West Dunbartonshire Local Engagement Network
People Living with Dementia and Carers Workshops:
28th and 30th November 2017

The Chair of the Dumbarton/Vale of Leven Local Engagement Network (LEN) welcomed everyone to both session and posed a series of 4 key discussion questions for consideration.

Q1: How well do you feel supported? How do you access services?

Discussion showed a level of variation in support across the area from 'amazing support' to 'patchy and inconsistent'.

Responses included:

- Support is amazing in this area. When we talk about it with people from other areas they are always surprised at what we have been offered
- I would say its patchy – I hear good and poor examples
- Well supported but now my situation has changed
- Getting support was difficult in the beginning but that was 7 years ago and I know things have improved
- Denial (on both sides) can be a barrier to looking for support and so feeling supported
- Stigma is still an issue and some people still try to just manage rather than accept support
- Support can vary depending on which service you are speaking to and your contact point (Telecare, Carers Centre, Social Work)
- Issues of patient confidentiality can be challenging for the carer – patients can keep things hidden from family members in the early stages of diagnosis limiting the potential for support to be accessed
- Can be difficult to get to know what kind of support is available
- It's difficult to get access to social work – it can take a long time for them to get back to you and you have to keep contacting them

- You are shell-shocked at the point of diagnosis (patient and carer) and it is hard to take in information so you can miss out on services until things have progressed quite a way
- Most of the time you can only access services by going out and looking for them. The Carer’s Centre and Alzheimer Scotland centre have been really good
- Accessing a broader range of service is easier if you are coming in from the health side but it seems to be a lot harder on the social work side

Q2: What does Link Worker provision look like for you?

Discussion showed varying experiences and perspectives on the provision of one year post-diagnostic support. Participants also expressed conflicting views on the most beneficial timing of the support Link Workers could offer.

Responses included:

- Link Worker has been very important as our situation improved greatly since she became involved. However the time from notification of the link-worker to actually seeing her was 8 weeks
- We were told about Link Worker support but we had to chase it up
- Need to be referred as soon as you are diagnosed – Link Workers save lives
- I’m not sure who the Link Worker is. A mental health nurse comes to visit I think it might be them. Jargon can be a problem to understanding
- Link Worker service is good but they made it clear that they were there for my husband and not for me and that wasn’t helpful
- GPs don’t have time and don’t know everything about dementia so the Link Workers are vital – but there aren’t enough of them
- There is a poor level of understanding and recognition of the term. Is it the same as a Dementia Advisor?
- Having access to the Link Worker at the point of diagnosis was crucial – my husband is only 52 years old and the diagnosis came out of the blue and we wouldn’t have known where to turn
- When you are first diagnosed both the patient and the carer can be in denial. Things don’t seem too bad and you are managing so you don’t need much

support. Then a year later when you need it, it’s gone. You should be able to dip in and out of it as you need to

Q3: What community supports work well? What would you change if you could?

- Respite care has been useful – short breaks and hourly respite to allow me to go out shopping and go to appointments
- Day care services have worked well for us. It would be good to see a broader range of activities
- Care and Repair and Greenspace have been great for helping us manage the house and garden
- Carers Centre and the Alzheimer Scotland centre have been really useful
- Alzheimer Scotland groups like the Dawdle Group are good places to go
- We use the library and the leisure centre. However the changing room set up can be difficult. It would be easier if the carer could go in with the person to help them get changed. Maybe the family cubicles could be used?
- Being able to access toilets in public building can be an issue
- Using the Leisure Centre facilities can be difficult as the person finds it harder to follow instructions. Some more flexible provision would be helpful
- Dementia Friendly community work seems to have increased awareness and made people more sympathetic. Some areas are very friendly like Dumbarton East
- There needs to be a greater awareness of SDS (self directed support); it’s not mentioned at all by social workers unless you ask. We should all know that it is an option for us
- Services need to be more flexible. My husband will only get up when he wants to get up so having a carer come in at set times to get him up or help get him to bed doesn’t work for us
- West Dunbartonshire don’t include washing (due to incontinence) in with personal care but this would be really helpful for me
- There needs to be better follow up from social work. You can speak to the duty social worker then wait weeks for them to call you back

- Provide counselling support services for the carers to help them feel more part of the support package
- There is never a named person you can contact. Something like the Named Person service for children would be really useful for people with dementia
- It would be good to have access to a factsheet on diagnosis – things which we should think about eg. Power of Attorney, claiming the council tax rebate. It may not be the right time to do all of those things, but having the factsheet to refer back to and use the information when you are ready would save on all the time of trying to track down information and the right person later on
- More support for people diagnosed at an early-age is needed
- Have consistency in home carers – having different staff members come in and out is disruptive for the person and their carer
- Community Alarm system is really valuable but billing via standing order is causing problems for people and could cause people to stop using the service. Why can't the billing be changed to Direct Debit?
- Empower us by creating a 'road map' for us so that we can see all of the available supports
- Need to give some more thought to what happens if the carers get ill. I've had some bad health and really struggled. I hope the new Carers Plans will help address this
- It would be good if staff understood that carers can be frustrated and don't take our frustration as an attack on them – it's the 'system' that we find difficult

Q4: What current activities could be halted to allow service improvements to be made?

- All services should be reviewed and any that have poor attendance should be curtailed
- We know that the HSCP funds a range of services including those provided by voluntary organisations – all of these need to be in place
- I don't think there is anything that should be cut. I know funding is tight but we should look at how some government money could be taken from weapons and aid and reinvested into health

- Nothing should be halted but if we improve communication and information and work in slightly different ways we should be able to do more. Having information sheets would help us to find the right services at the right time

Key actions arising from the session:

- Consider how to improve information and communication options that could help support carers in their caring role
- Address the general desire for increased public information around SDS and its potential benefit for people living with dementia
- Review payment methods for the community alarm/telecare services.