



Report Title	Response to Healthwatch Isle of Wight Report – Living with Dementia: Experiences of people with dementia, families and unpaid carers
Background	<p>Healthwatch Isle of Wight is the consumer champion for people using health and social care services on the Island. Feedback is continually received from local residents on a wide range of services, with issues being discussed regularly with commissioners and providers. Each year a small number of topics are chosen for more detailed examination and in spring 2017 Dementia Care was chosen as one of Healthwatch Isle of Wight’s priority topics.</p> <p>Healthwatch Isle of Wight engaged with a range of people living with dementia or affected by it. They undertook visits to local dementia-focussed groups, held structured discussion sessions with people with dementia and unpaid carers and spoke to people with dementia living in care homes.</p> <p>A report “<i>Living with Dementia: Experiences of people with dementia, families and unpaid carers</i>” was produced by Healthwatch Isle of Wight in October 2018. Healthwatch have requested a formal response to their report and in particular the six recommendations for positive change which appear within it.</p>
Response	Healthwatch Isle of Wight’s report has been shared with senior managers and commissioners within adult social care and the feedback from all areas is included in the responses to the reports’ recommendations set out below:

Recommendation	Actions	By when
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.	Adult Social Care will continue to work with the NHS Trust and Clinical Commissioning Group to support the development of improvements in the co-ordination of post-diagnostic support for people with dementia. There are clear benefits to working in this integrated way and this will be supported by the continued development of the Integrated Locality Services across the Island which gives GPs direct links to a range of professionals and other agencies including Fire, Police, and the voluntary sector. This	On going

	<p>improved communication between partner agencies working within specific areas of the Island will create opportunities for earlier intervention, targeted support and a more co-ordinated response.</p> <p>Adult Social Care have established the duty worker system which ensures a consistent and reliable response is provided to all adult social care contacts. For all open cases the duty worker will undertake an overview of the situation over the phone, in conjunction with the person, family and professionals and then take the appropriate action. This action could include the provision of advice & guidance or an urgent or planned reassessment or review.</p>	In place
<p>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".</p>	<p>We have a systematic approach to care planning in place. However, we are constantly reviewing processes to ensure that social work practice continues to improve and adapt. We strive to keep the individual and their family at the centre of all that we do by reviewing best practice models and recognising what is working well elsewhere in the country.</p>	Under constant review
<p>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.</p>	<p>Adult social care are working hard to ensure that all staff use a person centred approach when completing any assessments, reviews or support planning. Staff will involve, where appropriate and in line with the individual's wishes, family and carers in this process and will aim to maximise each person's independence by focussing on their strengths and capabilities.</p> <p>Adult social care currently fund carer support services provided by Carers IW based at the Riverside Centre, Newport. Carers IW provide support to a large number of people caring for someone with dementia. This support can include advice, information and signposting to local support groups, weekly ring around service which keeps in touch with carers over the telephone, monthly dementia café, and provision of a carers assessment which can include the development of strategies tailored to the carer's individual circumstances which aim to help to avoid crisis events.</p> <p>During 2019 adult social care will be working to refresh the existing Carers Strategy and also undertaking a review of our current carers support services. As part of this process, we will seek the views and experiences of carers. The information and feedback that we</p>	<p>Under constant review</p> <p>In place</p> <p>By the end of 2019</p>

	<p>receive will be used to shape future carer support on the Isle of Wight.</p>	
<p>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.</p>	<p>Adult social care do not have any current plans to create a new development worker post. However, we continue to support the Island's local organisations that provide much valued dementia support groups, activity groups and support the carers of people with dementia.</p> <p>Better Care Fund monies have been used to facilitate the development of a Dementia Awareness Partnership between Alzheimer Café IW and Carers IW. The partnership has been formed to develop a network of trainers from across the health and care system, members of the public and from the voluntary and independent sectors. These trainers will deliver dementia education and create the leaders in the system to support the transformation of dementia care. The project will create a network of trainers who will be individuals with an interest in dementia either by profession or through their own experience, they will be trained to deliver the materials and resources provided. The project, which was launched at the Dementia Awareness Conference in July 2018, is working with St Mary's Hospital, the voluntary and independent sector and health and social care to ensure Island wide coverage.</p>	<p>Ongoing</p>
<p>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).</p>	<p>Alzheimer Café IW and Carers IW both facilitate regular forums in a safe and informal setting where people can share their experiences of living with dementia. These forums can stimulate conversation and provide people with the opportunity talk about the challenging aspects of living with or supporting someone with dementia. These forums are also a valuable resource for adult social care in enabling us to speak to people with dementia and their carers to gain an insight into their needs and priorities. This is something that we will do as part of our co-production work when reviewing the support that we provide for carers later this year.</p> <p>Adult social care is currently developing new service specifications for the domiciliary and residential care services that we commission. A series of workshops are being held which have included experts by experience including a carer for someone with dementia and</p>	<p>In place</p> <p>Ongoing</p>

	<p>providers of dementia services to ensure that we have a clear picture of what is and isn't currently working well. By hearing the voice of people who currently use these services we will ensure that services are improved and provide support in a way that best meets the needs of individuals and their families.</p>	
<p>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.</p>	<p>Adult social care receive feedback about how people are describing their experiences of care through our contract monitoring meetings with the various organisations that we commission including Carers IW, Healthwatch and SEAP Health Complaint Advocacy. This information provides insight into the difficulties that people are facing and enables commissioners to shape service delivery in a way that supports people to overcome these challenges. The use of Improved Better Care Fund money to facilitate the development of The Dementia Awareness partnership demonstrates how we have listened and invested in a project which we hope will have a really positive impact on dementia awareness and care.</p> <p>The establishment of the new Carer's Lounge, as part of the Living Well initiative, in St Mary's Hospital has enabled Carers IW to gather feedback about carers current experiences and challenges, providing an opportunity to intervene with advice and support at what is often a time of crisis.</p> <p>Carers IW were also, until recently, able to attend hospital ward meetings, this enabled them to identify carers that may need support and assist in the process of hospital discharge. However, this involvement is currently on hold due to issues regarding GDPR and information sharing, we are working to reinstate this as soon as possible.</p>	<p>Ongoing</p> <p>In place</p>

In addition to the information provided in response to the recommendations, the council has recognised from the report the need to review how we provide the information that people need. To this end, the council is undertaking a comprehensive review of its website in 2019. This will commence with market research that will include analysis of user experience in order to shape an appropriate solution for users of the future site. It is anticipated that part of the project will include the engagement of focus groups and we would be grateful for Healthwatch representation as part of this process.

Drawing upon the conclusions of the report, specifically that: "it was felt that information could be provided in a more tailored and co-ordinated way, with

support offered more pro-actively”, “navigating the care system was felt to be challenging, even to people with good levels of involvement with local dementia groups”, and “local information websites may contain useful information but again, these are only part of the picture” it is felt that some barriers currently exist. This feedback will be included as part of the scoping phase of this broad project and subsequent recommendations made as the project progresses. This may discover support requirements across the wider system and the council will be able to provide guidance (for example www.islefindit.org.uk or www.islehelp.me which are partner-managed websites).

Ultimately, the outcome of the council’s website review will be to ensure that effective information, signposting and usability is paramount for digital interaction and ease of use by web users in the right way for all whom we serve.