

Powys Dementia Network January 2021

How can the diagnosis process in Powys be improved?

What stops people seeking help when they first notice symptoms of dementia?

How can we make things easier for people?

A compilation of comments made by those living with dementia, their carers and professionals working with them during the workshop session

Powys Dementia Networks happen every six months. They are jointly organised by Dementia Matters in Powys and Powys Association of Voluntary Organisations, with much support from other third sector organisations. If you wish to be added to the list of invitees, please contact Sue Newham, sue.newham@pavo.org.uk



How can the diagnosis process in Powys be improved?

Consistency of pathway which allows patients to be treated holistically and as individuals

- By acknowledging that no two patients are the same, a one size fits all approach doesn't work and every patient has different requirements. Some may wish for a non-medical approach.
- Although the process of diagnosis needs to be individualised, there does also need to be consistency around it. There needs to be a seamless process of diagnosis.

Length of diagnosis process

- The time between appointments needs to be reduced and the diagnosis process would benefit from being quicker overall. This is currently affected by covid, so support for people during this time is very important.
- Sometimes people are not being diagnosed with dementia because of mental health and other issues masking the problem.



“In general, people don't know enough about dementia and so there is a stigma around it. People do not realise that dementia is not just about memory loss.”

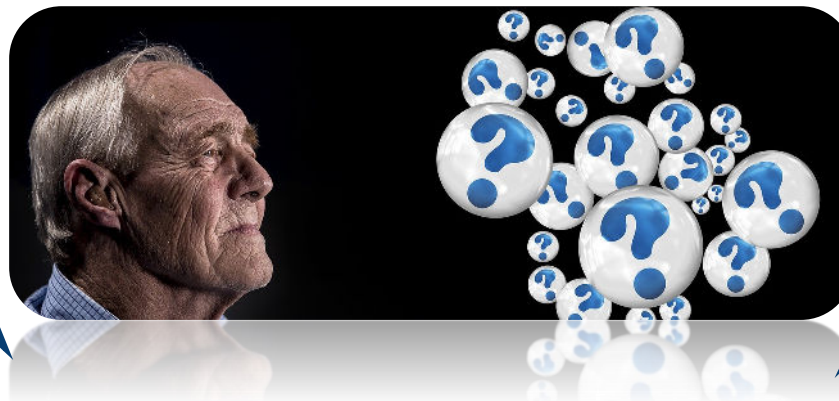
“A single point of contact would be very useful.”

How can the diagnosis process in Powys be improved?

Information for patients

- The process needs to be explained to people so that they know what is going to happen and they know to expect at each stage. It would be useful to have a target timeline to give to people.
- A lot of information is given out and it can be overwhelming. It would be good to have an information pack or wellbeing pack as a printed booklet that supports the person with their dementia journey.
- Notes and information from the clinician could be shared with the patient after an appointment in written form. This makes it easier for the person themselves to remember what has been discussed and for family members to be aware too. It's not easy to remember details from appointments.
- People should be made aware that they are entitled have an advocate supporting them at appointments, either family member, friend or professional advocate.
- It would be great to have a "faces and names" directory of staff to help people know who they are likely to be seeing and what their role is.
- How can organisations work better with GP surgeries and cluster groups to support people before they actually get a diagnosis?

"Someone needs to prepare people for the conversation about the diagnosis."



"Notes from the clinician could be shared with the patient after an appointment in written form."

How can the diagnosis process in Powys be improved?

The diagnostic process

- The memory test questions could be improved. If you can't answer what seem like simple questions, you feel very embarrassed.
- There is a lack of communication between different services, so you feel as if you are repeating things again and again.

"The person coming in may come alone, and may forget to mention relevant events and patterns. You can't mention what you can't remember."

Family involvement

- The involvement of family members/ friends is important to allow Memory Clinic staff to get a true picture. A case was cited when a family member was not listened to so a dementia diagnosis was delayed unnecessarily. Another case highlighted the lack of information and support for family members.



"Family involvement is encouraged and welcomed by the Memory Clinic, but can only happen with the consent of the patient."

"Support is needed for families before, during and after diagnosis, as they often feel very uncertain and stressed."

How can the diagnosis process in Powys be improved?

Differences across Powys

- There's a discrepancy between services offered in the North and South of the county. A more coordinated approach would be better.
- Communication between different services can be improved.
- Advocates in appointments would be useful. Anyone can access advocacy services and family members can be advocates.

"The ideal would be one, named, support worker who can provide tailored support from the time of diagnosis."

Post diagnosis support

- It would be good to have an information pack that supports the person with their dementia journey.
- People need a phone call the very next day to give reassurance and information. People don't need everything at once while they are still dealing with the shock of the diagnosis.
- Support is offered to people at the point of diagnosis, but they may be too shocked or too muddled to take up the offer straight away. A support worker could be allocated to an individual at diagnosis, so they can contact the person at intervals to see if they now need additional support or information. Having Admiral nurses in Powys would really be helpful. (Dementia UK scheme)
- People need to be able to talk to someone who has been through it. People living with dementia connect more with other people who are living with dementia. Support groups are very important.
- The Herbert protocol needs to be explained and promoted to people living with dementia and to their family/carers. The police can put a marker on an address to help them when attending an incident, even before a diagnosis of dementia.

What stops people going to their doctor when they first notice symptoms of memory loss?

Personal fears and attitudes

- Fear of the unknown and of change
- People may prefer to deny what is happening
- They may be scared that it is something other than dementia, or may not realise that health issues other than dementia can affect memory and thought processes.
- People may not recognise issues in themselves or not accept that something is not right.
- Families may be worried about mentioning to their parents/ relatives that they need to seek help, or to other family members that they have concerns about that person.
- People may be worried and unsure about the diagnosis process.

“People fear the loss of liberty and their independence being taken away.”



“They have concerns about the impact on their life. If they lose their licence in an isolated, rural area it could be really difficult for them. This may be particularly an issue in the farming community.”



“People may be fearful that it is the end for them.”

“They are scared of ending up in a care home.”

What stops people going to their doctor when they first notice symptoms of memory loss?

Social and relationship barriers

- People don't know that it is possible to live well at home with dementia.
- A fear of people treating you differently, changes to relationships and friendships.
- If people are providing care for others, they may be afraid of the consequences if they receive a diagnosis of dementia.
- People are worried about becoming isolated from family members.

“The triage system puts people off contacting their GP. In rural areas, it is likely that people will know the receptionist. They worry about having to tell someone they know about their health issues.”



Stigma

- There is a real stigma around the term dementia which makes people fearful of such a diagnosis.
- TV/media shows dementia in a negative way, or avoid the subject, making it seem taboo.

GPs and GP surgeries

- There may be physical/ transport issues with getting to the GP surgery.
- The relationship with the doctor can affect how willing people are to seek help. They may not feel that their doctor really knows them. They may not have seen eye to eye with them in the past. They may worry that the GP won't take them seriously.
- Men are often less willing to accept that they need to see their GP.
- Access to GPs is perceived as being difficult anyway and people put off making appointments particularly during covid.

How can we make it easier for people?

“Individuals living with dementia telling their story is the most powerful way of reducing stigma around dementia. People can and do live well with dementia.”

“We need to show that it’s alright to talk about memory loss and dementia.”



Raising awareness

- Raise awareness with a collaborative approach that involves statutory bodies, private sector, third sector and communities to provide support, remove stigma and raise awareness.
- A campaign to show people in the early stages of dementia might alter people’s perception
- People need to be aware that memory problems may be associated with other conditions other than dementia. Putting off going to the GP can mean you don’t receive help with other illnesses.
- Encourage and develop Dementia Friendly Communities.
- Providing information about where to seek help, diagnosis, support through a wide variety of channels. No single way of raising awareness is sufficient on its own.
- Develop guidelines for neighbours and friends about raising the subject of dementia with individuals or carers if they have concerns.
- Develop an online self-assessment checklist that people can run through which can tell them if they should seek further help.