Imagine

You are in.......Late 40's

You have children at school...

You are the main wage earner

You have a mortgage...

You do BBQ, family holidays, parent evenings, school fetes
And you are told you have dementia.......
Please keep that in mind both during this presentation and throughout the day......
How do I manage, financially, emotionally, socially and practically?
Why?
How?
Should we have known?
Should others have known?
Could I have done anything differently?
Keep imaging as if this was happening to you.......
* Initial diagnosis confirmed my fears...
* GP initially thought it was depression....
* Lot of wondering what life would be like for us....
* For my part is an acceptance of what life had thrown at us...
* (my wife) was rather numb in her reaction....
* Do remember that she was worried that I would stop loving her........
* Initial experience poor but current experience “she and her team have been brilliant”.....I think from this experience that NHS Dementia Services are a bit of post code lottery”
* Confused and frightened”
* Apprehension about the future...disappointment that It had taken so long to get a diagnosis...fear of the unknown”
* Finding YPWD and meeting new friends.
* The lack of support form local services, and sometimes feeling that we are on our own.
* Delivery of the diagnosis was totally lacking in compassion...not enough time to let the terrible news clear in our heads...left on our own in the waiting room...totally unprofessional.
* Putting us in touch with the specialist Dementia Care Adviser ( a life saver)

* Diagnosis and Support

YPD B WR
When we got the diagnosis…”felt that my life has ended……what life have I got to look forward to…..are we getting ready to die?”

Planned so much for retirement….everything had been taken away

(after a couple of weeks) “this is not going to be the end of my life……pulled my trousers up and getting on with it……not going to let it beat us”

On diagnosis this is the opportunity to ask questions but “you just want to get out…still a shock…..takes the wind out of your sails”

“A heart stopping shock followed by agonising disbelief…we were both about to enter a terrible and agonising life changing situation”
* Never had a problem being called a carer...I have always thought of it as being a privilege, it is like looking after a child, their life is your responsibility.

* “I feel that your magazine suggests that being a carer, particularly when the person being carer for is your spouse, is an acceptable place to be. It’s not, it is a bad place to be. The role of a carer is long, hard and unremitting. Regardless of help and respite breaks, the responsibility is always there. It is a life of watching your loved one deteriorate before you and coping with all that that brings and of always being aware of the inevitable final outcome. Having said all that, I will always care for my dear wife at home, I would not have it any other way”

* What emotion would I use? Satisfaction certainly, satisfaction at seeing my wife contented within her world. But joy and happiness - never.”

* I was worried that this would be my label and I would lose my identity (which I have to a certain extent - but I am fighting back!)

* Totally exhausting, full on 24/7. Often frustrating and very sad watching your partner drifting away from you. I think of it as a slow bereavement because the person you knew is not there anymore, their personality has completely changed. Always nervous about the future, I now hate anniversaries, birthday, Christmas etc as I always wonder what will next year bring us.
I don’t particularly like being called a carer. I don’t think of myself as a Carer I am my husband’s wife. It never crossed my mind that I would be anything other than my wife’s carer….I know without any doubt that (my wife) would have done the same for me.

Agencies outside of our regular mental health professional...that they kind of stereotyped myself, possibly assuming that either I wouldn’t or couldn’t care for my wife... without any knowledge of either of us.

Mental health team have always been proactive.

I have no problem with the term carer because that is what I chose to be for my wife 24/7/365 over 15 years ago.

To be honest everybody is so hung about things.....so PC.....I know what I do so I am not bothered what I am called.
Frustrating and sad...then you feel happy about things that (my husband) can do...they can surprise you

You can feel protective, more alert, watchful

Spend more time analysing danger and consequences.

Tend to put yourself second

Sometimes you feel that that you have to tell them that they can do it.

I am quite pleased with myself in that I have been able to continue to care for her at home, as I intended.
Admiral Nurses are available to support families throughout the dementia journey. They provide family carers with the tools and skills to best understand the condition, as well as emotional and psychological support through periods of transition.

They work with family carers in the following ways:

• They focus on the needs of the family carer, including psychological support to help family carers understand and deal with their feelings
• They help families better understand dementia and use a range of interventions that help people live well with the condition and develop skills to improve communication and maintain relationships
• They are an invaluable source of contact and support for families at particular points of difficulty in the dementia journey, including diagnosis, when the condition advances, or when tough decisions need to be made such as moving a loved one into residential care
• They provide advice on referrals to other appropriate services and liaise with other healthcare professionals on behalf of the family

Admiral Nurses also uniquely join up the different parts of the health and social care system and enable the needs of family carers and people with dementia to be addressed in a co-ordinated way.

In addition, Admiral Nurses provide consultancy and education to professionals to model best practice and improve dementia care in a variety of care settings.
* Rikki visited and telephoned me on several occasions; he was very helpful in trying to get me to become more pro-active
* To encourage me in what I might want to do for myself and to give guidance where appropriate and just be a listening ear
* Outlined the importance of completing the forms for Power of Attorney which I have done at long last.
* Encouraged me to organise Respite for my husband which to date I have managed to do this once.
* Admiral Nursing is a very relevant service being aimed specifically at carers. Some years ago, when I first heard of Admiral, I found out that there was no support in our area. I am glad that there is now.
* Should be available to everyone.

* “Lifeline…..your for me”
* “All the years of being a carer never had anyone to see me”
* “Just talk things through….guided in the right direction”
* The job is “invaluable, crucial…don’t know how I would have coped if you had not been around”
* You are always available for me and although sometimes I am fine when you visit, you are still prepared to make another appointment, as at another time I could be finding things more difficult.
* With the Admiral Nurse I know you have my welfare in mind, you are never critical and allow me to voice my fears and these are discussed. I like the fact that the Admiral Nurse is basically for the carers!

* Admiral Nursing

Younger People With Dementia

Dementia UK

Improving quality of life
50 families supported
Post-bereavement counselling
Psychological support
Placement counselling
Advocacy