

**EXPLORING THE EXPERIENCE
OF PEOPLE WITH DEMENTIA
AND THOSE WHO CARE FOR
THEM**



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Executive Summary

Dementia is a growing problem that is affecting more and more people and those who care for them. Nationally, over 850,000 people are living with dementia with over 700,000 informal carers caring for a loved one. Two thirds of people with dementia live in the community (rather than a care home)

As the local "consumer champion for health and social care", Healthwatch Sutton opted to merge 2 overlapping issues which local people had highlighted as of concern; "dementia" and "carers". In response to these priority issues we wanted to explore the experiences of local people with dementia and those who care for them, with a view to identifying whether local health and care services are successfully supporting them and meeting their needs.

We set out to engage local people and provide them with opportunities to share with us their views, needs and concerns about current local services for people with dementia and their carers. We held a community event and provided an online and paper survey where we were able to capture feedback on a range of relevant issues.

We took this intelligence to a Healthwatch Sutton project group (made up of local people with an interest in the project theme) who, because of the nature of those involved, opted to gather qualitative data to capture personal experiences through interviews, case studies and telephone conversations.

We hope that by sharing these stories we will all better understand the diverse experiences of those involved and learn how best our communities and health and care services, now and in the future, can address their needs and concerns.

We found that, overall, issues could be divided into 4 key areas which people told us were almost equally important;

1. Early diagnosis
2. Support for carers
3. Support for people with dementia
4. Raising awareness

People told us that the Dementia Action Alliance and voluntary sector support services are working well, but that improvements need to be made in the understanding and awareness of dementia across professionals and the community, information on available support and the provision of services that offer specific and much needed help and support.

In order to reflect what local people told us we used the insight gained to make the following recommendations;

Executive Summary

Key recommendations

The provision of a 'Dementia Hub' in Sutton - a 'one stop shop' is the one single provision which would address many of the issues highlighted in our findings. The provision of a 'dementia friendly' dedicated building with information and advice, activities, key services, working in partnership, under one roof in the community would go a long way to meeting the needs of people with dementia and those who care for them.

Improvements to the patient experience of getting an early diagnosis - patients and carers identified a lack of information about how a diagnosis may be made, a slow process which is stressful whilst recognising the importance of an early diagnosis and support at the outset.

Healthwatch Sutton to obtain, from Sutton CCG

- current diagnosis rates and actions planned, if necessary, to meet or exceed the required 67% diagnosis rate.
- the current dementia pathway and waiting times.
- Information on where people can obtain clear, accurate, information on what to do and what will happen if they are concerned that they or someone they know may have dementia.

More services to support carers of people with dementia

Carers identified a range of services and the need for more support that would contribute to improving their wellbeing and ability to care safely and effectively for the person with dementia. To include;

- A recognisable ID for Carers
- A 24/7 helpline for carers of people with dementia or information/promotion of any such service if it exists
- Accessible crisis, emergency and respite for carers, often at short notice
- The inclusion of carers of people with dementia in the eligibility for a "Blue Badge" parking permit where it can be evidenced that parking close to a destination is in the interests and safety of the person with dementia.
- Involving carers at every stage
- **More Admiral Nurses**

Ongoing raising of awareness about dementia and the profile of carers

Our findings demonstrate the need for more to be done to increase the awareness and understanding of dementia and the role and needs of those who care for them, by professionals and within the community.

All those involved in supporting people affected by dementia should review and evidence training programmes to ensure staff and volunteers are appropriately trained to meet the specific needs of people with dementia. (Including home care workers)

A range of services to support people with dementia

People affected by dementia spoke of needing more services, support and opportunities so that the person with dementia can continue to maintain their independence, their physical health, social connections and the best quality of life possible.

For all organisations involved in the support or care of people affected by dementia to address key issues raised by this report.

The Sutton Dementia Action Alliance to note our report and consider exploring the areas highlighted that relate to issues within the community (that are not specifically health or social care related)

We plan to take forward these recommendations with the relevant statutory and voluntary sector health and social care providers, with agreed actions progressed and reported on. We will monitor the progress of our recommendations in 2017 and keep local people and stakeholders informed of progress and actions to deliver improved services.

Healthwatch Sutton will explore what role there may be for Healthwatch Sutton through its relationship with the Sutton Information and Advice service - Advice Link Partnership Sutton (ALPS) <http://www.suttonalps.org.uk>

The role of Healthwatch Sutton

Healthwatch Sutton is an independent organisation set up to champion the views of patients and social care users across Sutton.

We listen to and represent local people, working to help get the best out of our local health and social care services, whether it's improving them today or helping to shape them for tomorrow -

Healthwatch Sutton gives people a voice locally and nationally.

As a volunteer led charity we have a number of committed volunteers who support different aspects of the work we do. They bring a range of skills and experience. Our volunteers are 'authorised' following a process of training and checks.

THE EXPERIENCE OF PEOPLE WITH DEMENTIA AND THOSE WHO CARE FOR THEM

Our project

The aim of this Healthwatch Sutton project is to reflect the voice of local people who have experience of living with or caring for someone with dementia with a view to challenging and influencing the provision of health and care services, to ensure that the needs of local people are met.

Our objectives

- To engage and speak to people caring for someone with dementia and the person living with dementia (where feasible).
- To provide opportunities for local people to share their views, needs and concerns about local health and social care services.
- To capture people's experiences and highlight areas where gaps in support services exist, where improvements could be made and where services are working well.
- To identify the key health and social care issues that impact on this group of people.
- To report the findings and use the insight gained to make recommendations which can be taken forward by those responsible for the planning, commissioning and delivery of services.
- To follow up and monitor progress on actions determined by the recommendations

Defining a "carer"

For the purpose of this report a carer is defined as;

"Anyone who provides unpaid support to family or friends who could not manage without this help." The term "care worker" will be used to describe anyone carrying out paid care.

Limitations

Please note that this report only relates to feedback received as a result of this project. Our report is a snapshot of experiences that were reported and contributed at the time.

The picture nationally and in Sutton

Figures produced by the Alzheimer's Society, in March 2016¹ identify that currently, there are in the UK;

- 850,000 people living with dementia
- Over 40,000 people under 65 years living with dementia.
- Two thirds of people with dementia are living in the community (rather than a care home)
- The Department of Health estimate that 59 per cent of people with dementia in England have a formal diagnosis
- Approximately 700,000 informal carers in the UK are caring for their loved ones with dementia; this is expected to rise to 1.7 million by 2050.
- Dementia is now the most feared condition amongst people over 55 years in the UK.
- There is currently no cure or disease-modifying treatment for the diseases that cause dementia.

In 2014 the Alzheimer's Society estimated that;

- Over 670,000 people in the UK are acting as primary, unpaid carers for people with dementia.
- Carers save the UK economy an estimated £11 billion each year

The future;

- By 2025 the number of people with dementia is expected to rise to over one million and by 2050 it is projected to exceed 2 million.
- By 2025 it is expected dementia will cost the UK economy £32.5 billion and by 2050 it could be costing the UK economy £59.4 billion at today's prices
- People with dementia have a lower self-reported quality of life than both the population as a whole and those over 65, this gets progressively worse as the severity of the condition develops

¹ Alzheimers Society website - <https://www.alzheimers.org.uk/>

The picture locally

In Sutton we know;

- An estimated 2000 people have a diagnosis of dementia; this figure, by no means, reflects the number of children, extended family and friends whose lives are also affected.
- Families currently provide the majority of care and support for people with dementia and this can be both tiring and stressful - physically, emotionally and financially. A large number of people with dementia also live alone and can be at particular risk of isolation or abuse.
- If people with dementia are diagnosed early, and they and their families receive help, they can continue to live a good quality of life.
- Whilst Sutton Clinical Commissioning Group has improved its dementia diagnosis rates since 2010, in 2015² it fell short of achieving the national requirement with a rate of just over 60%. *(The Government have set a target that 67% of the estimated number of people with dementia should receive a diagnosis and appropriate post-diagnosis support.)*



² <http://www.londonscn.nhs.uk/wp-content/uploads/2015/03/dem-ldn-diagnosis-rates-032015.pdf>

PART 1 Capturing Feedback

Methodology

During a Healthwatch Sutton community event, incorporating a prioritisation exercise, (to inform our future areas of work), local people identified "carers" and "dementia" as 2 of their top areas of concern. This prompted us to merge the themes and investigate the health or social care issues that currently arise, for people with dementia and their carers.

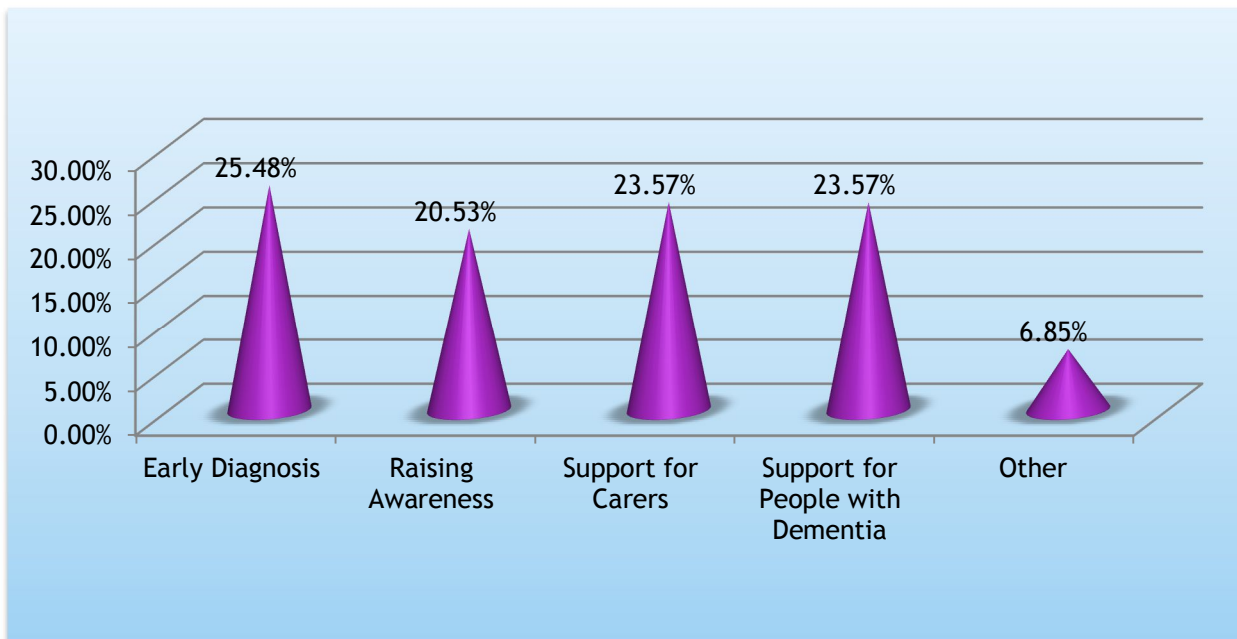
In order to gather more information and evidence we held a themed information and engagement 'Dementia Forum'. Over 50 people attended the event to share their knowledge, experiences and views. The event included presentations from London Borough of Sutton, the Alzheimer's Society and Sutton Carers Centre.

During group feedback sessions participants were asked to identify, what, in terms of local services, works for them, what doesn't and where improvements or changes were needed. For those carers who were unable to attend the event online and paper questionnaires were made available, after the event, to capture their feedback. An additional 9 people completed the questionnaire.

This was followed by an open Healthwatch Sutton project group which brought together people with an interest in dementia/carers to explore the issues in more depth.

Findings

What people told us is important to them



Overall themes from the Dementia Forum

What works well in Sutton?

- **The Dementia Action Alliance** -Very well organised locally, getting excellent outcomes. Good partnerships with other organisations e.g. Community pharmacist.
- **Dementia Friends Initiative**- *(a Government sponsored initiative run by the Alzheimer's Society to enable people to better understand dementia)*, seems to be working well locally helping to improve understanding and reducing stigma mostly just in services/organisations but promotion in communities too.
- **Admiral nurses**
- **Voluntary sector support from the Alzheimer's Society, Age UK and Sutton Carers Centre**
- **Technology that supports/reassure carers** (e.g. green cross bottles, ID bracelets ICE number on phones)
- **Services that work in partnership/integration** - *"good partnerships with other services"*

What needs improving in Sutton?

- Information and advice for all
- Understanding and awareness of dementia by professionals and in the community
- GP diagnosis and onward referrals
- Support for carers
- Communication across professions/between agencies
- Treatment of people with dementia in hospital
- Capacity to deliver services within the voluntary and community sector
- Reaching communities and individuals who do not seek help with dementia/caring responsibilities

What would local people like to see in Sutton?

- More information for all - particularly around finance, funding, care packages, professional care options
- Initiatives in the community to generate greater awareness and understanding around dementia
- More Admiral nurses
- Blue badges for carers of people with dementia where it helps
- More support for carers and raising of their profile
- Dementia being acknowledged as a health issue
- "Joined up services" - between professionals, agencies and across health and social care
- Better knowledge and understanding by professionals
- Continuity in social care
- Recognition of and involvement of carers
- A way of reducing the number of agencies involved for one person or a lead person to act on their behalf
- Better hospital care for people with dementia
More information and support for self-funders

Key themes from the carers questionnaires

Information

Whether in the early stages of caring, or for those who have been a carer for some time, almost all reported gaps in having sufficient, readily available, information and knowledge on where to go to get help or support.

Diagnosis

The current process is described as too slow-referral on to memory clinic /further tests leaves patients vulnerable and carer in a dilemma.

More information is needed on how a diagnosis is made - "Thought the GP would make the diagnosis, that's the impression you get from the media."

Life as a carer

In describing the experience of caring for someone with dementia people reported;

- "Bad. Debilitating. Lonely, Bewildering. Frustrating."
- "It's very hard when it is someone in your family"
- "I find caring for someone with vascular dementia stressful."

What local people would like to see in Sutton

- Carer respite
- Access to help 24/7
- Recognising that some carers are a distance away and working across local authorities/CCGs
- Meeting with other people in the same situation
- More volunteers to provide help/buddy/mentor
- Advice on options and choices
- More information on technology/adaptations

Healthwatch Sutton Project Group

The project group reviewed and reflected on the feedback received from the event and questionnaires, identified and discussed further the key issues raised and explored how best to take forward the feedback.

The group agreed an action plan to gather more information to strengthen the evidence that would enable Healthwatch Sutton to represent local views and recommend and influence changes (if needed).

In view of the target group the decision was made to undertake a small project that would provide mostly qualitative information using interviews with people with dementia and their carers, and telephone interviews with carers of people with dementia.

PART 2 Capturing feedback - Case Studies

The aim of this information is to capture, in the form of case studies, a 'snapshot' of the reality of living with dementia and caring for someone with a diagnosis of dementia. By exploring, in greater depth, the day to day experiences and difficulties faced we hope to portray a more realistic picture of the key issues than data alone.

We were interested to see whether the participant's experiences reflect those already gathered and strengthen the evidence to take forward with local people and those responsible for making decisions about health and care services for this specific group of people.

We worked in partnership with Sutton Alzheimer's Society and Sutton Carers Centre to identify and support participants for the project and provide training to the volunteers who undertook the interviews.

Methodology

We developed a process of identifying participants by working with the Alzheimer's Society and Carers Centre. This ensured that there was known trusted support available, to the participants, should anything arise during the course of the conversations.

We produced bespoke materials for those taking part in the case studies explaining the role of Healthwatch Sutton, purpose of the project and contact details.

We recruited and trained volunteers, from our existing cohort of authorised volunteers. The training included dementia awareness, safeguarding, (including duty to report), data protection for material recorded and questioning and listening skills. All of the volunteers had some current or prior experience of people with dementia/carers either in their employment or in their role as a carer for someone with dementia.

We produced guidance notes for volunteer interviewers that would prompt free flow conversations around potential key areas.

We planned a series of sessions with 3 participants -each session was scheduled to be no more than 2 hours per session at least 1 week apart over a number of weeks, as convenient with the participants/volunteers. We arranged for volunteers to always attend in pairs, with one to note take and one to manage the conversation.

An introductory visit was conducted, by a member of HWS staff, to explain the project and proposed process - written details were left for reference. Participants were reassured that they could withdraw at any time and any written material could be anonymous should they wish. A member of staff also accompanied volunteers on the first visit to facilitate introductions. We ensured that the relevant support staff at the Alzheimer's Society were aware of their participation.

Case Studies

Case Study 1 - Life after diagnosis

Tom and Giselle (names have been changed to protect the participants identity).

We spoke to Tom and Giselle about 9 months after Giselle's diagnosis of Alzheimer's. They were already involved with the Alzheimer's Society and both had attended courses and groups,

They agreed to take part in our project saying they had received so much help they would like to "put something back."

Both are in their early 60's. Tom is semi- retired; it is his own business so he is able to work flexibly. Giselle is a former secondary school French teacher. The couple's son lives nearby.

Giselle, was born in France but has lived in the UK for over 40 years. Giselle's general health is good and she loves walking. She likes to walk for half an hour every morning; Tom describes her as "very fit".

Giselle takes sleeping tablets at night and something for anxiety, but described this as "not helping" a lot. She asked that we do not use the word dementia but rather Alzheimer's because she links the word dementia with demented which suggests, to her, madness.

When asked about her diagnosis Giselle told us that she was not worried at the time of diagnosis but that she is worried now. She thinks she was diagnosed following an MRI scan. She described the GP and staff at the hospital as "very helpful." She would like to understand how the illness will progress and what her life expectancy is.

Tom described the concerns which prompted pursuing a diagnosis. These included seeing Giselle not being as organised and efficient in managing the household and having problems with the finances. His concerns were heightened when Giselle began cooking the Christmas lunch at 3am.

The process of obtaining a diagnosis took about 3 months. At first Giselle saw her GP alone, returning to say the GP thought nothing was wrong. Tom accompanied her on a second visit to the GP and this time she was referred for an MRI scan.

Following the scan they were informed that the results would be conveyed to them at an appointment 6 weeks later. Both were angry at how long they were expected to wait. Tom was able to bring the appointment forward and 2 weeks later the diagnosis was given by Dr Stinson (Consultant Psychiatrist in Older People's Mental Health



Services) Getting a diagnosis was important for Tom, although he had no doubt about what it would be, he described the confirmation “as a relief in a strange way”

Since the diagnosis, there have been 3 occasions when Giselle has left the home in the middle of the night, on one occasion picked up by police in central London. They have agreed that Tom locks the front door at night.

Giselle now has a tracker on her I phone but this requires that the battery is charged. Tom is looking into alternative tracking. He doesn't want her to stop walking as she enjoys it and is an important part of her remaining independent.

Giselle described being frustrated by memory loss, not being able to find the right words and not liking having Alzheimer's, but otherwise describes herself as “fine”. Giselle has “read everything about Alzheimer's.” “I don't like it, but put up with it.”

During the first 3 visits Tom described himself as “coping at the moment” but is concerned about how he will cope as time goes on. He is “learning” as he goes along and “bumbling along all right”. They agree they don't feel they need any further support at the moment.

Both have attended Alzheimer's Society support groups. Tom found the group very helpful and received help with legal issue e.g. Power of Attorney. Giselle enjoys her trips to the Alzheimer's group describing them as “uplifting”.

Tom and Giselle try to maintain a social life with friends and family, including their annual trip to France and sharing their mutual interest in Rugby. Most friends are understanding and supportive but one friend, having heard of Giselle's diagnosis, made no contact as he “didn't know what to say”. They have neighbours who they can rely on to help if asked.

Tom pursues his interest in art, attending weekly classes and Giselle continues to enjoy reading and walking. Both agreed that regular activities help give the week structure.

At the first scheduled visit Giselle was not at home but at the bus stop outside their home. With a gentle reminder and her agreeing to postpone her visit to the bank the session was carried out with just Giselle as Tom was held up at work.

Throughout this visit Giselle was very anxious about some issues relating to her bank and her French passport which she said had expired. She struggled to focus on the conversation and was easily distracted. She asked the volunteers to help her with finding her bank PIN number which they declined to do. At one point she left the room to try to find something. She said that Tom wasn't being helpful with renewing her expired French passport and that they had an argument because he had refused to take her, on Tuesday, to the Alzheimer's Society support group. (the support group is held on Thursdays) she also said that “Tom wants to take over the money” which she seemed unhappy with, describing herself as not confused and fine and that she doesn't worry over the finances.

At later visits Tom explained that there was no problem with the passport as it hadn't expired and that she had insisted on going to the support group on the wrong day.

Whilst they agree that they do not need any further support at the moment Tom had a leaflet from the Carers Centre and is thinking about looking into further information/support.

The next scheduled visit with Tom and Giselle did not go according to plan. On arriving at their home the volunteers found a note pinned to the door

"I have gone looking for you, back 10.30am, please ring."

An email, to the office, from Tom, said "can't do today Giselle has been missing for 24 hours"

Giselle was eventually found some 50 hours after leaving home. At some point she had walked into central London (she used a cash point) and made her way to Coulsdon, where she was found. Tom described her as "fine" but with blisters on her feet. It was possible she was trying to sort out her passport.

At this point we withdrew from the visits and were reassured that the Alzheimer's Society were providing all the necessary support.

Case Study 2 - Life after diagnosis

Garry and Jackie are in their early 60's, married for 37 years, they have lived all their married life in their home in Wallington.

Jackie has Turners Syndrome (a genetic disorder which affects females resulting in her being shorter than average and unable to have children) and at the time of the interview she is awaiting a hip operation and experiencing pain and discomfort.



Gary has a diagnosis of vascular dementia although this isn't entirely clear. Information from different medical professionals varies. Originally, he was diagnosed with Sneddon's syndrome (a disease that affects the arteries causing blood clot - especially those supplying the brain and skin) about 20 years ago following a series of small strokes in his 40's. This is also uncertain as it is a rare condition. All agree that Gary has cognitive impairment and he accepts a diagnosis of dementia.

Gary trained and worked as a jeweller, an apprenticeship with Cartier, worked in Hatton Garden and Harpers and Queen used his designs. Gary worked until 6 years ago, in a series of jobs each of which he was forced to give up following a number of strokes eventually affecting his eyesight, hands, legs, left side and cognitive abilities.

Jackie is a clinical hypnotherapist but can no longer practice her therapies except she says, "on herself" .

Talking about the diagnosis of dementia, they agreed that "communication of the diagnosis could have been kinder, but it was not unexpected." Gary described the

diagnosis as a "dawning" and for Jackie it gave a name to a whole series of things which had been building up over years. Getting an accurate diagnosis is important to both Gary and Jackie, they say they need "some sort of sense of what to expect in the future and an idea of Gary's life expectancy"

Life today isn't easy, for Gary, "on a good day I function pretty well, on a bad day I feel as if I'm in a fog, walking on treacle" Gary struggles now with managing everyday tasks, needing very specific directions, still having TIA's (mini strokes) cognitive impairment (as a result of 3 strokes), a tendency to "overreact" and be "impatient," and difficulties with organisational skills. Gary needs help dressing.

Jackie describes herself as "not coping". "Gary may say that he is living well with dementia but I'm not." As a clinical hypnotherapist and a Buddhist she thinks that helps her but wonders how someone else, without her philosophy, would manage at all. In addition to her own health issues, which leave her in pain and tired, she is also a carer for her parents.

"I get frustrated and I'm not as tolerant as I would like to be. The Gary I see is not always the Gary that other people see - like Jekyll and Hyde." "Gary always wants things NOW and for me to sort them out immediately"

Jackie tells Gary "you take me for granted"

Gary agrees that he isn't as understanding and empathic with Jackie as he should be. He knows he can overreact and be impatient. He acknowledges that he relies heavily on Jackie and tries not to take her for granted or make demands on her time and energy. He tells Jackie that he "trusts her implicitly" and knows that this places an additional burden on her. "If Jackie wasn't around I would do lots of silly things, I wouldn't cope"

A good week for Jackie is when "Gary is more supportive and helpful."

Day to day activities present a range of problems for them both, "shopping is a nightmare", Gary struggles now to work out money and spends the wrong money...Jackie points out that if Gary shops alone "he doesn't stick to the shopping list". Gary no longer has a debit or credit card, "I must use cash." "We have arguments when I ask for money."

Meals are a problem, Gary's sense of taste has changed. Jackie is now so nervous of Gary's reaction when she cooks that they buy takeaways - if he doesn't like the food it's not Jackie's fault.

Just before we met Gary and Jackie they had a holiday, somewhere they had been before, both noted, with sadness, how things were different this time and it brought home to them the gradual deterioration in Gary's functioning.

Jackie has a large family and enjoys getting together and socialising with them. Gary is increasingly reluctant to go to these events, his social skills are deteriorating and he can't remember who people are.

During the course of our volunteer interviews it was very apparent the amount of time that Jackie spends dealing with her parents health issues liaising with hospital, social

workers, GP and district nurses. Jackie visits her parents' every day. She admitted to experiencing a great deal of additional stress adding to the burden of her already extensive caring issues with Gary. The interviews were frequently disrupted by emergencies, frequent or lengthy telephone calls and an occasion when Jackie had to leave immediately. Gary is aware that the burden of caring for her parents falls mostly on Jackie

The future is of concern to them both,

JACKIE. I worry that we don't know the prognosis. If it was Alzheimer's we would know a little more. Ten years, could be not much worse; next year could be dead.

GARY. You've said you've noticed some changes gradually, always in a downward spiral. In the back of my mind, am I going to be able to do this next year? Organising Christmas - am I going to be worse?

So what, if anything, helps with the issues the face?

Gary wears a medical ICE bracelet (In Case of Emergency) which identifies him and his condition which they both find reassuring.

His time spent in his shed, "my man cave" offers some space and independence for him and respite for Jackie.

"Having a blue badge helps when Jackie takes me places"

The Alzheimer's Society - they came across them "by accident" when in PALs at St Helier, someone from the stoke team offered them a place. They were an "essential stepping stone". Jackie - "if I knew then what I know now.... without the Alzheimer's Society the pair of us would have been lost"

Jackie tries to have a life of her own and carry on with things she enjoys, meeting with friends, attending Buddhist meetings, personal development courses, a carer's support group and she goes to Slimming World, not to lose weight now but for the company.

They agree that their own resourcefulness and being proactive in finding help has served them well. "Knowledge is power"

Anything else that would improve things for them?

Gary; "a befriender I had one who used to do things with me outside that Jackie couldn't do with me. I would like one again"

To maintain his physical health through exercise, he tried riding a bike but fell off, he had 'forgotten' how to ride a bike. He paid for private gym membership where there was a trainer who helped him, but they can longer afford the fees.

More help for Jackie as a carer - "it's not recognised enough the stress and strain that Jackie has to deal with now that I can't do much" he thinks she needs more emotional support.

A taxi card- "getting a cab would mean more independence for me and Jackie wouldn't have to drive me everywhere."

More understanding and support in supermarkets - I can scan shopping in Waitrose and know the total before I get to the checkout. This helps give me more control and confidence, knowing I have enough money.

A dementia hub? - "absolutely" that sort of thing in Sutton would be helpful, that would be fantastic"

Jackie; Mostly more help and support, getting my Dad sorted, help caring for Gary, help with the cleaning.

Some advice on cooking/food/taste for Gary - if the food doesn't taste nice to Gary "he gets angry"

"Financially I think we are getting all that we're entitled to; I had a carer's assessment and got a discretionary £300 - so I got a body massage!!

Case study 3 - Life after diagnosis

Cathy (not her real name) spoke to us just a few months after receiving a diagnosis of dementia. She lives alone now following the death of her sister earlier in the year. She cared for her sister so described herself as able to manage the everyday things needed to run the home.

The diagnosis came as a shock to Cathy and she said she hadn't told any of her family. She "manages" but relies very heavily on her friend who is a neighbour. The friend accompanied her to the GP and scan appointments. She described herself as a bit forgetful and had 'post it notes' for reminders. She enjoys watching TV and looking after her cat.

When she spoke to us her friend was recovering from surgery so she was without anyone to help. Cathy continues to go out alone to do her shopping.

Cathy was looking forward to seeing her friend as soon as she has recovered sufficiently.

As Cathy was in the early stages of diagnosis and coming to terms with the diagnosis and the carer was not able to provide further insight we did not continue with the interviews at this time.

Carer Calls

To facilitate further conversations, with carers of people with dementia, we opted to carry out telephone interviews at a time that suited carers. Willing participants were recruited, by Sutton Carers Centre, from their existing client group. We were provided with names and telephone numbers.

Carer 1

Caring for her mum who was diagnosed with vascular dementia about 7 years ago. The carer does not have a partner, children or siblings to help her. Mum is currently living in an 'extra care' housing scheme that specialises in dementia care.

Prior to this the carer provided support to her mum who lived nearby. After 5 years of caring for her Mum, she remains unconvinced that assisted living is the most appropriate care for her mum now but acknowledges that it has eased her workload and given her "more freedom" She worries that it is not as much care as she had thought and described feeling 'misled ' about the level of support, when the placement was recommended.

She continues to visit 3 times a week to provide her Mum with basic essentials such as milk and bread.

With a holiday planned, her first time in 5 years, she will have to make arrangements for her part of the care to be undertaken by a friend.

She described the 5 years, caring for her mum on a daily basis, as "something you just get on with but it takes its toll"



Carer 2

A carer who cared for her sister, who is now living in a nursing home.

Previously her sister, who lived alone, received care in her own home (2 short visits per day)

She described the 5 years of support by care workers in the home as a very stressful time for her, she remains very angry about the issues she encountered with the GP, social services, carers and St Helier hospital. She became distressed just remembering 'a very bad time'

She spoke in detail of;

- medical professionals writing off her sister, on her number of occasions and once being told that her sister didn't have long to live (that was over 2 years ago)
- Social services arranging her sisters discharge from hospital (following a broken hip) without ensuring there was care or provision for a downstairs toilet.

- visiting her sister to find faeces on door handles, where she was not managing the commode alone,
- Care workers not seeming to have sufficient time to do what was needed, "it was only ever the bare minimum", there were many different workers, they did not seem to look at information files, there was no consistency in care as they also changed very often. Sometimes they didn't call at all for scheduled visits - leaving a note to say no one had answered the door.
- Following her own holiday, she visited her sister reporting that one of her sisters 2 cats was missing. 8 months later, during which time carers were going into the home, the body of the cat was discovered in the living area.
- Care workers didn't prepare or cook meals so these were delivered but often her sister would not know what they were.

She described often feeling bullied by agencies that she came into contact with and didn't feel that the contribution of carers and their concern for family was acknowledged or respected.

She is now reassured that, in the nursing home, her sister is well cared for, clean, comfortable, eating properly and most importantly has dignity.

"Keeping people in their homes with carers going in just does not work for people with dementia."

Carer 3

Cares for her husband who was diagnosed 18 months ago, with vascular dementia, he also has physical limitations, following a stroke. She also cares for her nonagenarian mother, who lives with them, along with an adult son.

This carer describes her situation as currently "managing", taking on everything that her husband used to do and trying to meet the different needs of the 2 people that she carers for.

She appreciates that it will not stay this way. She is aware that soon she will need some help with her husband's bathing.

She and her husband enjoy walking and she tries to accompany him each day, so far he has never got lost. Her husband enjoyed swimming and was missing this form of exercise. The Alzheimer's Society have arranged for a volunteer to accompany him.

When asked if she receives any support to help with her caring responsibilities, she spoke of family and friends giving her a few hours of respite, but that this is no formalised or regular.

So what does help? - *"her response - "Faith and patience."*

Findings

A number of themes emerged from all the feedback gathered, the first 4 being the areas described by people who contributed to the feedback;

Early Diagnosis

Participants reported;

- Information is needed pre diagnosis on identifying concerns and what to expect in the process of getting a diagnosis.
- The process of getting a diagnosis is too slow, leaving people vulnerable and without support whilst they wait for potentially life changing news.
- The importance of having a diagnosis, particularly for the carer
- That early diagnosis is essential to ensure prompt access to support and services and identifying carers at the outset.
- People would like to see GPs making more referrals, following diagnosis, to voluntary and community services.
- The need for sensitivity when professionals deliver life changing diagnoses

"GP's should make more referrals to the Memory Clinic"

Raising awareness

People were very positive about the work of the Dementia Action Alliance and the Dementia Friends information sessions which they would want to see continued. However they spoke of the need for more to be done to increase knowledge, awareness and understanding by professionals and in the community. Suggestions included more training for professionals, sessions in schools, intergenerational work and the need for more "myth busting" and reducing the stigma attached to the condition.

Support for Carers

A participant's GP had told the carer of a patient with dementia - "You are the thread that holds things together" Being that "thread", being pivotal in ensuring the wellbeing and safety of the person they care for and given the unpredictability of the disease it comes as no surprise that many people reported stress as their key issue.

Carers also reported feeling that they don't get the recognition and support that they need to enable them to carry out their caring responsibilities and maintain their own health and wellbeing. Carer's spoke of needing more respite, support outside office hours, someone to talk to and support which is ongoing rather than just in times of crisis.

They also spoke of their issues, as the person most likely to be responsible for sourcing information, advice and support. As demonstrated in the case studies voluntary sector services had been their principle and much appreciated 'place to go'.

They also emphasised the importance of involving the carer in the journey and the decisions. They spoke of the importance of support groups, friendships, maintaining their own hobbies and activities for carers, being able to share and learn with others.

In terms of how improvements could be delivered their feedback identified the need for;

- A formal ID for carers
- Information and support, not just signposting
- Provision of practical help when carers take on everyday tasks that the person with dementia used to perform
- A telephone 'help line' for times of stress or crisis.
- Involving people (volunteers) to help others -(peer support, /mentors/sitting service)
- Dealing with carers at the same time as the person with dementia and registering carers at same time as the dementia diagnosis
- Raising the profile and enhancing the status and "feel good factor" of being a carer (Both family and professional)
- More voluntary sector capacity to continue to deliver excellent services
- Acknowledgement and support that carers of someone with dementia often have additional caring responsibilities (e.g. at a time when parents are elderly)

A volunteer who carried out a case study interview - "***What seemed to come out from the people we spoke to was a need for a 'lifeline'***"

Support for people with dementia

People with dementia spoke of the importance of

- exercise and maintaining physical health
- continuity in support
- maintaining/having supportive friendships
- maintaining their independence
- volunteers acting as buddies

Other themes which emerged from the feedback;

Information

Evidence suggests that most people are proactive in sourcing information about dementia but they don't have a clear picture of where to go for all their information and advice needs.

Accessing information is dependent on the issues and stage of the illness with many people describing that they are coping or managing but will look for more help when they need it. At different stages as the disease progresses

- Information is key and that this is best if it is in one place
- Information specifically - pre diagnosis, at diagnosis, early on in the journey, a the journey - stages - pathway, entitlements, legal advice, People need more information on what services are available, where and what support can be accessed.
- That the same information and support is needed by all, regardless of funding

"Those in the know, get good services and better outcomes"

Specific issues for self-funders who

- Describe themselves as “vulnerable”, “not so well supported”, “discriminated against” and “isolated.”
- Find it harder to get information
- Need more information about their options and choices including respite care
- Access to respite care

“Statutory services and social services are not interested” (in self funders)

The need for continuity in care

The participants in case studies 1 and 2 were interviewed at a time when the Alzheimer’s Society was undergoing some changes which had unfortunately resulted in a change of their support workers. They spent some time talking about this and the impact it had on them. Both couples spoke of how hard it is to build up a trusted, supportive relationship and that it takes time. They were pleased to receive the support but worried about starting over, with someone new.

Their feedback echoed issues reported in the feedback responses and carer calls around a specific need for people with dementia to have continuity and consistency in social care teams and care workers.

The need for joined up services

- People identified a need for health and social care to be better integrated to deliver better services, make it easier for people to navigate the system and offer the potential for coordinating care
- People need well-coordinated services and would like to see a ‘lead person’ who undertakes the liaison between agencies on behalf of the carer
- Carers identified that they often live some distance away from the cared for which makes it more difficult to find out about and access services

“you’re expected to cope, get on with it, all you get is a provider list”.

Voluntary sector support

Current services, specifically from the Alzheimer’s Society, Sutton Carers Centre and Age UK are highly valued and providing essential support, however people spoke of wanting to see more capacity in the voluntary sector to expand existing services and provide new ones.

Feedback identified a clear need for a range of schemes (possibly volunteer) to provide buddies for people with dementia, mentors, befrienders, and a telephone “helpline”. Both carers and those with dementia spoke of the importance of meeting with others in similar situations and the benefits of peer support including reducing feelings of isolation.

More Admiral Nurses

(Admiral Nurses are specialist dementia nurses who give much-needed practical and emotional support to family carers, as well as the person with dementia.)

Hospital services

People with dementia and their carers need appropriate support whilst in hospital and on discharge and would want to see specialist dementia wards, support on discharge and more use of the "This Is Me" (a tool for people with dementia receiving professional care which records their needs, preferences, likes, dislikes and interests)

Technology

Some participants reported finding a number of things helpful and reassuring in identifying a person with dementia and providing contact details for the carer in an emergency (e.g. lanyards/bracelets, message in a bottle) also using mobile phone technology. Not everyone was aware of these or where to go to find out about what is available. People need more information on what aids and adaptations might make life easier or safer (door alarms, sensors, tracking, etc.)

General concerns about how;

1. People with dementia, who do not acknowledge or seek help or who do not have family to support will be identified
2. Reaching individuals and communities who do not engage or seek help for those with dementia

Additional information

Sainsbury's

Representatives from Healthwatch Sutton and the Alzheimer's Society met with the manager of a local Sainsbury's supermarket to put to them that supported shopping schemes can help those with dementia and their carers.

It seems currently that the support the local store would need (financially) from the company is not yet available, through the store did identify that it is already carrying out some supported shopping with 7 older people and 2 with visual impairment. They also indicated that nationally supported shopping schemes are being considered.

Sutton College

In light of the feedback received on continuing exercise we spoke to Sutton College who identified that they do run exercise classes which take into account the needs of people with dementia and carers. It is now possible for carers, in some instances, to pay on a weekly basis for classes, rather than by term as the nature of their caring responsibilities may often mean they are unable to attend classes on a regular basis.

Recommendations

Given a rapidly aging population and a steady increase in the number of people with dementia careful planning for the future is essential to ensure that people with dementia are adequately supported alongside those who care for them.

Dementia presents a significant and rising challenge to health and social care in terms of the numbers affected and the cost.

Whilst initiatives, nationally and locally, to raise the awareness are viewed positively, people with dementia and their carers clearly need real practical help that supports any aspect of day to day living to ensure the best quality of life possible.

The findings of this project have enabled us to arrive at a number of recommendations that address the key issues that the people we spoke to identified;

1. A Dementia Hub in Sutton

A Dementia Hub would be the one single thing that would address many of the issues highlighted in this report. By providing a 'one stop shop' specialised information and advice could be accessible to all (regardless of funding/financial criteria).

Information and advice could be readily accessible on an 'as and when' basis as the need arises in the journey of diagnosing and subsequently living with or caring for someone with dementia.

By bringing together statutory health and care services and voluntary sector resources and working in partnership an integrated health and care service could be delivered from 'under one roof' in a 'dementia friendly' building dedicated to partnership working and providing more opportunities for 'joined up services'

A non clinical service that is integrated in the community has the potential to increase understanding and awareness of dementia and provide a venue for the opportunities that people spoke to us about, exercise, activities and events to reduce social isolation, meeting and making friends and sharing with people in the same situation.

2. Make improvements to the patient and carer experience of obtaining an early diagnosis

The Alzheimer's Society report that an early diagnosis is hugely important as it enables people with dementia to understand their condition; access treatments that could help relieve their symptoms and gives them time to plan for the future. (It may also reduce outpatient costs) Support following the diagnosis is also vital if people with dementia and their carers are to have the best quality of life possible.'

We recommend that health and care professionals note the feedback, from the people we spoke to, about the importance, both for the person with dementia and their carer, of an early diagnosis of dementia, a clear speedy process for a diagnosis which is sensitively delivered in those cases where either or both will benefit from that diagnosis.

- For Sutton Clinical Commissioning Group (CCG) to update Healthwatch Sutton on current diagnosis rates and actions planned, if necessary, to meet or exceed the required 67% diagnosis rate.

- For Sutton CCG to advise Healthwatch Sutton on the current dementia pathway and waiting times.
- For Sutton CCG to identify where people can obtain clear, accurate, information on what to do and what will happen if they are concerned that they or someone else may have dementia.

3. Improve services specifically to support carers of people with dementia

That all providers of support to carers, voluntary and statutory, consider providing, working towards or supporting;

- A recognisable ID for Carers
- A 24/7 helpline for carers of people with dementia or information/promotion of any such service if it exists
- Accessible crisis, emergency and respite for carers, often at short notice
- The inclusion of carers of people with dementia in the eligibility for a “Blue Badge” parking permit where it can be evidenced that parking close to a destination is in the interests and safety of the person with dementia.
- Involving carers at every stage
- **More Admiral Nurses**

Research demonstrates that Admiral Nurses have a positive impact on carers and professionals and the potential to create savings in health and social care.

A study of the Admiral Nursing service in Sutton³ reported that the service brought positive outcomes for families as well as saving the health and social care economy money by avoiding inappropriate admissions to hospital and care/nursing homes. The Sutton evaluation report showed:

- Cost savings of £296,466 in health and social care in Sutton, in its first 12 months of launching.
- 100% of carers said the service had improved the support they receive for caring
- 100% of carers said the service had improved their quality of life
- 88% of carers said the service had reduced the stress they were incurring due to their caring role.

4. Ongoing raising of awareness of dementia and the profile of carers

Initiatives which delivered dementia friends training were seen as very successful. This or similar initiatives should be continued.

Feedback in the report is that more needs to be done to increase awareness and understanding by professionals and within the community.

All those supporting people affected by dementia should

- Review and evidence, where necessary, training initiatives to improve awareness and understanding of staff and volunteers around dementia.
- If people are to be supported to remain in their homes this should include home care staff.

³ A Case Study of Admiral Nursing in London Borough of Sutton, Pepper and Maio 2014/15

The Sutton Dementia Action Alliance has gone a long way towards raising awareness and developing a dementia friendly community. But the feedback indicates that there is further to go.

We would ask the DAA note our report and consider exploring the areas highlighted that relate to issues within the community (that are not specifically health or social care related)

- More dementia friendly initiatives and training in the community and private enterprise
- Support for people with dementia and their carers shopping in Sutton
- Encouraging exercise providers to consider the needs of people with dementia and carers

5. Improve services for people with dementia

Our findings clearly evidence the importance and need for more local activities for people affected by dementia. They identified a need to be able to access support and activities which allow them to stay physically active and connected to others, to be able to continue with activities and hobbies that they previously enjoyed, with or without a carer, which also support maintaining their independence.

Service providers should explore the provision of such activities either specifically for people with dementia or incorporating activities for them with existing programmes. Being visible in the community will also help break down the barriers and stigma associated with the condition.

6. For all organisations involved in the support or care of people with dementia to address the following;

- The provision of information on the range of issues identified in this report, to meet the needs of all those supporting someone with dementia (rather than signposting) in Sutton, regardless of funding criteria or living outside the borough and particularly where reliable support can be found in the statutory, voluntary and private sector
- Undertake to do what they can to improve the understanding and awareness of dementia.
- Recognise the need for continuity and consistency in the care of people with dementia and work proactively towards achieving this.
- To work in partnership, reducing the number of agencies involved and offering support to carers in coordinating multi agency care.
- Reaching communities and individuals that do not seek help
- Providers of assistive technology to ensure information is readily available at the most appropriate time following diagnosis to support people to live safely in their own home.

What is not included

We are aware that Epsom and St Helier hospital have, since the data was collected, developed initiatives to improve care for people with dementia and we trust/hope that this report will further inform their work. We will continue to monitor progress.

Some references were made to issues arising with formal paid carers caring for people in their own home. Whilst this was included to evidence the strain on family members the issues raised have not formed part of this report but may be an area for consideration in the future. It is also acknowledged that some feedback reported issues that existed some time ago and services may have improved since then.

Next steps

Influencing decision makers

This report will go to;

- all stakeholders responsible for the provision of services which have been referred to in the report and recommendations for both information and a formal requirement for a response.
- all statutory and voluntary sector agencies in Sutton who are involved in the care and support of people with dementia and their carers
- The Dementia Action Alliance

Following up on agreed action

Healthwatch Sutton will follow up on any agreed action, by service providers

Monitoring progress

We will be reporting on the progress of our recommendations in the coming year, providing updates of work and achievements.

In addition we will explore what role there may be for Healthwatch Sutton through its relationship with the Sutton Information and Advice service - Advice Link Partnership Sutton (ALPS) <http://www.suttonalps.org.uk>

Acknowledgements

Healthwatch Sutton would like to thank the volunteers (Clare, Rosemary, Jackie, Sally and Annette) who undertook the interviews, which were at times challenging.

"There were times that questioning participants seemed quite intrusive, you could see and feel their pain when talking about a life changing event."

Our sincere thanks to the participants, in the case studies and telephone interviews, for taking time out of their busy and often stressful lives to share with us some very personal and poignant experiences.

We would also like to thank Sutton Alzheimer's Society and Sutton Carers Centre for their help, guidance and support.

Our thanks also go to Sainsbury's Wallington and Sutton College for the information they provided.

Do Not Ask Me to Remember

Do not ask me to remember,
Don't try to make me understand,
Let me rest and know you're with me,
Kiss my cheek and hold my hand.
I'm confused beyond your concept,
I am sad and sick and lost.
All I know is that I need you
To be with me at all cost.
Do not lose your patience with me,
Do not scold or curse or cry.
I can't help the way I'm acting,
Can't be different though I try.
Just remember that I need you,
That the best of me is gone,
Please don't fail to stand beside me,
Love me 'til my life is done.

Attributed to - Owen Darnell

A Carers Response
by Albert Reinsch, Sr.

(This poem is a humble response to the inspirational and informative poem, [An Alzheimer's Request, by Owen Darnell.](#))

I shall do my best beloved,
To do all you've asked of me.
When I fail you must forgive me,
For where you are I cannot see.

What I know is that I love you,
More than the world can ever know.
Yet, so often I fail to show it,
I'm so ashamed that this be so.

Please forgive me for my failings,
It is not for lack of trying.
I know you need me to be strong,
But it's so hard when I am crying.

I, too, need you so much my darling,
Until we're renewed in heaven above.
Your smiles reward and give me courage,
Our hugs and kisses seal our love.



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