

Information Provision and the Dementia Adviser Service

What is this report about?

Information about dementia and services provided for people living with dementia and their carers was identified by people at our first workshops as an important issue of concern. In our second round of engagement we wanted to find out more about what information people felt they needed and in what form.

This report focusses specifically on what people told us about the dementia adviser service and issues which may relate to this service.

What we did

We talked to people living with dementia, unpaid carers, people with learning disabilities, older people, the general public, volunteers and professionals.

We held four workshops around the county. We also felt that it was important to carry out more targeted engagement with people living with dementia and their carers and carried out a number of outreach to groups and services. We have also reached people through our engagement at Acute Hospital Trusts and through Community First's Community Organisers who carry out 'listening's' with isolated elderly people in rural areas. We carried out a small number of case studies where we spoke to people on a 1-1 basis in order to illustrate personal stories.

We spoke to 145 people in total:

- 41 people living with dementia (28%)
- 71 carers (49%)
- 33 professionals or others (23%)

Accessing the Dementia Adviser Service

Most people we spoke to heard about the Dementia Adviser from their GP surgery, either via the GP or Care Coordinator. Others had contacted Alzheimer's Society or Alzheimer's Support directly and been referred to an adviser. Very few people we talked were referred by other voluntary organisations.

No one mentioned any delays in seeing an adviser or getting hold of them. The people who had accessed the service viewed it as being responsive. A number of people said that they were now using the service, but would like to have been told about it sooner.

There were still a number of people who didn't know about the service but felt it would be useful. Many of these people felt that they should have been referred to the service by their GP, but had not been. Some of these people were newly diagnosed and some had been living with dementia for

a number of years and would have been diagnosed prior to the adviser service starting. Both these groups felt there were gaps in their knowledge which a Dementia Adviser could support with.

Where people have told us they haven't had enough information it often seemed to be because they haven't seen an adviser or known about the service. We signposted a number of people to Dementia Advisers during our engagement.

What people said about the Dementia Adviser Service

Many people we spoke to had seen a Dementia Adviser. This is what they said about the service:

People thought it was a useful and valuable service. Face to face meetings with Dementia Advisers were thought to be a positive feature of the service. A number of people living with dementia and/or their carers knew the name of their adviser.

People viewed their dementia advisers as being knowledgeable about dementia and about local services. Information about local services for people living with dementia and their carers was particularly valued as this is what people have said they have found most hard to find out about themselves.

People talked about being signposted to other agencies for further support, for example Wiltshire Council Adult Social Care Team, Carers Support Wiltshire and Age UK. This was thought to be helpful, particularly as the Dementia Adviser were able to describe the type of support that different agencies could offer.

People said that their Dementia Adviser had discussed legal and financial issues with them. These included Power of Attorney and benefits. It was reported that Dementia Advisers were able to signpost people to relevant agencies if they needed further support with these. This would seem to be an important feature of the service as people living with dementia have consistently told us that they want to be involved in making decisions about their future care and support. Some carers have told us that they find these conversations difficult so it may be that Dementia Advisers can support in facilitating these discussions.

No one we spoke to who had seen as Dementia Adviser said that they had not received enough information. Some people said that they found the amount of information they were given at one visit overwhelming. People found information targeted to what they wanted at that particular time most useful.

Some people said that they knew that they could go back to their adviser when they needed more information. These people found this reassuring and helpful. A number of people talked positively about further support they had been given when they contacted their adviser again because of changes due to the progression of dementia. Both further visits and support on the phone were mentioned and were valued. The people who were most positive about the service were those who knew they could go back to their adviser when they needed further information and advice.

Other issues which may relate to the Dementia Adviser Service

Some other key issues arose. These were not raised as comments about the Dementia Adviser service but are relevant to the service as they may be issues that the service could support people with.

- Many people said they used the internet as a way of getting information and thought 'Your Care, Your Support Wiltshire' online directory will be useful. Concern was also expressed that those who don't use the internet are supported to get the same information.
- Information needs to be timely – right information right time – people said they found information easier to process if it was given gradually at the time people want it.
- Transport is an issue for people living with dementia and their carers, some people were not aware of all the available transport services.
- Many people living with dementia told us they want to be involved in making decisions about their care and support and future planning.

Going forward

Overall what people said about their experience of using the Dementia Adviser service was very positive. The Dementia Advisers should be given recognition for their high quality professional service. The issues raised in this report could be used to further develop and enhance the service according to what people told us they would find most useful.

Points to take on board going forward are:

- All GP surgeries should refer into the Dementia Adviser service. This should happen at the point of diagnosis, but GP surgeries should also refer people who are already diagnosed but have not yet accessed the service.
- Promote further awareness amongst voluntary organisations about the service and how they can refer into it.
- Dementia Advisers should be conscious of not giving too much information on first visit unless specifically asked for
- Dementia Advisers should emphasise that people can come back for more information and advice as and when they need it.
- As people have told us that transport and people with dementia being involved in advance planning decisions are important issues, it should be ensured that Dementia Advisers have all the information and support they need to advise on these.