

A Good Life With Dementia - Market Weighton Spring 2024

Our Manifesto:

Everyone needs to know.

- We have put the course together. There IS life after a diagnosis.
- **It doesn't stop us! and we CAN still do so many things.**
- 'I keep getting into trouble'. That's not fair. Other people make things more difficult unnecessarily!
- **Dementia is not our fault**
- We are told we say 'stupid things'. In fact, 'They are NOT stupid things – it's not our fault and we SHOULD be allowed to say them!'
- **Nowhere else, other than amongst peers, would you get such encouragement from somebody who can truly say 'I know how you feel!'**

Everyone should understand what dementia is like for us!

- We go through a process adjusting to a diagnosis of dementia. Support us and acknowledge our feelings along the way, as Bob put it:

'There's that initial inclination to withdraw; a fear of embarrassing those around you; the loss of not being able to return to the 'old me'; and the adjustment to be easier on myself; to know I'm still me and to ask for love and a gentle reminder in case I've forgotten to put my trousers on!'

At the start

- 'My head started to feel really empty... I felt I was always in contention with someone else but didn't know who they were.'
- **'It was strange because you knew something was different'.**
- Some of us feel confused and don't want to admit it. **So, reassure us.**
Don't rub it in!

- **'It's a struggle – when your loved ones know you have it and you don't and they try to point out every mistake to prove it!' Don't rub it in!**

Generally

- 'You don't know danger'.
- **'Other people saying 'don't be silly' and 'why did you do that?'**
- 'Your brain is not connecting'
- **'I can't think before I speak'**
- 'It's like the Tin Man in Wizard of Oz, 'If I only had a brain!'
- **'It's not about dying over and over. No. It's about being born again!'**
- 'It's about taking all your opportunities, life is great, look at us'
- **'Whatever I've got I make the most of it'**
- 'It can really challenge our reason for being'
- **'The loss of independence, having to ask for help, is not easy to get used to'**
- 'The panic sets in when feeling suddenly lost'.
- **'I have real difficulty in having to unscramble the sound to make a sentence to mean something – whether that's asking a question myself or trying to respond to someone else'**
- 'Although grandchildren are fantastic and you love to see them, it's often an ordeal because of having to unscramble or through the fear of upsetting the children'.

So, what we expect of YOU, whether professionals or family members

- ‘I insist that we MUST be able to continue to meet as peers.’ **Help make that happen!**
- About driving, ‘I made the decision’ – **so important to support us to own all decisions ourselves**
- ‘We can often be made to feel afraid, embarrassed, useless and stupid and this can make us less sociable’ – **It’s so unnecessary. Don’t do it!** It didn’t happen in our course ‘because we felt safe there’.
- ‘We don’t want suffocating, bossy or condescension – but **we DO want collaborations**’ – ‘We know our care partners are learning about this too’. **Help us have these talks together with our partners.**
- ‘We are both learning this new dance with dementia! And it’s inevitable we will tread on each other’s toes at times!’
- I’ll follow the conversation but won’t initiate. It’s crazy – **so over to you to keep me included!**
- We know dementia is a disability. So, through our insight, **YOU can make adjustments!**
- ‘I feel like I’m by myself’. – **Acknowledge me!**
- ‘I get, ‘What do you mean?’, ‘What are you doing that for?’ **Don’t rub it in!**
- ‘You know you do it but **don’t wrap us in cotton wool**’.

What we learnt together.

About what's going on in our heads:

- **We've got billions of brain cells. We don't lose them all in one go!**
- My long-term memory is so much better than what I did five minutes ago.
- **It's good to know I'm not the only one.**
- I can forget things in record time!
- **Dementia affects different people in different ways.**
- Dementia can affect our balance. 'I'm forever falling over!'
- **Dementia is not our fault!!**
- Dementia can affect not only the way we walk, but also how we see (or not) steps and kerbs, for example.
- **You must declare if you have dementia, but you may still be able to drive following more tests.**
- How great to be able to laugh about making mistakes and it not mattering. As J said, 'We've all got dementia, so what?!'
- **What Happens? – Well, the mind boggles!**

About getting the best out of your GP

- The GP wants to review my medication and explain it over the phone. That's no good for me! The GP practice needs to readjust to accommodate my disability not to expect me to fit into what's convenient for them.
- **My GP gives me a double appointment so I have time.**
- Get your GP to write down what they have said to you
- **Write some questions down before you go to see the GP so you don't miss anything out!**
- If they don't want us to miss an appointment, maybe come out and see us at home! - Especially if we live on our own.

Some top tips:

- **When stopped in your tracks, just pause, take a couple of minutes to compose yourself and then ask for help. People are so friendly.**
- Keep connected and stimulated with friends, family, each other
- **When reading, it's good to use short stories and also poetry.**
- It's good to laugh and one still can! This is something we have done a lot of on this course.
- **We still CAN do so much!**
- If you don't use it, you lose it! - Keep moving! There are plenty of opportunities.
- **Research: It's not all white coats and laboratories – far from it! It's also about our real daily lives and how we live with dementia.**
- Research is about asking question and seeking answers.
- **There are many opportunities to take part in all sorts of research. Sign up. We can and should take part!**
- Occupational therapists (OT's) can help make your environment more inclusive and accessible for you. They can help you achieve the goals that matter most to you!
- **'I have a medicine box with all the days of the week written on it. It would be ok if I knew what day it was!'**
- **D** came up with the genius idea of a pill dispenser with a **flashing day of the week!** We could all be millionaires this time next year!
- **So, what if we make mistakes? Take it in your stride, 'We've all got dementia, so what?!'**

A rallying cry

People with dementia CAN!

Before she died, Wendy Mitchell, was part of the small group of course ‘tutors’ helping put this course together. Bob, another tutor, shared this beautiful poem. Inspired by the example of Wendy, it is a call to action for all of us.

Wen-dy – by Bob Long

Wen-dy day is looking grey
Wen-dy ‘dos’ don’t go your way
Then it’s time to turn your mind
To Wendy Mitchell

Wen-dy head don’t seem to know
Wen-dy worries seep and grow
Then you **MUST** blow off the dust
With Wendy Mitchell

Wen-dy evening seems too long
Wen-dy ‘*should I?s*’ go all wrong
Then remind yourself the ways
Of Wendy Mitchell

For without a single doubt
Think of Wendy you will shout
‘she can do it!
‘so can I!’
She has shown me how to fly!
Take on all those conflagrations!
To exceed all expectations!
I am here!

And, best of all, I’m ME!

Bob Long 2024.

What the course has meant for us

- The course is very much about helping us all to adjust to this change
- **‘I feel like I’ve learnt more than I ever did after years at sea!’**
- ‘As the most recently diagnosed, it is so wonderful to see and realise there is so much less to worry about now’.
- **‘We’re not alone in this’. ‘I found out I’m exactly like a lot of you’**
- ‘I’ve met so many nice people to help you with your thinking’
- **‘It’s super lovely. You can feel it in people’s voices. You feel loved. You feel that someone has got their arms around you.’**
- ‘This has been a lifesaver’
- **‘The thought that someone is there to help you is nice to go home with’**
- It’s been great, realising there are a lot more people like me in the same boat.
- **‘It gave us so many chances to support each other ‘What you’ve got to say helps all of us’.**
- I tended to think I’d be the only one but there are things we can do and re-learn. This has helped me so much.
- Dementia is frightening – at the start when things go wrong. It has been wonderful coming here. I’m getting relief from that fear.
- **I’m among friends you can talk to. I sit and listen and learn. It’s lovely to see friendly faces and it’s a good morale booster**
- I went blank one day. I couldn’t understand why and what was happening. I came here and that’s when it all started to make sense
- **I’ve enjoyed it. It knocks your confidence but I’ve met people here in a similar situation. I do like it. As the BT advert used to say, ‘It’s good to talk’!**

- Dementia is horrible. I get angry with myself and others but this has been a place where I didn't have to put on a façade. To be able to come here has helped me so much, being able to talk. It's because this is a safe place.
- **I'm pleased to be here. We've had a wonderful programme. I'd like to record my thanks for that and for everyone around the table. We know we are with friends.**
- It's been super. That's the word. To look at someone and get a smile back. It's important. You think you have helped them and they're the same, helping me. When I came in today and saw all these faces it was lovely to be back here again.
- **It's just amazing to be here. 'Coming out' and saying what you want to be**
- Thoroughly enjoyed it. I don't like the idea of having dementia but I have accepted it. We all have it and so what!
- **'Absolutely Excellent!'**
- 'I'd been quite low but coming here made me feel more like my normal self'. 'I can't make a fool of myself here'
- **'It's like that feeling you get when you whoosh down a slide as a child in a playground and spring to your feet at the end'**