

Dementiaville: The Series – Channel 4

Creating Memories through 'Being Together'

Memory makes us Who We Are

Memory - it's made us who we are today. Memory helps to reinforce our identity. Our memories help to anchor us in the here and now. We live in the present by knowing who we have been in the past.

"I know who I am because I know who I was."

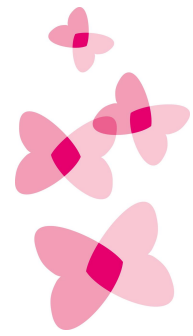
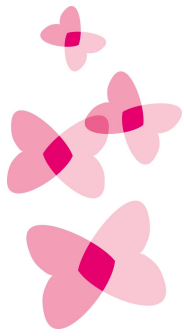
We are all individually a collection of our own emotional memories. With memory we recall the positive feelings we have had in life. We know memory can also take us back in time - to painful feelings and experiences.

Memory reminds us of important people and places. Memory takes us back in seconds to specific times in our life with special meaning. Memory recalls the good times and helps us through the bad times. We remember our past because it's brought us to who we are now.

Memory can also be a time or a place to be locked away. Memories can cause fear and distress - the sense that we might have to live the memory, the feeling all over again. Memory can restore us back to a time when we felt we mattered. Memory can give us purpose. Memory reminds us too of times that gave us a sense of belonging and security. Memory remembers the feeling we had of being loved - in the past or in the now.

Losing your Memory

But what if your short term memories began to feel like they were slipping away? What if you started to lose track of time, muddling up recent time and past events? What would you do if you could not hold on to present day facts? What would you feel if familiar places, people and events seemed less certain to you? How would you cope forgetting the names of your family and everyday familiar objects? Imagine not recognising money or not remembering when to pay household bills. Consider how we take for granted the steps it takes to do a task - getting dressed, making a meal, going to the toilet.



Then think about how you would feel if you could not put all the steps of a task together. Put yourself in the position of never being able to quite concentrate hard enough to ever finish something. Feel the frustration, fear and anxiety this would cause. Imagine wondering how you would ever get through a day surrounded by so many confusing sounds, people and objects. This is as close as it is to imagining having a dementia.

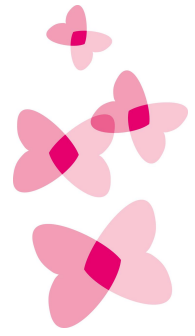
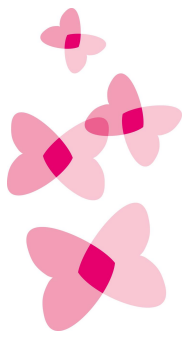
Dementia is a group of different diseases. When someone is said to have a dementia the first thing someone should ask is - Which one? Just as the word cancer covers a wide range of different conditions so too does the word dementia. All of the different types of dementia affect brain functioning but differently in each person. All cause disruption and deterioration to someone's mental functioning - not just to memory but also to the wider aspects of everyday living. The things we all take for granted can no longer be.

Holding on to Life

We all live in such a busy world. A busy world that tends to rely on memory, facts, logic and reason. We function in this busyness by holding onto this factual world in our head. The world of emotions we know is out there surrounding us but can become submerged. More value is placed on the cognitive and intellectual - our thinking ability - than on the emotional, feeling based world in which we all live. Losing our memory - dementia - this has become one of the most feared conditions in old age because of society's over reliance on a world of 'sense.'

However when a person's experience of a dementia begins the person's individual world of memory, facts, logic and reason becomes more uncertain, less reliable and difficult to hold onto. Holding onto life becomes the key goal with most people experiencing early dementia, including the person's family and friends.

A person with an early diagnosis of a dementia has the same reality as everyone else. Someone in the early 'stages' of having a dementia is no different to you or I. Yes some gaps may be appearing in memory, reasoning and functioning. With help, advice and support the person can still hold onto the here and now. It is important at this stage to keep someone reorientated. With gentle cues, prompts and reminders the person can be reassured that there is no inevitability in the course of dementia progressing. Each person's journey is an individual one. There is a saying: "If you've met a person living with a dementia then you have only met one person."



Crossing the Bridge

However for some people there comes a time when in small ways they begin to cross the bridge into a different reality. In the early stages the person can be brought back to our reality. But there comes a time when this does not work. We all have our own individual reality. So too does a person living with a dementia. However as they progress and cross the bridge the person is no longer able to hold on to our reality. Recent facts, memories, reasoning and logic cannot be easily stored in the brain. Dementia destroys neurones - cells in the brain - recent short term memories are destroyed first. This crossing of the bridge can be subtle at first. The person can sometimes return to our reality and sometimes not. At some point this return will largely cease and the person will have crossed the bridge. At this point the person will not be able to accept our truth. Instead they will be living in as real a way as us in 'their own truth.'

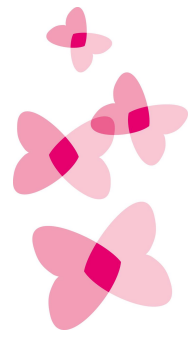
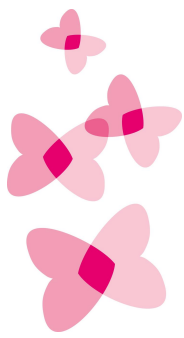
In the early stages of experiencing a dementia the approaches you see being used in the Dementiaville series would be inappropriate and even harmful. Dementiaville in all three episodes is looking at how to meet the needs of people who have crossed the bridge.

The Filing Cabinet analogy

It is important to hold onto the fact that an individual person is always a person. However the best simple analogy when thinking about living with a dementia is to think of our brain as a filing cabinet. Dementia begins in the top drawer of our filing cabinet where our most recent memories of today are stored. What we had for lunch, who visited us today, what we did this morning is all there stored safely - until dementia comes along. Dementia starts to delete these files ie this recent information in our short term memory. It is possible for quite some time to get by in life with some of these files, some of this short term information, having gone.

But for some people the file deletion continues into the second drawer and remembering simple everyday tasks becomes difficult and the person may even start to get things wrong - leaving the door unlocked, the oven on, putting the kettle in the oven, putting laundry in the fridge. Everyday steps, objects, facts and reality all start to become muddled up. The filing cabinet - our brain - is becoming disordered.

Imagine then being left in disarray, with only a few short term memory files left in your top two drawers of your brain. You then have nothing left to draw on to hold onto present reality. At this point you have no choice but to go further back into your filing cabinet. You have to dig further back into your two remaining lower drawers of your brain, to go further back into your past, to make sense of the now.



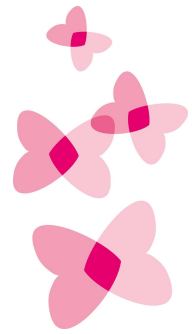
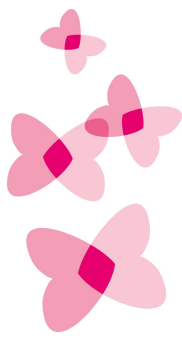
There is now almost nothing in the top drawers of your brain, in your short term memory to help make sense of reality and life. So finally you have to draw on your past reality, safely stored untouched in the lower drawers of your brain. This is all you now have to give you a reference point in knowing who you are and what the life around you actually is. But it is the wrong reference point as it relates to many years ago. As you have no recent stored memories you have nothing to contradict what your lower drawers are telling you. No amount of other people telling you will work as you now have nowhere to store this new information - the top drawers are empty. Therefore you now firmly believe what your brain is telling you from the past and you have no new storage that will change your beliefs - your past is now who you are.

Accepting you can't fix someone

For many decades in dementia care most professionals - doctors, nurses, social workers and care workers were taught that we had to make every attempt to bring the person back to our reality - into the here and now. So for years this approach was tried - it relied on constantly correcting someone, forcing facts - our truth - onto a person and reminding the person constantly about the gaps in their short term memory. I marvel that as a fairly intelligent young man working in dementia care that I went along with this for so many years. It now seems staggeringly obvious that you can't force back into the damaged areas of a brain new information that the person can't compute.

What did this old approach achieve? Nothing other than distress and failure - distress because the person couldn't remember. Failure because it led to a restrictive culture of care being created that reacted to peoples so called 'behaviours.' When facts and 'our reality' were forced upon the person this inevitably created fear, frustration and anxiety. If you feel you know your truth and someone else is forcing theirs on you, then you are going to become very agitated. We all know our own truth. We tend to not want this challenged by someone who is telling us they know our truth better than we do.

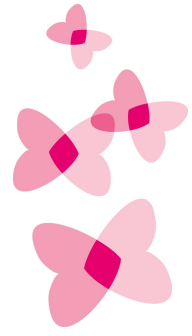
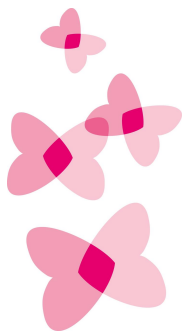
As a result this old approach caused more severe reactions and inevitably what was termed at the time 'difficult or challenging behaviours' in people. People living with a dementia in these circumstances were being pushed to the edges of being a person. By having what was believed to be false truths forced upon them people living with a dementia had no option other than to express their ill being through shouting, hitting, crying out, or sitting head down lonely, lost and defeated. This is and was the premise on which dementia care was built. Namely that dementia led to symptoms which caused behaviours which meant people could only be cared for as 'bodies' in controlled locked buildings with chemical restraint.



1995 new ' radical ' beliefs

So from 1980 when I commenced using the old approach to realising by 1995 it was all wrong it meant ditching all my past training and starting again. This time it meant working with the real truths coming from being with people living with a dementia themselves which were:

- * Seeing as Feeling beings not thinking beings - living with a dementia means people have no choice as their brain cells deteriorate but to leave the world of short term memory, facts and logic behind and to rely more on their feelings.
- * Realising Feelings matter most - as feelings never die these matter more as they are the things to trust, relying more on feelings compensates for the loss of short term memory and facts - as memories and logic slips away feelings are what living with a dementia you trust and as a result people living with a dementia are more authentic, genuine people than we tend to be - they are living unmasked in the raw and what you see is what you get.
- * Feeling memories not just remembering them - mistakenly people have presumed that when people go back into the past that they are remembering their memories from long ago whereas now we realise in dementia care that people's memories are an emotional memory as well as a factual memory and people living with a dementia FEEL their memories from the past as if they were feeling and living them now.
- * Going with the person's truth - you can't fix a dementia, you cannot repair neurones once they are damaged so forcing our truth and trying to put back into a person's brain our truth, our reality, is a waste of time.
- * Accepting someone's reality - a person, once they have crossed the bridge, needs to be accepted as they are, they cannot be fixed but we can fix our approach to accept the persons feelings as being as real, if not more real, than our own.
- * Preventing the searching - people need to be reached - if left in a lost world this comes out in people as ' searching behaviours ' commonly seen as pacing hallways, calling out repetitively, trying to get out of exits etc - when all along the ' outer searching behaviours ' are a search inside themselves - the person cannot get through a day just being a person living with a dementia they are looking and searching in order to get rid of the negative feelings inside caused by not being reached on the inside as a person - the search is to have their feelings met by us.

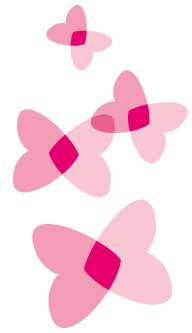
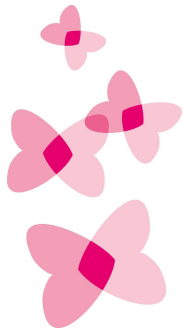


- * Going with and adding to a person's reality - if you have no recent short term memories then all you have left are your past memories to make sense of the now - so a person uses their past memories to make sense of who and where they are and their brain says you are a young mum again you are at work etc in other words you can't be this you can't just be a person with a dementia you had a full life and were loved and needed - they are needing us to recreate those same feelings in order to get through the day and to have well being.
- * Learning the language of dementia - just as people rely more on feelings rather than facts so their language is a language of feelings , the language of dementia isn't literal you have to interpret the Feeling behind the words or actions.
- * Interpreting the meaning - people commonly say they are looking for their mum, dad, children, school, work or home - they are not looking for these actual people and places they are looking for the feelings they used to get from these roles and people in their past life - in other words they are needing us to provide the same feelings to them that these people and roles used to.
- * Filling a person's world - it just isn't possible to get through the day just being a person living with a dementia - as dementia progresses so your world is shrinking - as the files in your brain get less people need, as their world comes closer, that world filling up with the stuff of life in order to remain active, busy, purposeful and for it to have meaning.
- * Bringing out the best - living with a dementia is stressful enough to get through the day - this approach is all about loving and accepting people as they are in order to reduce the stress and anxiety of having a dementia - to give a sense of well being and to help people feel needed and that they can still contribute and have a purpose in life.

Creating, adding and sharing new memories together

Once these beliefs are accepted and the evidence speaks for itself, with people living with a dementia coming alive again, then it's not such a massive next step to see that people need to be helped to be who they were. If this is the life people are living anyway on the inside of themselves then it really is our responsibility and duty to enable people to just ' be' this.

What could be worse than living your reality on the inside and this never being acknowledged or validated externally and living in an empty, sterile, clinical environment that reinforces your worst fears inside and abandons you to an empty life of other people's meaningless truth?



Whilst forcing truth doesn't work also leaving people stranded in their pasts doesn't either. People living with a dementia can't create their own opportunities they need us to do this for them. Seeing people come alive cradling a doll they tell you is their baby, seeing people doing 'parts' of their work - in their way they used to do in the past - with real energy and determination is humbling and totally rewarding.

In this series Dementiaville you will see people not only being accepted as they are but the approach going this one step further. In all 3 episodes people are being helped to have new added memories which draw from the past and make links into their present.

The viewer may think but surely this is colluding a step too far - it's adding new false truths to a person who is already in a different reality by making up or creating false new memories?

You will see a former Matron now living with a dementia being encouraged to bandage a staff members arm, a former Riley car factory worker being taken out in a Riley car as if it was an everyday event in the present, a former Doctor in the Navy being treated as a best friend and not like a 'resident' and a family going camping again as they did many years ago.

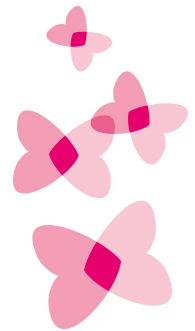
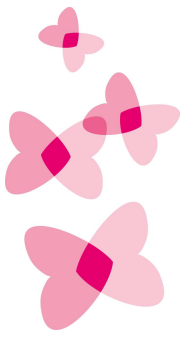
People may ask but what is the point of creating new false memories? Surely it is better to live again a recreation of a past memory than to live a life of frustration and emptiness. But are they new false memories - they draw on the past to fill the real moments now, to make sense of the senseless things that dementia can cruelly do to someone, to help people not be defeated by a dementia but to enjoy the moment as much as any of us in life.

The answer is if the person is slowly living in the past and living in that role - when they had a purpose and mattered - how can we leave them stranded in that time with no real experiences that fit with who they are?

Recreating these experiences and new memories is an opportunity for the person who is also living in the moment to just be in that moment, feeling good again because who they were and who they are has been joined together - to ease their tension and create a sense of Being Together not being alone with a dementia.

Clearly the actual memory of the recreation will not remain as they cannot store new memories of bandaging, being in the Riley car or going camping but the FEELINGS of living in the moment and the remaining longer term feeling of well being is worth every moment

For families and people working in dementia care it is also about reinforcing to ourselves all the memories of the whole person's life. The person is still here now - it is still possible, rather than just treating the person although alive as if they've gone, to make new memories which really reach and connect with the person.



None of us would ever choose for dementia to come along in our lives but we can choose to balance the grief and loss with remembering the person is still here now. You can choose to make new happy loving memories together that will stay with you long after the person has gone. You can still ease in part the pain of eventually losing the person you loved with knowing that you in the end held onto creating new moments in Being Together

In the words of the song Memories from the musical Cats

Touch me
It's so easy to leave me
All alone with my memory
Of my days in the sun
If you touch me
You'll understand what happiness is
Look a new day has begun

Thank you for watching this series and believing that there is hope for the future of dementia care

David

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www.dementiacarematters.com