

Welcome back to another series of On the Air, a podcast brought to you by Stonewater. Every month, we'll be bringing you a brand new episode that will explore the role collaboration has in tackling challenges and opportunities to ensure everyone has the opportunity to have a place they can call home. Host Anisha Patel will be joined by a guest co-host as well as special guests to explore the latest insights and stories from across the social housing sector.

Anisha: Hello, and welcome back to another episode of On the Air. In this episode, we're finding out more about the Invite research project, funded by the Longleigh Foundation that, in partnership with Stirling University, will look at the role that assistive living technologies have in older people's well-being. I'm really pleased that not only am I joined by my lovely co-host and Stonewater colleague, Lisa Lembergs, but also by Dr Grant Gibson, lecturer in dementia studies and co-investigator, and Dr Steve Rolfe, research fellow from Stirling University, but also one of our retirement living customers, Pat.

Lisa: At Stonewater, we talk a lot about the use of technology to keep us all connected, and this, of course, has been hugely important during the Coronavirus pandemic, particularly for our older residents living in our retirement living schemes. I was actually really surprised to hear that one of the reasons this project is so important is that there is so little evidence currently available about the use of technology to help support older people in their own homes to live well for longer. Steve, perhaps you could start by telling us a bit about the research project?

Steve: Yeah, thanks, Lisa. So, I think that's quite an important place to start. There is a bit of a gap in the research evidence and some of that is just because assistive technology is still relatively new, so it's still emerging as research. But, also, the research that has been done over the last couple of decades as technology has developed is a bit disappointing. It's not... technology hasn't really delivered the benefits that everybody hoped it would do for people's quality of life and reducing need for support and care services. But a lot of that is because older people themselves haven't really been involved in the full process.

So designers have come up with technology, organisations have introduced it, and maybe not really involved people in that full process. So it doesn't always meet the needs that people have or actually work in their day-to-day lives and they tend to abandon it and then that, you know, undermines the impact.

Anisha: Thanks, Steve. When I did my research ahead of this recording, I was really shocked by some of the statistics that I read. By now, we're all really familiar, I think, with the term 'ageing population', but I didn't realise that there are currently around 850,000 people with dementia in the UK. This is projected to rise to 1.6 million by 2040.

After the COVID pandemic, numbers are making a lot more sense to me now just in terms of comprehending how many that actually is. But, yeah, it's really quite stark. And we also do have an incredibly special guest here with us today. I think she deserves her own introduction. So, we've got with us today Pat Harvey, and her husband, Bernard, has recently moved to a specialist dementia nursing home, and

we've brought her on to find out first-hand about living with dementia. So, Pat, welcome and thank you so much for joining us today.

Pat: Thank you for having me.

Anisha: Any time. And do you think you could start off by telling us a little bit about the impact your husband's dementia has had?

Pat: Well, Bernard was diagnosed about five years ago now with frontal lobe vascular dementia. But, prior to that, he'd been doing very odd things. I mean, it was obvious his memory wasn't very good, but he was doing all sorts of strange things, which at the time you don't even begin to think of dementia, you just think for some reason they've just done something odd or something a bit silly. And it went on for a while. He didn't want to go to the doctor and wouldn't let me go in with him anyway.

And in the end, our son said: 'You're going to the doctors, I'm coming with you'. And he listened to our son and eventually went, and tests followed and scans and all the rest of it, and received the diagnosis. It had already had an enormous effect on our lives because he'd got to the stage he wouldn't go away on holiday, wouldn't stay anywhere. He really couldn't be left alone because he got very anxious and worried.

He was still going out himself to the barber's and what have you. But it got to the stage where he really couldn't because he would get a little way and couldn't remember where he was going or what he was going for. So, it affected everything, really. I mean, I lost all sort of freedom in the sense that I always had to be with him and looking out for him. And that went on for about three-and-a-half years. And some days he wouldn't want to come downstairs, and we had a very difficult, twisty staircase, which was getting a bit much for me – going up and down all the time and trying to look after him.

So, that was when we began to look for different accommodation, something on one level. We fortunately found this flat at Stonewater and moved in just a couple of weeks before the first lockdown, which wasn't terribly helpful, but it wasn't for anybody was it.

And everything was fine, we were carrying on the same, good support here. And then unfortunately, in September, I took him as a treat to the local farm shop and I tripped and fell, broke my femur, smashed my knee in. I was in hospital for nearly two months. And after saying a month with our son and his family, it was obvious he needed more care. But it was a very sad way to do it because I... it just happened in a second that our whole lives changed. But now, with hindsight, although I was very sad he was going into a nursing home, I realised that it is the only place he can be, because he does need the care that I can't give him. With the best will in the world, I can't do 24-hour, seven-days-a-week care, although part of me, like I think most partners, would want to, but it's just not possible. And it wouldn't be right for him either.

Anisha: Can I just ask, how are you doing now after your injury?

Pat: I'm doing a lot better, it's taken a long, long time. I still can't walk without a heavy walking frame, and it looks as if that is going to continue. I don't want another operation, especially where they say there's less than 50 percent chance of success and it might be worse. So, I couldn't go through that. At the moment, I'm working with

Stonewater trying to find a solution because the only way I can get out is with a mobility scooter, which I need right by me.

I can't walk to the scooter shed and manage to unlock it and get it out. And I also need the front door adjusted because I need to be able to open it electronically, and we are working towards that at the moment. Apart from that, I think I manage quite well and I'm extremely glad to have my iPad and have a means of stimulating my brain and looking up things and doing things. And I have a lovely flat to live in and it's absolutely ideal for me, and Bernhard's down the road.

Once I can get out on the mobility scooter on my own, I should be able to pop by every day because his window faces the main road and I can talk to him through the window without even having a, you know, a special visit. Just because he asked me the other day, on the phone – he can't speak very easily on the phone – but he wanted to know if he was still married, if I was still his wife, because, you know, it's been such a huge and sudden change. And, although I obviously reassured him and my son has been to the window numerous times and talked about me and reassured him, I just want to go and see him.

Anisha: Of course you do, and I mean, I know that...so Bernard's recently moved and you mentioned that, you know, when you had your injury and you were staying with family, that it was clear that he needed additional support. What additional support does he need?

Pat: Yeah, my son runs his own business, and he hadn't realised until Bernard was actually with him that he wanted 24-hour-a-day attention, and he couldn't run a business at the same time. And I was getting distressed in hospital, eventually the hospital gave me phone numbers and the rest is history. Someone came to visit him and...the system has been marvellous and really looked after both of us.

Anisha: How is he settling in to his new place?

Pat: He settled very well, really. The main thing for Bernard, especially recently...well, it's always been routine. And he loves it that his lunch appears promptly at 12:30 every day. Everything is on time and done properly. He's got company there when he wants, all these different people to say hello to. And from what we can see and from what the staff are saying, he's settled in extremely well. So, this is obviously a big relief for the family that... because we all just want him to be as happy as he can be and as fulfilled as he can be.

Anisha: Definitely. And what do you hope for the future?

Pat: I obviously want to be able to spend time with him as much as possible. I want him to receive...carry on receiving as much care, and when that progresses that the care will progress with it, which at Waverley, where he is, that happens. So, that's lovely. And for myself, apart from being able to see Bernard and we're a very close family all together – although some of the children are in far flung parts of the country – my son is just around the corner. And I suppose I want freedom to be able to go out when I want to, be able to go to church, to go and see friends, to go to the library, go to things that the University of the Third Age run in Leominster, and just have that freedom. So, my own mental health and emotional health and everything else is as good as it can be.

Anisha: I completely understand that. And I... it makes... and I'm sure everybody on the episode can agree with me that it's really comforting to know that you're in a really great place now and so is he, and getting the support that you both need.

Lisa: Listening to Pat, I can really see the huge potential for understanding more about how technology can support our customers to live well for longer in our retirement living schemes. Grant, perhaps you can tell us a little bit more about your role on the project and what our customers should expect.

Grant: Thank you for the invite to this podcast. So I'm a lecturer in dementia studies and social gerontologist at the University of Stirling. I've been at Stirling for about six years, but I've been doing research around dementia care, and particularly around the use of technology in dementia care, for about 15 years now.

So, I've seen a lot of research over the years; I've seen a lot of different technologies that have sort of been invented and over that time, and we've gone from the initial sort of creation of telecare systems that many of you will be familiar with; and now we're sort of looking towards an age of things like advanced smart care platforms and the role of robotics and dementia care, and care of all the people, for example.

But, actually, I'm not a technologist by background. My interest is less about the actual technical aspects of the technology and more about how people with dementia and their care is actually engaged with technologies, and actually make them work for them and make them useful and beneficial in their everyday lives.

And I think this comes down to the core of what the Invite project is trying to do, which is not so much to look at technical aspects of development of technology, but actually to look at this question of how do we actually provide technologies for people in meaningful ways that they will actually engage with, to make it work for them and have the benefits and solutions that they actually want from technologies.

Lisa: Thank you so much to all of our guests for joining us today, particularly Pat, who describes so well her own experience of caring for a loved one with dementia. I cannot wait to hear more about the project as the research progresses but if, in the meantime, you'd like more information on the project, please take a look at our webpage about the Invite project featured on the Stonewater website's rolling banner.

We hope you enjoyed listening to the latest episode On The Air. We'll be publishing a new episode every month but, to stay up to date, subscribe to our channel. Thanks again for listening and don't forget to share your thoughts with us on LinkedIn or Twitter by tagging #SWOnTheAir.

