



Channel 4 Series – Dementiaville Programme 2 – Supporting Families Being together - living with a dementia

“You face two quite stark choices; one is to continue to want the person back and therefore your time with them is about that – you want memories to be held, you want to get the person back to your reality and your time together may be traumatic and difficult and you’ll probably end up feeling very distressed because it didn’t work. Or you have to go on another different painful journey which is to follow the person into their dementia, which will take them to a different reality and you’ll have to - with a lot of love and support – learn to love them as they are now, and that will mean learning to love them in a new way. And if you do that, that journey, though painful, can bring you to a place where you will form different, but new, positive, loving memories that will stay with you.”

Dr David Sheard, CEO and Founder Dementia Care Matters

About Dementia Care Matters

We are a leading Dementia Care Culture Change organisation in the UK and Ireland. There is a large UK network of care homes using our ‘Butterfly Household’ model of care within the public, charitable and independent sector providers, for further information go to: www.dementiacarematters.com

The Dementia Care Matters Approach

Feelings Matter Most

When a person’s cognitive abilities decline a person cannot always rely on their facts, logic, reasoning or short term memories. As a result, relying on feelings becomes even more important. The reason for this is a person’s feelings, when experiencing a dementia, remain intact. Feelings are what the person can trust. Therefore the emotional world of a person living with a dementia becomes even more important.

This requires us all to tune more into emotions and to listen carefully to the feelings behind the words people might be using. Someone who is asking for their mother or wanting to go home, for example, might not be actually wanting the actual person or place but instead be seeking the comfort and security that ‘mum’ and ‘home’ represent.

A positive response therefore might need to be to offer love and reassurance. Relying on correcting the person about their confused reality saying “Your mum has died” or “This is your home” will often not work. This sort of response is only likely to add to the person’s distress. The reason this does not work is it forces a ' present ' reality onto that the person which the person by asking the question in the first place is unlikely to accept. They are really trying to show how they are feeling insecure, lonely or lost. Providing reassurance on how someone is feeling is more likely to work than forcing facts that the person living with a dementia cannot retain.

It is easier to change our own approach

It is easier to change our own approach than to try and change another person! This is true of life in general but particularly true when relating to a person living with a dementia. When a person living with a dementia appears to be ‘difficult’, even though we are often aware that this is probably caused by the condition, it is hard not to show anger or frustration. Many relatives feel very guilty when they react in an irritated way and these feelings can add to the isolation and pain of supporting someone living with a dementia. This is especially true when the person is behaving in a way that seems out of character, or different to how they used to be before they experienced a dementia.

It is really important to remember without having dementia we can choose to be difficult or not. We can still choose to put aside our feelings in order to think differently. However, people experiencing a dementia cannot change their thinking due to the damage in their brain. We can change because we can still decide to think differently in a way a person living with a dementia cannot.

People are not being deliberately difficult

A person with a dementia is not being deliberately difficult to cause us stress. At Dementia Care Matters, we use the comparison of traffic lights to explain the consequences of living with a dementia. Traffic lights go Red, Amber, and Green. Imagine the Red light represents a person’s feelings, the Amber light represents a person’s thinking and the Green light is a person’s actions. The Amber light is therefore the filter which processes our feelings and will sometimes mediate what actions a person takes.

When experiencing a dementia, the Amber light is either faulty or not working at all. So very often a person will move directly from a feeling to an action without regard to consequences or the effect on other people’s feelings. In other words their thinking ability - their Amber light is damaged. If we respond by using questions or giving rational explanations, we are using ‘Amber light’ responses, which the person is unlikely to be able to understand. This will often make the situation worse.

When feeling stressed by someone living with a dementia, take a deep breath and try and remember the person’s Amber light - their thinking isn't working.



Feeling busy and needed are vital to wellbeing

- **Being positively occupied and continuing to feel busy and needed are vital to wellbeing.** Asking someone a question can be over-taxing to someone's Amber light. When trying to involve your relative or friend in doing something, it is sometimes better to just start something off, such as washing up, and then handing them the drying-up towel and asking them to give you a hand. The reason is - people living with a dementia can find it difficult in their brain to start things themselves but once their starter motor has been triggered into action by us, people can do more than you suspect.
- Be aware of the benefits in a person just watching others doing something as this isn't too demanding on their brain - for example seeing children playing in a playground or looking out of the window at the birds. The reason for this is activities which have lots of complicated steps to complete the full activity can be too taxing. Whereas simple activities that don't tax the brain and focus more on the senses and feelings can work.
- Don't under-estimate the magic of living in the moment - small moments such as laughing at something on the television, or becoming animated when looking at an old photograph. In other words adapting to living with someone with a dementia means adjusting to things we take for granted and being more able to just 'be' with the person.
- Dementia Care Matters has an 'Activity Ideas' list which might be of interest and National Activity Providers Association (NAPA) produces a helpful handout on '101 things to do when visiting someone living with a dementia.'

Different approaches work at different points

It is said: "If you've met one person living with a dementia then you've only one met one person," as the experience of living with a dementia is very individual.

There is no set path someone's dementia will take and no automatic progression. At the early point of experiencing a dementia, the person will welcome holding onto our reality and be able to be re-oriented with general cues and prompts. Once the person's Amber light (their thinking) is very faulty it is better to not question or challenge the person and to accept and go with their reality. If the person's dementia progresses to the later points then looking to the feelings behind the person's expressions and behaviours will be key. Providing close, loving comfort as well as sensory comfort items to hold and feel will help give a sense of nurturing.

Looking after yourself is vital for you *and* the person you support

Whilst this seems very obvious, it is surprising how many families can find themselves extremely tired, depressed and sometimes physically ill as a result of the demands of being a care partner. There are a number of useful helpline numbers on the Channel 4 website: <http://www.channel4.com/4viewers/help-support/dementia> if you feel that talking to someone might help. These national contacts might also be able to point you to the support you need in the area in which you live.

Feelings matter most for relatives too. Feeling alone on your journey can be particularly tough and so recognising when you need to ask for help – sooner rather than later – is important.

Come and meet us!

You are warmly invited to one of our [free events](#) called The 'S' Factor in Dementia Care, these are being held in various locations around the UK and are led by our CEO Dr David Sheard who features in this TV Series and was the Series Consultant. For further information please go to: www.dementiacarematters.com

If you belong to a support group, please let your facilitator know about Dementia Care Matters course for people to help to run support groups. This course called '**Being Together**' can also be found at our website at: www.dementiacarematters.com