

Expert Critique

Table 2

P5	I don't know a huge amount about dementia, but I think music is one of those things you retain.
P8	My mother had dementia for years but music was always something she remembered.
P9	It's surprising what they remember, they may not be able to remember what they had for breakfast but these long-ago memories.
P8	Even just hearing it brings back those memories even if they can't speak. They beam, and there is something there that contributes.
P5	How would you do that, just talking about them or photos, or?
P7	Just bringing something up, my brother in law had dementia, and he just loved trains, models, going out. Just past interests and hobbies, obviously.
P8	Sometimes it's just that little trigger than can bring back a memory, sometimes you don't know but you keep on trying. It might be one of the senses, could be a smell, the smell of flowers. That's memory, a sound, a tinkle of a bell. A small sound that opens up that compartment in the mind, that has been blocked.
P7	It's like people with strokes can see clearly, but they say music being essential, it's also a good route of communication.
P8	Also with languages. If the person is multi-lingual, you find that maybe during a dementia period or stroke that they can speak in a different language than they normally did. This happened to my mother. It was absolutely incredible. The things that they would come out with. Where did you get that word from? And who knows? And she also talked about her childhood which we hadn't heard about. Those memories came flooding out.
P7	If someone is in care with dementia, it's so essential that carers know their past so they can communicate. Then they have a unique person with those interests or those, everything to make a person happy is much better than getting something totally wrong about them. I think in care it's much more difficult to get someone to stipulate -
P6	The problem is that most care homes the amount of attention that staff will spend on one person is relatively small because they've got a lot of people to look after. A few people command a lot more time from them and they don't have any background, whereas the family has background, they don't. I think the interesting point is he was talking about my nana. That's two generations away from you, we're talking about people one generation away from us, or in fact not even one generation. That's easier because not only were we involved in some of those things but they are more common things to us. You see, you said about trains, and the thing about trainspotting, when I was a kid, yeah you went and stood at the side of a track. You took the numbers down. You knew every local style and all the wheel arrangements. So, I will go down York Musuem, and I know it all, whereas he doesn't, he didn't meet with those sorts of things. That's the problem two generations away, it's so much more difficult because the world has changed so much over those two generations.

P5	That's where photos and images would be useful.
P9	I think it's important when you're talking about photographs to have the photographs of the person and the people around them in their youth, rather than say, last month, because they wouldn't necessarily remember it.
P7	You could have a whole family contributing to the profile, the person with dementia chooses, to look at whenever. I think the spoken word isn't always that penetrating but I think visually -
P6	I think this app could be useful I think to actually anyone not just something that would be useful for a younger person talking to an older person, but actually I would find it useful if I were talking to a friend say with dementia. My next-door neighbour had dementia and lost speech quite early and I ended up going to see her, but I didn't know an awful lot about her. I completely had no way of engaging. I always regretted it because I thought there must be a different way of doing this but -
P7	That's why this is good because you've got anyone visiting able to see what was of interest. It's a visual aid for everyone.
P9	Talking about the age differences though as I particularly remember if I showed my mum a photograph of anyone in the family she didn't exactly know who they were. But, if I showed her a photograph of say from 20-30 years ago she could identify them straight away. She knew straight away. The current day, she doesn't necessarily recognise.
P6	I think in some cases the events in their life which impacted on them most strongly which they're going to remember and it and which they have over the subsequent years, which they have rehearsed. There is this thing where you have to rehearse memory or it goes further and further down sort of into the junk pile. My mum she worked for a very rich man, she was his PA in the 1930s, she could remember that beyond any other memories from the past. She was in a in fact a hospital here, and the hospital staff said, who is this man which your mother talks about? I told them they said well we went and looked him up on the internet and they said is it the one with the museum named after him? She was his PA when he was buying those pictures, and she negotiated with him and she still remembers this because she's always talked about it.
P7	So achievements?
P6	That's right! The things that were important. Knowing two generations away, they wouldn't know. My kids didn't really know what my mum was interested in whereas I did. It's that double generation thing. Sometimes it's three generations away for old people. That's even more difficult. The world has changed so much. Kids have got such different interests.
P7	I find that the person with dementia, my brother in law, we'd worked together. He'll start conversation with and that one there and that one there and you think he's relating something to you and you just don't know what to say back. You need to find out because he thinks you know what he's talking about. It will be something to do with when he was at work and he was annoyed about something. It's difficult you know, you've just gotta let things go, and initiate a conversation yourself. But, it's very difficult, very hard to sort of let on you have no idea.

P8	With my grandmother, my maternal grandmother she used to get very confused with us. When she saw us she couldn't work out who was who. Are you so and so's daughter? It was that confusion which makes them angry, which exactly, you say no! I'm your, I'm your granddaughter! No, no, you're not! I am telling you who you are. That was the difficult thing, the confusion.
P6	There could be something in this app which might be key tips for certain things. When someone gets angry what should you do to diffuse it? Or if someone is talking about something and you haven't got a clue, how should you. Maybe it could also do some kind of key, key tips for...
P8	There is no point in carrying on confusing the person and getting your point because you're not going to get there.
P9	The thing I was told afterwards, after I dealt with all this was don't argue, just agree with what they say. Don't try and say no that didn't happen or for their piece of mind just agree to it.
P8	Instead of arguing, ask them?
P5	Well, a very long time ago before we knew about Alzheimer's and dementia, my great aunt, I used to go and stay with her in ?. She would start, and she would tell stories, something or other, and five minutes later she would do it again. Of course, I got so fed up of hearing this five times! Of course, no one would have told us about it. And we would say you've told us already, and you know she would keep on all evening, going over the same damn thing. How do you, if this app, if it could advise people on how do you deal with some of these behaviours, the repetition, they'll ask you the same question. You're the second child, and try to deal with it, and of course, two minutes later you're gonna be asked it again. And not you losing the plot of how it's so difficult. It's the distraction, you need someone to get them off.
P7	It must be terribly frustrating for them, to think these stupid people don't know -
P6	I mean do you think the things that might be of interest, are things like key historical moments important. Like mentioning the coronation, the kind of things with they would they?
P7	I don't have much experience, but I think keep away from anything negative, things that have upset them in the past. A distraction rather than something to talk about.
P5	That would by music is so effective, think of songs and dances when they were young, because in my mums case we had an Italian girl whod been working there for a while. She came up with 78, I had to show her to use the 78 because it was a wind up 78. She'd never seen one these before and didn't realise you've got the record on there before you put the stylus on it. All the other old ladies used to sit in a circle and sing away, and they really enjoyed it.
P8	I wonder with music and any sort of radio, something in the background, if that helps to stimulate the person's mind. When I'm really tired I put the radio on and listen to some music, my ideas seem to develop. It's relaxing. You feel your muscles relaxing, and you get these ideas. I wonder if it's the same in dementia, whether that happens sub consciously. It calms them down. Could that be what is happening?

P6	I think the thing about the app is this is an app for somebody else, it's not for the person with dementia. It's for somebody like us all in this case a younger person, who is trying to find a way of communicating. So what are the things that are gonna help that communication?
P9	The way I approached this was I put it on my phone and I said I'm the person, what would I want? What I want someone to tell me about if it happens to me. That was the way I used it and made notes about me. I don't know why it can't be used to be put on your phone so if something happens to you they can look at your phone and go oh she likes reading, she likes this, she likes that. We could create it for ourselves as well. That would prevent some of the problems of people who have already reached that stage where you can't ask them because they don't remember.
P7	Whatever helps the person with dementia helps the carers. It would be of interest to the carers, yes.
P6	I'd find it really hard to create it for myself, isn't that interesting? I would sit and think what might I find. You'd really have to get yourself into it.
P5	All you've got to do is talk about yourself, people want to know about you and your life.
P9	Don't you think if we can't do it for us, how on earth are people going to do it for us.
P6	Sometimes over people can observe things in you that you don't recognise yourself.
P8	Has anyone seen the film, Still Alice? You should really see that, I forget which actress it is, one of the famous ones. She, in the film, is a lecturer, a professor at a university, and she has these moments of forgetfulness, no but then she thought something is not quite right. She had a brain scan and then it was discovered that she was on the early stages. This shows what it's like for the person on the outside. She knows that gradually it is happening. The first stages are labelling the cupboards and things like that. Having more contact with the family, but then it goes further and further, and you see it from her point of view, that everything is hazy. People are in the distance, her family, her loving family, is caring about her but she doesn't know where anything is. And that is the frightening part. So yes, starting at the beginning when the person is in the early stages and getting all the memories down then that might help. But then once you get to her stage where it is complete then you can't get anything. You can't. Because in the film, and I have seen this in the hospitals, people just sitting there, like they're not there and just doing anything. Just repeating, complete vacant. You go to them and you ask them something, mmm, mmm, mmm, that's it. That's complete end. I think that is hard.
P6	Is that when music sometimes is the last thing that actually you still retain. So, something about bringing music in I think is.
P7	That might help with thinking about how a younger person can communicate with a person with dementia. How do you get people to feel comfortable to engage with someone who can't tell them what they like or don't like?
P6	If they are a family member it might be these things about what kind of music your grandmother liked, let's get the family photos out, let's remember the stories we told about key events. Can we get any pictures about that? Or

	anything that was happening. Some of those you'd have to just do trial and error, just try.
P7	That's where it's hard, it can't be about them it has to be all about yourself and that's where it's hard for younger people. It's usually older people asking them questions.
P6	Going in with your phone or your iPad and just showing a photo saying I found this photo of your camper van and just seeing whether that took you anywhere? If it didn't you might click onto the bit of music and see if that was going to work today.
P8	That's the biggest problem because that didn't used to happen. Because they sat around the kitchen with each other, it's so dysfunctional now these things don't happen.
P5	I think it's easier to persist with your parents. In a way, you've got a guilt set that you owe them a lot because they looked after you. Grandchildren do not have that same they don't owe their grandparents anything. I know my, when I was helping mother, my mother had dementia, the grandchildren stayed very much away. They were very little seen. When we were off on holiday and we asked them to they were not, they were actually quite good when they actually turned up, but they didn't turn up very often. They were very easily put off. Dementia goes through all the stages, starting from being initially forgetful through blaming other people when they can't find things. Someone stole it was my mother's one. She actually used to phone the police. In the end, I had to deal with a local coppa, he wouldn't look into anything. He would tell me that she had phoned. We usually found it when we went and hunted. It's these sort of things that are things we need to help kids understand that you might be blamed for things which you didn't do.
P6	<p>See with school, it might be a really bad memory, a really distressing memory. It's the sort of thing you said, try and think about positive things.</p> <p>There are things you're saying about what school did you go to, where did you live? I've lived abroad a lot, you've lived abroad a lot. So things might trigger our memories about different places. What work did you do, what hobbies did you enjoy? Those isn't it. Those kinds of things.</p>
P5	<p>You're talking about things like your said Nana, which is two generations away from you. But, somewhere in the middle there is another generation that would know more than you about that person. They're their children. You can ask them about their children, which are your parents and they might tell you some very interesting things about your parents! Which possibly they didn't want you to know.</p> <p>...</p> <p>Most of us obviously do, we're a generation older than you. That's where getting younger people to ask their parents, the intermediate generation if they're still alive ect, what their interests were ect. This might be a good route</p>

	<p>to get some of that information which you could turn round and ask them. One of the things we've been concerned about is asking them things which are negative, which turn out to be negative, something they didn't enjoy, like school. They might have had a really good time but they might have had a really bad time. Because, it's the way they might react to that. Really, it's advice to people about what do you do when you get a negative reaction, when you get into something repetitive, how do you get out of it?</p>
P6	<p>The other thing you were mentioning earlier which might be really interesting is thinking of places to go. You might go to visit an older relative in a care home, but in the fairly early or intermediary stages of dementia it might be about where can you go. Not just something that's got a dementia label. For example, ? Cinema has done dementia friendly cinema, we're finding people with dementia are going to ? at any time. The staff are well trained and it's a comfortable place to be. And dementia cafés tend to be places run by dementia organisations where people with dementia tend to go together, where the idea that you might be able to go to any café and you know if you've got dementia you would feel comfortable there if you started to do something slightly out of the ordinary no one was going to bat an eyelid kind of thing. Places to go could be quite you know.</p> <p>...</p> <p>I think it could be as a young person it could be very challenging, unless I was a very comfortable young person, to take an older relative out, whereas at my age I wouldn't be so challenged about that, I would feel more comfortable about that. Thinking if this app was used by older people and not just younger people this might be more useful.</p>
P7	<p>You've got to have responsibility of taking that person. When dealing with younger people they have to know how to deal with people with dementia. That much responsibility, would they feel happy being with someone.</p>
R	<p>Shall we think about our get rid of column, is there anything you want to put in there?</p>
P7	<p>Is there a thing, this sounds negative, but a thing where you can say the person with dementia does not like that. It sounds negative.</p>
P6	<p>One think I was thinking about is when you start using this you are asked the person's age. If you then put that it in as someone in their 90's they were in school in the 30's and in the second world war. If they were in their 50's they were born in the 19-late 50's probably. They have a very different world to that previous one, your, if you've got some of the very early onset dementia their gonna be, the things you would need to talk to them about for their childhood are different. With the Stone's onwards generation. For a 90 year old you're going to get a different set of content from a 50's or 60's year old. You need different inspiration for the different times. Rolling Stones and Beatles, or one of your later groups. Your Led Zeppelin is probably history, one person's history is another person's present. What was life for them, what period were they brought up in? What was going on?</p>
