Dementia Together Co-Production Group

Minutes of Meeting – 25 June 2026
10:00am–12:00pm, Hybrid meeting (Council House, Derby + Microsoft Teams)
Co-Chairs: Phil Wall (PW) & Wendy Burton (WB)

In Attendance
Phil Wall (Derbyshire County Council, co-chair)
Wendy Burton (Co-Chair)
Vicki Baker (Alzheimer's Society & minute taker)
3 x Individuals with lived experience (KOR, BM, LS)
Andrew Wilson (Commissioning, Derby City Council)
Lorraine Stokes (Healthcare Public Health Practitioner, Derbyshire County Council)
Elena Martin (Operations Director, Langdale Care Homes)
Malik Mandani (Compliance and Quality Assurance Officer, Langdale Care Homes)
Jasbir Rattu (Social Worker, Derby City Council)
Karen Smith (Social Worker, Derbyshire County Council)
Angela Donnachie (Carer Liaison Worker, Derbyshire County Council)

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1. Welcome and Introductions

PW welcomed everyone attending both in person and online.

Introductions were made around the group.

PW explained that the focus of the meeting would be care homes and respite care, with contributions from care home providers, Adult Social Care colleagues and people with lived experience.

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2. Review of Minutes and Actions from April Meeting

The minutes from the April meeting were accepted as an accurate record.

PW provided a brief update on actions:

- The Brain Health Toolkit has now been formally launched and is moving into its promotion phase. Work is underway with partners across Derby and Derbyshire to share the resource with communities, professionals and voluntary sector organisations. Early feedback has been positive, particularly regarding its accessibility and practical approach to supporting brain health.
- Work continues around sharing lived-experience stories and improving information for people affected by dementia.

- Discussions have continued regarding hospital dementia awareness, communication tools and care home provision.
- Progress has been made in raising the profile of the group through updated materials and communications.

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3. Brain Health Toolkit Update - https://jsnaderbyshire.org.uk/bhtk/

Speaker: *Lorraine Stokes*

LS provided an overview of the Derby and Derbyshire Brain Health Toolkit.

The toolkit has been developed as part of the Dementia Strategy's prevention and risk reduction work and focuses on practical, evidence-based actions that may support brain health throughout life.

Key points included:

- The toolkit focuses on modifiable dementia risk factors and encouraging small-step behaviour change.
- National and local evidence has informed the content.
- Local services and support opportunities have been incorporated throughout.
- Accessibility has been a key priority, including font size options, clear design, colour contrast and development of an Easy Read version.
- This group's endorsement has been included within the toolkit.
- Promotion is now underway through community groups, professionals and partner organisations.

Feedback and Reflections from the Group

Members responded positively to the toolkit and praised:

- Its attractive and engaging design.
- Simple navigation and accessibility.
- Practical information and links to local support.
- The balance between evidence and clear everyday language.

There was particular praise for the visual design and artwork which members felt made the content more inviting and easier to engage with.

Discussion also considered future developments, including:

- Translation into community languages.

- Further work with under-represented communities.
- Continued feedback and refinement as usage increases.

The group agreed that the toolkit was a strong example of successful co-production.

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4. Care Homes and Respite – Provider Perspective

Speakers: *Malik Mandani and Elena Martin, Langdale Care Homes*

Representatives from Langdale Care Homes provided a care home provider perspective on supporting people living with dementia.

The presentation focused less on buildings and processes and more on understanding the person behind the diagnosis.

Understanding the Individual

The speakers described how referrals often arrive focused on diagnoses, risks and behaviours rather than the person's history and identity.

Examples were shared demonstrating how understanding an individual's life story can help staff respond more effectively and reduce distress.

The presenters highlighted:

- The importance of life stories and family involvement.
- Looking beyond behaviours and understanding behaviours as communication.
- Positive risk-taking and supporting meaningful roles and activities.
- Seeing the individual rather than focusing solely on dementia.

Working with Families

The provider described their approach to involving families from the earliest stage, including:

- Pre-admission conversations.
- Completion of "All About Me" and life story information.
- Ongoing communication and partnership working.
- Involving relatives in care planning and decision making.

The presenters emphasised that families remain the experts on the person and should be viewed as partners in care.

Staff Training and Culture

Discussion highlighted a shift away from relying solely on formal dementia training towards:

- Daily reflective practice.
- Scenario-based learning.
- Peer discussions.
- Helping staff understand how dementia may affect a person's experience.

The provider described behaviour as communication and stressed the importance of understanding fear, confusion, discomfort and unmet need rather than simply responding to behaviours themselves.

Young-Onset Dementia

Members discussed the challenges faced by younger people living with dementia.

The group heard examples of people developing dementia in their 40s and 50s, and the significant impact on families, partners and children.

The provider acknowledged the difficulties of finding suitable support and care environments for younger people, particularly when specialist provision is limited.

Visiting and Family Involvement

The provider confirmed:

- Flexible visiting arrangements.
- Encouraging family participation.
- Support for outings and activities where appropriate.
- A commitment to maintaining relationships and quality of life.

Feedback and Reflections from the Group

Members reflected positively on the examples provided and welcomed the emphasis on seeing the person beyond their dementia diagnosis. Attendees felt the presentation demonstrated a genuinely person-centred approach, particularly through the use of life stories, individual interests and meaningful activities to support wellbeing and maintain identity.

Several members commented on the importance of families being recognised as partners in care and valued the provider's commitment to listening to relatives and involving them in decision-making. The examples shared highlighted how understanding an individual's background, occupation, hobbies and personal preferences could help reduce distress and create more positive experiences for both residents and families.

There was also positive feedback regarding the provider's approach to staff development, with attendees appreciating the focus on empathy, relationship-building and understanding behaviour as communication rather than relying solely on formal training programmes. Members agreed that this approach reflected many of the principles promoted through the Dementia Strategy and co-production work.

Particular interest was shown in the discussion around young-onset dementia, with members recognising the unique challenges faced by younger people and their families when accessing suitable support and care. Attendees welcomed the provider's willingness to support people with more complex and less typical dementia presentations.

Overall, the group felt the presentation offered a helpful insight into how high-quality dementia care can be achieved through compassion, flexibility, meaningful engagement and strong partnerships with families.

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5. Care Homes and Respite – Adult Social Care Process and Procedures

Speakers: *Jasbir Rattu & Karen Smith*
Representatives of Derby City Council and Derbyshire County Council Adult Social care provided an overview of how respite care is accessed and arranged.

Purpose of Respite

Respite was described as an important intervention that can:

- Support carers' wellbeing.
- Prevent carer breakdown.
- Promote independence and wellbeing.
- Sustain existing care arrangements.
- Provide opportunities to review support needs.

The group discussed how respite may be delivered through:

- Residential care homes.
- Nursing homes.
- Day services.
- Home-based support.
- Shared Lives schemes.
- Emergency and planned respite arrangements.

Assessment and Decision Making

Adult Social Care colleagues outlined the role of:

- Care Act assessments.
- Carer assessments.
- Mental Capacity Act considerations.
- Best interest decision making.
- Lasting Power of Attorney arrangements.
- Strengths-based practice.

The importance of understanding both the wishes of the person living with dementia and the needs of carers was emphasised throughout.

Also, Adult Social Care colleagues encouraged carers to make contact early and ask questions before reaching crisis point.

Funding and Financial Information

Members received an overview of financial arrangements including:

- Different approaches in Derby City and Derbyshire.
- Financial assessments.
- National capital thresholds.
- Local authority contributions.
- Top-up arrangements where applicable.

Discussion highlighted that funding arrangements can be difficult for families to understand and that clearer information is often required.

Feedback and Reflections from the Group

Several challenges were openly discussed:

- Carers often seek respite in crisis situations.
- Families may not be aware of available options until reaching breaking point.
- Information can be difficult to navigate.
- Accessing healthcare assessments and supporting documentation can create delays.
- Self-funding families can struggle to identify where to seek advice and support.
- Care arrangements can become increasingly complex when multiple organisations are involved.

Members shared experiences of:

- Emergency respite placements.
- Feeling overwhelmed by decision making processes.
- Difficulties obtaining timely support.
- Variations in experiences between different services and funding types.

Despite these challenges, the group welcomed the openness of the discussion and appreciated hearing directly from frontline Adult Social Care staff.

There was strong agreement that better information, earlier planning and improved awareness of respite options would benefit carers significantly.

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6. Respite Care Discussion

Speakers: *Angela Donnachie*

AD led a discussion exploring the realities of respite care from the perspective of people living with dementia and unpaid carers. She acknowledged that respite is often viewed simply as a service or placement, whereas for many families it can be an emotional and complex decision involving trust, guilt, anxiety and concerns about the wellbeing of the person being cared for.

AD introduced the draft respite/carers guide that had been developed in response to previous discussions about the lack of accessible information available to carers. She explained that the guide aims to provide practical information about respite options, assessment processes, funding arrangements and local sources of support.

Attendees were encouraged to read the draft document and provide feedback based on their own experiences and perspectives. Attendees were asked to consider whether the information was clear, easy to navigate and reflected the issues that matter most to carers and people living with dementia. Feedback would be used to further refine the guide before wider circulation and promotion. The group welcomed the opportunity to contribute to the resource and supported the continued co-production approach.

AD encouraged members to reflect on their own experiences of respite care and identify practical actions that could improve the experience for people living with dementia and their carers.

Attendees were also encouraged to reflect on occasions where respite care had led to positive outcomes and time when it had not met expectations.

Members highlighted several factors that contribute to positive experiences:

- Staff take time to know the person.

- Families are listened to and involved.
- Activities are personalised and meaningful.
- Communication is open and consistent.
- Care providers value life stories and personal histories.
- Examples were shared where care homes had successfully connected activities and experiences to an individual's previous interests, identity and life experiences.

Members also identified common concerns including:

- Poor communication.
- Limited information before admission.
- Lack of understanding of dementia.
- Restrictive visiting arrangements.
- Delays in accessing support.
- Families feeling excluded from decision making.
- Feelings of guilt and anxiety often associated with seeking respite, particularly when accessing support for the first time.

There was agreement that providers and commissioners should continue working together with carers to improve understanding and access.

Agreed conclusions from the discussion were:

- Respite remains one of the most important and complex topics for carers.
- Better information for self-funders would be particularly valuable.
- Carers often delay accessing respite until they are at crisis point.
- More proactive support and planning would help prevent emergencies.
- There is support for developing clearer information resources and practical guidance for carers about respite options, funding and processes.

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7. Next Meeting

27 August 2026 - (venue will again be hybrid: In-person + Microsoft Teams)

Topic: Groups and creative activities

Actions

1. **ALL –** Review and share the Brain Health Toolkit within their networks and provide feedback to support future improvements.
2. **LS** – Explore opportunities to improve accessibility further, including consideration of community language translations and engagement with under-represented communities.
3. **VB** – To coordinate and collate shared 'lived-experience' stories about hospitals or other service use.
4. **PW / Adult Social Care Representatives** – Continue work on improving information and guidance relating to respite care and care home processes.
5. from carers regarding respite care experiences and information gaps.
6. **ALL** - Review the draft respite/carers guide and provide feedback to Angela Donnachie to support further development of the resource. **VB** will support collection and collation of feedback.