

EARLY ONSET DEMENTIA

Interview with Ann and Timothy

Ann: I do have days where things are totally fuzzy, you know if your tea comes out in ten different pots and one's burnt and one's not it's not a good day, don't ask

I'm Richard Fox and this is Messages Of Hope. You've just heard Ann describing her experience of early onset Dementia. How do you face the future when you feel like you're losing your past?

Ann: I don't panic about it I just sort of say this is it. This is what you are. You can't dwell on all the if's and but's and things you might have done.

Dementia is affecting more and more Australians but it's not just about memory loss. It's a complex disease that affects people in different ways. Ann was diagnosed with Dementia five years ago at the age of 59. Here's Celia to continue the conversation.

Ann and Timothy, how did you first react when you got the diagnosis that Ann had a form of Dementia?

Timothy: There have been some very sad times, I remember us both hugging each other and bursting into tears while we were watching the dogs being shown at the Royal Adelaide show. We were sitting up on the bleachers and had a miserable time when you were first properly diagnosed. That was show time 2012.

Ann: Until then they'd just talked about mild cognitive impairment, which can be anything really.

Celia: So how does that affect your everyday living?

Ann: Little things slip like the ironing of a shirt for example. I can't seem to get the sleeves, the cuffs, the way they used to be and I can't do the embroidery I used to do, I used to do really detailed stuff. It's also the cleaning and things. Little things get more difficult and you need to be reminded without wanting to be reminded.

Tim: Was the cat fed?

Ann: Well the cat will tell us.

Tim: The fact that the cat is getting fatter and fatter and fatter probably means it's been fed five times!
We decided that we wouldn't cover the kitchen yet with posters of don't forget to turn off the gas.

Ann: Oh yes well I did have a little incident the other day where I forgot about.....

Tim: We had a tiny bit of a fire wasn't it, two tea towels caught on fire and you weren't going to tell me.

Ann: No, except for the singed tea towels in the laundry!

Tim: We'll have to start having reminders at some stage which they say you should have.

Celia: Were there other symptoms apart from the memory loss?

Ann: The memory issue is really just one. I mean there's the spacial things, like my balance is pretty bad and I stumble from time to time. I'm very self conscious of that.

Tim: Executive functioning, there's behavioral changes, there are personality changes. There are physical symptoms as well too. You might've noticed that Ann has a tremor and she also has some balance issues. Basically little parts of the brain are dying.

Celia: Ann we've talked about some of the things that you can't do in the same way you used to. Have you been able to adapt to those changes?

Ann: I used to do really detailed stuff and now I've just had to give up and do things that don't require counting and I can't do the embroidery things I used to do. I have to read facts rather than crime and fiction which I used to like. I can't follow the plots on a television series anymore. There's been an increase in the trendiness, and not just the people with dementia, to do adult colouring. That's meant to be for, what's it called? Well being?

Tim: Mindfulness, it has sort of a slightly meditative aspect to it as well, it can be used for that.

Ann: And now I just sit and colour in. There's no right or wrong which of course with my life was always, it had to be right. Now I just use colours and things I would never have used before.

Tim: You're bolder.

Ann: Much bolder. You become much freer and much more....

Tim: Taking some braver steps in some areas.

Ann: I think you're truer to yourself when you have all the barriers broken down. So now I take risks with this sort of thing. I do embroidery that doesn't work out and it doesn't matter. Knitting, I used to knit really intricate patterns and now I find that I've cast on 55 stitches and it says 40 and I just constantly smile and undo it and cast on again. It doesn't matter whereas before it did matter, it mattered a lot.

Tim: You've been a perfectionist and that's been a hard lesson in a way.

Ann: I've lost that need to do the perfect things but I still like that creative part of me, that's still there.

It just means that you have adapt. I think that's the main thing you just have to cut back and adapt what you do.

I'm Richard Fox from Messages Of Hope. If you've found ways to support a family member with Dementia please share your experience on our Facebook page at messages of hope. Your story could encourage someone else. This is Messages of Hope and Celia Fielke is talking with Ann and Timothy about coping with early onset Dementia.

Celia: Are there any things you've discovered that can help lessen the impact of Dementia?

Timothy: One of the things that is encouraged is that people with dementia maintain social contacts. Don't avoid social situations. Ann's natural inclination is to avoid social situations.

Although we have wonderful friends, and we're all close to our family and our lovely home group through our church who are very understanding people, there's still this idea that you don't want to appear to be stupid in what you say.

Ann: That's how I feel.

Timothy: And Anne feels a little bit that way at times.

Ann: I used to be able to walk into a room and engage with anybody. Now I walk into a room and I don't want to engage with anybody because it's really too hard.

Timothy: Ann always wants me close by and I love that, I've always wanted you close by anyway.

Ann: I tend to do a lot of nodding and just smiling. I smile and nod and just look for Tim.

Timothy: Ann will stick close by me so that if there's anything awkward that she can't continue with in the conversation, I will.

Ann: I still have the long term stuff still there and you can see the implications and you can draw on the knowledge but it's hard to get it out which is really weird because I've still got it.

Timothy: Anne frequently feels that she has the thoughts inside her but she can't translate them into the words that make sense.

Ann: And when they come out it just seems that it's missed the point. It's almost as if your intellect is dumbed down a bit and I find that confronting. You expect older people to muddle along and if it was an older person nobody would think twice. I'm very self-conscious of that. You feel it's a bit belittling in some ways, but then I think well, it proves that you're not in control of everything and that you can't rely on yourself all the time.

Tim: We're very trusting in God and his promises.

Ann: That God's there and that this is given to us for a purpose, even if it's just to help other people. I'm not happy having dementia. I accept it.

Tim: You wouldn't have it by choice of course.

Ann: No

Timothy: I might mention on a positive side that we love to do crosswords and we love to do cryptic crosswords as well too.

Celia: So how do you manage to do crosswords when language has become difficult?

Ann: It must be another part of the brain. It's bizarre but words have always been something I've been tuned into, so if I see 5 letters a word comes.

Timothy: The cryptics are really interesting because even though words may be hard for Ann to use in speech, she'll find those words to put into a crossword.

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Celia Fielke is talking with Ann and Timothy about coping with early onset Dementia. Can they look forward to the future even with the changes that Dementia will continue to bring?

Celia: So where do you look for hope to face what's ahead?

Ann: Well I guess you are so far from it, who knows, nobody's aware of when they're actually going to die. I don't dwell on that. I'm not thrilled about the concepts of losing, not the memory as much as the other.

Timothy: Control

Ann: Yes, and the ability to sort of manage to do things and the shakes and the things like that I find more debilitating really.

Timothy: I guess there's a certain aspect where we protect ourselves, we're a little bit you know, there are some things that we don't want to think about for the future. I'd have to admit that.

Ann: I guess I've got more of a realistic understanding of what things are like towards the future because I've cared for people, nursed them and known what happens to people as they're in those last final stages. My concerns are more for the carer. I'm not so concerned about myself as much as the carer and the family.

Timothy: If we have a little text I suppose which is our motto it's the latin text, Dominus Illuminatio Mea, which means the Lord is my light. It goes on The lord is my light and my salvation, comes from Psalm 27 verse 1. That whole idea I think, of what shall I be afraid when God's in charge, of what shall I be afraid. I think that whole idea we just have to trust that God is there before we are even there.

Ann: Things that are really meaningful, that are deep, what do you call it when it's deep, is music. I know that's a great sense of peace and more so perhaps lately.

Timothy: And often it's that marriage of words and music which I think leads one into a closer connection with God. You pray through the words and you sort of pray through the music.

Ann: It all centres very much on Christ being the centre of our lives.

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