



Recapturing the past by creating *Memory Moments* to help those living with memory loss or dementia

## Living with Alzheimer's Not Suffering with it

### As told from the inside – out

25<sup>th</sup> January 2014 | Tommy Dunne | @Tommytommy18



I'm Tommy Dunne I'm 61 years old and I live with Dementia.

I thought you had Alzheimer's not Dementia a lot of people will say so let's clear up this misunderstanding straight away:

*There are well over 100 types of Dementia and Alzheimer's is just one of the types of Dementia for example lets say Dementia is a Car so there are many manufactures' of cars then there are different models of cars i.e. VW polo, golf, Ford fiesta etc but they are all Cars just a different type. So you cannot have Dementia or Alzheimer's.*

**Alzheimer's does not stand alone it is Dementia and Dementia is the umbrella that all the others sit under.**

Next the saying that we suffer with Alzheimer's or Dementia.

**We do Not suffer. There is no physical pain. You do not have a headache or migraine symptoms. You are very frustrated and lonely yes, but there is no physical pain - so please stop saying we suffer from it. It causes fear to people who are worried about getting Dementia.**

Since I learnt to talk again (when you are diagnosed with Dementia you go into a shell) I was able to tell people and the medical profession what it is like to live with Dementia and the loneliness that goes with it.

**When you are in a full room it can be the loneliest place on earth.**

People will talk over you, around you, about you but never to you. Then people used to come up to my wife while I was standing or sitting by her and say to her "how's Tommy it must be very hard for you" and "how are you coping with him" "I don't know how you do it?".



**It was around this time that I realised that when you have Dementia you developed a super power, the power to become invisible in public.**

Sometimes I felt as if I was at my own wake and when I heard my wife saying "I feel as if I've lost him I'm grieving and want my Tommy back" my heart use to break, I mean I don't feel any different a bit stranger but not different.

So when did I start to get my life back? It began at a meeting of Service Users and Carers in 2012 (a service user is a new name for patient i.e. I use the services of MerseyCare Mossley Hill hospital therefore I'm a Service User (S/U).

The course was to last 8 weeks and after that well get on with it. A question was asked if any S/U would like to volunteer to help with the Year of Action on Dementia group as 2013 was going to be the Year of Action on Dementia. My wife/carer Joyce said Tommy will do it. I was a bit shocked as I found it hard to put a couple of sentences together but I agreed to do it.

I attended a few meetings thinking that I was just going to be a token figure for the minutes but at the meetings while the group was talking I remember thinking that's not right, it should be.. and the next thing I



knew everyone was looking at me as I had said it out loud the group then asked me to put my point of view and they all listened and said this is what we need to know and from there it went from strength to strength.



I got involved in more groups within the group and found out that **Innovate Dementia** was starting to help the needs of the S/U and build round them not build it and try and make it fit.

**I was filled with the most important thing a person living with Dementia needs. Hope.**

In 2013 I was asked to do a talk at the opening of the Florence Institute on what it was like living with Dementia, this was going to be a big challenge.

The day came, the Lord Mayor of Liverpool and other dignitaries were there, I delivered my talk you could hear a pin drop my god I thought they are actually listening to me, at the end some people were crying and people came up to me and said they didn't know and that I had inspired them to look at how they treated their own loved ones.

At this meeting I met Chris Clarke and Henry Moody from Everton football club and they invited me to the launch of their **Pass on the Memories Group** the following week I said I was happy to attend and again this was a life changing decision.



When I attended Henry asked me if I would like to attend the group which I did and I loved it so much I became a volunteer to help at the other groups that were growing within the group to the extent that there are now 2 different groups on Tuesday and Wednesday's am/pm every week.

I am in a Merseycare video called living with Dementia which is on their website under videos and have spoke on the Tony Snell radio Merseyside show about living with Dementia and appeared on BBC northwest twice.

We need to get Service Users out and about (they will not want to do it at first).

Talk to the S/U as much as you can and listen if they respond, keep up to date with things that are happening now and happy times from their past, Yes there are times we repeat ourselves but please understand it's the first time we said it, if you keep saying you just said that we will withdraw and not speak.

Get them involved in S/U groups

Don't keep telling them someone is dead if they ask for them just say where do you think they are and it will pass why cause people to grieve everyday the feelings are real and grieving hurts.

**We are still the same person, we are in a maze we can hear your voice but don't know which direction its coming from, keep talking to us we will come back, we may look and sound as if we don't appreciate you but that is the illness talking and acting don't give up on us.**

Why can we remember things from the past and not recent memories?

I can tell you the memories from the past have been made and stored so can be recalled, with Alzheimer's the memory is not made in the first place because the electrical signal that carries the message over the gap between one part of the brain to the other gets blocked by a build up of protein so it shorts the message out just like they use to jam radio signals during the war.

**So how come I live well with Dementia?**

I was lucky that my wife Joyce gave me the initial push and still had belief in me otherwise I would have done exactly what the illness wanted and that's withdraw within yourself, sit in till you get cabin fever and can do nothing for yourself.

***I still feel it now and again trying to pull me into a place within my brain from where I will not be able to get back, but by keeping busy and helping others understand the illness I found that loneliness is Dementia's greatest friend and that conversation and company is its greatest enemy.***

*This is the first in a series of 3 articles coming over the next 3 weeks. Please follow: @Memory\_Moments to keep posted as they appear.*

