

Rough Guide: A LIVED EXPERIENCE

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A Dementia Guide



With thanks to the members of
Butterflies Memory Loss Support Group
and all who participated in this project
for sharing their stories and experiences to
help others

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Rough Guides to dementia

Welcome to our Rough Guide to dementia series.

These guides were created by people living with dementia, family carers, staff at Butterflies Memory Loss Support Group, and other voluntary and statutory organisations.

They are based on our experiences of dementia - the rough and the smooth - we didn't want to leave anything out.

It's important to understand that not everyone has the same experience of dementia.

We hope these guides are useful to you.





Joe and his friends Jess and Hamza are going to share with you some of their experiences of living with dementia.

Please be aware that everyone's journey is personal to them. Not everyone will experience the same symptoms and challenges.



*“Listen to me.
I know what I’m talking about.”*



*“Stop talking about me and not including me
in the conversation.”*



GUILT



People around me are so caring, I don't deserve it sometimes.



I wish I could still do the jobs I used to do. It's just an extra thing he has to do now, and to 'look after me'. I know I take it out on him sometimes.



I feel so bad, she still has to go to work each day to pay the bills, and here I am sat at home, useless and a burden.



I hate that I can't share the driving with my wife anymore.

Diagnosis



I struggle when even doctors fail to hear me. Stop treating me like I am a child. I know my health is hard on others, but remember it's ME.



I hate the word dementia, when I was in the army if you were 'demented' it meant you were mad.



I was still working when I was diagnosed. I wasn't sure who to tell. I kept it to myself because I was fearful of the impact on my working life.



People are always saying 'of course you remember'. I just don't!!!!



Why does dementia only affect some people?



When I was diagnosed I felt I had a big label on my forehead saying I am a burden on my 'poor' wife. It was like she was the only one that mattered.

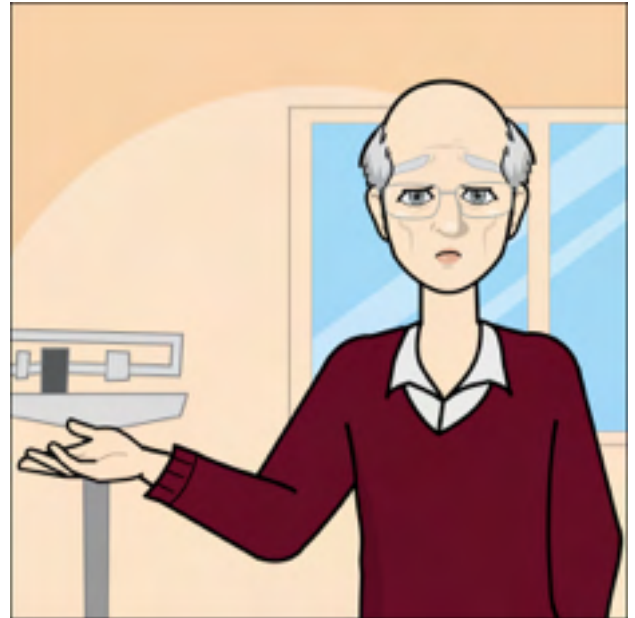


The doctors over-egg your symptoms and talk to your partner.

I just want to know, now it takes me longer to follow a conversation, and that is getting worse, will it keep getting worse until I can no longer join a conversation?

I was told to give up my driving license by the doctor, and my family gave me pressure about it. When the DVLA tested me, I was fine to drive, for now at least.

I have frontotemporal dementia (FTD), my doctor told me that I would say horrible things and upset people and not even care. He was wrong, I do care. When I have been to a group, I sometimes worry all night that I might have said something or gone too far with my jokes. I often phone up the ladies at the group afterwards to check.





I just get so frustrated that people are not listening to me. It takes me longer to find the words, but why can't people just wait, instead of guessing and getting it wrong.



Please stop talking about me as if I don't know what you are talking about. And stop talking about me behind my back.



I HATE HAVING DEMENTIA!! It's hard trying to 'explain' things to others. It's hard when my family get frustrated with me. It's hard for all of us. Just because I struggle to express, it doesn't mean I don't know what's going on around me. I know it's important for my husband to talk to someone.





Hallucinations

I feel things crawling all over me.

My husband tells me it's my imagination.

I know it is. I try to tell myself it is, but it's still very real to me, and I am still being crawled all over!!!

Telling me my hallucinations aren't real, really doesn't help them feel less real to me.

When family question and confront me about when I can hear children playing, I know I can't trust them anymore.

Driving

I was told to give up my driving license by the doctor, and my family gave me pressure about it. When the DVLA tested me, I was fine to drive, for now at least.

I sat a driving assessment with the DVLA, but I honestly felt they were just ticking boxes, they had already decided that I shouldn't be on the road.

I can see danger now, like crossing the road, boiling a kettle, but I worry there might be a time I am unaware of danger.

I hate that I can't share the driving with my wife anymore.

I decided I was not fit to drive, I think that makes a difference to how you accept it.



Keep active

You go on holiday throughout your life knowing that will be a change of routine and surrounding, I was not prepared for the confusion when I returned to my own home, I couldn't find anything.

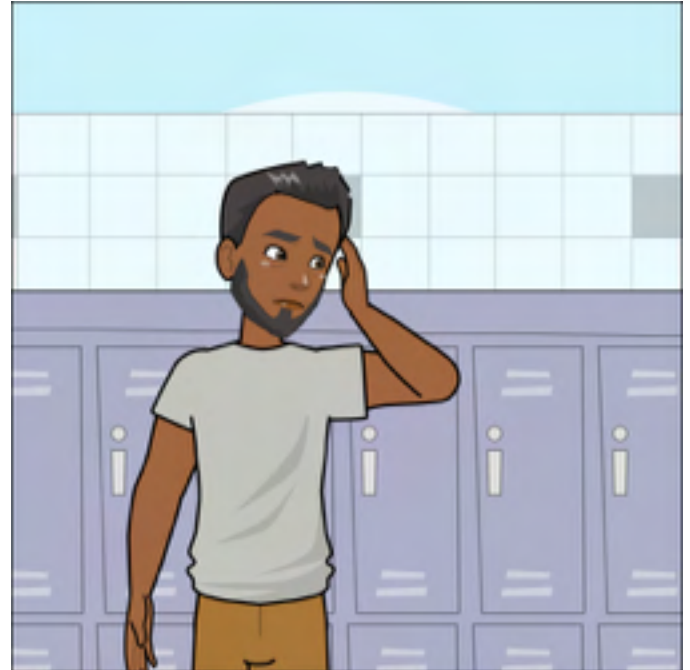
I went to the gym, I had no idea where to stand, I could have sworn I was in the right place, but everyone else was telling me I was wrong.

Just because I have Alzheimer's, it doesn't mean I want to play carpet bowls!

Meet friends, try new things.

Keep your brain active, but mindful you are only human, and your limits will change.

It's boom or bust!





Relationships

My head is so mixed up, I am mad that she shouted at me, but then I don't blame her.

My family ask me what is making me anxious, I have no idea, its just a horrible feeling in my stomach.

I worry about how dementia affects my relationship with my wife and other members of my family.

*Life is S**T but I am grateful to my family.*

I miss who I used to be.

I wish I could still do the jobs I used to do. I just don't know what to do to help in the house. It's just an extra thing she has to do now to 'look after me'. I know I take it out on her sometimes.

Symptoms and our experience.



Symptoms and our experience

I am afraid to go out in case I get lost. It's awkward when I see someone I don't recognise but they seem to know me.



It was only when talking to someone at the group that I realised my change in taste is not separate from my dementia.



I have loads to do, but no motivation. I think people think that because I have dementia, I can't suffer from depression.



I can't explain why, but sometimes I am so anxious.



With posterior cortical atrophy (PCA), my eyesight is badly affected, I thought it could be sorted with an eye test, but no, nothing can be done to improve it.



I have lost confidence and all concept of who I am.



I sleep more than I used to, 14 or 15 hours a night!!



It's like a cloud across my head! That's what it feels and looks like.



It frustrates me that my short term memory is shot, but my long time memory is as clear as a bell. Why is that?

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Find out more Top Tips by checking the website.

You can also share your own tips and coping strategies, we'd love to hear from you!

www.butterflies.org.uk



