

IW Dementia Strategy Co-production Survey Results

Date 20/12/19

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1) Acknowledgements

Age UK Isle of Wight, Alzheimer Café IOW, Carers IW and Healthwatch Isle of Wight are working in collaboration with the IW Council, NHS Trust and IW Clinical Commissioning Group to develop a strategy for dementia care for the Isle of Wight.

The partner organisations would like to thank everyone who contributed to the success of this piece of co-production work. Particularly the people with lived experience of dementia, their family, friends and carers who completed the online survey and the people who shared their experiences and views through the focus groups held by Carers IW and the Alzheimer Café. The partners would also like to thank the volunteers from the partner organisations who gave their time to support this piece of work.

2) Executive Summary

It is important to recognise the life changing impact of dementia on both the affected person and their family. Dementia will affect a person's day to day life and will require the person, their family and carers to adapt how they do things in order to maintain a sense of normality for as long as possible. Many people will struggle to cope with the emotional losses attached to loss of independence, and their ability to communicate and make decisions and will be frightened about the future.

Dementia prevalence on the Isle of Wight is high and expected to increase with a predicted increase of 24% in the population of over 85 year olds in the next 10 years. Dementia is a condition that has a significant impact on services delivered by health, social care and the community and voluntary sector as evidenced by the IW Dementia Stocktake undertaken as part of the development work undertaken for this strategy. The impact can be particularly seen in secondary care at the IW NHS Trust where a high proportion of patients across the hospital at any one time have a diagnosis of dementia.

To support the development of the Isle of Wight Dementia Strategy a survey was developed which invited Island residents to tell us about their experiences of dementia care on the Island including the initial diagnosis, provision of information and advice and support within the community. The survey also asked people with dementia, their family and carers to tell us how services and support could be changed or improved to better meet their needs.

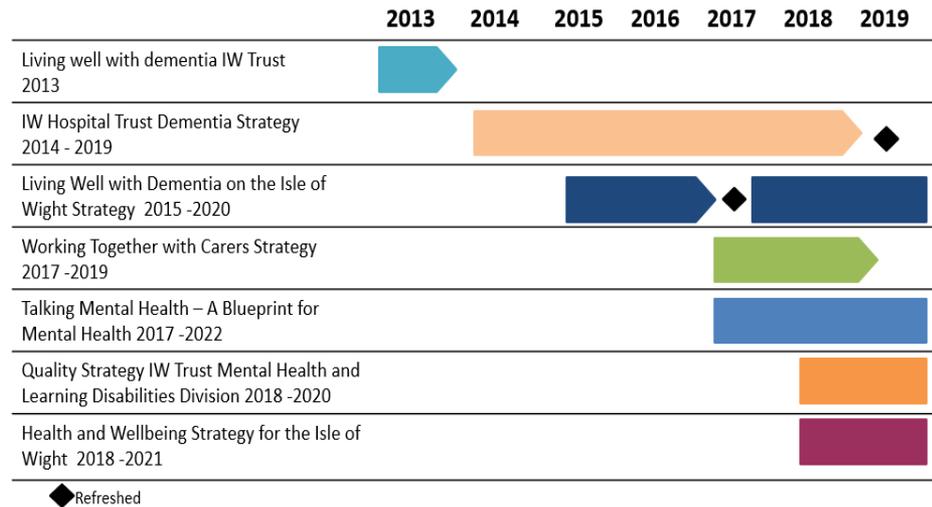
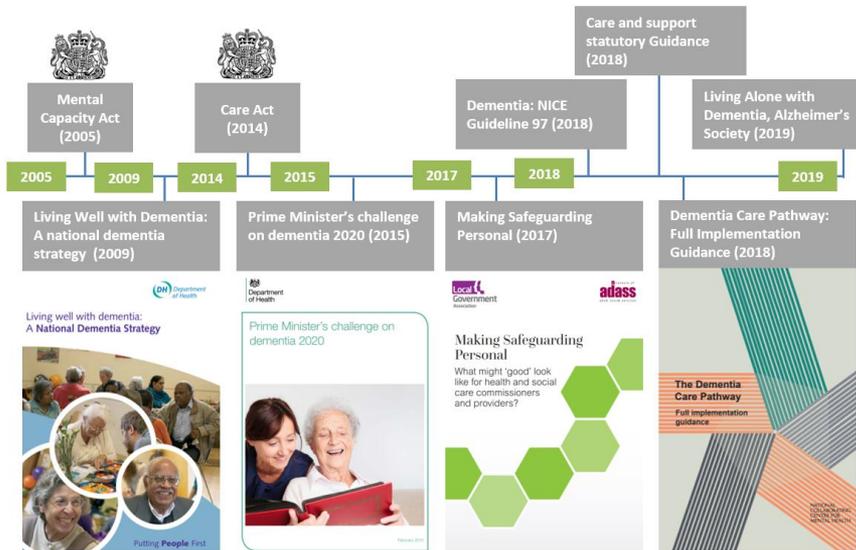
To ensure that we heard the views of as many people as possible we undertook a programme of public consultation and engagement, which included talking to local organisations that support people with dementia and holding public events across the Island where people were able to drop in and speak to us face to face. Focus groups were also held with carers and people who regularly attend the various Alzheimer Cafes, these forums gave people the opportunity to speak openly about their experiences.

Executive Summary cont.

Feedback from these consultations highlighted the following:

- A need for greater recognition from GPs of the impact of memory loss and the positive impact of early diagnosis.
- Following diagnosis people are feeling abandoned and are seeking co-ordinated support and information at this time to enable them to deal with the diagnosis and life following this diagnosis.
- The current support, information and services provided by local voluntary and community sector organisations are universally valued, and often seen as a lifeline by families.
- Families and other unpaid carers are overwhelmed by the intense nature of their caring role and need respite and day care services which would enable them to take a break from their caring role and allow them to focus on their own wellbeing.
- Communication between and from health and social care agencies needs to be improved, to ensure that support is person centred and family and carers, who know the person best, are not excluded.
- Many people have expressed the need for a central hub for information, advice and services and ideally a named point of contact to support them as the condition progresses and at times of crisis.
- There is a need for improved dementia awareness and training across all areas of health and social care, including primary care, acute health services, adult social care, residential care, nursing care and domiciliary care services.
- There are many examples of supportive local communities including local shops, pubs and public transport, but people identified a need for greater public awareness and acceptance.
- The findings from this consultation mirror many of the conclusions and recommendations of the Healthwatch Isle of Wight report “Living with Dementia” published by in December 2018.

3) Background



There have been a number of the key national policy, guidance and legislation documents produced over the past 10 years relating to the provision of health and social care support for people with dementia.

Locally, over recent years Island partners including health, the local authority, voluntary, community and the independent sectors have contributed to the development of a number of strategies which have been specific to dementia or have impacted on people living with dementia and their carers. Unfortunately implementation of many of these strategies has been limited and little has changed for the people that they sought to support.

Background cont.

In May 2019 it was agreed that a system wide approach was needed to better support people on the Isle of Wight living with dementia. The aim of this work is to improve the experience for people from pre-diagnosis through to end of life. It was agreed that the development of this system wide strategy should be led by partners from the voluntary and community sector who already support people living with dementia and their carers to ensure that the voice of these people is central to the development of this strategy.

This piece of work follows the “Living with Dementia” report published by Healthwatch Isle of Wight in December 2018, which included feedback from unpaid carers and people living with dementia in both the community and residential care. (Appendix A)

4) Co-production Survey

A copy of the survey can be seen in appendix A of this document

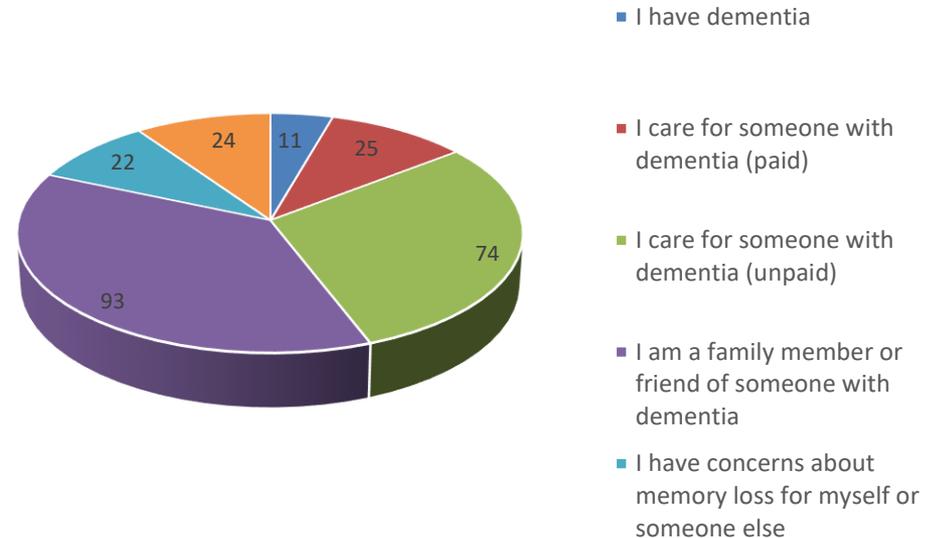
We received a total of 180 survey responses. This number includes surveys completed through an online survey hosted by Age UK Isle of Wight and paper copies which were completed and returned by members of the public. Paper copies of the survey were distributed at a number of public events across the Island and were also available from Age UK IW, Carers IW and the Alzheimer Cafés. The survey was promoted through various social media channels including Age UK, the Isle of Wight Council and the IW NHS Trust

Co-production Survey cont.

Question: How would you describe yourself?

178 respondents answered this question. Many people identified themselves as the carer for someone with dementia and also as a friend or family member, we therefore have a total of 249 responses.

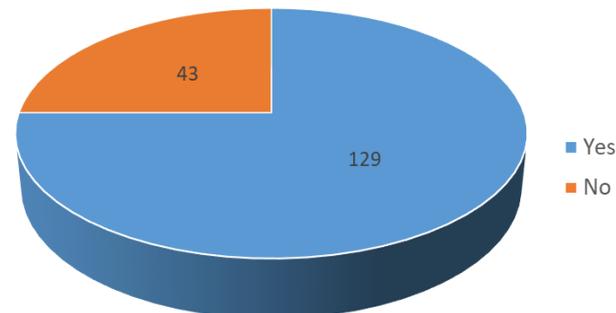
The responses who chose the option of "Other" indicated that they were professionals working with people with dementia including social workers and people who have a general interest in dementia.



Question: Have you or someone you care for received a diagnosis of dementia?

172 respondents answered this question.

75% of these people had either received a diagnosis of dementia themselves or care for someone who has received this diagnosis

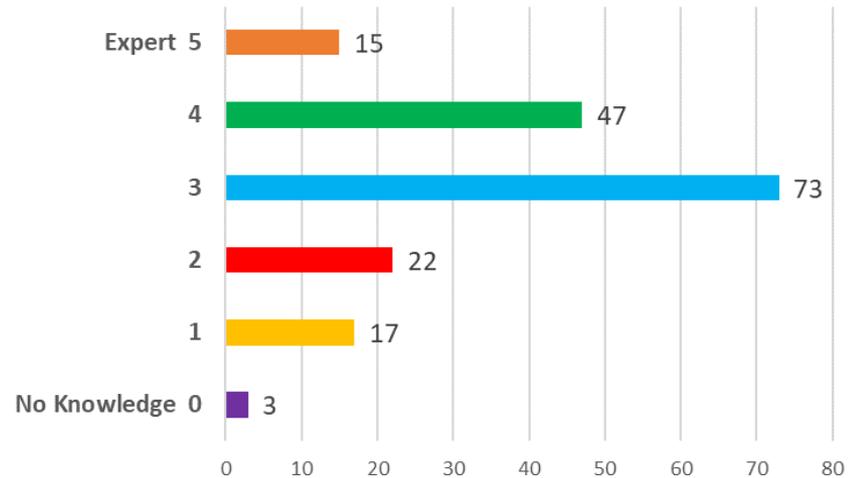


Co-production Survey cont.

Question: How confident are you in your knowledge about dementia?

177 people provided a response to this question.

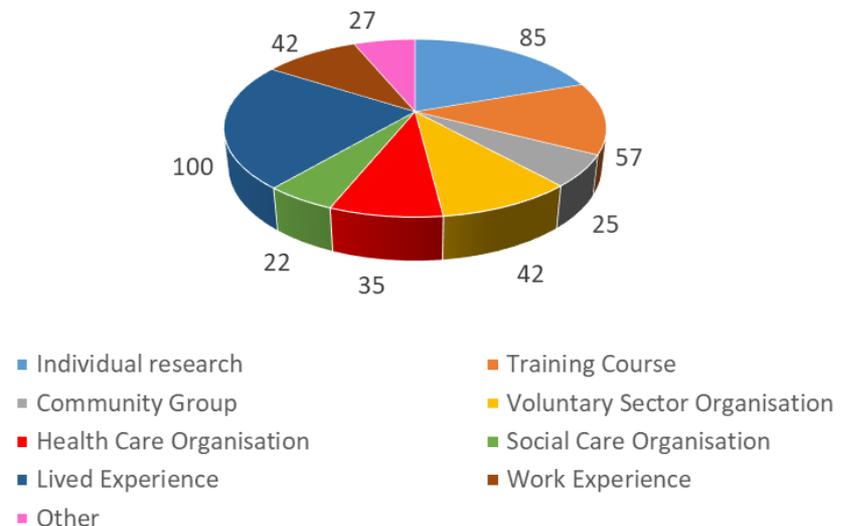
People indicated that they had varying levels of knowledge about dementia. 23% of respondents felt that they had limited or no knowledge about the condition.



Question: Where did you get your knowledge from?

Respondents were able to choose more than one option for this question and many people had received information and knowledge from a variety of sources.

Most people indicated that they had gained their knowledge through lived experience or individual research. Other popular sources were the voluntary sector and knowledge gained from training courses.



Co-production Survey cont.

We asked a number of questions relating to how long it took people to seek the help that they needed following their initial concerns about memory loss:

How long to arrange a meeting with professionals to discuss your concerns?

112 responses received.
62% of these people sought this initial help and advice within 1 year.
21% of these people waited more than 2 years before speaking to a professional.
Most people sought this initial advice from their GP (70%) with others choosing to discuss their concerns with family, the voluntary sector or hospital services

How long did it take to get a diagnosis of dementia?

106 responses received.
70% of these people received their diagnosis in 1 year or less.
10% of these people waited more than 3 years to receive a dementia diagnosis.

How long did it take to get support following your diagnosis?

90 responses received.
67% of these people received support within 1 year of their diagnosis.
11% of these people waited more than 3 years before getting support.

People said

"My Step-Dad went to see his GP about his concerns several years before his diagnosis and was told it was nothing to worry about"

"Because the GP would not refer him, I was so alone for over a year, struggling with the fact my husband had an illness but I had nothing but worries and no one to share it with, I felt so so alone"

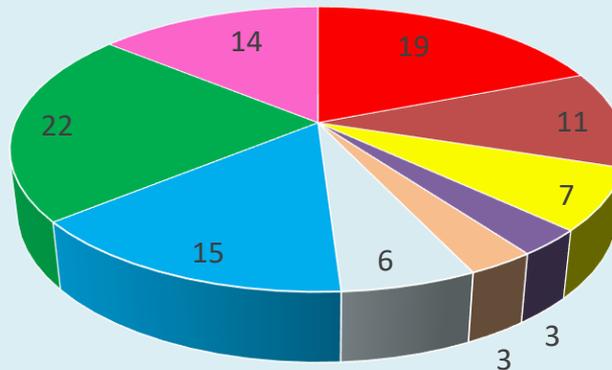
"Each department has a different method or system. Disconnected communication between professionals is awful. As a carer I have wasted many hours/days trying to fill that gap as my husband cannot speak for himself"

Co-production Survey cont.

Question: Could anything have been improved about the way the diagnosis was given?

71 people responded to this question to indicate that something could be improved, this is 40% of the total survey responses.

People often indicated that more than one area that could be improved, but the responses fell into 9 key themes:



- Time taken to diagnosis
- Better GP knowledge
- Less stigma/negativity
- More information/signposting to support
- More support for family/carers
- Manner/approach of doctors
- Provision of a named worker
- Clearer information/less jargon
- More support for patient

People said

"No constructive help was given at the point of diagnosis, I didn't know what to do next and I remember crying and feeling helpless"

"When we got the diagnosis I felt like I was put in a boat without any oars"

"I was told to put my life in order and I felt like I was going to die that night."

"It could have been improved if the person carrying out the diagnosis had displayed greater sympathy and had greater empathy. My wife was left feeling frightened after the occasion."

Co-production Survey cont.

Question: Have you or the person with dementia that you care for received support or advice from any of the following places, and how would you rate this service?

As can be seen from the results below, people reported to have had both positive and negative experiences across all areas of dementia support services.

Adult Social Care and Admiral Nurses received the poorest satisfaction scores. People indicated that the services that they currently valued most are those being delivered by voluntary sector organisations such as Carers IW, Alzheimer Cafés and Age UK IW and support provided by local community groups.

People stated that they found it very hard to find the information and support that they needed. Provision of information from professionals appears to be inconsistent and patchy, with people often relying on word of mouth to find the help and support that they need.

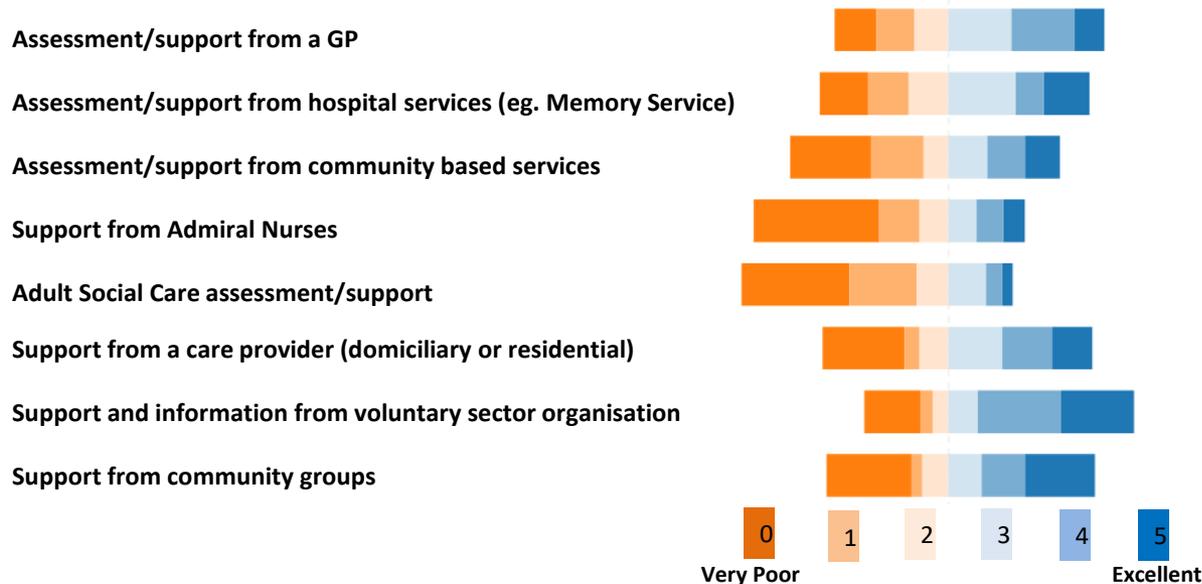
People said

"Our main support and information has been provided through the Alzheimer Cafes"

"At a time of crisis NHS support was exemplary, but the rest of the time it felt minimal and inaccessible. Voluntary and third sector support was really responsive, especially the Alzheimer café"

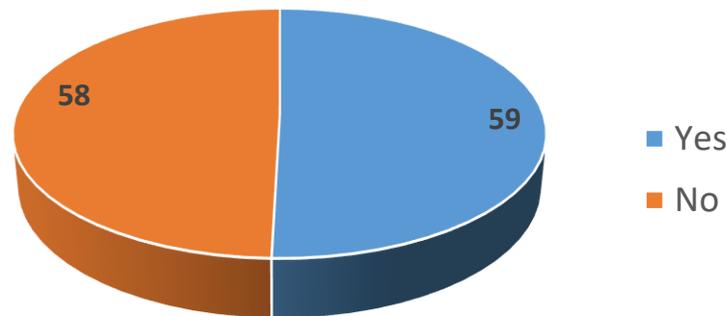
"We are fortunate that we have good family support. I feel we would be in real trouble if my husband was reliant on community services to ensure he receives necessary support and assistance to remain well and functioning on a day to day basis"

"Carers IW and Alzheimer café helped me so much. No one else cared"



Co-production Survey cont.

Question: Do you as a person with dementia or a carer feel that you can still take part in the things that are important to you?



117 respondents answered this question. 91% of these responses were from family, friends or unpaid carers and 9% from people with dementia. There was a very even split between the number of people who indicated that they felt able to enjoy the things that were important to them and those who did not. This result was surprising and did not correlate with the additional comments that were made.

Many people who answered “Yes” also told us that this would not be possible without the support from family and paid carers that currently exists. Others who responded positively to this question were no longer in a caring role as the person with dementia had moved to residential care or sadly passed away.

The people who answered “No” provided a graphic insight into how their lives had become smaller and hugely restricted either from receiving a diagnosis of dementia themselves or from needing to care for someone with dementia. Carers told us about the relentless nature of their caring role and the difficulty of finding suitably flexible respite options which would enable them to have a break or take care of their own needs whilst feeling secure in the knowledge that the right support was in place.

People said

“I am for the most part trapped in the house. I cannot leave mum who has dementia alone as she cannot do anything for herself and is scared and anxious ”

“My whole life is now caring for my husband, I cannot visit family and rarely meet friends. I can no longer contribute to voluntary work and take part in keep fit etc. There is no financial help.”

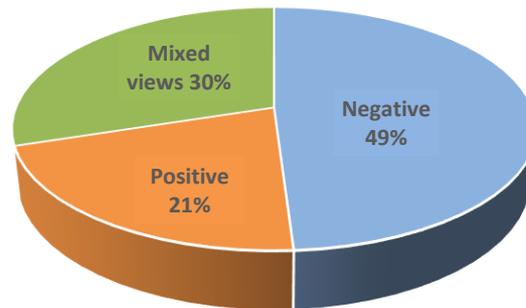
“Our lives have shrunk and even just simple task like shopping are so difficult ”

“My sister has had to reduce her working days in order to care for our mum. She cooks cleans and shops for mum as those services are just not available to us. We dread hospital appointments as it is so stressful to sit and watch mum be bombarded with questions that she cannot answer.”

Co-production Survey cont.

Question: What is your experience of people with dementia being supported in their community?

120 people provided a response to this question with a mixture of positive and negative experiences being shared.



Positive themes:

- Some experience of supportive local communities including local shops
- Positive experiences of public transport including local buses
- Family networks providing care
- Admiral Nurses are valued but support is short lived
- Alzheimer Cafes valued for support, advice and education
- Carers IW
- Age UK Isle of Wight

Negative themes:

- Feel abandoned and left struggle on alone
- Poor follow up from health teams
- Difficult to get support from social care services
- Little support from GPs
- Carers often young and inexperienced in dementia care
- Respite is valued but hard to find and inflexible
- Information is hard to find
- Transport options and costs are limiting
- Friends often fall away

People said

"It feels like you are very alone, admiral nurses closed us, but luckily Carers and Age UK help us"

"Difficulty around transport to get to groups or activities, making it impossible for some people to take part in these"

"Alzheimer cafe really helped us in early days, then we met Lizzie from Carers and we see someone every 6 weeks. I am not sure what I would have done without them"

"Local shops and bus drivers have been very helpful"

"The Island is generally a kind and supportive place"

Co-production Survey cont.

Question: What would enable or support people with dementia to live a full and active life?

150 people provided a response to this question, with a number of common themes arising from these responses:

- More support for carers including flexible respite options and day care services which would enable the carer to get a break from their caring role
- Provision of a point of contact who knows and understands the person's individual circumstances and case history, and who is able to provide advice and support when things deteriorate or at times of crisis
- Better dementia awareness training for GPs and all other health and care professionals
- Better trained and experienced domiciliary care provision, offering continuity of care for individuals whenever possible
- More practical support and help in the early stages post diagnosis, not just when things deteriorate or there is a crisis
- Provision of a variety of activities linked to people's previous interests, supporting people to feel useful, retain some normality and remain as active as possible
- Access to free, accessible transport options to enable people to engage in social activities and groups where they feel safe and supported
- Better public awareness about the condition of dementia to break down the taboos
- A central hub for dementia information, advice, help with benefits, activities and support which can be contacted 7 days a week and out of hours at times of crisis
- Public areas which provide better lighting and quiet spaces to support people to remain calm and not feel overwhelmed

People said

"Regular support and contact from those with the knowledge of what is likely to happen next"

"More resources to support people with dementia in the community and provide respite for their carers when it is needed and BEFORE a crisis is reached"

"A hub where we can go when we want support, information, activity sessions, company, stimulation, friendship"

A better understanding of the disease by ALL professionals and care givers.

Having access to advice and support during evening / night time and weekends

Being able to access information and help from one central point. My father is self funding and living on his own; I live on the mainland

More understanding from society. More places being dementia friendly

Focus Groups

Alzheimer Café Focus Groups

Alzheimer Cafés incorporated a short focus group within 5 of their regular sessions across the Island including the ACE7 group attended by people with early-onset dementia. The discussions included people with dementia and their family and carers. People highlighted the following concerns about the current system and priorities for the future:

- People are concerned about delays in diagnosis and a reluctance by some GPs to refer to the Memory Service
- People spoke about the importance of delivering any diagnosis with compassion and face to face
- People are feeling abandoned and alone following diagnosis and are struggling to find information and advice about local sources of support
- People would really value an allocated professional to be their point of contact and support them through the dementia journey
- People want a central dementia hub where they can access information, advice and activity groups
- People really value the help and support that they receive from voluntary and community sector organisations
- People are frustrated by the poor communication between health and social care services and feel that the onus has to be on them to make sure that this is done accurately
- Family and carers want to make sure that they are included in important discussions and reviews to ensure that professionals have the full picture of needs
- People really value the pockets of acceptance and support that they have experienced in the wider community including public transport and local shops etc.

Carers Focus Group

Carers IW facilitated a focus group with carers including those who care for someone with dementia. Themes matched the ones expressed in the Alzheimer Café sessions, but also focussed on the following:

- A need for flexible respite options which can provide carers with regular breaks from their caring role
- Family feel that it is unfair that the care provided for this health condition is often subject to charges
- Carers would value longer term support from Admiral Nurses
- Carers expressed real concern that they are often excluded from reviews and important correspondence
- People are frustrated at needing to find sources of support through their own research or via word of mouth
- Family carers are concerned that agency staff do not have enough time to work effectively with people with dementia

People said

"I need a single, seamless support network. There is far too much repetition of details required to access statutory services"

"Early dementia connectors linked to the person at the point of diagnosis keeping in contact throughout the person dementia journey, either directly or indirectly with the person and or their family being able to provide advice, information, signposting if needed. This should be available at the point of diagnosis"

"As a carer I feel so tired"

"I want to meet with other people in supportive groups so that I feel safe and also feel part of society"

Conclusions

The survey was able to gather the views from a variety of people including those who have a diagnosis of dementia, family members and paid and unpaid carers. A mix of methods were used to engage with people including a survey which was available online and also widely distributed in paper format. We ran a series of focus groups which enabled people to have a less structured conversation about their experiences, these focus groups were held within established support groups that are regularly attended by people directly affected by dementia.

When talking about experiences of diagnosis people told us about their frustration when GPs had delayed this process by not recognising memory issues as being linked to dementia. Many people felt that professionals delivering a diagnosis need to consider the impact of this information on the affected person and their family, examples were shared of the impersonal and unsympathetic approach experienced by some.

People feel that information and support following diagnosis needs to be improved. People are often feeling uninformed and abandoned during this period and it was felt that information should be provided in a co-ordinated way, ideally with a central place where advice and information can be sought when needed.

The current support, information and services provided by local voluntary and community sector organisations are universally valued, and often seen as a lifeline by families. There is a clear call for this type of provision to be increased and expanded to provide focussed support for people at different stages of dementia.

Family and many other unpaid carers talked about how small and isolated their lives had become since taking on a caring role. They spoke about the often intensive and stressful nature of caring for someone with dementia and the impact that this had on themselves and their wider family. People talked about the positive impact that flexible and reliable respite care and day care services would have on their wellbeing and their ability to continue.

Conclusions cont.

There was criticism of the seemingly poor communication between health and social care services, often resulting in family carers needing to co-ordinate this process to ensure that information is correct. Families are also frustrated by statutory organisations excluding them from important correspondence and meetings when their support would be needed to help the person they care for understand and engage. People highlighted how much they would value a single point of contact, who knows and understands their case and is able to provide guidance and support at times of crisis.

People expressed concern about the perceived lack of dementia knowledge by professionals across all areas of health and social care. People shared their experiences of how this had impacted them when the person that they care for has required a stay in hospital or residential or nursing care. People really value the care that they receive at home from domiciliary care agencies, but again they are concerned about the level of experience and training that staff receive and the time the fact that too little time is allocated to enable staff to take to coax and support people with dementia in the most effective way.

Many people shared positive experiences of supportive local communities and services such as shops, pubs and public transport and described how this had enabled people to remain independent for as long as possible. However, it is felt that there is a need for greater public awareness and acceptance of the dementia condition to breakdown taboos and create dementia friendly communities across the Island.

The findings from this consultation mirror many of the conclusions and recommendations of the Healthwatch Isle of Wight report “Living with Dementia” published by in December 2018:

https://www.healthwatchisleofwight.co.uk/sites/healthwatchisleofwight.co.uk/files/main_report_-_dementia_care_dec_2018.pdf