

For Broadcast: 15th September 2019

DEMENTIA – THIS IS OUR STORY

Interview with John

John: She was 15 when I first laid eyes on her at my 16th birthday party, and the girl I was going with never got a look in after that. 51 years married on Saturday.

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Celia: It's hard to imagine what it would feel like when the person you've loved for 50 years doesn't know who you are. I'm Celia Fielke and you're listening to Messages Of Hope. Stay tuned for John's inspiring story of loyalty and love.

John, you were smitten by Maureen when you were 16. You keen to get married, can you tell us how that all came about?

John: When she was 18, we both decided it was a good move to get married. There was no question in either of our minds. So we went to Maureen's folks and said, "Look, we'd like to get married, what do you think?" Her mother said, "Absolutely not. He's got to be at least 21." She was 18 when she got married. So I thought, "Not telling me what I can and can't do, this is going to be my wife." So I took them to court, a terrible thing to do. Took them to court and won the case. The judge said we were of age and I could support her because I was running the service station. Anyway, I went round to get her after that and she said, "No, I don't think it's wise." Darn. So we waited till she was 21, her birthday's the 3rd of August. We got married on the 29th of August. 51 years married on Saturday.

Celia: You went on to have three kids, you became a pastor and you both traveled and ran businesses together. Maureen was quite a major support and partner for you in that, wasn't she?

John: When we were running business, goodness, she did all the banking and running around with the kids and the business and everything else. She's always done the books, paid all the bills, got on the computer and done all ... I can turn mine on. She is just an extremely clever girl and seeing her now, it's just nothing there, it's awful.

Celia: Maureen was diagnosed with dementia around 2012, which has obviously had a major impact on you both. What were some of the everyday things that changed?

John: She came to me, she says, "Can I make you a cup of tea?" She boiled the kettle and we've got one of those juicers that plug into 240 volt power and it was just sitting there on the bench because I used it quite a bit and she promptly poured the water straight into it. Thankfully I was there and I ripped the plug out and emptied it out and that's the last time she's ever made a cup of tea. I mean, she'll often ... Valerie, our friend, at that stage was cooking a Sunday meal for us, which was very gracious of her and Maureen would feel bad. She'd say, "What can I do to help?" And Val say, "Can you set the table love?" So she'd open the drawer and just stand there and stare at it. No idea.

- John:** We were lying in bed one day and I'm just sort of leaning on my elbows like this and she's there looking up at me and talking and she just said, "Who are you?" Ripped me apart.
- Celia:** This is Messages Of Hope. We're talking with John about life with his wife Maureen, after being diagnosed with dementia.
- John:** Government came in, this lady, and did a check on her and said, "She's high care." "What does that mean?" "She needs to go into care." And it blew me away. Yeah, I think there's years waiting and knowing that she was going to have to go into care thinking, "Well that could be Aldinga, Strathalbyn, Gawler and to get Hope Valley and this has got such a good reputation, so to get into here was a miracle provision of God. I didn't really like the room to be very frank because it's shared. I'd rather her be on her own with an en-suite, but the staff there, I can't speak too highly of them, they're wonderful and I know she's being looked after.
- Celia:** So what's your relationship like with Maureen now? Now that she's in full-time care and you're not living together anymore.
- John:** I visit her every day pretty well, unless I'm crook. I mean she lights up when I walk in the room, "I've been wondering where you are," and it's a bit of a joke, so I appreciate that. My normal practice is to be there 3:30 or so, till 5:00 then we lie on the bed, and have a cuddle and a sleep and I'll just strike a face and she relaxes and then I get her up and do her hair and put makeup on her and make sure she's dressed properly and take her up to the dining area. At the moment she can feed herself, so I leave her to it.
- Celia:** A lot of people find it really difficult to visit their loved one and maybe even harder to leave them at the end of the visit.
- John:** Well, I've got to confess, there are times I'm too chicken and can't face it. That's where I've just got to melt away. Normally if one of the staff come up and talk to her, I'll just look them in the eye and walk backwards and she doesn't know. That's when they said, "Don't look back."
- Celia:** Well how do you keep going back day after day, year after year. How do you keep going?
- John:** Well I'll get told off by different people for going in too much. I'm sure a very well-meaning lady came to me, because I'm broken up. She says, "You've got to get on with your life now." "What do you mean?" "Get new relationships." "No way, I'm married till death do us part, in sickness and in health." We've had the health, she's had her turns over the years, we've had malaria both of us and I really, really struggle to see why people can just turn their backs on their partner. I could no more do that and then fly to the moon. She's my wife.
- I hate this, I absolutely loathe it. I just don't want to let her down but ... so hard. Just don't know what to do. It is a day by day experience. It's not like she's just away for a while or she's got some disease they can cure. She's gone.
- Celia:** John, there's no denying the pain of watching the person you love kind of disappear. Where do you find the strength to keep visiting and stay committed to loving her during this really difficult time?
- John:** I know God loves me, loves Maureen. He's got our best interest at heart and this is our journey, but it's hard to handle. I have punched the wall a few times.
- Celia:** So how do you make sense of it?

- John:** As someone said years ago, we look up and we go, "My life's a mess." But God's looking down on the tapestry and it all makes sense to Him and He's got a reason for this. In the early days, I was saying to Maureen, "These people here, you got opportunity to love them," and she does. She goes up and puts her arm around people and their noses are running and she's so sweet and they all love her.
- Celia:** What about you, John? Have you found a new purpose in this community?
- John:** I've got this unit which I'm so grateful for. I've got everything I could ever need and I mean I'm volunteering everywhere and the lady that runs the disposal shop's 87, I think, ready to pull back and looking at me to take it over and I'm not sure about that. Then some other guy came to me, Dennis, and he just said, "Can you help me with the bread?" I love that because I'm really meeting an awful lot of people. We pick up bread from a bakery, which ... two, three hundred dollars worth of bread and cakes and pasties and stuff, load it into the car and then we go around at least 60 homes. There's about 300 in here and deliver it to those people that really need it. We have a lot of fun, I ding dong the bell and run to the next one, ding dong. "Oh John. Hello John." I don't even know who they are, but they know me. It reminds me of my childhood, so it's been good.
- Celia:** John, it's been four years since Maureen needed full time care. How is Maureen now?
- John:** She had a seizure, September two years ago, so it's two and a half years nearly. Then they said, "Oh maybe she will last two weeks." Well here we are two years later and she's still just lies there, can't do anything, can't talk, can't ... No, it's horrible but I walk up to her and sometimes I get just this ... because she's got the Parkinson, I get this slightest grin that moves me to tears. I'll sit and hold her hand or try to.
- Celia:** And that's okay, she lets you?
- John:** Sometimes. I feed her her afternoon tea and yeah, she's in control. She knows, "No, don't want anymore." I say, "I love you." And occasionally you'll get a, "Love you too." Wow. That moves me. But very rare now.
- Celia:** So what do you hold onto John?
- John:** That thing there, the best is yet to come. I read that to her or I tell her that every day, "Sweetie, you're going to get a new head and you'll know who I am and what we can do and forget the new body. I'll get a new heart." Because she leans on me and she can hear me pounding away it's so loud, we joke about that.
- John:** So I know I'll be with her when we're both whole. Heaven, we're going there, sooner or later. The best is yet to come, that's our faith.
- Celia:** You've been listening to Messages Of Hope. For more encouragement for coping with a difficult experience like dementia, go to messagesofhope.org.au, or for the free booklet Dementia, call 1800-353-350.

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