

ARC East of England
Stevenage Dementia Involvement Group

Receiving and sharing a Dementia Diagnosis



February 2021

Stevenage Dementia Involvement Group

Stevenage Dementia Involvement Group aims to provide opportunities for people with experience of dementia to have their voice heard and to have influence on research and the planning of new services. Each session the group will discuss a particular topic relating to living with dementia or health and social care services in Stevenage.



Photos shared with permission from the group.

This group is based on a similar model to SHINDIG- a collaborative project between Sheffield Health and Social Care NHS Foundation Trust and Alzheimer's Society. Stevenage Dementia Involvement Group asks for people's views to shape research as co-researchers or experts by experience rather than as research participants.

Stevenage Dementia Involvement Group was held virtually on 9th February 2021. In attendance were five people with experience of living with or caring for somebody with dementia. Facilitating the group was Nicole Darlington and Elspeth Mathie (Researchers from the University of Hertfordshire) as well as Su Harvey from [The Red Shed Project](#), Stevenage. The group welcomed Gianna Kohl (Researcher from University College London) who is doing research on disclosing a dementia diagnosis to other people and how technology can support this decision. This tied in with the topic of the session which was **experiences of receiving and sharing a dementia diagnosis**.

Summary of discussions

The different experiences of receiving a diagnosis

The group shared their different experiences of receiving a dementia diagnosis. Age of diagnosis, time since diagnosis and type of dementia diagnosis (e.g. Alzheimer's Disease, Vascular Dementia) differed between group members.

- The first contact for advice was their GP who would perform dementia screening tests (such as counting back from 100 in 7s) and refer onwards to The Memory Clinic in Stevenage.
- Before The Memory Clinic was set up, patients were referred to a specific department at their local hospital.
- Experiences of attending post-diagnostic support groups were shared and rated highly however these were only available for a limited time after the diagnosis (usually 6 weeks).

Most of the group agreed that receiving a diagnosis for themselves or their family member was helpful, "*made life easier*" and made sense of changes in behaviour. The group also mentioned the experience of family members (parents) who had also received a diagnosis.

"*Fear of the unknown*" was mentioned as an emotion felt a lot by the group at point of diagnosis. The group felt that they were given lots of information at their appointments with little time to process.

The language used by health professionals and the manner in which the diagnosis was explained was crucial; negative phrases such as "time to get your affairs in order" had remained with one carer. The importance of positive language was emphasised.

Sharing a diagnosis with other people

- All the group had experience of sharing their diagnosis with others soon after receiving it.
- Carers felt that a diagnosis provided an explanation of any unusual or inappropriate behaviour when in public.
- The idea of wearing a bracelet or something to identify someone with dementia was discussed.
- The group found that sharing experiences with peers who were going through similar experiences was helpful as they were sometimes more understanding than family members.
- People were often understanding when told about the diagnosis however some group members had experiences of losing friends after revealing their diagnosis.
- Carers found that their social life reduced after their family member's diagnosis as friends often assumed that they were managing.
- COVID was mentioned as a factor which had further reduced social contact, increasing isolation and the need for carer support. Some carers had connected through WhatsApp.



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What would help make life easier?

Group members acknowledged the support and information put in place when first diagnosed but often felt alone after the 6 week post-diagnostic period.

The group appreciated that health services were busy.

The group's recommendations on what would help:

- A “*dementia hub*” – a single point of support was mentioned, where people can go for information and find out what services, groups are available locally.
- Support available in the middle and later in the dementia journey, not just at diagnosis.
- Contact from health professionals post-discharge every now and again to check up on their wellbeing. The members felt that support was only provided straight after diagnosis or when in crisis situations.
- A shorter wait to be re-referred to health services.
- Documents specifically for the person with dementia or carer on what to expect at different stages of the dementia journey. Although it was important not to overload with too much “*scary*” information.
- The session ended with one member reminding us that every person's diagnosis and situation is different, and services must be able to adjust accordingly.

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Conclusion and next steps

This group provided people with experience of living with dementia the opportunity to share their experiences on receiving and sharing a dementia diagnosis.

At the end of the meeting the group agreed to think about possible topics for the next meeting. The next meeting will take place in April/May 2021. Information about the next group will be sent to group members.

This group is organised by researchers from the University of Hertfordshire as part of the National Institute of Health Research Applied Research Collaboration (ARC) East of England. For more information, or if you are interested in joining or visiting the group, please contact Nicole Darlington, n.darlington@herts.ac.uk or ARCOffice@cpft.ac.uk

or visit <https://arc-ee.nihr.ac.uk/stevenage-dementia-involvement-group>.