South Tyneside Dementia Engagement Report

1. Introduction

This report outlines the outcomes of recent dementia engagement initiatives, including a community “Dementia Dance” held on 2nd June at St. Matthew's Church Hall in South Tyneside, and a dedicated weekend social event aimed at capturing feedback from those unable to attend the initial session. It presents key themes that emerged from the engagement, strategic recommendations, and proposed next steps in the co-development of a future-ready dementia care model.

These engagement activities form a core part of our commitment to co-designing an integrated, evidence-based dementia care model shaped by the lived experiences of older adults, people living with dementia, and their carers.

Findings from the engagement highlight several systemic challenges, including:

- Significant gaps in post-diagnostic support
- Fragmentation across services and care pathways
- Duplication of information shared between professionals and services
- A lack of carer recognition and support
- Insufficient understanding and awareness of dementia, particularly in the early stages

This feedback provides an opportunity to review the overall dementia care model — not just the proposed changes — to ensure it effectively responds to the challenges and priorities identified through engagement. By building on this input, we aim to shape a sustainable, person-centred dementia offer for South Tyneside, aligned with the wider ambitions of integrated care.

2. Engagement Objectives

We recently delivered two dementia-focused community engagement events. The first was a Dedicated Afternoon Dance, created to bring together individuals living with dementia, their carers, and local stakeholders in a welcoming and supportive environment. In addition, we conducted visits to existing social events and hosted a dedicated weekend session.

These engagements provided valuable opportunities to share and test a proposed care model, with the overarching aim of co-producing a service that truly reflects the lived experiences, aspirations, and priorities of people with dementia and those who care for them.

The events combined structure with informality, creating a welcoming and interactive space for meaningful dialogue. A range of inclusive engagement methods enabled participants to contribute in ways that felt natural and accessible. The insights gathered provided valuable intelligence that is now informing the development of a more person-centred, future-ready approach to dementia care across South Tyneside.

The engagement sessions aimed to:

- Present a draft dementia care model for community feedback.
- Gather insights into the lived experience of dementia care in South Tyneside.
- Co-produce "I Statements" that articulate service users' priorities.
- Create an inclusive, respectful space that empowers participants through creative and conversational methods.

3. Methodology

A dementia-friendly, interactive engagement format was purposefully designed to create an inclusive environment that respected the varying needs of participants. Structured activities were blended with informal moments to promote comfort, spontaneity, and authentic conversation. These included:

- **The Memory Lane Wall** – encouraging reminiscence through visual storytelling
- **Chat Tables** – guided small-group discussions around key wellbeing themes
- **Creative Feedback Stations** – such as the “I Feel…” area and Proposal Corner
- **Group Activities** – including games like Bingo to stimulate engagement
- **The Feedback Tree** – capturing future hopes and aspirations in a symbolic display

Facilitators employed flexible communication techniques, visual aids, and sensory prompts to ensure accessibility for individuals at different stages of dementia. The atmosphere throughout the day was vibrant and welcoming, marked by meaningful conversations, shared laughter, and music-led movement.

Special thanks go to Grahame Cassidy, who served as an engaging and attentive director of ceremonies—keeping the event on track while ensuring everyone remained involved and uplifted.

The combination of formal and informal interactions yielded a wealth of community insight, which has been thematically analysed in the following section.

4. Thematic Feedback Summary

Insights were categorised into the following priority themes:

i. Gaps in Post-Diagnostic Support

- Many individuals described the post-diagnosis journey as fragmented and poorly supported.
- Practical information was often front-loaded but lacked follow-through or tailored communication for people with dementia themselves.
- A “link person” or navigator role was repeatedly suggested to support individuals and carers through early-stage decisions and service navigation.

ii. Fragmented Service Delivery and Communication

- Carers expressed frustration with disjointed systems, unclear roles, and inconsistent professional engagement.
- The lack of cross-service integration (e.g., GPs unaware of diagnoses made elsewhere) emerged as a safety risk and stressor.
- Lack of clarity in relation to who does what and who to turn to – especially after the initial discussions post diagnosis - this included who is monitoring medication – how do we get support if they have physically deteriorating and well as presenting with dementia - felt like there was a gap – passed between PH services and MH services
- Carers needs were not always identified nor catered for. The expectation was that as a career you would have to beg for support which makes it hard to seek it out. One carer spoke of being forgotten and or losing that connection with their husband.

iii. Social Connection and Meaningful Activities

- Participants deeply valued opportunities for socialisation, activity, and belonging.
- The Making Memories group and ACTS staff received particular praise for their role in fostering safety, engagement, and joy.
- There is clear appetite for expanded day services and accessible activities across the week.

iv. **Recognition and Support for Carers**

- Carers are often navigating support systems independently, experiencing emotional fatigue, role strain, and inadequate recognition.
- Despite their vital role, some carers reported being treated dismissively or paternalistically by professionals.

v. **Transport and Accessibility**

- Cost, availability, and accessibility of transport were recurring concerns, particularly in relation to group attendance and appointments.
- Suggestions included subsidised transport options and increased availability of dementia-accessible buses.

vi. **Emotional and Practical Impact of Diagnosis**

- The emotional shock of diagnosis and uncertainty about “what next” were prominent.
- Feedback highlighted the importance of delivering information at the right time, in the right way, and through trusted relationships.

vii. **Financial Barriers and Health Inequality**

- Parking and travel costs were cited as barriers to attending services.
- A few individuals questioned how dementia-related services are funded and expressed concerns about the use of public funds for non-frontline expenses.

While much of the engagement work identified areas for improvement, it is important to acknowledge the significant positive feedback received about current dementia service provision. Many participants spoke highly of the dementia day centre, describing it as a safe and welcoming space where their loved ones could enjoy socialising, engaging in stimulating activities, and benefiting from the care of dedicated staff. For carers, this provision was invaluable, offering regular opportunities for respite—sometimes on multiple days each week—which helped them sustain their own wellbeing.

The Admiral Nurse Service was also singled out for praise, with families emphasising the expertise, compassion, and practical support it provided. One participant shared that they would have been “lost” without the guidance they received from the service, which helped them navigate the challenges of caring for a loved one with dementia.

In terms of diagnosis, most felt the process of visiting their GP and being referred to the memory clinic was relatively straightforward and that waiting times were not excessively long. Additionally, the ACTS groups were repeatedly described as transformative. Attendees reported feeling more supported, better informed about services and resources, and more connected to others in similar situations. The peer support and friendships formed within these groups were seen as deeply valuable—one woman shared that she had felt “very lonely and lost” before joining, and that ACTS had given her a renewed sense of belonging and hope.

5. Key "I Statements" from Participants

These co-produced statements reflect the values and expectations of the community:

- *“I want health and care staff to understand me, not just my condition.”*
- *“I want services that talk to each other, so I don’t have to repeat myself.”*
- *“I want more support after diagnosis – not just a leaflet.”*
- *“I want to feel safe letting others care for my dad, without guilt.”*
- *“I want to keep dancing and being active – not just wait around.”*

6. Impact on Future Model

The feedback and insights gathered during the engagement sessions will play a central role in shaping the continued development of the dementia care model. By actively incorporating the voices of those with lived experience such as, older adults, people living with dementia, carers, professionals, and the wider community — we are ensuring that the model genuinely reflects the priorities, concerns, and suggestions expressed by the public. In fact, one of the clearest demonstrations of our commitment to listening is that many of the proposed elements in the revised model directly mirror what people told us they wanted. Building on this, we are enhancing the model further to ensure it is resilient and adaptable, so it can meet the evolving needs and changing demographics of our population both now and in the years to come.

7. Next Steps

We will:

- Thematically code all feedback for inclusion in service development planning.
- Review and revise the draft care model based on this input.
- Implement a transparent "You Said, We Did" loop, sharing how community insights shaped the proposal.

8. Conclusion

This engagement has reaffirmed the need for a person-centred, connected, and compassionate dementia support system in South Tyneside. By listening to those with lived experience, we are building a care model that not only meets clinical needs but reflects real lives, aspirations, and dignity.