

Fundamentals

Receiving a diagnosis of dementia can be a life-changing and traumatic experience – not just for us, but also for our family and friends.

Our leaflet is designed to help medical professionals who do this difficult job. Our hope is that this will make things better for all of us. We suggest:

- Listen carefully to what we say. Sharing a diagnosis should be a conversation between us; it helps if you adapt your language to fit with what we understand.
- We should be given the choice of whether we would like to have our partner/significant other(s) with us when a diagnosis is shared.
- The diagnosis should be shared in an empathic, sensitive and caring manner. It should not be rushed.

“Trust has to be built up between us and the clinician.”

What information should be communicated

We will all have our own questions, concerns, and anxieties about the future. It is important to be mindful of such issues and to ask us directly what we would find most useful to discuss.

Some of us may find it helpful to know how the specific diagnosis was reached in the first place. A discussion about the assessment process and how the diagnosis was formally confirmed may be validating for some of us.

Most importantly, we would like to be reminded that it is not the ‘end of everything’ when a diagnosis is shared with us. We find it invaluable when we are told that we can live well with dementia.

“My doctor should have had a chat with me and not left it to my husband.”

“Clarity and honesty is key in the way information is communicated.”

Post-Diagnostic Support

Once a diagnosis has been shared, we found it important to talk about the diagnosis. We need space and time to take in what we have just been told. With this in mind, it is important to be mindful that there is a limit to what information we can take in at the current time.

Taking into account the situation, it may be useful if we could have a follow-up appointment after a diagnosis is shared. Not all the information we are given at the time of diagnosis will sink in. We are likely to have more questions once we have had time to process the diagnosis.

Additionally, information about how we can link to other services in the community for post-diagnostic support for me and my carer would be helpful.

“Nothing was said to me; it was all said about me. It was like being a child again. I was immediately demoted – like I was no longer capable of making a decision myself.”