

Dementia: What do people think of support and information in Kirklees?

Healthwatch Kirklees worked with the Safeguarding Adults Board in Kirklees to understand more about what people with dementia and their carers think of the support and information that is available to them across the area. They talked to people at support groups and activity sessions, and their views were fed in to Safeguarding Adults Review Action Plan that focuses on improving Kirklees wide services so they are safer and more responsive for people with dementia.

Below are the 5 key things that Healthwatch Kirklees learned:



1. Carers value the support that they get from voluntary sector services, but feel they face more challenges when trying to get support from the local authority and NHS

Caring for someone with dementia can be very challenging. Services provided by the local authority, NHS and voluntary sector should help with those challenges, making the process of caring easier, but that this isn't happening in all cases.

Voluntary sector support services for people with dementia and their carers received almost universally positive feedback, especially for Alzheimer's Society and Making Space. People felt that the staff were welcoming and the environments were supportive.

Carers really appreciated the flexibility provided by the voluntary sector services, which were primarily drop-in sessions, where you didn't lose your place if you didn't attend. They needed this as the needs of the person that they care for are constantly changing, meaning they can't always consistently go to or be involved with a group or activity.

Carers feel they have to be willing to push hard to get the services and support that they need from Kirklees Council. This requires a great deal of confidence and personal resilience which carers can sometimes lack because being a carer can be very overwhelming.

Navigation

2. There is a lot of information about dementia, support and services available, but people struggle to navigate it.

Carers like to be able to choose how they get the information they need; some appreciate the good quality online resources, others want to be able to ask questions of support staff with a high level of knowledge of dementia, and other people want to read printed materials. For those people who wanted to talk to someone to get information, they were less positive about the information they received from Gateway to Care and NHS services than they were about other information channels, such as the Alzheimer's Society and Making Space.

Carers and people with dementia need to be actively signposted to useful information for them, as it is not always easy to start the search for information or support.



The volume of information about dementia and the support available can be overwhelming and confusing, and people would like to be guided through this to the most appropriate resources or information for them, especially during a period of crisis. It can be very time-consuming to look through a lot of information to find what you need, and if someone is has a question because the situation has changed or something upsetting or confusing has happened, then there isn't always time to do this.

The Housing Action Plan is a useful resource for information about housing that is personalised to the individual's situation, however, helpful details in the plan can be overlooked, because applying for housing with Kirklees Council is lengthy process and people cannot dedicate time to reviewing the information.

The online assessment for the Housing Action Plan is not fully accessible; those people with low levels of literacy, who do not understand English well or who are not experienced in using computers all face barriers with completing the online forms. These difficulties are also faced by these people when they are searching for information about dementia and available support.



5. The NHS and Kirklees Council say a lot about putting a person at the centre of the plan for their care, but in practice, carers feel that not enough is being done to put the needs of the person they care for first

Focus is placed on putting a person at the centre of their care, and carers speak very highly of services that are accommodating, where criteria are not so specific and there is flexible access, because these fit around the needs of a person with dementia, which are always changing. Too often carers feel that they are the people navigating an over complicated system where people aren't put first.

Carers are experts in the person they care for, so when they are planning care, carers are keen to get in to the mind-set of the person they care for, so they can get the most useful parts of what is available, but carers have been left feeling that this is not the priority for professionals. When people are assessed by staff who do not know them, and who do not stay involved with them, carers feel those staff cannot understand the full picture of what is going on in their lives. This feels to carers like an example of services fitting around professionals, not around service users.

But what impact does this have?

We have taken the views that people shared with us and fed them in to the Safeguarding Adults Review Action Plan, the Dementia Strategy and the Kirklees Dementia Action Plan. All the organisations and partners involved in supporting people with dementia and their carers will now have to complete actions as part of the Kirklees Dementia Action Plan that relate specifically to what people told us as part of this work.

Healthwatch Kirklees are really grateful to all the people who shared their experiences and views as part of this work. We thank Making Space, the Alzheimer's Society and Carers Count for making us welcome at drop-ins, groups and events. Your voice really does count, and it makes a difference.