Dementia: participation in development of dementia care

June Hennell:
00:00:27
Lots of ducks there.

Brian Hennell:
00:00:29
I'm Brian Hennell, I am now 72 years old. At the age of 70 I was diagnosed with frontal temporal dementia, something that was a completely closed book to me then.

Narrator:
00:00:49
Brian Hennell lives with wife June in Stonehouse, Gloucestershire.

It's, you know, it's one of those silly things, because some things I can remember, some things I can't. There's nothing more frustrating than thinking in five minutes time I must do so and so, and an hour later it's not done because I couldn't remember to do it. But I've learned to live with it now, accept it. There's no going back, there's no getting out of it, so I've got to accept it, otherwise it'll drive me doolally. (Laughs) Simple as that.

June Hennell:
00:01:34
So you're happy that I ring the Alzheimer's Society and say yes?

Brian Hennell:
Yeah, no problem.

June Hennell:
Yeah?

Brian Hennell:
No problem.

June Hennell:
Okey-dokey, no problem.

Brian Hennell:
Roughly when?

00:01:42
I think the popular conception of somebody with dementia is that they should be put away somewhere in a corner quietly and left to vegetate, taken care off, but they weren't capable of doing anything particularly for themselves or to help other people. We decided that it would be a good idea to get into the nitty-gritty of dementia and find out what it is, and then see if we can help people come to terms with it.

Narrator:
Their involvement began shortly after his diagnosis. In their area, Gloucestershire NHS and social services have jointly
In the quiet Kent village of River, the members of the Dover Choral Society raise their voices.

For John Ravenhill music and choir practice are the centre of his life. He is an enthusiastic bass.

Music has always been an essential part of my life. I enjoy singing.

But only a couple of years ago John, together with his wife and daughters felt that music making and much else which required John’s memory might become a thing of the past.

The girls on their own had noticed and so had I. We hadn’t said anything to each other, but he was in fact getting things wrong.

In 2007, John started to display early symptoms of memory loss, and a slight personality change making him unusually argumentative.

A huge problem was to decide what to do about it. You’ve got to decide how you’re going to say to the person, you know, I think there’s something wrong with you, and not upset them, because he was totally unaware.
Narrator:
00:01:37 When Geri was diagnosed with breast cancer the same year, that crisis finally convinced John that he also had a problem.

Geri Ravenhill:
I was diagnosed with breast cancer and John was so upset by this that he did lose it.

John Ravenhill:
What happened when is, in my mind, scrambled.

Geri Ravenhill:
00:02:01 You were totally shaken by it and didn’t know whether you were coming or going. And I don’t think you realised how much until to you went to Choral, and somebody said, an ex-doctor in fact said, and how’s Geri getting on, and you almost said, ‘Who’s that?’.

John Ravenhill:
00:02:18 That’s when I suddenly, my mind went a total blank; just for words, pictures I knew what was happening; the words I couldn’t find. I said, I’m sorry, I can’t tell you.

Geri Ravenhill:
00:02:28 So that was the first time actually that you decided for yourself there was something more wrong with you than old age, and that was a turning point.

John Ravenhill:
Yes.

Geri Ravenhill:
00:02:37 Putting all those jars out on those shelves over there John was a pretty good brain wave wasn’t it.

Narrator:
00:02:44 Geri is a good organiser, and was able to convince her husband to see a doctor. But the visit proved as distressing as the symptoms.

Geri Ravenhill:
Unfortunately, it didn’t go too well at that point, because the young doctor that we had to see because our own GP’s very busy, simply said, ‘Well what do you expect? You’re nearly eighty’, and sent him out with tears in his eyes actually.

John Ravenhill:

I turned up at home here, and I was crying, and saying, ‘Something’s wrong, somebody has told me I’m old, so what do you expect’. And I was so bewildered and I’d lost sort of, lost touch, I couldn’t find words to express Being a visual person, I knew what I wanted to say. I couldn’t find the words to say it.

John Ravenhill: When I was teaching art ...

Narrator: As an art teacher all his life, John was used to putting his thoughts into pictures, and now his worried wife provided the words.

Geri Ravenhill: I put my foot down, and said, ‘It’s ridiculous to say that this is old age. Yes, we’re getting older, but not that fast, and this has been too obvious and too rapid’. And so I insisted that we hang around and get an appointment with our own doctor, and he said get him in on any excuse and I will deal with him definitely, and he was wonderful. And the next person he saw was a psychiatrist who was also wonderful.

John Ravenhill: He put me through a number of questions. I couldn’t remember what my birthday was, and then he sort of generally talked with me and so on, and he said well, I think we’ve caught you; you’re right on the edge. I think we can do something for you, but you’re definitely starting to go off as it were.

Geri Ravenhill:
At the end of it he said yes, well you do have late onset dementia but the good news is that I can prescribe Aricept which will, should stabilise it. I can give it to you for five years and em, it in some cases, it has even improved it, so we came away with hope.

John Ravenhill:

I had no idea how bad you could get, or you could get to the stage where we don’t give this medicine away.

John Ravenhill: 

... and you didn’t want me to do that, did you.

Geri Ravenhill:

No, well you can tell that because I’m lying there with a sort of, oh for God’s sake, get on with it then.

Narrator:

John was lucky that he had someone close to him alert to the problem.

Geri Ravenhill:

... but you know, that’s the nicest thing that’s happened to us recently, because that was just a small sketch wasn’t it and ...

Narrator:

In some ways, they feel their experience has brought them closer together.

Geri Ravenhill:

But I reckon oddly enough, that since we’ve both been pretty ill, we’ve got a new em ...

John Ravenhill:

... understanding of each other.

Geri Ravenhill:

... aspect on life. Well, I’ve always understood you ...

John Ravenhill:

Well that’s true, yes.

Geri Ravenhill:

But we’ve got a new raison d’être, haven’t we?

John Ravenhill:

Yes, yeah.
And we’ve got something to fight over and something to fight for.

John Ravenhill: Yes.

Narrator:

John’s fight has been helped by being successfully treated with Aricept, a drug which helps boost the brain function and slow down the decline.

John Ravenhill:

It gave me a new life really, because my memory, increased almost instantly. That I could remember things that I would have thought I would have forgotten. Details of just anywhere. It was all, it became flashing up in picture form, obviously, for me, right back to when I was aged three.

John Ravenhill: You didn’t think you looked like that, did you?

Geri Ravenhill: I didn’t know what I looked like. Did you know what you looked like?

John Ravenhill: Yeah, you looked like that!

Narrator: They’re both aware of what could be lost.

John Ravenhill:

Well you know a lot of people whose wives or husbands have lost touch with one another. They almost don’t talk to one another. There doesn’t seem to be anything that they have in common anymore. It’s as if their past didn’t exist or they didn’t have a past.

Narrator:

But their access to Aricept was not automatic. Again, it paid to be persistent.

Geri Ravenhill:

Our local GP wouldn’t prescribe it. The psychiatrist, we have to keep going back to him to prescribe it, and since we’ve met up with loads of
other people who have Alzheimer's, we've discovered that not everyone prescribes it.

**Geri Ravenhill:** You have to get on with each other to work in a space like this, I tell you.

**Narrator:** Geri felt that the important thing was to face the situation and not be frightened of it.

**Geri Ravenhill:**

00:07:36 I kind of get a feeling with a lot of people that they don't want to face that there's a possibility that one of their, their partner or their parents, have got what has to be called dementia. And em, therefore, they don't want to find out that they have, so they don't take it any further. And I think an awful lot of people don't benefit from early diagnosis in Aricept for that reason.

**Narrator:**

John's condition is currently manageable, but as his wife and carer, Geri has to adapt her own reactions.

**Geri Ravenhill:**

00:08:11 You've really got to change your whole mindset. Really got to stand back from it all and try and imagine what it's like for the other person to genuinely not know one thing from another. There's no good being exhausted and sitting here and saying 'oh, would you just start off the lunch love, that would be lovely. Just put the potatoes in the oven and turn it onto 200' and so on. And a minute later, he's out saying, 'what was it I was supposed to put in the oven?'

**John Ravenhill:** Not totally incompetent.

**Geri Ravenhill:** No, you're not incompetent.

**John Ravenhill:** Put, give too many bits of information together, and I remember the last bit, but not the first bit.

[singing]

**Narrator:**
00:08:54  John’s condition also threatened his music making.

**John Ravenhill:** Obviously I was going off.

**Geri Ravenhill:**

00:09:05  You did find it harder and harder, because you kept losing your place in the music, but when you discovered that you had actually got something wrong with you, I mean …

**John Ravenhill:** It was such a relief …

**Geri Ravenhill:** Yes.

**John Ravenhill:** … to realise that it …

**Geri Ravenhill:** He told all the fellow basses and said, ‘please, look after me.’

**John Ravenhill:** Yeah, ‘look after me’. I’m not going to be the fella that I was, but I need help.

**Narrator:**

00:09:29  All the choir knows about John’s condition, because John and Geri don’t see anything to be secretive about.

**Geri Ravenhill:** He’s got Alzheimer’s. There’s nothing to be ashamed of.

**Narrator:**

00:09:39  John’s diagnosis has spurred them both on to new adventures, including a first time visit to their daughter in South Africa.

**John Ravenhill:** Do it now before you can’t.

**Geri Ravenhill:** Yes, I suppose …

**John Ravenhill:**
I mean if you're going to deteriorate, you're going to deteriorate. You can't stop that, so while you feel you can, do it.

Geri Ravenhill: Now we need Aricept...

Narrator:

Packing nowadays includes an essential new element.

Geri Ravenhill: Because you started off at 5mg didn’t you.

John Ravenhill: Mm.

Geri Ravenhill: And you had to move onto 10mg.

[singing]

Narrator:

John owes his current good fortune to an early diagnosis, access to the right medication and a perceptive and persistent wife.

John Ravenhill:

Looking at Geri is a joy because I'm aware of how much I love her how, what a wonderful wife she's been, I mean where would I be now if I hadn't had all the support from you. I’d be practically a dead person with … I’d be a nobody.

Title: Key learning points

Dementia is not just part of the ageing process

Sometimes family or friends may notice changes in an individual's behavior which may be a symptom of dementia; it can be difficult to discuss these changes with the individual

It is important that medical staff handling the process of diagnosing dementia do so sensitively and offer appropriate treatment, care and support for the individual and their family
Medication can sometimes slow down the decline of an individual’s memory

END