



# Forget-Me-Not Buddies (Tameside)



## **‘Our Journey’ – by Carrol Ashton (Trustee & Founder Member)**

### **DEMENTIA**

When you hear the word Dementia it’s possible that the first thing you associate with it is ‘memory loss’ – for some people the next thing they think of is ‘death’. Dementia is everywhere you look, TV, Radio, Newspapers, Social Media – it is consistently 1 of the top 3 causes of death in the UK and has been so for a number of years.

People who have witnessed a loved one living with a diagnosis of Dementia, watching them through the different stages – sometimes slow, sometimes rapid, but always deterioration – can tell you the distance between ‘memory loss’ and ‘death’ is a long, heart-breaking and harrowing journey for all concerned. If anything, the person living with the disease suffers less than the Carers and families because there will come a stage where they are unaware of the situation – Carers and families with full cognisance have no escape, they witness and live through it all.

You never think that you would be ‘willing’, ‘wishing’, ‘hoping’ that a loved one, Mum, Dad, Wife, Husband would just go to sleep and die. People caring for a loved one with the latter stages of Dementia can find themselves in that position – I did.

My Mum (**Irene Bate**) was an intelligent, funny, opinionated, assertive woman – not the easiest person in the world to deal with – we argued a lot – people said it was because we were so alike ! She worked all her life, mainly in supervisory roles and didn’t suffer fools gladly. She and Dad (**Roy Bate**) were courting at 16, engaged at 20, married at 23.

So, let me take you through a whistle-stop tour of our Dementia journey.....

**2012 – Forgetfulness** - Mum was forgetting little things, misplacing the odd item but hey she was 74 – it was to be expected. Easily irritated but she had always been like that.

**2013 - Moderate Decline and Diagnosis** - Forgetfulness getting worse, losing confidence, GP refers to Memory Clinic who diagnose Alzheimer's and take away her Driving Licence with immediate effect after over 50 years as a driver – that was a shock to Mum and Dad. Next time Mum and Dad go shopping Mum picks up a bright red mug, puts it in the basket and tells Dad “That’s for you” – the mug said ‘Keep Calm and Carry On’ – Dad still uses that mug. Mum starts to make excuses not to write or read; she can’t sign her name. She likes colouring in pictures. She lays the table for a meal and puts out 2 knives, she looks at it and says ‘that’s not right’ – but she doesn’t know why it’s not right, just that it isn’t. She laughs off similar incidents as do the family. An ardent Manchester United fan who watched all the matches on the TV and discussed the tactics with my husband, she now sits watching the screen but has no real understanding of who the players are or what the game is about, Tommy explains to her only to be asked the same question again 10 or 15 minutes later... and so it goes on.

**2014/2015 Moderately Severe Decline** - Mum is frustrated and angry a lot of the time, people trying to help she sees as ‘telling her what to do’. Dad gets a telephone with pictures on so Mum (who was a telephonist most of her working life) can ring family members if she wants to without asking him for help. Struggling to dress herself properly now, puts things on inside out or just sits looking at item as she doesn’t know how to put it on. She is constantly asking to be taken ‘home’ even though she is home, threatening to ring the Police because she wants to go home to ‘Roy’ and this strange man (Roy) is keeping her against her will in this strange place (her home for over 30 years). She is prone to falling as she ‘forgets’ she needs her walking frame – even when she remembers she doesn’t remember she has to push it. She does have unexplained ‘bursts’ of energy when mobility isn’t such an issue and is found knocking on a neighbour’s front door asking for help – so Dad has to start locking front and side doors and hiding keys. She can’t get in and out of the car unaided – she has to be told to lift her leg and swing round but still doesn’t understand so Dad lifts her leg out of the car and coaches her movements to get her to stand. She is still colouring in pictures but can’t keep the colours within the lines – she wants praise for them like a child bringing a picture home from nursery. Dad is 78, her 24/7 Carer and he is tired.....

**2016 Severe Decline** - She is fighting Dad to keep him out of the bedroom because ‘Roy’ sleeps in there and he isn’t ‘Roy’. She is ‘pinching’ and hitting out at Dad when he is caring for her or helping her eat. She is waking at night, screaming and pushing Dad out of bed because she doesn’t know who he is. She

is waking him up at 3 am because it's time to go out somewhere. Dad buys an alarm pad for side of bed so it goes off if she gets out of bed and steps on it – she is more prone to falls now and if she is up and about, he needs to be too. Dad is advised to make a 'safe room' – a room where he can lock himself in if she gets aggressive and physically attacks him. He is also advised to put away anything that could be used to harm him. She is asking where her Mum and Dad are. She complains of strange men in the room or noisy children in the corner, asking Dad to get rid of them – there is nothing there. She now has an obsession about Elvis, always liked him but now she talks about times she was with him, convinced that she knew him personally years ago – she wants a picture of him on the wall so Dad duly obliges.

**9<sup>th</sup> December 2016** - Mum can no longer stay at home – her care needs are too much. She doesn't recognise Dad or me most of the time and is getting more angry, sometimes kicking out. She needs help going to the toilet, showering, eating. She can't do anything at all for herself without 1 to 1 assistance and her walking aid. Her ability to pick up a fork or spoon has gone – she just stares at them – she doesn't know what to do – she has forgotten how to feed herself. She is having regular 'toilet' accidents. She is angry at people telling her what to do and having to man-handle her to help her with personal care. Dad is at the edge of Carer burn-out. It is decided by the Mental Health Team that the time has come for the safety, health and wellbeing of both Mum and Dad that Mum go into a Care Home. Because of her inclination to lash out she is classed as EMI (Elderly Mental Infirm) which means she is deemed to have behavioural issues. Most Care homes won't take EMI patients so we have a choice of ONE.

*What happens in the Care Home is a whole new story – suffice it to say – if I could turn back the clock we would have done things differently – how I have no idea – but we would have found a way. Numerous complaints, daily tears and a subsequent CQC rating of Inadequate tells it all; sadly, though lack of staff and therefore care would appear the 'norm' with the majority of Dementia Care Homes.*

**September 2017** - Mum has gone from 13 stone to under 8 stone. Her mobility is now almost zero and she has to be lifted from her bed and chair in a hoist. Dad visits every day and feeds her but she will only take very little food and drink – she likes ice-pops, they cool her mouth – she lets the ice melt on her tongue she is swallowing but cannot remember how to bite or suck the ice pop. She is susceptible to infections and her ability to speak has all but gone. She looks at you and smiles but her eyes are glazed and there is no real recognition.

**October 2017** - Mum is literally withering away in front of us – she has forgotten how to swallow – Dad is feeding her with a syringe but she isn't taking it. We had the Palliative Care talk today and signed the Do Not Resuscitate Forms. Mum spends a lot of time in bed now in her room with the radio playing in the background.

**Monday 6<sup>th</sup> November 2017** - 2.45 a.m. Dad rings to tell me he has been called into the home as Mum is unwell and he feels I should also go in. We both sit with Mum holding her hand and talking to her albeit she is unresponsive.

3.40 a.m. Mum dies. Bizarrely in the background the radio is playing Elvis singing Suspicious Minds.

I hope by sharing this with you it has given you a bit more insight into Dementia and possibly offered more of an understanding of what Carers and families go through. Believe me... if it was diagnosis and quick death without the long journey between, the road would be much easier to travel.

*Carrol Ashton*



**Irene Bate**  
'My Mum'

**For more information on Forget-Me-Not Buddies  
(a local group for Carers of & Persons living with Dementia)**

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