

## Dementia Together Co-Production Group

Minutes of Meeting – 26 February 2026

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

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

### Professionals 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)

Gemma del Toro (Dementia Palliative Care Team)

Julie Smith (Dementia Palliative Care Team)

Claire Travis (Derbyshire Carers Association)

5 x Carers attended this meeting

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### 1. Welcome and Introductions

PW opened the meeting and welcomed everyone who joined both online and in person.

Attendees introduced themselves.

PW shared that today's topic was end-of-life care. This topic was chosen because the group felt it needed more attention and clearer information.

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### 2. Review of Minutes and Actions from November Meeting

PW summarised the actions agreed at the November 2025 meeting.

#### Logo for the Group

The group had discussed simplifying the group name to “Derbyshire and Derby Dementia Together”. Two updated logo designs were shown, both using the Forget-Me-Not symbol (with permission from the Alzheimer's Society).

Attendees agreed on the preferred version, and PW confirmed the logo would now be adopted.

Approved versions seen below with both a white and black background.



## Terms of Reference

PW confirmed the Terms of Reference had been shared. These outline the purpose and workings of the group and will also be placed online for ongoing reference.

## Promoting the Group

Previous meetings highlighted the need to increase attendance and reach more carers.

WB shared ideas discussed earlier, including:

- A simple digital leaflet using the new logo
- Sharing upcoming meeting topics in advance
- Asking carers what they would like discussed
- Including real stories showing positive outcomes from past sessions

Attendees agreed that clearer promotion could encourage more carers to join.

PW, WB and VB will meet separately to plan a refreshed promotional approach.

## Podcast Updates

A previous action was to share the Young Onset Dementia podcast. PW noted that it had now reached several hundred views.

A new podcast on end-of-life and dementia care is now being developed with the Dementia Palliative Care Team, outside of this group, including a carer with lived experience.

## Financial Support and Accessible Information

PW will follow up with the finance team about making financial information easier to understand.

Updated information on dementia apps and Reading Well books has now been uploaded to the Alzheimer's Society website.

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### **3. Presentation: Dementia Palliative Care Service**

**Speakers:** *Gemma Del Toro & Julie Smith*

Gemma explained the meaning of palliative care. She stressed that palliative care:

- is not only for the final days or weeks of life
- is about improving quality of life from early after diagnosis
- supports the whole person, including physical, emotional, and social needs
- also supports family members

Only a small part of the public understands what palliative care means. Many people think it is only about end-of-life care. The group discussed how this misunderstanding often stops families asking for help.

Gemma shared statistics showing how few people know dementia is a terminal illness (42%) and that 9 out of 10 people do not know that dementia is the leading cause of death in the UK (many think cancer is the leading cause).

She also explained how unpredictable dementia can be and why early planning matters.

Julie then shared examples of her daily work. This included:

- helping families think about future wishes
- giving practical advice (e.g., nutrition, managing pain, personal care, sleep)
- supporting carers with their worries
- helping families talk about plans in simple steps
- using techniques such as soft-touch “Hearts Therapy” to reduce distress

Both speakers described how early involvement helps avoid crises and gives carers confidence.

Several carers in the group shared personal experiences. One member spoke warmly about how the palliative care service supported her husband and herself, saying it made a major difference.

A strong shared message emerged: People need clear information that palliative care is not only for the end of life, but can help from early on.

#### Action and Next steps:

Attendees agreed that:

- A new information leaflet or booklet is needed to explain palliative care clearly.
- The leaflet should help remove fear around the word “palliative”.
- It should be simple, friendly, and used across dementia groups, clubs and services.
- Attendees agreed to aim to present the new palliative care booklet at the April meeting, aiming for a public launch during Dying Matters Week in May.

Several attendees volunteered to join a working group to design this leaflet. PW to set up a meeting with those interested.

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#### **4. Presentation: H-Connect Project (Derbyshire Carers Association)**

**Speaker:** *Claire Travis*

Claire introduced 'H-Connect', a hospital discharge liaison project funded through the Accelerated Reform Fund.

She explained the purpose of the project:

- to identify carers early when someone is admitted to hospital
- to include carers properly in treatment and discharge planning
- to reduce hospital readmissions
- to support carers with clear information and practical advice

Claire shared findings from work on hospital wards. Carers often felt:

- they were not asked about the support they give
- their knowledge was ignored
- they were rushed into decisions
- they were given little or no clear information

H-Connect trains hospital staff, updates ward information, gives guidance on carers' legal rights, and helps staff signpost carers to support.

The project has:

- delivered carer awareness training to many staff
- created carers' noticeboards
- offered community grants
- recorded podcasts by and for carers
- created resources in easy-read formats
- supported hundreds of carers through clinics, groups and events

Research interviews show both carers and staff are seeing improvements, though there is still work to do.

Claire explained that funding for the project ends in August 2026, but the team is hoping for an extension.

Attendees expressed support for the project.

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## 5. Day Services Review – Input from the Group

PW asked the group for views on what makes a good day service for people with dementia.

Key ideas included:

- Music, singing and calming lighting
- Activities based on personal interests
- Space to talk and socialise
- The option for quiet rest when needed
- Larger rooms or open spaces to move around safely
- Reliable transport to and from the service

These comments will be passed to the team reviewing day services across Derbyshire.

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## 6. Any Other Business

An attendee raised concerns about the online service “Lottie”, which appears not to support people under 65 seeking a care home. PW explore this.

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## 7. Next Meeting

**23 April 2026** - (venue will again be hybrid: Council House + Microsoft Teams)

A main focus will be the first-year review of the Derby and Derbyshire Dementia Strategy, with an interactive session planned.

### Actions

1. **PW, WB and VB** – meet to design improved promotional materials for the group, using the new logo.
2. **PW** – Set up working group meeting to create a simple booklet explaining palliative care for people with dementia.
3. **PW** – follow up with finance team about making information on paying for care easier to understand.
4. **PW** – look into concerns raised about the “Lottie” care home search tool.
5. **PW** – provide input from today’s discussion to the team reviewing dementia day services.
6. **CT** – share the H-Connect research report with the group once published (expected May/June).
7. **VB** – share the presentation slides and useful links with the group.