SECRETS AND LIES

Sometimes I sit here and evaluate my life living with Dementia so far and how we have dealt with it. Sometimes it's a good outcome, sometimes not; it depends on my mood I think! There is one thing, no matter what I think about, is the Secrets and Lies that's connected with this awful illness dementia. I think that's why I campaign as hard as I do, because the more I learn, the more questions there are, this is what I mean.

Secret's

When I was first told I had Dementia I was advised to "Use it or lose it" and sent on my way!! If I had just been diagnosed with Cancer or HIV would they have said the same? What were they holding back? What SECRETS did they hold about this disease? As time went on I realised that not only was there nothing in place for somebody like me aged just 50yrs old with this kind of diagnosis but nobody talked about it openly?? WHY NOT? Was that a SECRET too? All I learned about this awful disease I learned via the computer but here are something's I had to find out as time went on.

1, sometimes when I walk into the room and see my Angels face, drawn with worry and trying to figure out the best way forward for the future, what am I suppose to say? Do I say I am sorry? Do I pretend I haven't seen her? Do I lie to her and say everything will be ok when quite clearly its not going to be? Nobody told me this would happen!

- 2, Never having lied to any of my grandchildren, when they ask "Grandad, are you going to die soon?? How do I answer that one? How do I look them in the eye and say "Not to worry, I am not going anywhere " How do I look at their wonderful innocent faces and tell them that I might not be here to see them grow up, or see them married and have children of their own? Nobody told me this would happen?
- 3, When my Angel holds me so tight and whispers "What am I going to do without you?" How do I answer her? How do I calm her fears and trepidation? Nobody told me this would happen!
- 4, The nightmares, the hallucinations, the constant pressure of always being in the wrong, getting nothing right, dates, times, remembering holidays and places I have been!! WHY DID NOBODY TELL ME THIS WOULD HAPPEN??

ALL THESE SECRETS AND MORE!!!

WHY ARE THESE THINGS NEVER DISCUSSED??

LIES

Well, where do I start??

- 1, It's only an Age related disease? Err excuse me?????
- 2, it's contagious? Yes some people walk away from me as if I have the Bubonic plague.
- 3, I don't LOOK LIKE I have dementia?? Please explain to me "What does somebody "look like "with dementia.

- 4, it's no use talking to him/her as she/ he won't understand you?? Please tell me how do you know that?? When did you pass your degree in matters of the mind?
- 5, Just dress them in anything, they won't know ?? Again, how do you know this??
- 6, A member of my family has a "Touch "of Dementia, that's just like saying my sister is a "Touch Pregnant!!!
- 7, Dementia comes on suddenly!! NO IT DOESNT!!! Its actually a Critical chain of events that lead up to the later stages, its just all about becoming aware of the signs.
- 8, and the biggest one of all, its all about losing YOUR MEMORY!!

NO ITS NOT!!!

It's about losing your lifestyle skills, your ability to walk properly, to talk properly, to count money and understand the simple tasks of life which you wouldn't normally give a second thought to. Its about putting the milk in the oven and the hot cup of coffee in the fridge!!

SECRETS AND LIES, EVERY ONE OF THEM, with a lot more besides.

My dear friends, until these secrets and lies are stopped, until the truth comes out about this awful disease and until each and every one of us stand up and shout's that enough is enough!! We will struggle to overcome something we are in the dark about. No more should we hide in the shadows and whisper about Dementia. No more should those of us who have this disease be looked at as if we have two heads!! And no more should this disease be the Silent Enemy! Because I for one will not go quietly and will campaign long and hard until there are no more SECRETS AND LIES, Just

TRUTH AND HONESTY!!