

Consultation about Dementia Services within NHS Forth Valley with Yvonne Cairns, Nurse Consultant for Dementia and Delirium and Emma Douglas, Team Lead from the Community Mental Health Team.

Held on Thursday 17th September 2026

At the Carers Centre, Falkirk.

Chaired by Sharlene Ramage Carer Participation Development Worker.
Online option facilitated by Amanda Rutherford Adult Carer Support Worker.
Notes by Dana Horsburgh Carer Representative and Zoom note taker.

Quick recap

This consultation focused on updates and improvements to dementia services in Forth Valley. Yvonne Cairns, the Nurse Consultant for Dementia and Delirium, provided updates on several key initiatives including the implementation of carers cards, training programs for reception staff in emergency departments, and the importance of "Getting to Know Me" documents. Emma Douglas the Team Lead from the Community Mental Health Team shared progress on developing a new post-diagnostic support (PDS) pack and personal care plan, which will be rolled out in the coming weeks with QR codes linking to online resources. The discussion highlighted challenges around measuring carer experiences versus system metrics, improvements that are underway that have been shaped by Falkirk's carers and finished with Emma and Yvonne planning to continue these discussions to update carers about the progress made.

Next steps

Emma Douglas and Yvonne Cairns

- Share the Personal Care Plan document with Sharlene for distribution to carers who requested it. Emma and Sharlene have done this.
- Drop into the Carers Centre physical copies of the "Getting to Know Me" document, which can then be available for those who want them.
- Arrange with Sharlene dates for 2027.

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- Contact Carly Crooks at the Carers Centre about "Getting to Know Me" how to complete sessions (carers requested to have these sessions and Sharlene explained this would be up to Carly who is a training co-ordinator).
- Send the list of wards with Dementia Representatives to Sharlene.

Sharlene

- Send the link for the out-of-hours palliative care questionnaire to anyone who requests it, especially those with palliative care experiences.
- Follow up with anyone who wants to share their experiences with the palliative care review team.
- Once received "Getting to Know Me" documents, Sharlene will contact attendees who have requested them.

Upcoming Consultations and Events

Sharlene discussed upcoming consultations and events, presentations from NHS Keep well Service and Falkirk Football Foundation on the 28 September 10am -12 noon. Briefly mentioned a review of out-of-hours palliative care services and invited participants to share their experiences with Sharlene who would then share at the next palliative care meeting and announced an upcoming Alcohol and Drugs Partnership event on the 13 October 1:30pm - 4:30pm.

The importance of carer engagement.

Yvonne discussed the importance of carer engagement in health and social care services and emphasised the importance of listening to carers' voices. Yvonne shared personal experiences where her initial assumptions changed after she had direct engagement with carers.

Emergency Department Staff Training Implementation and Development.

Yvonne discussed the implementation of training for reception staff in emergency departments and assessment units to better recognise and support carers who attend these reception areas with their loved ones, this training is scheduled to begin soon. **This training is a direct result of carers at these sessions saying that they are often not recognised as partners in care, so thank you!**

Yvonne described the development of another form of dementia training for staff in care homes and NHS wards, that was initially piloted in August-September and is now running monthly except in July and December. The training covers topics including aging brain, dementia, delirium, and

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stress/distress management through interactive sessions and case studies. The program has been successful with 73% of staff choosing to attend and has expanded to include various healthcare professionals across Forth Valley. Yvonne reported that care homes participating in the training have shown reduced hospital admissions for delirium and falls, while those not participating have higher admission rates.

Dementia Hospital Care Challenges

Carers discussed challenges in hospital care for people with dementia and their carers, highlighting issues with first impressions, communication gaps, and stress factors. Carers suggested establishing clear points of contact for carers to address concerns during hospital visits.

Yvonne emphasised the importance of carers providing feedback while their loved ones are receiving care, particularly in emergency departments. Yvonne has asked patient relations to forward all complaints regarding dementia to her, if people have good or bad experiences, please try to speak with staff first and let them know, you can also share your experiences on care opinion, if possible, look at name badges and provide names please.

Dementia Champions Program Status Review

A carer asked about Dementia Champions. Yvonne discussed the history and status of Dementia Champions in the hospital, explaining that while there were 34 champions in Forth Valley before COVID, many have retired or no longer work within Forth Valley, making it difficult to find current representatives. Yvonne noted that the University of West Scotland has reopened the program but now charges for participation.

New Dementia PDS Pack Launch

Emma presented the new post-diagnostic support (PDS) pack for dementia patients, which replaces the previous "horrible brown envelope" with a more user-friendly format. The team worked with Alzheimer's Scotland, carers and people with lived experience to improve the information provided and developed a personal plan to complement the pack. The new PDS pack will be rolled out in the coming weeks with a QR code linking to additional resources on an NHS Forth Valley website and will be stored in protective wallets to keep the information safe. Sharlene now has a copy of this and if you would like one, please ask.

Carers Views/comments/Suggestions

- A carer mentioned going to a recent vaccine appointment with the person that they care for, staff did not ask if the person had a dementia diagnosis, this carer stated that the RSV vaccine can interact poorly with other vaccines and this carer worries about patients with dementia attending solo and not having capacity to explain that they had for example their flu vaccine in the morning. Sharlene has contacted NHS staff to inform them of this.
- A carer mentioned the importance of being well when you receive your vaccine.
- A carer mentioned stages of dementia and another carer asked if there are stages of dementia. One carer spoke about Alzheimer's Scotland's information about the 7 stages of dementia; these 7 stages are only for Alzheimer's and Yvonne and Emma both emphasised that as individuals everyone's dementia journey is different.
- A carer said that they asked their GP to tell the person that they care for it was unsafe to drive, the carer said that the GP told them that they couldn't do this.
- A carer said that their GP was a great help and informed the cared for person that it was now unsafe for them to drive, the carer really appreciated this support as it "took it out of their hands".
- A carer said that their GP does an annual dementia check, some carers commented that they did not know that they could ask for this.
- A carer said that during a hospital visit the staff member asked them, "what stage do you think C's dementia is at?" this carer had never heard of stages and panicked that they did not know.
- A carer suggested a QR code for the "Getting to know me" document, this carer said that if they had a QR code they could easily log into the form to make changes.
- A carer raised concerns that dementia and Alzheimer's are not monitored by health professionals, this carer said that other illnesses like cancer are monitored and they feel that this should be the same for all illnesses, many carers in the room agreed with this.
- A carer said that they got post diagnostic support at the beginning of their cared for person's journey, however now that the condition has progressed, they feel like there "is nobody there".
- A carer said that their Alzheimer's worker is great, however they are worried that "she won't be there forever".
- A carer commented that Post diagnostic support "is far too early, you need it later on".
- A carer commented that the old post diagnostic support pack was far too big.
- A carer commented that the new post diagnostic pack was "wonderful" they said that they wish that they had received this pack.

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- Many carers in the room preferred the new pack, it was great to see that carers ideas and thoughts were added to the pack.
- A carer shared their frustrations that due to system incompatibility they need to re share their "Getting to know me" document each time they visit the hospital.
- A carer said that she forgot to show her purple Alzheimer's Scotland card, and she wishes that the staff had asked for this, Yvonne will show staff these purple cards during her training sessions.
- A carer suggested that reception staff at A and E should ask carers if they have a "Getting to know me" document, if they need it updated or don't have one they could complete/update this whilst waiting to be seen.
- A carer mentioned that staff in NHS FV seem very busy and they wonder if staff will have time to read the "Getting to know me" document, Yvonne said that during the training she will emphasis to staff that reading this will save them time and support good connection with the patient and carer.
- A carer asked how Yvonne plans to capture carers experiences when audits of accident and emergency are occurring, Yvonne is going to meet with this carer and Sharlene to discuss ways to do this.
- A carer asked about dementia champions, this prompted conversation above, Yvonne will share the list of wards where dementia champions are present.
- A carer mentioned that there should be prompts for carers to update the "Getting to know me form"
- There was discussion about power of attorney and the importance of this, whilst recognising the need for anyone applying for this to be aware of the complexities of this.
- A carer said that there should be guidance on how to complete the "Getting to know me forms" carers would like a how-to session in the centre and Yvonne will speak to Carly the Carers Centre training co-ordinator about this.