

# Living with Dementia

## Introduction

As part of 'A Healthier Manchester' locality plan it aims to support the health and well-being by identifying the most effective and sustainable ways to improve the health and social care of people living in Manchester.

NHS Manchester CCG has been working with patients and their carers to understand their experiences of using health and care services when living with, or supporting someone who is living with dementia. By listening to these experiences and acting on them we are better placed to commission the right services to meet patients and carers individual needs.

The aim of this work was to understand some of the barriers facing patients and their loved ones and to establish what elements of the patient journey had improved their experience of using health and social care services, along with identifying what services and support were helping the patient to live a fulfilled life within their local community.

The Communications and Engagement team of NHS Manchester Clinical Commissioning Group have worked with a number of local organisations, including [Manchester Carers Forum](#), Alz Café, [Together Dementia Support](#) and Harpurhey Health and Wellbeing Centre in north Manchester to identify possible service users who felt comfortable with sharing their experiences with us.

## Maria's story



Maria Walsh lives in south Manchester with her daughter Nadia and her three month old granddaughter, Isla.

Maria is 63 years old and has been living with early onset Alzheimer's for six years following her diagnosis in March 2011 when she was 57 years old.

Maria explained that she was 55 when she initially started to display symptoms of her Dementia. She was working at a primary school in south Manchester and said that she was forgetting to record vital information which really concerned her as she felt as though the children were in danger.

Maria also started to put her handbag and other 'random' things like scissors or cellotape in the freezer and leave the gas on in her house as she would forget to light the fire. Maria explained that she had worked for the school for 12 years prior to this illness and she had been off sick for 12 months prior to the diagnosis of Alzheimer's as she was unable to cope with the symptoms she was experiencing.

In 2008, Maria went to see her doctor at her GP practice in south Manchester to discuss her concerns about her memory and behaviour. The GP diagnosed her with depression and she was provided with anti-depressant medication, she was also referred for counselling. Maria explained to the counsellor that her behaviour wasn't normal as she was now at a stage where she was plugging in the vacuum cleaner but couldn't remember how to switch it on. She explained how she used to do all her own decorating but had reached a point where she was no longer able to match patterns on the wallpaper.

Nadia stated that the way she felt her mum was treated by the doctor was awful. She was made to feel as though she was depressed and making things up. Both Nadia and her mum, Maria, feel as though when a younger person presents with memory difficulties at the GP, they put it down to depression rather than sending the patient for a brain scan which can simply diagnose the problem. Maria said that valuable time was lost in obtaining a diagnosis whilst she was receiving treatment for depression and on unnecessary medication and accessing counselling that she didn't need. She was made to feel 'like she was going mad', which she found very stressful.

Both Maria and Nadia stated that other people who also attend the Together Dementia Support Group have had a very similar experience in that initially they were treated for depression and valuable time was lost delaying a diagnosis and causing stress and anxiety for the patients and their relatives.

In 2011, Dr Allan from the memory clinic visited Maria at her home and requested that she attend the memory clinic within the Rawlins buildings, in Manchester for a brain scan.

Following the brain scan in March 2011, she was invited to an appointment at Salford Royal Foundation Trust where she was told that she had early onset Alzheimer's disease. Maria said that she felt "like she had been hit in the face with a brick". She asked the nurse "whether the diagnosis meant that she was going to die early?" Maria was not given any information about the condition or support about what was available for her and her family. Fortunately, despite the hospital not advising her to take someone with her to the appointment, Maria's sister had accompanied her so she was not alone.

Maria explained that at the time of the diagnosis she then fell into a depression for about 2 years, she was not offered any counselling or advice on what to expect when living with this condition. She felt very alone and isolated. Her youngest daughter was 19 years old at the time of the diagnosis.

Initially her condition was monitored by Salford Royal Foundation Trust hospital. Maria explained when she turned 60, her care was transferred to Dr Allan who practices from the Memory Clinic within the Rawnsley Building, next to the Manchester Royal Infirmary. Maria says that Dr Allan was fantastic. After 3 months and some further heart tests, Maria was put on medication to slow down the progression of the disease. She stated that the nurses from the memory clinic also monitored her condition by visiting Maria at home and undertaking the memory test reviews. Maria stated that the care Dr Allan and the nurses working in the memory clinic provided was very good care, and that “they really looked after me”.

More recently, in the last few months Dr Allan informed Maria that he was retiring and her care will be transferred to another doctor, who she has not yet met as she attends the clinic every 9 months. Maria said her memory reviews are now undertaken by the doctor’s surgery.

Nadia said that the way the GP practice undertake the memory test reviews is not very effective. She explained that when they attended the surgery recently the staff were not aware of why they were there. Nadia wanted to discuss some issues with the GP but he wasn’t available. Maria expressed her disappointment that since her diagnosis in 2011 until recently, her GP practice have never acknowledged that she has early onset Alzheimer’s. When she finally heard from the GP and was invited to attend an appointment with the practice to discuss her dementia, she saw a locum doctor who she has no established relationship with.

Maria feels as though she has not received any support from the medical profession, stating that the only support that her and her daughters have received is from Sally Ferris and the Together Dementia Support group.

On one occasion Maria stated that she went to her doctors to have a review of her condition and she was told, ‘you do know that you will never recover from this condition’ which she did not find helpful. She feels training for GPs and receptionists is required to raise awareness about the symptoms of dementia and how to support patients living with this condition.

Nadia also stated that more recently, in January 2017, Maria had her memory review over the telephone and neither Maria nor her daughters were aware that this review was taking place. Consequently Maria was alone at home when this review took place and the GP surgery have not spoken to her daughters to see if there is anything that they have concerns about in relation to their mums health needs. Both Maria and Nadia stated that they do not think that these reviews should be undertaken over the telephone.

Nadia also said that the way that health care professionals liaise with Maria and her family isn’t very good. As Maria does not fit the normal stereotype of an older person living with Alzheimer’s, hospital staff don’t tend to believe them when they tell them that Maria is living with this condition. It would be helpful if the patient’s records could reflect their health conditions so staffs are aware of the patient’s condition prior to the patient arriving within the clinic.

Maria has also recently been diagnosed with early stage breast cancer, and mentioned that last year she had forgotten to attend her mammogram appointment. Maria informed me that there are no reminder facilities in place to prompt her that she has an appointment at Wythenshawe Hospital to attend for a mammogram.

Maria said that she also suffers from pain in her knees, she recently attended a review at her doctors surgery and the doctor informed her that she has bad joints as she is ‘top heavy’ and has been diagnosed with osteoarthritis.

The GP informed Maria that she should “go and buy a bike” which both Maria and Nadia thought was very strange as the doctor didn’t seem to acknowledge that Maria is living with Alzheimer’s. She has been prescribed co-codamol to manage this condition; however, Dr Allan has informed her that she should not be taking this drug as it has a reaction with the Aricept drug that Maria takes to manage the Alzheimer’s.

Maria also has Diabetes type 2 and states that when she had a diabetic review recently she was prescribed some medication which she believes causes bladder cancer, a condition that her father had. Maria feels as though there does not appear to be a review of her patient notes or any conversations between healthcare professionals to ensure that the medication she is taking does not have any contra indicators or implications on her health as a result of her family history or new medications prescribed.

Maria said there are a lot of locum doctors at her practice and it is difficult to have any continuity of care as you frequently see a different doctor.

Maria explained that she has received brilliant support from [Together Dementia Support](#). Maria attends this group on a Monday and is able to participate in a number of activities, including baking which gives her a real sense of achievement. Both Maria and Nadia feel that without the support of this group and information that they have been able to source from the internet, they would have been at a complete loss of what support is available. Maria explained that these types of groups ‘make you feel like you belong and you are not an outcast’. She explained that it keeps her feeling positive.

Maria explained that she has difficulty reading words now as although she can read, her brain doesn’t process what she is reading. She can watch old films but struggles to watch anything new as she finds it difficult to keep up with the story. I asked Maria what would be the best communication method to ensure that she can understand the information being provided is shared. Maria stated that it would be useful if information provided by hospitals could be provided in audio format so that she can listen to advice or instructions. Text message reminders for appointments would also be useful, followed up with a telephone call.

Nadia explained that when someone has cancer there are several support networks and information leaflets within dedicated centres at hospitals, but for someone diagnosed with Alzheimer’s or Dementia there are no support networks or information points within hospitals. It would be really useful to have leaflets that explain the different types of dementia and the types of behaviour associated to each type, along with support groups for patients and their families. Maria also explained that through the chemotherapy treatment she is receiving for her cancer, she will be able to access some of the holistic treatments available. However there does not appear to be anything available like this for patients who do not have cancer and are living with Dementia.

Fabulous Forgetful Friends is a support group that is run by Maria with the support of Sally Ferris and they meet once a month. This group is specifically for patients who live with early onset dementia and they can express their points of view. Transport is provided by Ring and Ride for those who are eligible and are over 70 years of age or disabled. There is a mini bus that is available to transport other patients. Maria explained the difficulties of using public transport buses to travel around Manchester as she has on occasion forgotten to get off at her stop. She explained that an announcement on the buses of which stop is coming next would be really helpful and enable people living with this condition to travel independently.

Maria explained that shopping can be a problem as she frequently forgets to purchase shopping items that are on her list. It would be really useful if there was someone within the large

supermarkets who could check the shopping, against the list to ensure she returns home with everything she needs.

It was also felt that it would be really useful if doctor's surgeries had access to a directory of service of information and support groups that are available locally. Maria said that there are a lot more facilities available in Salford for people living with Alzheimer's, including exercise classes where you can ride a bike with simulating riding through the countryside, however she is unable to use these facilities as she lives out of the area. Maria feels as though the facilities to support people living with dementia in Manchester are behind those available to patients living in Salford.

Maria also provides speeches to raise awareness on Alzheimer's that she is working with the support of the council to deliver. She has provided talks in Brighton and Birmingham.

Nadia asked whether there was anyone who was able to come out to their home to undertake an assessment of what adjustments and support may be needed to enable Maria to remain living independently in her own home. Maria stated that they do not have a named social worker and is unsure of who would undertake this role.

## **What can we learn?**

- It is recommended that GP and hospital records contain a 'flag' for patients who are living with dementia
- It is recommended that patients who live with these conditions should receive text message alerts reminding them of their appointments, followed up with a telephone reminder on the morning of the appointment
- It is recommended that all GP practice staff (clinical and non-clinical) receive dementia training to raise awareness of the condition
- It is recommended that a review of the mapping completed by the Alzheimer's Society is completed of all support services in Manchester and shared again with GP practices, families and voluntary and community groups
- It is recommended that as commissioner's we ask how University Hospital of South Manchester is addressing the needs of women living with dementia as part of the breast screening service
- It is recommended that a reminder is shared with all Manchester healthcare providers to ensure that any information they provide is also available in audio format
- It is recommended that a link is made to the Fabulous Forgetful Friends support group by a representative from the Clinical Commissioning Group
- It is recommended that a review of the pathway of care is undertaken for newly diagnosed patients and those patients living with this disease. Patients need to be aware of who and what support is available around house assessments, support groups available, what to expect when living with this condition etc
- It is recommended that there is a review of what holistic treatments are available for patients living with Alzheimer's
- Share this patient story with Greater Manchester Passenger Transport to consider the possibility of introducing 'next stop information'
- Information leaflets would be useful to explain the different types of dementia and how they affect the patient