The following information was recorded from a discussion held on 7th May 2026, facilitated by Innovations in Dementia with a group of people living with dementia in the community. All the participants also attend the volunteer led Right Minds Dementia Support Group which meets monthly in Bridlington.

1. What being part of Bridlington Right Minds Dementia Support Group means for you

- “You think you’re not on your own… it’s good, it’s really good.”
- “If you sat there like a lemon… what am I doing here… but once you get used to it, you can join in.”
- “It’s being amongst friends… you make friends.”
- “There’s always somebody who’s going to be a sympathetic ear.”
- “Don’t think you’re a stranger… just join in.”
- “You must be a community… otherwise you would never find out what’s wrong with you.”
- “A brilliant group… who made everyone feel at home.”
- “A group of friendly people… friends together.”
- “It’s a good group. It’s friendly. Everybody makes you feel at home.”
- “It gets you out of the house.”
- “It’s important to get out and about.”
- “It’s a great place to occupy yourself… I just enjoy life.”
- “We go out together for meals… cafés… coffee shops.”
- “Even if you don’t drive… you can still get out.”
- “We do a lot of socialising… concerts and meals out.”
- “We have a lovely friendly group… welcoming to new people.”
- “Encourage people to join… point them in the right direction.”
- “Groups like ours are here… we are proactive in the community.”
- “When we first came… we were scared… but then we felt very welcome.”
- “I thought we couldn’t leave the house… then realised ‘there is life’.”
- “This group really helped and supported me.”
- “I believe so much this is important.”
- “It’s a space where people say ‘I know how you feel’ and mean it.”
- “It’s an interesting place to come.”

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2. Message to the wider community (myths, understanding, reality)

- “I’m still here.”
- “Just because I’ve got dementia, don’t ignore me.”
- “Large elements of me are still there.”
- “I can still do things… crosswords… lots of things.”
- “Dementia doesn’t make you stupid.”
- “We’re not daft.”
- “It’s just a label.”
- “People don’t see beyond the diagnosis or label.”
- “People think you’re deaf.”
- “Don’t talk to us like we’re deaf.” *(also expectation)*
- “Let us tell you exactly what it’s all about.”
- “Listen to people who have dementia—they know.”
- “Don’t be afraid to speak to us.”
- “It’s not catching.”

- “Approach us and chat… ask what daily life is like.”
- “There is still life.”
- “You can still go out… do things.”
- “Focus on what we can do, not what we can’t.”
- “Don’t think you have to stay in the house.”
- “Don’t worry about it… take it as it comes.”
- “It’s another name for growing old.”
- “You don’t feel any different.”
- “Negative portrayals don’t relate to me.”
- “TV adverts show really bad situations… that’s not my reality.”
- “I’m not crazy—it’s just my reality.”
- “Other people don’t understand what it’s like.”
- “Half the problem is not dementia—it’s people around you.”

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3. Expectations of people and organisations

- “A bit more consideration… that’s all.”
- “Recognition that I’m still here.”
- “Don’t ignore me.”
- “Don’t label us.”
- “Don’t talk to us like we’re deaf.”
- “Talk to us… find out what we’re saying.”
- “Listen to people who have dementia.”
- “Don’t be afraid to approach us.”
- “Engage with us… not avoid us.”
- “Stop assuming we are stupid.”
- “Give us plenty of consideration.”
- “You should talk to us, not just diagnose and walk away.”
- “They tell you ‘you’ve got dementia’ and give no information.”
- “We weren’t given anything about what to expect.”
- “Support people to get out—not stay at home.”
- “Encourage more groups like this.”
- “Work together across organisations.”
- “Don’t put everything down to dementia.”
- “There are other problems too—don’t ignore them.”
- “Better understanding of the whole person.”

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4. How did it feel being told you have dementia?

Initial confusion / disbelief

- “I didn’t realise there was anything wrong.”
- “I was told I had it.”
- “It didn’t mean anything because I didn’t feel anything.”
- “You don’t feel any different.”
- “You never feel you’ve got it yourself.”
- “Other people tell you.”

Shock / fear / uncertainty

- “It was really scary.”
- “We thought we couldn’t leave the house.”
- “We thought we were back in lockdown.”
- “We didn’t know what to expect.”

Lack of information

- “We weren’t given any information.”
- “Nobody told us what dementia is or what happens next.”

Gradual realisation

- “You think you’re alright... then realise you’re not.”
- “When the penny drops...”
- “You realise something’s not right.”

Emotional impact

- “I got annoyed... thought everyone else was an idiot.”
- “I felt very lost.”
- “I feel very bewildered.”
- “Trying to come to terms with it.”
- “I’m feeling less of a person.”
- “I can’t be the person that I was.”

Gradual decline / lived experience

- “It’s gradual—one thing goes, then another.”
- “Some days are good, some not.”
- “I’m surprised when I can’t remember things now.”

Narrative perspectives

- “I saw it happen to others before I realised myself.”
- “You live with it before you understand it.”

Other complexity

- “Dementia is minor compared to other things (e.g. eyesight).”
- “People blame everything on dementia when it isn’t that.”

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5. What helps and what hinders

☑ What helps

- “Groups like this—talking about it.”
- “Being with people in the same situation.”
- “Friendship and support.”
- “Feeling at home.”
- “Getting out of the house.”
- “Social activities—meals, concerts, trips.”
- “Humour—it makes a big difference.”

- “Someone organising and supporting you.”
- “Hearing ‘I know how you feel’.”
- “Encouragement to join groups.”
- “Focusing on what you can do.”
- “Keeping active.”
- “Supportive relationships.”
- “Services working well together.”
- “Talking openly about it.”

✖ What hinders

- “People being derogatory—it makes you clam up.”
- “Makes you withdraw.”
- “People shouting at you unnecessarily.”
- “Being treated like you’re deaf or stupid.”
- “People avoiding you.”
- “People being afraid to talk to you.”
- “Lack of information after diagnosis.”
- “Being told and then nothing else.”
- “Everything being blamed on dementia.”
- “Negative media portrayals.”
- “Adverts showing worst-case scenarios.”
- “Assumptions that stop people going out.”
- “Thinking life is over.”
- “Isolation—people staying at home.”

Additional practical / lived realities

- “I forget names within minutes.”
- “I put things down and can’t find them.”
- “I know I’ve got a problem but don’t know what it is.”
- “My independence is affected.”
- “Changes in relationships—others make decisions.”
- “Life changes—moving house is stressful.”
- “Other health issues can be harder than dementia.”