

## Facing it alone: experiences of dementia support

A report from Dementia UK November 2020

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## Foreword

#### **Dr Hilda Hayo,** Chief Executive and Chief Admiral Nurse, Dementia UK



Many families affected by dementia were already facing a lack of adequate or available support, even before the Covid-19 pandemic. Now, many families are reaching breaking point. Many feel they can no longer cope. Families feel they

are facing dementia and Covid-19 on their own.

Last year when we carried out our initial research, looking at support for families following a diagnosis of dementia, the findings were sobering. Families told us that they did not have access to the information and support that they needed. The Covid-19 pandemic has greatly exacerbated these challenges, both for families affected by dementia, and for the health and social care professionals who are trying to deliver care and support under very intense pressure.

As a clinical charity, we are concerned about the greater level of unmet need that we are seeing on a day to day basis. We continue to hear from families who are really struggling, and GPs who do not have the time or resources to offer the specialist dementia support that families need.

We know the situation is complex – and that it cannot be resolved overnight. Everyone is stretched too thin.

There are many challenges ahead and we will be dealing

with Covid-19's impact for months and years to come. It has stress-tested the ability of the UK's health and social care systems, which were already under immense strain. Getting a diagnosis has been problematic and the waiting list has grown considerably over the last few months. This has led to significant delays in accessing support, adding to the distress experienced by families.

Admiral Nurses (dementia specialist nurses) say that the pandemic has increased the level of difficulty that families are facing, without their usual support mechanisms of respite, peer group support and activities. The resulting social isolation has in many cases resulted in cognitive decline in the person with dementia and increased psychological distress in the family carer.

Dementia UK and Admiral Nurses can help. We are here when compassionate and specialist dementia care and support is needed. We can't fix the situation on our own but we can make a difference by working together. Now, more than ever, is the time to work in partnership to ensure specialist dementia care and support is available to everyone who needs it, when they need it.

Only together can we make sure that people affected by dementia can have a single, clinically trained point of contact to provide them with specialist support when they need it. Only together can we make sure families have access to the right information at the right time. And only together can we deliver the dementia support all families deserve.

## Executive summary

Caring for someone with dementia can be rewarding and life-affirming. However, looking after a person with dementia can also be a 24/7 job. As a result, families affected by dementia – both the person diagnosed and family members providing love, care and attention – deserve support.

Dementia diagnoses are on the rise in the UK, with around 1 million people projected to have dementia by 2025<sup>1</sup>. At the same time, health and social care services, including GPs face significant rising demand – which was the case even before the Covid-19 pandemic struck. This means that for complex conditions like dementia, it can be harder and harder for families to receive the support they need.

Dementia UK and our network of Admiral Nurses (dementia specialist nurses) work tirelessly to provide information, advice and support for families affected by dementia. As a result, we wanted to understand what specialist support is available to families affected by dementia, and how both access and quality of this support could be improved. Recognising the pressures on GPs and specialist dementia support services, we decided to seek out the experiences of families, GPs and our own Admiral Nurses to learn more.

Our Facing it alone research clearly shows that many families affected by dementia want and need more support. GPs and other health professionals are committed to helping, but are too often undersupported, overworked and often lack other specialist services locally which could help families.

We did our research in two phases. Firstly, from August to early December 2019, we undertook survey and focus group research with people affected by dementia, Admiral Nurses and GPs to explore what support services are available locally for families and how these could be improved. We heard from 580 people affected by dementia (the vast majority being family members), 55 Admiral Nurses and 76 GPs and other primary care professionals.

We were planning to release this research in March 2020, but were delayed by the Covid-19 pandemic. However, the urgent care needs of families impacted by dementia changed significantly during this time – and we elected to extend our research into what this would mean for families now and into the future.

We undertook our second phase of research over in August and September 2020. We surveyed 169 current family carers and undertook nine follow-up phone interviews to assess the impact Covid-19 has had on families and any concerns they had about the easing of restrictions at that time.

Perhaps predictably, many families reported that their access to specialist support has greatly worsened, while the pressures of caring have continued or been exacerbated. While some family carers reported feeling closer to the person they care for in this challenging time, many families told us they felt alone and/or abandoned. They also shared their fears about future local or national lockdowns' impact on the availability of support services.

Our research findings and methods are described below, and we discuss the limitations of the data collected in our Appendix. Based on the insights kindly shared by the families, Admiral Nurses and the GPs we spoke to, we have produced an accompanying paper, Only together: towards better specialist dementia care. Only together outlines our recommendations for change.

#### Key findings included:



Family members

The majority of family members told us:

They felt poorly supported (if at all).

They did not receive the information they needed, when they needed it.

Many families have not been able to access any specialist support following a dementia diagnosis, due to a lack of provision locally, or simply that no offer of support was made.



GPs and other healthcare professionals

GPs and other healthcare professionals told us:

They want to help but they face severe time and capacity issues to provide support needed to people affected by dementia and their families.

GPs often reporting a lack of specialist support locally, giving them fewer options to which families could be referred.



#### Admiral Nurses

Admiral Nurses reported similar pressures on GPs. Many have observed a lack of followup with families by health services following a dementia diagnosis; with a lack of consistency and coordination among the local services which exist.

Many Admiral Nurses emphasised the need for consistent, continuous and person-centred support to be available for families.





# Background





#### **About this report**

Dementia UK and our network of Admiral Nurses have been working with families affected by dementia for over 30 years, and are well-acquainted with the challenges these families face. Given the complexity of different dementia diagnoses, and the progressive nature of these conditions, families often need in-depth, specialist support – not only to help support the health of the person diagnosed, but also to understand and manage the wide variety of other issues involved in dementia care. These include balancing work and caring, financial pressures, recognising and dealing with behaviour changes in the person with the diagnosis, navigating complex local health and social systems, and more.

Given these common challenges, we wished to understand the experiences of people affected by dementia when it comes to accessing specialist support, as well as what support they would want. We also wanted to hear from Admiral Nurses (dementia specialist nurses) and GPs (General Practitioners) to understand their perspectives, and what solutions they would suggest. Providing the right support at the right time to families is vital, but we all – people living with dementia, their families, health professionals, commissioners, government, charities and other stakeholders – need to work together to make that a reality.

This report Facing it alone: experiences of dementia support is intended to share our findings from this research. Our accompanying paper, Only together: towards better specialist dementia care shares our recommendations for change, based on these insights from families, Admiral Nurses and GPs. We also offer our commitment to improve and expand the specialist support families tell us time and again they need.

#### **About us**

Dementia UK provides specialist dementia support for families through our Admiral Nurse services, our Admiral Nurse Dementia Helpline, and via our wide range of information resources. When things get hard for people with dementia and their families, Admiral Nurses are there to support them. Admiral Nurses work in a variety of settings, including in the community, and in care homes, hospitals and hospices. We are increasing the number of Admiral Nurses across the UK, so everyone who needs this support can receive it. As of November 2020 there are currently 305 Admiral Nurses supporting families living with dementia.

Dementia UK is an independent national charity entirely funded by donations, and receives no government funding. More information about us and our Admiral Nurses can be found on our website:

www.dementiauk.org

# **Our findings**

#### **Overview and methods**

From August to early December 2019, we undertook survey and focus group research into the experiences of people affected by dementia, Admiral Nurses and GPs regarding what support is available locally for families and what could help improve this support. Overall, we heard from 580 people affected by dementia (the vast majority being family members), 55 Admiral Nurses and 76 GPs and other primary care professionals.

We intended to release this report in March 2020. However, given the impact of the Covid-19 pandemic at that time, we decided to delay release. Instead, we prioritised the urgent care needs identified by many families. This included our ongoing work to highlight impact of Covid-19 on families affected by dementia to national government, and working in collaboration with other leading dementia charities including the **One Dementia Voice** partnership<sup>2</sup>. These included challenges for families such as their access to essential food and medicine, and ability to visit or support family members in care homes. We undertook follow-up research with family members who care for someone with dementia (family carers) in August and September 2020, to assess the impact Covid-19 has had on families and any concerns they had about the easing of restrictions at that time. We surveyed 169 current family carers and undertook nine follow-up phone interviews. The results from this 2020 research are discussed separately from our 2019 research below.

All results have been rounded to the nearest whole number, so combined answers to questions may not add up to 100% exactly. Where we have used quotes from the respondents, we have included their name and/or location where they consented for us to do so\*. More detail is available in the Appendix on our methods, and the limitations of the data we received. Full results and question details are available on request.

\* We have edited these quotes for grammar and tense, but not changed any of the words used.







#### **Results from 2019 families research**

Our 2019 survey for people affected by dementia included both multiple choice quantitative questions and free text qualitative questions. 97% of the respondents identified themselves as family members, with only 3% identifying as a person with a dementia diagnosis. We also ran two focus groups with people affected by dementia to discuss their experiences in more depth, as well as ask them for their views on what could have been improved. In total, we heard from 580 people affected by dementia.

Below we outline the key results and themes from the 2019 survey and focus groups.



Three-quarters (77%) of respondents were dissatisfied to an extent or with some aspect of the support received from GPs and other services, though there were some positive examples. In this figure, we are including those who responded that they were **Very Dissatisfied** (14%), **Dissatisfied** (20%) or **Somewhere in the middle** (43%). Comments given by respondents who answered 'Somewhere in the middle' highlighted the aspects of the support received which they felt had fallen short as well as support they had welcomed

Getting a diagnosis was like wading through treacle. I attended surgery with my Mum on several occasions in the 18 months prior to formal diagnosis, flagging up that there was a history of dementia in the family. Mum did have mild depression and anxiety and it was always put down to this, rather than further investigation. I felt at that stage the GP simply wasn't listening to my concerns. Where a family history is evident, this should be taken into account." (Janice, carer, Llanelli)

Initially support was excellent. However, that was six years ago and it tailed off miserably after the first six weeks or so." (carer)



One-third (35%) of respondents stated that no service or support was offered to them at all. This was echoed by one of the strongest themes from our free text responses, which was little or no support following a diagnosis. Some respondents described feeling 'abandoned' or left to 'get on with it'. There was a lack of communication, contact or follow-up following a diagnosis, which led us to the title of *Facing it alone* for this research

It was a very lonely time for me...there was very little support from outside agencies...In the end I had no choice but to put my mother in residential care because I was on the verge of a nervous breakdown." (Claire, carer, Gravesend)





Even among the respondents who had received support (65% of those who completed our survey), **just over one-fifth (24%) of respondents said that they were Very satisfied or Satisfied with the support they had received, compared to just over a third (34%) being Very Dissatisfied or Dissatisfied.** Combined with those who stated their satisfaction level was **Somewhere in the middle** (43%) shows that 66% of respondents had some level of satisfaction with the support received

It's a minefield trying to negotiate your way through all the services when you are still trying to process the diagnosis and the long term implications for ALL involved." (carer)

There was a range of potential reasons for this lack of satisfaction outlined in the free text responses. Some respondents reported a lack of dementia expertise among professionals, and a need for specialist support. Others highlighted the so-called NHS 'postcode lottery', with some people being unable to access the services, or quality of services, they needed because of where they live.

Get rid of the postcode lottery... lives are being put at risk when there aren't services, help and support in place. I had so many questions but no one to answer them" (Christine, carer, Eastbourne)

Some respondents identified a lack of focus on carers and the family by health professionals, meaning they did not receive recognition of their needs.

The state is not providing anywhere near enough support and relies on family members to do all the caring... It's a massive safeguarding issue and more needs to be done to provide support to carers to keep them safe and supported." (carer, Gosport)

Finally, many respondents identified a lack of coordination or joined up approach between services.

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Many respondents outlined there is a lack of information on dementia given as part of the treatment journey (only 44% of respondents received this information) and the changes in behaviour, personality or abilities the condition may cause (only 22% of respondents received any information on this topic). In the free text responses, many respondents explained there was a lack of information about dementia and what to expect, meaning family members had to find information on their own

...we very much had to do our own research as a family as to what was available locally, what benefits to assist with care were available etc. The support we received was very much from a medical perspective" (carer, London)





There was strong backing for more support and information, including for a single professional point of contact. We offered respondents a range of 11 prompted support options, including emotional support, a named care coordinator and information resources. All these options were chosen by a majority of respondents, with all but one option chosen by at least threequarters of all respondents. In the free text responses, a strong theme was respondents' desire for better care coordination, in particular for one professional to be a consistent point of contact who can support and advise families throughout their journey

I think one worker should be allocated at the point of diagnosis. They should offer support about the diagnosis and its future impact. They should advise about benefits, legal issues and the importance of advance care planning early on. I took over my aunt's care about three years after her diagnosis so there were a lot of missed opportunities and I'm catching up all the time and trying to guess what her wishes would be now she has less ability to tell me." (carer)

Contact was not well coordinated. I had to keep ringing Adult Social services, without knowing or understanding the structure of the service that was being offered to help Dad and me help Mum. Once referral had been made and the initial visit completed, I was never sure when the next visit would be. The action points decided upon at the meeting were slow to be followed through. Linked services were vulnerable to staff shortages and cancellation." (carer)

I believe [the support] should be offered to the patient and the carer from day one. I felt lost, alone and scoured the internet for information which obviously may or may not be relevant." (carer)

From the free text results in our 2019 survey and our 2019 focus groups, there were a range of solutions identified including:

- a dementia 'how to' guide covering practicalities, as well as wider life, eg how you can still go out and socialise with the person diagnosed with dementia
- a single page of key information for families receiving a diagnosis
- a template where you can make your own notes and keep track of key appointments and medication

Participants in our 2019 focus group and many respondents to our 2019 survey also championed the value of:

- a named care coordinator
- printed leaflets as well as online materials
- a GP-produced care plan
- an Admiral Nurse within a GP practice

The findings from people affected by dementia gives an impression of fragmented services, with many families not knowing where to start and some health professionals unable to provide what is needed. Information, practical and emotional support are all required – but it would appear many areas have gaps in one or more of those aspects.



#### Results from 2019 GPs research

76 people responded to our GPs survey in 2019. As highlighted in the Appendix, a small number of responses to our GP survey appeared to be from other primary care professionals working in GP surgeries. We have used 'GP' as a shorthand below for the respondents, but this should be understood to encompass GPs and other primary care professionals working in GP surgeries.

The key challenge is 'time and capacity pressures'; 82% of all respondents highlighted this as an issue in supporting people affected by dementia

Patients with dementia sometimes have very difficult care needs and assessing them can be very time consuming and challenging, particularly if they have both medical and mental health needs." (GP)

74% of respondents highlighted 'more time in appointments' would help better support people affected by dementia, which was also reflected in the free text responses. Other respondents also said there was a need for drop-in sessions at GP practices for dementia patients and families

The main challenge is time and capacity. And also that we are 'the first port of call' for everyone. If other services also knew about what is available they wouldn't always have to come to the GP as most of the issues are social or support based needs. As much as I would like to be more involved in individual cases there just isn't the time to do this." (Dr Taylor, Nottingham)



**53% of the respondents reported a 'lack of local support services for people affected by dementia'**. In the free text responses, some respondents expanded on this point to say that the services were also disjointed, with gaps in support available

The added issues are that services keep changing locally after losing funding, dementia cafes etc and carer support have changed a few times locally." (GP)



72% of the respondents see patients with dementia on a daily basis or multiple times weekly





42% of respondents said they were either knowledgeable or very knowledgeable about available support in their area. However, 49% felt they could know more. The latter point was echoed in some of the free text responses, with many respondents stating that more information is needed about what is available locally for themselves and resources for people affected by dementia

**76% had heard of Admiral Nurses.** However, a few free text comments from respondents did make it clear that while they were aware of the term, they did not know what Admiral Nurses were or do

Other themes arising from our qualitative analysis of the free text responses included respondents **identifying the need for a single point of contact for families**, given the wide range of professionals they and patients may need to see. There was also a common view expressed from the respondents that while dementia is a clinical condition, **there is a crucial need for more social and practical support**.

We need A SINGLE POINT OF CONTACT for... families to access quickly, who holds all the relevant, up to date signposting knowledge as to who to contact, what they can offer and contact numbers with estimated waiting time to be seen. Hopeless as a GP trying to keep up to date on all this info as well as everything else we have to do." (GP)

We did not hold focus groups for GPs during 2019, given the logistical challenges presented in the timeframe for our research. Given the pressure on GPs since the Covid-19 pandemic, we judged that it would be even more challenging for us to engage a significant number of GPs to join an online focus group in August-September 2020.



82% of GPs highlighted time and capacity pressures as a key challenge in supporting people affected by dementia

74% of respondents highlighted 'more time in appointments' would help better support people affected by dementia



#### **Results from 2019 Admiral Nurses research**

55 Admiral Nurses responded to our 2019 survey, and we ran a follow-up focus group with 11 participants. Key results from the quantitative survey questions included:

Outside of the support they offer as Admiral Nurses, around **three in five** Admiral Nurses (58%) agreed there was a lack of information on the condition and/or its impact given to people affected by dementia at diagnosis

Participants in our focus group gave more detail on what could help in terms of information. In particular, they emphasised that providing information is a process; resources given need to be person-centred, and it is vital to follow-up with individuals to make sure they understand and can process the information at their own pace. Participants to the focus group also emphasised the value of advance care plans.



9 out of 10 Admiral Nurses surveyed (89%) agreed there was a lack of follow-up with people affected by dementia by GP after diagnosis. Key themes from the free text responses included a need for regular reviews of people with dementia

A true regular review for people diagnosed with dementia and their families, providing time and space to discuss any concerns." (Admiral Nurse, Cheshire)

Information on dementia is available locally. A quarter of respondents (25%) agreed that there was little or no information on dementia available, with 58% disagreeing with this statement. This contrasts to the majority view from families (see above) that there is a lack of information given during the treatment journey. Considering these two results together, this may suggest that whilst there may be information on dementia available in the majority of local areas covered by Admiral Nurses, this information is often not available or given to people at the time of diagnosis



3 in 5 Admiral Nurses (58%) agreed there was a lack of information on the condition and/or its impact given to people affected by dementia at diagnosis





A significant gap in dementia support services in many areas. Almost half of the respondents (47%) disagreed that there was no significant gap in dementia support services, with one in five (20%) agreeing that there was no significant gap. From the free text responses, Admiral Nurses told us that families are often receiving little or limited support from fragmented services. There were also challenges reported for families around services' cost, accessibility or transport links to access them

There is an Alzheimer's support worker within this area however I believe their caseload is over 300. In practice this means that individuals and families are seen once a year for a review." (Joanne, Admiral Nurse)



Other themes from the free text responses from the above survey and our 2019 focus group included the **need for continuity of care and joining up services to work collaboratively**, including using a clear and consistent pathway and the **need for a named contact or co-ordinator.** Currently, key services including social care, memory services, and Admiral Nurses are often split up, meaning support can be disjointed and people living with dementia and families must explain their situation to multiple people.

...most importantly [families] having a named care co-ordinator who can either provide or signpost to the above. Families often report feeling lost and don't know where to turn, they need support navigating everything." (Admiral Nurse, Cheshire)

As a solution to the above challenges, Admiral Nurses in our focus group made it clear there needs to be **more standardisation between services**. This would provide **a baseline level of services**, but with a **person-specific, tailored approach in delivery**. For example, memory services should reflect the neighbouring boroughs. This would help to avoid a perceived current postcode lottery of varying service provision between areas.

Participants in the focus group also urged that there should be a **dedicated dementia team in place for each individual post diagnosis**. This could be made up of professionals from social services, memory services, palliative care, occupational therapists, Admiral Nurses, and others. For instance, an Admiral Nurse could mainly work with the family while other nurses and occupational therapists would work with the person with dementia.

Both respondents to the survey and participants in the 2019 focus group acknowledged the **overall need for more money and resources in dementia care**.



9 out of 10 Admiral Nurses surveyed (89%) agreed there was a lack of follow up with people affected by dementia



## Results from 2020 follow-up research with family carers

In August and September 2020, we ran follow-up research with family carers to ask what impact Covid-19 has had on them, and any concerns they had about the easing of restrictions at that time. This follow-up research included a survey with 169 respondents, plus nine in-depth, semi-structured telephone interviews with family members in a caring role (family carers) who filled in the 2020 survey and who had consented to further contact.

The survey contained a mixture of qualitative (free text) and quantitative (multiple choice in this case) questions. The semi-structured telephone interviews explored background details about support and information pre-Covid, and discussed the pandemic's impact on access to services, support and information as well as the health and wellbeing of the person with dementia and family carer. Interviews also explored any concerns the family carer had for the future or what they feel would be most helpful to meet their needs in the future.

All percentages cited in the findings below are from the survey multiple choice questions. We have also highlighted additional information from the free text questions or telephone interviews.

A significant majority of the family carers who responded felt their caring situation had deteriorated as a result of the Covid-19 restrictions. Since the Covid restrictions were put in place:

- 83% of carers said they have had fewer opportunities to take a break from caring. Many carers expanded on this point in their free text responses, explaining that the closure or reduction in services meant they had far less time available for respite from caring

Losing the day care at the centre has been so incredibly hard as my mam loves being there and it's the only respite I get. I am also disabled and so is my son so having this time is vital for our home life. I'm scared about how long this will be unavailable." (daughter of person with dementia)

Covid-19 restrictions have made my life harder. They have just put more pressure on, revealed more responsibilities that I have to deal with. There are no positives at all in my experience. There is no rest, no peace of mind, no support, no recognition of how shocking and difficult the sudden and ongoing separation from my relative in a care home was, has been and still is five months on." (sister of person with dementia)



- 78% have found it harder to cope in their caring role
- 78% said there had been a negative impact on the wellbeing (physical, mental or social) of the person they care for. Examples given in the free text responses included that the person with dementia had noticeably deteriorated in their confidence or abilities, which was ascribed to the lack of social contact. In the telephone interviews and free text responses, the curtailment of services providing social activities such as face-to-face support groups for people with dementia was cited by some carers as having a significant negative impact on that person's wellbeing

I understand that care homes are trying to protect residents and staff. However I believe it is morally wrong and mentally cruel to keep people from their families. Procedures can be put in place to protect people... I believe my mum's mental decline accelerated during her time in hospital due to a lack of visitors and a lack of stimulation. "It's been so long" she said when she finally saw me." (daughter of person with dementia)

 86% said there had been a negative impact on their own wellbeing (physical, mental or social). One carer reported taking redundancy in order to have time to care, given that the day centres had been shut. Others reported feeling "helpless", "exhausted", and being concerned that the person they care for did not understand or remember about social distancing, making it harder to take part in outings

The worry and concern about my mother's deteriorating mental health and lack of any meaningful physical contact with a relation has had a very bad effect on my own mental health. I am stressed and depressed and have many sleepless nights. I would like the care homes to move to a more humane response and consider allowing at least one relative to have a Key worker status and be able to go into the home." (daughter of person with dementia)

- 47% said they felt isolated all or most of the time, with 42% saying they felt this some of the time
- 36% said they felt lonely all or most of the time, with 49% saying they felt this some of the time

I've been very affected with lack of contact with friends and family. I feel lonely and as though no-one cares. I feel that we've been forgotten by the GP and social services. I think it will not be back to normal for a long time. I don't think that I will be able to look after my husband much longer without help unless the day centres open again and I can get some time to myself." (wife of person with dementia)

Other than visits to the GP's surgery, dentist and vets, neither of us have been outside of our house and garden since March. Similarly, except for a visit from the carer today... no one has visited us.... My wife has missed visits to our children and grandchildren... her weekly coffee mornings in the village, going to the Sunday church service in the village, and college chapel during term time..." (husband of person with dementia)





There have been **serious impacts on carers' reported access to care and** support services:

- 71% of carers said that home visits from care and support staff have been cancelled, either by the carer or by the service
- 57% said they were offered an alternative type of support (such as via telephone or online) instead of the home visits
- Most carers (88%) who tried to make a GP appointment were offered a telephone or online appointment, in line with Covid-19 restrictions, with 12% offered a faceto-face appointment. However, only 52% of those who were offered telephone or online appointments said this type of support met their needs, or those of the person with dementia. In the free text responses and telephone interviews, several carers said this approach means they were unable to be part of the discussion with health professionals adequately. This made it challenging for the person they care for to hear or understand what the professional was saying. Worse, some carers highlighted that the remote recommendations on diagnosis or treatment had been poor, on occasions leading to significant health problems for the person they care for. That said, several carers highlighted in the free text responses that online or telephone appointments had been a positive means to keep in touch, both with health professionals and family
- Of those who access care and support services for themselves as carers, 20% of respondents said that they had not been able to access any of the care and support services they needed (68% said they could access some, with 12% saying they could access all those services)

I have felt largely abandoned by the NHS during lockdown where my mother's health is concerned. I have been left to make clinical decisions which I shouldn't have to make such as whether I start my mother on antibiotics and steroids and when to nebulise her." (carer)

- Of those who access care and support services for the person with dementia, 26% said they had not been able to access the care and support services the person with dementia needs (60% said they could access some, with 14% saying they could access all those services)

The telephone appointment system broke down for over six hours and resulted in the wrong meds being prescribed and the following day I called NHS 111 and we ended up in A and E." (daughter of the person with dementia)

As the dementia has been picked up and diagnosed during Covid lockdown, not being able to access services - at all in some cases and only on the phone in others - it has been very difficult and entirely reliant on the presentation of symptoms as relayed by my husband and I. It would have been / be good to have an independent and medical direct viewpoint. Services have been slower to respond and there has been a lack of clarity about what is available. My biggest concern is being able to access face to face support (both medical and otherwise) for my mother in law and currently there is no change forseeable to our GP practice's approach of telephone appointments only." (daughter in law of the person with dementia)





Carers were pessimistic about future support being available or accessible, and about their ability to cope long-term with future lockdowns:

- 75% said they worried face-to-face support would not be available for the foreseeable future
- 62% said they worried about whether they could continue to care for the person with dementia at home. In the survey free text responses and telephone interviews, many carers spoke of feeling 'abandoned', 'left on their own'. Carers also spoke of having to take on more personal care and other responsibilities, while the condition of the person they cared for has deteriorated
- Only 41% of carers felt they would be able to continue coping in their caring role if there were future lockdowns. As we write at the start of November 2020, varying degrees of regional restrictions have been in place across the UK, and both Wales and England have implemented additional national restrictions

#### (CC) I just feel so unsure about what is going to happen" (carer)

Many carers said there was 'nothing positive' in the situation with Covid-19 - which many of us could empathise with, even if we do not have caring responsibilities. However, some carers reported positive experiences; for example, 16% of respondents said that lockdown has enabled them to spend more time with their loved ones at home including the person with dementia. 33% said they felt more supported in their caring role by family or friends over this period.

#### **Helpline context**

Covid-19 was also a significant concern to carers who contacted our Admiral Nurse Dementia Helpline this year, as might be expected. Contacts were made via phone or email. Between 1<sup>st</sup> March and 30<sup>th</sup> September 2020, there were **4,223** contacts received (either new or follow-ups) which had an enquiry reason including Covid-19 – this equals **26%** of all contacts during this time period. This was the second most common reason for contacting our Helpline, with 'Accessing support' the first and 'Behaviour' (of the person diagnosed) the third most common.

While we would expect to see an increase in overall volume of contact year-on-year, given our efforts to promote this service more widely, we saw a 35% increase in our total Helpline contacts from January-September 2020 compared with the same period in 2019. This would appear to suggest that concerns about Covid-19 were a significant driver to people seeking specialist help and advice from our Helpline.



# Facing the future together

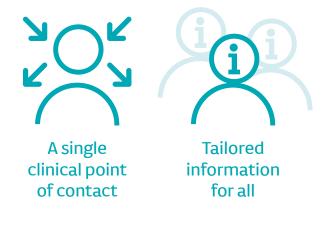
What does all this research tell us about what families should expect?



Everyone we spoke to - be they living with the condition, caring for someone, or treating patients - is exposed to the stress and complexity of coping with dementia. If there is one common theme from our research, it is that too often both families and health professionals are stretched too thin. In short, most people we spoke to - families, GPs and Admiral Nurses - acknowledged that families often do not receive the specialist support they need, when they need it. GPs and other primary care professionals are also often stretched too thin, under constant pressure given the huge demands on their services and a lack of resources to adequately address these needs. These challenges have only worsened with the impact of Covid-19 reducing the support available to families caring for someone with dementia as well as increasing the pressure on the entirety of the health and social care system, including on GPs and other health professionals.

Moreover, many respondents – be they families or professionals – recognise that living with dementia is challenging enough. The current reality of delayed diagnosis, a paucity of support services, insufficient or irrelevant information, and poor or no communication only add to the challenges that families face. Equally, we know that GPs and other health professionals want to provide the best support possible, but need the time, training and resources to enable them to do that – as well as a reasonable caseload that does not impact on their own health or ability to do their jobs. Indeed, we are in this together; many professionals including GPs have personal experience of dementia in their family. And only together can we make the changes needed for people affected by dementia. We do not have all the answers, but we know families need better support, and know what that support should look like, as outlined below. GPs also need more resources to be able to have the time to provide information and support, and there needs to be more availability of local specialist support services.

Building on our research, and over 30 years of experience of working in dementia, we have laid out two key starting recommendations on which to build better dementia specialist services for everyone:



We explain these recommendations in depth in our companion paper to this research, **Only together:** towards better specialist dementia support.

Dementia UK November 2020





# Appendix





#### Methodology

Our findings are based on two tranches of research, one in 2019 and one in 2020.

#### Our 2019 research

From August to early December 2019, we undertook survey and focus group research into the experiences of people affected by dementia, Admiral Nurses and GPs regarding what support is available locally for families and what could help improve this support. This involved an online survey for people affected by dementia, shared via Dementia UK's recipient and supporter mailing lists, and promoted on our social media channels.

580 people responded to **our survey for people affected by dementia**, though not all respondents completed all questions. The survey included questions about: the respondents' experiences of support offered to them or their family; their satisfaction with those services; what they felt could have been done better; and what they felt all families should be offered following a dementia diagnosis. Most questions were multiple choice, all with an optional free text section for respondents to add more detail. Respondents to the 2019 carer survey were asked for their consent to use their responses and were given three choices: may use responses with name and area; may use responses with area only; may use responses but without name or area.

- one in-person family focus group (six attendees), drawn from respondents who said in their survey responses that they would like to be involved in further research
- one telephone family focus group (two attendees), as above
- one carer phone interview, as above
- an online survey for Admiral Nurses, circulated via Dementia UK's Admiral Nurse distribution lists

55 Admiral Nurses responded to the survey, though not all respondents completed all questions. Among other topics, the survey included questions about: the support available for people affected by dementia in their area; gaps in provision; the support they felt should be available; and improvements that could be made. As with the other surveys, most questions were multiple choice, and all had an optional free text section for respondents to add more detail.

- one in-person Admiral Nurse focus group (11 attendees), as part of their practice development day
- two online surveys for GPs. Our initial pilot survey was shared and distributed by Assura (a corporate partner of Dementia UK who develop, invest in and manage a portfolio of primary care medical centres across the UK) with 15 GP practices within their buildings. After confirming through this pilot that the question phrasing was suitable, we sent the survey questions out again to a much wider cohort of GPs via the Royal College of GPs' (RCGP) distribution channels to their regional Faculties in England. Assura also circulated the survey more widely to 520 practices within their buildings as part of one of their regular communications to occupiers. We added a single question 'Have you heard of Admiral Nurses' to the main survey, which was the only difference to the pilot survey

76 people responded to our GPs survey, though not all respondents completed all questions. Among other topics, the survey included questions about: how often the respondents saw people with dementia in their GP surgeries; their knowledge and confidence signposting to local dementia support services; the challenges they face in providing support; and what would help them better support people affected by dementia. Most questions were multiple choice, all with an optional free text section for respondents to add more detail.



#### Our 2020 follow-up research

We undertook follow-up research with families affected by dementia in August and September 2020 to assess the impact Covid-19 has had on families and any concerns they had about the easing of restrictions at that time. This research involved:

• an online Covid-19 carer survey. The survey was circulated from 7th August to 7th September via Dementia UK's: Campaigns Network eNews, General Dementia UK eNews, Corporate Partners, Volunteer Ambassadors, Dementia UK fundraiser Facebook page, Dementia UK Twitter and LinkedIn pages. The survey link was also available on the Dementia UK website (campaigns page)

This survey was a mixture of qualitative and quantitative questions. 169 family carers responded to this survey.

• nine telephone interviews with family carers. Two members of Dementia UK's Insights and Evaluation Team conducted nine semi-structured telephone interviews with current family carers. Family carers were recruited via an email to people who had filled in the original family survey about post diagnostic support that Dementia UK conducted in summer 2019 and who had consented to further contact from the charity regarding the issues raised in the survey

The semi-structured telephone interviews explored background information about support and information pre-Covid and then discussions about the pandemic's impact on access to services, support and information as well as the health and wellbeing of the person with dementia and family carer. Interviews also explored any concerns the family carer had for the future or what they feel would be most helpful to meet their needs in the future.

#### **Data limitations**

While the data received gives us valuable insights into the views of people affected by dementia, Admiral Nurses and GPs and other primary care professionals in GP practices, it is important for us to be clear about the limitations of the data received and methods used.

More detailed information on the research data limitations and methodology used is available on request.

#### Limited response rates

Given the approach and response rate to our surveys in both 2019 and 2020, we do not and would not claim that these results are representative of the views of these three groups. However, they do give an insight into the experiences of those who did respond, and suggest the need for more in-depth research with GPs to better understand their experiences.

For instance, 76 GPs responded to our 2019 survey in total. The total number of GPs in England alone was estimated at roughly 34,434 full time equivalents in September 2020<sup>3</sup>. Therefore our sample represents around 0.2% of this total (even if we were to count the non-GPs who responded) of the total GP workforce. Therefore, these results cannot be claimed to represent the likely views of all or most GPs, as our results might well be very different if we had received a greater response. The same could be said for our surveys of people affected by dementia and Admiral Nurses, though in the latter survey, around 20% of the Admiral Nurse workforce did respond, thus representing a significant portion of that cohort.

3 This figure is drawn from the General Practice Interactive Dashboard available at: https://digital.nhs.uk/data-and-information/ publications/statistical/general-and-personal-medical-services/30-september-2020-biannual-regional-and-joiners--leavers-tables, accessed on 26th November 2020. Figures provided by different sources vary, and naturally are subject to change over time as outlined here https://fullfact.org/health/gp-numbers-or-down/, accessed on 7th February 2020

#### Self-selecting samples

While Dementia UK took great efforts to share our 2019 and 2020 surveys with as many people affected by dementia, Admiral Nurses and GPs, there was little the organisation could do to make this sample representative of the total populations of these three cohorts.

While this approach was necessary given the resources available and deadlines to which we were working, it is important to highlight that the responses are likely to be skewed to respondents who are particularly interested in the subjects we have asked about, as well as those who have had more notable (better or worse) experiences around support.

This also meant that for our people affected by dementia survey in 2019, we heard significantly more from families (96.6% of respondents) than people with a dementia diagnosis themselves (3.4% of respondents). As a consequence, the views we received were likely to be far more balanced towards family members, rather than people with a diagnosis. Our 2020 survey was however exclusively directed at family carers.

## Non-GP responses to our 2019 GP survey

It appears that a selection of responses was submitted by GP practice staff, despite the survey being explicitly directed at GPs. We made clear in our communications that GPs were the only intended respondents.

It was not compulsory for respondents to give their job titles, but nine out of the 76 respondents (11.8%) gave an alternative job title to that of GP, such as practice manager or healthcare assistant. As a result, it may be that there are other respondents who did not give details of their job title who were also not GPs. This means that it would be invalid simply to exclude the responses from those who identified as non-GPs, in order to present 'just' GP responses, as we cannot know for sure how many non-GPs may be included in the rest of the results. We have used 'GPs' as a shorthand for those who responded to this survey at points in this report, but to be clear these results have come from GPs and other primary care professionals working within GP practices.

#### **Thanks and acknowledgements**

This research would not have been possible without the contribution made by the people affected by dementia, GPs and Admiral Nurses who responded to our surveys, joined our focus groups, participated in our telephone interviews, and shared our surveys with their networks. Thank you so much for your time, insight and support.

Thank you also to the Royal College of General Practitioners (RCGP) for their support in sharing the GP survey with their members in 2019. We are also very grateful to our corporate partner Assura for helping distribute the survey to a selection of GPs as well as Platypus Digital for hosting one of our focus groups for people affected by dementia in 2019.





If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org Open Monday – Friday, 9am – 9pm Saturday and Sunday, 9am – 5pm



www.dementiauk.org · info@dementiauk.org

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).

