Empowerment healthwatch Blackpool

Blackpool Understanding Dementia

2019

COMMUNITY FUND

Community Futures Trust CIC

Introduction

Healthwatch Blackpool and Empowerment Charity worked together with an aim to establish and strengthen understanding on Dementia and experience in Blackpool. Part of this report is based on the responses of forty-six people in 2019 to a questionnaire co-produced by both organisations, alongside engagements with individuals, groups and care homes across the town.

Blackpool has the second highest prevalence of Dementia in Lancashire, which is significantly above the National Average. In 2016/17, approximately 0.76% (436,805) of the UK population were diagnosed with Dementia. In Blackpool that figure for the same period was 1.04% (2016/17 QoF). It should also be noted that only 488 people with a primary care need that relates to a dementia diagnosis solely are in receipt of social care services in Blackpool (Blackpool Adult Services 2019).

With this in mind, Empowerment and Healthwatch Blackpool endeavoured to use an approach involving more users in identifying priority needs, ensuring that those living with Dementia had their voice heard. The research looked to build up a picture of what it actually feels like to live with Dementia and to recognise the experiences of those residing within the Blackpool community.

Aim of Research

The aim of the research was to identify the needs of people living with and affected by dementia in Blackpool. The research sought to engage with the community, gathering views and experiences to make clear recommendations as to developments service providers could undertake to improve conditions for those affected by dementia living in the town.

Methodology

Empowerment Charity and Healthwatch Blackpool engaged with Community Futures Trust CIC to train peer researchers who could help direct the research, decide on engagement methods and implement research activity. Those trained were supported to conduct surveys, one to one and group interventions. Community Futures Trust CIC had successfully used similar methodology with other organisations and peer researchers have developed new skills in engaging with communities.

A draft survey structure was initially used as a basis to develop the research. The peer researchers were asked to confirm what methodology they preferred. There was a strong preference for using a survey, to be backed up by one-to-one interviews and focus groups for this research project. The group then undertook a research training and a scoping exercise, which resulted in a re-drafted survey with thirty-two quantitative questions backed up by twenty-three qualitative questions. Fifteen of these were for additional commentary following quantitative question answers.

The researchers agreed to have both an online questionnaire utilising Survey Monkey as well as hard copy surveys, which would be implemented with user groups to facilitate participation.

Empowerment Charity and Healthwatch Blackpool then set to work promoting, distributing and

assisting people to complete the questionnaire. Researchers were also keen to gather stories and experiences from those of who engaged to shine a true spotlight on those in Blackpool living with and supporting those affected by Dementia. Whilst the number of those fully completing the survey was lower than wished for, the qualitative data collected enabled the researchers to come to some of the conclusions and recommendations where the quantitative data alone was not sufficient.

Groups were largely targeted initially, with visits to the Carers' Centre, Day Care Centres, Dementia Hubs, Care Homes, GP Surgeries and Hospitals. The survey was also promoted to professionals in Blackpool supporting people with Dementia, and utilised social media to get the views of as wide a cross section of people as possible. This report is the product of this work.

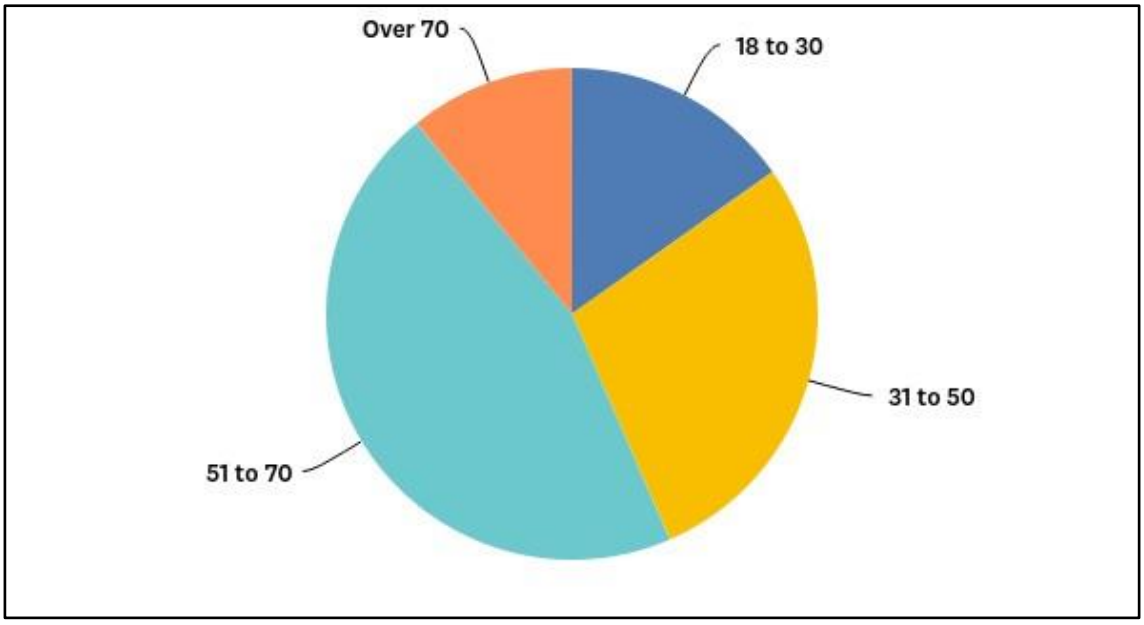
Throughout this report we use the term "affected by dementia" to include those who have, are caring for or are supporting people with dementia and their families.

Findings

Profile of respondents

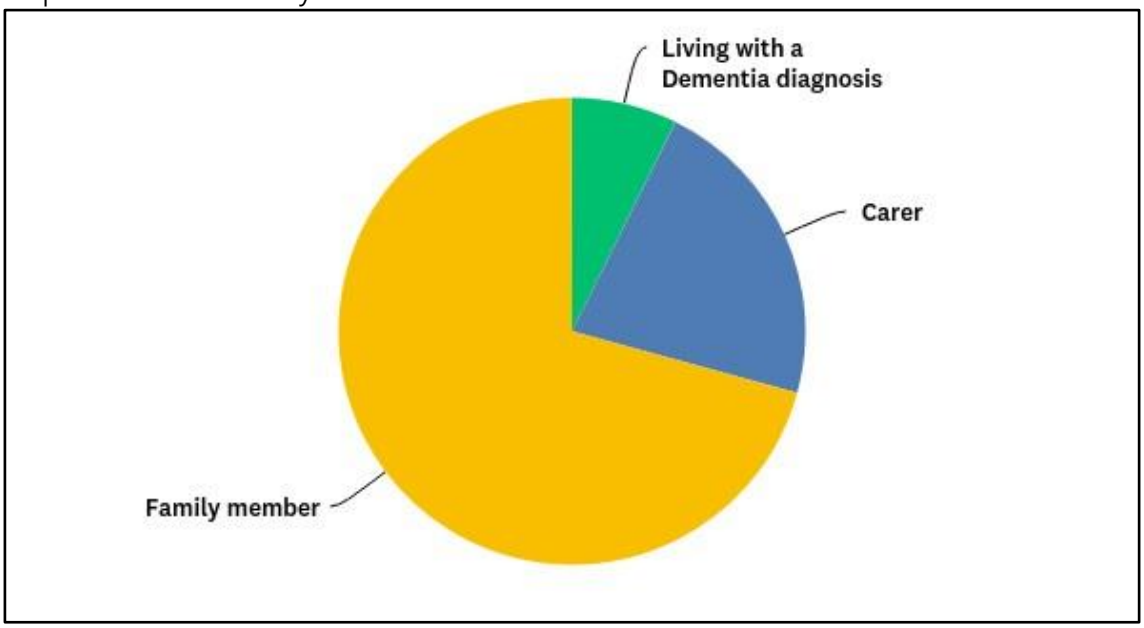
Age

Just under 58% of respondents were over 50, with all being over 18. Over 90% of respondents were carers, family members or friends, whilst completing it as far as possible with the perspective of the person living with a dementia diagnosis. Of note is the difficulty for those people living with dementia to engage fully with the survey, hence, this was backed up by over 30 one-to-one and group interviews.



How are you affected by Dementia?

The quantitative question asked people to define themselves and shows that the majority of respondents are family members or other carers.



However, responses given by people from further discussions included:

"On my own as a carer. Very limited other family support."

"I'm 11 years down the line now but I can say that I have got more help in the last six months than before. There's lots of arguing and fighting and advocating for what support is needed."

"I have problems with my memory and don't always know where the butter is but we get by."

"My wife was diagnosed with dementia. I know it is a gradual process and there is lots of forgetfulness. I find it hard work as she is incontinent; she is 80."

"*I am a carer for my Dad with dementia. He has repetitive behaviours and can often brush his teeth x6 times."*

"I have accepted that I have dementia. It's memory problems and can't remember what I'm doing, its forgetfulness. The Doctor diagnosed me and I come to Warren Manor for my husband to get respite."

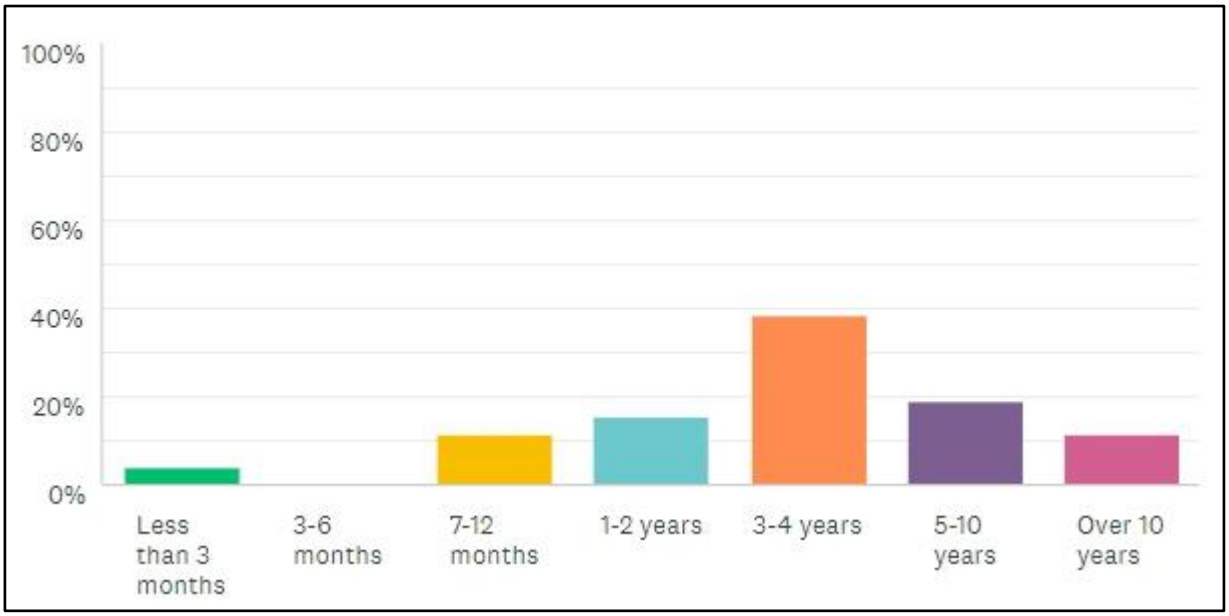
"I don't have capacity for answering questions because of my memory. But I like to talk."

"My Grandparents have had Dementia for ten years, I have learnt to join them where they are and not to mistreat them by trying to change this."

The researchers found a reticence to openly discuss the issue and, in some cases, a sense of unease responding to direct questions about dementia. In care homes many residents did not identify with having a diagnosis but even professionals were reticent to talk about their experiences. The lack of discourse in the survey also shows this reserve.

How long have you been living with Dementia?

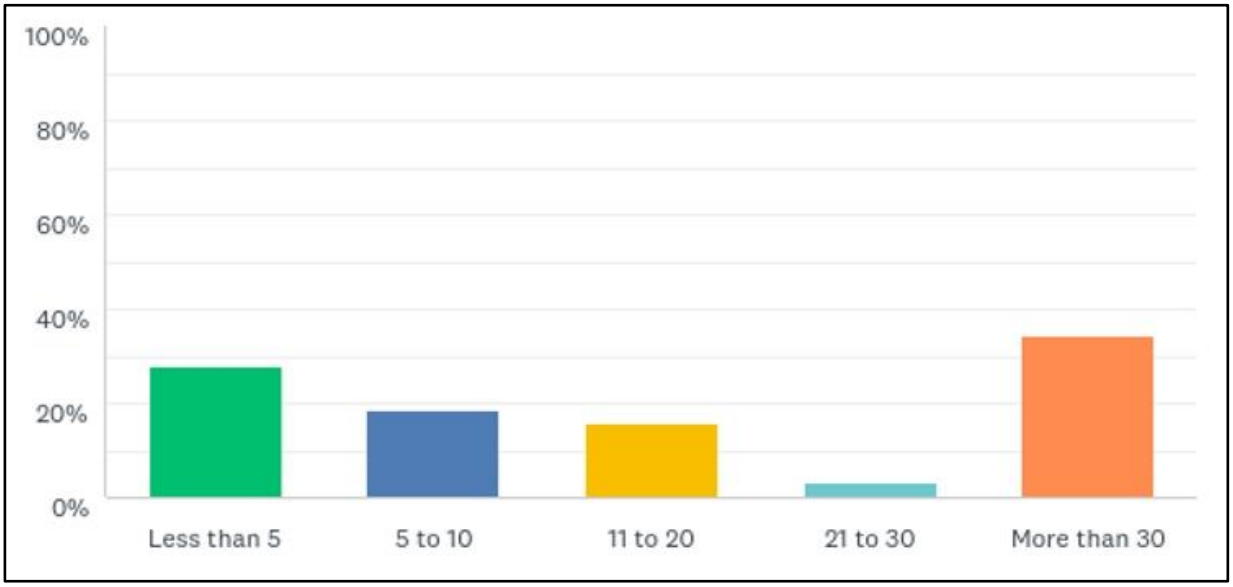
The majority of these respondents indicated that they or the person living with dementia had been diagnosed over a year previously. Indeed over two-thirds had been living with dementia for over 3 years. One of the notable points made by several people was the inability to access support services pre-diagnosis. More work should be undertaken to investigate how people can get earlier diagnosis including what marketing and publicity could help facilitate this. This must go hand in hand with de-stigmatisation, emphasising that diagnosis helps to improve quality of life.



"Lived with parent with dementia for 11+ years. Hard work, frustrating, worrying and stressful."

If you are a carer, how many hours per week on average do you provide care?

Over a third of respondents reported giving care for over 30 hours a week. This amount of care clearly takes a great toll on mental wellbeing, as can be seen from the comments given.



"It's exhausting I have no life of my own."

"It's a 24-hour job."

"I did a course at Beaverbrook House and also through the Alzheimer's Society years ago but it doesn't really help and prepare you for what to expect, what your life will be like."

"Getting through the daily routine is difficult."

"As a carer, I take it one day at a time. You don't, and can't, plan."

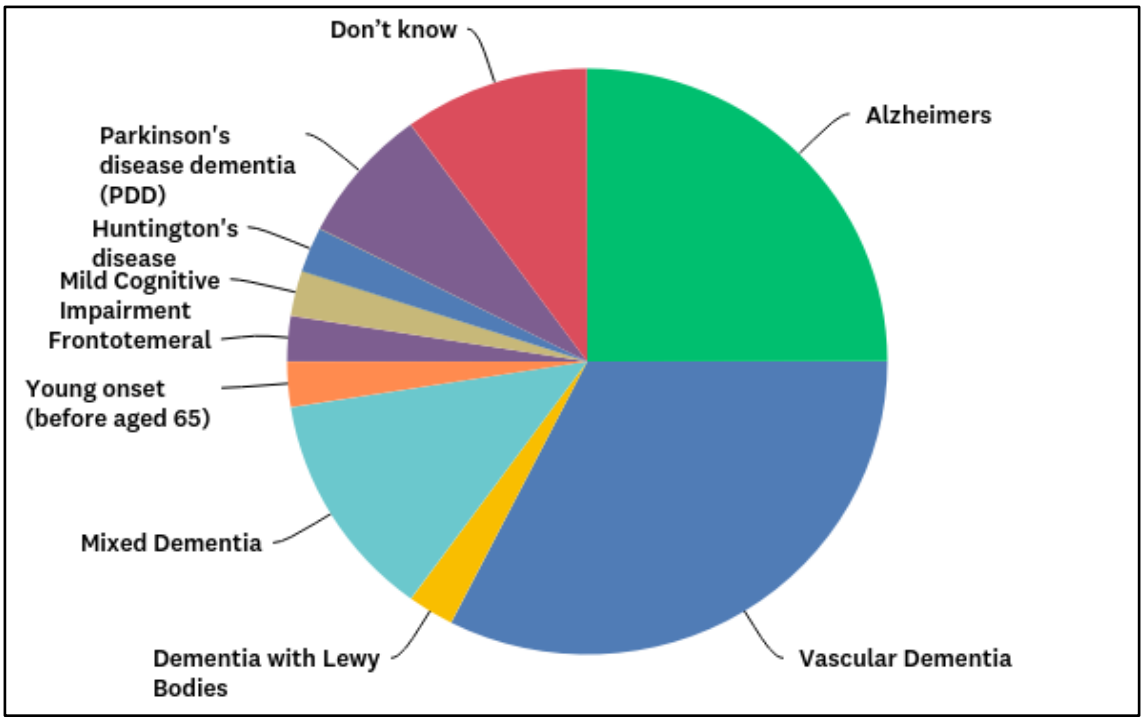
"Having dealt with my mother's dementia for the last 10 years, it's been hard, heart breaking, frustrating, soul destroying, unbearable at times and has completely destroyed my health and wellbeing trying to keep her safe."

There is, therefore, a clear need for respite provision, both short term for a few hours but also longer term, so that carers can get away for a couple of days. This is further addressed later in the report.

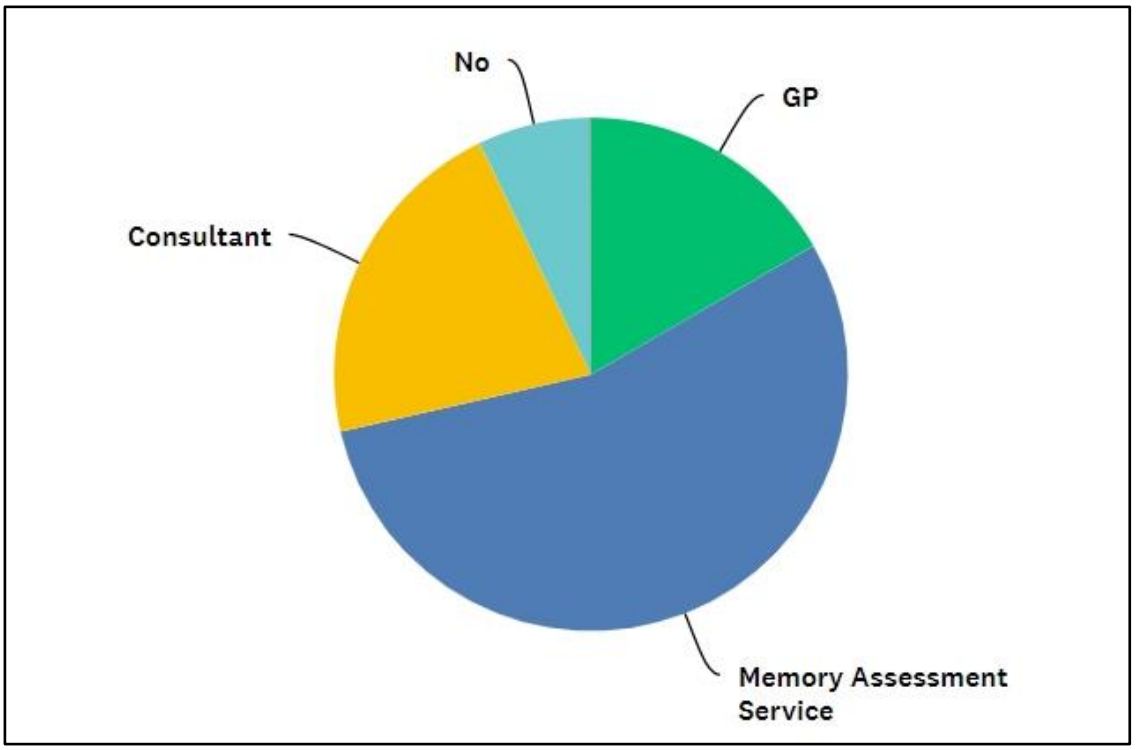
What type of Dementia are you/the person you are caring for living with?

Alzheimer's, Vascular Dementia or Mixed Dementia were indicated by 70% of respondents, which is not overly dissimilar to the national picture. 93% had had a diagnosis from a healthcare professional.

Type of dementia of respondents



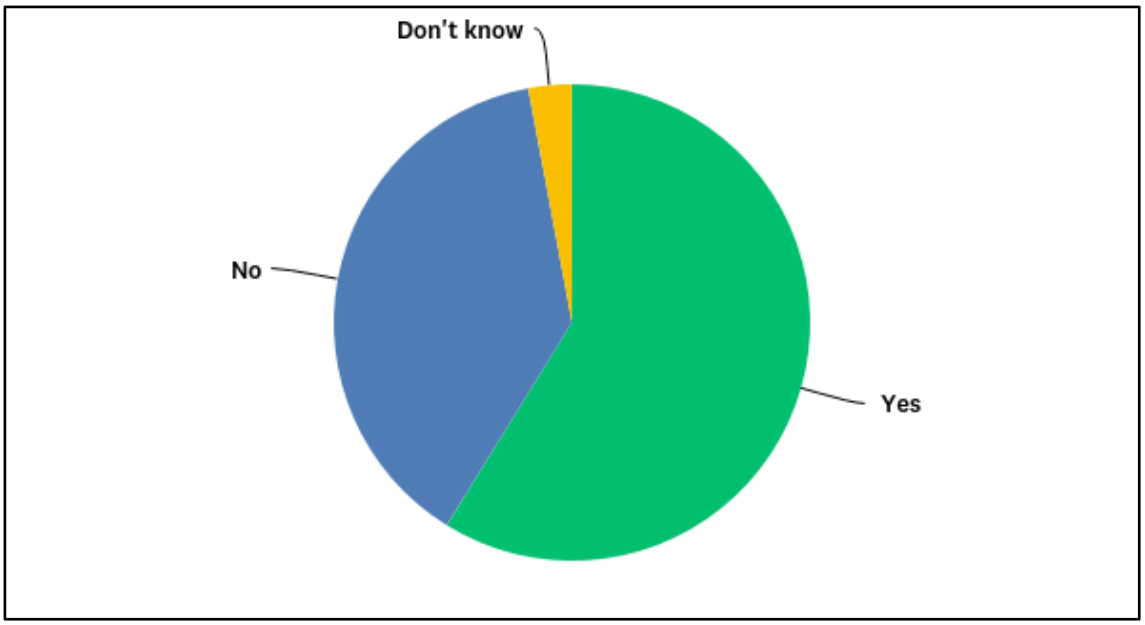
Has this been diagnosed by a medical professional?



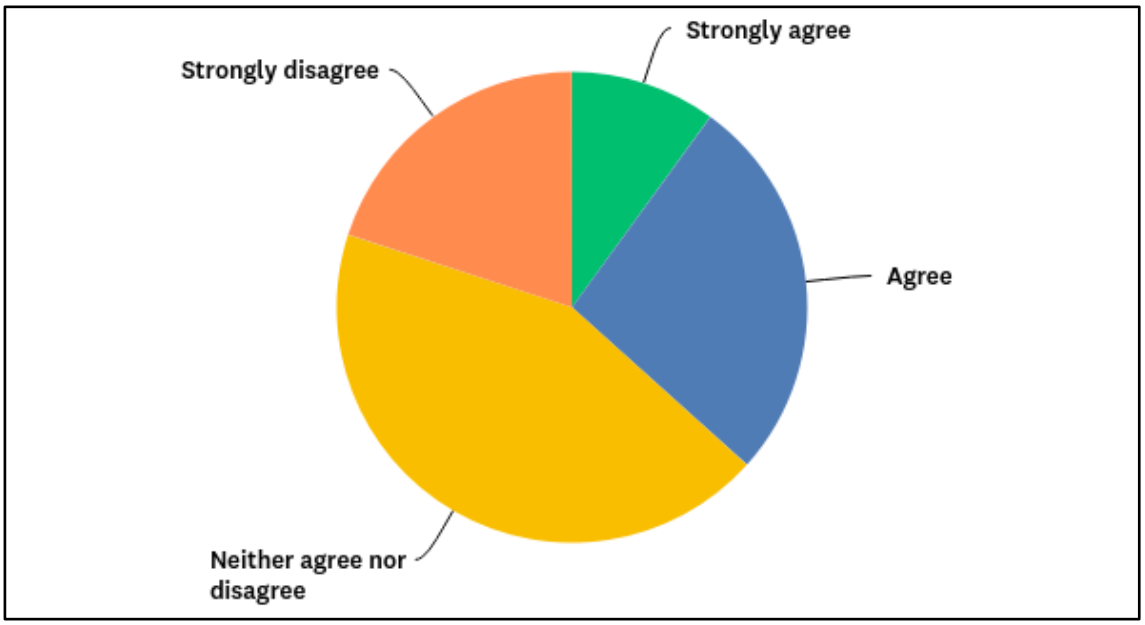
CARE PLAN

Is there a care plan in place?

Whilst 59% of respondents had a care plan in place, it is concerning that over 38% did not. It is also of concern that only 37% report understanding their care plan!

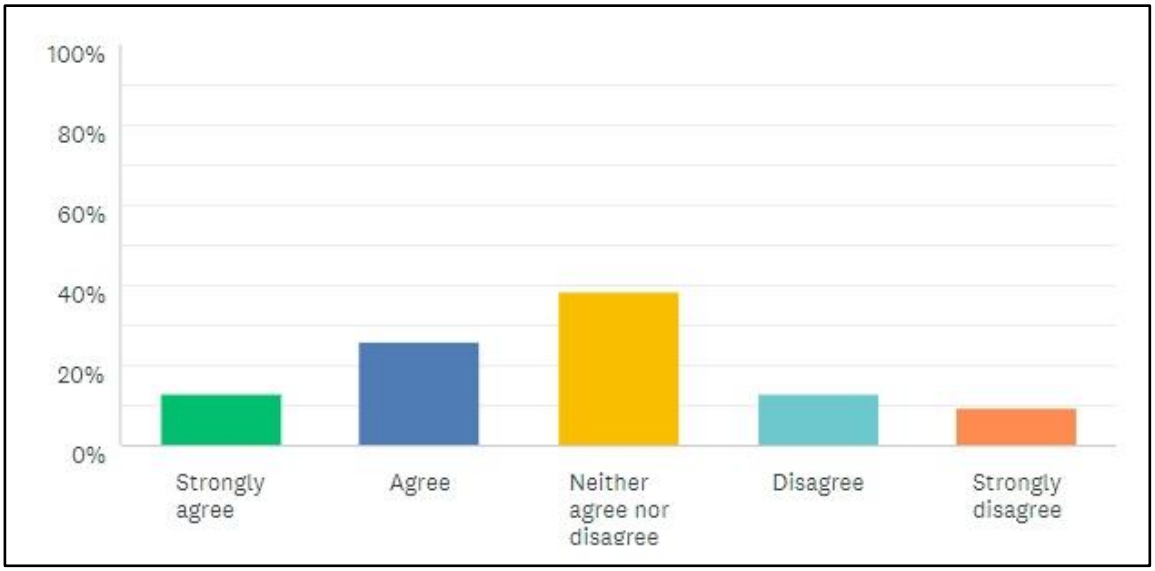


I understand my care plan

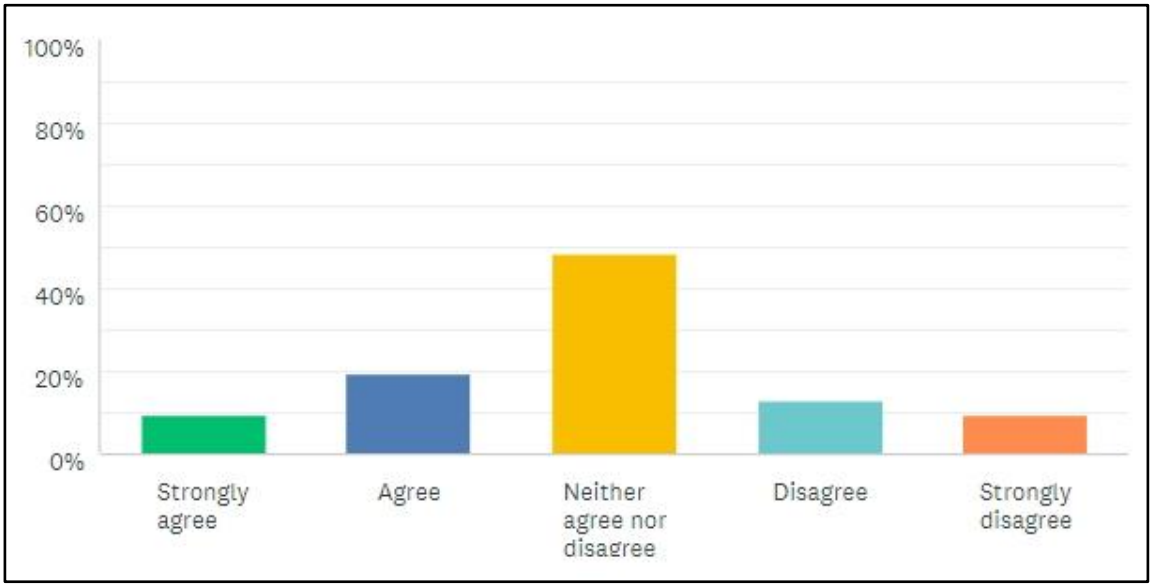


Over 22% of respondents said that they were not given the opportunity to be involved in developing the care plan, with a further 39% not being clear if they were or were not. 29% agree that their care plan is effective and meets their needs whilst 22.5% say it is not. Over 32% say that their care plan is never reviewed. What is clear from this, alongside qualitative feedback, is that the duty to ensure a care plan review is undertaken at least annually, as well as when there is a change in circumstance, is not being met.

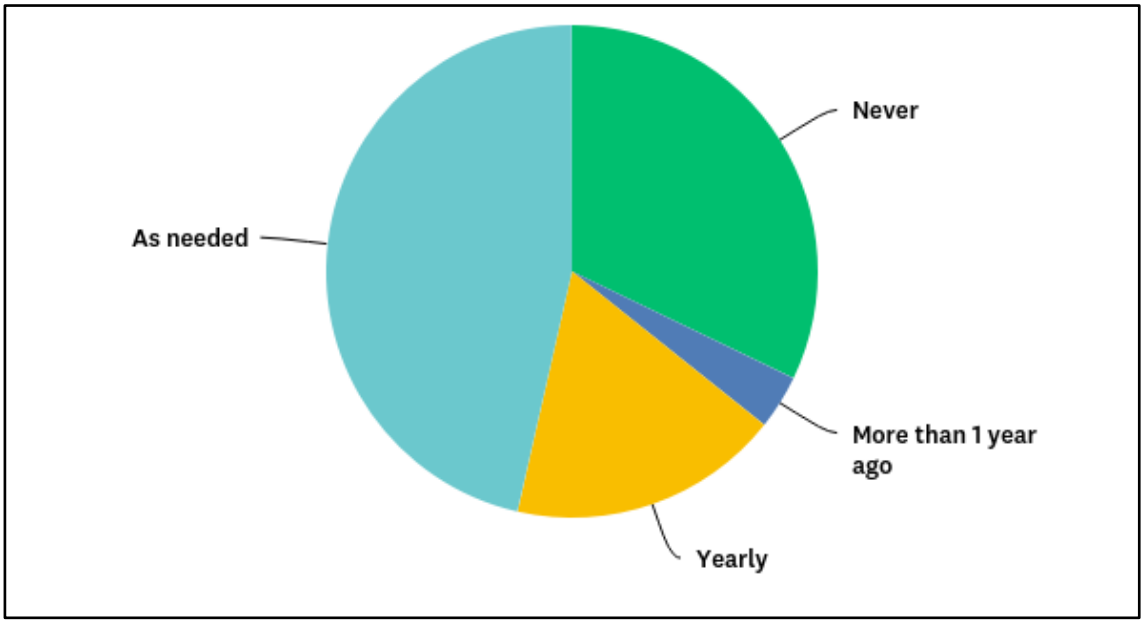
I was given the opportunity to be involved in developing my care plan



My care plan is effective and meets my needs



My care plan is reviewed



"Following an operation, I will be off my feet for about six weeks. My social worker is on annual leave so I spoke to a duty one. I was telling her that I will have trouble with personal care and showering whilst recovering she offered me a walking frame, this does not solve the problem. It's only going to get harder."

"You are just given a list of care homes and are expected to go and see them yourself. All of the homes that I liked are expensive. The Council will pay some but there are top ups for the good ones, obviously this then comes out of savings."

"The incontinence service couldn't help with incontinence pads/ nappies because he can walk to the toilet. I am washing bedding every day. It's a simple thing that would make things much easier."

"You are on your own. Sometimes I want to just shout HELP. I spoke to the social worker; I do

get respite units but I asked if a support worker/council worker could come out once a month or call to talk to both of us. I was told that they don't send anyone because they are too stretched and can't send anyone, it's out of the question because of funding."

"Both my parents have dementia diagnoses - myself and my siblings have never been made aware of any care plan for either of them."

There seems to be a need for those responsible for care planning to be retrained, both in terms of their responsibilities for regular review and in ensuring a person-centred approach. Whilst the researchers found several instances of good practice, there were more people unhappy with both the process and the outcomes. This is backed up by this quote from a Support Worker in Blackpool for post-diagnostic support, who is on the sharp end of seeing the consequences of poor care planning:

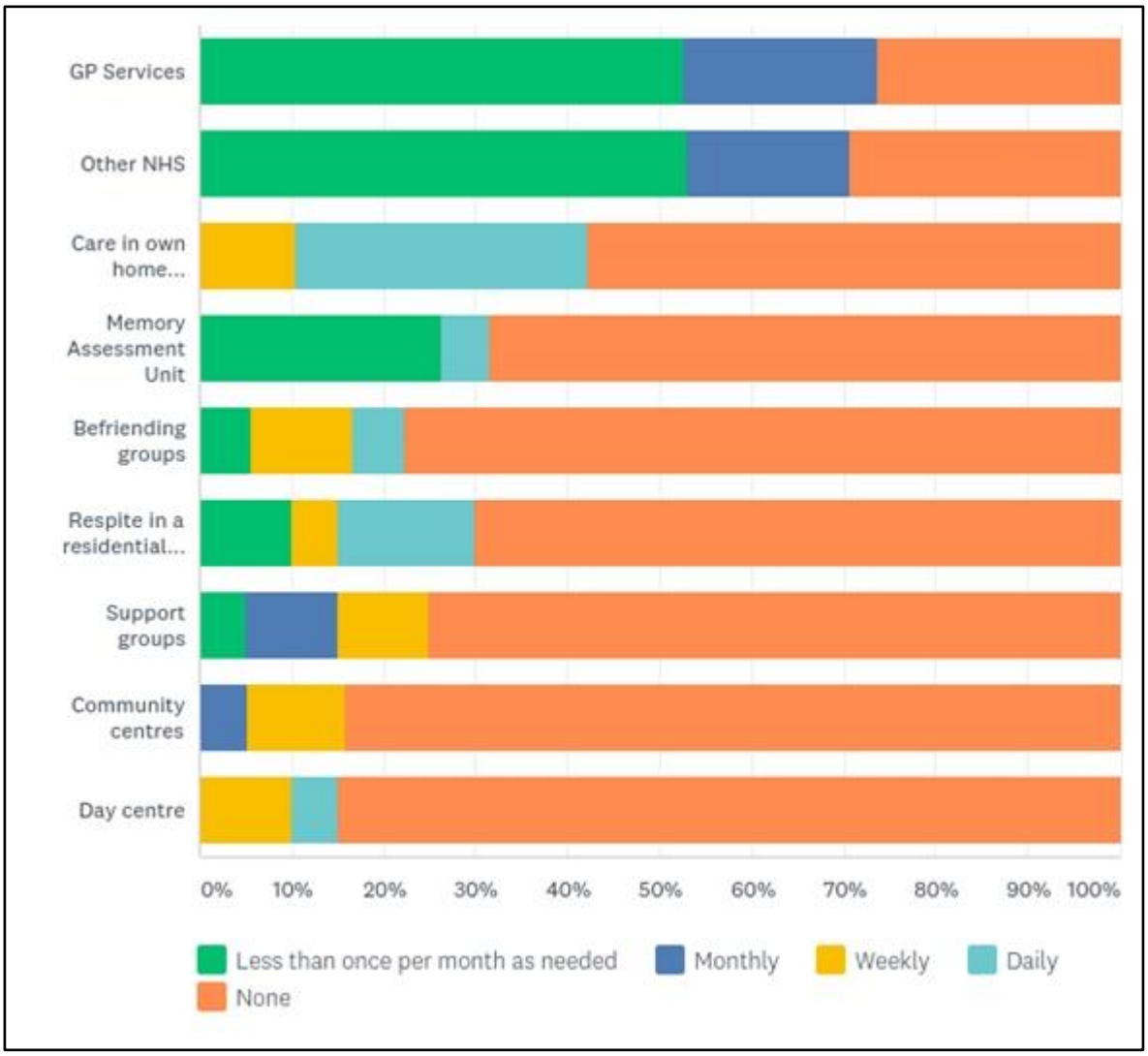
"Blackpool is one of the most deprived areas in England and would benefit from providing much needed support for vulnerable, lonely or isolated people often avoiding a crisis and further financial burden on government spending. This is a service that, if increased, could lower the urgent referrals to Social Services. It seems to be completely false economy not providing support for people diagnosed with dementia."

The opportunity to use care planning to ensure constructive and effective responses to meet the needs of people living with dementia and their carers should be central to the work of statutory authorities in this area. There should also be work undertaken to analyse themes arising from care plans to inform provision that should be in place, for both people with dementia and their carers. When gaps are identified, funding should be directed to fill these.

SERVICES

It is of concern to see a majority of respondents reporting that they do not use services that could be of great benefit to them. Whilst the vast majority use GP or other NHS services, there needs to be work undertaken to promote use of opportunities such as befriending and support groups and community and day centres. Alongside this, feedback suggests that there needs to be more such provision available in Blackpool. Design of these should be based on replicating successful provision, where possible, asking for help from those successful organisations. Singing for the brain, dementia cafes and advisory services appear to be well received in other areas. Healthwatch Blackpool received a supporting letter from a support worker at the memory assessment service noting the challenges for Blackpool (see appendix 1).

What services do you use and how often?



"Services are available but difficult to access until parent diagnosed. Took 3yrs through doctor to highlight as father answered questions they expected and fooled people to believe he was capable of looking after himself. E.g climbed 6 steps, make toast and tea but could leave gas taps on etc."

"I visited the memory assessment clinic at Shorelands, I've had two memory assessments so far. I have cognitive impairment it's called degeneration of the hippocampus. Nobody gives you signposting information and I don't have access to computers to look online."

"I am really bothered about my benefits as I have been refused PIP three times. I went to appeal and this was resolved thanks to the help of citizen's advice. I feel on my own since my diagnosis I have been involved with services historically including mental health as in 2011 I had a nervous breakdown."

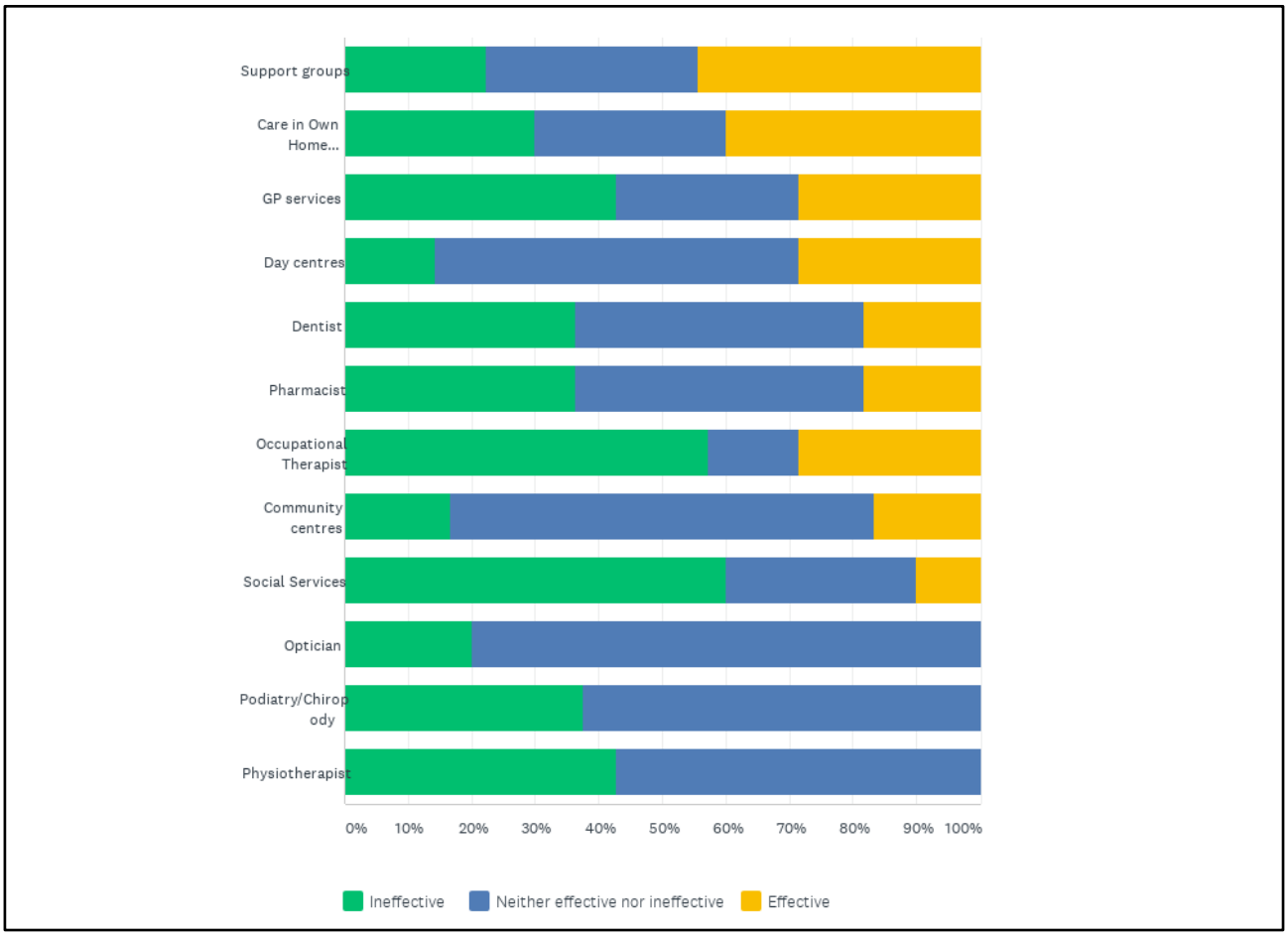
"It would be good if someone would give me a call every now and again to see how I am getting on. I come to the library a lot which is good but sometimes I get lost and don't remember where I live or where I have put something."

"It would be really helpful if I had the name of one person or one place with all the information

and advice I need. Sometimes I feel very alone especially now, I don't get the help I once did."

"I think there needs to be one place for information but apart from that I like it here [day care], they are good to me and it gets me out of the house."

Effectiveness of services



Feedback suggests that engaging with social care and occupational therapy has been particularly ineffective, with more than 50% of responding participants highlighting this. Community conversations seem to evidence the lack of funding for support with dementia. *"If they needed nursing (which I would argue everyone with dementia does need some level of) then nursing homes would be free to get in to"*. Some respondents highlighted that it is often particular members of staff that have made an interaction/service a positive experience.

'COPD nurses visit Mum but they don't deal with Dementia'

'We were given advice regarding the stroke first, not the Dementia'

'The nurse was brilliant in giving advice for swallowing'

'The speech and swallowing clinic, really helpful'

'I've really benefitted from 1:1 contact'

'GPs tend to categorise Dementia and that's hard as everyone is different. It's an uphill battle'

'The opticians are really good'

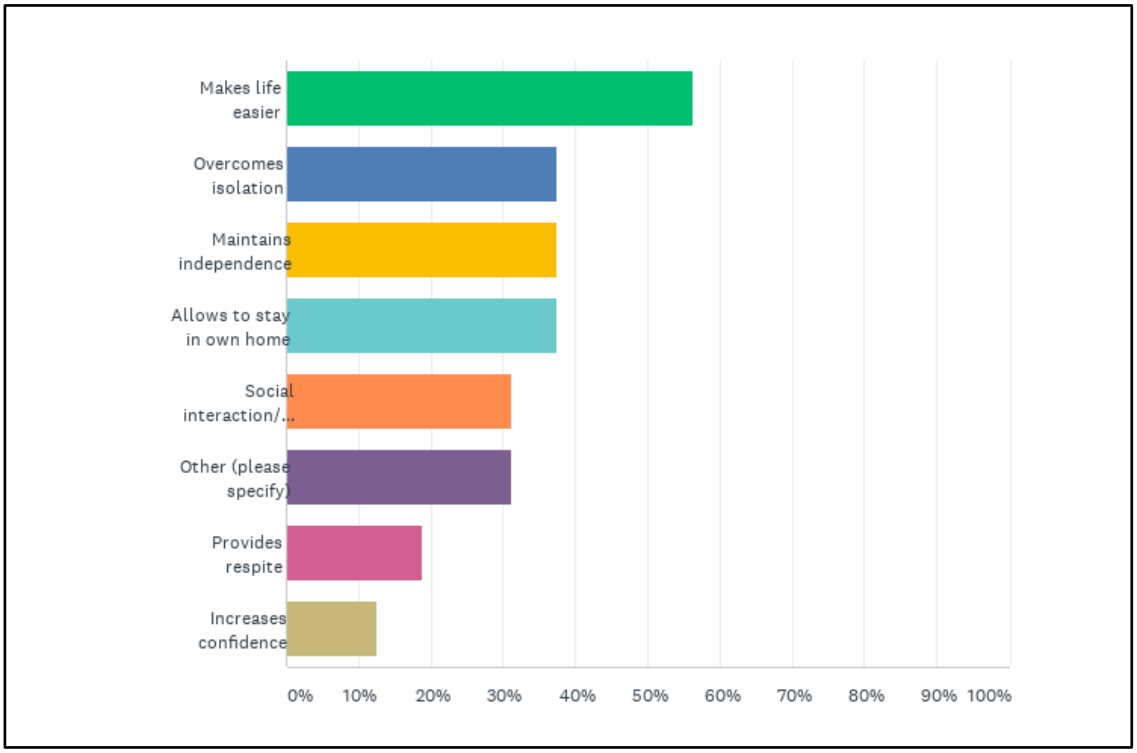
'The dentist is OK now. I had to pull him to one side and remind him that my husband has dementia because he was having a go at him for not brushing his teeth'

'Sometimes on the phone it's like talking to robots, if you don't fit they give up'

'I feel like social workers don't have any idea of what they are dealing with'

'Dementia is a terminal illness and many people forget that. They talk to you like you're an imbecile'

How do you benefit from these services?



Services and community support have largely been described as 'making life easier'. It appears however, that some participants struggle to find and access Blackpool specific services. *"We went to an Ncompass coffee morning once, we were allowed to stay for that one but not go back as it wasn't for Blackpool residents"*. Accessibility and the 'postcode' nature of service access seems to be a barrier. Some comments evidenced the need for talking and the value in friendships. Services and peer support have been described as a lifeline for some. More community engagement may support those who feel isolated since diagnosis.

'It's great to see people talking, when people first come here no one talks' (day care centre)

'When we attend the Singing group (Fleetwood) I talk to other carers, mainly partners of people with dementia, the group is a life line to them as they are able to get out and join in and meet people so I think more groups like that would be a bonus'.

'It's important that people know what's happening'

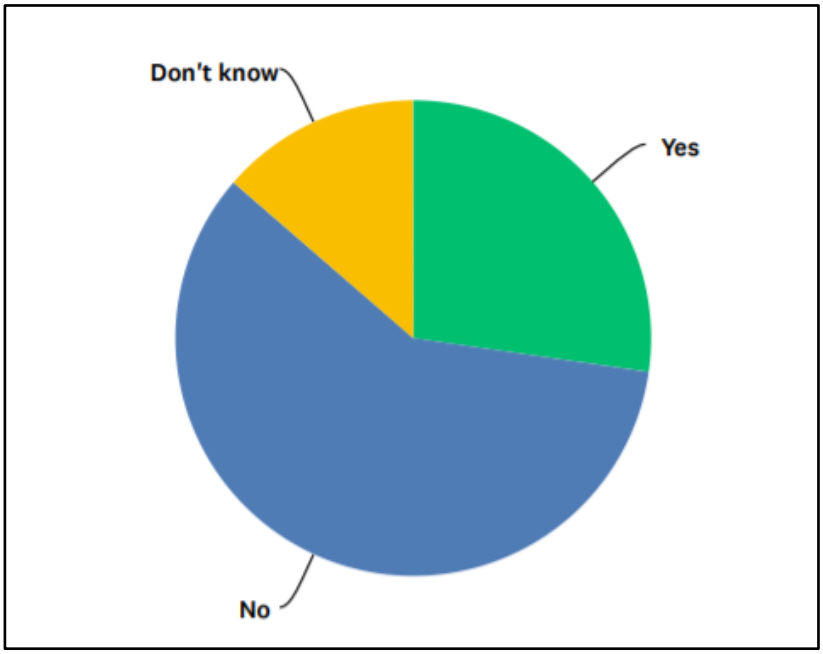
'Friendship and talking is so important'

'Once he was diagnosed it was easier to get support, it was difficult before this.'

'Services in Blackpool are extremely stretched'

'Mum enjoys the singing; it's nice to meet other carers. X advised there is currently no similar group in Blackpool. Me and Mum and I think the carers and service users would agree we benefit greatly from. It is a social and uplifting group to attend and we all get something out of it'.

Financial Support (Local authority personal budget)



"I have been given a personal budget to manage some respite care, although the council will only fund up to a certain amount per hour, I don't mind topping up to what the care company charge. It is just a shame that it's not enough to cover 3 hours a week for a whole year. However, I am very happy just to get a break".

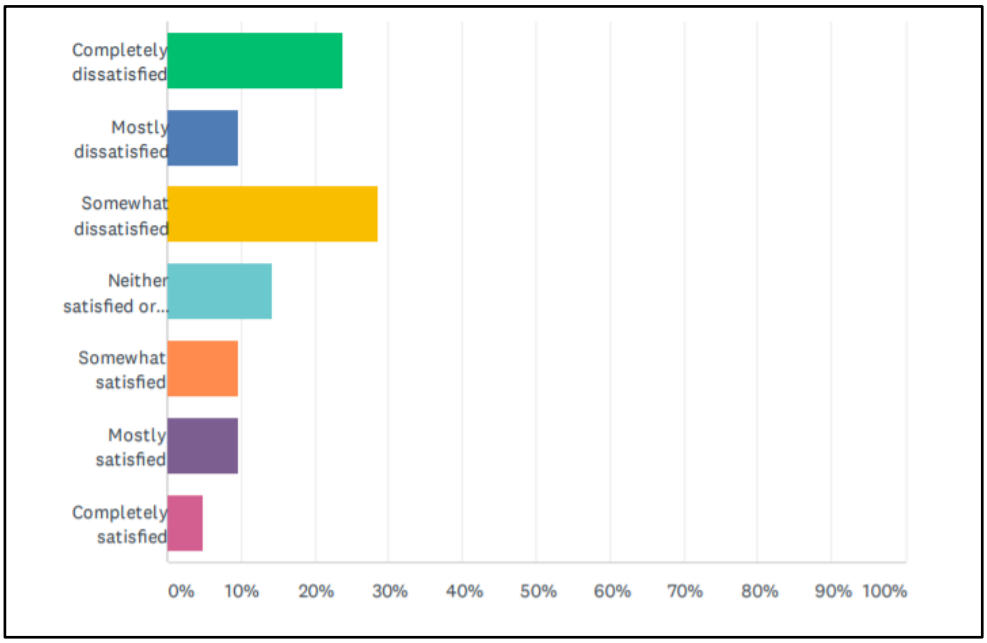
'All of the care homes that I like are expensive. The Council will pay some but there are top ups for the good ones, obviously this then comes out of savings'

"'I get a good pension and am happy with my services'

'You seem to be told nothing when you are diagnosed. There needs to be more information on benefits and council tax allowances'

'I receive attendance allowance and care for my wife'

Satisfaction of care and support



Inconsistency of services and difficulty accessing pre diagnosis have been relayed within the feedback. Respondents have noted that navigating and finding support has been a challenge. One respondent highlighted that support had not been made obvious from Primary Care. Care planning and carers support appear to have been key to getting the right person centred support. The difficulties highlight the concern for those who live alone or who may have struggled to get a diagnosis.

"Blackpool Carers service for carers. This is a fabulous service for the carers"

'Many of my patients live on their own. We offer a short-term service. I struggle to find a service that will 'pop in' and see patients to see how they are, checking that they are eating, sleeping, medication is taken'.

'Professionals are unaware of people with dementias needs'

'I've had no support for years, now she attends day care'

'Services are good once they are in place, would be good if we had faster referrals'.

'What is out there for carers and how they go about obtaining? , I work in the Primary Care setting I was aware of some services and to get in touch with the Council in order to get mum assigned to a Social Worker who could give advice regarding respite and help with activities of daily living. This was not made obvious when Mum was diagnosed by her GP, although the Memory services did assign a mental health worker after initial diagnosis but there is a lot to take in re: meds and lifestyle'.

'It's not individually assessed, you are not treated with compassion, social services are extremely difficult to deal with and do not understand the impact it has on the carer or family'.

'No help/support. Carers allowance now allocated but no help, advice on agencies and how to

access care'.

'Finding out what support is available is difficult. We asked GP and they were of limited help, but since then we have been contacted by Extensive Support (out of the blue) and they are proving very helpful'.

'Once assessed and diagnosed only interested in commencing medication and not always listening to real home situations. Difficult to talk to professionals in front of mum as mum very distressed and this made her worse'.

'Although my parents' GP surgery are aware of their ongoing difficulties, there has been no attempt to reach out to me, my sister or brother to tell us what other support is available. We have to try to negotiate our way through as best we can'.

'I feel isolated. Unless my Mum has an accident or is unwell the only contact we have is once a month from the district nurse. Mum does not want to go out full stop. I have no other support'.

'Care & help has been inconsistent. You never seem to see the same person. Carer's sent do not seem to understand the person's needs or arrive at inappropriate times'.

'Diagnosis could have been quicker, struggle to find home for weekend respite'

How to make things better

'More understanding, a fairer financial assessment, more support for sole carers, more research and training on how to deal with dementia patients and a much better care for elderly patients'.

'Respite'

'As a carer, I find there is plenty of advice about making the disabled person feel happy and comfortable, but nothing out there to actually help the carer deal with the stress and frustration we experience'.

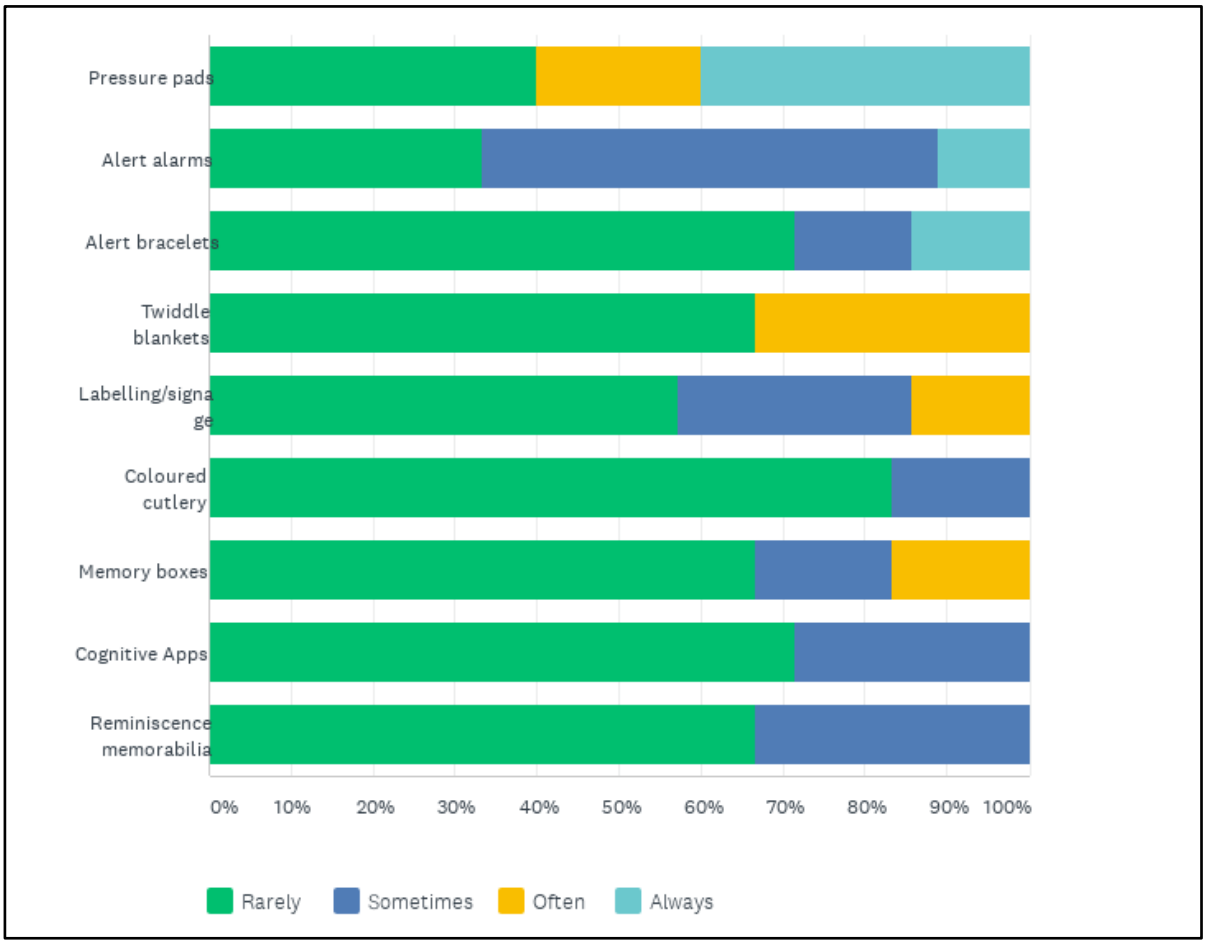
'The diagnosis was long winded and took the GP long time to pick up on despite a couple of visits to the surgery to try and get a referral'

'Opportunity to speak to professionals separately'

'A service that could look at their home situation and provide advice to us (family members) as a whole. The provision is very fragmented and we have tried to navigate our way through the services the best we can'.

'Talking through a care package & making sure family members are there when this is discussed. Better services for carer's for support for them'.

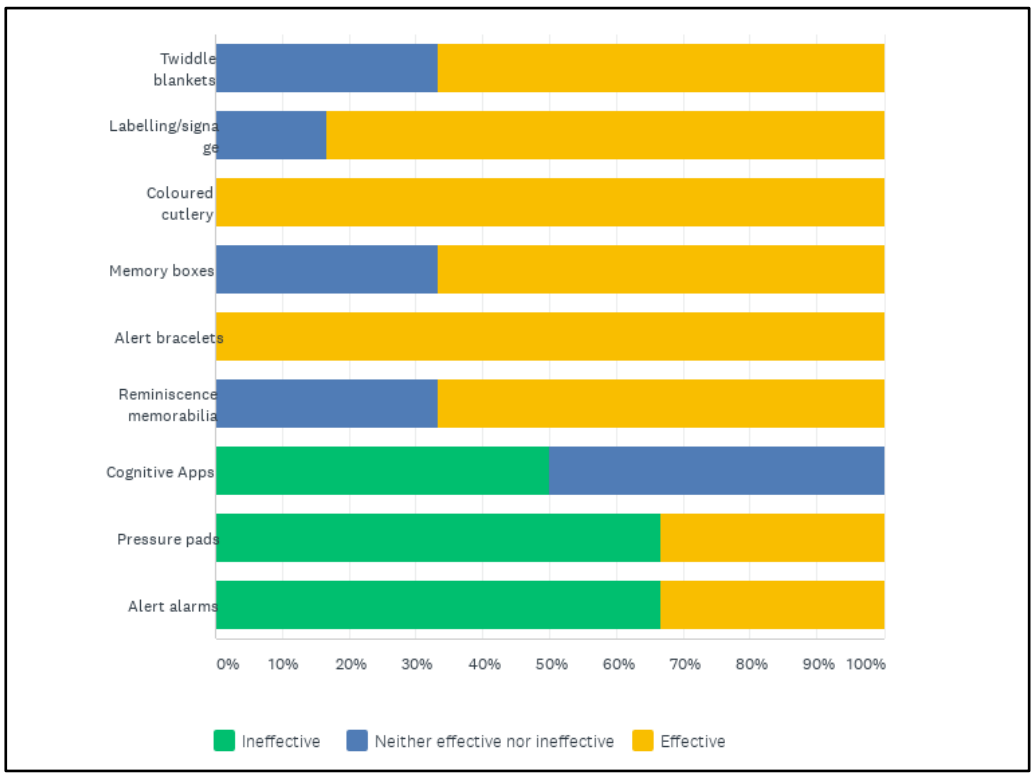
Aids to support



'999 Re:unite has been launched in Blackpool , Fylde and Wyre it is a band that has an NFC tag inside with details of emergency contact. Feedback has been positive; it's a twelve-month pilot'.

'I have one of these bands because my memory is getting worse'.

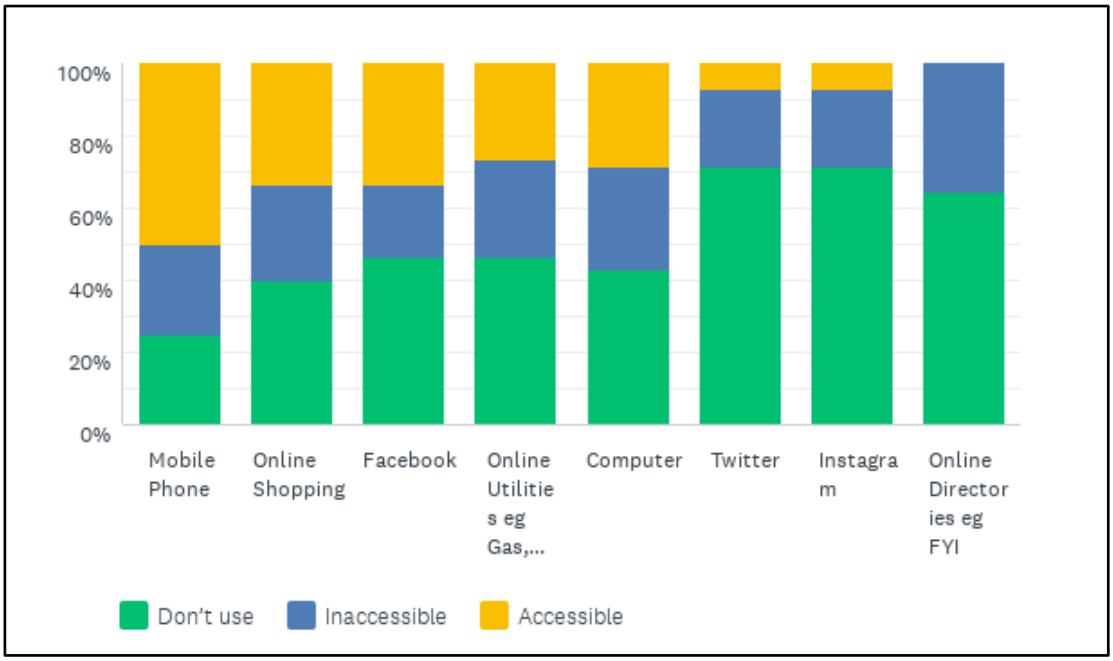
Effectiveness of aids to support



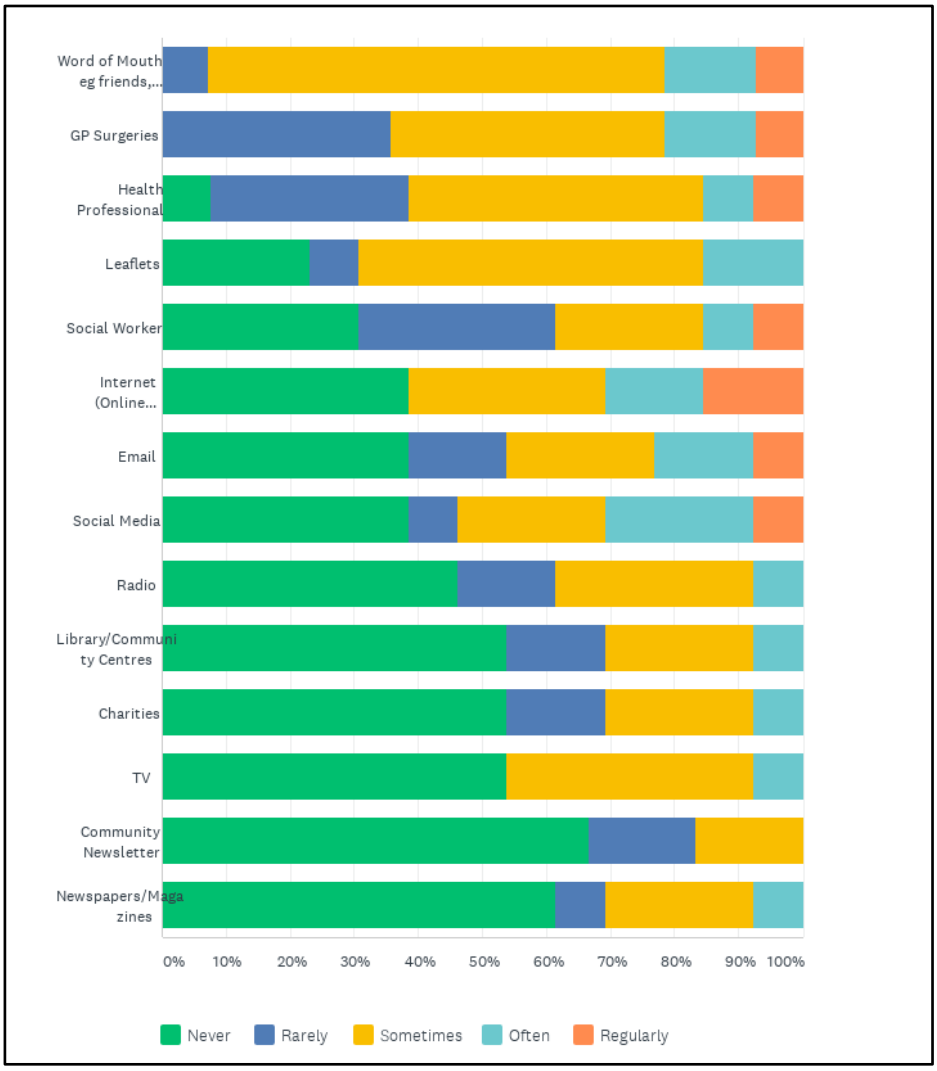
'I am currently trying to help Mum get used to her medicine blister packs'

'The memory book is great to settle her with and reminisce about her past life where she talks about a lot'.

Digital accessibility



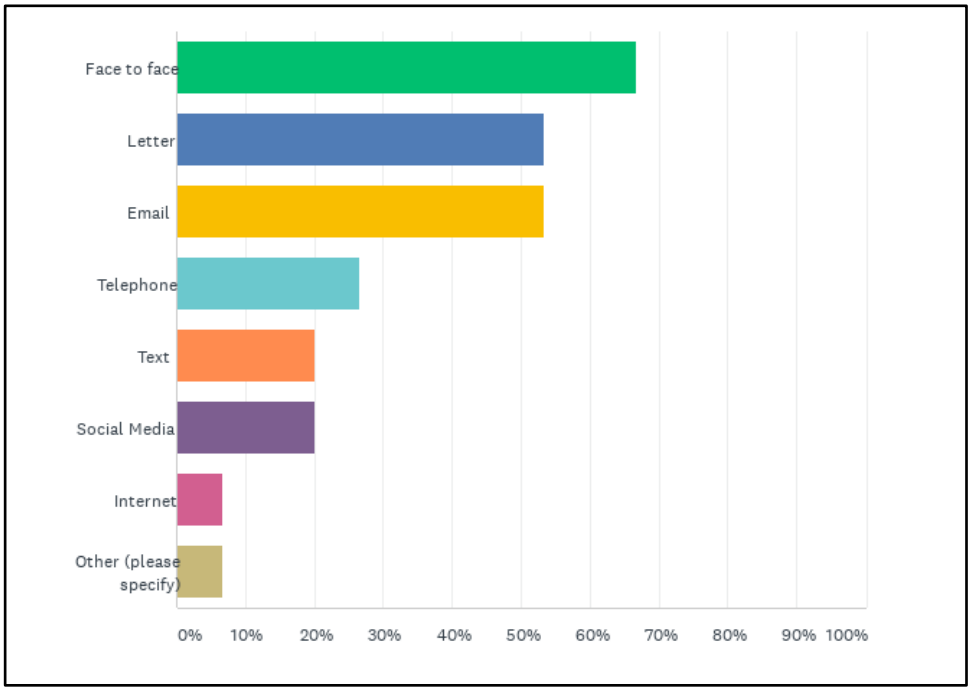
How do you find out what services are available?



'How can we promote 'living well with Dementia' if we cannot provide the basic services the people of Blackpool deserve which stood in mid-2018 over 25,000 over 65 year olds'.

'Services need to be more openly advertised. It's difficult to find out what's available'

Preference for receiving information



'I have really benefitted from one to one advice and support'

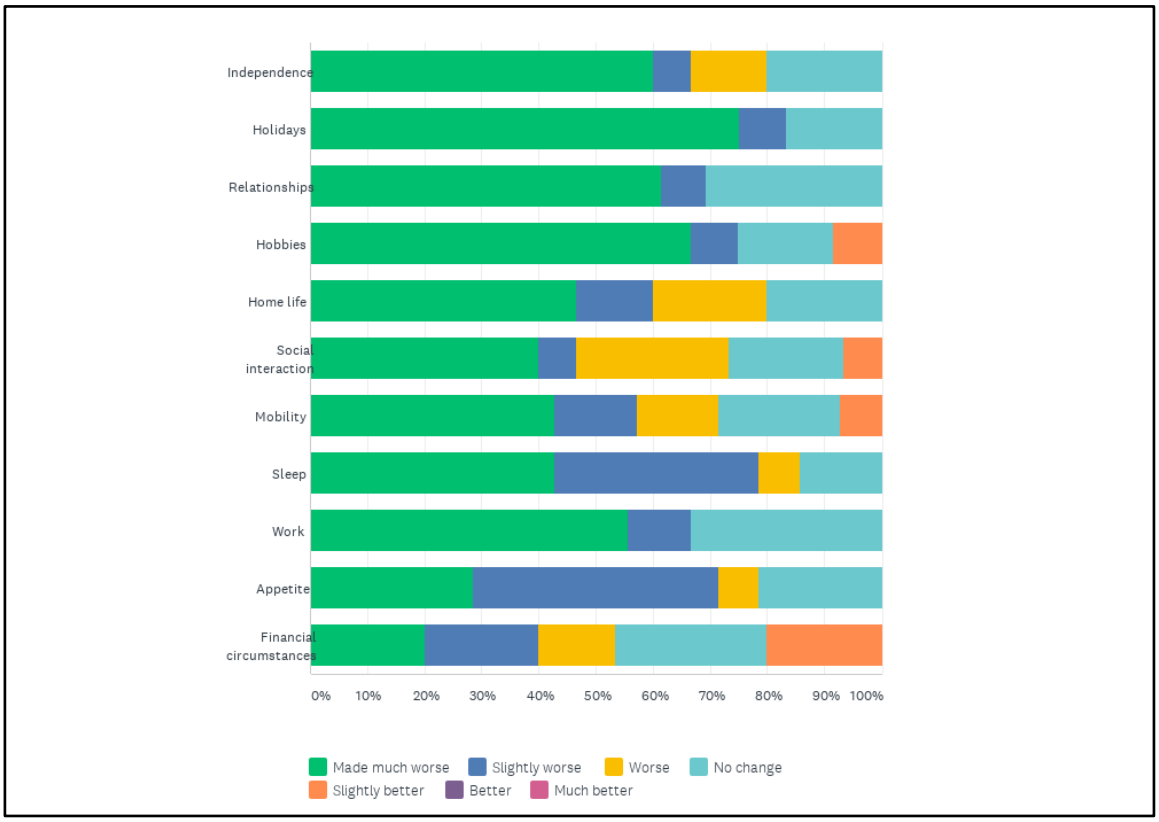
'When he was first diagnosed we were given lots and lots of leaflets to read. I was overwhelmed as I was upset at his initial diagnosis'

'You are on your own, services are stretched and they can't send anyone because of funding'.
'Having someone to talk to is really important to us'

'People don't know what it's like until it affects them directly. The Dementia Hubs are good as you can speak to people face-to-face'

'Difficulty talking openly when husband with dementia present'

How has dementia changed the following?



'It's a 24-hour job'

'It's stressful and upsetting'

'I'm not sleeping at night'

'Sometimes I can't do right for doing wrong. I have had to leave my job to care'

'There is lots more to it that just losing your memory. You have to take one day at a time, you can't plan anything'.

'Mum says I'm poisoning her'

'I use a medication dispenser to keep her safe'

'I'm often wasting money as it's hard to predict what she will eat'

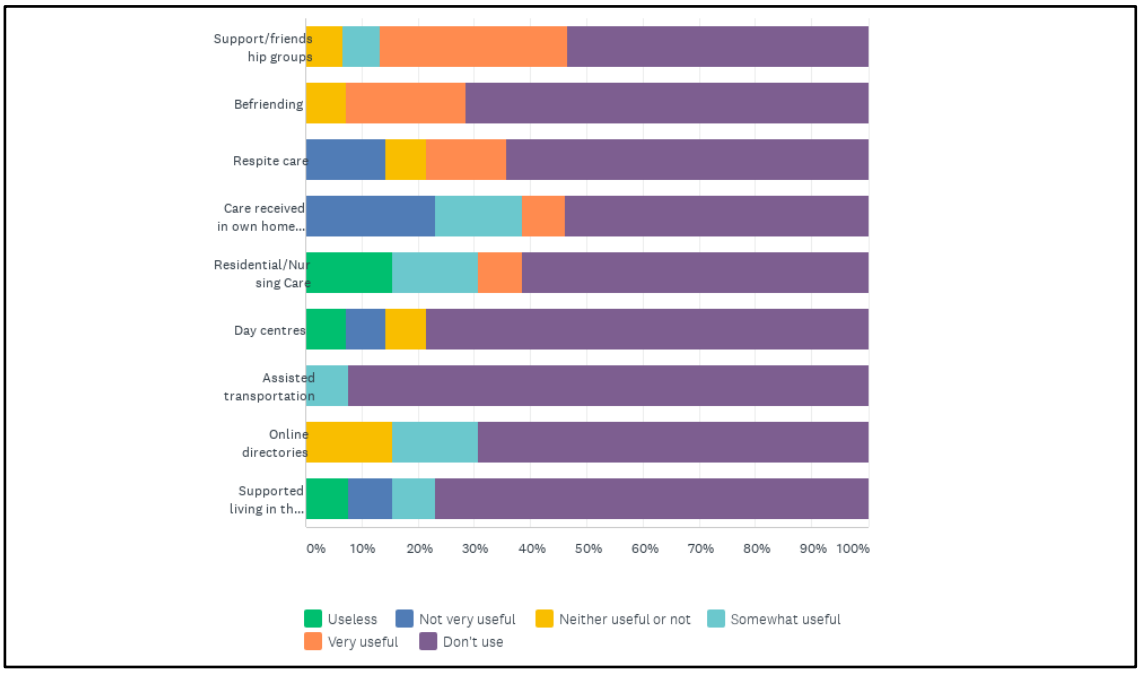
'It's hard to say the right things; I get my head bitten off'

'We use ensure as he's not a big eater'

'I have to buy the 'right marmalade'; you can't do right for doing wrong'

'Swallowing can be hard'

Usefulness of support



'Warren Manor day care is good; my husband enjoys it'

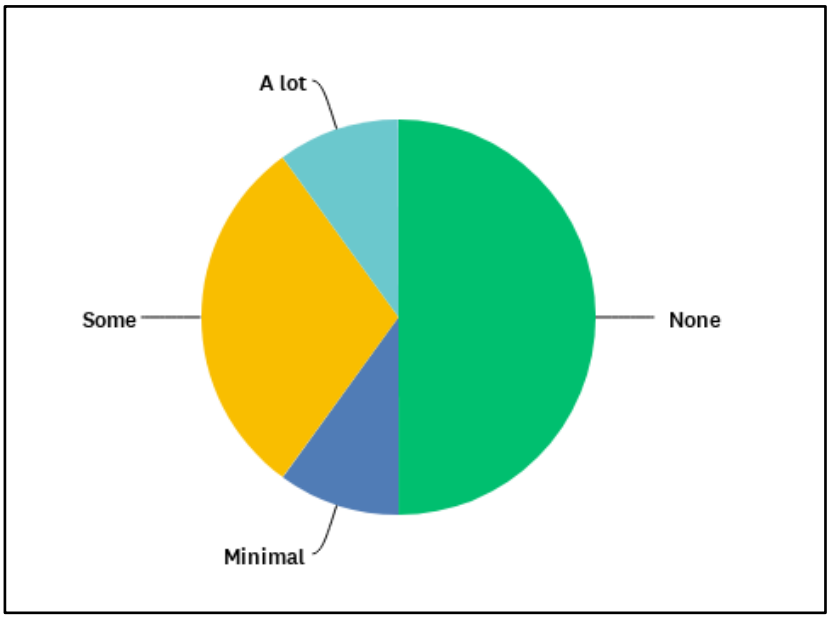
'Age concern used to have a befriending and sitting service so I could go to the hairdressers and my own health appointments. It doesn't exist in Blackpool anymore'

'Coming to this group is good because I know I am not on my own. We play bingo, drink tea and have a chat'

'Many people in Blackpool are living alone. I struggle to find services'

'We love singing for the brain. It's a social and also uplifting group to attend and we all get something out of it. Hope you are able to get a similar group in Blackpool'.

Carer support



Training

'I did a course at Beaverbrook House and through the Alzheimer's Society years ago but it doesn't really prepare you for what to expect and what your life will be like'.

'Professionals should give information at consultation'

'GP's signposting to dementia training before diagnosis would be helpful'

'The carers centre course is 100% worth it'

'As carers we need more than just a pat on the back when attending appointments'

What could improve and make life easier for carers

'More support and understanding and compassion'

'Support and respite'

'Flexibility re: work to take time out to visit Mum. Lot better now in care as know she is safe. Work have been very understanding but as part time difficult to keep asking for time off. We also struggled at weekends if we wanted to just go away spontaneously so we took in turns to look after Mum'.

'Joined up package of care for both parents'

'Approaches to dealing with stressful situations'

'There needs to be more practical and emotional support for carers'

'I feel that there needs to be an ongoing assessment by professionals as to what stage of dementia the person I care for is at. It's extremely isolating and I have limited family support'.

'More respite options are needed'

'I feel that more help is needed to plan for the future, for example incontinence and how it will impact the wellbeing and what practical support is likely'

'I think that someone else should decide when changes are needed, for example what care is in the best interests of the person'.

'The care system needs sorting soon'.

'WE are lucky as a supportive family but feel sorry for husbands/wives with no immediate family who really do need a break from the caring role'.

'I think all the services I have encountered since my Wife's diagnosis are doing their best to help and support us. I am very grateful'.

Conclusions and Recommendations

The aim of this pilot was to encourage peer researchers to find out what it is like to live with Dementia in Blackpool. The feedback above provides a clear insight into some of the issues experienced by both people living with dementia and those that care for them. Professional insight has also mirrored feedback provided by carers. The responses have been invaluable and we are grateful for all participants who shared their stories. We recognise that talking about dementia is particularly difficult and in some cases extremely emotional.

This pilot has highlighted the following recommendations:

- "What could be done to make life better for you?" Receive an advisor or advocate helping people navigate the systems and their rights and entitlements.

- Communicate what is available – it is clear that there is a need to do better in informing people of the Dementia Directory and other resources. However, there is recognition of a major lack of support services, especially social groups, in Blackpool, which becomes very apparent when comparisons are made with the rest of the Fylde coast and other areas.

- Best communication is face-to-face but there continues to be a need for hard copy information to cut through the noise of electronic communication.

- A process needs to be established so that sharing of useful literature from the Alzheimer's Society and other agencies, whether national or local, is undertaken for those living with dementia.

- The lack of carers receiving training mainly appears to be due to a lack of communication rather than availability. Low-tech solutions need to be explored such as producing hard copy literature; phoning round; visits to community groups and care homes; press releases to newspaper; radio and TV; billboards.

- Carers support appears to be an area for development. Carers fed back the limited support that they have received from social care including the lack of funding and time for respite and support.

- There is a need to reduce stigma, possibly exploring humour, music and drama as a way of reducing fear around the issue e.g. 'Singing for the Brain' or a video of a comedy routine by people dealing with dementia or sharing the films 'Head Full of Honey' and 'The Notebook'.

- Participants noted "It would be really helpful if I had the name of one person or one place with all the information and advice I need."

- Training in dementia awareness needs to be considered along with further support for primary care, health and social care professionals so that people with dementia are assured and understood.

We look forward to sharing this report with our statutory partners and working closely to understand the lessons learnt whilst amplifying the experiences above.