with dementia and their carers a platform to have their voice heard by professionals and an opportunity to influence the Newcastle Dementia Strategy.

Background

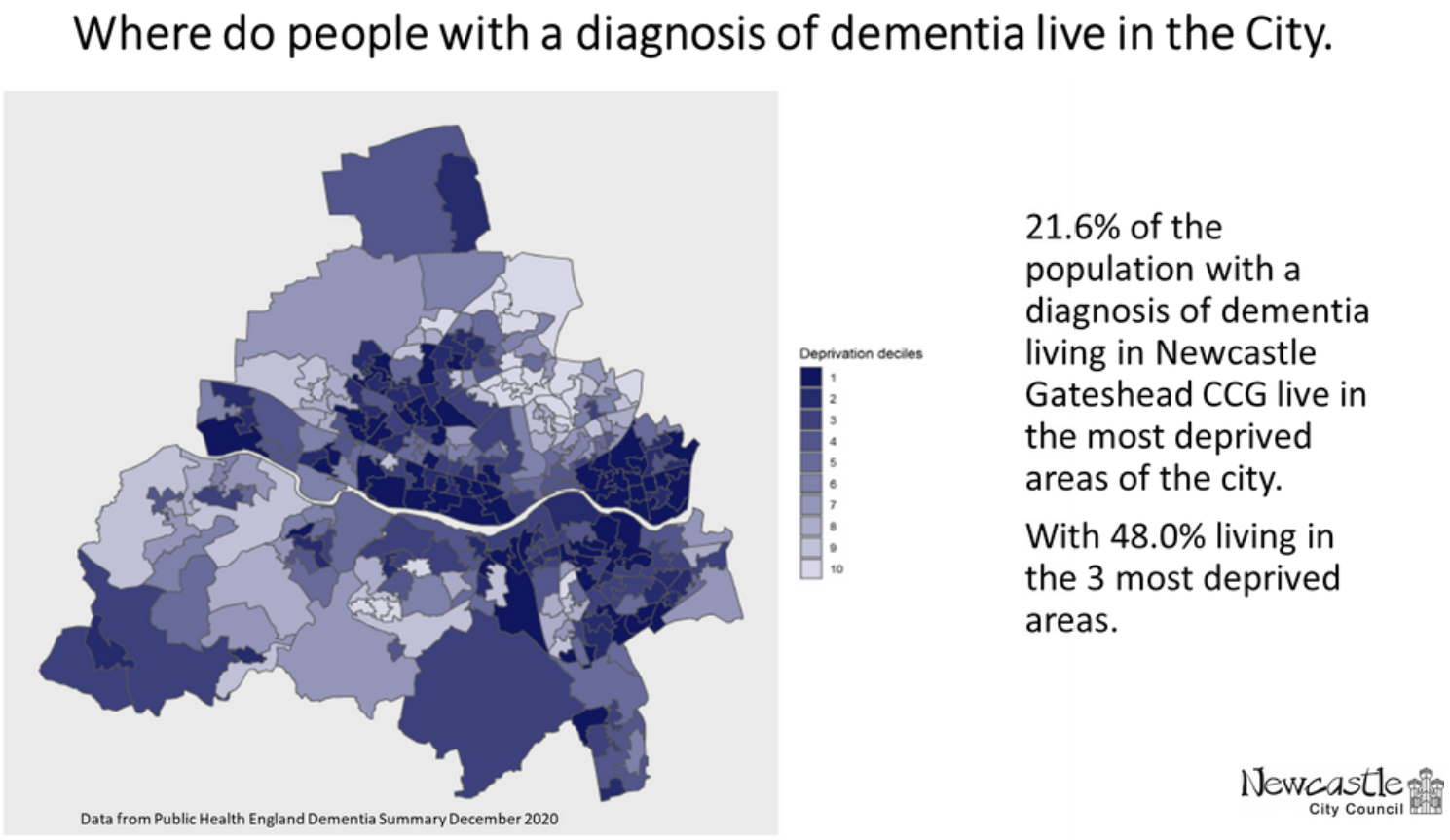
December 2021 - the publication of 'People at the Heart of Care' white paper which sets out the government's strategy for a 10 year vision for Adult Social Care. We are awaiting the addendum which is a specific strategy for dementia which will follow on from the Prime Minister's Challenge 2015 – 2020.

Figures

Secretary of State recently said by 2025, 1 million people in the UK are expected to have dementia and is expected to rise to 1.6 million by 2040.

In Newcastle we have approximately 3750 people living with dementia over 65 and 152 under 65 (Public Health England 2020). We also know there has been a dip of diagnosis due to the pandemic and we also recognise not everyone living with dementia has a diagnosis, so we know these numbers are underestimated.

The image below highlights where people with dementia live in the city and the level of deprivation.



Conference programme

Welcome- Simon Luddington and Jen Bell

Presentation by Councillor Kilgour- Newcastle City Council's commitment to support people living with dementia and their carers.

Presentation by Beth Jones- Newcastle Dementia Strategy and how we can be involved in shaping it.

Presentation by Kathleen Dickinson and Penny Easton- Dementia Friendly Communities, what Search and the Alzheimer's Society are doing in the city.

Facilitated round table discussions

- What would you like to see in the Newcastle Dementia Strategy?
- What makes a Dementia Friendly Community?

Presentation by Dr Alison Killen- living well and prevention.

Presentation by Dr Frank Lai- Research around how caring responsibilities might impact carers.

Facilitated round table discussion

- How can we Raise awareness and encourage involvement in research?
- How can we support sharing knowledge around prevention and living well?

Conference findings

What makes a dementia friendly community

· Local businesses and services being aware of dementia friendly ways of working
· Access to in person and telephone services – too much online!
· Dementia symbols/lanyards to recognise when people need extra support
· Locations of services to help should be accessible
· Education and training on awareness for all – Starting in schools
· Recognising the person and their skills before dementia
· Encouraging tolerance and understanding
· Local Hubs- North, East and West – Spaces to go when and where
· More human interaction- Less technology
· Slow Shopping- dementia friendly
· Preventing change to services and bus routes
· Don't start the bus until everyone is seated
· Importance of local dementia friendly groups and spaces which are easy to reach- buildings without stigma
· Buses to announce stops (Like the Metro does)
· Clear information in the community
· Holistic approach for people with dementia and other conditions (Don't treat in isolation)
· Organisations working together
· Day opportunities that are dementia specific and welcome carers
· Help to navigate, with support and clear information
· No geographical boundaries – Regions working together
· Good social spaces
· Services for carer respite (Sitting Services etc)
· Meaningful activities and occupation through the day
· Social activities that are dementia specific, but also mainstream activities being dementia friendly
· GP's better informed about what is available and sharing that information
· CAV/Memory Clinic giving clear advice about "In between" periods of diagnosis etc, not just left with a leaflet
· Tailored individual plans and guidance, what you can expect for the future
· People talk to us, give leaflets, but it doesn't help
· More than sign posting to services- introductions and face to face support
· Admiral Nurse- or Dementia Champions
· Dementia services, befrienders, gender neutral activities, and groups
· Invest to keep people independent and support carers
· Befrienders

What would you like to see in the Dementia Strategy

· Quick diagnosis (Online screening)
· Admiral Nurse- Dementia and older people's champions
· Support navigating services
· Places to feel useful and enjoy yourself- forget your worries
· Training for everyone staff, security, carers
· Seeing beyond the top layer – beyond dementia
· Dementia Friendly Community awards/incentives
· Prevention and Healthy Ageing centres
· After diagnosis support and a contact person
· Inclusion (all communities, faiths, languages)
· Don't keep changing what there is, build on it
· Advice points or hubs that are discreet
· Easy read information that is not online
· Preparation for what to expect as symptoms worsen
· Less reliance on online services
· Longer term funding – too much comes and goes
· Support right from the start
· Support for cognitive and physical complications
· Dementia specific Occupational Therapist
· Include faith groups in reminiscence activities
· Central hubs time and place to go very clearly advertised
· Carers services easy to access
· More community support – not all about medical services
· Opportunities to stimulate and prevent need for care homes
· Quick access to financial assessment when needing help with Support
· Hubs in the 3 localities of Newcastle
· Information and training for carers
· More funding for community groups
· Yearly check ups health and mind
· This is Me, should be used (Alzheimer's Society support tool)
· Planning and reassurance for the next pandemic
· Cognitive impairment support

Raising awareness of involvement in research

· Break down the fear of research
· Research doesn't mean taking medication
· Lose the university speak
· Feedback from research explained clearly and what it will be used for
· Professionals listen and not assume
· Additions to donor card for medical research after death
· Take away myths about research
· Use layman's terms
· Recognise and reward participation
· Research done with and not to
· Social media
· Reduce appointments needed and make it easier to engage
· Go to the person don't expect them to come to you
· Make it simple to sign up
· GP to offer research opportunities
· Pay people and acknowledge their time
· Make it simple to sign up
· Involve everyone
· Advertise on buses, television and newspapers
· Transport provided or covered

Sharing and supporting prevention

· Lots of community support and groups to help
· Carers shown good practice/training
· Carers sharing experience and good practice
· Public Health announcements like "stop smoking"
· Give it publicity like 5 a day… only 3 steps a day for dementia
· Early education for everyone, start in schools
· More networking events and conferences
· Awareness at events like Pride, Mela, themed football matches
· Use existing networks build on what we have
· Community Champions
· Work with public bodies- city life magazine and newsletters
· Information in GP's, Dentist and Pharmacy
· Be realistic- gradual changes

Informing the Dementia Strategy

The round table discussions were valuable and have provided insight into what those living with dementia, their carers and wider community want to see in the Dementia Strategy in Newcastle. The strategy will cover five main points for consideration; prevention, diagnosis, information and advice, living well and end of life. For a clearer image of what this might look like we have separated the information collected from the table discussions into these five categories.

Prevention

- Clear easy to read information in the community (not online) about prevention of dementia
- Healthy ageing centres
- Public health announcements like "stop smoking"
- Publicity like 5 a day but 3 steps a day to prevent dementia
- Early education for all
- Place prevention materials in GP surgeries, dentists and pharmacies
- Awareness at events like Pride, Mela, themed football matches
- Raise awareness of the importance of research and research involvement in prevention
- More networking events and conferences
- Information in local magazines and newsletters

Diagnosis

- Quick diagnosis
- Campus for Ageing and Vitality/Memory clinic to give clear advice about what support is available in between periods of diagnosis and not only left with a leaflet
- GP's better informed about what is available and sharing information
- More support than just signposting needed, introduction to services face to face after diagnosis
- Use laymans terms
- Help to navigate services
- Admiral Nurse or appointed dementia worker
- One main point of contact after diagnosis
- Tailored individual plans

Advice and information

- Access to in person and telephone services as online is difficult to access for some
- Education and awareness for all
- Clear information in the community
- Dementia Champions
- Advice hubs

Living Well

- Local businesses and services being aware of dementia friendly ways of working
- Dementia symbols/lanyard to recognise when people need extra support
- Locations of services should be accessible
- Recognising the individual and their skills before the dementia diagnosis
- Slow shopping
- Prevent changes to services and bus routes
- Buses to wait until everyone is seated before driving and to announce stops
- Local dementia friendly groups and spaces that are easy to access
- Meaningful activities and occupation
- Places to feel useful and enjoy yourself
- Include faith groups in reminiscence activities
- More community support
- Day services that welcome carers
- Services for carer respite (sitting services)
- Holistic approach for people with dementia and other conditions (do not treat conditions in isolation)
- Yearly check-ups for physical health and mind
- Organisations working together
- Individual plans and resources such as 'This is me'
- Befriending
- Invest to keep people independent for as long as possible and more support for carers
- Admiral Nurse and Dementia Champions
- Longer term funding, too many services come and go

- Don't keep changing what is there, build on it
- More funding for community groups
- Planning and reassurance for the next possible pandemic
- Hubs in the three localities of Newcastle
- Dementia specific Occupational Therapist
- Carers shown good practice and training
- Transport to groups provided

End of life

- Tailored plans
- Information on what to expect for the future
- Admiral Nurse
- Community support groups
- Preparation and planning for when symptoms worsen
- Support and training for carers

Next steps

We will use all the information gathered from the Dementia Conference to help shape the Dementia Strategy for Newcastle, once the Dementia Strategy is drafted we would like to hold another event for those living with dementia to have their say once again, it is important the strategy is shaped by those living with dementia. This report will also be shared with other organisations to allow them to see what people living with dementia and their carers want and need, allowing them to make changes or improvements to their service. Here at Search we will continue to develop our dementia friendly offers prioritising the points raised at the conference, specifically dementia friendly spaces where people can access advice and information, join meaningful activities and feel well supported. We will continue to develop networks with other services so that the journey between organisations is as seamless as possible.

Summary

This conference was very powerful in bringing together the voices of people living with dementia and those whose lives have been touched by dementia, to talk openly about the challenges that are faced everyday if you have memory concerns, are living with dementia, or supporting and caring for someone who has dementia. By listening and learning from the lived experience, which was shared so openly in the conference, we can now begin to understand the challenges and set about putting a Dementia Strategy in place that will work for everyone.

We heard how important it was to have somewhere to go, where you could talk to someone and say "I am worried, my memory is not what it was" leading to accessing an early diagnosis, but their GP was probably not the person they would initially confide in. People told us about the despair they felt not having someone on their journey to help them navigate systems and guide them while they await a diagnosis and to help them in the first weeks and months when they come to terms with a diagnosis.

It was evident that the availability of education and training for people to have a basic understanding of dementia and be able recognise when someone might need a little extra help, starting with unpaid carers but including customer facing staff, such as security guards, bus and taxi drivers and domestic staff, would make a big difference in helping people continue to enjoy life and have more independence.

People told us how important it was to continue to do "normal things" like go to the bowls club, how they worried about having to access buildings of a formal nature and daycentres while they still felt they could manage their life. People told us that accessing discrete support like the former "Dementia Advice Centre" which used to be based in West Denton library felt comfortable. We heard how much people value informal places to go, where people living with dementia and their carers could gather and support each other and not feel they are alone on their journey but having advice and information on hand was comforting when you needed it. People stressed the importance of local, neighbourhood spaces and services without labels early in their diagnosis, but they recognised that this changes as they go along their journey. Carers and family members expressed how they valued being able to pick up the phone and talk through what they should be doing for their loved one or being reassured what they were doing was right.

People also told us that having access to the correct entitlements, benefits and allowances enabled a much better quality of life, freedom to get about and buy in the support they needed. Having advice on wills and last power of attorney gave people peace of mind. Carer respite, equipped Day Service provision and reliable care provision for people later on in their diagnosis is vital, not only for the person living with Dementia but for the unpaid carer's peace of mind too.

We heard about the life of carers after the person they had cared for had gone into a home or was sadly no longer with us and how vital it is that the support network they have relied on during their time as carer is not taken away because their role ends, but how their experience could be harnessed to help other people while making the carer still feel valued.

Feedback from the conference

Excellent afternoon and useful presentation on prevention and living well and dementia friendly communities

The round table discussions were very helpful, and the presentations helped to understand further

All the presentations were informative and interesting and I will use all information given, very inspiring

Interesting afternoon, a lovely opportunity to hear all that is going on and find out more information

The presentations were all different, interesting and the right length

Great venue, food and presentations, an enjoyable and informative day

The day was a great opportunity to speak with professionals but also others in similar situations

It was nice to have our experiences heard and to also find out more about what is happening in Newcastle for people living with dementia