



DementiaUK
Helping families face dementia

Admiral Nurse Dementia Helpline

**Annual Evaluation Report
January – December 2020**

Summary

Admiral Nurse Dementia Helpline 2020

"This has been the best of the helplines I have rung for assistance" - Carer

"This was my first step at reaching out for help and I feel I struck gold"
- Carer

"Just keep doing what you are doing. It is a key service to me as I have not found another service that matches your support and with the growth of dementia it is going to be even more important" - Carer



Admiral Nurse Dementia Helpline 2020

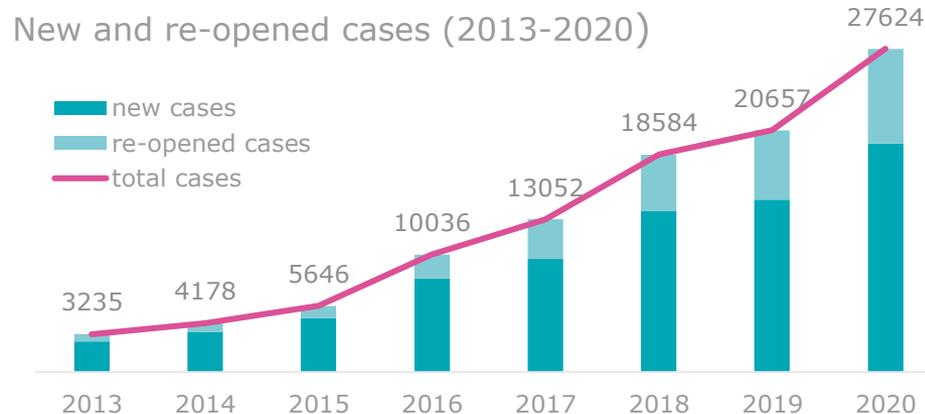
2020 has been the busiest year so far for our Helpline in terms of contacts recorded by our nurses and calls logged on the telephone system.

Helpline contacts

Between January and December 2020, our nurses recorded **27,624** contacts as new or re-opened cases:

- an average of 2,302 cases per month – June & July were the busiest months with over 2,500 cases recorded in both months.
- 29% were re-opened cases - indicating a large number of repeat contacts (8,121).

The chart shows how Helpline cases have grown over the period 2013 to 2020 – with **34%** more cases recorded in 2020 than in 2019.



Calls to and from our Helpline

The table shows the increase in the number of calls logged between 2017 and 2020 (and the % increase from the previous year). In 2020 there were:

- **72,423 calls** logged on the Helpline telephone system – this includes calls made or attempted to and from the Helpline at any time - a **34%** increase from 2019.
- **67,802 calls** logged during Helpline opening hours - a **32%** increase from 2019.

Total	Any time		Opening Hours Only	
Jan-Dec 2020	72,423	34% ↑	67,802	32% ↑
Jan-Dec 2019	54,092	19% ↑	51,224	17% ↑
Jan-Dec 2018	45,546	23% ↑	43,659	26% ↑
Jan-Dec 2017	36,964		34,721	

How are people contacting our Helpline?

- Mostly by **telephone** (75%)
- 20% were by email



Who is contacting our Helpline?

Most contacts were from a **carer** (90%) who is a close family relative:

- 76% were female
- 68% were the child of the person with dementia
- 20% were the spouse/partner

Almost all contacts came from within the UK (98%).

Of these UK contacts:

- 95% were from England
- 3% from Wales, 2% from Scotland, 1% from Northern Ireland

Why are people contacting our Helpline?

There are 33 categories which our nurses can use to record reason for contact. A total of **59,185** reasons were recorded against these categories for the 27,624 cases – representing an average of two reasons per case. Listed below are the **seven** most common reasons (and the reason **as a percentage of all cases** created):

- Accessing support (26%)
- COVID-19 (20%)
- Behaviour (18%)
- Psychological emotional support (17%)
- Getting a diagnosis (16%)
- Dementia understanding & support (14%)
- Wants an Admiral Nurse (14%)

Average calls to our Helpline in 2020:

- 12 calls per hour on weekdays
- 9 calls per hour on weekends

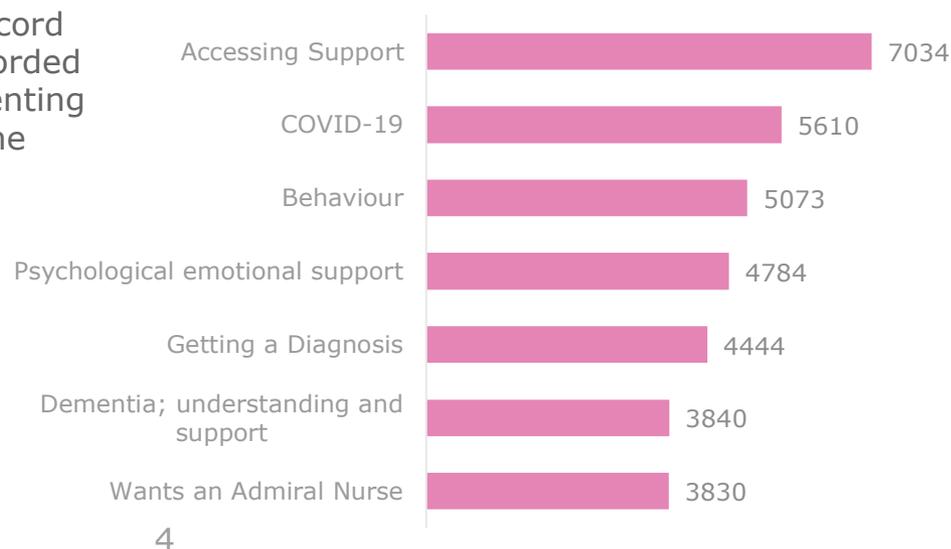


Other Helpline contacts:

837 contacts were from a person living with dementia

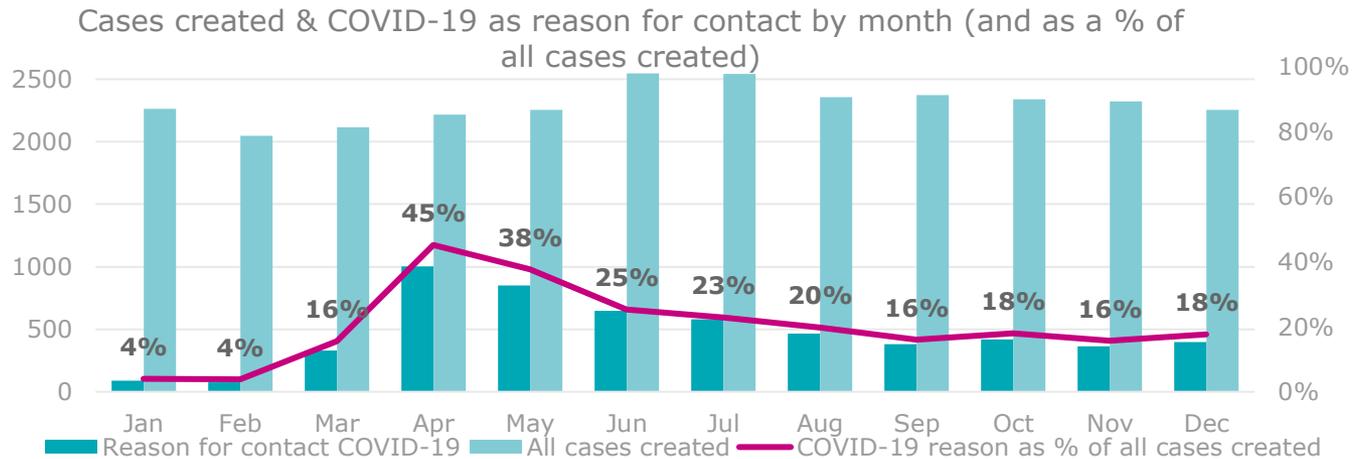
1,170 contacts were from a professional

Most contacts within England came from the South East (25%) and the Midlands (20%)



Coronavirus pandemic

The Coronavirus pandemic has had an impact on the number and type of calls to our Helpline – with Covid-19 recorded as a reason for contact in 20% of all cases created this year. This peaked in April and May where this reason was recorded in 45% and 38% of all cases in those months (see chart below).



What our nurses said about calls since the start of COVID-19

We asked three Helpline nurses about their experiences working on the Helpline since the start of COVID-19. The nurses felt that during the initial period the volume of calls increased and that the calls were often more complex and intense.

After the initial few weeks, the Helpline Nurses reported that the calls were more about how COVID-19 was impacting on families affected by dementia, including visiting loved ones living in care homes, difficulties getting a dementia diagnosis, lack of support available in the community and carers at crisis points.

"A lot of community services were cancelled, dementia cafes, no respite. Carers were breaking down". Helpline Nurse 1

"Thank goodness for the Admiral Nurse helpline - they have helped me as a carer keep my sanity and filled the gaps left by NHS and Alzheimer's Dementia navigator". Wife of person living with dementia

What carers have said about the support they received from our Helpline

Carers (n=253-356) said that the Admiral Nurse was **helpful** in:

- sharing information and explaining the impact of dementia (100%)
- providing them with emotional support (97%)
- providing ways of responding to and coping with changes in behaviour (97%)
- providing support to manage risk and prevent possible crisis (96%)

99% of carers (n=439) said that the Admiral Nurse was **good at** listening to them, showing compassion to them, and explaining things in a way they could easily understand.

Carers said the **support received from the Helpline was different** from that given by other health and social care professionals in the following ways:

- their specialism, experience, expertise and knowledge of dementia
- their compassion, empathy and understanding
- their ability to listen

What carers have said about the difference our Helpline has made

Carers (n=305-357) said that our Helpline has **made a positive difference** to their:

- ability to make important decisions about the care of the person they look after (95%)
- ability to take better care of the person they look after (94%)
- confidence in their ability to cope (91%)
- knowledge of local services offering support (92%)
- ability to communicate with person they look after (90%)

If carers (n=336) **did not have access** to our Helpline:

- 73% said they would have struggled on their own
- 30% said they would have seen a GP more for the needs of the person they look after

*We have collected feedback on our Helpline through a survey with carers (which is implemented bi-monthly) – a total of 460 carers completed our survey between December 2017 and December 2020. Response rate to each question varied depending on whether carers felt it was applicable to them – numbers above show the total response to each question, excluding those saying not applicable.

Almost all carers (**96%, n=427**) responding to our survey said they would be '**extremely likely**' or '**likely**' to **recommend our Helpline** to someone who needs similar support and advice.

What carers have said about our Helpline and the support they received in 2020

"I would like to thank the Admiral Nurses for their support and help. They were **a lifeline** on the end of the phone and I could not praise them more! I am **incredibly grateful**". - Daughter of the person living with dementia

"I felt she had **time to speak to me** and her **knowledge was specific to Dementia** rather than when I speak to the GP or Social Workers". - Daughter of the person living with dementia

"She was **compassionate** and 100% 'there' for me at a time when I was very stressed about caring for my mother. She was totally 'on it' professional and human. The **best supportive tel call experience** I've had". - Daughter of the person living with dementia

"I can't thank the person who spoke to me enough - I was so stressed and burst into tears - and they were patient, kind, really listened - and then offered opinion on my self-made care plan plus practical support. I have spoken to many professionals in this process and **this one call was a life-changer**". - Son of the person living with dementia

"They were **accessible and there for us as carers with a holistic approach** not just focused on my mother in laws needs (Which are of course central for us all). Focused on supporting us to resolve problems rather than what they can or cannot do". - Daughter in law of the person living with dementia

"I think your helpline is very valuable. It's the **strategic, integrated and actual provision and support for "carers"** which is **shamefully lacking**".
-Wife of the person living with dementia

Contents

Introduction		8
Section one	Database recording and reporting	9
Clinical database (COMPASS) data	Number & type of contacts, number of new & re-opened cases	12
	Demographics	15
	Reasons for contacting our Helpline	19
	Location of contacts	21
	How did you find us?	28
Call management database (Puzzel) data	Volume of calls	29
Section two	Impact of coronavirus pandemic	33
Section three	Carer experience survey 2017-2020	37
Findings	Who responded to our survey and reasons for contacting our Helpline	38
	Positive experience	40
	Difference the service has made	46
Appendices		49

Report Introduction

Our **Admiral Nurse Dementia Helpline** offers support to people who are caring for somebody with dementia including family, friends and professionals, as well as those living with dementia themselves. The Helpline is fully staffed by Admiral Nurses, who are clinicians experienced in supporting families affected by dementia.

Our Helpline is open **7 days a week** Monday-Friday 9am-9pm and Saturday and Sunday 9am-5pm, including all bank holidays, except for 25th December. People can contact our Helpline via telephone, email or online.

This report brings together data collected for our Admiral Nurse Dementia Helpline during the 12-month period from **January–December 2020**.



Section 1 - Database recording and reporting

Introduction

This section of the report provides an overview of the data, which has been collected and extracted from two data sources: clinical database (COMPASS) and call management database (Puzzel).

COMPASS was used by Helpline Admiral Nurses to record their clinical data, including:

- Number of contacts – new and re-opened cases
- Demographics of those contacting the Helpline (and the person the contact is about)
- Reason for contacting the Helpline
- Location of contacts
- How people found out about the Helpline

Puzzel is a cloud-based telephone call management platform, which records the volume calls and attempted calls to and from our Helpline.

COMPASS DATA

- **Number of contacts – new and re-opened cases**
- **Demographics of those contacting the Helpline (and the person the contact is about)**
- **Reason for contacting the Helpline**
- **Location of contacts**
- **How people found out about the Helpline**

"It's really the only place I can go to for help for myself, rather than directly for the people I care for. I sometimes struggle a lot, and the Admiral Nurses on the end of the phone have given me SO much help." Son of the person living with dementia

Contacts to our Helpline

A total of **27,624 contacts** were recorded in 2020

How are people contacting our Helpline?

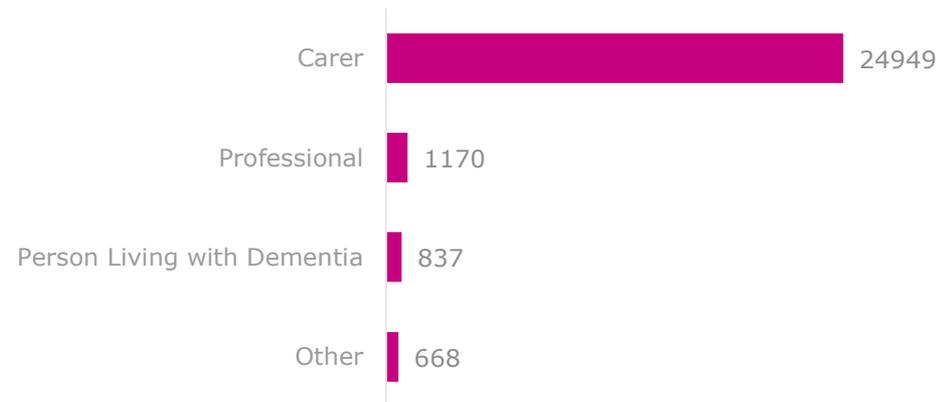
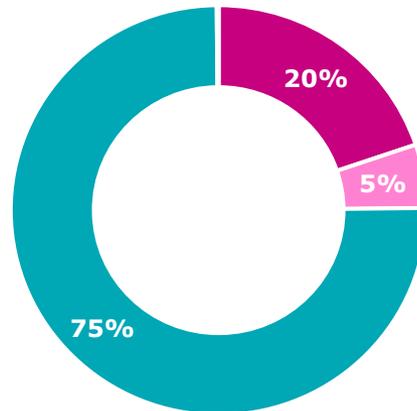
- Contact source was logged for the majority of contacts (n=27,181).
- Most contacts (where method was recorded) were made via **telephone** (n=20,391, **75%**).
- **Email** was the 2nd highest means of contact (n=5,387, **20%**).
- A small proportion of people made contact via the Dementia UK website (n=1,363, 5%) and 'Other' (n=40).

Who is contacting our Helpline?

- Most of the contacts made to our Helpline are made by a **carer** (n=24,949, **90%**).
- **837** contacts were from a **person living with dementia (3%)**.
- **1,170** contacts were from a **professional (4%)**.
- 668 contacts were recorded as 'Other' (2%) (this is when a person does not fit into the categories e.g. a family member or friend who does not identify themselves as a carer).

Method of Contact

- Email
- Dementia UK Website
- Telephone
- Other

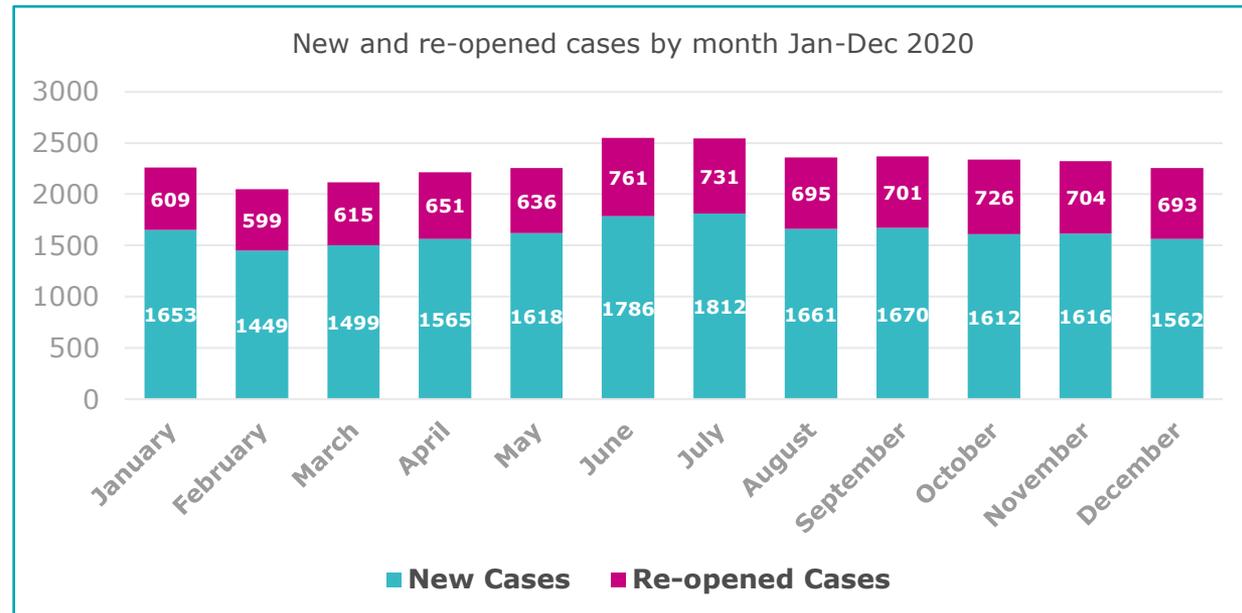
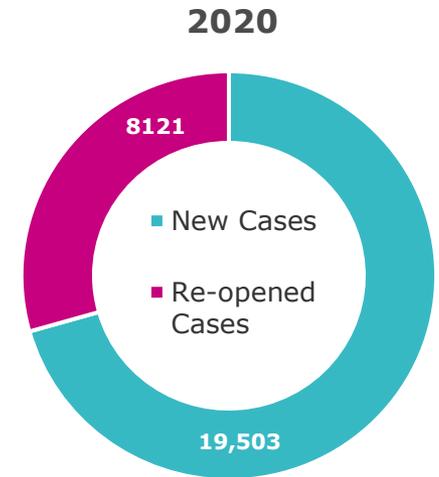


The method of contact was recorded in 98% of cases

Total number of cases (Jan-Dec 2020)

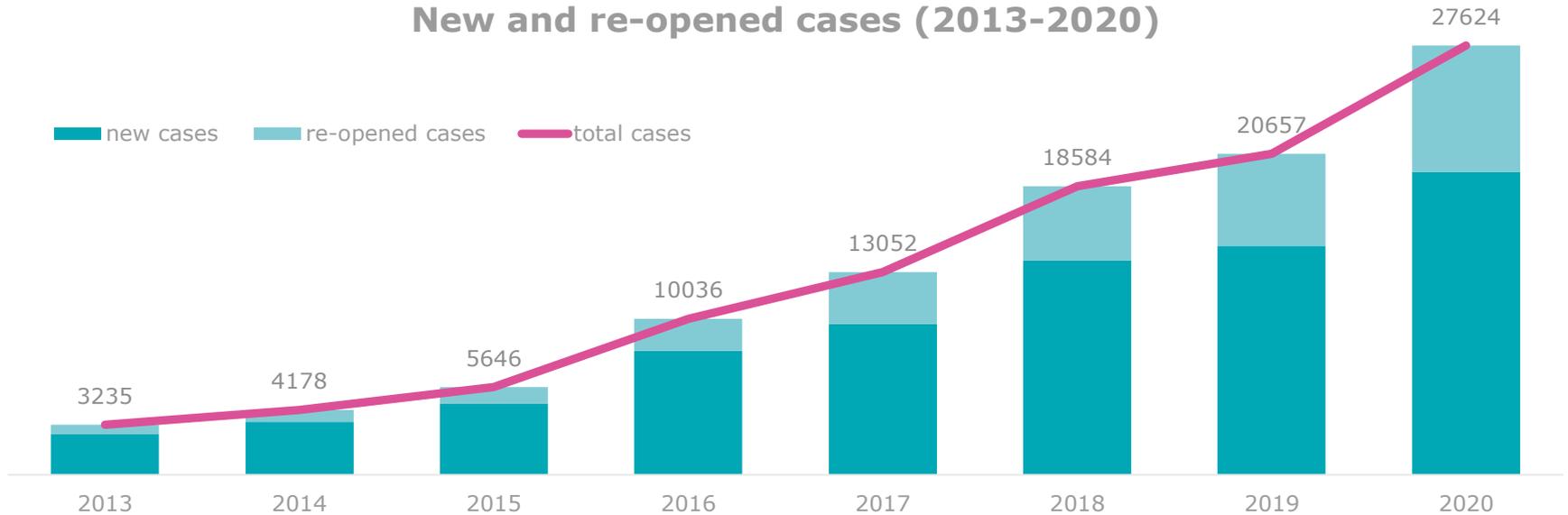
Contacts are categorised as either **new cases** (first contact) or **re-opened cases** (those who have previously contacted the Helpline).

- **The total number of new and re-opened cases in 2020 was 27,624**
 - 19,503 new cases
 - 8,121 re-opened
- The total number of new and re-opened cases **increased by 34%** from 2019 to 2020.
- 29% of all cases were logged as re-opened in 2020.
- June and July recorded the greatest number of cases (2,547 & 2,543) during the year.



Increase in total number of cases (2013-2020)

New and re-opened cases (2013-2020)



Year on year the total number of cases has increased steadily, with 24,389 more cases recorded in 2020 than in 2013. This reflects not only developments within our Helpline service (including increased opening hours and staff numbers) but also an increased demand for the service.

	2013	2014	2015	2016	2017	2018	2019	2020
New	2606	3412	4582	7986	9686	13780	14728	19503
Re-opened	629	766	1064	2050	3366	4804	5929	8121
Total	3235	4178	5646	10036	13052	18584	20657	27624

Demographic information (Jan-Dec 2020)

The clinical system used by our Helpline nurses records demographic information* for each contact (and the person the contact is about), including: gender, ethnicity, relationship and dementia diagnosis.

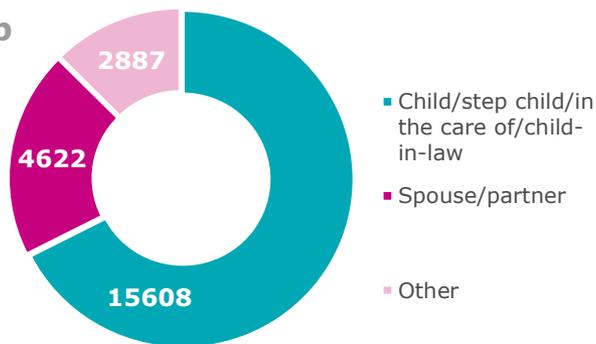
Most carers calling** were a close family relative of a person living with dementia:

- 68% were the child
- 20% were the spouse or partner
- 76% were female
- 91% were recorded as White British (4,052 of 4,452)

Person living with dementia** who the call relates to:

- 59% of those living with dementia were female
- 84% were recorded as White British (3,046 of 3,629)

Relationship



Gender	Carer	PLWD
Female	13,928	10,547
Male	4,416	7,456
Transgender/Transitioned Male or Female	8	5
Other/prefer not to state	1	4
Total recorded	18,353	18,012

Ethnicity	Person contacting	PLWD who contact is about
White British	4,052	3,046
Asian – any	133	140
White - other	115	290
Black – any	54	81
Mixed ethnicity	35	24
Other	56	46
Prefer not to state	7	2
Total recorded	4,452	3,629

* Where contact has been made by email, the same level of data is not collected.

** Numbers provided are where data was recorded, data recorded includes new and re-opened cases

Relationship of caller

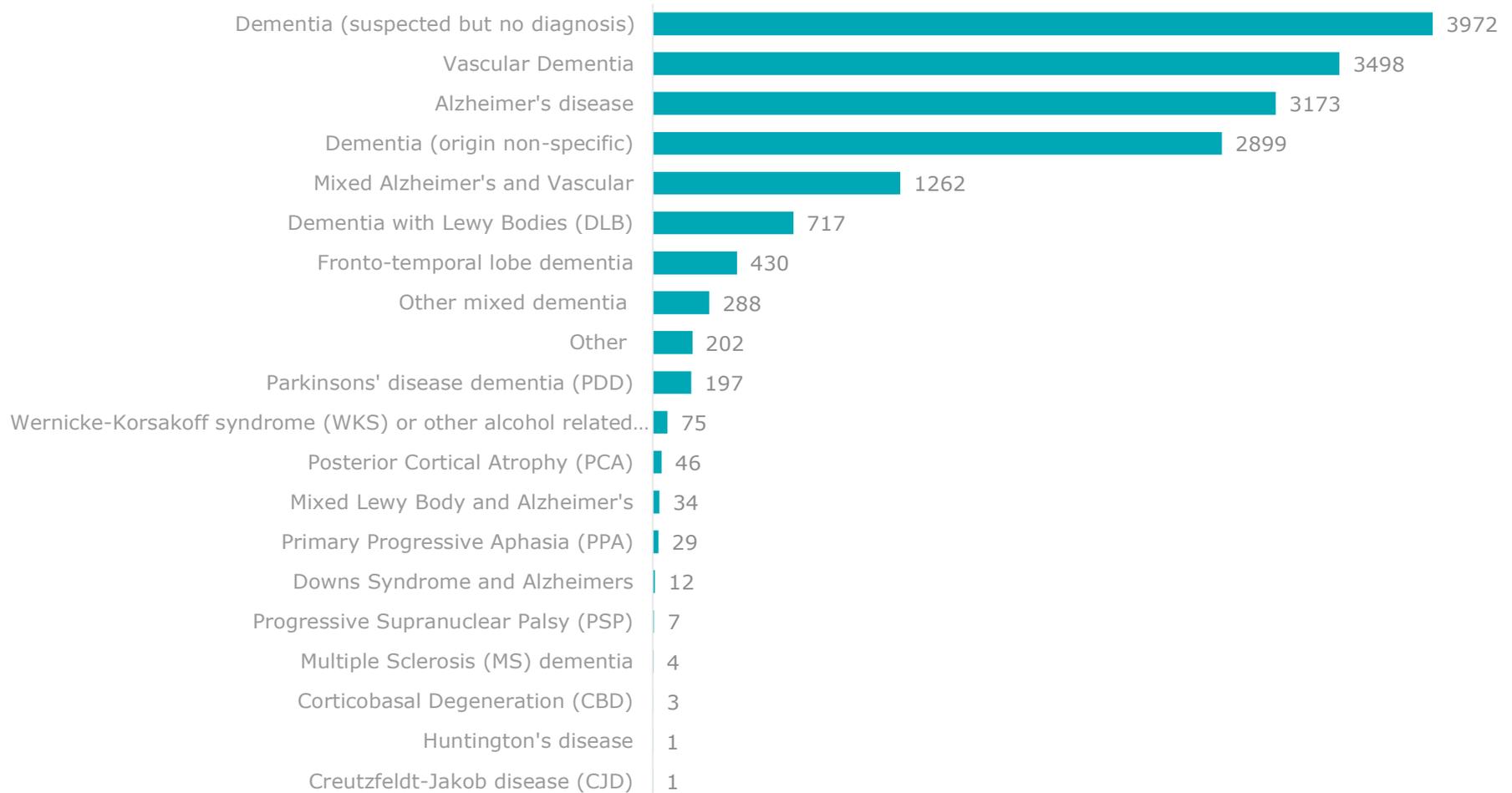
The table below provides a detailed breakdown of relationship of the caller to the person living with dementia. The relationship of the caller was recorded for 23,117 (84%) of contacts.

Relationship label	Total
Child/Step Child/In the care of/child-in-law	15,608
Spouse/Partner	4,622
Grandchild	827
Friend/Neighbour	653
Sibling/Step sibling/sibling-in-law	625
Nephew/Niece	379
Other relative	148
Parent/Step Parent/Parent-in-law/Guardian	111
Ex spouse/Ex partner	61
Aunt/Uncle	37
Cousin	34
Grandparent	12
Total recorded	23,117

Dementia diagnosis

Dementia diagnosis was recorded for 16,850 contacts (61%)

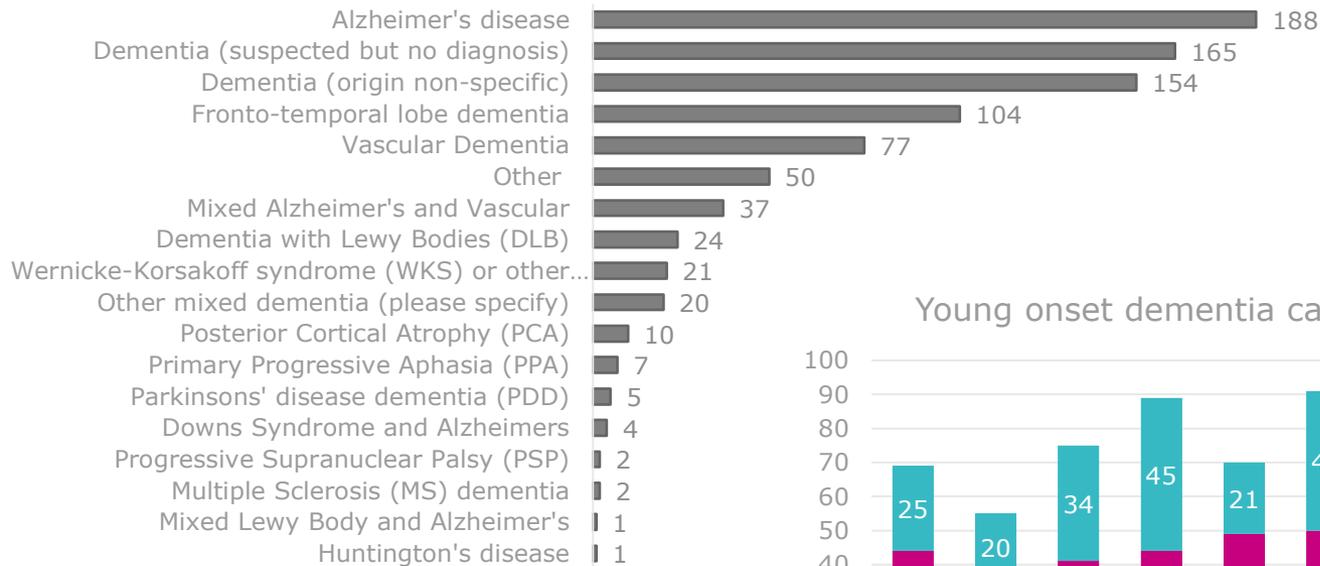
- Vascular dementia (21%) and Alzheimer's (19%) were the most commonly recorded diagnoses
- 24% did not have a formal diagnosis of dementia



Young onset dementia

From January to December 2020 there were 904 contacts recorded as young onset dementia - 554 'cases created' and 350 'reopened cases'. The chart below shows the type of young onset dementia recorded against these created and reopened cases - diagnosis was recorded for 872 (97%) contacts.

Young onset dementia diagnosis recorded (Jan-Dec 20)



Young onset dementia cases by month (Jan-Dec 20)



Reasons for contacting our Helpline

There are 33 categories which our nurses can use to record reason for contact (including 'other'). A total of **59,185** reasons were recorded against these categories for the 27,624 cases – representing an average of two reasons per case. The **seven** most common reasons (and the reason **as a percentage of all cases** created) are:

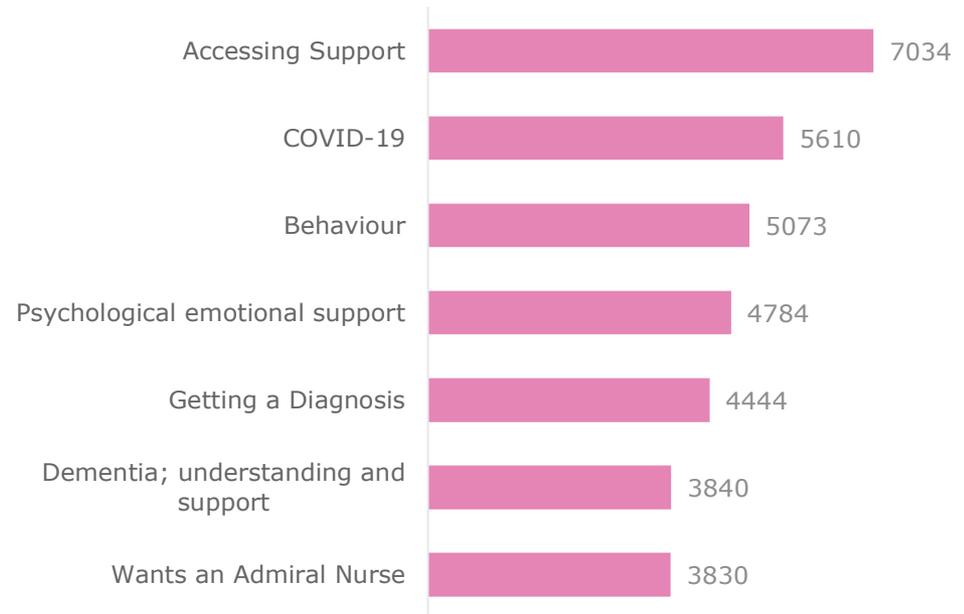
- Accessing support (26%)
- COVID-19 (20%)
- Behaviour (18%)
- Psychological emotional support (17%)
- Getting a diagnosis (16%)
- Dementia understanding & support (14%)
- Wants an Admiral Nurse (14%)

"I rang for specific practical advice, which I got, but I also got a load of personal psychiatric help for myself to help me cope with the challenges of the situation. I love your service, and thank you for providing it!"

Son of the person living with dementia

"I was enquiring on behalf of a friend. I believe the help and advice given saved the life of my friend's relative"

Neighbour/friend of the person living with dementia



Reasons for contacting our Helpline by category

Accessing support (7,034)

COVID-19 (5,610)

Behaviour (5,073)

Psychological emotional support (4,784)

Getting a diagnosis (4,444)

Dementia; understanding and support (3,840)

Wants an Admiral Nurse (3,830)

Care options (3,721)

Communication (2,136)

Physical health – person with dementia (1,758)

Living with dementia (1,653)

Financial advice (1,552)

Medication (1,399)

Legal issues (1,194)

General information (1,167)

Family dynamics (1,151)

Grief adjustment and loss (1,040)

Risk identification and management (959)

Personal care (820)

Mental health – person with dementia (786)

Palliative – EOL (696)

Hospital concerns (673)

Nutrition/diet/swallowing (649)

Capacity issues (566)

Safeguarding (542)

Mental health – carer (524)

Continuing care issues (294)

Pain control (202)

Falls (84)

Wants to be an Admiral Nurse (46)

Sexuality (32)

Unrelated to dementia (71)

Other (855)

Geographic location of contacts*

Location was recorded for 13,102 contacts (47% of all contacts recorded).

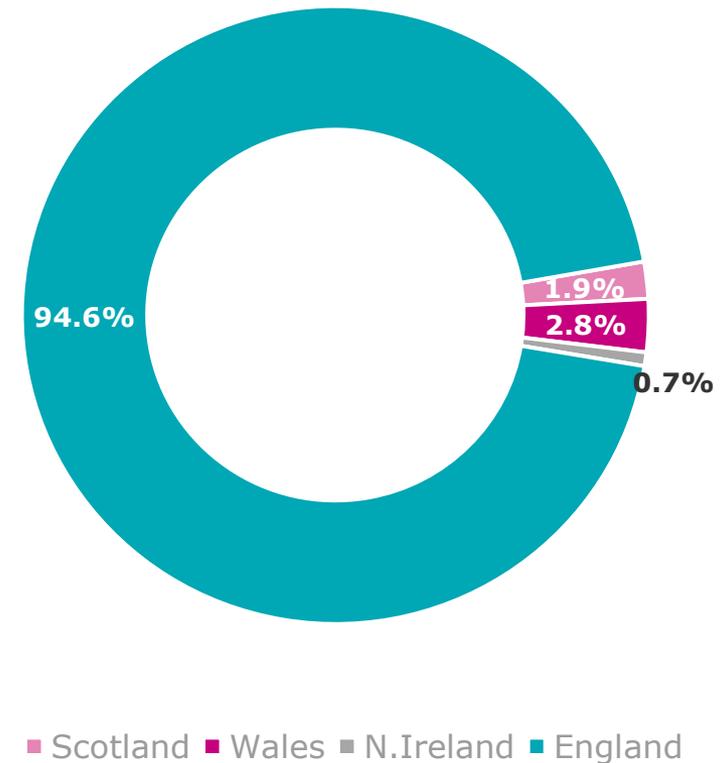
12,848 were UK contacts:

- 95% (n=12,151) from England
- 3% (n=356) from Wales
- 2% (n=249) from Scotland
- 1% (n=92) from Northern Ireland

254 contacts were from 34 other countries:

- the top 5 were - Australia (43), France (34), Spain (31), Republic of Ireland (22) and United States of America (21)

Origin of contacts by UK country (n=12,848)



* Where contact has been made by email, the same level of data is unable to be collected.

Origin of contacts - NHS England regions (n=12,151)

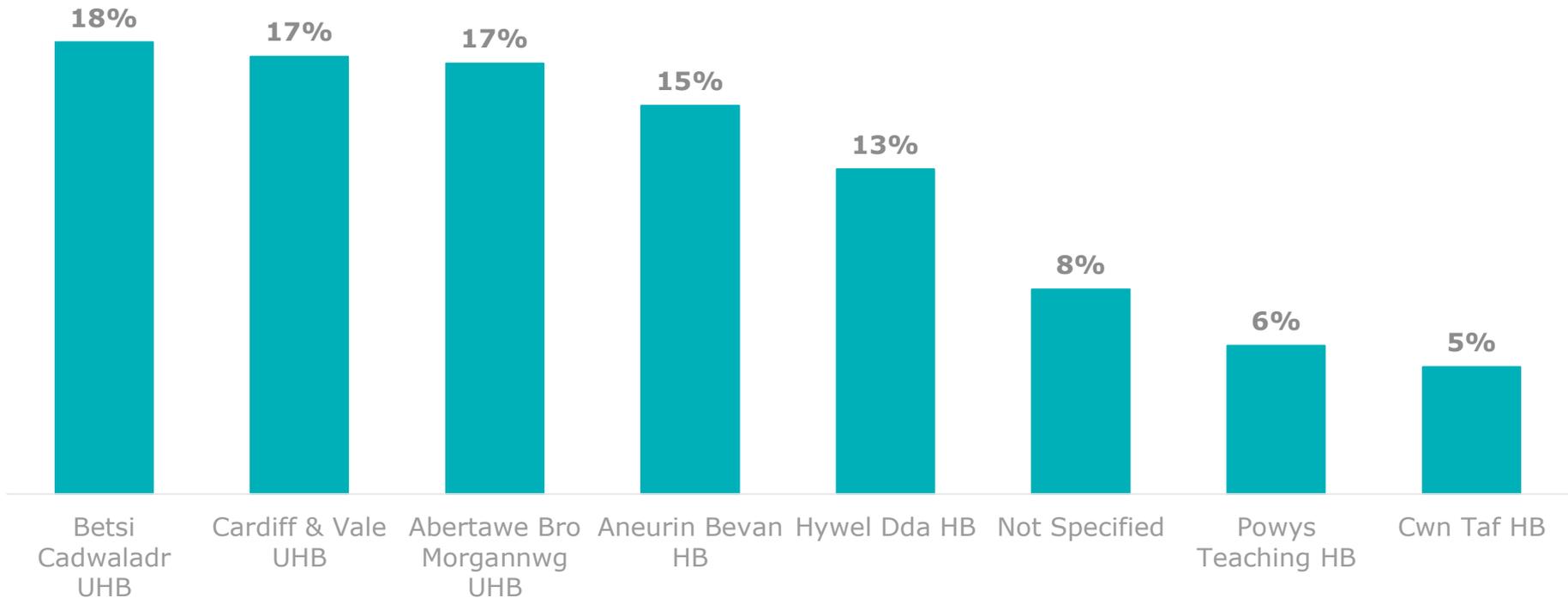


South East – 25% (n=3,014)
Midlands – 20% (n=2,395)
East of England – 14% (n=1,760)
North West – 11% (n=1,384)
North East & Yorkshire – 11% (n=1,342)
South West – 9% (n=1,131)
London – 9% (n=1,125)

Counties with most contacts:

London – 1,125
Kent – 723
Essex – 582
Hampshire – 461
West Midlands – 455

Origin of contacts - Wales Local Health Boards (n=356)



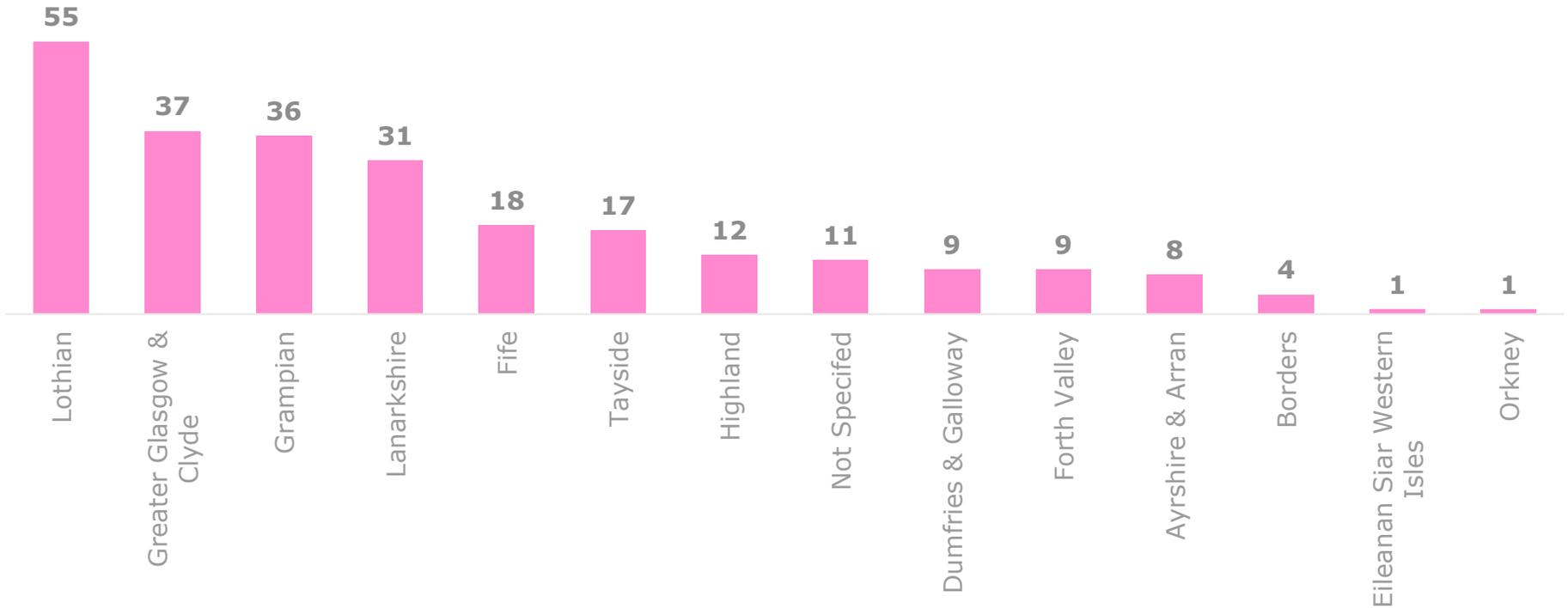
Betsi Cadwaladr University HB – 18% (n=64)
Cardiff & Vale University HB – 17% (n=62)
Abertawe Bro Morgannwg University HB – 17% (n=61)
Aneurin Bevan HB – 15% (n=55)
Hywel Dda HB – 13% (n=46)
Not Specified* – 8% (n=29)
Powys Teaching HB – 6% (n=21)
Cwn Taf HB – 5% (n=18)

Local authority areas with most contacts:

Swansea – 39
Cardiff – 37
Monmouthshire – 29
Ceredigion – 23
Powys – 21

*Recorded as North Wales/Nr Wales/South Wales/ Wales (n=29)

Origin of contacts - NHS Scotland Regions (n=249)



Lothian – 55
 Greater Glasgow & Clyde – 37
 Grampian – 36
 Lanarkshire – 31
 Fife – 18
 Tayside – 17
 Highland – 12
 Not specified* – 11
 Dumfries & Galloway – 9

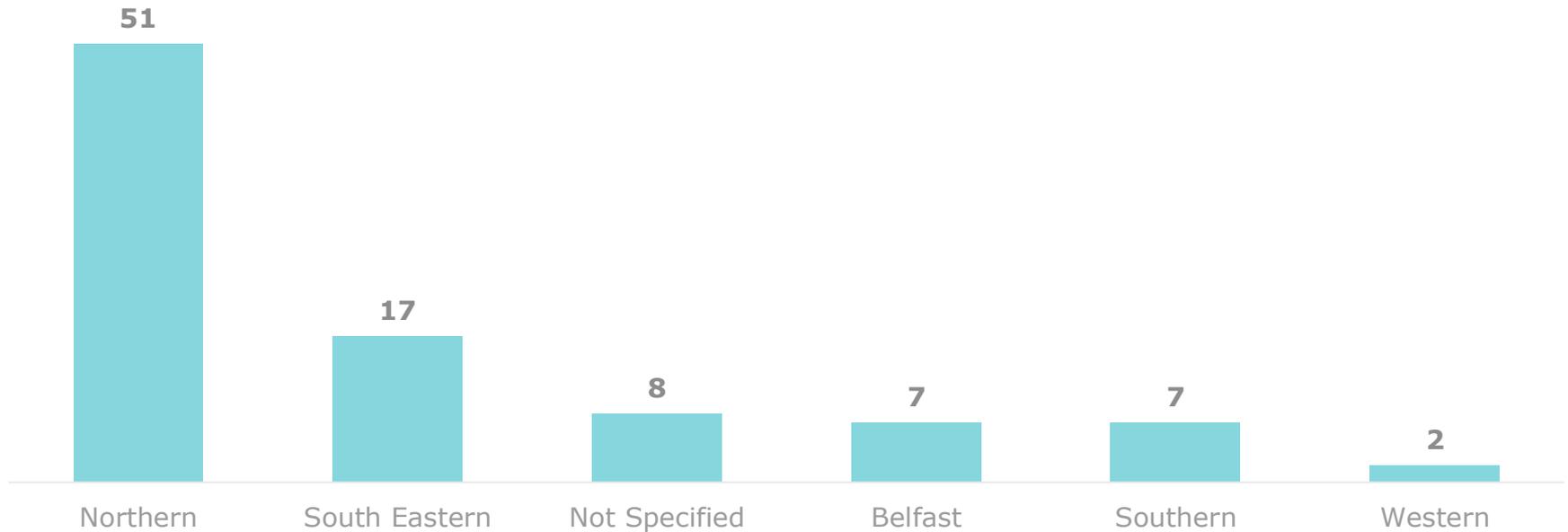
Forth Valley – 9
 Ayrshire & Arran – 8
 Borders – 4
 Eileanan Siar
 Western Isles – 1
 Orkney – 1

Local Authority areas with most contacts:

Aberdeenshire – 30
 Edinburgh, City of – 28
 Fife – 18
 Glasgow, City of – 17
 Lanarkshire, North – 16

*Recorded as Scotland (n=11)

Origin of contacts - Northern Ireland Health & Social Care Trusts (n=92)



Northern – 51
South Eastern – 17
Not Specified* – 8
Belfast – 7
Southern – 7
Western – 2

Local authority areas with most contacts:

Magherafelt – 32
Antrim – 19
Down – 17
Belfast, City of – 7
Armagh – 4

*Recorded as Northern Ireland (n=8)

London contacts – Jan-Dec 2020

1,125 contacts recorded for Greater London in total:

- 736 recorded as Greater London
- 389 recorded by London borough council area (this figure also includes 32 recorded as Middlesex)

Greater London	736
Middlesex	32
Waltham Forest & East London	15
City & Hackney	7
North Central London	91
North West London	98
South West London	69
South East London	55
Barking & Dagenham, Havering and Redbridge	22

Origin of contacts London borough councils & Middlesex by NHS footprint (n=389) January – December 20



How people found our Helpline

Top 6 ways recorded	
Dementia UK Website	3104
Internet	2954
Word of mouth	1449
Health professional	1117
Voluntary sector	581
Other	186

From the data recorded **95%** of contacts found our Helpline via the top 6 ways listed above. The top two ways of finding our Helpline were recorded as:

- Dementia UK Website
- The internet

How did you find us was recorded for 9,893 (36%) contacts.

Other ways recorded	
Dementia UK Clinic and Awareness	103
Television	65
Facebook	63
Social services	62
The Lewy Body Society	50
Magazine	34
Twitter	31
Newspaper	27
Radio	17
Young Dementia UK	16
NHS 111 (SECAMB)	8
Charity for Civil Servants	8
RAF Benevolent Fund	7
Chartered Accountants Benevolent Association (CABA)	7
Herbert protocol (Police missing person referral)	2
Islington Memory Services	1
Islington Alzheimer's Society	1

PUZZEL DATA

Record of all incoming and outbound calls

"The times of the service including Saturdays is great!. The only improvement would be the call waiting times BUT I fully understand how busy your helpline service must be and it's worth the wait!. Also the option to get a call back is a really great feature which I have used and found the call operator to be extremely friendly, caring and gave me the information I needed to carry on giving the best support to my mother who has Vascular Dementia!"

– Son of the person living with Dementia

All incoming and outbound calls



The data below has been extracted from the Puzzel cloud-based telephone call management platform. This system records the volume of all incoming and outbound calls made or attempted to our Helpline. The data presented in the table below shows all calls recorded at any time plus calls during opening hours only.

An increase in calls recorded can be seen in the table below:

Total	Any		Opening hours only	
Jan-Dec 2020	72,423	34% ↑	67,802	32% ↑
Jan-Dec 2019	54,092	19% ↑	51,224	17% ↑
Jan-Dec 2018	45,546	23% ↑	43,659	26% ↑
Jan-Dec 2017	36,964		34,721	

This reporting year (Jan-Dec 20) has shown the largest increase in total calls, compared to the previous three years.

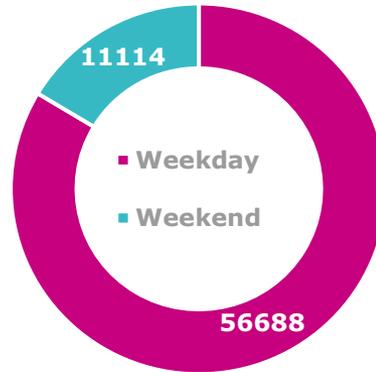
Whilst calls to our Helpline can be attempted at any time of the day, the data presented on the following pages (p31-32) show calls to and from our Helpline **during opening hours only.**

Calls made to and from our Helpline during opening hours (Jan-Dec 2020)

There were a total of **67,802** calls* made to and from our Helpline

56,688 calls were made to and from our Helpline during **weekdays** with an average of:

- 1090 per week
- 218 per day
- 18 per hour



11,114 calls were made to and from our Helpline at **weekends** with an average of:

- 214 per weekend
- 107 per day
- 13 per hour

Comparison to Jan-Dec 2019

Weekdays	44,677
Per Week	859
Per Day	172
Per Hour	14
Weekends	6547
Per Week	126
Per Day	63
Per Hour	8

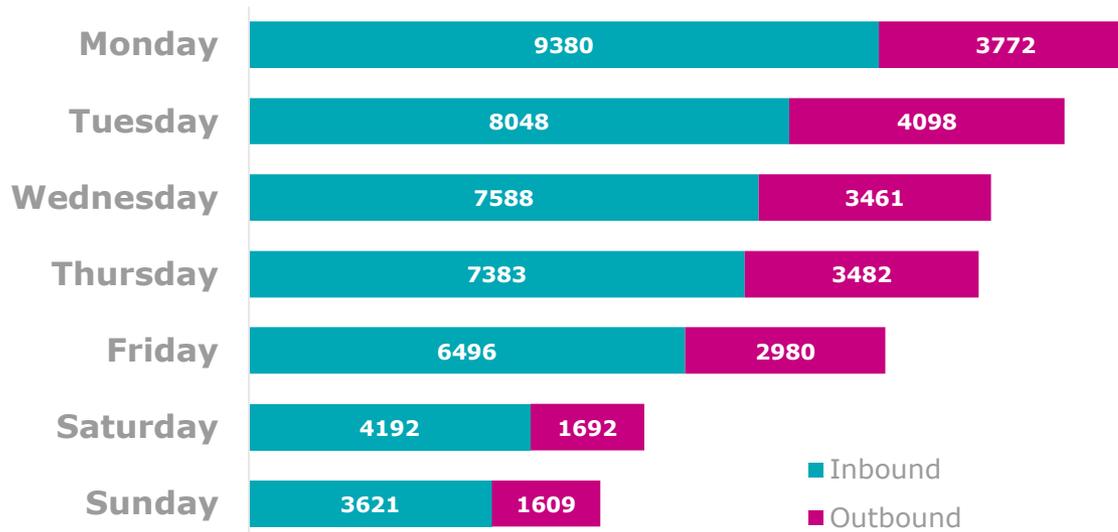


This chart shows a monthly breakdown of total incoming and outbound calls to our Helpline – June was the busiest month in 2020.

* The data shows the number of calls recorded, this figure includes calls made and calls attempted to and from our Helpline

Calls by day of the week* (Jan-Dec 2020)

Incoming and outbound calls by week day



The chart details the breakdown of calls to and from our Helpline on each day of the week and shows:

- more total calls on a Monday than any other day
- Mondays were the busiest day for incoming calls and Tuesdays (closely followed by Mondays) were the busiest day for outbound calls

69% of calls recorded are **calls made or attempted to our Helpline**, (incoming calls) with:

- **38,895** calls made to our Helpline during **weekdays** (22% increase from 2019). This is an average of 12 per hour.
- **7,813** calls made to our Helpline during **weekends** (64% increase from 2019). This is an average of 9 per hour.

Comparison to Jan-Dec 2019

71% of calls recorded were incoming calls, with:

- 31,769 calls made to our Helpline during weekdays (an average of 10 per hour)
- 4,779 calls made to our Helpline during weekends (an average of 6 per hour)

* Opening hours Monday-Friday 9-9, Saturday and Sunday 9-5 figures include calls made and calls attempted

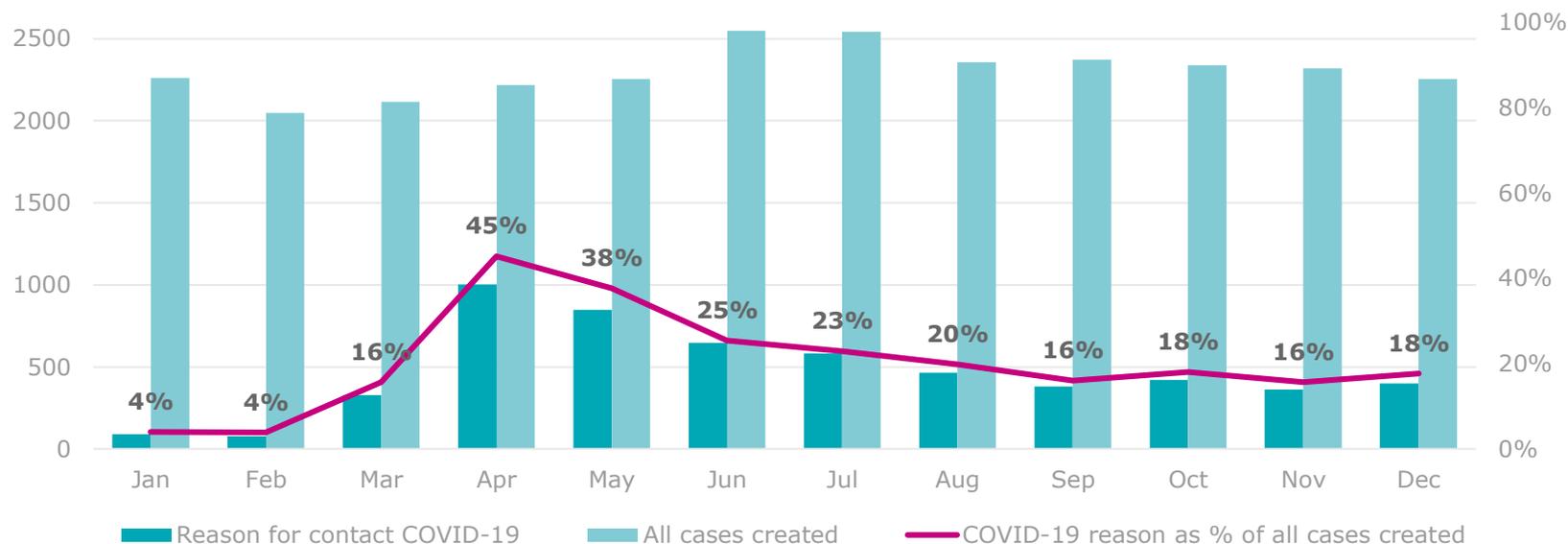
Section 2

Impact of the coronavirus pandemic

The impact of the coronavirus pandemic (Covid-19)

The coronavirus pandemic has had an impact on the number and type of calls to our Helpline – with Covid-19 recorded as a reason for contact in 20% of all cases created this year. This peaked in April and May where this reason was recorded in 45% and 38% of all cases in those months (see chart below).

Cases created & COVID-19 as reason for contact by month (and as a % of all cases created)



What our nurses said about calls since the start of COVID-19

We asked three Helpline nurses about their experiences working on the Helpline since the start of COVID-19. The nurses felt that during the initial period the volume of calls increased and that the calls were often more complex and intense – their experiences are summarised in the following pages.

What our nurses said about calls since the start of COVID-19

The nurses felt that during the initial period the volume of calls increased, with call content increasingly relating to COVID-19 guidance and rules

"When this first started, and with the lockdown, the call volume suddenly exploded. There was call after call after call with the same questions around the guidelines.. Carers would call saying their loved one had dementia, but the call wouldn't relate to that at all. (...) A lot of the calls initially were in relation to the rules and regulations..." Helpline Nurse 2

"A lot of calls came from people, daughters and sons who would visit their parents daily. They were asking 'Can we still do that?' People cancelled formal carers because of the risk and were now realising they would themselves be unable to go and visit them. There were a lot of people in this very difficult situation... People not knowing whether their loved one can wear a mask, how to do that, where to get shopping from..." Helpline Nurse 1

The nurses described that in addition to the increase in the volume of calls, the calls were often more complex and intense:

"Calls are more complex, and intensity has increased. The carers/callers are not only dealing with the everyday struggles of caring for a person living with dementia, but added onto that are the additional challenges they are now facing." Helpline Nurse 3

"Calls have intensified....a lot of calls still in relation to agitation, communication,...but the number of calls we are getting expressing those kinds of concerns have increased. The topics in relation to dementia haven't changed so much, but calls are more severe and more frequent." Helpline Nurse 2

After the initial few weeks, the Helpline Nurses reported that the calls were more about how COVID-19 was impacting on families affected by dementia, including visiting loved ones living in care homes, difficulties getting a dementia diagnosis, lack of support available in the community and carers at crisis points.

Impact on the person with dementia and the carer

"After a few weeks calls started to be more in relation to dementia and the effect lockdown was having on the person with dementia and the carer. Calls lasting longer and were emotionally more challenging. This period meant a change of routine for people with dementia – so we had lots of calls about increased agitation and behaviours that were a challenge to the carer. There was also a high increase in people calling concerned about families. So, we would have a call from the carer, but also from family members expressing concerns about the carer. People who feel quite helpless." Helpline Nurse 2

"Then the calls started to come through about the person living with dementia not understanding the situation and difficulties around this. How to keep their loved one safe (wearing masks can be daunting) and socially distanced .." Helpline Nurse 3

Care Homes - calls were about the rules in care homes and being unable to visit a loved one.

"During the last few weeks, we've had more calls in relation to people who can't visit loved ones in care homes. Quite a few calls about the lack of clear guidance, and discrepancies between one care home and another.." Helpline Nurse 2

Difficulties getting a dementia diagnosis

"There are lots of calls from people suspecting a dementia diagnosis, but they can't see GP and memory clinics are only just slowly starting to open up via telephone and online.." Helpline Nurse 2

Lack of support in the community/Crisis/breakdown

"A lot of community services were cancelled, dementia cafes, no respite. Carers were breaking down". Helpline Nurse 1

"Carers are in crisis more since COVID due to the lack of services and social isolation, not seeing family members as much, increased burden of care... They are emotionally exhausted." Helpline Nurse 3

"People are closer to crisis point. The crisis has actually hit for a lot of people.. We've had quite a rise in number of safeguarding calls..." Helpline Nurse 2

"I found the Admiral Nursing helpline linked to Dementia UK the most helpful support. I have tried many avenues and become increasingly frustrated by my failure to unlock access to my mother... She should be able to have the comfort of a close family relationship. Dementia is confusing enough for the sufferer with out this enforced separation". Carer - daughter of person resident in a Care Home

"Thank goodness for the Admiral Nurse helpline - they have helped me as a carer keep my sanity and filled the gaps left by NHS and Alzheimer's Dementia navigator". Carer - wife of person living with dementia

Snapshot of themes

To further illustrate the impact of COVID on the type of calls to the Helpline, a snapshot of the type of calls has been gathered from two time periods (March & November 2020).

March 2020 - social distancing and understanding the restrictions

Carers had concerns about the COVID guidance/restrictions and their loved one not following this – they wanted advice on how to explain social distancing/hand washing and the new restrictions on going out/visiting in a way that didn't upset the person they care for, as well as advice on the restrictions for themselves:

- **Those they care for do not understand and continue to follow their usual routine of going to the shops, talking with neighbours, getting on the bus and refusing to stay at home**
- **Loved ones forgetting to wash their hands upon returning home**
- **Carers making sense of the restrictions and whether they can visit their loved ones in care home; how they can support the person with dementia with shopping and how they can explain to their loved ones the reason for no visits**

March 2020 - keeping their loved one's safe

Carers also expressed concern about how to keep their loved one safe and supported:

- **Why people who have dementia aren't included as a vulnerable group and being shielded**
- **How the risk of their loved one contracting the virus can be minimized**
- **What would happen if their loved one did contract the virus – how would they be supported**
- **What services are still available to support them**
- **How can PPE be obtained for the carers**

March 2020 - practical concerns

Carers also wanted advice on what they could do practically to ensure the wellbeing of their loved one:

- **Concerns about their loved one who is living alone - should they temporarily move in with family; what to do if moving in with family is not an option**
- **How can carers ensure that their loved one still receives shopping if relatives can't visit them**
- **How to provide emotional and social support**

March 2020 - care and support services

Carers were concerned about the lack of or limited services and support available:

- **What carer and support services are still available for their loved one**
- **Where and how they can address memory problems and suspected dementia**
- **With day services limited or stopped completely, how can they fill this gap**

November 2020 - swab testing

Later in the pandemic and as testing became more accessible, carers reported levels of anxiety around their loved ones being tested, including:

- **Concerns around getting their loved ones to tolerate the swab test, with worries that they would find it invasive or had low pain thresholds**
 - **Loved ones refusing to allow the swab testing and how carers can navigate this**
 - **Lack of information as to why swab test has been requested and what this means**
-

Section 3

Carer experience survey 2017-20

*"I would just like to say that the Admiral nurses have been a **life line** to myself and my family, we hadn't been able to get any help from anybody until I found out about the Admiral nurses."* – Daughter of the person living with dementia

*"I really believe the helpline service is **a true lifeline to carers** of people with Dementia!. The helpful, friendly and knowledgeable staff are truly excellent!.."* – Son of the person living with dementia

Findings

Findings from our carer survey are presented as follows:

- Survey responses
- The demographics of people responding to our carer survey
- The reasons respondents gave for contacting our Helpline
- Positive experience of our Helpline
- Difference our Helpline has made

Responses

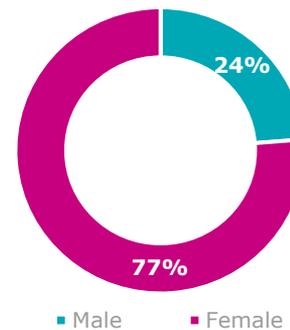
460 carers have responded to our survey from 2017-2020 (25% response rate).

Demographics

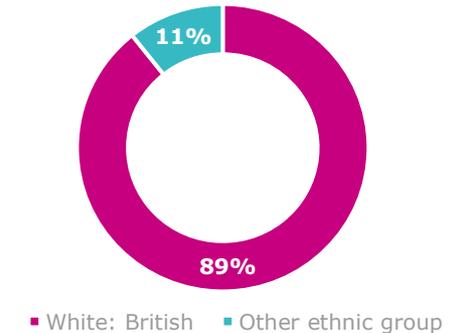
Those responding to our carer survey:

- were more likely to be **female** (77%)
- were most likely to be **White British** (89%), a smaller proportion described their ethnic group as Black/Black British; White Irish; White Other; Asian; or Mixed.

Gender (n=431)



Ethnicity (n=430)

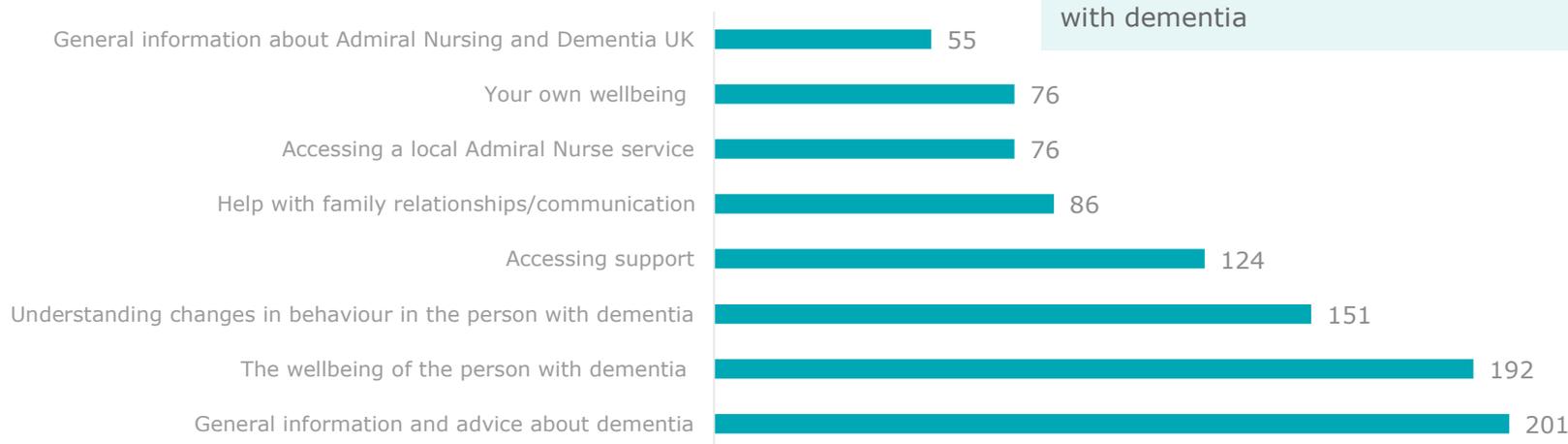


Top 8 reasons carers contact our Helpline

We asked carers why they contacted our Helpline - respondents were offered a range of options. The most commonly ticked reasons were:

- 'information and advice about dementia' (n=201)
- 'the wellbeing of the person with dementia' (n=192)
- 'understanding changes in behaviour' (n=151)
- 'accessing support' (n=124)
- 'help with family relationships/communication' (n=86)

"Admiral Nurse know what you as a carer are going through! They show true empathy and understanding of the situation! Other health professionals you have to explain in detail what a person with Dementia does and while they listen they do not understand or are surprised by the actions of a person with Dementia. Admiral Nurse can relate to the carers situation by the knowledge and experiences they share in the calls. The advice and support they give is brilliant and relevant!" Son of the person living with dementia



26% of respondents (n=121) had contacted our Helpline more than once in the last year

"It was specialist information that helped my family decide what to do with a family friend suffering from memory loss." Family friend of the person living with dementia

Positive experience

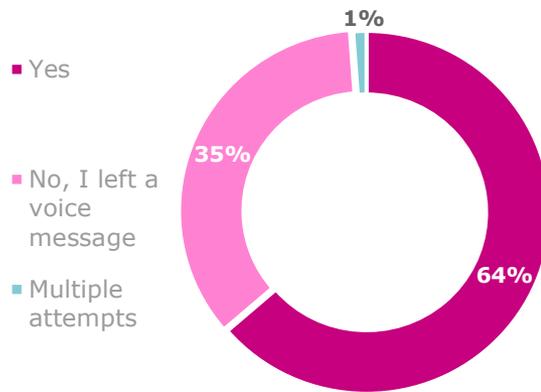




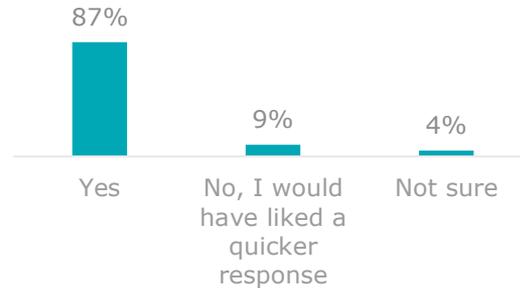
Responsiveness



64% had their call answered immediately (n=432)*



Did you feel that you received a quick enough response? (n=181)



"I was pleased they kept trying to get hold of me rather than leaving a message and waiting for me to call back."
Daughter of the person living with dementia

"They phoned me back the next day and was very helpful."
Daughter of the person living with dementia

"Called back within the hour."
Son of the person living with dementia

Out of the people who didn't have their call answered immediately, a majority felt that they received a quick enough call back, however 9% (16 people) wished that they had received a quicker response.



* 14 respondents told us that they had a different initial contact method to our Helpline (e.g. an Admiral Nurse had called them back following an initial email) hence the question was N/A. Their response to this question has not been included here.

** This includes respondents with alternative initial contact methods (e.g. email).

Support from our Helpline

We asked carers* who had contacted our Helpline whether the Admiral Nurse had been helpful.

Carers (n=253-356) said that the Admiral Nurse was **helpful** in:

- sharing information and explaining the impact of dementia (100%)
- providing them with emotional support (97%)
- providing ways of responding to and coping with changes in behaviour (97%)
- providing support to manage risk and prevent possible crisis (96%)

"The Admiral nurse I spoke to was extremely helpful. This charity is providing a fantastic service!"

Daughter of the person living with dementia

99% of carers (n=439) said that the Admiral Nurse was good at **listening to them, showing compassion to them, and explaining things in a way they could easily understand.**

"The support was amazing, they listened, gave me time and understood completely what I was going through. They were professional and personal. They were brilliant support at the end of the phone and always got back to me quickly. They always had answers and suggestions. I felt I could cry down the phone without being judged and felt at ease doing that with them more than any other health professional." Daughter of the person living with dementia

*We have collected feedback on our Helpline through a survey with carers (which is implemented bi-monthly) – a total of 460 carers completed our survey between December 2017 and December 2020. Response rate to each question varied depending on whether carers felt it was applicable to them – numbers above show the total response to each option in the questions, excluding those saying not applicable..

We asked carers how the support provided by our Helpline was different, if at all, from that given by other health and social care professionals. This is what they told us...

What set Admiral Nurses apart was...

Their specialism, experience, expertise and knowledge of dementia

They provided answers to their questions

Their compassion, empathy and understanding

They were patient

Their ability to listen

They were given time and they didn't feel rushed

The call felt 'personal' and there was a focus on the whole family

"She was **compassionate** and 100% 'there' for me at a time when I was very stressed about caring for my mother. She was totally 'on it' professional and human. **The best supportive tel call experience I've had**". - Daughter of the person living with dementia

"I can't thank the person who spoke to me enough - I was so stressed and burst into tears - and they were patient, kind, really listened - and then offered opinion on my self-made care plan plus practical support. I have spoken to many professionals in this process and **this one call was a life-changer**". - Son of the person living with dementia

Friends and family test (n*=427)

96% of carers would be **'extremely likely'** or **'likely'** to recommend our Helpline to someone who needs similar support and advice.

"It's an outstanding service. Thank you very much. The other services are so fragmented they are difficult to access." Son of the person living with dementia

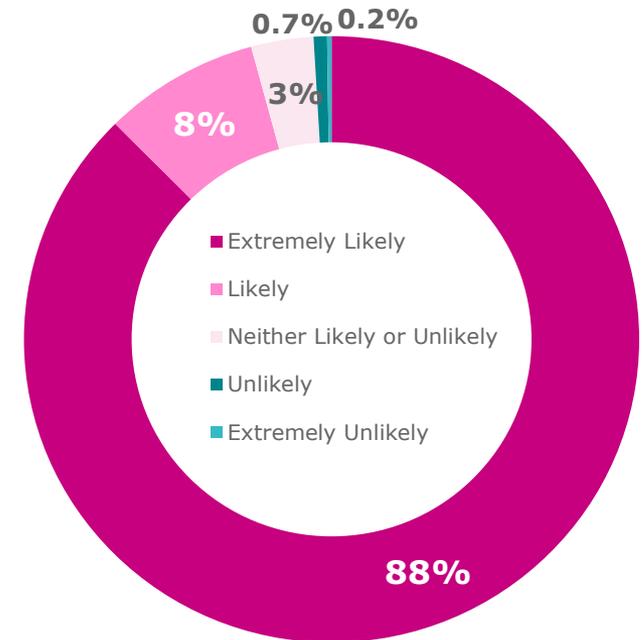
"An excellent service I would recommend to others." Daughter of the person living with dementia

"Brilliant service which I would use again." Daughter of the person living with dementia

"The service is excellent - I have already recommended your service to friends." Daughter of the person living with dementia

"Have found the service provided by Admiral Nurses second to none. I can't ever thank them enough for the support and guidance they have given each time I have spoken to them." Daughter of the person living with dementia

How likely are you to recommend our Helpline to someone you know who needs similar support and advice?



Only three respondents said they would be unlikely to recommend our Helpline.

Follow-ups and leaflets

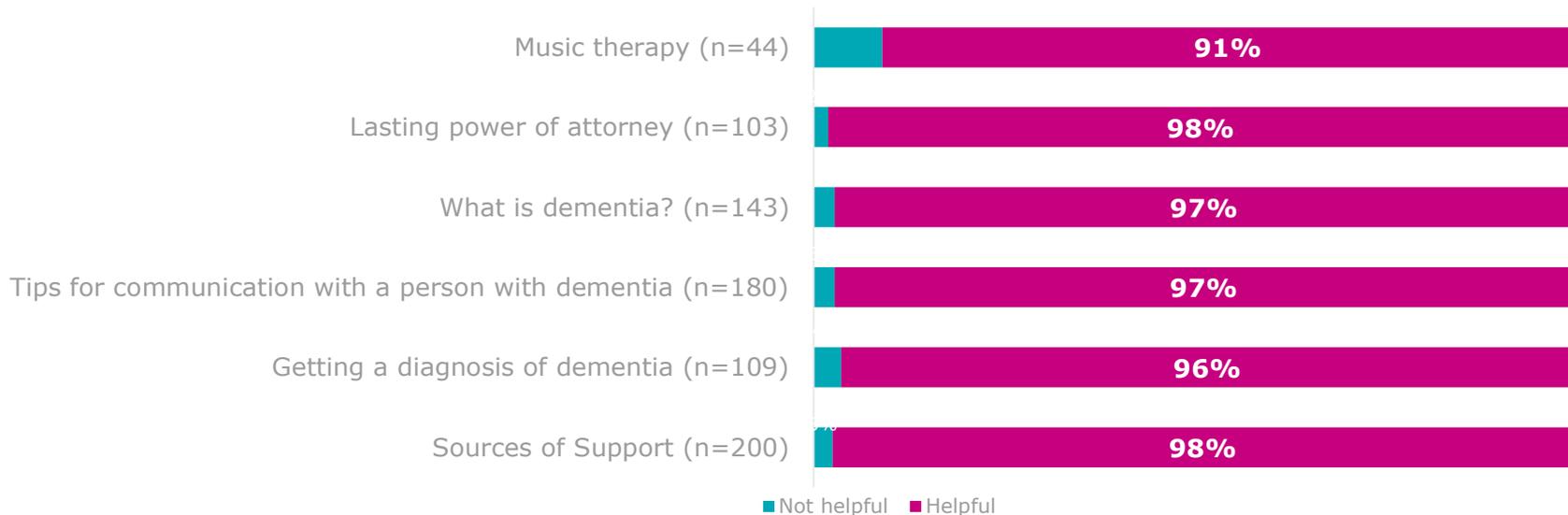
99%

(301 out of 305 respondents) who received a **personalised letter or email** from the Admiral Nurse following on from their call found this **helpful**.

"I thought it was really helpful, thank you for making the service available. I especially appreciated the personal email I received following the call, it has proved invaluable, and I have used the ideas on it."
Female neighbour or friend of person living with dementia

Following on from a call a mix of leaflets are sometimes sent to carers where appropriate.

We asked carers which leaflets they had received and whether these were helpful*. Those who received Dementia UK leaflets following on from the call mostly found these helpful.



**Difference
the service
has made**



Whether our Helpline made a difference to carers

We asked carers whether our Helpline had made a difference* (n=305-357).

Carers reported that our Helpline has made a positive difference in a number of areas:

- **Their ability to make important decisions about the care of the person they look after (95%)**
- **Their ability to take better care of the person they look after (94%)**
- **Their knowledge of local services offering support (92%)**
- **Confidence in their ability to cope (91%)**
- **Their ability to communicate with person they look after (90%)**
- **Their ability to take better care of themselves (86%)**

"Really good helpful and informative. The nurse I spoke to was understanding and patient and help me make some decisions about my mum." Daughter of the person living with dementia

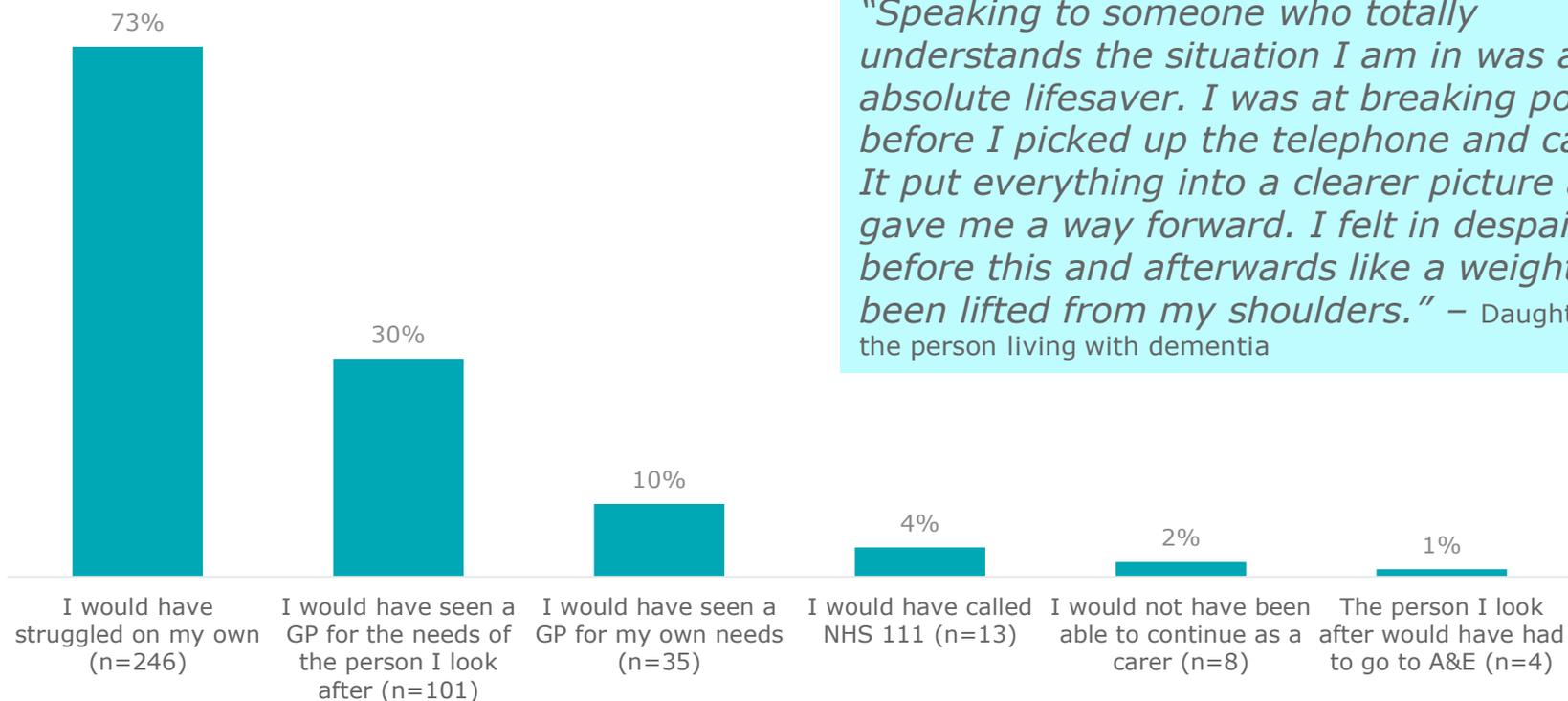
"I had spoken to my brothers' doctor and other people they all suggested methods to help me that didn't work. The Admiral [nurse] suggested an idea that worked immediately. It was a real weight off my mind. With peace of mind, I was able to offer better all-round care for my brother." Brother of the person living with dementia

* Response rate to each question varied depending on whether carers felt it was applicable to them, 'n' is the total number responding to each option in the question

Difference to carers if they could not access our Helpline

We asked carers if they hadn't had access to our Helpline what they would have done:

- 73% would have struggled on their own
- 30% would have seen a GP for the needs of the person they look after
- 10% would have seen a GP for their own needs



"Speaking to someone who totally understands the situation I am in was an absolute lifesaver. I was at breaking point before I picked up the telephone and called. It put everything into a clearer picture and gave me a way forward. I felt in despair before this and afterwards like a weight had been lifted from my shoulders." – Daughter of the person living with dementia

Appendices

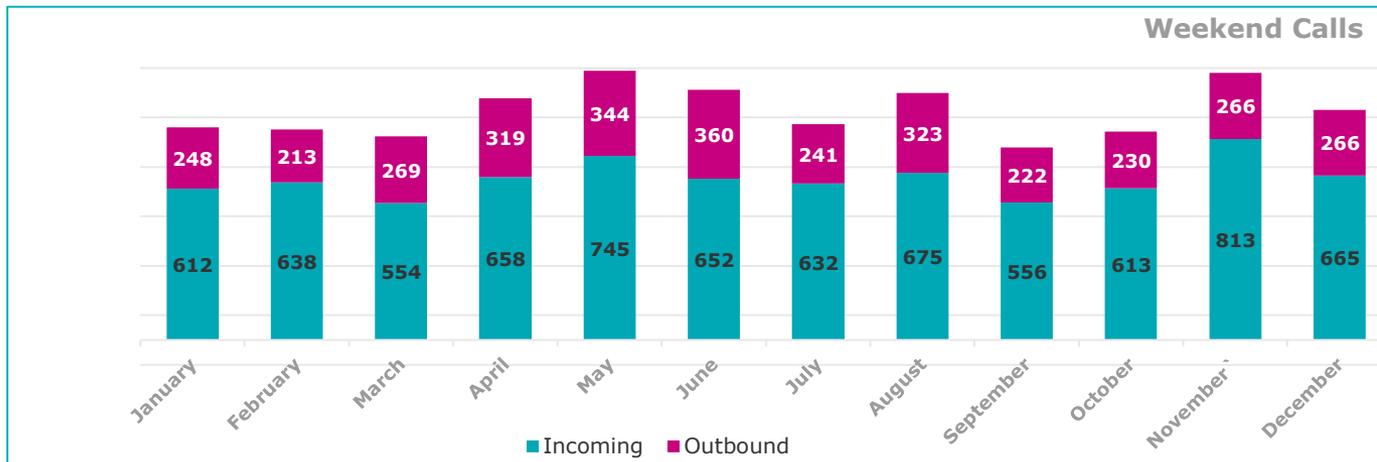
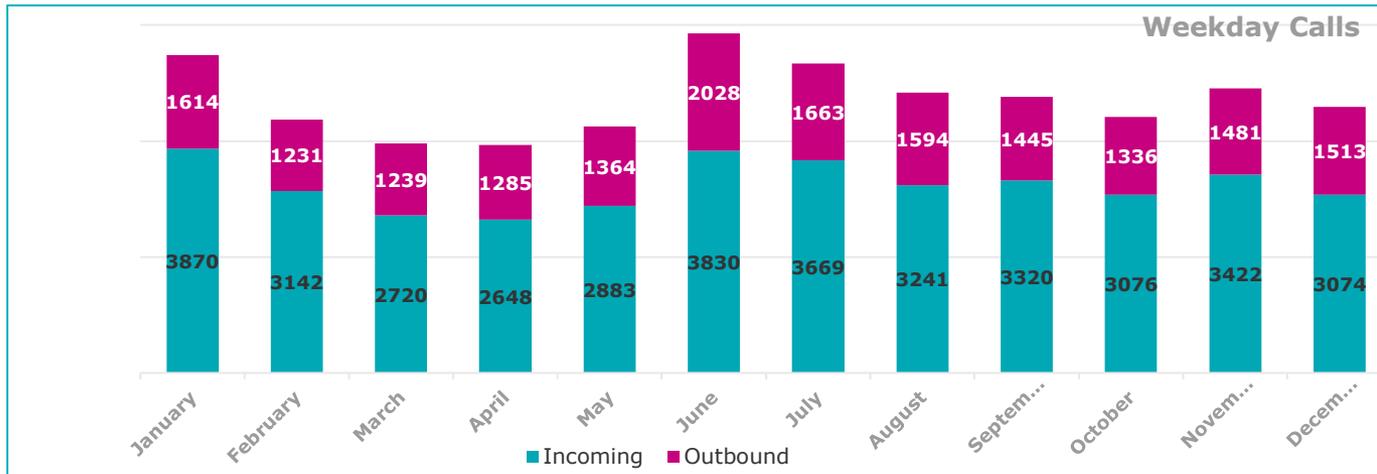
1. Data completeness (COMPASS data)
 2. Puzzel data – calls per month by weekday & weekend
 3. Carer survey – methodology
 4. Carer survey – additional data for questions on 'helpful', 'good' & 'difference'
-

1. Data completeness*

Category	Data Completeness
Method of contact	98%
Enquirer country	47%
Person living with dementia diagnosis	61%
Relationship of the caller to the person living with dementia	84%
Enquirer's ethnicity	16%
Person living with dementia's ethnicity	13%
How the enquirer found out about the Helpline	36%

* Where contact has been made by email, the same level of data is unable to be collected

2. Puzzel data - calls made to and from our Helpline (Jan-Dec 2020)



The charts opposite shows a monthly breakdown of incoming and outbound calls* by weekday (top chart) and weekend (bottom chart).

* Opening hours Monday-Friday 9-9, Saturday and Sunday 9-5

The data shows the number of calls recorded, this figure includes calls made and calls attempted to and from our Helpline

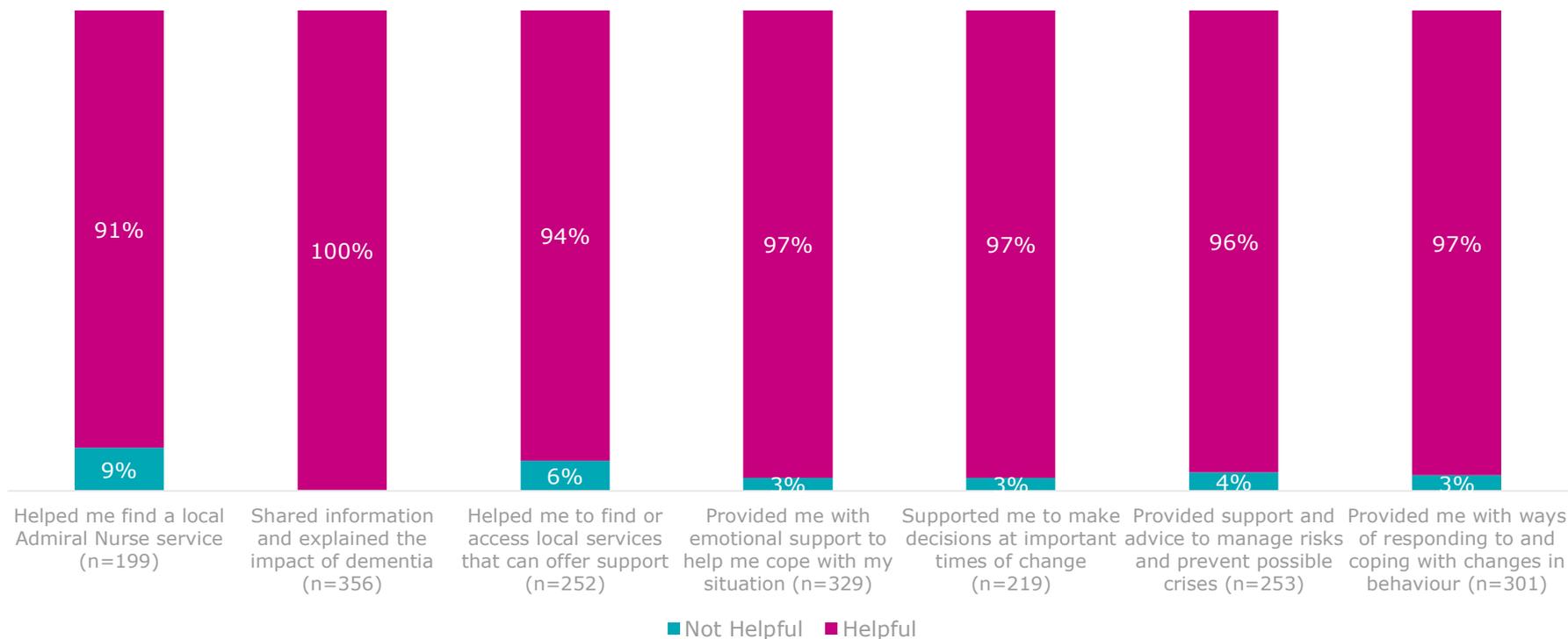
3. Carer survey - methodology

- To understand carers experience of our Admiral Nurse Dementia Helpline, data was collected via a survey.
- The survey tool was developed by the Insights & Evaluation team, in collaboration with our Helpline nurses, and was tested with family carers involved in the Lived Experience Advisory Panel (LEAP).
- Data was collected from December 2017 to December 2020. The survey was implemented bi-monthly (a total of 15 times to date) as an online web survey, which was open for 3 weeks each time, with 1 reminder circulated during this time.
- All carers who had telephone contact with our Helpline during the 2 months prior to the survey being sent out, and who had consented to being contacted for evaluation purposes (during their call with our Helpline) were eligible for inclusion.
- The sample included 1,820 carers in total and 460 carers responded to the survey (representing a 25% response rate) – however response rate to each question varied.
- A covering letter assured carers of their anonymity, explained how the results would be used and that their participation was voluntary. A web address providing access to the survey online was included.
- Quantitative responses were analysed using descriptive analysis and responses to qualitative questions were analysed thematically.
- If you would like to find out more about the methodology or if you would like to use any of the findings in this report please email evaluation@dementiauk.org

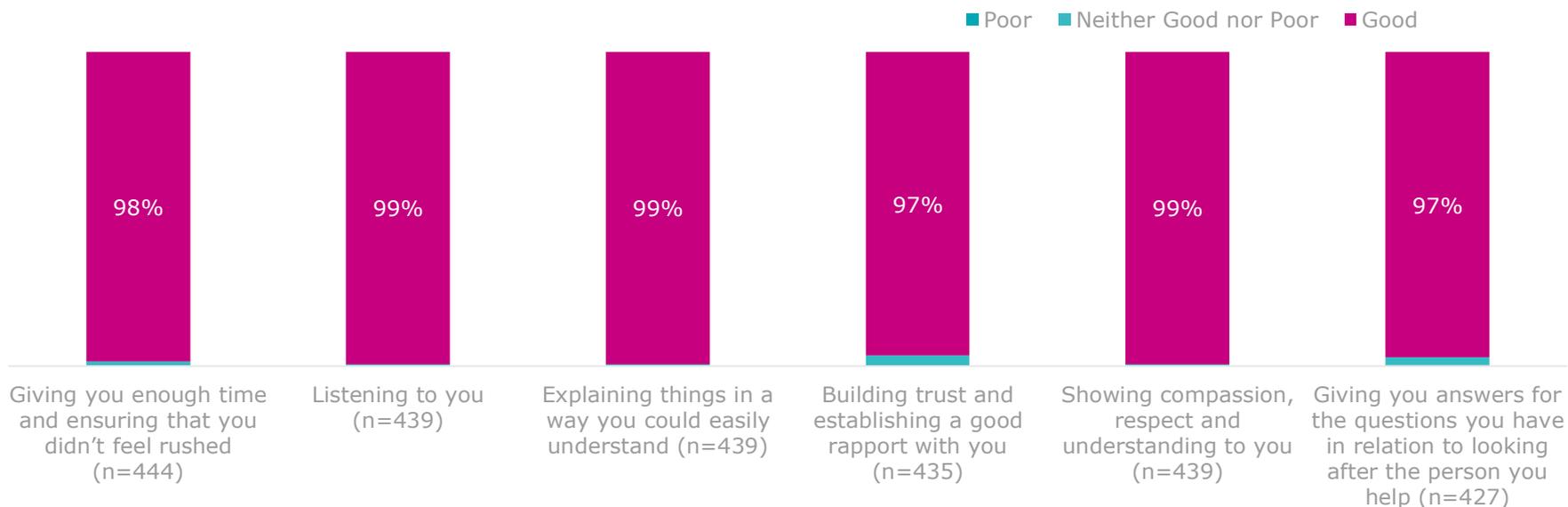
4. Survey data - The Admiral Nurses were 'helpful', 'good', 'made a difference'

The Admiral Nurses were helpful in...

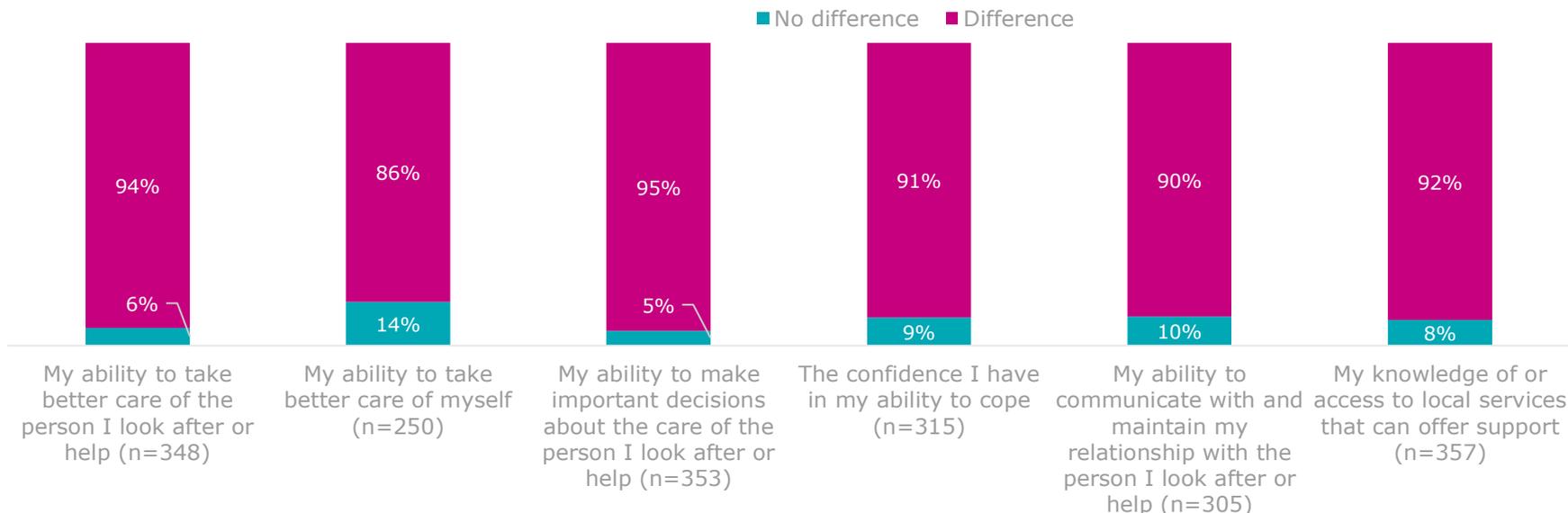
Note: response rate to each question varied depending on whether carers felt it was applicable to them.



The Admiral Nurses were good* at...



The Admiral Nurses made a difference* to...



* Response rate to each question varied depending on whether carers felt it was applicable to them.



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
All bank holidays except 25th December
@DementiaUK • www.dementiauk.org

Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).
