

# Caring for someone living with dementia

## Introduction

As part of 'A Healthier Manchester', our Manchester Locality plan aims to support the Health and Wellbeing Strategy by identifying the most effective and sustainable ways to improve the health and social care of people living in Manchester. In order to ensure we are meeting our priorities we want to ensure that we are improving people's mental health and well-being.

NHS North, Central and South Manchester Clinical Commissioning Groups have 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 speaking to and listening to experiences 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 carers 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 and carer to live a fulfilled life within their local community.

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



## Our Story – Les and Val

Val Meakin lives with her husband, Les and their son in north Manchester. Val and Les have been married for over 40 years. Val smiled as she recalled that they have shared lots of experiences and craziness during their married life together. She said that Les is a strong character who has quite a 'jokey' personality which he used to 'make light' of his difficulties with his memory and on some occasions had used this to cover up the problems he was experiencing.

Val said that Les had initially started displaying difficulties with his memory in 2012, and both her and their sons had prompted Les to seek help from his doctor. However she presumed he had been able to answer all the questions asked of him as he had not been provided with a referral as a result of the appointment with the GP in 2012. Val did expand that there were several issues such as Les losing his way and getting lost, but as she had not attended the GP appointment in 2012 it is unlikely that these problems were shared with the GP as Les never really admitted to losing his way.

Val explained that as a result of Les having difficulty remembering things he had lost his job early in 2013, she explained he had specific tasks to complete but had difficulty recalling how to do these tasks if he had a short break. Sadly his employer had to let him go as he was no longer able to undertake the role he was employed to do.

As a result of him losing his job in March 2013 both Val and Les visited their GP to seek help and a diagnosis. Val explained that Les was referred to the memory clinic at Wythenshawe Hospital and attended there in June. Val stated that it took quite a while for them to receive the results and in November 2013, a nurse came to see them at their home and explained that Les had dementia. Les was 61 years old.

Val stated that "It was like getting hit in the stomach" but for Les 'it was quite a relief' to receive the diagnosis as Les felt he no longer had to pretend and cover up his symptoms, he was able to 'let go' and Val was able to start to put plans in place for their future together.

Val explained that 'one thing that was crazy was she was given a wad of papers to read by the nurse who visited us and gave the diagnosis and Les was given his tablets that he had to start taking. The nurse then announced he would be back in 6 weeks'. and then left, it was really hard during those first 6 weeks with no support".

When the Dementia Nurse came back 6 weeks later, he explained that he had referred Les to Daisybank at the [Victoria Centre](#) in Longsight. Daisybank, who provided support for young onset dementia patients along with other services relating to complex mental health needs. Val stated that the group were 'amazing' and taught both Les and her to laugh at his illness, 'which was such a good thing'. She stated that they settled him into a group, which he could attend twice a week and as a result of this group he has made good friends with another gentleman who used this service. As the facility at Daisybank no longer exclusively supports people with young onset dementia, but is now a part of Later Life Services, Les and his friends are no longer able to attend the group activities, except for a garden group on Friday. Val explained that both Les and his friend continue to do activities together, with a shared support worker, Kay who ensures that their activities are tailored to their individual needs.

Val explained that the information and advice that Andy Price, the senior nurse from Daisybank, provided has been invaluable. She was given a telephone number that she could ring during office hours and advice and support would be provided, there was also a

telephone number to contact should advice be needed outside of normal business hours. Andy told Val about a tracker system that the council can provide, for a small cost which would enable Les to continue to live with a certain degree of independence as Val can track Les' movements on an 'App' on her mobile phone, which provides her with the reassurance he is safe and allows Les to continue to walk their dog, 'Prince' in the local park.

Although Les still attends a gardening club at Daisybank on a Friday and Val has good established relationships with Andy, and is able to speak to him should she have any concerns, this facility is unofficial. If she needed official advice she would have to contact the council and obtain the contact details of a social worker.

Val explained that the young onset element of Daisybank is no longer available as it has been changed to cater for the needs of 'later life' services. She is concerned that there is no longer this facility for young people and their carers who are living with dementia as the needs for younger people are very different than the needs of older people living with this condition. Val stated that there are no services available now in Manchester for younger people with dementia.

Val explained that earlier this year she was finding it difficult to cope emotionally. Through her contacts at Daisybank and the list of telephone numbers she had been provided with when Les was signed off from Daisybank in January 2016, she was signposted to Manchester City Council who put her in contact with Tracey, a social worker. Val has contacted her recently to try to arrange some respite for Les as there is concern that if he does not interact with other people for his care. he will find it difficult to adjust and cope with change in the future.

She explained that she didn't understand the respite facility and is unaware of how it works, although she has been told recently that it has something to do with the carer's assessment, this has never been fully explained and she would welcome the opportunity to sit down with someone who could explain how the system works.

Val explained that through Motiv8 Us Les has the support of a PA, Kay who Val says is brilliant. As Les likes to be outside and his friend likes to play pool and darts and they are both of a similar age, Kay alternates the activities to meet both their individual needs. Val said that 'Kay knows how to get Les into a good mood', she has built up a good relationship with both of them.

With the closure of the 'young onset group' Andy tried really hard to find alternative services for Les and his friend and provided different support service details to Val. She explained that she did contact a couple of the organisations; however some of them didn't work in the North Manchester area. One of the services suggested swimming; however they didn't provide transport or have the relevant insurance to enable Les to attend this facility.

Another service offered respite in the form of sitting with Les at home, however Val feels that this would not be suitable for Les because he is still young and needs to stay active to prevent depression and isolation. Val also stated that this respite service expected her to plan out Les' day, however this is not respite for her and she did not want the extra responsibility of planning his activities during this time.

Val explained the value in her having time to undertake some activities for herself whilst Les is supported and fulfilled undertaking activities with Kay. She explained how she is on the board of Trustees with the Manchester Carers Forum, she also runs a support group

for dementia carers, where she attends a mosaic group at Harpurhey Health and Wellbeing Centre. Val also provides talks in her local community to raise awareness of living with dementia through Dementia Friends. Without the support of Kay, she wouldn't have the time or flexibility to be able to undertake these accomplishments.

During a normal week Les will spend 8 hours with Kay enjoying a tailor made programme to reflect both his and his friend's needs. The remaining time during the week is spent attending the [Woodville Sure Start Centre](#) in Cheetham Hill, although Val says that Les isn't always keen to go to this facility.

On a Tuesday afternoon Les goes to Dunstan Court and participates in a dementia activities afternoon which is run by the [Alzheimer's Society](#). On a Wednesday and each alternative Thursday Les spends time with Kay and on a Friday Les attends a gardening club at Daisybank in Longsight. Val explained that if she did not have a mobility car she would really struggle to transport Les to these activities as taxi drivers have very limited awareness of the needs of patients living with dementia.

Val described how Les struggles with different colours in terms of floor mats and carpets or tiles. If the mat is a dark colour Les will think that this is a hole in the floor and try to step over it. Also recently on attendance to the cinema the floor was black shiny tiles and Les thought it looked like the sea. This caused great anxiety for him. She also explained that Les has difficulty in measuring depth due to visual problems as a result of the dementia and they have a special device which measures out one cup of hot water, this allows Les to be able to continue to make a coffee or tea independently. Val said that it would have been useful if she could have known what some of the symptoms might have been in terms of behaviour changes and then information to support some solutions to manage these symptoms.

Val and Les are registered with Simpson Memorial Medical Practice and Val states that the practice is supportive to her. She has found that if Les needs to take action on something specific, she can rely on the support of the practice nurse to issue these instructions which Les seems to respond to better. The practice acknowledges that Val is a carer. She also said that her Pastor at her local church is supportive.

Val explained that their son, Jonathan who is 30 years old, has up until recently been able to provide help and support. However, he is planning to get married and also works full time, so this support is going to be reduced and Val is trying to put measures in place to ensure she and Les remain supported going forward.

Val is very concerned that the facility at Daisybank will no longer provide support for young patients and their carers living with dementia. She is concerned that if diagnosis was at the present date what support would be currently available. Val expressed her gratitude for the extensive support and advice they provided relating to social and welfare care facilities available, advice around obtaining power of attorney etc. The value in this service in 'just knowing someone was there to support the carer' really made a difference to their experience.



## What can we learn?

- There is a need to raise awareness of the signs and symptoms and needs of people living with dementia with local transport providers such as Transport for Greater Manchester and private bus and taxi companies
- There is a need to raise awareness of the signs and symptoms of dementia using resources from the Alzheimer's Society to carers and the public, such as the initiative of Dementia Friends
- There is a need to promote and raise awareness of advice and support available to carers from Greater Manchester Mental Health NHS Foundation Trust and Manchester Carers Network
- There is a need to update and promote the Alzheimer's Society mapping of support services for people living with dementia and their carers in Manchester
- There is a need to work with Manchester Carers Network and Greater Manchester Mental Health NHS Foundation Trust to develop awareness sessions for carers around behavioural changes that carers may come across when supporting a patient living with dementia
- There is a need to promote Manchester City Council carers guide which has contact details of support and how to access social and welfare information
- There is a need to review the activities and services across Manchester to establish what services are available for patients living with early onset dementia
- There is a need to ensure that activities and facilities are available in north, central and south Manchester and are easily accessible by public transport. If services are not available locally to where the patient lives ensure they are included in the Service Level Agreement for transportation by the Patient Transport Service
- There is a need to raise awareness with employers of the signs and symptoms of dementia and promote resources from Alzheimer's Society on a dementia friendly business which would include staff support who are diagnosed
- There is a need to raise awareness of the educational support available on raising awareness of symptoms, characteristics and behaviour of people living with dementia to support early diagnosis