

# The Story of TellJoan – Technology Helping to Manage Dementia

My mum Joan, born in 1930, had many fine qualities but she wouldn't mind me saying that getting to grips with post 1970s technology was not one of them. Even prior to her dementia diagnosis, mum only ever watched channels 1 to 5 on the television – a Guide option and Up and Down arrow keys were completely alien. Our attempts to help her use a mobile phone, in case of a car breakdown or other emergency, proved fruitless and it was a relief to us all when she gave up driving.

Mum moved over to live near my family in 2007, aged 77. She had been living in a house that was too big and too remote without use of a car.

The change was needed but mum found it hard to settle. She had difficulty getting used to a new cooker and heating system and struggled to find her bearings in a new town. She never grasped the intercom system in her retirement flat. If you didn't have a key to the main entrance, you had to telephone her and she would come down to let you in. Looking back now we realise that things were not quite right even then.

We put instructions all around the flat – “Turn this switch on for the cooker”, “Do NOT turn this off, it's the switch for the fridge”, “Leave the heater on this setting”, etc.

Over the next couple of years it became clear that mum was suffering from more than just normal memory loss. For example, she worried constantly about getting her Christmas cards sent in time and began writing them in October. We received 5 from her that year and it cost mum a small fortune in stamps, sending cards out to her friends across the globe multiple times!

Previously reluctant to write reminder lists because she had always had a fantastic memory and was meticulously organised, she now began to write everything down on random bits of paper. These lists were forgotten and lost and written again. Mum constantly rummaged in her handbag searching for the answer to

something she was worried about but often couldn't remember what it was she was searching for. She carried her handbag everywhere, gripping it to her side and when it wasn't in her grasp she was looking for it. I could have built the ark in the time we spent hunting for her handbag, her keys, her glasses and her hearing aids.

We went to the doctors. She was diagnosed with dementia and medication prescribed.

I saw mum several times every day but she would still telephone many times. She constantly worried that she had missed someone's birthday or a hospital appointment (she had quite a few of these because she was in remission from cancer). She continually asked the date. We bought her a calendar showing family photographs and I studiously noted appointments and events. We placed it in a prominent position but it wasn't a success as she didn't know the current date and rarely thought to read it anyway.

She was anxious about all the 'missed appointments' and I was frantic trying to manage her activities when I wasn't physically with her. She needed something that provided permanent reminders and prompted her to actually read them. The idea for a computer screen with a permanent display of messages seemed a good one, along with a method of notification. As I had been a computer analyst for many years and my husband a computer consultant we were lucky that we could progress this ourselves. We decided to develop a web based Message Maintenance system for message entry. These messages would then be relayed via the internet to a Message Display system set up on an old, previously unused PC we put in mum's flat.

As well as telling mum what was happening that day, with a permanent display of the day, time and date, I wanted to include details of upcoming events such as birthdays and appointments so mum would know she had not missed them. We always went on holiday every year to a cottage, something she looked forward to for months. I had started to hold back on mentioning holiday dates as she would then constantly ask where and when we were going. She arrived at our house weeks early on more than one occasion with her suitcase packed, ready to go. Being able to tell

mum holiday dates, so that she could look forward to them would be a great bonus.

Mum had never used computers and I knew she would not cope with any kind of touchscreen technology or even a mouse or keyboard. I needed the system to be completely automated. It was therefore designed to display messages automatically and after a selected time to display family photographs as a screen saver. I set the photos to change every minute but mum didn't like them swapping so often so we updated the system with an option to choose how often photographs change.



We placed the computer screen in her living room on a table. Initially mum was wary of having the computer in the room, worried she would break it when she dusted it. We tucked the keyboard and box away under the table out of the way and covered the screen on/off button with sticky tape. We reassured her that she could dust it just like the television screen and that did the trick.

I also knew that mum would want to turn off the computer at night – she was conditioned to always turn everything off at the plug to save electricity. We included the functionality of a blackout screen for night time so that at a selected time the screen would automatically go black giving the appearance of being completely switched off. The system used negligible electricity anyway but in this mode even less. We also put a 'Don't switch off' message on the plug – paper messages still had their uses!

To provide a sense of control we used an inexpensive, luminous button. Mum could press the button if she wanted to manually swap between messages and photographs. Familiar with using

buttons she did press it on occasion. We record the last button press time and display it in the Message Maintenance system so we knew mum was actively using the system.

To prompt mum to look at the messages, we included the option to flash the screen at preselected intervals and also when a new message was displayed. I rather foolishly, for my mum, included the ability to play music as a prompt to look at the messages, but as she needed a hearing aid (which she often took out in her flat) this option was a waste of time for her – but hopefully not for others.

It worked! She loved knowing the date as well as birthdays and appointments. Phone calls reduced significantly. She thought of the screen as another television screen. I included greetings from her grandchildren with their photograph alongside. As messages can be scheduled in advance and repeated as required, I could set the same greeting to display every few days which worked a treat. I also included messages to confirm she had completed something, for example “You have written and sent all of your Christmas cards” or “You have paid your telephone bill”.

A friend of mum’s saw the system and wanted to use it too. This made me think that maybe it could help others. We made sure that the method of entering messages was as straightforward as possible so that people with little computer experience could manage the message entry side. Our focus was to provide a flexible but easy to use and reliable system. For example if the internet loses its connection, the system continues to display existing messages and automatically reconnects and updates when the internet is available again.

I showed the system to a local Alzheimer’s group and they gave very positive feedback which was encouraging. They gave me some great suggestions – for example, provide the ability to change the colour on the Message Display screen as some people struggle with certain colour combinations. They also suggested it would be useful to know whether a task had been completed so we introduced the optional use of a Priority Message screen. This screen shows one message only and prompts the client to press the button (or mouse/keyboard) when they have completed the task e.g. Please take your medication. If the button is not pressed

email notification is sent to the carer. In addition we included the option to speak messages if required.

Mum's cancer returned and she lived with us for the last few months of her life. Though she was bedridden she still liked to see tellJoan. I displayed fewer messages for 'Today only', as she became more confused and unable to take in much information. We also included the option to space out the messages. Messages now tended to focus on greetings or what time a relative/friend would be visiting that day. I also displayed more photographs to relieve boredom – she no longer had the concentration or enthusiasm for television.

We have given considerable thought to how people can access the system to make it as intuitive as possible. Registration from the tellJoan website logs you straight into the Message Maintenance system and download of the Message Display system has been made as straightforward as possible (download and copy a zip file into a folder). Comprehensive help guides are also available from the Message Maintenance system.

Before dementia, mum was strong minded, active and independent. Even with dementia she bustled through life with the same determination and energy but with a good degree of chaos following in her wake. tellJoan couldn't alleviate all of this but it did help her feel more in control, less confused and less anxious. I still had to organise day to day activities, foresee problems and too often manage the fallout when I failed, but tellJoan did help reduce the worry that mum might be setting off for a non-existent appointment somewhere and it certainly reduced the phone calls (and Christmas cards).

tellJoan is currently available for free from the website [www.tellJoan.com](http://www.tellJoan.com). We would be delighted if people would use the system and hopefully give feedback on what they like or how it can be improved.