Putting People First

Dementia
Community Appointment Day
Combined Outcomes Report
August 2025

NHS Grampian

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Dementia CAD Combined Outcomes Report

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Acknowledgements

The Dementia CAD Outcomes, outlining the processes, methods and outcomes of the day was conducted by project manager Caroline Anderson, it is with Caroline's kind permission that I include data, gathered via the patient survey collated from the patient passport, within this report.

I would also like to thank all the other staff that supported the collection of patient and carer feedback on the day.

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Dementia CAD Combined Outcomes Report

Executive Summary

This executive summary combines key findings from both the patient passport surveys report and the follow-up interviews with carers report to provide a comprehensive overview of the Dementia Community Appointment Days (CAD) impact.

The Dementia CAD was piloted as a new model of care to support individuals recently diagnosed with dementia and their carers. Designed around Alzheimer Scotland's Five Pillars Model, the CAD aimed to promote self-management, improve access to post-diagnostic support, and foster connections with clinical, third sector, and peer-led services.

Key Findings

Improved Awareness and Access to Support: Both patients and carers reported discovering services they hadn't previously known about, including CFine, Alzheimer Scotland, and local dementia-friendly groups. The CAD helped participants understand dementia better and plan for the future. For some the CAD was a catalyst for action, prompting carers to take practical steps such as applying for benefits, exploring legal planning, and engaging with community activities.

"Didn't realise there was so much support available."
"Now I know there are events and activities we can take my mother to."

Gaps in Initial Post-Diagnostic Support: Many participants described receiving little or no information, minimal initial support, also describing delays or lack of follow-up from primary care following diagnosis. Patients described the CAD as filling a critical gap in post-diagnostic care.

"We got no information when my wife was first diagnosed… we feel like we were just left to get on with it."
"Very poor – non-existent. Wrong diagnosis to start and no follow up, no help from GP."

Emotional Reassurance and Peer Connection: The event reduced feelings of isolation and uncertainty, especially for carers. Participants valued the opportunity to connect with others in similar situations.

"It was good to see everyone together and you realise you are not alone."
"The CAD took away that feeling that we were all on our own…"

Need for Carer-Focused Support: Carers expressed a desire for more tailored information and support for themselves, not just for the person with dementia.

"Would have liked better information for the carers… most patients are not able to care for themselves."

Environmental and Accessibility Challenges: The event was described as noisy and overwhelming, particularly for people with dementia. Suggestions included better layout, clearer communication, and more dementia-friendly design.

"Very noisy, I was very overwhelmed and I'm not the one with dementia."

"We had to leave."

Impact on Service Demand: While most participants still felt they would require follow-up appointments, a few felt the CAD provided sufficient support to avoid further professional contact, indicating potential for system efficiency. However, carers remained uncertain about future needs, reflecting the evolving nature of dementia care.

Comparative Insights

Newly Diagnosed vs. Longer-Term Patients: Those recently diagnosed expressed greater emotional vulnerability and need for immediate clarity, while longer-term patients highlighted systemic gaps and valued practical advice (e.g., Power of Attorney).

Conclusion

The Dementia CAD was a meaningful and empowering experience for both patients and carers. It successfully bridged gaps in post-diagnostic support, improved awareness, and fostered emotional connection. To enhance future CADs, attention should be given to improving accessibility, dementia friendly design, and ensuring carer-specific support. There is strong interest in continuing and expanding the CAD model, suggesting its potential as a sustainable approach to supporting individuals recently diagnosed with dementia and their carers dementia care across the region.

Dementia CAD Combined Outcomes Report

Background

The Community Appointment Day (CAD) initiative aimed to pilot a new model of care designed to empower individuals to self-manage their conditions. The CAD does not replace the current model of PDS service delivery but aims to augment the information supplied. It also sought to identify appropriate next steps for treatment by offering unhurried, direct access to a broad range of clinical, third sector, and peer support services focused on holistic health and wellbeing.

In line with SIGN Guidelines, service providers are encouraged to deliver coordinated post-diagnostic support that meets the needs of people with dementia and their carers, fostering engagement with relevant services.

The Dementia CAD explored an alternative model of service provision to ensure that the post-diagnostic support provided aligns with Alzheimer Scotland's Five Pillars Model, which supports individuals newly diagnosed with dementia and their families. The model includes:

- Planning for future care
- Planning for future decision-making
- Peer support
- Understanding the illness and managing symptoms
- Supporting community connections

The CAD adhered to its essential ingredients: a person-centred approach, a focus on what truly matters to individuals, and tailoring delivery to the local population. Feedback from service users, occupational therapists, and Alzheimer Scotland informed the selection of support services and organisational representation.

Initially, only individuals diagnosed with dementia within the past 12 months received an invitation to attend the CAD. Latterly, an open invitation was promoted, inviting members of the public to book an appointment slot. The letter explained that the event was an opportunity for them and a family member or carer to speak with professionals, ask questions, and receive guidance on living with dementia. Five appointment slots were available every 15 minutes.

Upon arrival, attendees received a Personal Health Passport to complete as they moved through different zones, encouraging self-management and ownership. Public health and HSC practitioners facilitated "What Matters to You Most" conversations. Volunteers guided attendees, and various services offered information and support. Refreshments were available to encourage attendees to pause, reflect, and engage with others.

This report presents findings from the Dementia CAD, combining insights gathered during the event and also from follow-up interviews conducted with carers and family members of attendees.

Methods

Patient Passport

The patient survey responses, included within the patient passport completed on the day, were transposed to an MS Excel spreadsheet.

The survey questions explored:

- Awareness of receiving post diagnostic support pre CAD
- What parts of post diagnostic support were received
- Who provided that support, and how it was delivered
- Impact of attending Dementia CAD

Comparisons were made between two identified patient groups: patients with a diagnosis of less than 12 months and patients with a diagnosis of more than 12 months.

Post CAD Follow up Interviews

Carers of patients who consented to follow-up (via their patient passport) were contacted by email six weeks after the Dementia CAD to confirm ongoing willingness to participate, ensuring informed consent was maintained. They were offered a choice of dates and times for a telephone follow up call, conducted by a single researcher (AG). A questionnaire, developed in MS Forms and reviewed by the Dementia Lead (AP), guided the semi-structured interviews.

The interviews explored:

- Had anything changed / done anything differently since attending the CAD?
- Did they receive any information at the CAD that was helpful?
- Would the information received at the CAD reduce the need for future professional appointments?
- Was anything learned at the CAD that would have helped when first diagnosed?

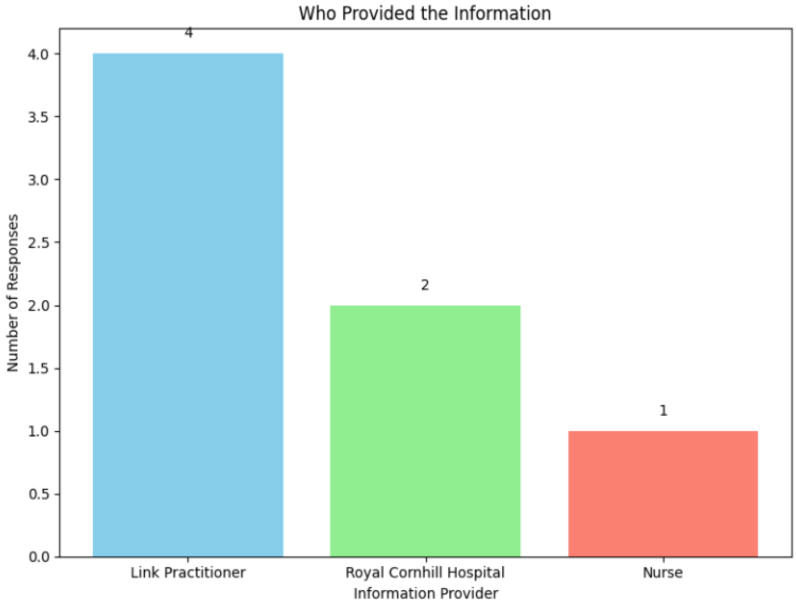
Patient interviews were analysed using high level thematic framework analysis (Gale. N.K et al. 2013). Thematic analysis involves identifying patterns and themes in qualitative data such as interview transcripts, coding and categorising into themes. This method ensures a comprehensive understanding of the data, reflecting participants' perspectives and experiences accurately.

Findings: Patient Passport Survey Questions

Thirty one (n=31) patient passport were completed. The majority of attending patients 56% (n=15) indicated they had received a diagnoses of dementia within the previous 12 months, 19% (n=5) within the last 1-2 years, 26% (n=7) diagnoses had been 2 or more years ago.

Patients with a diagnosis within the last 12 months

The following findings will focus on the outcomes of patients (n=15: 56%) with a diagnosis within the previous 12 months.



Forty seven percent (n=7) of respondents were aware of receiving post diagnostic support for dementia.
Of those who did, it was reported to be primarily from a Link Practitioner. Respondents (n=6) indicated they received aspects of information within the Five Pillars model either face-to-face or were directed to a website

Patient Experience of Post Diagnostic Support Prior to Attending the CAD

Respondents were asked whether there was anything else they would like to mention about the post diagnostic they received. Responses were themed and include patient quotes (*Italics*).

Navigating Uncertainty - This reflects the emotional and practical challenges faced immediately after diagnosis, highlighting the importance of early and clear support.

> ***"Diagnosis means entering a world of unknown. Initial support is incredibly important."***

Delays and Gaps in Support - These responses suggest frustration with delays and a lack of coordinated or timely follow-up, particularly from primary care services.

> ***"Took too long"; "No other support. No support from GP"; "Minimal support at the start"***

Scheduled Follow-Up - Indicates that some follow-up was arranged, though the timing may not have met the immediate needs of the patient or carer.

> **"Another appointment at Links at end of June"**

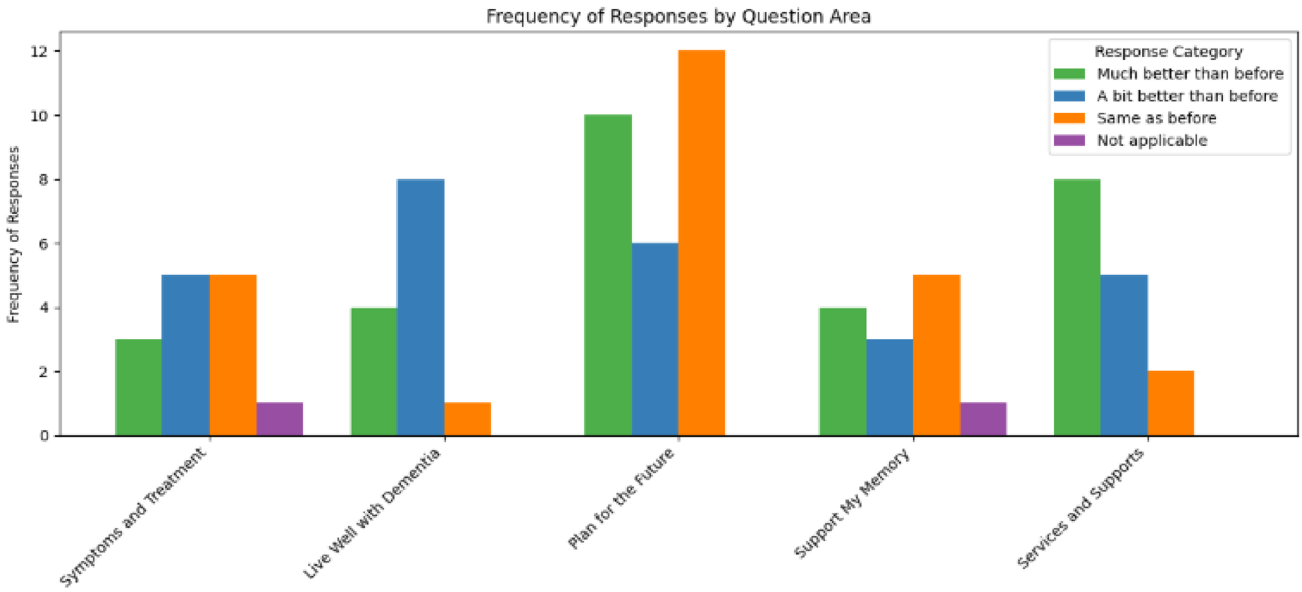
Proactive Outreach and Resources - Demonstrates a positive experience with proactive contact and provision of practical resources, which may have helped improve understanding and planning.

> ***"Telephone call and then visit from Aberdeen Links service. Info given on resources, agile booklet"***

Knowledge and Understanding

Participants were asked to give feedback whether attending the CAD had impacted on their knowledge and understanding within 5 key areas (responses are presented in the graph below);

1. Understanding of dementia, including symptoms and treatment
2. Understanding of what I can do to live well with dementia
3. Knowledge of how to plan for the future
4. Knowledge of what I can do to support memory
5. Knowledge of other services and supports that can help me live well



1. Positive Impact - The response "Much better than before" was especially notable in:

- Knowledge of services and supports
- Planning for the future

The frequency would suggests that the Dementia CAD had a positive impact on participants' understanding in these areas.

2. Moderate Gains - "A bit better than before" was noted in:

- Living well with dementia
- Understanding symptoms and treatment

This indicates that while some participants experienced improvement, there may be opportunities to strengthen content or delivery in these areas.

3. Limited Change - "Same as before" appeared across all areas. With the highest frequency in:

- Planning for the future

This may reflect either pre-existing knowledge or that some still felt low knowledge of how to plan for the future.

4. Not Applicable - This response was rare but present in:

- Understanding symptoms and treatment
- Supporting memory

It may indicate that some participants felt the content wasn't relevant to their personal situation.

Q- What did you find helpful?

Thematic Summary of Participant Feedback

1. Access to Information and Resources - These responses reflect a strong appreciation for the volume and relevance of information received, especially around dementia, memory support, and available services.

> ***"Getting more information, finding out more about dementia and why it has happened to me.***
>
> ***"It was helpful to find out what can help"***
>
> ***"Found out there is help out there if needed"***
>
> ***"Didn't realise there was so much support available"***

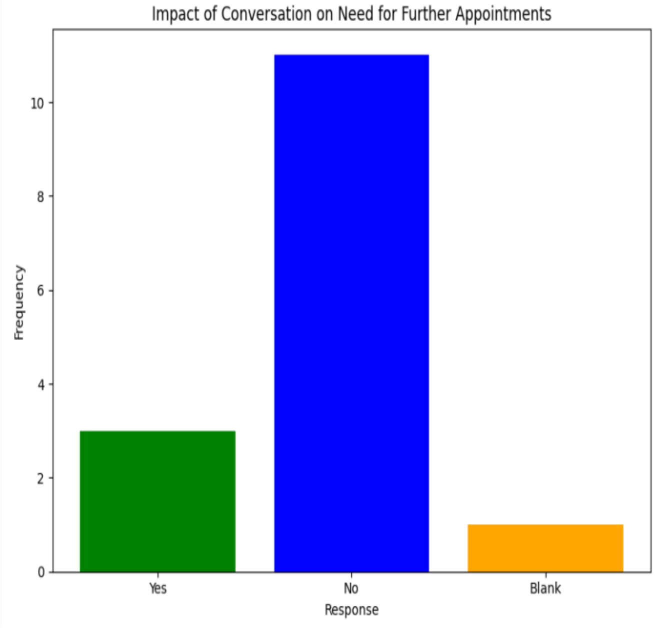
2. Connection with Services and Professionals - Participants valued direct contact with knowledgeable professionals and services they wouldn't normally access, which helped build trust and understanding.

> ***"Mental health OT provided a lot of useful info. Links team also useful re possible carers etc."***
>
> ***"Direct interaction with specific + specialised services. I have taken away a lot of useful info."***
>
> ***"Meeting different departments. Not normally known to someone out with the NHS"***
>
> ***"Meeting who were informed. I started a journey."***

3. Practical Support and Activities - These responses highlight the importance of practical, actionable support—such as benefits advice and social engagement opportunities.

> ***"All the different activities that he can go to"***
>
> ***"Assistance with claiming benefits. Information about activities available. Kind and informative."***

Q - Have any of the conversations that you had today meant that you no longer need an appointment with another health or social care professional?



Most participants (11 out of 15) indicated that the conversation did not replace the need for a future appointment.

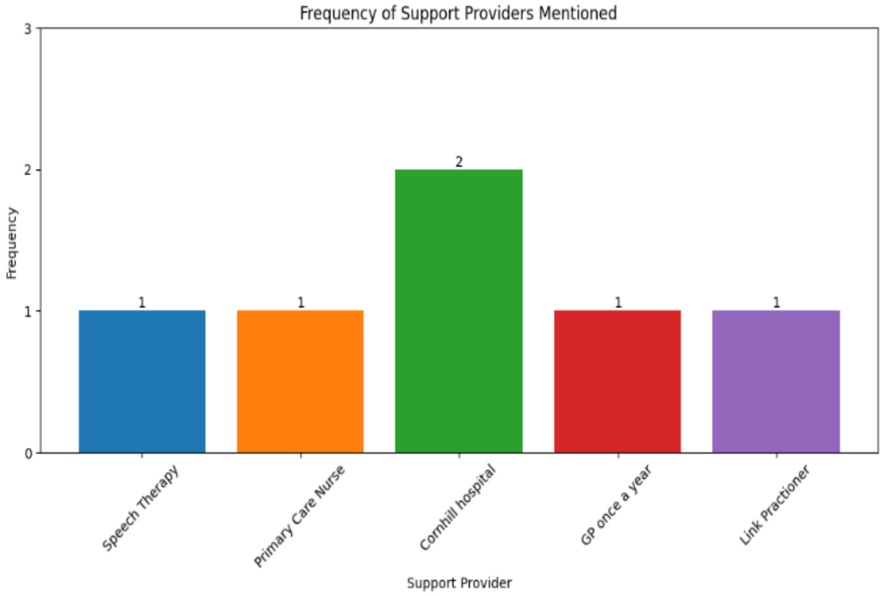
Only 3 participants felt that the conversation was sufficient to avoid another appointment.

The data suggests that while the conversations were helpful, they did not fully replace the need for follow-up with health or social care professionals for most participants.

However, the small number who said "Yes" indicates that for some, the session was effective enough to reduce service demand, which could be a positive outcome in terms of system efficiency.

Patients diagnosed more than 1 year ago

The following findings will focus on the outcomes of patients (n=12) who reported a diagnosis of dementia within the last 1-2 years (n=5:19%) and a diagnosis of 2 or more years ago (n=7:26%).



Fifty eight percent (n=7) of respondents were aware of receiving post diagnostic support for dementia. Of those who did, this was from different sources. Respondents indicated they received aspects of information within the Five Pillars model either face-to-face, telephone, handout or leaflet.

Experience of Post Diagnostic Support

Respondents were asked whether there was anything else they would like to mention about the post diagnostic they received. Responses were themed and include patient quotes (*Italics*).

Lack of Follow-Up and Continuity - These responses reflect a recurring concern about the absence of follow-up care and continuity in support, particularly after initial contact or diagnosis.

"Waiting for future tests from Cornhill and follow up about home situation, have not had follow up."

"Have seen psychologist but not had follow up."

"Very poor – non-existent. Wrong diagnosis to start and no follow up, no help from GP."

Self-Reliance and Prior Knowledge - This suggests that some individuals rely on personal or family experience due to gaps in formal support.

"Not really had any – have done most of this myself. It runs in the family so have knowledge and experience."

Mixed Experiences with Support - While some support was appreciated, uncertainty about ongoing care or next steps remains a concern.

"Have had support from Link Practitioner which was helpful, but now feel unsure of the next steps."

Medication-Related Concerns – This highlights a need for clearer communication and guidance around medication management.

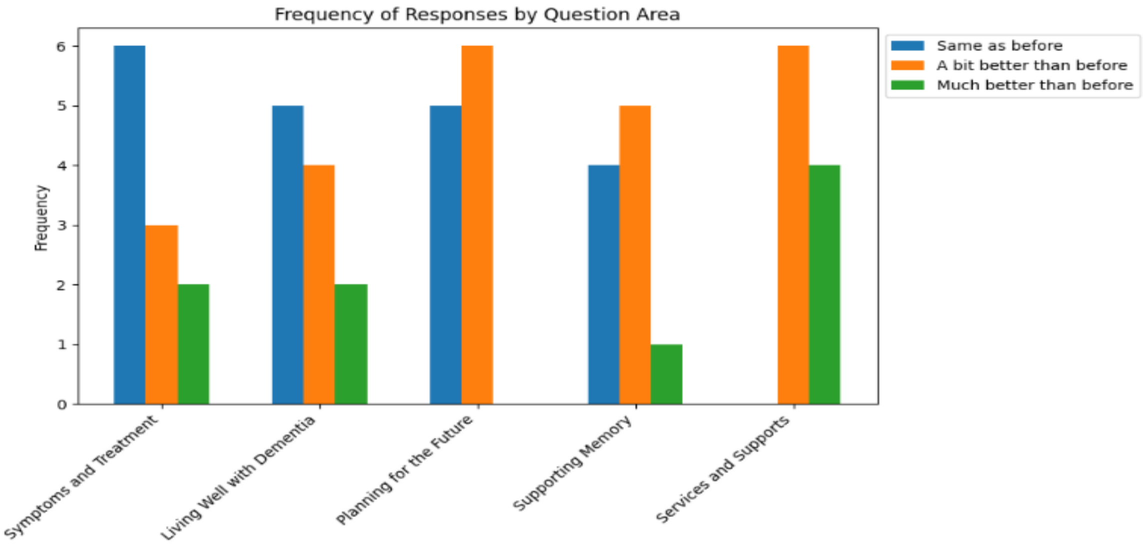
"Medication support – side effects / are meds needed."

Positive Feedback - A minority of responses indicated satisfaction with the support received with one respondent indicating that all was good, *"No – all good."*

Knowledge and Understanding

Participants were asked to give feedback whether attending the CAD had impacted on their knowledge and understanding within 5 key areas (responses are presented in the graph below);

1. Understanding of dementia, including symptoms and treatment
2. Understanding of what I can do to live well with dementia
3. Knowledge of how to plan for the future
4. Knowledge of what I can do to support memory
5. Knowledge of other services and supports that can help me live well



1. Most Common Response: “Same as before” - This was the most frequent response in:

- Symptoms and Treatment,
- Living Well

This suggests that many participants felt their understanding in these areas had not changed significantly after the intervention.

2. “A Bit Better than Before” Shows Moderate Gains - This response was consistently present across all areas, especially in:

- Supporting Memory
- Services and Supports
- Planning for the future

This indicates that some participants experienced incremental improvements in their understanding.

3. “Much Better than Before” Indicates Strong Impact and was most prominent in:

- Services and Supports

This suggests that the intervention had a notable positive impact for some participants, particularly in understanding available support and how to live well.

Overall, respondents reported mixed impact of their post-diagnostic support, which highlights areas where support may need to be strengthened, especially in symptom understanding and future planning.

Q - What did you find helpful?

Thematic Summary of Participant Feedback

1. **Access to Relevant Information** - These responses highlight the value of receiving clear, practical information—especially around legal matters, care responsibilities, and available resources.

> ***“I got the information I needed. Yes it was helpful to find out about power of attorney.”***
>
> ***“Getting the information that I needed as I care for my mum with dementia.”***
>
> ***“Very informative, everyone was very helpful.”***

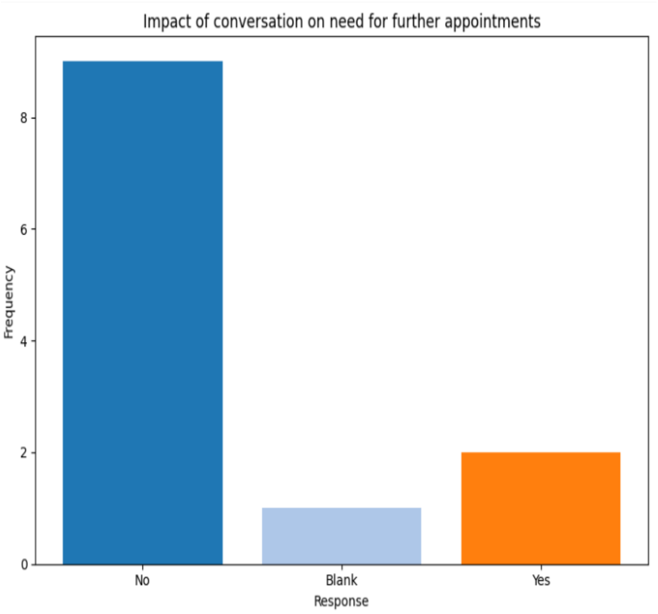
2. **Direct Engagement with Professionals** - Participants appreciated the chance to engage with knowledgeable professionals, which helped build trust and provided tailored advice.

> ***“Speaking directly to professionals, tips for handling situations.”***
>
> ***“Getting the opportunity to speak to people.”***
>
> ***“The staff were very helpful.”***

3. **Local Awareness and Navigation** - This reflects the importance of localised information and signposting to services that participants may not have previously known about.

> ***“Finding out what was available in Aberdeen.”***

Q - Have any of the conversations that you had today meant that you no longer need an appointment with another health or social care professional?



Most participants (9 out of 12) indicated that the conversation did not replace the need for a future appointment.

Only 2 participants felt that the conversation was sufficient to avoid another appointment.

The data suggests that while the conversations were helpful, they did not fully replace the need for follow-up with health or social care professionals for most participants.

However, the small number who said "Yes" indicates that for some, the session was effective enough to reduce service demand, which could be a positive outcome in terms of system efficiency.

Comparing the Outcomes of the two Patient Groups

Post-Diagnostic Support Awareness - Awareness was slightly higher among those diagnosed longer ago, possibly due to accumulated experience or exposure to services over time

Sources and Delivery of Support - While both groups accessed elements of the Five Pillars model, those with earlier diagnoses reported more variability and gaps in continuity.

Themes for Patient Feedback - Newly diagnosed patients expressed more emotional vulnerability and need for immediate clarity, while longer-term patients highlighted systemic gaps and a need for sustained support.

Impact of CAD on avoiding further Appointments - The CAD had a modest but similar impact across both groups in reducing service demand, suggesting its potential value in streamlining care.

What was found helpful – Both groups appreciated access to information, direct engagement with professionals and information of local services. However, respondents with a recent diagnoses were more focused on understanding dementia and finding out what support was available. Whereas, respondents who had had an earlier diagnoses valued practical advice (e.g., power of attorney) and navigation of care responsibilities.

Findings: Carer Follow-up Interviews

Nineteen respondents indicated they would be happy to be followed up for a telephone interview and were sent an email invitation to organise a suitable date and time. Eight did not respond, one email was undeliverable, one respondent indicated they would be out of the country and another respondent wished to withdraw. Nine participants booked, one did not answer calls, resulting in 8 completed telephone interviews.

All interviews were with the primary carer of the person who had been diagnosed with dementia in the previous 12 months. Carer's responses were thematically analysed for each question and where appropriate respondent quotes have been included (in Italics).

Q - Carers were asked whether anything had changed or were they doing anything different as a result of attending the CAD?

The dementia CAD was a catalyst for action - Many carers described taking new steps after attending the event — joining activities, contacting services, applying for benefits, and starting legal planning. This suggests the event was effective in prompting carers to move from awareness to action.

> ***"We've got things up and running now."***
>
> ***"That has pushed me to get more organised and I now have that in place."***

Carers are seeking connection and community - Social isolation is a common issue in dementia care, and carers responded positively to opportunities for engagement. The uptake of community activities like the AFC Football Memories and Living Well Café shows a desire for meaningful, dementia-friendly social spaces.

My husband is now going to the AFC football, memories or reminiscence… it is run by AFC."

"We have started going to the Living Well Café."

Access to services is improving, but still uneven - Carers were able to connect with services like Link Practitioners, Quarriers, and VSA, but some noted that location and follow-up responsibilities made access more difficult. This points to a need for more coordinated and equitable service pathways, especially for those outside urban areas.

"Quarriers got back in touch… told me to get in touch with VSA as we don't live in the city."

"You get lists of places… but you have to follow up with everything yourself."

Carers are thinking ahead, but need support - Several carers mentioned applying for benefits, exploring Power of Attorney, and discussing future plans with family. This shows a shift toward proactive care planning, but also highlights barriers like cost and complexity.

"We got told about putting the power of attorney in place… I have looked into that, but it is so expensive."

"Have applied for pension disability (used to be called carers allowance)."

Crisis situations still require escalation - One carer had to escalate concerns to the GP after a safety incident, showing that urgent support pathways need to be clear and responsive.

"Had to escalate to GP as mother was found wandering out the house during the night."

Rural isolation is a real barrier - Carers living outside Aberdeen expressed concern about transport, access to shops, and future care needs. Some are considering relocation to be closer to services and family, which reflects how geography can shape care decisions.

"We live out [Aberdeen]… trying to relocate into Aberdeen beside my son."
"No buses and no shops… waiting for a housing officer."

Not all carers are ready to act - A few carers said they were coping fine for now and would seek support when needed. This highlights the importance of timing and readiness in service engagement.

"Will contact if we need support, at the moment we are coping fine."

Q - Did you receive any information, at the CAD, that you feel might be useful or helpful for you in the future?

The event helped carers discover new services and supports - Carers were connected to services they hadn't known about before, such as CFine, Forget Me Not, Alzheimer Scotland, and local care providers. This shows the event was effective in raising awareness and signposting to relevant support.

"The Link Worker put my name down for CFine… they have information for me."
"I think it will be helpful in the future… now I know there are events and activities we can take my mother to."

There are gaps in follow-up and continuity of care - Several carers described missed follow-ups or poor initial contact with services like dementia outreach or GPs. This suggests a need for better coordination and continuity, especially after initial referrals or outreach.

"Dementia outreach were supposed to follow up with me, but they didn't."
"We went to the GP and he was a waste of time… the locum was very helpful and got the ball rolling."

Carers feel underserved and overlooked - There's a clear call for more carer-focused support, with some feeling that the event and services were more geared toward patients — who may not be able to engage meaningfully — rather than those providing care.

"Would have liked better information for the carers… most patients are not able to care for themselves."
"We were expecting to hear about the support a person needs."

Environment matters: accessibility and sensory considerations - The event was described as noisy and overwhelming, which made it unsuitable for some people with dementia. This highlights the importance of sensory-friendly environments and clear expectations in event planning.

"Too noisy and too much going on… would have preferred if it had been calmer and quieter."

"With hindsight, it would have been awful for her [mother] to attend."

Geographic inequity is a barrier - Carers outside Aberdeen felt disadvantaged, with some services only available to city residents. This points to a need for more inclusive service design and rural outreach.

> ***“Some things are only available if you live in the city.”***

Emotional strain and uncertainty are common - Carers are navigating complex emotions, especially when dealing with undiagnosed or early-stage dementia. Some feel dismissed by professionals, while others are overwhelmed by the uncertainty of what lies ahead.

> ***“I feel a bit patronised… GPs keep saying she’s doing well for her age, that’s not helpful.”***
> ***[Participant got quite emotional] “It’s just all so much to deal with..”***

Practical resources are valued - Leaflets, tips, and advice from Alzheimer Scotland, occupational therapists, and other providers were seen as helpful and something carers would return to. This shows the value of clear, practical, and accessible resources.

> ***“Dementia support and top tips… they were very good and helpful.”***
> ***“The OT was also very good… I may talk to her in the future.”***

Q - Do you think that the information that you received at the CAD will help to support you so you may not need an appointment with a professional in the future?

Carers are uncertain about future needs - Most carers expressed uncertainty about whether the information received would reduce the need for professional appointments. This reflects the unpredictable nature of dementia and the fact that support needs evolve over time.

> ***“Not sure… it will depend on how the illness progresses and the different stages my husband goes through.”***
> ***“I can’t really answer that question, as I don’t know what help we may need in the future.”***

The CAD helped raise awareness of support options - Even if carers didn’t feel the CAD replaced professional input, many said it helped them understand what support is available and where to go when they do need help. This shows the value of early signposting and resource awareness.

> ***“They [Link Worker] can’t do anything for us really, but they have given us links to what support is available.”***
> ***“I know a lot of support is available now having attended the CAD.”***

Timing of follow-up matters - Some carers felt the follow-up came too soon after the CAD, before they had a chance to act on the information. This suggests that timing and pacing of support are important to allow carers to process and apply what they've learned.

"This follow-up should perhaps have been a bit further from the initial CAD… we're currently working through applications and forms."

Gaps in initial support drive attendance - Several carers attended the CAD because they hadn't received any information at diagnosis, indicating a gap in early-stage support from professionals. This reinforces the CAD's role as a critical backfill for missed or delayed guidance.

"We didn't get any information when my wife was diagnosed… we wanted to know more."
"We don't feel that we are getting any information about what is happening."

Emotional and peer support was valuable - Even when practical outcomes were unclear, carers valued the sense of connection and reassurance from attending the CAD. This highlights the importance of peer support and shared experience in dementia care.

"It was good to see everyone together and you realise you are not alone."

Information was sometimes limited or missed - A few carers reported receiving minimal information or not engaging fully with the event, which may have limited its impact. This suggests a need for clearer guidance on what to expect and how to engage with the CAD.

"Only came back with the patient passport. Didn't pick up any other information."

Q - Is there anything that you learned at the CAD that you wish you had learned when the diagnoses was first made?

There's a significant gap in information at diagnosis - Many carers felt they were given little or no practical guidance when the diagnosis was first made. The CAD helped fill that gap, but ideally, this information should be provided immediately after diagnosis.

"Everything, we got no information when my wife was first diagnosed… she was given pills and we feel like we were just left to get on with it."
"Would have been helpful to know when he was first discharged from the clinic."

Financial and legal information is especially valued - Carers highlighted that learning about benefits, Power of Attorney, and other practical matters at the CAD was useful — and something they wish they had known earlier.

> ***"We got lots of information on areas like benefits and Power of Attorney that we didn't know anything about."***
> ***"The Doctor at Cornhill Hospital told us a lot… about benefits, Power of Attorney and DVLA."***

Timing and readiness for information varies - Some carers reflected that they weren't ready to absorb information at the time of diagnosis. The CAD was more useful once they had lived with the condition for a while and understood their needs better.

> ***"You don't know what you need then… six months down the line, you start to see and understand more of the problems."***
> ***"It was good to go to the CAD six months later… I had a better idea of what information would be helpful."***

Carers often have to navigate support alone - There's a sense that carers are expected to self-manage and chase up support, which can be overwhelming. The CAD helped clarify what they need to do themselves versus what services are available.

> ***"I was more clear about the things I would have to do myself… that there was not a service or someone else to take control."***
> ***"At the start you just get all this information thrown at you… then that's it, you are on your own."***

Peer support can fill gaps - Some carers relied on friends or informal networks for guidance, and felt that without those, the CAD would have been even more essential.

> ***"I have a friend who has gone through the same thing a year ago… if I hadn't had this information, a CAD would have been very helpful."***

Mixed views on cad content - Not all carers felt they learned something new. A few felt the CAD didn't add much to what they already knew or didn't engage with the materials.

> ***"No, I don't think so."***
> ***"Only came back with the patient passport."***

CAD format may be overwhelming for patients - Some carers noted that the event could be confusing or overstimulating for people with dementia, and recommended attending with support.

"We would strongly recommend that any patient invited to a CAD take someone along… the day was busy and could have been confusing."

Q - Have you any other feedback you would like to share about your experience of the dementia CAD?

The CAD provided reassurance and reduced isolation - Carers appreciated learning that support was available, even if they didn't need it immediately. The event helped reduce feelings of being left alone after diagnosis or discharge.

"The CAD took away that feeling that we were all on our own… it was good to learn that there was help out there, for when we need it."
"We found out about things that will be of help in the future… it was good to find out these things now."

The event environment was overwhelming for some - Several carers found the event too noisy, busy, or overstimulating — especially for people with dementia. Suggestions included better layout, quieter spaces, and more thoughtful design.

"It was quite busy… the noise level was a bit much for my husband."
"It would have been good if the coffee area had been in the middle… so I could talk to services while keeping an eye on my mum."

The CAD helped fill gaps left by clinical services - Carers described a lack of information from healthcare professionals, especially at diagnosis. The CAD helped bridge this gap by providing practical advice and signposting to services.

"We haven't had any information since my wife was diagnosed… it was really good to find out that there was so much out there."
"The psychiatrist at Cornhill tried to explain what was happening but it was very complicated and we didn't really understand."

The CAD should be clearly marketed as a carer-focused event - Some carers felt the event was misrepresented as a clinical appointment and suggested it should be marketed more clearly as an open day for carers.

"Marketing it as an appointment was a bit misleading — should be made more clear this is an 'open day'."
"Should make it clear it is a CAD for the carers, rather than for a diagnosed patient."

Some carers found the content repetitive but still useful - A few carers felt they already had much of the information provided, but still valued the opportunity to confirm details and connect with services.

> ***"We got all the information that we needed, which was mostly what we already had."***
> ***"The only person we would have liked to speak with was someone from housing… but they weren't there."***

Interest in future CADs - Carers expressed a desire for the event to be repeated, showing that despite its limitations, the CAD is a valued resource.

> ***"I would really like to see this event happen again… I would definitely go back as I found it very helpful."***

Combined Conclusion

The Dementia CAD has demonstrated significant value in enhancing post-diagnostic support for both individuals living with dementia and their carers. Designed around Alzheimer Scotland's Five Pillars Model, the CAD provided a person-centred, locally tailored experience that helped bridge critical gaps in care and fostered emotional and practical empowerment.

For carers, the CAD acted as a catalyst for action, prompting them to apply for benefits, initiate legal planning (such as Power of Attorney), and engage with community-based dementia-friendly activities. Many discovered services they hadn't previously known about including; CFine, Alzheimer Scotland, and local peer support groups, which helped them feel more confident and prepared for the future.

Patients and carers alike reported improved awareness and understanding of dementia, future planning, and available support networks. This was especially impactful for those who had received little or no information at the time of diagnosis. The CAD filled a void left by clinical services, offering clarity and reassurance where primary care had often failed to provide adequate follow-up or guidance.

The event also delivered strong emotional reassurance, helping attendees feel less isolated and more connected. Quotes such as "*The CAD took away that feeling that we were all on our own*" and "*It was good to see everyone together and you realise you are not alone*" reflect the powerful sense of community and shared experience fostered by the CAD.

However, the format and environment of the event presented challenges. Several attendees found the open-day style noisy, overwhelming, and confusing, particularly for those living with dementia. Feedback highlighted the need for clearer communication about the event's purpose, more private spaces for sensitive conversations, and a layout that better supports both patients and carers. These environmental factors were consistently raised across both data sources.

A notable insight was the need for carer-specific support. Carers expressed that their own needs were often overlooked, despite being central to the care journey. They called for more tailored information and resources that acknowledge their role and responsibilities.

While most participants indicated that the CAD did not eliminate the need for future appointments, a small number felt it provided sufficient support to reduce further professional contact. This suggests that with refinement, the CAD model could contribute to more efficient care delivery and better resource allocation.

Finally, there was a strong appetite for future CADs. Participants valued the opportunity to connect with peers, access practical advice, and feel supported in a welcoming environment. The CAD has shown its potential as a sustainable and impactful intervention — one that informs, connects, and empowers. With improvements in accessibility, stronger integration with clinical pathways, and a continued focus on both patient and carer needs, the CAD could play a vital role in transforming the dementia care journey across the region.