Summary Report

This report summarises the key themes arising from the discussion with people with dementia who are members of the Right Minds group during the Dementia Inclusion Network meeting held on 7 May 2026. The discussion provided insight into lived experience of dementia, the value of peer support, and the practical and emotional barriers that affect inclusion, independence and quality of life.

1. Peer support creates belonging, confidence and connection

A central theme in the discussion was the importance of the Right Minds group as a welcoming and supportive space. Participants described the group as somewhere they could feel at home, make friends and recognise that they were not alone. For several people, attending initially felt daunting, particularly when joining for the first time, but this anxiety reduced once they experienced the friendliness of the group. The discussion highlighted that peer support offers reassurance, social contact and encouragement to remain engaged in community life. Participants also emphasised that groups such as Right Minds help people to leave the house, maintain routine and avoid isolation.

2. People want to be seen beyond the diagnosis

Participants repeatedly challenged the assumptions that often accompany a dementia diagnosis. A strong message was that dementia does not remove personhood, intelligence or value. Several contributors expressed the wish for others to understand that they were still themselves and still present, even if some aspects of memory or daily functioning had changed. There was a clear sense that wider society, and sometimes professionals, can focus too heavily on the label of dementia rather than the whole person. This can lead to people feeling ignored, underestimated or spoken to in inappropriate ways. The discussion therefore underlined the importance of dignity, recognition and respectful communication.

3. Diagnosis and adjustment are complex and highly personal

The discussion showed that people experience diagnosis in very different ways. Some participants said they did not initially feel different and found it hard to connect the diagnosis with their day-to-day experience. Others described a gradual realisation through difficulties with memory, confusion or changing relationships. There was also a sense that diagnosis is not always accompanied by sufficient explanation or guidance. One participant reflected that, after receiving the diagnosis, they did not know what life would look like or whether they would still be able to go out and live normally. This points to the need for clearer information, better emotional support and practical reassurance at the point of diagnosis and afterwards.

4. Stigma and misunderstanding remain significant barriers to inclusion

Participants described a range of attitudes and behaviours that make living with dementia harder than it needs to be. These included people assuming that dementia means someone is foolish, talking down to them, shouting unnecessarily, or avoiding conversation out of discomfort. Participants also referred to negative media portrayals and advertising campaigns that present dementia only in bleak or extreme terms, which did not reflect their own lived reality. This kind of messaging was felt to reinforce fear and stigma rather than promote understanding. The discussion highlighted the need for more realistic, balanced and humane representations of dementia, alongside greater confidence among the public to speak with and listen to people living with the condition.

5. Dementia affects independence and relationships in different ways

Contributors described the impact of dementia on confidence, daily tasks and personal identity. Some spoke about forgetting names, misplacing items or becoming aware that abilities they once relied upon were changing. For some, this led to a sense of loss or reduced self-confidence. The discussion also explored the impact on close relationships, especially where partners or spouses gradually take on more organising, prompting or decision-making. While this support was appreciated, it could also be difficult for individuals who were used to being independent or in control. Humour, honesty and mutual understanding were described as important ways of coping with these changes.

6. Other health and practical issues must not be overlooked

One particularly important theme was that dementia is not always the issue causing the greatest difficulty in a person’s life. A participant who had recently lost much of their sight explained that visual impairment had reduced their independence far more than dementia itself. This included difficulty recognising people, reading, writing, travelling independently and navigating everyday environments safely. The discussion highlighted the risk that professionals and others may attribute all difficulties to dementia and fail to recognise other conditions or practical barriers. This reinforces the importance of seeing the whole person and responding to the full range of their needs.

7. Strengths, humour and opportunities to live well remain important

Despite the challenges discussed, the overall tone of the conversation was hopeful, grounded and practical. Participants spoke about continuing to enjoy outings, meals, music, friendships and shared activities. Humour emerged as an important means of coping and maintaining perspective. There was also pride in the contribution that people with dementia could continue to make to their communities and to discussions such as this one. The conversation challenged deficit-based views of dementia by showing that many people continue to live active, connected and meaningful lives, especially when they are supported by inclusive groups and understanding communities.

Conclusion

The discussion demonstrated that dementia inclusion depends not only on services, but also on attitudes, relationships and opportunities for connection. Participants placed strong value on peer support, respectful treatment and the chance to continue living full lives after diagnosis. The report highlights a need for better understanding of lived experience, more balanced public narratives about dementia, clearer support at the point of diagnosis, and continued investment in welcoming community spaces such as Right Minds. Above all, the discussion reinforced that people living with dementia are the experts in their own experience and should be listened to directly in the design of support, services and inclusive communities.