Living with Dementia:

Experiences of people with dementia, families and unpaid carers

Healthwatch Isle of Wight

December 2018

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1. Acknowledgements

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2. Summary

Engagement by Healthwatch Isle of Wight involved a range of people living with dementia or affected by it. The majority of people spoken to were unpaid carers.

Initial visits to ten dementia-focussed local groups were followed by structured discussion sessions with people with dementia and unpaid carers. These included three discussion sessions with people with dementia living in care homes.

People had a range of positive and more difficult experiences. Support from individual health and social care professionals was highly valued, as was the sense of community amongst local dementia-focussed groups and groups for unpaid carers.

A picture of a highly resourceful community of self-reliant people emerged, who nonetheless felt that improvements were needed to some aspects of support. Navigating the care system was seen as a major challenge, with different parts of that system experienced as poorly co-ordinated.

The intensity of life for unpaid carers meant the energy could not always be found to request help, or to be able to recognise signals if stress mounted to critical levels. Help in the event of crisis had often been experienced as inadequate.

Many experiences in hospital had raised concerns, although there was optimism about the potential for this to move in a positive direction.

Six recommendations for positive change appear at the end of this report.

Future work is likely to focus more specifically on the experiences of people who themselves have dementia, on experiences of specialist in-patient dementia care and developing engagement with people who live in residential care or nursing homes.

3. Background

Healthwatch Isle of Wight is the “consumer champion” for people using local health and social care services. It was formed in 2013, following legislation to bring in a Healthwatch organisation in every local authority area of England. Feedback is received from local residents on a range of services and discussed regularly with commissioners and providers. Each year a small number of topics are chosen for more detailed examination. In spring 2017 Dementia Care was chosen as one of Healthwatch Isle of Wight’s priority topics for the coming year.

What is Dementia?

The Alzheimer Society’s website[1] defines “dementia” as follows:

“The word ‘dementia’ describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour”

Dementia can arise from a number of conditions affecting the brain and nervous system. Alzheimer’s disease is the most widespread of these conditions. The speed with which dementia develops varies a great deal from one person to another, as does the exact way in which each person is affected.

Depending on the symptoms, medications may be prescribed to help, although there are currently no treatments that will cure dementia.

The likelihood of developing dementia increases steadily with age. Although this is more likely to happen to those over 65, some people under 65 are also living with dementia. When a person under this age has the condition, it is often called “early onset” dementia.

In recent years it has become recognised that with appropriate support, many people with dementia can continue to maintain a good quality of life. Communities can become more dementia-friendly through a greater practical understanding of the condition and through people becoming less fearful of it.

Dementia across England

It is estimated that there are 676,000 people with dementia in England, and 540,000 unpaid carers of people with dementia[2].

A person will be formally diagnosed with dementia by a clinician in a specialist NHS memory service, following a referral from a general practitioner or through a hospital memory service.

People may be assessed for support with daily tasks and this will be done through their local authority. The person may be required to pay in full or in part for such support. Very often unpaid carers, usually relatives, provide the bulk of care and support for people with dementia.

As the condition progresses, it may become necessary for the person to move into residential or nursing home care. Again this may involve some level of financial contribution, unless the person’s needs have reached a level of complexity to be eligible for NHS Continuing Healthcare funding.

The 2009 National Dementia Strategy for England, “Living Well with Dementia”[3], recognised the importance of prompt diagnosis of dementia, to help ensure that help could be given to maintain quality of life. It also acknowledged the importance of help with navigating the complex system of support with health and care needs.

In 2012 the “Prime Minister’s Challenge on Dementia 2020”[4] was announced, followed by implementation plans. During 2018 the initiative is being reviewed to identify which parts of it need to be worked on most energetically in the coming years.

Dementia on the Isle of Wight

The Isle of Wight is one of the four CCG* areas identified with the joint highest rate of dementia in England, as calculated by people with this condition on G.P. lists[5]. All four of these areas are coastal and noted for having a high proportion of older people.

Locally, a strategy exists, called "Living Well with Dementia on the Isle of Wight 2014-19"[6] and this is being reviewed during 2018. In line with national trends, more people who have dementia are now receiving a diagnosis than would have been the case ten years ago. Local initiatives include the recruitment of Admiral Nurses (employed by national charity Dementia UK) to work with members of the NHS memory service and the appointment by the Isle of Wight NHS Trust of two Acute Dementia Lead Nurses (sharing one full-time post) to work across departments at St Marys Hospital.

The number of community groups across the Island, geared specifically to people with dementia and unpaid carers, has increased over the last few years. Memory groups, some hosted by Age UK Isle of Wight and another run independently, offer a continuation of help provided in introductory courses run by the Isle of Wight NHS Trust. The Alzheimer Café movement has locally-based sessions monthly across the Island, with an additional fortnightly group for people affected by early-onset dementia. A number of other groups, many linked to local churches, offer a range of activity and support sessions to people with dementia and unpaid carers.

Amongst other organisations working locally in dementia support are the Alzheimer's Society and Carers Isle of Wight. Community arts organisations and animal-based charities also have a strong involvement.

Work has also been done to encourage a dementia-friendly approach in local towns and villages, as well as in a number of local GP practices.

** CCG – Clinical Commissioning Group: NHS body covering a specific geographical area, e.g. the Isle of Wight, North-East Essex, etc.*

4. What Healthwatch did

In October 2017 Healthwatch Isle of Wight staff and volunteers visited ten dementia-focussed community groups across the Island, including all the Alzheimer Cafés. Despite their name, Alzheimer Cafés welcome people with various forms of dementia. People were informed of discussion sessions to be held over the coming months, in which they could talk about experiences of living with dementia. They were invited to take part in these sessions, or to give brief feedback at the time on local services.

In November 2017, structured discussion sessions were held for people with dementia and unpaid carers. These took place in four local venues in Shanklin, Freshwater, Ryde and Newport. In February 2018, three similar sessions took place, all in Newport, specifically for people with experience of being unpaid carers. For these, there was a choice of a morning, afternoon or evening session. A parallel session was offered for the cared-for person at the same time as each of these three sessions.

Each discussion session was facilitated by a staff member from Healthwatch Isle of Wight, supported by at least one Healthwatch volunteer. In addition to the group sessions, three one-to-one conversations took place, each of these with an unpaid carer. Detail on running the discussion sessions may be found in Appendices 1 and 2.

In addition, all nursing and residential homes on the Island were contacted, to gauge interest in the idea of holding discussion sessions there. Following replies from several, three discussion sessions were held in local care homes in January and March 2018, using an adapted version of the materials used for the other discussion sessions. These sessions, emphasised including people with dementia rather than asking directly about the condition. Conversations were about people's lives now and in the past, and included experiences of care and NHS services.

A total of 32 people took part in the structured discussions; 11 of these had dementia and 21 had experience of being an unpaid carer. Twenty-six of those who took part were women and six were men.

5. What Healthwatch found

The following commentary is in two main parts. The first part outlines the themes emerging from the structured discussion sessions held from November 2017 to February 2018 and the earlier visits to community-based groups in October 2017. The second part is based on visits to nursing and residential homes in January and March 2018.

PART 1 – Experiences of living with dementia

Themes from the conversations are organised according to stages of people's experiences of dementia. These stages also form the structure of national and local dementia strategies.

It is important to emphasise that this report is specific to experiences of the people who chose to take part. It is acknowledged that there are other important areas of interest, which have not been referred to - in particular the provision of NHS specialist in-patient dementia services. It is also recognised that there is a place for future work to highlight the perspective of people who themselves have dementia.

A – Community awareness and accessibility

People spoke about this topic against a background in which dementia had long been regarded negatively and with fear. People with dementia that we engaged with often had a more positive view of their own lives and gave examples of the ways they related to other community members. One spoke of a positive experience volunteering in a community setting and being open about having the condition. This had prompted surprise amongst other community members who did not have a positive expectation of someone with dementia. Others spoke about being warmly received in specific community groups in which they were well-known. Amongst these were churches, sports clubs and other activity groups not geared specifically to people with dementia.

Greater apprehension could be felt about venturing beyond places where the person with dementia was well-known. There might be particular concern if the person showed physical symptoms which they felt self-conscious about. Some unpaid carers spoke of feeling uncomfortable in settings such as restaurants or pubs, if a person with dementia spoke in a loud or repetitive way. Sometimes, however, they were re-assured by the accepting approach of others in the community:

"…. There were people very close by at an adjacent table, and when I got the chance I did say sorry to them for having their meal ruined. In fact they were very understanding and said they did not feel that way at all – but some people might have done."

Speaking about the attitudes of wider family, the experience of unpaid carers was mixed. Whilst some spoke of receiving invaluable support from relatives, others gave accounts of family not believing a dementia diagnosis, or being critical of the unpaid carer's actions. One person with dementia, with otherwise positive experiences, had been asked not to mention the diagnosis to children in the family.

More broadly, participants spoke approvingly of intergenerational work, giving an example of a project which brought schoolchildren together with people with dementia, to the benefit of both. Examples were given of a hairdresser and of bus drivers who had been helpful in the way they related to people with dementia.

Some people felt that more could be done in communities to raise awareness of dementia, for example in churches. It was felt that other groups dealing with the public could benefit from a greater understanding that unexpected or unusually strong reactions to everyday situations might be a sign of a dementia.

The design of facilities was mentioned by some as being important in helping people get around and that being "dementia-friendly" entailed a variety of considerations, such as lighting and colour-scheme, not merely giving an environment a homely or old-fashioned appearance.

B – Early signs of dementia and getting a diagnosis

Descriptions of initial signs of dementia were many and varied. In many instances realisation had been gradual of an issue beyond expected “old-age forgetfulness”. Unpaid carers spoke of noticing a person starting to “lose track” of familiar tasks or “losing logic” when working out how to do something.

“We would go through a sequence of things with [my relative] and she would agree with each one, but she lost the ability to piece things together and come to a conclusion. She would say [far-fetched things about that she would be able to do], and be convinced this was correct”

Faltering speech was mentioned by some as an early sign, or irritability and attributing “blame” elsewhere if something had not gone to plan. Another experience was of someone keeping symptoms hidden until a late stage - symptoms which involved seeing things that others did not.

As the significance of early signs was not always realised, a visit to the GP was not always made with the anticipation of a dementia diagnosis. If the diagnosis was suspected, however, family members might feel the need to approach this cautiously, for example by writing a letter to the GP prior to an appointment being made.

People mentioned the process of going to the GP and then receiving a diagnosis from the NHS Trust’s Memory Service. Little detail was recalled by participants, although one highlighted in particular that a diagnosis was obtained quickly.

A number of people mentioned the helpfulness of receiving a more precise diagnosis about the type of dementia. This was useful for understanding symptoms and anticipating the development of the condition. One participant mentioned a detailed diagnosis being obtained after an unpaid carer had suggested the possibility to a clinician, having seen a television programme about a specific syndrome.

C – Support following diagnosis

Here, there was a contrast in experiences. Some people spoke positively of a six-week course about dementia and managing symptoms. However, others spoke with feeling about a lack of guidance after diagnosis.

“So we were given a diagnosis – told [my relative] had dementia, and then….. nothing! We did not get the leaflet that everyone is supposed to get. In my foolishness I thought that someone would be there to steer us towards help, but there was no-one… we just had to get on with it!”

Sometimes, memories of unpaid carers were imprecise about what had been provided – but it was also pointed out that when dealing with intense situations, information can be hard to take in. For some people this intensity had been added to by receiving a diagnosis of dementia around the same time for more than one relative.

For those who had attended a post-diagnosis course, mention was made of signposting to further help, for example to specific community groups, or to organisations that could help with practical issues. Others, though, spoke of needing to be proactive, for example through Internet searches, or making use of knowledge from previous health-related employment.

Mention was made of support from professionals in the Memory Service, G.P. practices and other local teams. People’s experience was mixed. Where it was positive, it was very much linked to particular individuals. Where individuals were named by participants, this feedback is being passed on to the relevant service.

Where experience was less positive, it was often due to the lack of a timely referral or information, an interruption to continuity when professionals moved on, or a lack of opportunity to talk through concerns. Many felt that the complexity and variability of living with dementia was poorly reflected in the range and accessibility of support.

Two recurrent themes from the discussions were of families feeling they had to take the initiative in any contact with services and that when support was offered, it was un-coordinated.

"…although we have agreed for information to be shared between all services and professionals, and there is supposed to be this wonderful system for sharing information, no-one seems to know about any part of the person's care other than the bit they are responsible for…. How can someone prescribe medication appropriately if they cannot see all the relevant medical details for the person?"

One unpaid carer described their family's task of co-ordinating care for two relatives with dementia as a "full-time job" with multiple files in use for recording contacts with a total of 150 professionals over a period of years.

Information on dementia-based community groups was typically not obtained from health or social-care agencies, but discovered by chance – most frequently in the local press - but also by word of mouth. Some people spoke about learning of other groups after discovering one, as "one leads to another". Although it was not the intention of the Healthwatch discussion sessions to be a forum for sharing information, people did learn about new sources of help through listening to each other's experiences, often to their own surprise if they had been attending local support groups on a longstanding basis.

The types of local groups which people were attending were many and varied – some with an activity focus, encouraging socialisation and mental stimulation, others for general interest and networking, with yet others offering mutual support for unpaid carers. The variety and extent of choice was important to those sharing their experiences – some felt more comfortable with certain groups than others and often felt a strong sense of allegiance to the group or groups they preferred to attend.

Amongst the comments was one that there was more room for groups for people with dementia based around sports or other interests. Another approach could be for volunteers to offer support in mainstream clubs.

Some of the community-based groups had been started by particular individuals, including unpaid carers. One of those attending a discussion session encouraged others to do the same.

Such community groups were not an option for all, however. Where a person with dementia was not gregarious, this might limit networking opportunities for the person themselves and the unpaid carer.

D – Living with dementia day-to-day

The majority of the people who attended the Healthwatch discussion sessions were unpaid carers and it follows that their experiences figure largely. This commentary is presented acknowledging that background. Ideas will be suggested later in this report for engaging more extensively with people who themselves have dementia.

- Signs and symptoms of dementia -

Unpaid carers mentioned a range of ways in which life had changed for them. From giving up work, or cutting back on social life and interests, to decreased contact with family. Some spoke of disrupted sleep and tiredness. The continuous nature of the caring responsibility was emphasised by many:

“She won’t let me out of her sight in the house – if I go into another room she’ll yell at me ‘Are you there?’….. she’s always been a very strong character, and still is!”

Whilst several unpaid carers mentioned changes in the behaviour of the person with dementia they cared for, there were also references to the unpaid carer having to adapt, for example by becoming more outgoing than previously, to find information or sources of support.

Many spoke of dilemmas, for example balancing the benefits of the unpaid carer taking a break with upset caused to the cared-for person, or risking of the person being given poor-quality support. Balancing travel independence against the risk of mishap might have an important bearing on maintaining identity. Discouraging unusual combinations of clothing might be important for the person’s dignity but had implications for the person’s autonomy and freedom to choose.

Symptoms of dementia varied in character and intensity. It should not be assumed that supporting someone with less vivid signs of dementia is without its stresses. Some forms of dementia are fluctuating in intensity, which brings its own issues and dynamic.

A number of unpaid carers spoke of the person’s manifestations of dementia being at their most intense at night, leading to interruptions in sleep for both. One unpaid carer contrasted the person with dementia being easily re-assured and going to sleep quickly, with their own delayed ability to relax and sleep following unsettled episodes.

Changes in the ability to communicate were referred to many times in the discussion sessions, sometimes as one of the earliest symptoms. One person with dementia described the frustration of having an idea what to say, but struggling to find the words. Hearing repetitive speech was mentioned by unpaid carers as becoming increasingly stressful over extended periods, however understanding they may be of the reason.

There were also descriptions of a person making forceful movements, putting others at risk. Unusual or conspicuous behaviour in public was described by some.

Some unpaid carers mentioned people of dementia who “wandered” although that term might be queried where the person themselves was clear what they were looking for or trying to escape from. The level of risk to the person was a concern and some families had been given contradictory information about who could be called on to help. Tracking devices had been found useful by some unpaid carers, although others felt the individual they cared for would not accept one.

For some people, incontinence had become an issue. Even for people who might in general be reluctant to receive care, this was seen as something for which support must be given of necessity. As well as the tasks around physical support for the person, people described the additional tasks around laundry this brought with it. Time for other household tasks such as shopping could diminish as a result.

With some forms of dementia people experience sights, sounds or smells that others around them do not. Several unpaid carers described living with people who had these experiences. In one instance the person had kept these symptoms well-hidden but had become increasingly reluctant to be left alone at home. Whilst being aware of how frightening these symptoms might be for the person, some unpaid carers spoke of the impact this was having on them, especially where this occurred at night.

Some unpaid carers talked of people with dementia who lived with fears of being pursued by hostile figures, or of people intent on entering their home. Sometimes, unpaid carers had adopted improvised coping strategies, or negotiated with the cared-for person over what level of precaution would be taken against whatever fears were expressed.

- Attitudes to own care -

As previously mentioned, people with dementia are affected in a wide range of different ways by the condition. Some have full awareness of the diagnosis and an ability to adapt their daily routines to accommodate it. Others have some awareness of their dementia and are able to explain to others, for example, that they may need to pause to think of a word. For some, however, part of the condition seems to be a lack of insight or “denial” of any impairment of this kind. This can lead to tension with those seeking to provide support, and for some a reluctance to receive care.

Some descriptions by unpaid carers mentioned people refusing medication, or interpreting an offer of help with washing themselves as an accusation of being dirty. One unpaid carer described giving life-sustaining medication by surreptitious means.

- Legal and money issues -

Legal issues arise around consent where a person lacks mental capacity. Several people in the discussion groups felt ill-informed even about basic principles. For example, some had not been aware until too late that a financial Power of Attorney would not cover health and welfare matters and that this can only be prepared whilst the person with dementia still has capacity to consent to its future use.

Where issues of consent and choice arise, the picture becomes more complex. As unpaid carers are very likely to have good intentions towards their relative or friend with dementia, they may feel on delicate ground when their view of the best interests of the person differs from the person's own view. Examples from the discussion sessions include a person choosing not to receive personal care, or driving when others feel this is no longer safe. One unpaid carer described being told only by going through a court process could the person's choices be over-ruled.

Handling money can also be an area of concern, where people lose an ability to keep track of spending. Again, this strays into legal territory of consent and questions of who makes decisions.

"Money issues are a particular concern, as he tends to give people his PIN number if asked for bank account details to pay for something. He's left his card in [the supermarket] quite a few times as well…. I'm thinking along the lines of saying that we should just use cash for a while…"

Generally, there was a feeling that information on financial help was hard to come by, many participants finding this information was "seldom volunteered by services". Where such help had been obtained, unpaid carers described it as having a significant positive impact on their day-to-day lives. For example there was one description of a person with dementia being able to attend regular day-care once a particular allowance was received and another where receipt of a personal budget had enabled a much more suitable pattern of homecare than had been offered directly through the local authority.

- Respite Provision -

Whilst unpaid carers spoke of the importance of having some time for themselves, there was little mention of formal respite provision, other than general comments that more is needed.

Some participants mentioned barriers to taking up respite care, including the person with dementia refusing to consider admission to a residential facility, or a laborious process to complete application forms. This level of bureaucracy prompted one comment that spontaneity went out of someone’s life once they become an unpaid carer.

It was unclear how much proactive work was done when a residential facility closed, in order to pick up on people receiving respite care there, and facilitate continuation elsewhere.

- Homecare -

Several unpaid carers spoke of care being shared with paid workers. Whilst most referred to the pleasantness of care staff, some had reservations about skill levels and the way care had been organised.

Drawbacks included unpredictability of visit times and a rapid change between different staff members, offering little of the consistency important to many people with dementia. One unpaid carer spoke of an experience of poor food hygiene practices.

A lack of skill in communicating and relating to a person with dementia was mentioned by two unpaid carers. For one unpaid carer the stress of this far outweighed any potential benefit. A trip to the hairdresser was found preferable, as staff there had known instinctively how to relate well.

For some unpaid carers paid homecare was not an option, as the person with dementia refused such provision. In one instance it had been arranged successfully when the person lived in their own home but after moving to the carer’s home, support from paid workers was no longer accepted.

People funding their own care described particular issues about finding suitable provision. One unpaid carer mentioned being handed a list of providers but without guidance about how to sift through these in order to find something appropriate. It was further commented that if the situation changes and more guidance becomes available, existing unpaid carers would need to be updated on the new situation.

- ***Social care contact -***

The social care department of the local authority was mentioned in several of the discussion sessions. Help had been particularly valued in finding suitable residential care when the need arose and talking through options for funded care with family members.

Something several participants mentioned, however, were experiences of needing to “chase up” contacts in social care and a lack of continuity in the individual worker the family would be dealing with. One unpaid carer commented that all the social workers she had dealt with had been “fine”, but none of them had an ongoing familiarity with her relative, which she regarded as vital to help with understanding.

Where contact with social care staff had lapsed, this could be keenly felt:

“…at family meetings it can be difficult for people to be frank – one reason why the social worker’s initial input had been helpful, as she asked us very apt and probing questions.”

- Family contact -

Contact with wider family was an important theme in the discussion sessions. People with dementia and unpaid carers alike mentioned family and particularly grandchildren as a source of pleasurable company. In some instances their ability was mentioned in communicating with the person with dementia. Provision of moral and practical support was much appreciated and in some instances, holidays could be considered, depending on the needs of the person with dementia.

For some people, family support was less forthcoming. Sometimes other family members can be “in denial” about the person’s condition and feel the main carer must be exaggerating. This had been experienced as particularly isolating for the unpaid carer.

Family dynamics had a bearing on which member might become the main unpaid carer. One unpaid carer wondered whether she would have agreed had the intensity of the caring task been known for that relative, though was unsure what alternative there might have been.

Some families had pooled their resources, either financially or in provision of care, in order to provide a suitable environment or support routine. Family involvement was described by several participants as being particularly important when caring had become more intense and the future needed to be discussed.

- Tensions and risks -

By its nature, becoming an unpaid carer is unplanned. Other life events and commitments must be faced, regardless. Unpaid carers spoke of adjusting to painful bereavements at the same time as becoming a carer, or having to temporarily prioritise the health needs of another family member over the broader needs of a person with dementia.

Where there was a need for constant vigilance about safety, due to potential actions of people with dementia, this was described by unpaid carers as wearing. Some mentioned reluctantly locking a door for safety reasons if they had to leave a cared-for person alone for a short periods. Others acknowledged that they used techniques, for example when lifting someone, that a paid worker might not be permitted to use. Unstated, but always implicit in what was being said, was that unpaid carers tend to offer support for much longer continuous periods than would be considered reasonable for any paid worker.

Little mention was made of any back-up plan for the person with dementia in the event of an unpaid carer being incapacitated or unwell. Where planned medical treatment for the unpaid carer had to be arranged, short-term support for the cared-for person might only be confirmed belatedly.

With day-to-day life of such intensity and unpredictability the good humour and forbearance of unpaid carers in the discussion sessions was striking. The support that many would prefer is a regular, dependable check-in with a known professional – in the few instances where this happened it was highly valued. The level of day-to-day commitment made it hard to take time to initiate contact, or to step back and realise that things were changing and needed to be talked through.

Many unpaid carers spoke of the additional energy required when a situation became unmanageable, to find a service or professional that could help. One participant phrased it in this way:

“.. a lot of energy is being used by unpaid carers to track down what is available, when energies are needed for supporting the person day-to-day. There is no pro-active system to check how people are getting on.”

E – Help at the most difficult times

This topic area(s) prompted particularly intense comment and a range of varied experiences were related.

Some participants, who so far had not experienced a crisis, were unclear who they might contact if that occurred, naming various possible services and teams but without confidence they would be able to help.

Where urgent help was needed, different levels of intensity were described. In one situation of growing complexity a call was made to the social care department, arranging an assessment within 10 days was seen as a helpful outcome.

For other participants, however, the situation had reached a level of such intensity by the time a call was made, that only an immediate response could be in any way adequate.

It should be no surprise that such situations occur where an isolated unpaid carer is the main source of support. As one put it:

“Despite having a background as an articulate professional, once dementia started to present significant challenges….as a family member, it was not possible to remain objective”.

Where help was required urgently, responses could be patchy. There were descriptions of a voicemail message giving a staff return date some distance in the future, or a staff member asking whether the situation could wait a further three weeks. Where the 111 service was contacted there could be an impression that they did not regard themselves as “being there for the carer”.

Generally, there was a view that services lacked awareness of the vulnerability of long-term unpaid carers, one participant summing up their impression of the thinking in this way: *“well, you’re there, so what’s the problem?!”* Again the episodic nature of support from services was felt to be unhelpful to an understanding of processes leading to crisis:

“Often, professionals do not have the familiarity with the person and the situation, so do not get the point about how all the circumstances build up to trigger a crisis.”

Some experiences of crisis involved an urgent move to residential care. This was most often arranged direct with a home that the family happened to have some sort of contact with.

“… as soon as possible we got in touch with [the care home] and begged them to take [our relative] in for residential care. Luckily, they were able to do so, and a very difficult process started to persuade [our relative] that this would need to happen.”

This raises the question of what might happen where families have no existing link, or where the person is not able to meet the full cost of care. In some instances, descriptions of crisis figured a trip to the local Emergency Department for a physical problem – sometimes with the person never returning home. No-one in the discussion sessions mentioned an admission to specialist in-patient dementia care services.

F – Residential care

As mentioned earlier in this report, unpaid carers often face dilemmas in supporting a person with dementia. Possibly the biggest of these is to balance feared adverse effects of a person entering residential care, with the impact on the carer when symptoms become sustained or complex.

There were many references to the lengths pursued to avoid admission to residential or nursing care and the difficult conversations that took place with a person with dementia once there was no other option.

The success or otherwise of such a move was felt to depend on the suitability of the home to the particular needs of the person and crucially to the skills of staff. Sometimes things could work out better than anticipated:

“In fact it turned out really well, and she loved it – as there was always activity and things of interest happening. In fact, I wished it had happened much earlier, and perhaps our relationship would not have deteriorated as much as it did. The staff had the skill to gently coax her into things.”

Some care homes specialised in supporting people at a particular stage of dementia, sometimes with a specific suitable design, along with staff skilled in supporting people showing associated symptoms or behaviour.

Factors that led to a less good experience included over-rigid routines and lack of safety for personal possessions. Poor staff skills in communication or assisting people with dementia were also felt to be unhelpful.

It is understood that local care homes are working together to improve leadership and spread existing good practice more widely.

Part of Healthwatch Isle of Wight's engagement involved holding three discussion sessions in care homes, with people living with dementia. These are described later in this report (pages 29 & 30).

G – Care in hospital

The experiences described in the discussion groups covered a period of several years, so it is not known how much these reflect current practice. As mentioned on page 8, two Acute Dementia Lead Nurses have been appointed at St Mary's Hospital to increase training for staff supporting people with dementia. A carers' lounge has also been set up and run by Carers Isle of Wight, where there are increased opportunities for unpaid carers to visit or stay with the person with dementia.

It should be noted that no participants talked about experiences of admission to specialist dementia in-patient care; therefore no commentary about this form of hospital care has been included.

- Admission -

Arrival at hospital for unplanned care entails being directed initially to the Emergency Department. There were descriptions of varying length of time before transfer to a ward. During this time unpaid carers described the same questions being asked repeatedly and of questions being framed in a way that would not be meaningful for a person with dementia.

Arrival unexpectedly meant unpaid carers not being prepared for a possible admission and, for example, needing to return home briefly for nightclothes, thus leaving the person without a familiar person nearby. One unpaid carer described the troubling experience of finding a relative being forcibly undressed, when the carer returned to the hospital from an unavoidable brief absence. A lack of clarity was also described about the arrangements for medications prescribed elsewhere to be administered to a person with dementia awaiting admission.

Screening for dementia is a standard part of hospital admission for people above a particular age. Past experiences of unpaid carers have not always been positive. One carer described a relative simply being asked if they had Alzheimers - a question not designed to receive a reliable response from somebody with dementia. Another carer spoke of a lack of staff curiosity regarding the possibility of dementia when a relative had been unable to give their own date of birth at admission.

- Supervision and care -

Participants welcomed the adoption of the “butterfly” symbol, used to indicate to staff which patients have dementia and will therefore need to be supported in specific ways.

Past experiences included poor support with nutrition, insufficient help with the choice of suitable menu options and meals being placed out of reach of the patient. There were descriptions of prominent instructions about seating positions not being followed and of poor management and administration of medication.

Whilst a start has been made to making the hospital environment better tailored to meet the needs of people with dementia, past experiences included a patient being acutely troubled by an artwork visible through a window, due to perception difficulties. Another unpaid carer expressed alarm at learning of a recent incident of a person with dementia leaving a ward, then the hospital premises in nightclothes, having had a similar experience with a relative some time ago.

Several unpaid carers spoke of feeling the need to be in almost constant attendance whilst the person with dementia was in hospital, to guard against untoward experiences. Whilst increased opportunities to be close by were welcomed, there was some wariness of an assumption that good care could not be provided unless an unpaid carer was present. Experiences were also mentioned of times that an unpaid carer was unable to be at the hospital, due to their own health needs, or to other caring commitments.

- Assessment and planning -

An experience shared by a number of unpaid carers was a lack of opportunity to discuss the progress of care, or to be involved in planning what would happen next.

Sometimes it seemed there was no chance to discuss care as staff appeared continually busy with other tasks. There was one description of an unpaid carer being told repeatedly that an assessment had yet to be done, later discovering that an assessment had been carried out hurriedly without any family input.

Other experiences included one of poor co-ordination between staff, for example of one professional trying to find a residential placement for a patient, despite a colleague of the same discipline being fully aware of plans already put in place by the family.

- Leaving hospital -

As the time of discharge approached, delays could be encountered whilst arrangements for necessary equipment were put in place. This had been particularly distressing for some people with dementia. There were also descriptions of a reluctance for unpaid carers to be given information.

Sometimes discharges had happened abruptly. There was one account of hospital staff being rather assertive in insisting the patient would have to be discharged, despite the friends with whom the patient had previously been living, stating clearly that they were no longer in a position to act as unpaid carers.

H – End of life and afterwards

A theme in the background of many of the structured conversations was the inability to see into the future, to predict how long it might take for the person's condition to progress, or how long they would continue to be alive. More than one participant spoke of preferring not to think too much about the future, whilst there were a small number of more candid comments, sometimes in the context of a stressful home situation:

"A friend of mine has a [relative] who is 100 years old, and admits to saying sometimes to herself '…so when WILL you die?' – and I know exactly how she feels. …. I love [my own relative] dearly, but there are times when I can't stand her!"

There were no descriptions of a person with dementia receiving end-of-life care in their own home, however there were several positive accounts of this happening in residential care. Where care had already been of a high quality, providing an environment for "a good death" seemed a natural extension of that, with appropriate support from health agencies.

One participant mentioned the sadness of not being able to be with a relative in hospital at the end of their life due to other caring commitments. Staff had not noticed the death at the point it occurred, due to the overall level of activity on the ward at the time.

There were two references to medical staff making an assumption that there should be no attempt at resuscitation if the person stopped breathing. There was a strong feeling that families should be involved in any discussion of how such circumstances would be handled.

After caring responsibilities ceased, there were descriptions of a long period of adjustment following. Some participants spoke of feeling lost or isolated at first and appreciated continued contact with carer organisations and dementia support groups. These descriptions are testament to the strong feeling of community amongst those on the Isle of Wight living with, or affected by dementia.

PART 2 – Discussions with people in care homes

Three structured discussion sessions were held in local residential and nursing homes at the invitation of the manager of each home. A Healthwatch staff member visited each of the three homes beforehand to meet people who staff at the home felt might wish to attend. Some did choose to attend; others preferred not to. People varied in the stage of dementia they had reached but all were able to understand and give consent.

- Themes -

People talked about the importance of where they had originally come from, childhood memories and things they had done as part of their families, or to help their families. Some people talked about places they had lived in the past and the different kinds of work they had done.

Interests and pastimes came into the conversations very strongly – memories, as well as activities that are still continuing. People had wide variety of interests and experiences of socialising, often individual to themselves and not shared with others in their care home. Some people talked about sadness of not being able to continue with certain pastimes. Opportunities to go out were important to several people - some went out quite often; others would welcome additional opportunities to go out.

Several people said keeping in touch with family is important to them. People did this in different ways: for some people ready access to a telephone helped, with others new technology was useful for keeping in touch. There was mention of patchy bus services making it harder for some relatives to visit a family member.

People mentioned things they liked about the care home they lived in, including the kindness of staff, the atmosphere and appearance of care home buildings and flexibility to meet their needs. Having choices, particularly about eating and listening to music, were especially valued.

Varying levels of communication skills amongst staff were also mentioned.

Some people talked about experiences of receiving care in their own home, either from relatives or paid workers, and the circumstances of moving to a care home. Some people had been in hospital and talked about what had happened to them whilst there, as well as after leaving.

It was important to people that they had regular checks on eyesight and hearing, as well as support with dental care. Being able to see a doctor was also mentioned, especially when there were particular concerns about health.

- Future Engagement -

The three discussion groups yielded important insights into the thoughts and preferences of people with dementia living in the residential settings that hosted the groups. Thorough preparation and good communication was crucial to the groups' success.

As people at different stages of dementia took part, participants' communication varied quite widely. Whilst some were fluent, others were hesitant or repeated things a number of times. It was important to accommodate this range of communication styles and to be aware that not all comments need be taken literally.

The main learning point for Healthwatch Isle of Wight was to understand more about how individuals with dementia can be included when engaging with people in care homes. It is hoped this can be developed in future work done by Healthwatch Isle of Wight.

6. Conclusions

This engagement included people living with dementia and unpaid carers. The majority of participants were unpaid carers.

People with dementia spoke of positive engagement with families and with their local communities. More could be done, however, in hearing the direct voice of people with dementia and acting on what is being said.

Experiences of being diagnosed with dementia did not raise many concerns, though several people felt that support following diagnosis needs major improvement. It was felt that information could be provided in a more tailored and co-ordinated way, with support offered more pro-actively.

Unpaid carers described the intensity of their experience and being too absorbed by daily tasks to pro-actively ask for help. Navigating the care system was felt to be challenging, even to people with good levels of involvement with local dementia groups.

Currently, people tended not to be aware of a specific named person they could call on for help with navigation, or who would check on how they were faring. Initiatives for community support are often generic in nature, and workers often have clearly-delineated roles, making it more of a challenge to locate suitable help. Local information websites may contain useful information but again, these are only part of the picture.

Dementia support groups were highly valued by those attending them, with a choice between groups of a different character and purpose being important. Depending on the purpose of the group, people found them most helpful for maintaining mental dexterity, continuing activities and for information and signposting. It was also important for many to be included in mainstream community activity. There is potential for extending the range of groups, using the experience of local people to guide and be involved in setting these up.

The intensity of the caring role was a recurring theme; some participants described this intensifying to a point of crisis. Support in recognising risks of crisis in advance would be very much welcomed, as well as access to prompt support at the point of crisis.

Past experience of in-patient hospital care had often been far from ideal. These involved people with dementia who had a physical illness, sometimes at the end of their lives. Whilst positive developments in hospital care are to be welcomed, descriptions of previous experiences are included in this report, to help ensure a continued vigilance against unhelpful approaches.

Descriptions of residential and nursing homes were quite mixed; a number of people described an initial poor experience, then later being pleased to discover an excellent standard of care elsewhere. End of life care was praised in these latter settings

7. Recommendations

1. A better co-ordinated and proactive approach to post-diagnostic support should be developed across agency boundaries. This would involve a clearly-identified, consistent contact person for each person with dementia and unpaid carer.

2. A more systematic approach to care planning should be adopted, based on existing models of good practice such as Alzheimer Scotland's "8 Pillars of Community Support"[7].

3. Care planning needs to include an individualised approach to minimising risks of crisis, along with a clear, immediate route for communication in the event of a crisis occurring.

4. The diversity and number of dementia support groups and dementia activity groups needs to be promoted, expanded and facilitated through a new development worker post, independent of any existing provider of such groups.

5. An initiative is needed specifically to facilitate people with dementia in coming together to discuss their own experiences and promoting their voice to be listened to in the planning of facilities and support. Models of good practice should be utilised, for example through the U.K. Network of Dementia Voices (DEEP)[8].

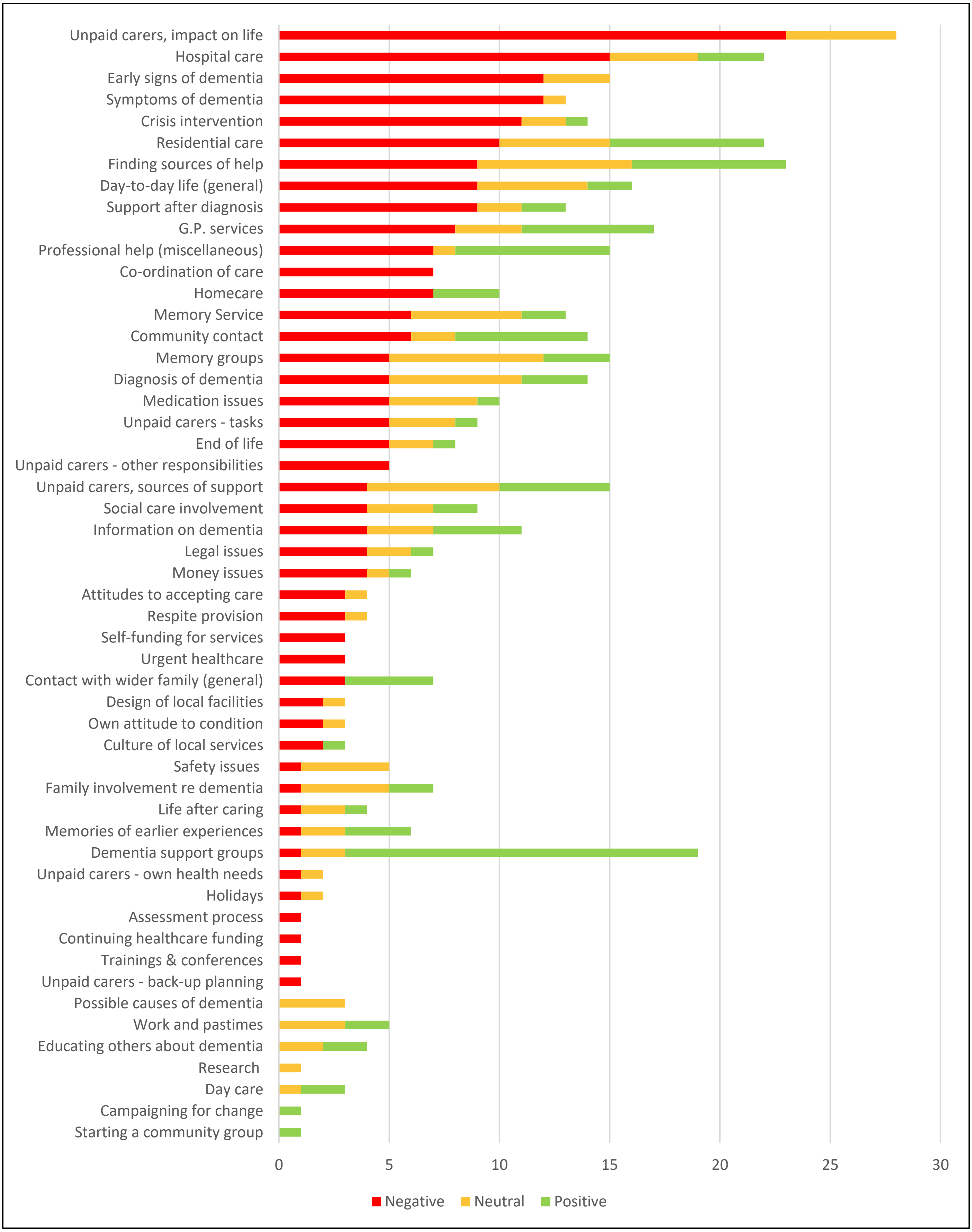
6. A systematic approach is needed to gather feedback on current experiences of people with dementia and unpaid carers in hospital. The intention would be to gauge the level of progress in improving experience and to pin-point areas where further improvements may be needed.

8. References

1. *“What is Dementia?”:* Alzheimer Society website, 2018
2. *“Dementia”:* NHS England website, 2018
3. *“Living Well With Dementia – A national strategy”:* Department of Health, February 2009
4. *“Prime Ministers Challenge on Dementia 2020”:* Department of Health, February 2015
5. *Public Health Profiles, 2017-18:* Public Health England website, 2018
6. *“Living With Dementia on the Isle of Wight 2014-2019 – A partnership approach to the development of services on the Isle of Wight for people living with dementia”:* Isle of Wight Clinical Commissioning group, Isle of Wight NHS Trust, the Isle of Wight Council and Partners, 2014
7. *“Delivering Integrated Dementia Care - The 8 Pillars Model of Community Support”:* Alzheimer Scotland, September 2012
8. *“What is DEEP?”:* The UK Network of Dementia Voices website, 2018

9. Appendices

Appendix 1 – Overall list of themes from discussion sessions



Appendix 2 – Information for people taking part in discussion sessions

healthwatch
Isle of Wight

Participant Information Sheet

Discussion Groups 2017-18: Experience of Dementia Care

Who are these discussion groups for?
These discussion groups aim to learn more about people's experience of dementia care. The groups in late 2017 are for people who have a diagnosis of dementia and unpaid carers. In early 2018 there will also be several discussion groups purely for unpaid carers. We will be talking to service providers and paid workers separately and not in the discussion groups.

How long will the discussion groups take?
About 2 hours, with a short break half-way through. Light refreshments will be provided. We aim to make the atmosphere friendly and informal, but there will be a clear structure to make sure that the main areas of dementia care are covered.

How will the discussions be recorded?
An audio recording will be made of each discussion. This is to make sure no-one's comments are forgotten when notes of the discussions are written down afterwards. As soon as complete notes of the session have been made, the audio recording will be deleted. No names will be included in the written notes of the discussions, but we will ask you to sign a slip of paper to show you have understood the purpose of the discussion, and agreed to take part.

What will be done with the comments people make?
All the comments will be considered, and the main themes will be identified that were raised in the discussion groups. A report will then be written highlighting what people value most about dementia care, and what the main things are that they feel need to be improved. The report will be made public so that everyone can read it, including people who provide services.

Can I be identified from my answers?
No, we will not record the names of anyone taking part. We might use short quotations from what you say, but would not include anything identifying you or anyone else mentioned.

Who is carrying out the survey?
These discussion groups are being run by Healthwatch Isle of Wight, the independent consumer champion for health and social care on the Island. We provide local people with the chance to say what they think about local health and social care services, so that good services can be recognised, and to help make improvements where these are needed.

How can I contact you or find out more?
The person you need to contact is Chris Gale, the Research Officer for Healthwatch Isle of Wight. You can phone the Healthwatch on 01983 608608. Alternatively, you can email chris.gale@healthwatchisleofwight.co.uk or write to us at Healthwatch Isle of Wight Freepost RTGR-BKRU-KUEL The Riverside Centre, The Quay, Newport, Isle of Wight PO30 2Q

Thank you for your interest

Appendix 3 – Structure to prompt discussion in discussion sessions

Topic Guide

Discussion Groups 2017-18: Experience of Dementia Care

Informal greetings, refreshments, information sheets, and sign consent forms

Welcome and Explanation

This **discussion group** is being run by Healthwatch Isle of Wight. I am a member of staff at Healthwatch – we also have two Healthwatch volunteers who will introduce themselves now.

Healthwatch I.W. is an organisation that looks out for the interests of people using NHS services or any kind of care service. The Isle of Wight public chooses the topics we look at, and this year one of the topics is dementia care. We would like to learn more about your experiences so that we can highlight what is working well, and point out the things that need to be improved.

You will be guided through various different **subjects** during the discussion, as we want to make sure we hear about all the main parts of dementia care. If we move away from the subject at hand I may suggest we wait till later to talk about other issues raised. At the end there will be an opportunity for everyone to mention any important matters that have been missed out.

If anyone becomes uncomfortable about staying within the group, and would prefer to talk to someone more **privately**, our volunteers are at hand to listen to you individually.

We would like to hear from everyone who would like to say something, so would ask that **one person** speaks at a time.

We want to hear different experiences and views – we don't expect everyone to agree the whole time, but would ask that everyone treat each other with **respect**.

You are asked **not to repeat** what was said this afternoon to people who did not attend, or to tell other people about who was here, unless the person concerned has said they don't mind

We will be making an **audio recording** of the discussion. It is purely to help us remember everything that was said, and will be deleted once notes have been made of the discussion. Nobody's name will be written down in the notes that are made.

There will be a short **break** of a few minutes at around 3.00 p.m.

Are there any **questions** about what will be happening this afternoon?

START RECORDING MACHINE

Introductions

Could we go around the group, with everyone saying their first name, and one thing they enjoy about where they live.

Finding out about having dementia

If you think back to first realising things were changing, how was it, finding out about a diagnosis? How long did the process take?

Support and Information following diagnosis

What happened after you heard the news about having dementia to help explain about the condition and any support available?

Day-to-day living

Do you have anything to say about living life day-to-day? Is there anything in particular that has been helpful, or any additional help that would be useful?

Contacts with the local community

What is your experience of getting around and using facilities in the community? Is there anything in particular that has been positive, or could be done better?

Continuing support from services

Have you needed continuing advice or support from services, and what has your experience been of finding and receiving this?

Help at difficult times

If there have been times when things have become especially difficult, how has it been to find help when needed?

Any experience of care services at home

Any experience of residential care

Any experience of being in hospital

Looking to the future

Thinking of the future, is there anything in particular that you would hope for, or are apprehensive about?

Is there anything else anyone would like to say?

Closing the session

It’s time to move towards the end of the discussion. Could everyone name one thing they enjoy in life these days, or something they really look forward to.

SWITCH OFF RECORDING MACHINE

What happens next?

After all the discussion groups have happened, a report will be written by Healthwatch to highlight the things people value about dementia care, and making recommendations about what needs to change.

There will be information in the local press when the report is published, you can call 01983 608608 if you would like a copy. It will also be available via our website. Alternatively if you wish to leave your address or e-mail we can send you updates direct. We will only use your contact details for this purpose, unless you request any other information.