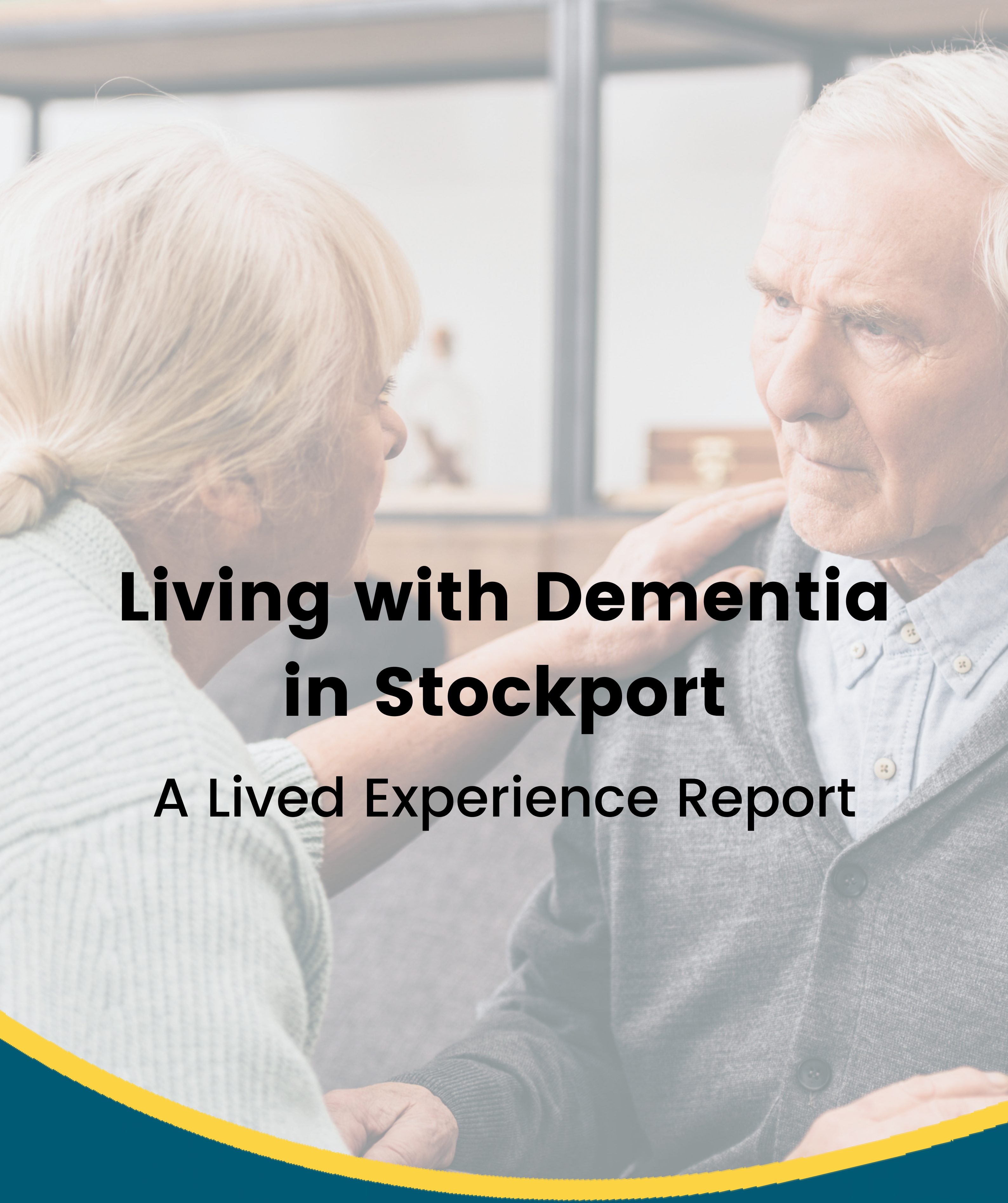

Living with Dementia in Stockport

A Lived Experience Report

healthwatch
Stockport

Contents

1. Executive Summary

Back in 2018 when we engaged with our members, stakeholders and members of the public about our Healthwatch Stockport priorities, good ongoing support and information provision for people living with dementia and their families was picked up as a theme of concern for people.

In 2017 we, along with many others from the community, voluntary and statutory sectors were involved in shaping the refresh of the dementia strategy for Stockport, and since have maintained a productive working relationship with our local dementia service commissioners and providers such as the Stockport CCG and the Meadows.

The Stockport Dementia strategy outlines the dementia pathway and support available in the prevention of, diagnosis, and support through to dying well of people living with dementia.

A lot of work has been done by Educate, a Stockport based group of people living with dementia, who raise awareness about the condition and provide a lived experience perspective to health and social care professionals. They have contributed extensively to the development of the strategy over the years. Healthwatch Stockport has picked up issues around end of life and through its end of life reference group has fed into the End-of-Life strategy for Stockport.

Now the strategy has come to an end [2020], we look to the system for an update and a refreshed strategy, expecting that the feedback provided from people with lived experience who attended our focus groups about dementia will be used to shape services going forward.

Although we were not able to fully carry out all the work on dementia that we had planned for early 2020, were able to carry out engagement with carers of people with dementia which is detailed in this report.

One of the statutory functions of Healthwatch Stockport is to ensure we monitor services and produce reports with recommendations to commissioners and providers of health and social care. However, the detail is in following up the recommendations and ensuring progress is made against them, which will be our commitment to the people who provided their time to share their experiences, which at times was very emotional.

2. Background

During Healthwatch Stockport's public priority setting engagement in 2018, dementia was identified as a priority by Healthwatch members, we therefore went on to select dementia as a work programme to look at in more depth. At the same time the government published a consultation on the new NHS 10 Year Long Term Plan. Dementia was a focus within the plan. We took this opportunity to engage local people on what they would do if they could influence the NHS Long Term Plan.

Two focus groups were held with people who had dementia and their carers, to find out about what they would improve in service provision. This work fed into a larger piece of work done with Healthwatch in Greater Manchester colleagues and a Healthwatch in Greater Manchester Report was published in October 2019 and this fed into the national work undertaken by Healthwatch around the country.

To complete our work around dementia, we had planned to undertake a series of Enter and View visits to local care homes and Stockport NHS Foundation Trust to view the care being provided for people with dementia. However due to the Coronavirus pandemic these visits could not take place. We therefore improvised and ran two online feedback sessions aimed at allowing people living with dementia and their carers to tell us about their experience of using services during the pandemic.

Healthwatch Stockport sought the views of people and their carers to provide an overview of services at a point in time. This research will add knowledge and help understand what the picture is like in Stockport and how things may have changed for people living with dementia over the last 12 months. We will share our data with colleagues in Public Health who provide JSNA data.

Stockport Picture

To give some context about the number of people living with dementia in Stockport, 2,850 people have received a diagnosis of Dementia. Prevalence rates for dementia are higher in Stockport than the national average and similar to the Greater Manchester average. In Stockport around 75% of the people estimated to have dementia have been diagnosed, meaning there are around 1,000 living with dementia who have not yet been diagnosed. By 2030 the expected prevalence of dementia is estimated to be 50% higher than currently[1].

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[1] Stockport JSNA 2017 - Dementia

Method

A steering group was set up to oversee this piece of work and included Healthwatch staff and members who have worked on similar projects with Healthwatch Stockport previously or have been through our lived experience training.

By holding focus groups we aimed to reach people living with dementia and their carers, who have had to access some form of health and social care service to support their dementia or have had to access a health and social care service not related to their dementia but it has led to an impact on their dementia.

Participants were recruited by promoting through our community members and stakeholders and their networks within their local communities and who might work with or support people with dementia and their carers. This included promotion through our Healthwatch Stockport website and social media channels and our news and info bulletins, VCFSE Forums, Dementia United, dementia support group leads and Team about the Place meetings.

We also searched our member database for members who have indicated an interest in dementia to inform them about the work we were doing and invited them to get involved.

Two online focus groups were held in an informal and friendly way to provide a safe place for people to open up and share their experiences. We ensured an extra member of staff was available online in case talking about their lived experience became upsetting and they needed extra support offline. For anyone who did not feel comfortable talking online, we offered 1-1 telephone conversations or zoom chat. In all we engaged with x people during our research.

Unfortunately, as mentioned previously, due to the Covid-19 pandemic we were unable to carry out any Enter and View visits to dementia care wards at the hospital, care homes and other dementia support facilities.

3. Key Findings

Below is a summary of the key findings we received from the participants who took part in the online conversations and from feedback via 1-1 discussions over the telephone. The feedback received has been broken down into the following themes:

4.1 Moving from home into a care home

Participants described how moving their loved ones into a care home was an extremely emotional experience. As much as people tried to keep their loved ones at home for as long as possible, many felt they were ill prepared for an eventual move into a care home. Participants reported feelings of guilt, shame and upset and found it difficult to come to terms with the decision they made.

One participant who had recently lost her husband, described how she felt heavily persuaded and almost forced by clinicians to put her husband into a care home due to his vascular dementia; over 12 months later she still feels very upset.

Another, whose father had Lewy Body dementia told of feeling totally unprepared for her father being moved into a care home. Sadly, as her father's behaviour became more challenging, it meant her home was no longer a safe environment for him to be in with her children. She felt she had been left alone to care for her father as well as supporting her family. Eventually, her father went on to be sectioned and she describes choosing a care home is like' finding the best of a bad bunch.' She feels she is leaving her father to 'rot' described the agony of the guilt she suffers consequently.

Another participant described how her husband also had to be sectioned and was taken from the family home by police. In general carers discussed and felt strongly that a person with dementia should not have to be sectioned to get them the right help at the right time.

4.2 Care provision for care home residents

The main issues people raised about care in care homes were about hygiene, lost property, dental care, GP care, visiting and lack of exercise/muscle wasting.

Several concerns were raised around **hygiene and personal care** of dementia patients in care homes. They report that many residents living with dementia are not given a daily shower, feeling this should be a daily task. Some residents are being charged in the region of £1,600 per week to reside in homes and they felt this was unacceptable and was akin to receiving a very shoddy service.

The **loss of personal property** within the care home was another issue, from clothes and false teeth but particularly residents who need to wear glasses. It was mentioned in one case that reading glasses had to be replaced over twenty times and sadly they have now given up on replacing them. It is difficult to understand where all these glasses could have disappeared to, all agreeing that this must have a detrimental effect on the wellbeing and health of the resident as they are an integral part of the resident's life in the home.

Dental care came up as an issue throughout the conversation (see case study below). Many spoke about their loved ones not having their teeth cleaned once moving into the home.

> *"Before my husband went into a care home, my son would come for three to four hours every evening to make sure he was settled and get him into bed, brush his teeth, and care for him.*
>
> *When he went into a care home, I feel he did not receive the same care he would have done at home. In the home they didn't brush his teeth properly. My husband must have been in agony for an extended amount of time with toothache, because of the cavities it was found he had. As far as I could see there was no dental care being offered to my husband or other residents.*
>
> *My husband was a man who was meticulous about taking care of himself and always had a set of lovely teeth prior to him going into the care home"*

One gentleman added that his wife had to have all her top teeth removed whilst in a care home. He was last able to visit over a year ago and her teeth did not look in good condition then. It was emphasised again that many residents with dementia are often unable to convey if they had a dental problem.

Participants were generally unimpressed by the **care provided by GPs** in care homes. They suggested it would be helpful if a dementia professional/specialist such as a community dementia nurse could see the residents on a regular basis, as those with dementia are not always able to say when something is troubling them or causing them pain. From their experience they felt that some GPs do not provide an equitable service to that of other residents in the community and rarely seem to visit the residents in care homes.

The care given by the GP was seen as key and that it was incredibly important, they were empathetic and caring. The group discussed this issue at length and surmised that perhaps GPs who were trained more recently were more empathetic and had better interpersonal skills.

Another issue discussed was about residents suffering with contractures, due to a **lack of movement or exercise** after moving into the care home, some quoted that the staff seemed ill equipped to deal with picking up on this. To help ease the contractures one participant said she showed the carers how to use folded pillows to stop the legs/knees of the resident contracting when in bed.

The lack of being able to **visit people** with living with dementia in care homes during Covid was having a huge strain on both the person with dementia and their families. Healthwatch agreed that this had been raised frequently from callers who contacted their Information & Signposting service.

All participants **understood the pressures** that care homes face with recruitment and retention of staff, they **acknowledged the dedication** of most and that they **work extremely hard and long hours**, however, all agreed there needed to be an increase in capacity and training within care homes when caring for people living with dementia.

4.3 Care plans

There was general concern about the **quality of care plans**, and it was suggested work needs to be done on modelling care plans on good practice.

Many reported that care plans are not developed with family and loved ones and that they had not been shown a care plan or if they had been shown it once but then not again.

It was commented in some instances it seemed the only time care plans were updated was when a CQC visit was planned.

Sometimes staff appeared busy and were spending time away from residents doing paperwork when it was felt this time could be better spent by providing the care that was needed.

A relating concern raised was about how quickly loved ones progressed from **eating a healthy diet** before moving into a care home to a 'mashed food' diet in a very short space of time. This resulted in rapid weight loss. It was suggested that residents could go onto a finger food diet in the first instance before ending up with a mashed food diet. Some commented that this was not documented in the care plan or they did not know whether it was documented in the care plan.

Sometimes the residents living with dementia have very little time in which to eat their food. One lady described that she would often help other residents to eat when they were struggling when there was no staff around. However, this stopped when a sign was displayed asking visitors to refrain from helping other residents to eat. Whilst it was acknowledged there may be good reasons as to why this should be, it was remarked by participants that sadly there seemed to be no level of compassion.

It was further highlighted that **swallowing difficulties** are a significant problem with Lewy Body patients and care/nursing home staff were not always fully trained and aware of this.

4.4 Hospital Care

When someone living with dementia is going to visit any hospital service it should be incumbent upon the service to think about **appointment times**; early appointments are always very stressful with little chance of getting a dementia patient there for an eight or nine o'clock appointment.

In one instance the hospital allowed a patient to stay in hospital the night before, for an early appointment the next morning and it was agreed this was a godsend at the time. However, if a process was in place for dementia patients to be given appointments at suitable times, this wouldn't have been necessary. An appointment later in the day would have given the carer and their loved one the time to get up and get ready and be in the right frame of mind to get to the appointment.

It was highlighted from a provider perspective that sometimes care agencies are waiting around three days for **discharge notes** and therefore patients are spending more time in hospital than needed. This, at a time when many patients are already struggling with not being able to have visitors. She went on to add that when Stepping Hill are contacted to chase the discharge papers, their telephone calls are not returned.

This instigated further discussion about **contacting the hospital**, it is often difficult to get through to Stepping Hill. When families are eventually transferred to the ward, the phone rings continually and without answer, this was very common.

After being admitted to Stepping Hill, one person highlighted to a nurse on the ward that **hallucinations** were part of her husband's **Lewy Body condition** and the nurse noted this on her husband's medical notes. However, when she went to collect her husband the next morning it was obvious to her that he must have had a 'bad night' with hallucinations. It seemed to her that staff were unaware that hallucinations were part of his condition.

On another occasion a carer was phoned several times over the course of a few days by the **Family Liaison Service** to say her husband was being discharged. She explained she had just had a double mastectomy and was in her late 80's and not well enough to look after him. Over the next couple of days, she received a further three calls from the service, each time stating her husband would be returning home and they would be increasing the number of times carers would be coming to visit him at home. This left the participant extremely frustrated and anxious as she was not in a fit state to care for her husband. She eventually rang a healthcare professional at **the Meadows**, who rang the hospital on her behalf. Her husband was then moved into a nursing home within days. The carer went on to comment that she still has little understanding of the remit of the Family Liaison Service, who at the time seemed to be little awareness of changes to the family circumstances despite the hospital being aware and informed by the family.

The same carer went on to comment that whilst her husband was in a local care home she was told he would be **'reassessed'**, she did not know what this meant and even when asked did not fully understand feels the process needs to be explained in more detail to families and carers in language that is easy to understand.

4.5 Dementia training

It is vital that all eligible health and social care professionals are provided with the **mandatory training** being offered to support the care of people with dementia. It was noted that care home staff receive their training from the Meadows.

It was suggested that staff with dementia specialist training need to visit support groups to deliver and provide information to people who are caring for people with dementia.

There was a suggestion that access should be given to data around dementia training particularly at the Foundation Trust, as Governors used to monitor this previously. Clarity is needed on whether this data is still being monitored.

4.6 What had worked well during lockdown [Good Practice]

- It was highlighted that **The Meadows** had continued to provide a wide range of mental health and specialist care services for older people, including dementia day care. They continued to hold several meetings via Zoom, including the Front Temporal Dementia group. This seems to have worked well as more people are joining online meetings whereas they wouldn't usually be able to get out.

- It was reported **The Meadows**, had been a fantastic help, especially in communicating with the **Family Liaison Service** in arranging care at care homes.

- One carer gave an example that her husband was always shaved and well turned out, always in his own clothes with his hair brushed and toenails were cut. She went on to say the team at **Arbour Court** were fabulous and always explained over the phone what was happening with her husband. She went on to state that the **GP** who visited Arbour Court had done a great job of keeping her up to date with her husband's condition, and when her husband passed away, the GP registered the death with the Registrar Office on her behalf.

- **The GP** sent the death certificate in the post along with one form to be completed which notified all the council services/blue badge/council tax, bus pass, etc that her husband had passed away, it was very useful to be able to do all this on one form.

- It was agreed that people with dementia seem to come alive when singing and can remember words and songs from yesteryear. A group called **Singing for the Brain** has continued to run online, whilst not as good as face to face, there is a waiting list to join. All participants agreed this group is beneficial for those who can access it. Healthwatch Stockport member, Ruth Turner, through her work as a Dementia Champion, made the group aware that Stockport Clinical Commissioning Group (CCG) have agreed to fund 'Singing for the Brain' for the next three years.

- One participant (from a provider organisation) highlighted that **supermarkets** had been very supportive during the pandemic and **Morrison's** were able to offer 'dementia friendly' opening times. This allowed those with dementia do their shopping at quieter times.

- **The Speech and Language Therapy Service** was also highlighted as a very supportive service that had continued with face to face appointments at home and it was felt had a very positive response to people with dementia.

4.7 Gaps in provision

Getting out and about is incredibly important for carers, to meet carers and others, and particularly to be able to go places which are dementia friendly. It was felt that it was essential that there were groups available where both the person with dementia **and** the carer could go. It was discussed that there is a need for more dementia friendly initiatives as there are far less support groups in recent years and even fewer now during the pandemic, with many people/carers feeling lonely, isolated, and trapped.

One participant who runs a dementia support group highlighted that from her experience 90% of the time, carers are on their own with a loved one and caring for them is really hard work. Support groups could be the salvation for many who are caring for someone with dementia.

Several participants used to use **Age UK Stockport's Befrienders Service**, where a staff member used to visit every six weeks to sit and talk to the person with dementia whilst the carer could shop or have an hour to themselves. Sadly, they report this service is no longer available. **Signpost for Carers Stockport** used to fund carers to go on a short break and meet other carers whilst their loved one with dementia was looked after back at home. This service is also no longer available. One participant commented that this was a few years ago and when services seemed to be more coordinated.

A provider organisation spoke about the perspective from their organisation; and felt there an increasing **decline of morale without the social interactions** of the groups, many of which have closed or moved online which means that those without **technology** miss out.

There are now long waiting times for the **Aids and Adaptation Service**, which is now being delivered differently with people using face time to select the equipment they need. Whilst this may work for some people, there have been problems with connectivity issues which has caused real frustration for those staff in the community when not being able to get through. Colleagues in community organisations have been cut off on several occasions yet when they immediately attempt to contact the service again their phone call is not answered.

It was commented that there is not enough **awareness about dementia** and other services available to support people and their carers. Whilst there maybe leaflets and booklets about dementia available, it was felt there was not the same level of professional help such as the practical help and support you would get if you were diagnosed with cancer. It would be more equitable if there were **designated dementia nurses as there is in cancer support services**.

Participants were unaware there was dedicated help lines, specifically for dementia, who the carer could contact when needing a friendly chat and support.   It was felt more could be done to **follow up support** offered after the initial diagnosis.

4. LIVED EXPERIENCE CASE STUDY

Below is a case study highlighting one family's dementia journey.

For a little background information Mum and Dad had two children, their son died of a rare cancer aged just 26 and Mum passed away of Malignant melanoma in 2010. That left just me and dad, I was married with two young children and dad became a huge part of the family joining us regularly for meals and dog walks to ease his loneliness.

In 2017 Dad went to have a knee replacement at a private hospital and I received a call in the evening to say he was angry and accusing staff of stealing his wallet, at 2am I received another call to say Dad was pacing the corridors shouting abuse and refusing pain relief. It was then the nursing staff told me that it was probably an underlying dementia. Although his GP was advised of the episode, he never mentioned it to us on a subsequent visit.

Dad was officially diagnosed with dementia in July 2017 and was prescribed a drug to help, he thrived on the medication for another 12 months but was becoming increasingly unable to operate household appliances. In September 2018 Dad took a real turn for the worse, his driving had become a problem and DLVA revoked his licence.

I tried to hold down my job, family and marriage but his behaviour was increasingly erratic, I arranged for a home care agency to call daily as he was taking the dogs medication rather than his own and eating frozen food, which made sense of previous sickness episodes. Dad wasn't happy about it and he would sometimes refuse to let them in.

I was in near daily contact with the memory assessment team out of sheer desperation who resorted to a different medication, this offered no improvement and I was told to stop the medication as they thought that *could be the cause but it wasn't. They reviewed dad and could clearly see the deterioration, but I was offered no further solutions.*

My employer was great letting me work from home in the evening, but it was an added pressure and was taking its toll on my health and the families wellbeing.

I decided one evening to call on dad with my husband just to check, maybe it was a feeling I had, we went in the house to find the employee of the home care agency making Dads tea- he told us he had let himself in as the garage was wide open and Dad wasn't in. The house was immaculate and completely clear, he had moved contents of the house into his car all neatly wrapped up in towels. We searched the streets for dad until we decided we needed to call the police as it was pitch black and freezing. The police were amazing and found Dad in a random back garden after becoming disorientated whilst walking the dog. He was wearing a shirt, shorts and one wellington boot - he was so cold.

I was then advised by a representative of the Meadows and dad's social worker that this was now a safeguarding issue and dad could not be left alone. He offered no solutions just kept repeating the safeguarding issue. I had no option but to leave my family and move in with Dad.

Dad's social worker was so supportive, she arranged for overnight care for 3 nights so my husband could work, and I could be with the kids. However due to the odd night carer proving to be unreliable and not arriving on time, I had to make the most difficult decision of my life and look for a care home for Dad.

Dad's diagnosis was changed to Dementia with Lewy bodies due to his problems with co-ordination and falls, he also had the shakes and hallucinated sometimes, sometimes horror but mainly small animals running *around the floor. Dad was lucid and normal in the mornings, he deteriorated throughout the day by evening he didn't know who I was.*

I found a care home around the corner from my house so I could be there daily for him, take him out, bring him to my house, walk the dogs together, he moved in in Dec 2018.

Some scenes I witnessed in that home I will never forget, the way some residents were treated by certain employees was so disgraceful, including degrading humiliation and shouting oblivious to the fact visitors were present.

Dad would tell me stories of the bandits coming in at night and shouting at him because he had obviously had an accident, he told me he was humiliated in the bathroom but couldn't say why so I started taking him for a shower when I went. They didn't appreciate nor were they aware of dad's ability to have lucid periods where he could remember.

I got a call one morning to say I needed to go straight away, Dad had completely trashed his room, brought down wardrobes and smashed everything. An ambulance was called, and we went to A&E. The ambulance staff and doctors were amazing with Dad and he was referred to the mental health team who were of the opinion Dad was to be sectioned. It is horrible terminology, but it was a relief I was actually being heard and that Dad's condition was recognised as unmanageable…why did it take this for someone to actually hear me and understand Dad was really ill. The only available bed was in Rochdale so at 11pm that night I had to take Dad and leave him there. Rochdale in the winter was not easy to get to. He was there for over a month when he was moved to the Meadows following an assessment. Dad was in the Meadows for nearly a year whilst they trialled different medication, he was well cared for and the staff loved him when they got to see his true personality. I was able to visit daily, and the staff were amazing.

Dad moved to his new nursing home in Sept 2019. I now feel his care has been taken out of my hands, his GP talks to the nursing staff and I feel out of control with decisions that are made but I can only assume that's the way nursing homes work.

Simply put, this journey has been the hardest one I have made despite knowing loss with my mum and brother, nothing compares to this tragic disease and the massive impact it makes on your own life. The guilt I feel is immense, if I had my time again I would have gone to any lengths to facilitate dad's care myself with assistance and not followed the government rules and regs of what we can and can't do as carers or family. On visiting a relative years ago Dad's words to me "I am begging you now Wen don't ever put me in one of them…..I'd rather you shoot me" I laughed and said "don't worry Dad I'll never do that to you" My dad is the loveliest, kindest gentleman and he doesn't deserve the choices I made or were forced on me and him to make.

Dementia is a severe illness and should not be interpreted as anything less, support and help should be the same standard for Dementia as it is with cancer and any other life limiting illness, Nursing / Care homes need to have properly trained staff that understand dementia fully and are paid a fair wage – not minimum wage.

5. Other areas of engagement

Dental Pathway

The Academic Clinical Fellow Special Care Dentistry at the University of Manchester Dental Hospital contacted Healthwatch Stockport to ask us if we could help provide feedback for a new referral pathway into special care dental services that is being developed.

The pathway will allow non-dental professionals to refer people for dental treatment who are unable to accept dental care in a high street dental setting because of significant impairment or disability. This might include persons with significant cognitive impairment (learning disability, dementia, brain injury etc), physical impairment (unable to physically access standard dental surgery), mental health conditions (particularly those who may be inpatients), the homeless and drug users.

An electronic referral form for use by non-dental professionals who work with these patients/clients has been developed by the University, the special care dentistry MCN and the local public health team. The team are keen to roll out the form as soon as possible to enable improved access to care for these vulnerable patients, however before doing this, they needed some feedback on its usability from professionals and non-professionals that work with this patient group.

The link was sent to the Dementia focus group members to enable them to add their comments.

We have contacted the university to request an update on the proposed new referral pathway and at the time of writing are awaiting an update.

Dementia Champions

The Quality Improvement Social Worker, SMBC came to the focus groups to update us on plans that aim to have two dementia champions in each care home. These champions will feed back to the dementia champions group, she said they are looking for views on how care can be improved in care homes. We suggested the focus participants may like to be involved in this work going forward.

Playlist for Life – Music for Dementia

A short while after the focus group was held, Healthwatch Stockport were contacted by marion.coleman@playlistforlife.org.uk, the Local Organiser for Greater Manchester. Marion explained that back in 2013 Sally Magnusson, writer and broadcaster, witnessed the effect of music on her late mother's dementia. She found that music was taking her mother back to a place of familiarity and belonging. After witnessing this Sally founded 'Playlist for Life'. As well as practical tools for families of those who have a loved one with dementia, they offer specialist training for heath and social care professionals. As part of her role Marion came along to offer training to Healthwatch Stockport staff about the benefits of loved ones having a 'playlist for life' and how to pull together a play list for them and what resources are available to help.

To help to raise awareness of this organisation and the great work they do Healthwatch Stockport went on to highlight 'Paylist for Life' as their 'organisation of the month in their weekly Information Round Up (IRU) bulletin which is circulated to approximately 500 groups and individuals.

Dementia United

Healthwatch Stockport have close links with Dementia United, a Greater Manchester organisation who are working towards improving the quality of life for people living with dementia or caring for someone who has dementia, supporting people to live as independently as possible and providing access to services when needed. Dementia United have asked that this report be presented at their Strategic Board on March 14th as they feel it is important for this board to hear the findings and recommendations of the report.

The Meadows is a facility that provides a wide range of mental health and specialist care services for older people, including a dementia day care service and community outreach. Below is the feedback gathered from staff

Training

It was felt that training across all levels needs to be available to all providers of care. Mark Perry of Stockport Dementia Care Training offers a Carers training programme, however this is now offered only four days a year. The EDUCATE group (Early Dementia Users Co-operative Aiming To Educate) are still involved in part of the dementia training and now with the easing of restrictions, are becoming more active again. Whilst these courses are often full, many people may not be free to attend as carers availability can vary from day to day due to caring duties. It was highlighted that GPs often do not refer their patients who are carers into the training, and this is sadly a missed opportunity for these. Unfortunately, due to the pandemic and the new working restrictions that have been imposed over time this has resulted in increased pressure on care agencies who may want to release their staff for training.

Social Workers

In the past there were some fantastic social workers, however over recent times these staff seem to have moved to areas outside of Stockport. It was raised that social workers used to work with specific groups such as older people and those with learning disability, however the system has now become 'ageless' and social workers are required to work across all groups. This has left to the morale amongst social workers hitting rock bottom with many going on to leave.

Respite

It is vital that carers have the opportunity for respite, to give them a well-deserved break from their caring responsibilities, however the reality is that it seems that no one want to provide this service. It was discussed that Stockport should look at block booking beds/a special unit with skilled staff to allow this to happen.

Care Homes

There was a discussion around the great disparity in the care given to residents in care homes with dementia, with an example given that some care homes ring an ambulance if a dementia patient becomes unsettled., whilst other homes have staff that are confident enough to cope. It was raised that as patients are now coming through the system who are of working age, Care Homes need to adapt their ways of working for these patients, however few care homes are adjusting.

Dementia Care Advisors/Admiral Nurses

It has been highlighted by both staff and carers that there is a need for Stockport to invest in having Admiral Nurses. These nurses are specialist dementia nurses who provide support for families affected by all forms of dementia. They can help give family and friends more confidence when struggling with a loved one

Community Groups

There are several services available in the community offering support to those with dementia and their carers. The services included an allotment group, Singing for the Brain, and a Young Onset group to name a few. The Meadows have worked well with both Age UK and the Alzheimer's Society.
It was discussed that the Ada Kay Centre, based in Romiley is an excellent friendly day care setting open Friday to Tuesday. The centre offers the opportunity for families/carers of those with dementia to have some time to themselves. The Memory Assessment Service hold a drop-in clinic at the centre and on Wednesdays the building is used by the Alzheimers Society.

Transport

Getting around in Stockport can be difficult for those with dementia, even though there is an excellent transport service, supported by volunteer drivers – the Stockport Car Scheme. The scheme is a local registered charity for Stockport residents who struggle to use public transport. However, staff raised concerns that transport with this service must be booked in advance.

6. Conclusion

Feedback from people with lived experience of caring for loved ones living with dementia is a powerful insight into the way services which support people with dementia are delivered.

The issues highlighted by our participants demonstrate several areas to focus some further work to improve outcomes for people with dementia and their carers and we ask the following:

How do we ensure that the right information and details of how to get ongoing support for carers and their loved ones continues long after initial diagnosis, when dementia deteriorates and care needs increase, placing increased pressures on family carers?

How do we help families seek the right care/nursing homes to support their loved ones? and how do we support families to cope with making some of the hardest decisions of their lives, and further support them thereafter with their feelings of guilt and helplessness? How do we support families to better understand the mental health care act?

How can we ensure our already stretched care home and home care sectors are better supported to deliver the best possible care for people with dementia? Are care homes equipped with the knowledge, skills, experience, and resources to provide high quality nutrition and can they provide the support to enable residents to have those nutritious meals?

Why are people in care homes disadvantaged in being able to access dental services?

Why are we still having to suggest that hospital appointment times should be taken into consideration to give dementia patients and their carers more time to get to them?

It feels that community services are now so under resourced we can no longer offer the support groups, carer breaks, and respite there once was available, and they are now only available to people who can afford to pay. Support groups where both carer and love ones can attend are the lifeline to many and to have a dementia friendly place to go to is vital.

Many of those caring for their loved ones at home feel most vulnerable and alone during the night, particularly those caring for someone with Dementia who experience hallucinations during the night, a number to call for support would really help.

7. Recommendations

8.1 Information provision – there is a lot of information produced by several national and local organisations. Ensuring that the right information and details of how to get ongoing support for carers and their loved ones continues long after initial diagnosis is key.

What do we know about ongoing provision of information and support for people when dementia deteriorates, and care needs increase, placing increased pressures on family carers?

8.2 The Stockport Dementia Strategy outlines its supports for people with dementia to stay at home for as long as possible. Home is the preferred place of care delivery, avoiding unnecessary hospital admissions and delaying long-term placements where possible. An appropriate care and support package and regular reviews should be in place to ensure the arrangement is sustainable. Practical and emotional support should also be available for family carers to support their health and wellbeing, including contingency planning and increased opportunities for peer support and respite care.

Opportunities for breaks, respite care and peer support [dementia support groups] appear to have decreased, can we have assurance that care packages and reviews are in place for people living with dementia and their families, so that they are enabled to stay at home for longer if it is their wish. More support is required to be put in place for people considering a care home as an alternative or step up from being cared for at home. Emotional and ongoing support is also needed to support families in decision making around placing family into care.

8.3 The Dementia Strategy describes implementation of a Stockport CCG dementia friendly GP practice award for practices meeting the CCG's standards.

There were mixed examples of good practice in relation to GP care in care home both good and not so good, in light of these comments from participants in our focus group, has this award been implemented? What assurance do we have that GP care is equitable across care homes in Stockport?

8.4 Carers Connect, a programme of support for current and ex-carers to build relationships and offer peer support

Follow up to see if this programme is still ongoing and whether support groups have started up again. Audit what we have lost and highlight areas where there are gaps.

8.5 The Stockport Dementia Strategy was developed to be delivered between 2017-20.

Has an evaluation been carried or if not is there an intention for one to be carried out? Will an updated/new/refreshed version be available for 2021 or 2022?

8.6 Access to dental care is a real problem in care homes

How will the system address the dental care support needed for people in nursing/care homes?

8.7 Training is highlighted in the Dementia Strategy

Could we have assurances that eligible staff in health and social care have full access to, and have undertaken, mandatory training to care for people with Dementia [in addition receive data about not only numbers trained but data about proportion of staff who have been trained categorized by provider]

8.8 Many champions were identified and trained over the last 10 years

Do we know where they are? Is there a network or forum for them to connect?

8. Next Steps

In the first instance Healthwatch Stockport will present this report to the Stockport Clinical Commissioning Group for comment.

It will be circulated to the list in section 12 and any actions followed up with relevant stakeholder partners.

An oversight group which will include participants of the online discussions will be set up by Healthwatch Stockport to monitor the recommendations and plan an update, in a set period of time, when the recommendations can be updated, and to look if the service for these service users has improved.

Healthwatch Stockport [October 2021]

9. Appendix I About Healthwatch Stockport

Healthwatch Stockport

Healthwatch Stockport is an independent health and social champion created to gather and represent the views of the public. We have three broad areas of work:

Inform. We provide information about health and social care support and services that works for you, helping you stay well. Our Information & Signposting service runs 5 days a week and we take enquires about health and social care related services and help to signpost people in the right direction – we can refer people who want to make a complaint about NHS Services to our partners – Stockport Advocacy who can support anyone throughout the process.

Involve. We gather your views and ensure you are listened to about what works well and what could be improved. We identify trends and themes and we use it as evidence to support our influence. Healthwatch Stockport is a member led organisation, we encourage as many people as possible to sign up as Healthwatch members so that everyone has the chance to be involved in our work.

Influence. Working with those that run services to ensure i**mprovements are made because of what you said**. We use feedback to work with commissioners to make services work for you.

10. Acknowledgements

We would like to thank all the people who took part in our focus groups, your views will help to shape services, improve the health and wellbeing of the local community, and reduce inequalities for all communities.

Healthwatch Stockport is an independent health and care champion created to gather and represent the views of the public. Healthwatch organisations exist in every local authority area in England, we have a role at both national and local level and through our statutory obligations will make sure that the views of the public and people who use services are listened to and acted upon.

You can get in touch with us by calling on **0161 974 0753**,

Email us on **info@healthwatchstockport.co.uk,**

Tweet us at **@HWStockport** using the hashtag #becauseweallcare

You can comment on our Facebook page or

write to us at **Healthwatch Stockport, 48 Middle Hillgate, Stockport SK1 3DG**.

The Healthwatch Stockport [name] Task & Finish group would like to extend many thanks to all the respondents who took time to complete our survey.

In addition, we would like to thank the following organisations for helping us in circulating the survey:

Thank you to all our stakeholders, your support of has been invaluable.

11. Dissemination

This report will be distributed to the following:

[ ] Healthwatch Stockport Board of Directors

[ ] Stockport Council Commissioning Managers

[ ] Health and Wellbeing Board

[ ] Stockport MPs

[ ] Adult Social Care and Health Scrutiny Committee

[ ] Stockport Safeguarding Adults Board

[ ] Clinical Commissioning Group Governing Body

[ ] Viaduct Care Board

[ ] Council of Governors Stockport NHS Foundation Trust

[ ] Council of Governors Pennine Care

[ ] Stockport Council Quality Team

[ ] Care Quality Commission

[ ] Sector 3 and other Voluntary Organisations [state which ones]

[ ] Healthwatch England

[ ] Other [state which ones]

[ ] Healthwatch Stockport website **www.healthwatchstockport.co.uk**

[Ends]