

Dementia framework survey findings

Introduction

In total 149 people completed the survey. Of those 41% (61) were a family or friend carer for someone with dementia, whilst 57% (85) were not. 3 per cent (6) people had dementia themselves.

Location

Table 1 provides a breakdown of the town nearest to the person a family or friend carer was providing care for. The data has been organised by Clinical Commissioning Group boundary. Respondents who were not carers were not asked to give their location.

Table 1: Nearest town to person caring for, by CCG Boundary

Coastal		Crawley		Horsham and Mid Sussex	
Arundel	0	Crawley	13	Burgess Hill	1
Billingshurst	1			East Grinstead	3
Bognor Regis	6			Hassocks	0
Chichester	6			Haywards Heath	2
Henfield	0			Horsham	11
Lancing	0				
Littlehampton	7				
Midhurst	0				
Petworth	0				
Pulborough	1				
Selsey	0				
Shoreham	4				
Steyning	1				
Storrington	2				
Worthing	5				
Total	33		13		17

Owing to the low number of responses from Crawley and Horsham & Mid Sussex CCG areas it is not possible to breakdown the findings by CCG area.

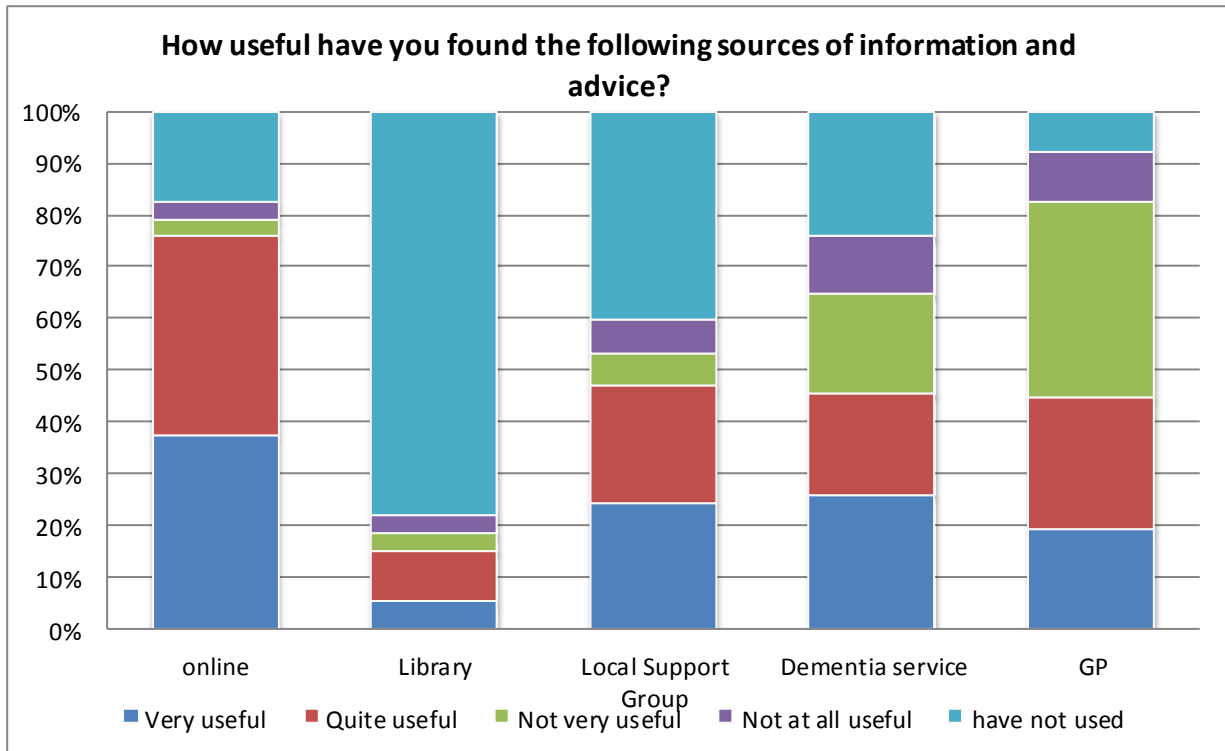
Diagnosis

- 61% of respondents were caring for someone who had received their diagnosis within the previous four years, whilst 34% had received it more than four years ago and 5% did not know.
- 83% had received their diagnosis aged 65 and over, whilst 16% had received it aged under 65.
- 30% of people respondents were caring for lived in permanent residential or nursing care, while 70% did not.
- 87% of respondents knew what dementia was before the person they were caring for received a diagnosis and 73% knew what the symptoms were before diagnosis.
- 73% knew where to get information about dementia and 60% knew where to get a diagnosis for dementia.

Sources of information and advice

As Fig (i) shows, the two most commonly used sources of information and advice were online and GP consultation. Whilst 80% of respondents found online a useful source (very/quite useful) this fell to only 44% for the GP, whilst 45% felt it was not a useful source.

Fig (i): How useful have you found the following sources of information and advice for helping people live well with dementia?



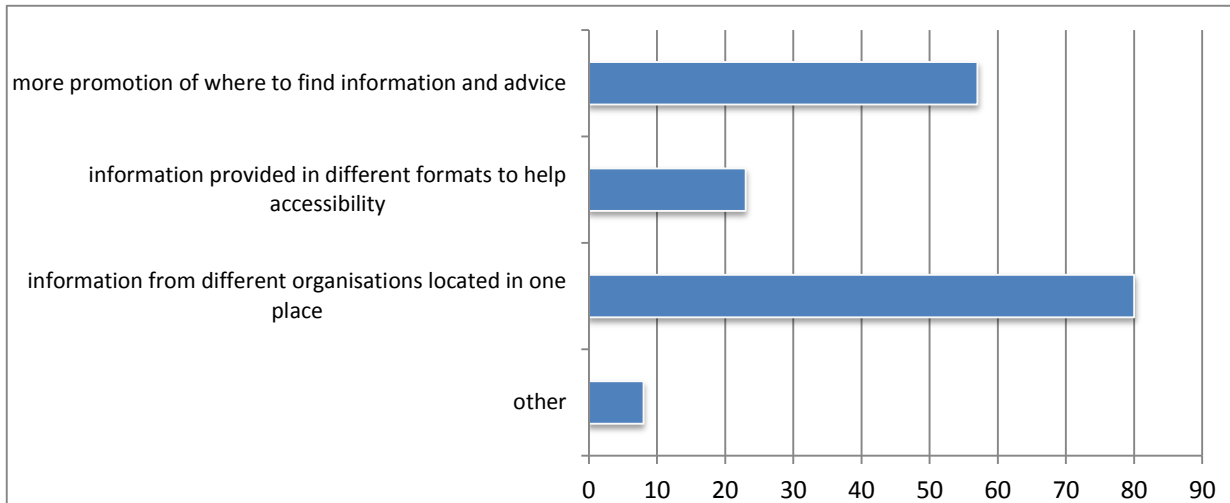
As Fig (i) shows the most commonly used source for information and advice was the GP, used by 92% of people. 88% of people had used online sources. As Fig (i) illustrates, online sources were viewed as considerably more useful than the GP.

Only 22% of respondents had used the library as a source of information and advice, whilst 60% had used a local support group and 76% a dementia service.

As per Fig (ii), 76% of respondents agreed that a 'one stop shop' for information and advice, where it was all located in one place, would make it easier to find information advice and information, whilst 63% agreed that more promotion of where to locate information would be beneficial.

Fig (ii): What things would make it easier to find information and advice? (% , select all that apply)

Appendix E



Health and Social Care Staff

Carers' experiences of health and social care staff were very evenly split, as shown in Fig (iii). 41% of respondents had positive personal experiences (very/somewhat positive) whilst 41% had negative (very/somewhat negative).

Fig (iii): Thinking about your own experiences as a carer for someone with dementia, how positive or negative do you feel about the care and support you received from health and social care staff? (%)

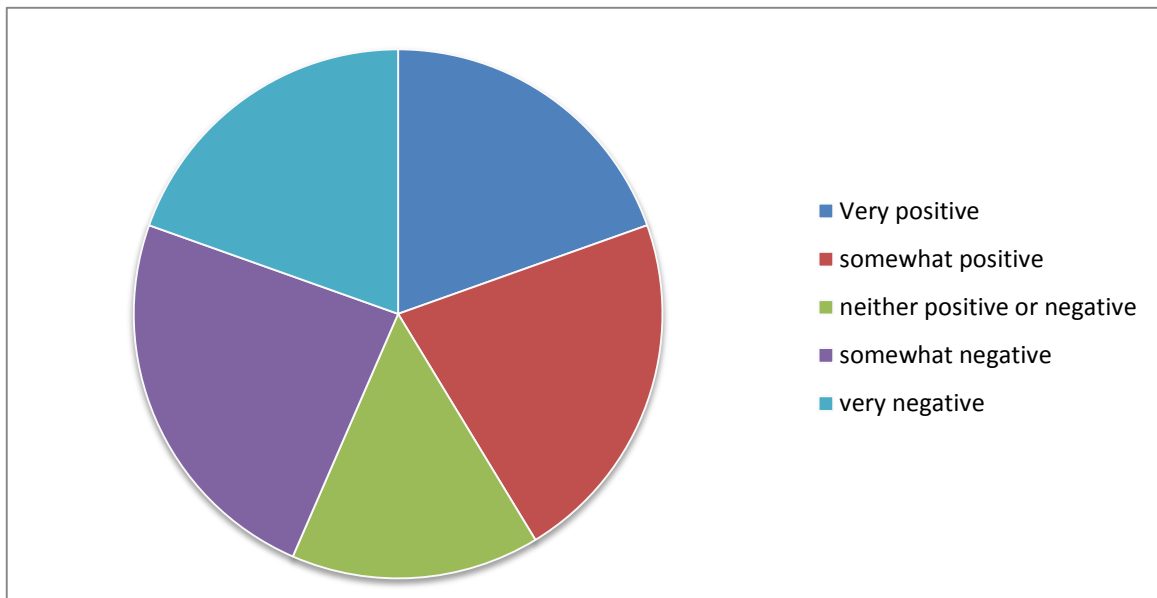
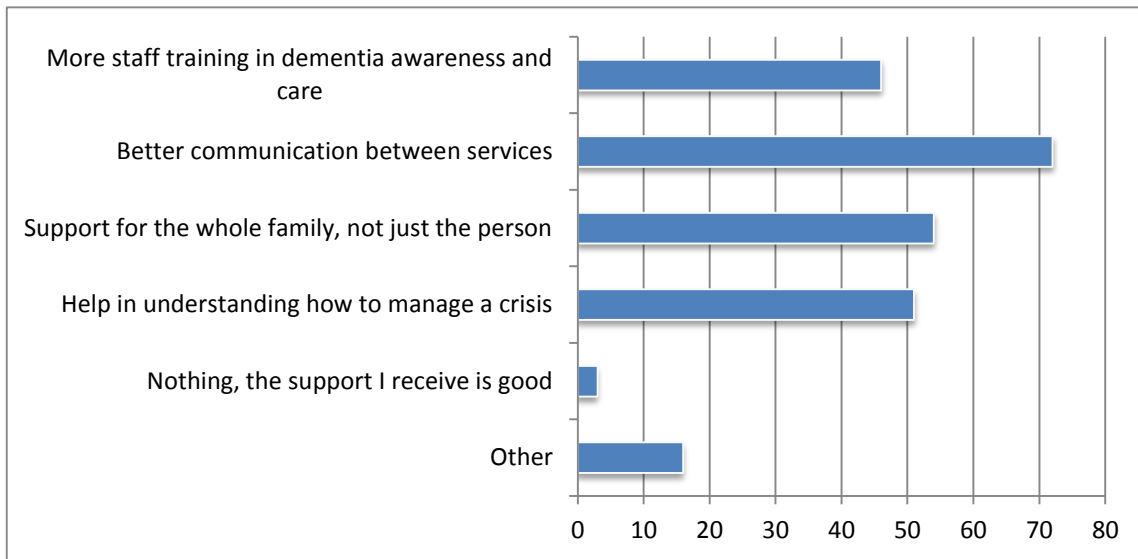


Fig (iv): What things could improve the care and support provided by health and social care staff? (% , select all that apply).



As Fig (iv) shows, only 3% of respondents felt that there was nothing needed to improve the support they received from health and social care staff. 72% of respondents felt that better communication between services would improve care and support, while 54% felt that support for the whole family and not just the person with dementia was important. 51% would benefit from help in understanding how to manage a crisis.

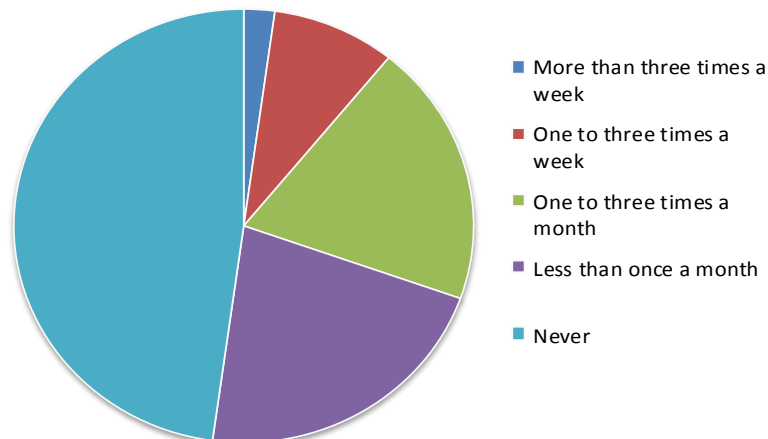
Additional comments included:

- Information and advice should give a realistic idea of the challenges of providing care – a 'gritty and practical approach' would be of greater value.
- To not just rely on leaflets, but also to provide someone to talk to.
- More staff training on how to support people with learning disabilities who develop dementia and their families.
- A lack of consistency in approach and attitude towards patients and their families and carers between different NHS services, for example Horsham CAMHS and Neurology at the Princess Royal hospital.
- More support for people with dementia to be continue to attend GP appointments independently and for the surgery to support them if they miss appointments or turn up on the wrong day.
- Simplifying the process for accessing proactive care, as the system can be slow and lack coordination.

Carers Groups and Leisure Activities

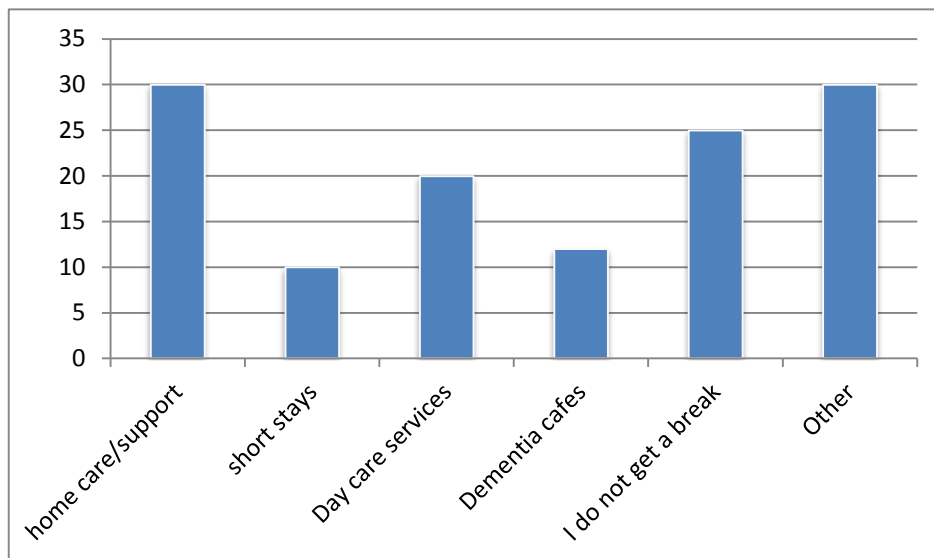
Just under half of respondents (48%) never attended carers groups or leisure activities, with 44% attending on a less than weekly basis. Only 9% attended once a week or more.

Fig (v): How often do you take part in carers groups, or leisure activities in your community? (%)



Respondents were also asked what stopped them attending groups and activities. Whilst a third (33%) of respondents were able to attend groups and leisure activities, a further third (33%) were unable to attend as they had no one to look after the person they cared for, whilst 9% could not afford an agency to provide care while they attended. 14% cited a lack of suitable activities and, possibly linked, 14% cited transport issues. Of the 23% who selected 'other', work and other family commitments were frequently cited reasons.

Fig (vi): What do you and the person you care for use to help give you a break from your caring role? (% , select all that apply)



30% of respondents used home care/support to get a break, whilst 20% used day care services. 25% of respondents did not get a break from their caring role. 'Other' options included, leaving the person with dementia at home alone for several hours, when in early stage or with mild dementia; informal arrangements with other family members; and the person with dementia now living in residential care.

Respondents were also asked what things stopped them getting a break from their caring roles. 24% said that there were no suitable respite opportunities, whilst cost was an issue for 9%. Some respondents were not happy leaving the person they cared for in a care or activity group setting, or the person would only agree to attend if their carer was with them. Others stated that the person they cared for did not recognise that their carer needed respite.

80% of respondents used their own car as the main form of transport for their caring role, whilst 7% walked, 3% of respondents used the train, whilst a further 3% used taxis. Only 2% made use of community transport.

Dementia Friendly Communities

This section was answered by all people completing the survey. 65% of people had heard of dementia friendly communities, whilst 35% had not.

Respondents were given a definition of dementia friendly communities and asked how far they agreed or disagreed that their local community was dementia friendly.

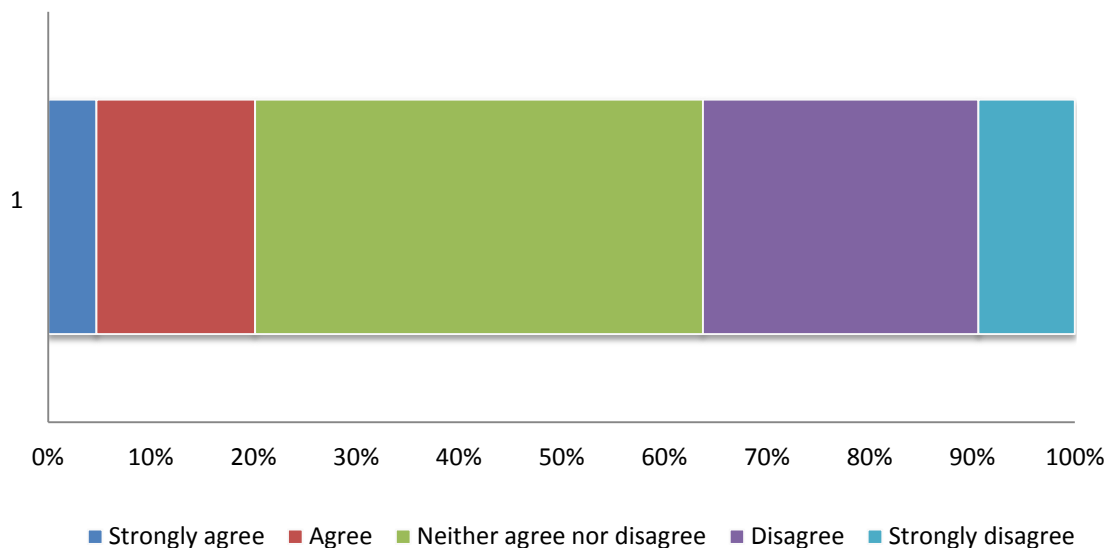
Definition:

People with dementia have described a dementia friendly community as one that enables them to:

- find their way around and be safe
- access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices)
- maintain their social networks so they feel they continue to belong.

Dementia friendly communities are those in which people with dementia have the best possible opportunities to live well.

Fig (vii): Thinking about your own local area, how far do you agree or disagree that your community is dementia friendly? (%)



Only 20% of respondents agreed that their local community was dementia friendly (strongly agree/agree), whilst more than one third (36%) disagreed (strongly disagree/disagree).

Respondents were also asked what things they thought could make their communities more dementia friendly.

Acceptance and understanding

“For it to be something we are not ashamed to admit to – we always end up making excuses for their behaviour and trying to hide it”

Respondents frequently noted that many people did not understand dementia or were unwilling to engage with the subject. Several respondents contrasted the

general perception of dementia with cancer, with the latter being widely understood and socially accepted. For some, there was a sense of frustration that dementia was not understood properly as an *illness* and that this was a significant barrier to broader social acceptance.

Divergent views as to people wearing visible signs, as some felt this could be helpful for people to be more aware of additional support needs and also public safety, whilst others felt that labelling people ran against the principles of an open society and that greater education and training for people and communities was a more suitable approach.

Public Awareness

Linked to wider understanding and acceptance, the need for information and campaigns was frequently cited including dementia information 'roadshows' to provide information in local communities and local poster and publicity campaigns. It was acknowledged that to be effective, local activity should ideally be supported by national campaigns.

Schools were also viewed as another suitable venue, particularly as some children may have relatives with dementia. Options for greater intergenerational contact, between younger children and people with dementia, should also be explored.

It was also viewed as important that communities who were dementia friendly actively promoted this locally, so that people were aware of this and had greater understanding of dementia and how to support people with dementia and their carers.

Local Community

The introduction of local schemes for shops and community facilities to indicate that they were a supportive space for people with dementia were frequently cited by respondents. This would require staff training to ensure that they were able to do this and this would likely have to be refreshed on a semi-regular basis.

Similarly, facilities such as libraries could act as local 'hubs' in the community for people with dementia and their carers; and these could provide a 'port of call' for information and advice.

Town maps and signage could be used to provide simple information to people, including where they could find shops and services that understood dementia. The potential for working with Business Investment Districts (BIDs) on such schemes could be explored.

Ongoing, high levels of change in town centres, which included the closure of banks and post offices, as well as the loss of facilities such as public toilets, was viewed as problematic for people with dementia.

Local authorities could provide information and support for services tailored to people with dementia, for example to assist people with dementia to remember which bin to use and collection days.

Information

Respondents were divided as to whether not enough information was available, or that people were 'drowning' in it. There was however broad recognition that information was frequently uncoordinated and fragmented and it could be time-consuming to piece it all together.

"It has taken me the best part of two years through word-of-mouth, internet searches, local newspaper and magazines...to get to a stage where Mum can be properly cared for"

One way of providing better coordination and tailored information could be through more effective and creative use of technology, including apps. These could also be used to support people with dementia and be designed to provide reminders of 'experiences, places and people visited'.

Some respondents felt that information leaflets were not the real issue in their role as carers and that support to help manage caring for someone was required.

Diagnosis and early-stage support

Diagnosis was viewed as a problematic process. It could be lengthy, sometimes taking over a year. It could also be challenging to get people to acknowledge that they needed a diagnosis and this potentially lengthy period could be very difficult for relatives.

Support and advice, available before formal assessments had been completed, would help people who were assuming new or additional caring responsibilities as a result of dementia.

Need for more staff training in talking with family members who are caring for people with dementia, particularly at the earliest stage, immediately following diagnosis, to help people come to terms with the situation and understand how to access support.

Respondents noted that often services did not communicate effectively and that messages could be inconsistent or contradictory. This could be addressed by a single nominated point of contact for each person who could coordinate care and communicate with the family.

Groups and Activities

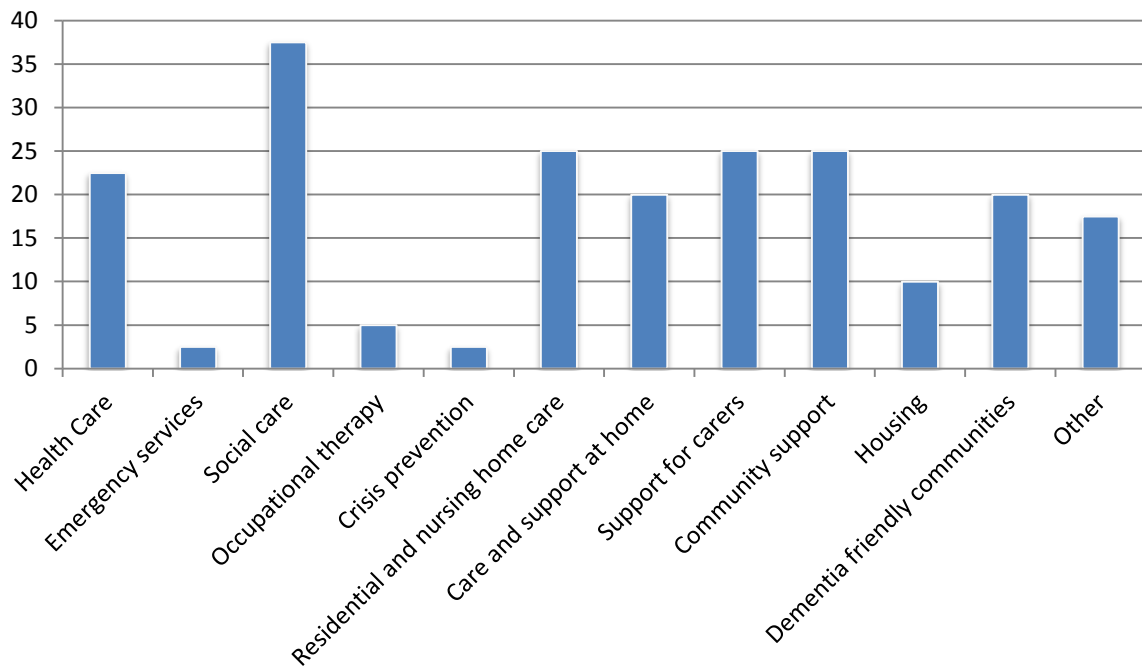
Carers groups should be tailored around different stages of the progression of dementia, such as early-stage/new diagnosis, to ensure that they are helpful for people.

Some respondents felt that there was a need to ensure that support groups and activities were accessible for people from different cultural backgrounds, and that content used in games and tasks was broad and inclusive.

Provider Survey

41 responses were received from a range of providers across West Sussex. Fig (viii) shows the range of services provided by respondents.

Fig (viii): What services or support do you provide? (please tick all that apply)



Respondents recorded providing a wide range of services to people with dementia, as illustrated by Fig (ix). Only 'end of life care' was provided by less than half of respondents (47%), whilst 'support to live well' (74%), 'health and wellbeing' (76%) and 'reduced isolation' (84%) were provided by over 70%.

Fig (ix): How do people with dementia benefit from using your service? (tick all that apply)

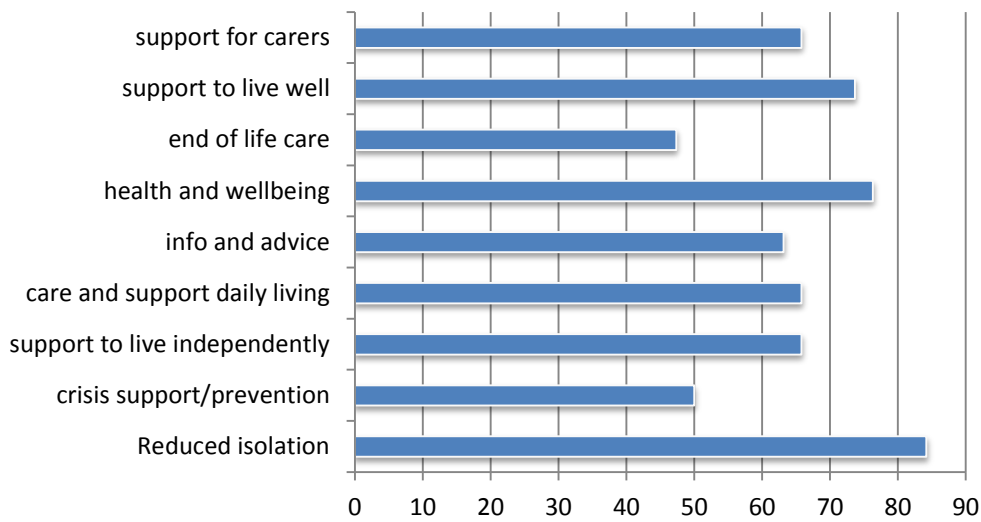
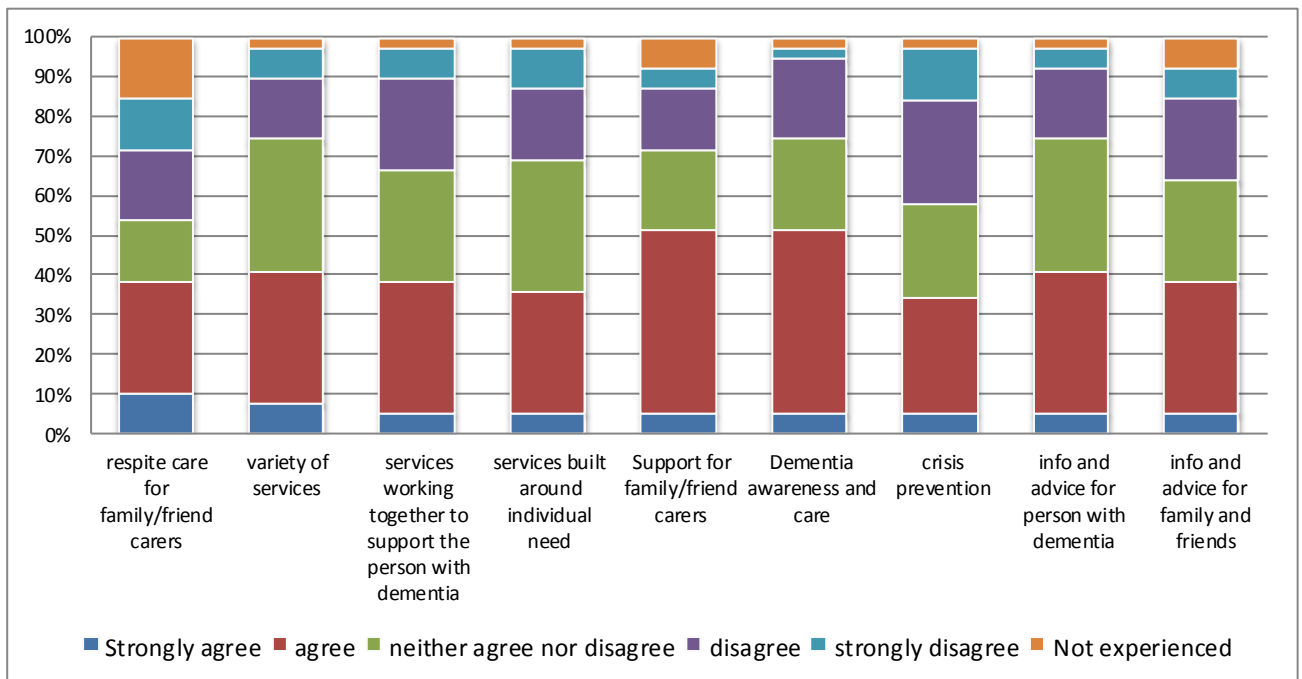


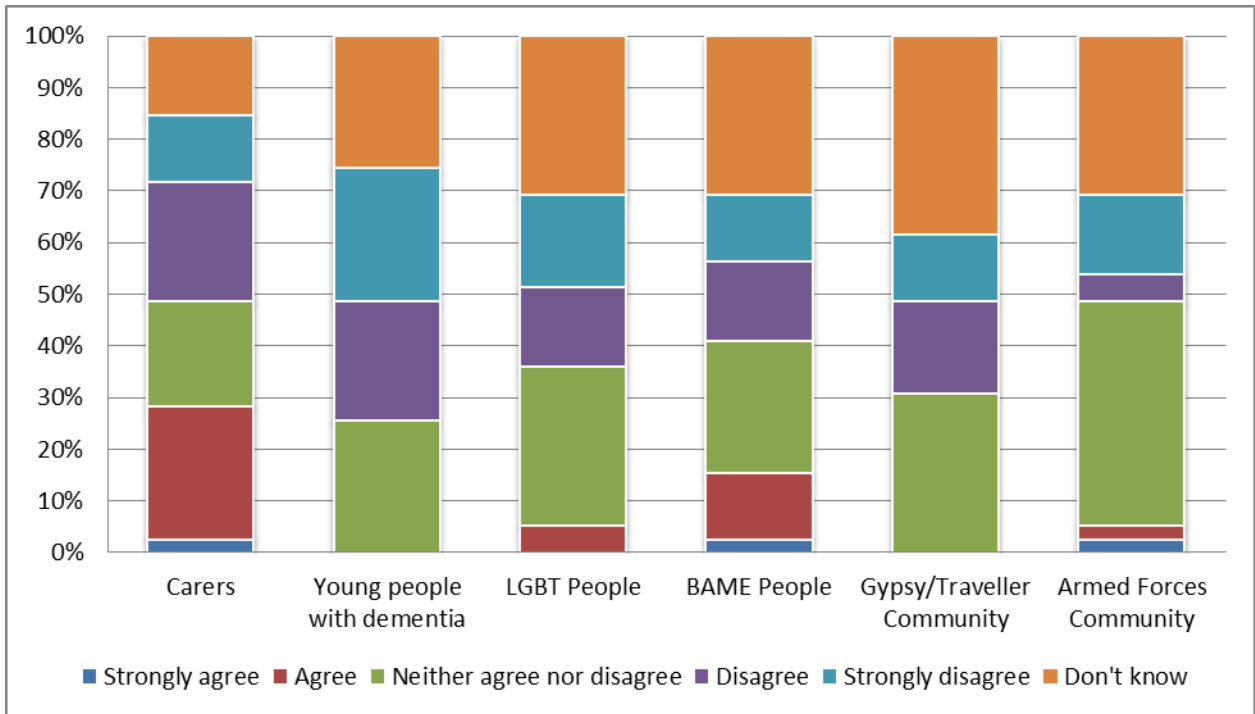
Fig (x) Thinking about the support available for people with dementia in West Sussex, in your experience how far do you agree or disagree that the following things are working well?



Respondents reported a mixed picture when asked about the things that worked well in West Sussex. As Fig (x) indicates only two elements – support for family/friend carers and dementia awareness and care’ – were felt to work well

by 50% of respondents (strongly agree/agree). Crisis prevention (34%) and the provision of services built around individual need (36%) were the lowest rated.

Fig (xi): How far do you agree or disagree that enough support is available in West Sussex for people with dementia from the following groups:



Respondents uniformly felt that there was not enough support for people with dementia from any of the groups listed in Fig (xi). For both Young People and Gypsy and Traveller Community, no respondents agreed that there was enough support.

Unmet needs

Respondents offered a range of views on the unmet needs in West Sussex, including the following common themes:

- Carers – a general lack of services to support carers in their difficult roles, including the provision of respite opportunities and easily accessible information and advice. The affordability of support, particular for home-care/respite was frequently cited as was supporting carers through the transition for the person with dementia from living at home to residential care.

- Funding – general issue impacting all areas of service coverage and the type and range of services that could be provided.
- Effective coordination of information and advice – this should be brought together and accessed through a single portal. A directory of support should also be prioritised
- Support for people with learning disabilities with dementia.
- Accessible, affordable transport – this was a particular issue for carers and people living in rural communities.
- Services and support for diverse communities

Making communities in West Sussex more dementia friendly

Respondents highlighted the following common themes:

- Awareness and education was the most frequently cited, with an emphasis on whole-community and cross-generational awareness to help people understand the condition and how they can support people with dementia to remain connected to their local communities.
- Promotion of dementia friendly communities – continue to promote the scheme, to encourage communities, shops and leisure facilities to become more accessible and dementia friendly. Many respondents felt that local awareness was low, even in places that were already dementia friendly communities.
- Expansion of dementia friendly communities - to increase the number of participating areas, particularly more isolated, rural communities. Working with key local partners such as parish councils to raise local awareness. Additional resources and volunteers would be required and the County Council should consider its role in providing support and funding for this.
- Greater coordination of information about the services available to people and how to access support. Network opportunities for different groups, including carers and people with learning disabilities and their families were also cited.

Background Papers

Stakeholder Engagement Report Horsham and Mid Sussex - available at <http://www2.westsussex.gov.uk/ds/cttee/hasc/hasc150319i8backA.pdf>

Stakeholder Engagement Report Crawley - available at <http://www2.westsussex.gov.uk/ds/cttee/hasc/hasc150319i8backB.pdf>

Stakeholder Engagement Report Southern - available at <http://www2.westsussex.gov.uk/ds/cttee/hasc/hasc150319i8backC.pdf>

Stakeholder Engagement Report Western - available at <http://www2.westsussex.gov.uk/ds/cttee/hasc/hasc150319i8backD.pdf>