

# Getting Alongside People with Dementia and their Carers

## How can we help?

Things we can do in order of increasing involvement:

- Develop an open, helpful and non-judgmental attitude towards people who are forgetful or confused; step in to help sensitively if we can see someone is struggling
- Get alongside someone you know – are you able to offer practical or emotional support that will offer relief or comfort and help to spread the load?
- Volunteer to help in local groups and services that help people with dementia and their carers stay part of their community

## **Top tips for communicating with a person with dementia**

Slow down

Don't panic

Let them show you the way – more listening, less talking

Use objects, cues, prompts in the environment to stimulate conversation

Keep trying to understand but know when to stop – remember that only 10% of all human communication is verbal:

- don't equate failure to understand the message with failed communication
- in trying and being patient you have communicated that you care
- you can learn to have 'wordless' conversations through touch, smiles and simple shared activities

Try not to worry about what onlookers might be thinking – critical spirits are not helpful so don't give them power by taking them to heart; this is difficult work and we need space to make mistakes and learn

## **Top tips for getting alongside the carer**

*Model – The Road to Emmaus (Luke 24:13-33)*

To us, walking alongside, some answers to the carer's problems may seem very obvious; and yet very often, and to our bewilderment and frustration, carers fail to take up these obvious sources of help and support that we suggest – why????

**Remember:** the carer is going through a time of intense confusion and emotional distress. In such a state advice and information can only be taken in and acted upon very slowly.

When I first read the story of the road to Emmaus I found it odd that Jesus did not just say, “Ta da! Here I am! Look, I have risen from the dead! Don’t be sad, be happy! Everything is going to be OK!”. Now I realize that it is because such a sudden revelation would have been too much; it was necessary for Jesus to take them right back to the beginning and talk them through it all as they walked so that, when they were ready, they would come to see the truth. We also see that he did not begin with the explanations, he began with questions about how they were feeling; **he began by finding out where they were.**

We can draw some useful tips from the road to Emmaus when seeking to get alongside the carer of a person with dementia:

- Listening is far more important than advising
- We need to wait for an opportunity rather than force the issue
- Don’t try to fix the unfixable
- But keep the ball in your court, don’t put it in theirs
- Inviting is better than suggesting

Carers report that one of the most unhelpful things a well-meaning person can say is “Just pick up the phone and give me a ring if you need anything”. Whilst the carer is hurt and confused he or she may have as much chance of climbing Mount Everest as picking up the phone. This is because:

- They are so exhausted they simply don’t have the energy
- They know they need help, but not exactly what kind of help, so they don’t know what to ask for
- They are afraid that the person at the other end may not be able to help after all

Related to the point above is **the manner** in which we encourage people to get involved with what is going on locally. People are more likely to come if you **invite** them to come, “This is going on ... it would be lovely if you could join me”, **rather than if you suggest** they come “This is going on .....why don’t you give them/me a ring if you would like to come”

Getting alongside is difficult because many people do not want to admit they need help and will reject offers of help. Much of getting alongside is appearing not to be there, knowing when to step back, whilst being ready to step forward with simple, practical and sensitive offers of help if the opportunity presents. Carers say these are things that would be most helpful:

- Someone to talk to, someone who listens, someone who cares
- Help with the practical tasks of life (shopping, cooking, cleaning, gardening etc.)
- Someone who can spend time with the person so they can go out, relax, get things done
- People they can rely on – there are both time costs and emotional costs attached to ‘getting alongside’ so it is important to be realistic about what you can offer – but maybe if you can’t do it you know someone else who can?