

## Case study – Joseph

### From passive recipient of care to activated self-manager

Joseph is 67 and has just stopped working after a long career in retail sales. He lives in his own home where he manages most of the household tasks as his wife is still working.

He previously had high cholesterol levels which he managed by small dietary changes. He has just been diagnosed with pre-diabetes (HbA1c of 41). He has a flu shot every year at the insistence of his wife. He tries to get regular exercise including regularly mowing the lawns of four of his neighbours as well as his niece and her family, and stays active thanks to the demands of a large family.

As a result of life-long hearing loss, he wears two hearing aids on which he is very reliant for managing face-to-face and telephone interactions. He also has a hereditary essential tremor which started in his 20s. His workmates and customers often used to tease him about having the DTs although he stopped drinking alcohol in his 30s.

After starting smoking in his teens, and smoking two packs a day, he finally stopped smoking at 59, to fulfil a promise to his daughter to quit before he turned 60.

Joseph has always been a passive recipient of care – only going to see his GP when he has been really unwell or when his wife has pleaded with him to go.

In 2016, his younger brother was diagnosed with prostate cancer and advised Joseph to get his PSA levels checked. Joseph went to see his GP and was surprised to be told his GP had been checking Joseph's PSA levels for more than 10 years.

Recently, Joseph's essential tremor has got much worse and is affecting his everyday activities. In particular, he is having to hold his coffee cup with both hands and ask for help with serving food.

Over the years Joseph has taken six-month courses of beta blockers on two occasions to reduce his tremor but these have not made any difference. In the last six months Joseph has experienced a number of situations where his tremor affected his ability to carry out important or meaningful tasks:

- He has been unable to key in his pin number when purchasing items and has had to get sales assistants to do it for him.
- He was unable to sign the condolence book at his friend's funeral.
- He has not been able to change the batteries on his hearing aids. Unfortunately his wife travels a lot and is not always at home to carry out this task.
- He was unable to put water into his car's radiator.

Joseph read an article in a magazine about a neurologist who performs surgery on people who are badly affected by essential tremors. He visited his GP who agreed to make a referral to the Neurology Department at the local DHB. In the meantime, the GP suggested that Joseph should again try a course of beta blockers. Joseph agreed to that. His GP also signed Joseph up to the practice's patient portal.

Joseph received a copy of a letter addressed to his GP from the Neurology Department saying they were not able to see non-urgent cases and instead suggesting that Joseph start on a different medication. Joseph was very upset as his tremor was affecting him more and more. His GP explained

that Joseph needed to go through the process of trying the new medication before his GP can follow up with the Neurology Department.

Joseph agreed to start the new medication and report to his GP using the portal about the results of the new medication. The GP also told Joseph about the side effects of the medication and gave him a website with information on essential tremor. Joseph said he and his wife would look online to find more information about the medication.

Joseph started his medication and noticed an immediate improvement in his tremor. He started writing short reports about these changes to his GP every second day through the email function on the patient portal. He used the scheduling function of the portal to book appointments with his GP and visited the results page, following a text notification his results had been uploaded, to check his most recent blood tests. After the first few weeks there were no further improvements to his tremor however, he kept up the regular reports via the portal and followed his GP's instructions to increase the dosage of the new medication every fortnight.

As a result of his condition starting to interfere more with things he wants to be able to do, and thanks to the accessibility provided by the patient portal, Joseph has had more contact with his GP in the last six months than during his entire life. Using the portal has meant being able to see and compare his test results, as well as track his regular observations of symptom changes. He is thinking and talking about his health with both his GP and his family in new ways. He is also more aware of the longer-term health outcomes which are possible with his condition, and motivated to work through a treatment plan with his GP which will result in the best outcome. Joseph is recommending the patient portal to his entire family and explaining its usefulness. He is no longer reluctant to visit his GP and is talking more about treatment and prevention/delaying any further deterioration.