
WEEK FIVE HANDOUT: RELATIONSHIPS – TO TELL OR NOT TO TELL?



Reactions of strangers

Often, people who have dementia worry that if other people find out about the diagnosis, then they will not want to know them, or will reject them in some way. Because of this, they may decide not to tell anyone and become very self-conscious when they're out in case they make a mistake.

However, in general, most people are either too busy getting on with life to notice, or would be sympathetic rather than rejecting.

Often, the biggest problem is that people cope with their dementia by staying at home or avoiding situations that might be upsetting for them. As well as having to deal with the memory problems that the dementia causes them, they also now have to avoid situations where other people might notice there is something wrong. This, in turn, adds to the problems that we've been discussing in the last few weeks.

The advantages and disadvantages of telling other people about your illness

Take a moment to list the advantages and disadvantages of sharing your illness with others.

WEEK FIVE

Advantages	Disadvantages

Would you want to tell people about having dementia?

Who would you feel you can talk to about having dementia? How would you like to tell them? Feel free to talk this through with your partner or family.

Who would you want to tell?	How would you want to tell them?

Coping with social situations

When you have a problem with your memory, the people around you may be keen to help, but may not know how to do this. It can be useful to think how you would like people to help you.

Here are some common examples of how people say they like to be helped:

People sometimes like

- ✓ Being given a suggestion if they can't remember a word.
- ✓ Being given a prompt.
- ✓ Having plenty of time to remember.
- ✓ Others joking *with* them (not at them).
- ✓ Getting help when they ask for it.
- ✓ Other people being sympathetic.
- ✓ People writing things down for them.
- ✓ Being tactfully reminded.
- ✓ Talking to one or at most two people at a time.



People don't like

- ⊗ Having it pointed out to them when they repeat themselves.
- ⊗ Being given too much information to take in.
- ⊗ Being interrupted so they lose their thread.
- ⊗ Having others jump in too soon without giving them time to work it out.
- ⊗ Being rushed.
- ⊗ Others speaking too quickly.
- ⊗ Being in large group conversations.
- ⊗ Having others take over and giving help when it isn't necessary.
- ⊗ Others being impatient.
- ⊗ Being put on the spot by questions like "What have you done today?"

Helping others to help you

In general terms, there are three golden rules:

- ✓ **Explain your situation.** For instance, you might tell people you have a problem, for instance, “My memory is not very good these days”, so that they can understand and make allowances for you.
- ✓ **Be clear about what you want.** For instance, let people know if you would rather do things yourself so that they don’t take over, or ask people to slow down if they are rushing you.
- ✓ **Show appreciation when help is given.** When people are helpful, make sure that you thank them. If you do need help, ask in a nice way.

Discuss with your family or friends what you find helpful and what you don’t. It might be useful to write a list together as a reminder. This will help you both decide what you need to do more of and what you need to do less of.

Some examples of ways of asking for help

- ✓ **Being put on the spot/asked for information (for instance, telephone number, reference number)**
 - Tell people that you have a memory problem and explain you need some extra time.
 - Ask if you can come back/ring back later.
- ✓ **Seeing the doctor and remembering what to ask/what was said**



- Write questions down before you go.
- Write down what is said at the time or while it is fresh in your mind.
- Remember that it can be helpful to have someone with you.
- ✓ **Being criticised**
 - Spend time talking to the person and explaining how you feel.
 - Ask the person to stop doing it/suggest an alternative that they might say so that you don't feel criticised.
 - Remember that they might not mean anything by it/nobody's perfect.
- ✓ **People jumping in/assuming you can't remember or do something.**
 - Find a way of telling them that you *can* do it or would like to do it.

Explain that sometimes you might not be able to remember something immediately but with a little more time you might be able to.