



# Spotlight on dementia

Experiences of people living with dementia,  
their carers and relatives





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# Introduction

**Healthwatch is the independent consumer champion for health and social care in England. Healthwatch's function is to engage with local people to seek views about locally delivered services, signpost service users to relevant information and to influence the design of local health and social care provision.**

Healthwatch Hampshire is part of a network of local Healthwatch across 148 local authority areas that launched in April 2013 to ensure local voices are heard and enable them to influence the delivery and design of local services. Our sole purpose is to understand the needs, experiences and concerns of people who use health and social care and to speak out on their behalf. Healthwatch have statutory powers, as stated in the Health and Social Care Act 2012, to ensure the consumer's voice is strengthened and heard by those who commission, deliver and regulate health and care services. Local Healthwatch helps people get the best out of their local health and social care services; whether it's improving them today or helping to shape them for tomorrow.



In England, it is estimated that around 676,000 people have dementia. Dementia has a huge impact on people living with the condition, their carers, families and the wider society. The term 'dementia' describes a set of symptoms that include loss of concentration and memory problems, mood and behaviour changes and problems with communicating and reasoning. Around 60 per cent of people with dementia have Alzheimer's disease and around 20 per cent have vascular dementia, which results from problems with the blood supply to the brain. There are other less common forms of dementia for example dementia with Lewy bodies and frontotemporal dementia.<sup>1</sup>

Dementia is a progressive condition, which means that the symptoms become more severe over time. People with dementia and their families have to cope with changing abilities such as the capacity to make decisions about major life events as well as day-to-day situations.

The Prime Minister's Challenge on Dementia 2020 is a recognition of the escalating pressure on services and commits to a series of national improvements including improved awareness, continuity of care, support after diagnosis, appropriate training for staff and more dementia friendly communities.

<sup>1</sup> Prime Minister's Challenge on Dementia, Dept. of Health, Feb 2015



# Facts and Figures



667,000 people in the UK are living with dementia

It is estimated that there are 540,000 carers for people living with dementia

Dementia is the leading cause of disability in people over the age of 65

8840 people in Hampshire are thought to be living with dementia

68% of people with dementia are over the age of 80

1/3 of people with dementia live in a care home

Approximately 69% of care home residents are living with dementia

The Alzheimer's Society is building public awareness of dementia through its 'Dementia Friends' scheme

There are now over 1.5 million 'dementia friends' in the UK

There are also 82 dementia friendly communities throughout the UK including 11 in Hampshire

Alton, Andover, Basingstoke, Eastleigh, Fareham, Fleet, Lymington, Lyndhurst, Milford on Sea, Romsey, and Winchester



## References

Prime Minister's Challenge on Dementia, Dept. of Health, Feb 2015

Joint Strategic Needs Assessment 2015, Hampshire County Council

Alzheimer's Society 2016, [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)



# Outreach Project

Throughout the summer and autumn of 2015 we embarked on a large scale outreach project looking into the experiences of people living with dementia, their families, carers and professionals. The evidence gathered on our database of feedback strongly indicated that people living with dementia and their families were finding it difficult to access the support they required, particularly as the disease progressed and increased pressure is faced by family members who provide care.

Working alongside the Alzheimer's Society and Andover MIND (the main providers of support services for people living with dementia in Hampshire) we visited numerous support groups, carers groups and day centres to gather people's feedback and experiences of accessing health and social care services. During our visits we were able to inform people of the services offered by Healthwatch and spend time talking to individuals about their interactions with health and social care services. We asked people to explain their experiences, both good and bad to try and identify if there were trends that could be identified. Over 3 months we gathered over 200 individual experiences and identified three key areas for improvement:



- **A lack of effective signposting to support services after diagnosis. There is a great deal of 3rd sector and charity support available but many people had only found it by accident or at a point of crisis.**
- **Lack of awareness of available financial support and how to access it (especially carers). Many of the people that gave feedback were unaware of Care Assessments and Carers Assessments for example.**
- **Inconsistency of care in the home. A reduced provision of Hampshire County Council approved care agencies has resulted in reduced quality of experiences for some people in receipt of council funded care. People gave examples of having different carers every day coming at different times and with a perceived lack of adequate training about dementia.**

As a result of this work Healthwatch Hampshire will be making a series of recommendations to commissioners and providers to improve experiences for people living with dementia and their carers. This report details the three key findings, highlights representative case studies and celebrates good practice already taking place throughout the county.



# Project feedback

## 1. Signposting to support after diagnosis

The most common feedback from carers and people in the early stages of living with dementia was around a lack of support after diagnosis. Most of the people spoken to as part of this work were accessing some kind of support group but the majority said that they had not accessed support as early as they would have liked. The majority of people received an initial assessment at either their GP surgery or at a memory clinic. Many people felt that once diagnosed they were not given appropriate information about local support services that may be able to benefit them.

This, in many examples, led to a deteriorating situation which would slowly build to a point of crisis (either a carer not being able to cope any more or the person with dementia developing more significant symptoms of the disease). At this stage it was more likely that carers would seek out further support. The following case study is representative of many collected throughout the engagement process:



“I am a carer for my husband who was diagnosed with Alzheimer’s Disease around 18 months ago. He was diagnosed at a memory clinic who gave good medical advice but no information about other support. I have been helped with allowance forms by a friend but wasn’t given any information by my GP or any other professionals. There is a real lack of support after diagnosis - I was given none. We have never seen the same doctor and although we now receive 6 hours a week of day care so I have some respite, I still feel the need for more support as a carer.”

Another commonly reported sentiment by people living with dementia was around not wanting to be a burden to others. Many put off a visit to the GP about memory problems as they feared a dementia diagnosis. Once a diagnosis has been made it is common for people to attempt to continue to live as they were before and not ask for further support when it is needed. This was also true of carers who would often provide a great deal of support before even recognising themselves as a carer. One woman who





had recently been diagnosed with early onset alzheimer's disease told us: "I had a good job but now I can't use my hands, I see my doctor and I hope they are doing a good job but it's horrible. I do everything as much as I can, I would like more support - I would love to go walking and get outside but I try not to be a nuisance to others."

There were many examples of good practice where GPs and memory clinics had signposted to local support groups and information. These however, were vastly outnumbered by examples where this was not the case. Where people has accessed services earlier their overall experiences had improved, often as a result of meeting others in a similar situation and having a support network to access and talk to: "I first realised I had Alzheimer's 4 years ago on holiday when I got lost. I experienced it all some years ago with my mother and back then it used to be seen as a joke, not now - there is drop-in support in numerous places and it's all very good. I'll never sit back and say 'I can't!'". After sharing their feedback a couple who had cared for and lost their mother to dementia said: "We have shared our experience and this is the one message I would deliver... find someone who has been through it as a carer".

There are many ways in which it might be possible to signpost people to local support services at the point of diagnosis. GPs are under increasing pressure to be able to provide this function and it is understandably difficult for an individual GP to know about a regularly changing landscape of support services, not just for

those with dementia but for other illnesses and long term conditions.

The Hampshire Dementia Advisor Service (DAS) is provided by the Alzheimer's Society and Andover Mind. The service is available to anyone with a diagnosis of dementia and people with suspected dementia to help support them through the diagnostic process. The service focuses on well-being rather than illness, supports people to think about how they can come to terms with and live well with dementia, assists with the health and social care support available to people with a diagnosed dementia and their carers and offers advice on state benefits and planning for the future.



### Recommendation

Healthwatch recommends that patients should be referred at diagnosis to their local Dementia Advisor Service who will have access to all local services and information about relevant financial support. This should be done via e-mail or telephone so that they can make contact with the patient and follow up on progress.



# Project feedback

## 2. Information about financial support

Many of the carers and family members of someone living with dementia that we spoke to reported difficulty in accessing information about financial support available to them. This was often in reference to care assessments and carers assessments but also ranged to wider concerns about issues like dealing with house-related paperwork and the sale of property. Many felt very alone during this emotional time, when a loved one has died or is moving to a hospice or residential care. Carers found it difficult to find any support during this time. Practical support, advice and signposting relating to lasting power of attorney needs to be addressed and supported early on so that carers and family members have more opportunity to discuss this with those living with dementia.

Many of the carers we spoke to were unaware of carers assessments and the entitlements it might give them. Those that had been through the process suggested the need for a professional to support the process to ensure that all carers complete a carers assessment and emergency plan. Generally carers wanted this practical support to be face to face, one to one support. Some carers shared experiences of completing forms ‘too optimistically’ (especially soon after diagnosis) and then not receiving the support they really need. If a professional were to assist carers to answer questions on forms and really focus on giving open and frank responses, it would ensure that carers are focused on their support needs as well as the cared for.



### Case Study

“I live with my mother who is aged 86 and has been diagnosed with Alzheimer’s. I’m not working and live on income from savings. I have some medical issues hence the reason for not working and I also act as a carer for my mother. I moved in with my mother when my father died about 15 years ago. My mother owns her own house and I am concerned that if she has to go into a care home that she will be forced to sell the house which is my home. She has not made a will and I don’t have power of attorney for her. My mother can be difficult about these issues... I have no other family to help me and we don’t get any benefits or other financial support.”



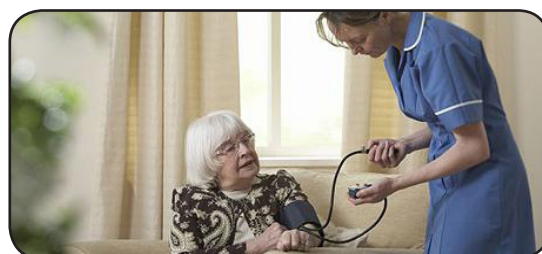


# Project feedback

## 3. Inconsistency of care in the home

Much of the feedback received from people who received care in their own home and from their family members revolved around inconsistency of care. This could be in part due to the reduced provision of Hampshire County Council approved providers. As of April 2015 the Council reduced the number of providers from 170 down to 20 with the aim of improving quality and the ability to effectively monitor that quality. During the time we were carrying out this engagement it was clear that some of the providers were struggling to maintain a high quality service as the numbers under their care had increased dramatically over a short space of time. As a result, this could be one reason for the reported inconsistencies.

Continuity of paid-for carers in the home is essential. Many carers said that when paid-carers change too often, they were unable to leave the house because the cared for person was unsettled or their needs were not being met: **“Paid carers come in twice a day but the carers and the time they come varies so much that I have to be there too. The carer is supposed to come in the evening but can come anytime from 4-9pm. Whenever they arrive, they want to do Dad’s dinner and put him to bed, but that’s no good at 4pm! Also it means that his medication isn’t being taken at a consistent time so I have to do it.”** Some family members also commented the importance of consistency in terms of gender. Some people living with dementia were more agitated or aggressive around



a carer of a particular gender. Consistency, regardless of gender, is of higher importance to many living with dementia in terms of building a relationship and avoiding unnecessary confusion and upset to those receiving care.

We also recorded a number of comments regarding the training of care staff entering the home. Some family members felt that care agency staff did not have a detailed understanding of dementia and as a result were unable to care effectively for people with more challenging behaviour which seem aggressive or inappropriate.



### Recommendation

Healthwatch recommends that all Hampshire County Council recommended care providers give adequate dementia training to all of their staff. Where possible they should prioritise consistency of carer to those living with dementia.



# Project Feedback

## 4. Other key findings

Many of the issues facing carers that support someone with dementia or Alzheimer's Disease are specific to these conditions, focusing on the diagnosis, hospital treatment, how the condition progresses and worsens and the type of care that they require. Please note that although the majority of carers we spoke to were retired spouses that considered themselves full-time carers, Healthwatch also engaged with sons and daughters that were caring for one or both parents as well as managing part-time or full-time employment with dependent children living at home.

### Support Groups

- Receiving help and support from other carers was really important to many of the carers that we engaged with. Being able to talk to other people 'in the same boat' that 'really understand' seemed to be the best type of emotional support for those that accessed it.
- Many carers said that groups run by support workers that were 'experts in their field' (e.g. Alzheimer's Society) enabled them to get advice and guidance that hadn't been available elsewhere from health or social care professionals.
- Carers often discussed initially avoiding support groups soon after

diagnosis because they were fearful of hearing 'horror stories' and being faced with 'what the future holds', but said that knowing the professional that ran the group prior to attending made the initial visit easier.

- Many carers said that transport and respite should be provided to enable carers to attend support groups so that they can receive the much needed emotional support from peers and professionals.
- Groups that welcome both the carer and cared for were liked by some but not others. For these groups to be successful, carers said that activities for the cared for need to be well staffed and offer varied activities and that the carers need to be able to congregate in a separate space to enable them to speak candidly.





“The initial mental health support was really good but then after my Father was diagnosed, he was discharged by letter and we had no one to call that knew our situation. My Mother and I suddenly felt abandoned. We had no idea who we could call or what would happen next. We had this devastating diagnosis, medication was prescribed... and then discharged! Nothing about our well-being or his. My Father used to care for my Mother because she has COPD and physical disabilities but none of this was taken into consideration. After being discharged, we were told to make contact with the GP if my Father’s condition changed or worsened...that left us, the family, responsible for monitoring his deterioration and making decisions about what to do next and when. We felt very under-supported.”

## Reducing stress

To reduce stress after a dementia or Alzheimer’s diagnosis, carers recommended that they need help to order their priorities. Carers listed the following as essential support:

- A face to face meeting at home with a specialist support worker a couple of weeks after diagnosis to signpost, advise and listen to fears, concerns and answer questions.
- Applying for and support with Attendance Allowance because it can’t be back dated
- Applying for and support with receiving reduced council tax (finances may help with care costs)
- Receiving an invitation to their local carers hub and being put in touch with local support networks.
- Putting an Emergency Plan in place
- Receiving support to obtain Lasting Power of Attorney where necessary
- Registering as a carer with the GP

In relation to reducing stress for carers caring for someone with Dementia or Alzheimer’s Disease, carers said that included...

- Emergency buttons, cords and alarms in the home reduced stress for some carers and enabled them to leave the house and know that the cared for person is safe but this needs to be introduced early so they can learn how to use it.
- Day Centres provide essential respite but carers discussed the need for more groups where cared for people can be left for more than a couple of hours so that the carer can be independent and complete tasks that aren’t possible when caring.





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## Spotlight on...

As part of the outreach carried out for this project we discovered a huge amount of innovative work taking place throughout the county that is aimed at improving experiences for people living with dementia. This section of the report puts a spotlight on some of that good practice.

### **Dementia friendly GP Surgeries (iSPACE)**

iSPACE is a number of actions designed to improve the patient experience through delivery of a set of improvements in care planning, communications and awareness of dementia for staff in primary care (GP surgery) settings.

Wessex Academic Health Science Network (AHSN) has funded a project to make GP surgeries dementia friendly. This was piloted in Hampshire, implemented on the Isle of Wight and then evaluated by the Wessex AHSN Centre for Implementation Science at the University of Southampton. This project has shown good outcomes for patients and is now being spread across Wessex.

- I - Identify a dementia champion,
- S - Staff Training,
- P - Partnership working with patients, carers, and the voluntary sector,
- A - Assessment and oversight of use of anti psychotics
- C - Care planning
- E - Ensure the environment supports people with dementia and other disabilities.

This work is now being spread across Wessex with 26 surgeries in the process of becoming dementia friendly. The programme is often carried out in conjunction with the Dementia Action Alliance and groups who wish to make their communities dementia friendly. More information can be found on their website: [www.wessexahsn.org.uk](http://www.wessexahsn.org.uk)

### **Dementia Roadmap**

The Dementia Roadmap provides high quality information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care staff to more effectively support people with dementia and cognitive impairment, their families and carers. The main audience is staff working in primary care, including GPs, nurses, dementia navigators and practice managers. The roadmap will also be of benefit to other professionals, people worried about memory problems, people living with dementia and their carers and families. The road map for Hampshire is currently hosted by West Hampshire Clinical Commissioning Group (CCG) but with signposting information to services throughout Hampshire.

The roadmap can be accessed here: [www.dementiaroadmap.info](http://www.dementiaroadmap.info)



## Hampshire Hospitals NHS Foundation Trust

As part of the project we utilised our enter an view powers make an announced visit to Royal Hampshire County Hospital in Winchester. They have two wards specifically designed to enhance the experience of people living with dementia and their families. They have a range of innovative services in place to improve patient experience including dementia specialist nurses, discharge coordinators, activity coordinators and specially designed wards. Full details of our visit are available in our enter and view report: [www.healthwatchhampshire.co.uk/sites/default/files/uploads/E&V\\_Royal\\_Hampshire\\_County\\_Hospital\\_7-12-2015.pdf](http://www.healthwatchhampshire.co.uk/sites/default/files/uploads/E&V_Royal_Hampshire_County_Hospital_7-12-2015.pdf)

**“It was a pleasure to be able to introduce the Healthwatch team to our staff on the wards and provide the opportunity for them to observe the care we provide and talk with patients, their families and carers to hear first hand about their experience.**

**We are proud that the report has highlighted the many aspects of good practice that have been developed by our teams and we know make a real difference to our patients, their families and carers.**

**We remain ambitious in our approach to improving the care we provide as we continue to develop our services for older people and for patients living with dementia and look forward to sharing our developments with you in the future.”**

Mary Edwards, Chief Executive, Hampshire Hospitals NHS Foundation Trust

## Dementia Friendly Hampshire

Hampshire County Council has a number of schemes that are aimed at ensuring the community at large have a greater awareness of what dementia is and how those who have been diagnosed might be feeling. They are working to promote the need for understanding, clear communication, patience and support throughout Hampshire. Ultimately, the aim is to forge a community spirit in which people with dementia will be able to live independently for longer, but with help and support when they need it. More information about all of the services below can be found at: [www.hants.gov.uk/dementiafriendly.htm](http://www.hants.gov.uk/dementiafriendly.htm).

The programme has included the creation of:

-  The Hampshire Dementia Action Alliance
-  Dementia Ambassadors
-  Dementia Friendly High Streets
-  Awareness Raising initiatives
-  Peer Support groups
-  Dementia Action Groups





### Third sector support

Healthwatch Hampshire utilised the support of numerous third sector organisations whilst carrying out the engagement work for this project. Despite one of the key findings of this report highlighting a lack of signposting to support, we witnessed numerous support groups for people living with dementia and their families and carers including Carers Hubs, Alzheimer Cafés, Memory cafés, Dementia Forums and Dementia Action Groups. Some of the groups we visited included:

**Carers Hubs** - The Princess Royal Trust for Carers (PRTC) run regular carers hubs throughout the North of the county. These are drop-in sessions where carers can access information and support. The PRTC also provide emergency plans for carers as a free service for any carer. This gives carers the peace of mind that should they be unable to care for their loved ones for whatever reason then a plan will go into operation to ensure that caring duties are still undertaken.

**Alzheimer's Cafe UK** - An Alzheimer Café is a gathering of people affected by and/or interested in dementia. Monthly gatherings are for the purpose of education, discussions, exchanging information about dementia, and for opportunities to socialise and meet others.

**Memory Cafés** - Numerous memory cafés throughout Hampshire provide a friendly and supportive environment where people can meet, talk, and learn more about dementia and what support is available.



The Princess Royal Trust  
*for Carers*



[www.alzheimercafe.co.uk](http://www.alzheimercafe.co.uk)







# Summary & Recommendations

As a result of this work Healthwatch Hampshire are asking commissioners and providers of health and social care services that effect people living with dementia and their families and cares, to consider the following recommendations.

This report will be sent to relevant professionals for a direct response. All responses and feedback will be published alongside this report on our website: [www.healthwatchhampshire.co.uk/our-voice](http://www.healthwatchhampshire.co.uk/our-voice)



## Recommendations

- We recommend one point of access for signposting and support information. Healthwatch feel that the best placed organisations to do this is the Dementia Advisor Service (DAS). Patients should be referred at diagnosis to their local DAS who will have access to all local services and information about relevant financial support. This should be done via e-mail or telephone so that they can make contact with the patient and follow up on progress.
- All new health and social care settings commissioned, built or re-designed should consider the needs of patients with dementia and become 'dementia friendly'. If a setting is suitable and accessible for someone with dementia then it is very likely to be accessible for everyone else.
- All staff who come into contact with people living with dementia should have adequate awareness training.
- We would recommend that all commissioners encourage GP surgeries to become dementia friendly. The iSPACE model is a good example of how this could be achieved but other options are available.



## Recommendations

Services for people living with dementia require consistency of service between Health and Social Care settings so Healthwatch Hampshire recommend the continued use of integrated care teams to ensure smooth transitions between services at all stages of the patient pathway.

Integrated Care Teams (ICTs) aim to develop person centred care planning and support for eligible adults, particularly elderly people and those with long term conditions, complex needs or who are approaching the end of their life, ensuring that services:

- Maximise well-being
- Maximise choice and control
- Maximise independence and functioning
- Minimise intervention, unnecessary hospital admission and premature admission to long term care

We would also ask commissioners and providers of services that are for, or could effect, people living with dementia to carefully consider all aspects of this report, not just the above recommendations. It is clear that there is a large amount of good work being carried out throughout the county but we are still receiving feedback about poor experiences of accessing services and support. Healthwatch are ultimately accountable to local people

and prioritise the work we do to reflect the intelligence and evidence we have gathered from local people. Our independence from the NHS and local authorities mean that we are not bound to adopt the priorities or messages of those bodies. We would always encourage commissioners and providers to carry out their own consultation and engagement to support their decision making processes.



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## Contacts and useful links

For information about the Dementia Advisor Service in your area visit:

[www.hants.gov.uk/adultsocialcare/adulthealthandwellbeing/dementia/dementia-advisor-service](http://www.hants.gov.uk/adultsocialcare/adulthealthandwellbeing/dementia/dementia-advisor-service)

For further information the Dementia Friendly Hampshire scheme and tools visit:

[www.hants.gov.uk/dementiafriendly](http://www.hants.gov.uk/dementiafriendly)

For information about care and support available for adults in Hampshire visit:

[www.hants.gov.uk/gettingstartedguide](http://www.hants.gov.uk/gettingstartedguide)

For information about receiving support as a carer visit:

[www.hants.gov.uk/carers.htm](http://www.hants.gov.uk/carers.htm)

Details of the dementia friendly GP scheme, iSPACE can be found here:

[www.wessexahsn.org.uk/projects/45/creating-dementia-friendly-gp-surgeries-ispac](http://www.wessexahsn.org.uk/projects/45/creating-dementia-friendly-gp-surgeries-ispac)

The Dementia Roadmap with details of local support can be found here:

<http://dementiaroadmap.info/westhampshire/>

The following charities and third sector organisations also provide further support and information:

Alzheimer's Society - [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Mind - [www.mind.org.uk](http://www.mind.org.uk)

Princess Royal Trust for Carers - [www.carers.org/partner/princess-royal-trust-carers-hampshire](http://www.carers.org/partner/princess-royal-trust-carers-hampshire)

Age Concern - [www.ageconcernhampshire.org.uk](http://www.ageconcernhampshire.org.uk)

Alzheimer Cafe UK - [www.alzheimercafe.co.uk](http://www.alzheimercafe.co.uk)

Citizens Advice Hampshire - [www.citahants.org](http://www.citahants.org)

To download a copy of this report or to share feedback and experiences about health and social care services in Hampshire get in touch with us at Healthwatch Hampshire:

**[www.healthwatchhampshire.co.uk](http://www.healthwatchhampshire.co.uk)**

**01962 400262**

**In person at any Citizens Advice Bureau**







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# Thanks

This work would not have been possible without the support of numerous people who gave up their time to talk to us about their experiences - thank you to all of the people living with dementia, their carers, relatives and friends who contributed. We would also like to thank all of the professionals that we worked with throughout this project. Special thanks go to the staff of Andover MIND and the Alzheimer's Society in Hampshire for their help and assistance throughout the project.



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