Enabling people living with young onset dementia to continue working: a study

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A short bit about us...

Jannine

Sue
About our project...

• One UK care provider employer
About our project...

• One UK university employer
We are speaking to:

- Staff who are line managers - who have people reporting to them
- Staff who are not line managers
- Human resources and occupational health staff
- Union representatives
We are reading the policy documents...

For example:
– Equality and inclusion
– Disability
– Capability
– Performance management
– Absenteeism
Guided by:

• An ‘expert by experience’ – a person living with dementia who continued working

• A researcher from the School of Dementia Studies
What we found

• We were not able to talk with any existing employees living with young onset dementia

• Some people talked with us about what happened when staff developed - or entered the workplace - while living with young onset dementia

• There were mixed views among the different groups we spoke to about the best way forward
Good practice we have encountered

• Observing when colleagues are struggling

• Team members feeling able to alert their managers

• Constructive and non-judgemental communication
Sally: We could spot the lady was, erm, quite disorganised and if we were all talking at the same time she was really confused and she couldn’t handle a lot of information at the same time, er, she really couldn’t follow orders, if I could say it that way. Erm, she was disoriented. She couldn’t ... erm.. one minute she went to one room and the next minute she forgot where she is and how to find that room again.
Team members feeling able to alert their managers

**Rose:** well, what we did, we spoke to her and just... and you know, we didn’t raise it with anybody else. We spoke to each other about it, didn’t we?

**Sally:** First.

**Rose:** First. ......[Then] we spoke to Beth, didn’t we, and then you [Beth] spoke to Maggie...

**Beth:** Well, we went together, didn’t we, to speak to Maggie, and then Maggie and I just spoke to her.
**Maggie:** So I had a chat with her, erm, and I said I would support her through it, erm, and I rang the Job Centre and saw the Job Centre and I suggested she went to see her GP erm because I did explain, you know, I know she was only young but there is things they can do for you. …As I say I [contacted] the Job Centre because I felt it was unfair that she was made to look for jobs. I felt that because she was put under pressure by […] the Job Centre to say you’re going to have to look for jobs. So I explained to the lady at the Job Centre that, you know, what happened. With her [Anne’s] permission … and she [Anne] accepted everything I said, and she actually thanks me very much for being so kind. But I weren’t being kind. I were worried about her.
Other examples...

To:

– Discuss alternatives in an open minded way

– Explore on-going adjustments to work and the environment

– Take a positive approach to risk

– Achieve a dignified exit from work when that time comes

– Continue contact with the workplace where the person living with dementia wants this
This study and next steps

Next steps…we will:

• Write a proposal for a larger study

• If we get funding for this we will:
  – Include more organisations
  – Work with more people who are living with young onset dementia
  – Explore different models for helping work organisations to be more inclusive for people living with dementia
Some questions for you....

What support structures are people using?

Who should we speak to?
Thank you