

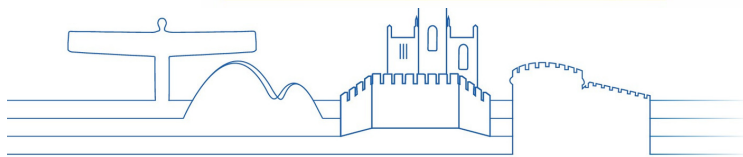


Search Newcastle

Supporting older people in Newcastle



North East and
North Cumbria



Dementia Conference Report 2023

17th May 2023

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Introduction

This report is from the second Dementia Conference, facilitated by Search in partnership and funded by Northeast and North Cumbria Integrated Care Board (ICB), the first was held in September 2022.

Over 100 invites went out to people living with Dementia, their carers and professionals.

This conference had a range of speakers on subjects which the delegates of the previous conference requested more information on. We were particularly delighted to have the findings of the PriDem project presented at this conference.

The round table discussions were an opportunity to reflect on the draft Dementia Strategy and directly influence further development of the strategy, while giving people living dementia and their carers the opportunity to talk to a range of professionals and organisations from across the city.



Conference program

Welcome - Simon Luddington and Jen Bell.

Presentation by Rachel Watson - Update on the PriDem project.

Presentation by Frank Lai - Health and its determinants in the spousal caregivers of a dementia partner.

Presentation by Beth Jones - Dementia strategy.

Facilitated round table discussions.

Presentation by Carers Centre - Newcastle Carers.

Presentation by Glenda Devlin - Peggi.

Presentation by Beth Jones - Dementia strategy.

Facilitated round table discussions.

Close - Simon Luddington and Jen Bell.



Informing the Dementia Strategy

What you told us



Prevention

- Produce newsletters that meet the needs of diverse communities, who may not be as involved in current dementia services on offer.
- Fill the gaps between services and communities to reach everyone.
- Raise awareness and address language barriers.
- Digital inclusion, more electronic provisions.
- Information needs to be simple and basic.
- More information around preventions.
- More research.
- Better mental wellbeing from physical activity, walks, swimming etc - issues as facilities have closed.
- Promoting the benefits of mental health.
- Socialising - not being socially isolated due to lack of activities.
- Brain health - how to access the information.
- Raise awareness via campaigns / tv and radio adverts.
- Knowing the signs of dementia early on rather than later down the line.
- Preventative messages that also educate children - make the signs recognisable from an early age.
- Do people know the risk factors of dementia?
- Challenge stigma and fear of diagnosis.

Diagnosis

- Only certain communities know support is available and how to access this, especially without a professional referral.
- Avoid seeking external help as the diagnosis is scary - care is not tailor-made for all communities.
- Fears that once there is intervention it is out of caregivers/ family's control.
- Need providers to go out to the community- provide support in homes and communities.
- Fear of social services involvement.

- Nature of the disease might make people more resistant to seek help.
- Young caregivers make face specific challenges/ gender of care givers.
- If the caregiver is the sole caregiver, it would be very difficult if additional support was needed or can not provide care.
- Caregiving is very difficult, and you never stop, could spiral out of control if alone.
- Listen to the family.
- It is difficult to know when to screen with technology as some people want a diagnosis and some do not.
- GP's to be onboard to listening to the full family and input about the person.
- More research and information.
- Early diagnosis – being believed by medial professionals.
- Where do you get guidance? – better signposting.
- Accurate information – we all get memory loss, we need to be able to read the signs.
- Prompts from others – awareness raised.
- Early diagnosis – pressure on GP's, temptation to go private.
- Most people don't know what is available to help/support.
- Experienced no support for ages. Still waiting on a social care assessment since last summer.
- Gap in pre-diagnostic services. NUFC Café
- Search
- No clear pathway.
- Some voluntary support but not enough capacity.
- Need for pre and post diagnostic assessment.
- Risk checkers/ check list.



Support

- Services have shrunk.
- Don't know who to go to – even health services might not know where to signpost.
- Are there charities that can support?
- Knowledge of support must be widely available.
- GP' should be asking caregivers if they need support.

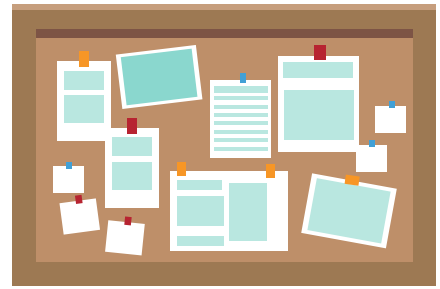
- Service provision inconsistent, even across the city.
- Support needs to be available offline.
- Used to be able to go to a physical space and ask for help.
- Even if GP 's would be good to hold information, cant get appointments or only 10 minutes.
- Funding inconsistency is disruptive.
- Lack of human touch in GP's.
- In the past when referred to social services you developed relationships with the social worker over time, now new people/ no consistency with social work team.
- Need updated information on a regular basis and for it to be distributed to communities.
- Make sure access is free and available.
- Currently charities are having to pick up a lot of this work as health services have become fragmented.
- A nurse in the GP's practice who specialises in Dementia (Not social prescriber).
- A tailored package of care.
- Understanding medical, mental, social/emotional care is linked.
- Continuity with the same medical professional, not having to explain the situation repeatedly.
- More research and information.
- Support before diagnosis.
- Care should be integrated – one stop shop.



Advice and Information

- TV Soaps – Emmerdale etc. (These can be sources of information)
- TV Personalities – Barbra Windsor etc (These can be sources of information)
- Sports Personalities – Footballers etc (These can be sources of information)
- More research and information.
- User friendly – needs to be understandable.
- Personal contact is becoming less frequent.
- In community settings.
- Reassuring and not alarming constructive support.
- Reducing stigma and accessible information.
- Effective communication.

- Notice boards.
- Education.
- Information in libraries.
- Voluntary organisation in the community.
- Knowledge of support is poor.
- Toilet doors - clear signage.
- A large % of carers don't know what is out there to access for the support.
- Sometimes can be an information overload.
- A level of support to meet individuals needs at the time they need it.
- One person to talk it through works – person centred. Care in one place and not all over the city.
- Need more 1:1 support available for people.
- Just providing contact details is not enough.
- Forward with dementia website.
- Need for good signposting.
- Need for 1:1 support – different formats than just online.
- Person centred approach.
- Diagnosis is flagged to GP's receptionist so they can be supportive.
- Importance of hearing checks.
- Need to know signs, hidden not something you can see. Symptoms, changes that could occur.
- Worrying/ scary sleeping.
- Car parking – pay on app as to not have to worry about using coins.
- Feeling like the family are being left to deal with the disease alone and without support.
- Simple information to file and refer back to.
- Helpline.
- Training and development for all staff across all sectors.
- Newcastle councils website is hard to navigate.



Living Well

- Search groups
- Carers supported to have a social life, looking after oneself and eating well.
- Need good public transport.
- Bus passes.
- Letting people know what is available – paper copies not just online.
- Leisure Centres – daily rates, not just on annual passes.
- Charities to have groups closer to home.
- Participate in research.
- Voice North – not much since lockdown.
- Know the age cut off for research?
- Loss of driving licence was really hard + limits activities.
- Issues with the caregiver receiving the care they need as they can't leave the person with dementia home alone for long periods of time or at all.
- Activities that aren't restricted by postcode.
- Reduced barriers for carers and dementia patients.
- Consistency of services.
- Reducing travel to groups by having more diverse groups in all areas.
- Support groups for younger people diagnosed with dementia.
- Easily accessible transport.
- More diverse groups to reflect people hobbies.
- Social workers have a lack of dementia knowledge.
- Lack of time and capacity for organisations.
- Get involved with research.
- Misconceptions of what research involves – lack of knowledge.
- Vulnerability as a career.
- Cultural difference of how family members are looked after.
- Barriers – money/ funding/free at point of delivery – refreshments and venues.
- Opportunities to share experiences, talk, safe space, put down burden for the time.
- Understand family dynamics.
- Different locations – offer different opportunities.
- Social disengagement – don't want to leave house, intimidated by the community.



- Access to activities needs more development – more link workers connected and informed. Better access to mini hubs.
- More resources/ activities for carers only to support each other.
- More people would be open to taking part in research, dementia affects families on a wide scale.
- Barriers for carers who feel it is their duty.
- Lots of family support.
- Limited wheelchair access in the local area/ transport.
- Dementia friendly hairdressers/ post office etc.
- Just get on with it attitude – pride, accepting support and care.
- Dementia friends.
- Give the community a better understanding of how to talk to someone with dementia.
- Enjoy life – get out and about.
- Adaptations and managing risks.
- GP trackers.
- Promoting independence.
- Positive risk taking – simplify the problems.
- Good communication.
- Losing coin payment and reduced parking drives people out of the town centre.



End Of Life

- Lasting power of attorney – awareness of how important this is.
- Loss of caregiving role – everything stopping, especially if they have no family.
- Carers – joined all groups, support while people need it.
- When end of life a care plan should include how carers will be supported – what their needs are.
- Carers still attend some support groups – have developed some real friendships.
- Carers can feel abandoned.
- Lasting power of attorney is slow, dementia is a time sensitive condition and the delay of this can cause huge issues in the lives of the caregiver and the person living with Dementia. .
- Making people aware of health Lasting power of attorney, not just financial.
- Bereavement support needed for carers/ families.
- Ensure there is support for a period of time after the death of their loved one.

- Early discussion is vital.
- Fear of raising a sensitive topic.
- Advanced care planning.
- Professionals will instigate – but frequently brushed off, don't want to talk about it.
- Some have specific requests.
- What happens when the caregiver becomes ill?
- What happens if the caregiver has an emergency?
- Duty bound – married for life, don't want "outsiders" help.
- Referrals can take so long – circumstances can change.
- Services for mediation – to help with any tensions.
- Streamlined information pack with information for all stages of dementia.
- Emphasis on support provided around end of life so that families/ carers feel more prepared.
- No care plan in place.
- LPA – no knowledge of how to organise this, too expensive.
- Difficult to discuss.
- LPA – a relief when it was done.
- Carers – "we still have a future ahead of us".
- Language can be ambiguous and distressing.
- Fear of pain as opposed to dying.



Next steps

The rich information provided directly through discussion in round table discussions will be shared with decision makers and used to influence further development of the draft Dementia Strategy.

The information is presented in this report and the report will be shared widely among professionals and organisations who work with people living with dementia to shape and improve services. The report will influence the work of the Dementia Partnership (a broad range of professionals, organisations and stakeholders who are working on the Dementia Strategy).

Search along with other organisations across the city will use the information provided by people living with Dementia to shape, inform and improve their work to ensure that they remain Person Centred and meet the needs of the people they serve.



Summary of findings

There was a lot of information shared so openly in the conference, below we have summarised the key themes coming from the report into headings.

Information – having the correct information at the correct time, in a format that people understand whether that is easy read, in a native language, in paper form or online is important. Continuing to receive up to date information and understanding the different stages of Dementia from pre -diagnosis through to end of life is also important and will reduce anxiety for all involved. A file of information to refer to was a suggested solution, as well as information being available in public spaces such as libraries and noticeboards to encourage people to seek early help.



Digital - while some people have a preference for online and digital services and information for many people this is not accessible, presents barriers and can contribute to the feeling of stress and abandonment. Digital should not be the only format in which information is provided.

Transport – Good transport links and services, accessible parking is vital to living well with dementia, changing of bus routes, times cause anxiety and stress and often contribute to isolation and disengagement. While some people embraced parking apps others found them difficult and shifting away from cash for parking would mean they could no longer enjoy facilities particularly Newcastle City Centre.



Services – There was a general feeling that the availability of services had shrunk, it was unequal across the city and felt like a post code lottery. Having one person to contact for information, help and support was essential to living well with Dementia and was a big support for caregivers along with Continuity of support and sufficient capacity for organisations to deal with enquiries timely was important and reassuring. Having services based in local communities as a “one stop shop” would be the ideal.

Activities – People told us the ability to engage in community-based activities for general health, fitness, wellbeing as well as being able to socialise and enjoy hobbies was important to live well. These activities should be local reducing the need to travel and be welcoming to diverse communities.



Research – There was an overwhelming interest in research both in taking part and understanding the findings. People were keen to have the misconceptions around research addressed, know how to take part, and wanted these opportunities more widely known.

Support – People expressed that there was still a lot of learning needed around dementia with professionals such as GPs, GP Receptionists and Social Workers. Flags on systems that highlighted a person was living with Dementia or caring for someone living with dementia might help them to show more understanding and empathy.



Lasting Power of Attorney– This was highlighted as an important step to take and big relief to know it was dealt with, cost was highlighted as barrier but many people felt that information on this should be more readily available.

Caregivers – Acknowledging the role that informal caregivers provide and having contingency plans in place should that caregiver have a health problem or personal crisis will give peace of mind. Acknowledging that after the loss of their loved one they will need support with bereavement and transition, services shouldn't stop when the person living with Dementia passes away or goes into a care home.



Feedback from the conference

Great event. Very informative. It is good to know there is lots of help and support out there to reduce or manage dementia.

Search is a trailblazer in raising awareness about dementia. Wonderful range of activities.

Very informative and interesting discussions. Well organised. Thank you.

I really enjoyed the round table discussions.

Had a really informative day, really enjoyed the discussions.

Lovely range of speakers. Round table discussions very engaging and great to be connecting with people impacted by the strategy.

Enjoyed everything very much.

A very informative event. Thank you.