



'Time' - parent carers who also look after an adult with dementia

June 2018

Report Summary:

1. Introduction

This consultation looks at how to improve diagnose of dementia among people living in Brighton and Hove and how to maximise engagement and support for people with dementia, and in our case, for their carers too.

Amaze and PaCC contribute to this city wide consultation by asking our parent carers if in addition to caring for a child and/or a young person they are also looking after a relative or a person with dementia.

More specifically we wanted to know more about parent carers' experiences of getting help and support for the relative or person they look after. What sort of impact the caring for a relative or other person who has dementia is having on parent carers?

We found that whilst **parent carers do get in touch with their GPs** if they are worried about memory capacity of the adult they are looking after **they also struggle with attending appointments with their GPs due to competing demands** of looking after a child or young person with additional needs and/or disabilities and looking after an adult with dementia. **Time to attend appointments and accessibility to GPs in terms of parking** are the biggest barriers. **Respite being offered when parent carers need to attend appointments would facilitate that.**

Referral system works OK and **parent carers juggle the extra needs** but a **more flexible appointment system, more information about appointments**, for example the Memory Assessment System and a **follow-up session after diagnose** would really help. Our carers also recommended **more suitable activities for those people who are diagnosed with dementia.**

Economic hardship is also a factor as parent carers find themselves managing an extra complex caring situation.

As a result of this consultation we recommend that:

- **GPs and Memory Assessment Service to offer parent carers a more flexible appointment system**
- **Respite to be put in place for children and/or young people so that their parents can take adults with dementia to their assessments and annual appointments**
- **Clear and accessible information on appointments to be provided when the booking is made**
- **Follow-up sessions to be provided after diagnosis and expand offer of activities to keep people healthy**
- **Better financial support for those parent carers who also look after an adult with dementia**

2. Report:

2.1 What Amaze does

Amaze is Brighton and Hove's 'one stop shop' for families with children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze also manages the Compass Database and the Compass Card, a free leisure incentive card for 0 to 25 year olds with significant disabilities or special needs who live or go to school in Brighton and Hove.

Since 1997 Amaze has been engaging parent carers at all levels of services provision for their child or young person, for themselves and for the whole family. Their aim is to increase parent carers' resilience and confidence which in turn has a direct effect on the lives of their children. Since September 2014, in line with the new Children and Families Act, Amaze has been supporting families, and young people with SEND themselves, up to the age of 25.

2.2 What PaCC does

The PaCC, hosted by Amaze, is a city-wide engagement group with over 350 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

PaCC also has 9 partners, some of them service providers, others community groups formed by parent carers.

PaCC gives a voice to parent carers using different engagement methods as for example focus groups and forums to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve services for families.

3. Dementia

Brighton & Hove City Council (BHCC) and the local Clinical Commissioning Group (B&H CCG), through their Brighton & Hove Communities and Third Sector Investment Programme (TSIP), fund Amaze and PaCC to gather views and ideas from parent carers around provision and delivery of health care services (*See Annex 1: PaCC engagement diagram*).

For this consultation the local Clinical Commissioning Group wanted to focus on how to improve diagnose of dementia among people living in Brighton and Hove and how to maximise engagement and support for people with dementia, and in our case, for their carers too.

Amaze and PaCC contribute to this city wide consultation by asking our parent carers if in addition to caring for a child and/or a young person they are also looking after an adult with dementia. We wanted to know about parent carers' experiences of getting help and support for the adult they look after and what sort of impact the caring for a relative or other person who has dementia is having on parent carers.

4. Methodology

To gather data and information for this consultation we used an online questionnaire, easy to navigate and designed with help from Amaze Database Manager. The online questionnaire had a few questions with 'please select' and 'tick boxes' options and boxes to provide extra information and feedback (*See Annex 2: Dementia - questions*).

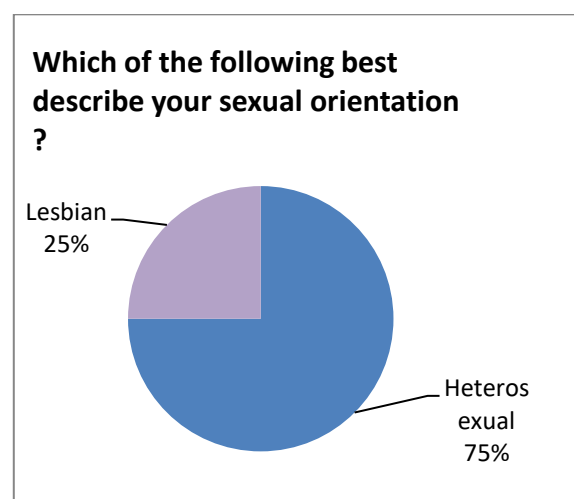
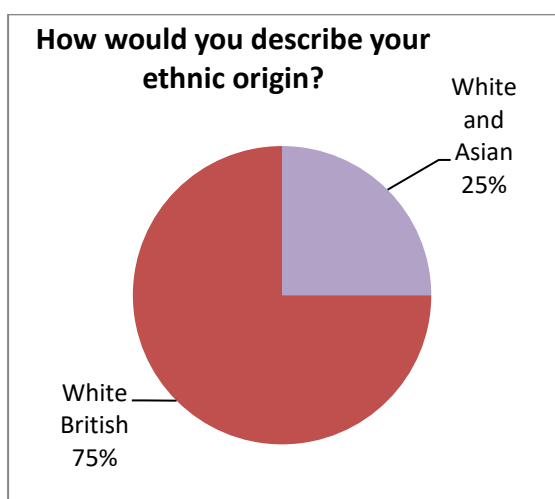
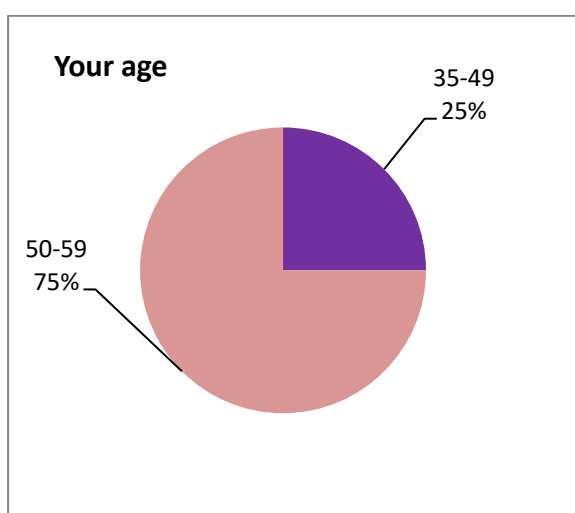
The online questionnaire was sent to all parent carers on the Compass database held by Amaze. We received only **4 completed questionnaires** which were collated into a summary

https://data.surveygizmo.com/r/91359_5b191d70569a14.69253110 and used to inform this report. We are mindful this is a small number (compared to what we usually receive) and this needs to be borne in mind when reading the % in charts below but again is probably symbolic of the fact that carers of both a child with additional need and a person with dementia will have no free time to get involved with consultations.

In addition to the data from the online questionnaire we also referred a previous Amaze and PaCC reports where topics about accessing GPs and support for carers were explored ([See Annex 3: Parent Carers and GP surgeries in Brighton & Hove – January 2015 report](#)) and a January 2018 Speak Out report 'Awareness of Dementia and Age Related Issues in People with Learning Disabilities' ([See Annex 4: Dementia Speak Out Report](#)).

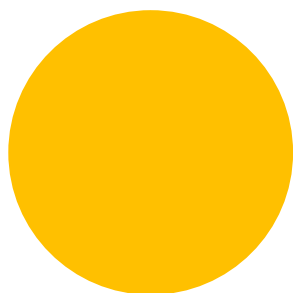
Parent carers' contributions to this consultation are reported in verbatim so to better reflect their experiences and comments.

5. Demographics from the online questionnaire



Do you consider yourself to have a disability?

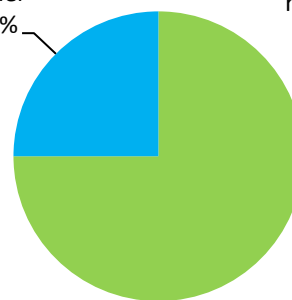
No 100%



What are your religious beliefs?

Other
25%

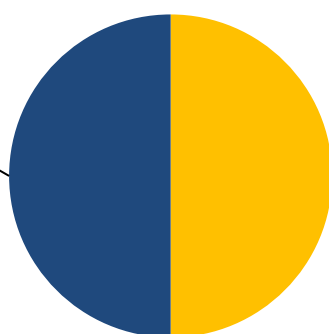
No
religion
75%



Are you the carer of an adult (that is, someone aged 18 or over)?

Yes 50%

No 50%



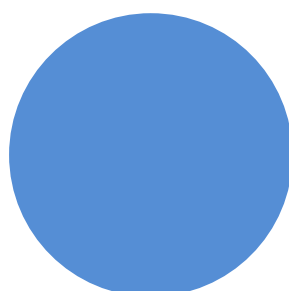
6. Findings from online questionnaire

6.1 Parent carers who also care for an adult

First of all, to direct our parent carers we wanted to find out if they care for an adult too. To the question *'In addition to your role a parent carer do you also care for an adult with dementia? Please tick all that apply.'* respondents told us:

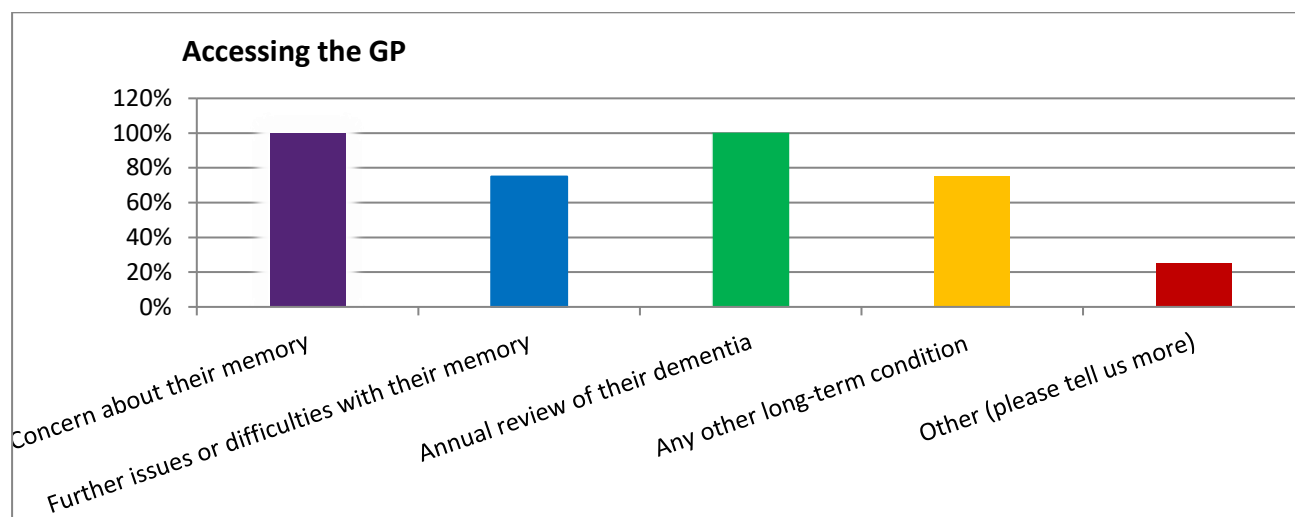
Caring for a child/young person and for an adult

Yes 100%



6.2 Accessing the GP

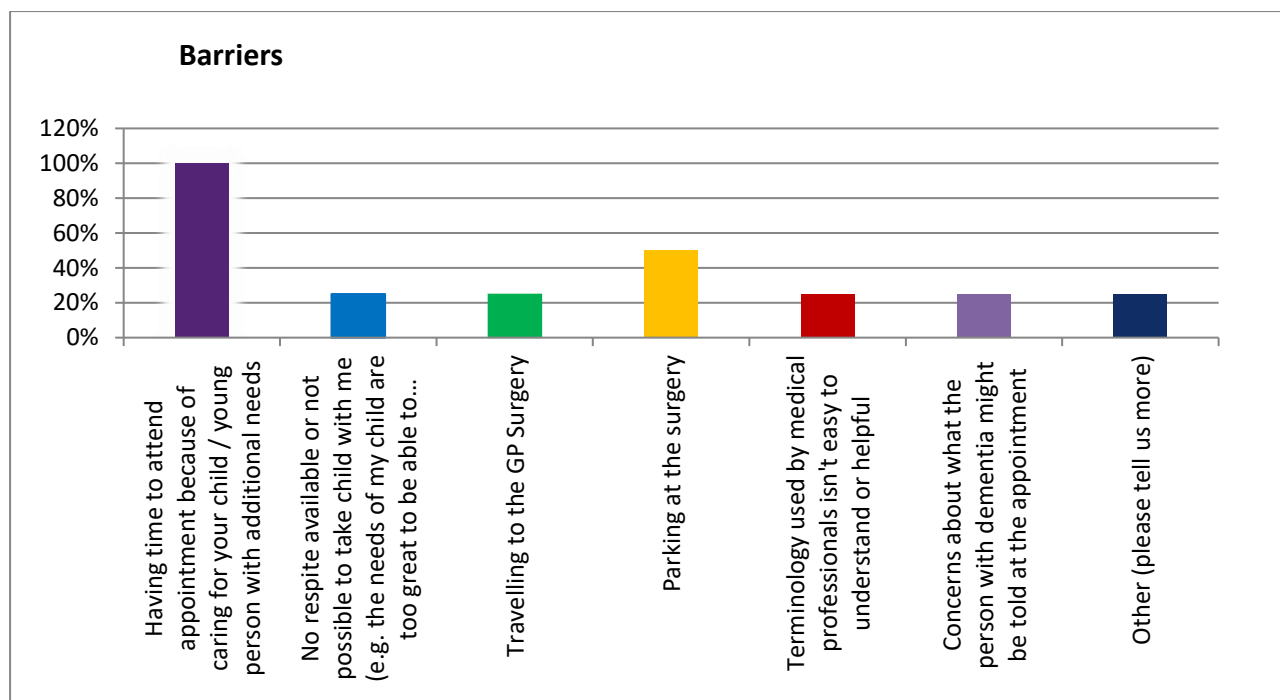
To the question 'Have you, or the person you care for, accessed the GP as for any of the following reasons? Please tick all that apply' respondent told us:



Every parent carer who completed the online questionnaire got in touch with their GP because they were concerned about a relative of other adult's memory. Similarly everyone has also attended GP appointment for the annual review (more of this further on this report). In addition 75% of respondents contacted their GP because they were worried about other issues to do with memory loss and/or other long term conditions. One respondent commented - '*many other issues*'

6.3 Barriers on accessing GP

To the question 'What barriers or difficulties have you experienced, or do you think you might experience in the future, in accessing this support from the GP? Please tick all that apply' respondents told us:



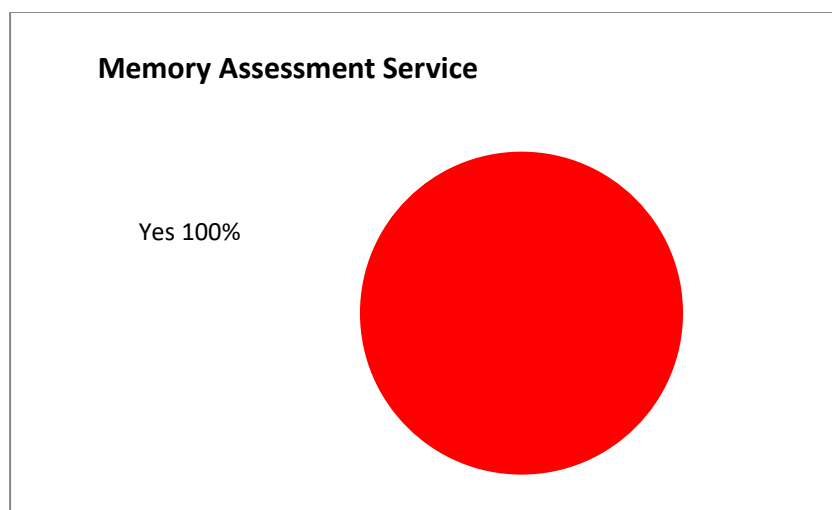
100% of parent carers who completed the online questionnaire reported that the main barrier to attend GP support is 'having time to attend appointment because of caring for your child / young person with additional needs'. This is an issue which we come across over and over again, in fact caring for a child or young adult requires lots of time – and energy. For example our previous consultation on Parent Carers and GP surgeries in Brighton & Hove highlighted the fact that the time when people can start calling the surgery, 8am, coincides with preparing children to go to school. Some respondents commented that it takes ages to get through and find a time that fits with school, work or weekend ([See Annex 3 page 4](#)).

One of the respondents to our consultation on dementia commented - *'my daughter who has cerebral palsy, is now far more independent, aged twenty, and actually helps me to care for my mother (her grandmother) who has dementia/Alzheimer's. However, sometimes fitting enough time in to attend to both my daughter's and my mother's additional needs is very difficult. Usually, my own paid work is the thing that suffers and therefore, the family income'*

50% of respondents also reported parking at GP surgery a barrier, a finding similar to our previous consultation ([See Annex 3 page 5](#)). This is probably to do with the fact that parent carers have to drive to GPs with their child or young person as they can't leave them at home by themselves.

6.4 Memory Assessment Service

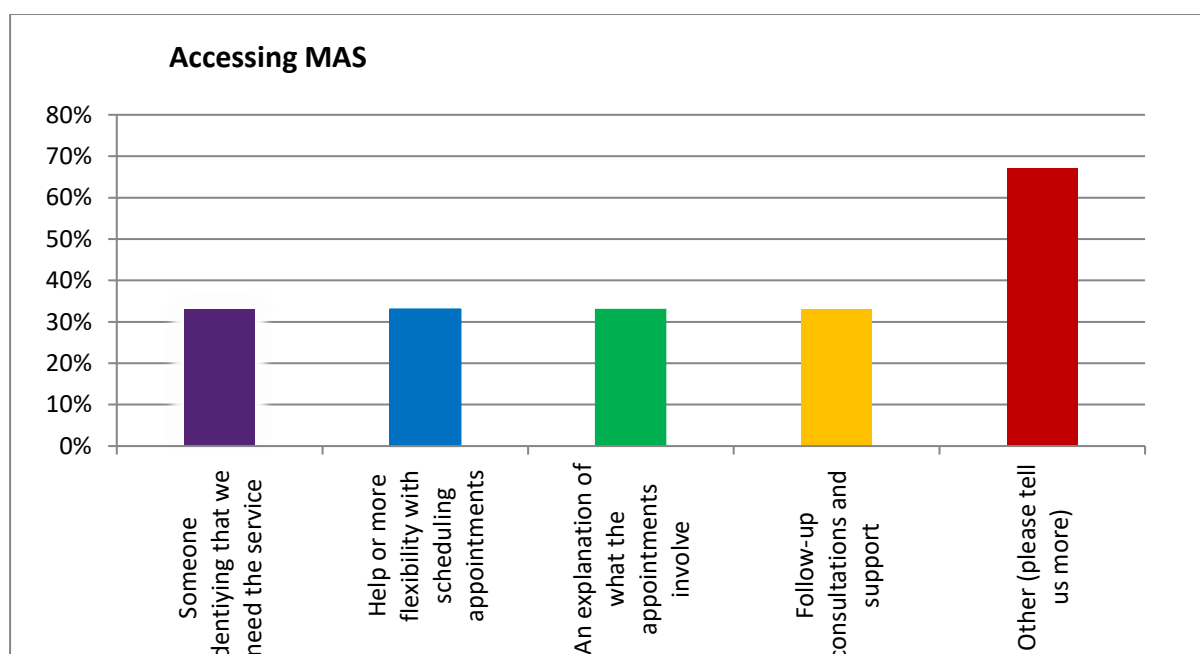
One of the services offered by GPs to diagnose dementia is a Memory Assessment Service (MAS). We our parent carers *'Have you or the person you care for been referred to or treated by the Memory Assessment Service? To which are respondents said:*



All parent carers participating in our consultation have been referred to MAS. This is a positive finding as it means the referral system is working.

6.5 Accessing Memory Assessment Service

Are there any barriers to accessing MAS? To determine that we asked *'If yes, what support would have helped you to access the Memory Assessment Service for the person you care for with dementia?'* Our respondents told us:



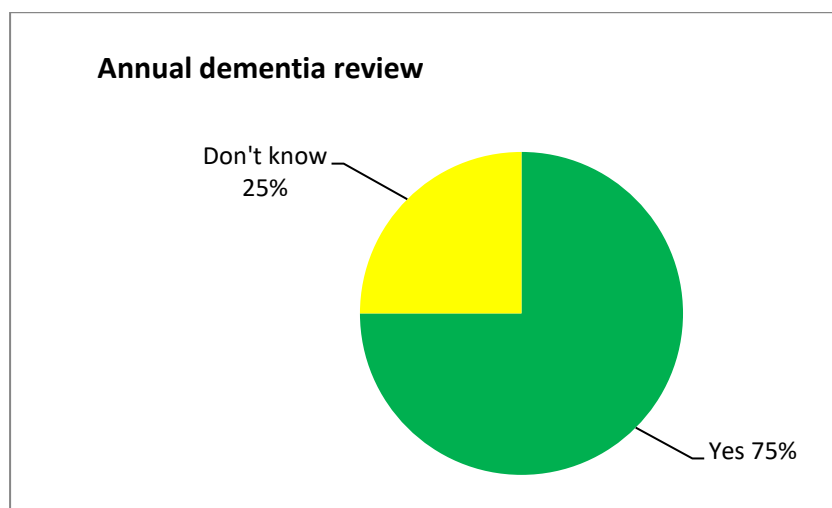
An equal percentage, 33% of parent carers feedback that a more flexible appointment system, more information, extra support though a follow-up session and a better diagnose of the need of MAS would help.

One parent carers suggested – *'more personalised advice'* whilst another commented – *'my mother refused help as she didn't agree with the diagnosis, and therefore it has been hard to follow up with this service, although the Alzheimer's Society has offered me appropriate support as her carer'*.

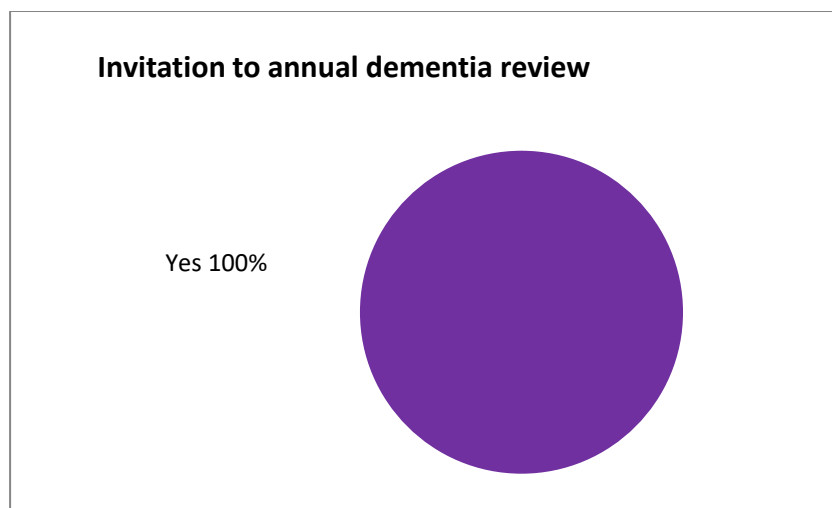
Whilst we consulted parent carers a similar recent report from Speak Out on 'Awareness of Dementia and Age Related Issues in People with Learning Disabilities' advocates for more information, accessible and clear advice. The report states that considering people with Down syndrome are predisposed to early onset dementia and people with learning disabilities are more likely to have secondary disabilities and conditions that become more complicated with age, those providing and planning medical care, accommodation, support and care are facing a growing challenge. They need to take in to consideration views and experiences of people with learning disabilities and their support network (*See Annex 4 page 4*).

6.6 Annual dementia review

A person who has been diagnosed with dementia will be offered an annual review. To the question *'Has the person you care for ever received an invitation for an annual dementia review at your GP practice?'* our respondents said:



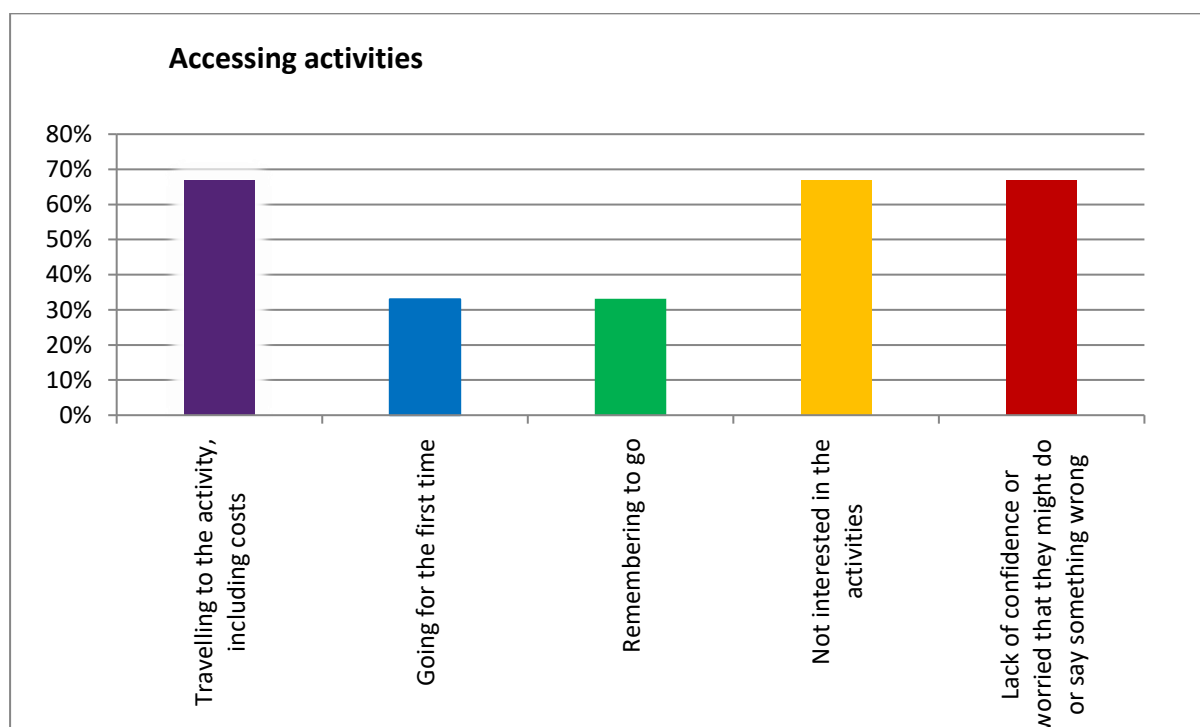
Overall 75% of parent carers who participated on this consultation reported been offered an annual review for the adult who care for. To further explore GP annual review invitation we asked *'If yes, have you had an annual review invitation from your GP every year since?'* Our respondents told us:



All parent carers who were invited to an annual review had then offered the appointment every year.

6.7 Accessing activities

One of the ways to keep healthy when been diagnosed with dementia is to keep active. We asked *'The local NHS has commissioned some mainstream activities, as for example, gardening, singing, cookery, music making and so on, to help people who have been diagnosed with dementia. What might stop the person you care for from taking part in these activities? Please tick all that apply'. Parent carers told us:*



75% of respondents feedback that travelling and costs, lack of confidence and worries about the adult they care for behaving 'inappropriately' stop them for

attending activities. A same percentage indicated that they were not interested on the activities been offered.

6.8 Impact, worries and difficulties

And finally we wanted to know more about parent carers' experience of looking after an adult with dementia. We asked *'The PaCC understands about the extra demands that looking after a child or young person with SEND and a person with dementia can place on families. Please tell us more about the impact, worries and difficulties you have experienced'*.

What we find out was that limited income and poverty experienced by many carers does have a huge impact on the quality and quantity of support they can offer to both their child or young person and the adult the care for – *'our family income has been the main thing that has suffered. I've managed to cover all the basic needs of both my twenty year old daughter (and son who is 18 but doesn't have additional needs) and my mother with dementia/Alzheimer's, but haven't managed to earn any real, significant amount of money for the past two years and have therefore been relying mainly on benefits'*.

And to reiterate an issue mentioned as the main barrier to accessing GPs, parent carers commented again – *'time'* and competing demands from looking after a child or young person and an adult *'the biggest issue is simply time... I constantly feel as though I am failing my daughter and my mum - they both have many appointments & neither can really go anywhere unless I take them - I know I should do more to help them stay well but I am always juggling competing demands'*.

7. Recommendations

- **GPs and Memory Assessment Service to offer parent carers a more flexible appointment system**
- **Respite to be put in place for children and/or young people so that their parents can take adults with dementia to their assessments and annual appointments**
- **Clear and accessible information on appointments to be provided when the booking is made**
- **Follow-up sessions to be provided after diagnosis and expand offer of activities to keep people healthy**
- **Better economic support for those parent carers who also look after an adult with dementia**

8. Annexes

Annex 1: PaCC engagement diagram

Annex 2: Dementia – questions

Annex 3: Parent Carers and GP surgeries in Brighton & Hove – January 2015 report

Annex 4: Dementia Speak Out Report