

Dementia Together Co-Production Group

Minutes of Meeting – 23 April 2026

10:00am–12:00pm, Hybrid meeting (Council House, Derby + Microsoft Teams)

Co-Chairs: Phil Wall (PW) & Wendy Burton (WB)

In Attendance

Wendy Burton (Co-Chair)

Phil Wall (Derbyshire County Council, co-chair)

Vicki Baker (Alzheimer's Society & minute taker)

Andrew Wilson (Derby City Council)

Claire Biernacki (Dementia Programme Lead, Derbyshire Healthcare NHS Foundation Trust)

4 x Individuals with lived experience

1. Welcome and Introductions

PW opened the meeting and welcomed those attending both in person and online.

Introductions were made around the group.

PW explained that the main focus of this meeting was the first-year review of the Derby and Derbyshire Dementia Strategy, with time set aside to reflect on what has worked so far and to help shape priorities for year two

2. Review of Minutes and Actions from February Meeting

PW summarised key developments since the February meeting.

The group's new logo has now been agreed and is being used on refreshed promotional materials.

A new digital leaflet and a short newsletter have been created to help increase awareness of the group and encourage more carers and people affected by dementia to attend when they are able.

The end-of-life dementia podcast, developed with the Dementia Palliative Care Team and a carer with lived experience, has been well received and has reached several hundred listeners in a short time. All agree this was a good example of sharing clear, helpful information in a way that feels manageable for carers.

The revised 'waiting well' letter and leaflet for people waiting for a memory assessment have now been simplified into clearer English and are being used by Memory Assessment Services. Work is continuing to ensure these are visible and easy to find online.

PW also shared that WB has been shortlisted for a National Dementia Award (People's Choice). The group congratulated Wendy and recognised this as a reflection of her commitment and the value of lived experience within the group.

3. Presentation: Dementia Strategy – One Year review and progress update

Speakers: *Claire Biernacki*

CB presented an overview of progress during the first year of the Derby and Derbyshire Dementia Strategy. She explained that the strategy was co-produced with people affected by dementia and carers, and that progress has been made despite very limited new funding.

CB outlined improvements in waiting times for memory assessments, with some areas now seeing people within 8–10 weeks. However, she acknowledged that other areas remain under pressure due to staffing shortages, clinic capacity and rural geography. The national 18-week target remains difficult to meet consistently.

CB highlighted work on prevention and risk reduction, including the development of a Brain Health Toolkit. This resource, co-produced with lived experience input, is designed to give practical advice on steps people can take to support brain health.

CB also described work to improve hospital experiences for people with dementia. This included the introduction of the ‘yellow box’ at Royal Derby Hospital. The yellow box is used during hospital stays to keep personal items, key information and prompts together, helping staff understand the person better and supporting clearer communication and reassurance. She explained that early feedback on the yellow box has been positive, with reports that it helps reduce anxiety, supports safer care and makes it easier for staff to focus on the person as well as their medical needs.

CB also described progress in supporting people with dementia who have other health conditions such as frailty, diabetes and heart disease. Training from the Dementia Palliative Care Team is being shared with a wider range of health and community staff so dementia is more consistently recognised alongside physical health needs.

She noted developments in post-diagnosis support, including evening and online Living Well groups, and targeted provision for younger people with dementia and people from different cultural backgrounds, including Asian-language support.

4. Group discussion and reflections following CB’s presentation

Assessment waiting times

Members reflected positively on improvements in assessment waiting times, while stressing that delays are still very difficult for people and carers in some areas. The group emphasised the emotional impact of waiting and the importance of clear communication during this period.

Meaningful activity after diagnosis

There was strong discussion about living well after diagnosis. Attendees highlighted that people impacted by dementia want meaningful activity, social contact and support that reflects their age, interests and abilities, rather than a 'one size fits all' approach.

Communication

The group also discussed access to information. While digital resources are helpful, it was agreed that many people affected by dementia cannot rely on online information alone. Local, face-to-face support and clear printed information remain essential.

A&E and hospital care

A significant part of the discussion focused on experiences of A&E and hospital care. Several carers and people living with dementia shared concerns that dementia is often not acknowledged during emergency admissions. The focus is usually on the immediate physical problem, with little consideration of mental health, confusion, anxiety or the impact of long waiting times. There was strong agreement that dementia needs to be recognised as part of safe and effective emergency care.

Attendees really like the 'yellow box' used in hospitals and felt this simple idea made a real difference and discussed whether it could be promoted more widely, including within care homes.

Lived experience stories

The group agreed that real stories are powerful and help services understand what life is really like for people and carers. It was agreed that carers and people with dementia should be encouraged to share short written or recorded accounts of hospital and service experiences. These should be collated and shared with strategy leads to help influence change.

Care Homes

Concerns were also raised about care home choice, particularly for people under 65 and for those with more complex or rarer forms of dementia. Members felt more consistent training and clearer information about levels of dementia care are needed.

Looking ahead – Prioritises for year 2

CB outlined proposed priorities for the next year of the strategy, including continued improvement to memory assessment services, the launch of the Brain Health Toolkit, clearer information 'hub' models, expanded training, and further focus on young onset dementia and care home provision. Attendees discussed the value of local 'one-stop' events where people can meet several services in one place.

Capacity, safeguarding and carer pressure

The discussion closed with reflections on difficult decisions around loss of capacity, safeguarding concerns and carer breakdown. Members described how confusing and

distressing these situations can be, particularly when behaviour changes or abuse is present. The importance of timely professional support and clear guidance for carers was strongly emphasised.

6. Any Other Business

Attendees reflected on the impact of hearing honest experiences from others and noted how helpful the recent end-of-life podcast had been. This led to a shared view that a future podcast could be a helpful way to talk openly dementia care and support. The group felt that hearing both lived experience and professional perspectives could help carers feel less alone and better informed about difficult decisions.

7. Next Meeting

25 June 2026 - (venue will again be hybrid: In-person + Microsoft Teams)

Topic: Care Homes and Respite Care

Actions

1. **CB** – Feedback discussion points to the Dementia Implementation Partnership Group
2. **CB** – Explore current practice around dementia awareness in A&E and report back to the group at a later date.
3. **VB** – To coordinate and collate shared ‘lived-experience’ stories about hospitals or other service use.
4. **PW** – to explore whether the ‘yellow box’ communication aid can be promoted more widely, including with care homes
5. **PW / WB** – to explore future podcast ideas focusing on difficult topics drawing on lived experience and storytelling.
6. **All** - to continue promoting the group using the new logo and refreshed materials.