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Participant Characteristics

Survey	148
Focus Groups:	21
• Wadebridge Memory Cafe	12
• Truro Memory Cafe	4
• Bodmin Memory Cafe	5
Interviews (telephone and video)	15

Survey participants were asked whether they wished to be contacted again to take part in interviews or focus groups. 43% of participants agreed to be contacted about taking part in an interview; 20% in a face to face group discussion and 16% in an online group discussion. We held interviews by telephone and online video and held face to face group discussions at Memory Cafes. Participants were selectively approached to take part in interviews in order to include a range of carers from different areas of Cornwall with different characteristics, such as a range of ages, genders and carer relationships.

The tables below list characteristics of carers taking part in the survey, focus groups and interviews. Percentages are derived from the number of carers who have provided demographic information, i.e. percentages exclude carers who have ticked 'Prefer not to say' and those who have not provided any information. The number of carers who have not provided demographic information are provided in grey text at the bottom of each table.

What is your age?	Survey (148)		Focus Groups (21)		Interviews (15)	
Under 25	0	-	0	-	0	-
25-49	20	14%	1	5%	1	8%
50-64	43	29%	3	15%	3	23%
65-79	64	43%	9	45%	7	54%
80+	21	14%	7	35%	2	15%
Prefer not to say/not provided	0	-	1	-	2	-

How old is the person you care for?	Survey (148)		Focus Groups (21)		Interviews (15)	
Under 65	8	5%	0	-	2	14%
65 to 74	26	18%	0	-	3	21%
75 and over	113	77%	19	100%	9	64%
Prefer not to say/not provided	1	-	2	-	1	-

What is your gender?	Survey (148)		Focus Groups (21)		Interviews (15)	
Male	32	22%	2	10%	6	40%
Female	116	78%	18	90%	9	60%
Non binary	0	-	0	-	0	-
Other	0	-	0	-	0	-
Prefer not to say/not provided	0	-	1	-	0	-

Who do you care for?	Survey (148)		Focus Groups (21)		Interviews (15)	
Spouse/partner	80	54%	10	53%	10	67%
Parent/parent in law	53	36%	7	37%	5	33%
Grandparent	4	3%	0	-	0	-
Other relative	3	2%	0	-	0	-
Friend of neighbour	3	2%	1	5%	0	-
Other	5	3%	1	5%	0	-
Prefer not to say/not provided	0	-	2	-	0	-

Do you have other caring responsibilities?	Survey (148)		Focus Groups (21)		Interviews (15)	
No	91	64%	13	76%	8	62%
Yes, I have children	22	15%	0	-	2	15%
Yes, I care for other relatives / friends	18	13%	2	12%	1	8%
Yes, I care for people in my work	13	9%	0	-	3	23%
Other (Yes, myself)	8	6%	2	12%	0	-
Prefer not to say/not provided	6	-	4	-	2	-

Which of these statements describe your work situation?	Survey (148)		Focus Groups (21)		Interviews (15)	
I am in full-time paid work	24	17%	0	-	2	15%
I am in part-time paid work	18	12%	1	5%	3	23%
I look after the home full time	8	6%	1	5%	1	8%
I am fully retired from paid work	71	49%	13	68%	6	46%
I have a long-term illness or disability that prevents me from having paid work	4	3%	1	5%	0	-
I am unable to work due to caring responsibilities	8	6%	2	11%	0	-
I am currently unemployed	0	0%	1	5%	0	-
I am in full-time education	2	1%	0	-	0	-
I am in part-time education	1	1%	0	-	0	-
Other	6	4%	0	-	1	8%
Prefer not to say	3	-	2	-	2	-

How would you describe your sexual orientation?	Survey (148)		Focus Groups (21)		Interviews (15)	
Heterosexual/straight	132	95%	18	100%	13	100%
Gay man	0	-	0	-	0	-
Lesbian/Gay woman	0	-	0	-	0	-
Bisexual	0	-	0	-	0	-
Pansexual	0	-	0	-	0	-
Asexual	2	1%	0	-	0	-
Other	0	-	0	-	0	-
Prefer not to say/not provided	9	-	3	-	2	-

Which of the following best describes your current financial situation?	Survey (148)		Focus Groups (21)		Interviews (15)	
*I have more than enough for basic necessities, and a lot spare that I can save or spend on extras or leisure	16	13%	1	6%	3	23%
*I have more than enough for basic necessities, and a little spare that I can save or spend on extras or leisure	74	59%	11	65%	8	62%
**I have just enough for basic necessities and little else	31	25%	5	29%	2	15%
**I don't have enough for basic necessities and sometimes or often run out of money	2	2%	0	-	-	-
Prefer not to say/not provided	22	-	4	-	2	-

* & **Combined responses to question above as:	Survey (126)		Focus Groups (17)		Interviews (13)	
*Spare income for extras or leisure	90	71%	12	77%	11	85%
**No spare income for extras or leisure	33	26%	5	23%	2	15%

Ethnicity	Survey (148)		Focus Group (21)		Interviews (15)	
White: British / English / Northern Irish / Scottish / Welsh	117	81%	14	74%	9	69%
White: Cornish	22	15%	5	26%	3	23%
White: Irish	0	-	0	-	0	-
Gypsy, Traveller or Irish Traveller	0	-	0	-	0	-
Roma	0	-	0	-	0	-
Any other White	2	1%	0	-	1	8%
Arab	0	-	0	-	0	-
Asian / Asian British: Bangladeshi	0	-	0	-	0	-
Asian / Asian British: Chinese	0	-	0	-	0	-
Asian / Asian British: Indian	0	-	0	-	0	-
Asian / Asian British: Pakistani	0	-	0	-	0	-
Any other Asian / Asian British	0	-	0	-	0	-
Black / Black British: African	0	-	0	-	0	-
Black / Black British: Caribbean	0	-	0	-	0	-
Any other Black / Black British	0	-	0	-	0	-
Mixed / Multiple ethnic groups: Asian and White	0	-	0	-	0	-
Mixed / Multiple ethnic groups: Black African and White	0	-	0	-	0	-
Mixed / Multiple ethnic groups: Black Caribbean and White	1	1%	0	-	0	-
Any other Mixed / multiple ethnic groups	0	-	0	-	0	-
Any other ethnic group	0	-	0	-	0	-
Prefer not to say	4	-	2	-	3	-

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months (include any problems related to old age)?

Day-to-day activities limited because of a health problem or disability?	Survey (148)		Focus Groups (21)		Interviews (15)	
No	84	58%	7	37%	11	85%
Yes, limited a little	37	26%	9	47%	1	8%
Yes, limited a lot	18	12%	3	16%	1	8%
Prefer not to say/not provided	3	-	6	-	2	-

If yes, please indicated your disability	Survey (55)		Focus Groups (11)		Interviews (2)	
Vision (e.g. due to blindness of partial sight)	3	5%	1	9%	1	-
Hearing (e.g. due to deafness or partial hearing)	11	20%	3	27%	1	-
Mobility, such as difficulty walking short distances, climbing stairs, lifting and carrying objects	24	44%	4	36%	0	-
Learning or concentrating or remembering	6	11%	4	36%	0	-
Mental Health	9	16%	4	36%	0	-
Stamina or breathing difficulty	11	20%	2	18%	0	-
Social, behavioural or communication (e.g. due to neuro diverse conditions such as Autism, Attention Deficit Disorder or Asperger's Syndrome)	4	7%	2	18%	0	-
Other impairment	14	25%	3	27%	1	-
Prefer not to say/not provided	4	-	0	-	0	-

How would you describe your environment (the area that you live in)?	Survey (148)		Focus Groups (21)		Interviews (15)	
Rural	70	50%	5	33%	6	46%
Semi-urban	49	35%	7	47%	3	23%
Urban	18	13%	3	20%	4	31%
Prefer not to say/not provided	7	-	5	-	2	-

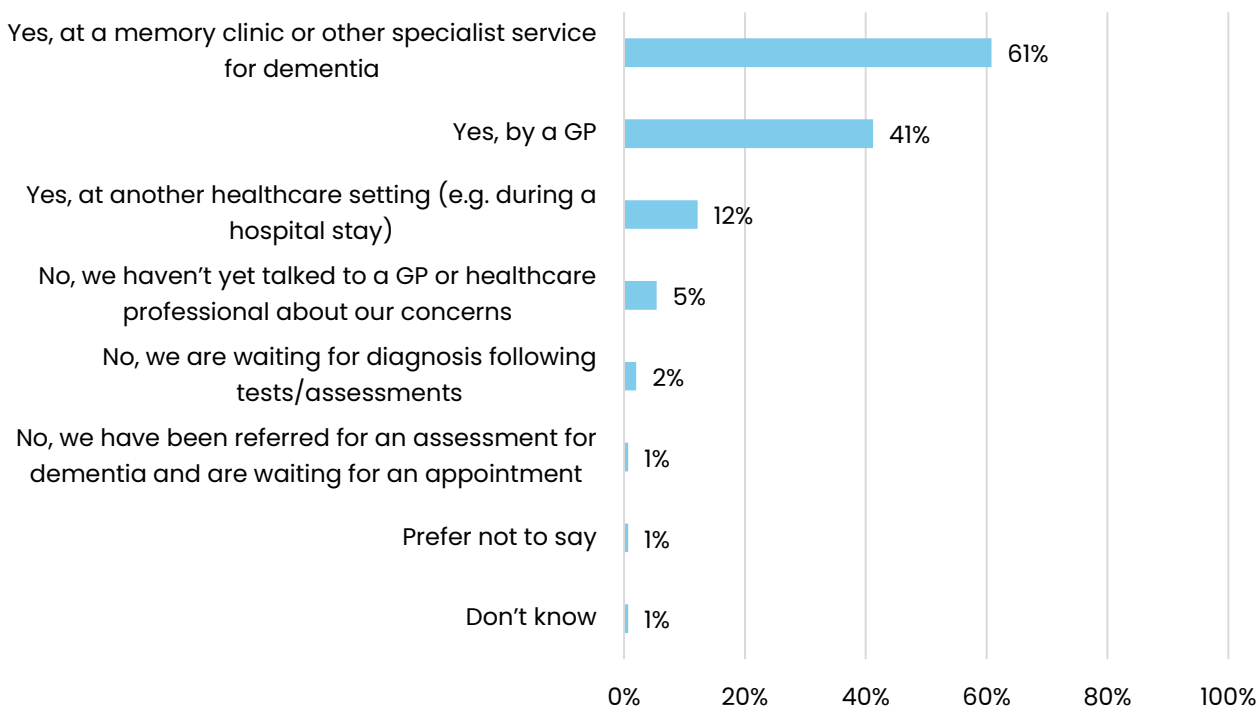
Integrated Care Area based on postcode	Survey (148)		Focus Groups (20)	Interviews (15)	
Central	50	34%	Truro Memory Cafe	3	23%
North & East	53	36%	Bodmin and Wadebridge Memory Cafes	5	38%
West	40	27%	*(Redruth Memory Cafe attended; FG was not held)	4	31%
Prefer not to say / not provided	5	-		2	-

* We also attended Redruth Memory Cafe to listen to carers informally. It was not feasible to hold a focus group at Redruth as carers remained with their relatives throughout the Cafe session. Memory Cafe members across the network were encouraged to share their experiences via the survey as well.

Survey results, including group comparisons

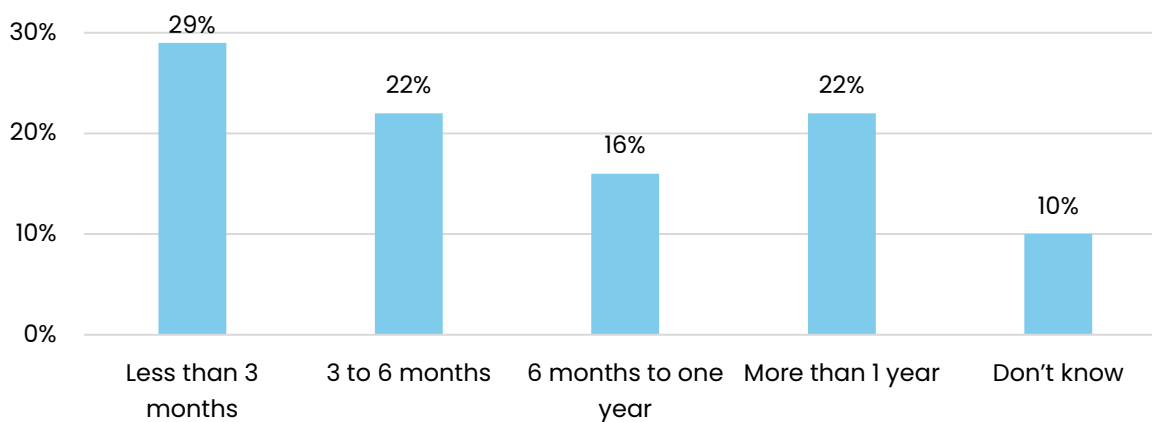
1. Has the person you care for been diagnosed with dementia by a healthcare professional? Tick all that apply

148 respondents:



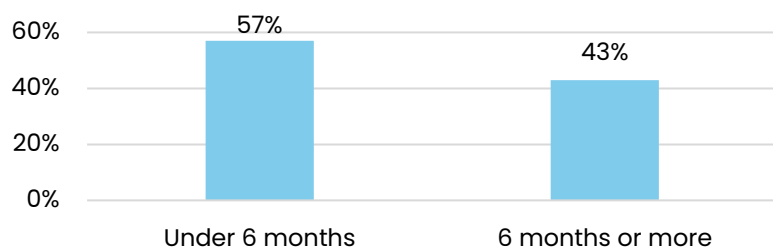
2. How long did it take from first discussing this with a health care professional to receiving a diagnosis?

125 responses:



Responses were categorised into '6 months or more' and 'Under 6 months'

121 responses provided a diagnosis time:

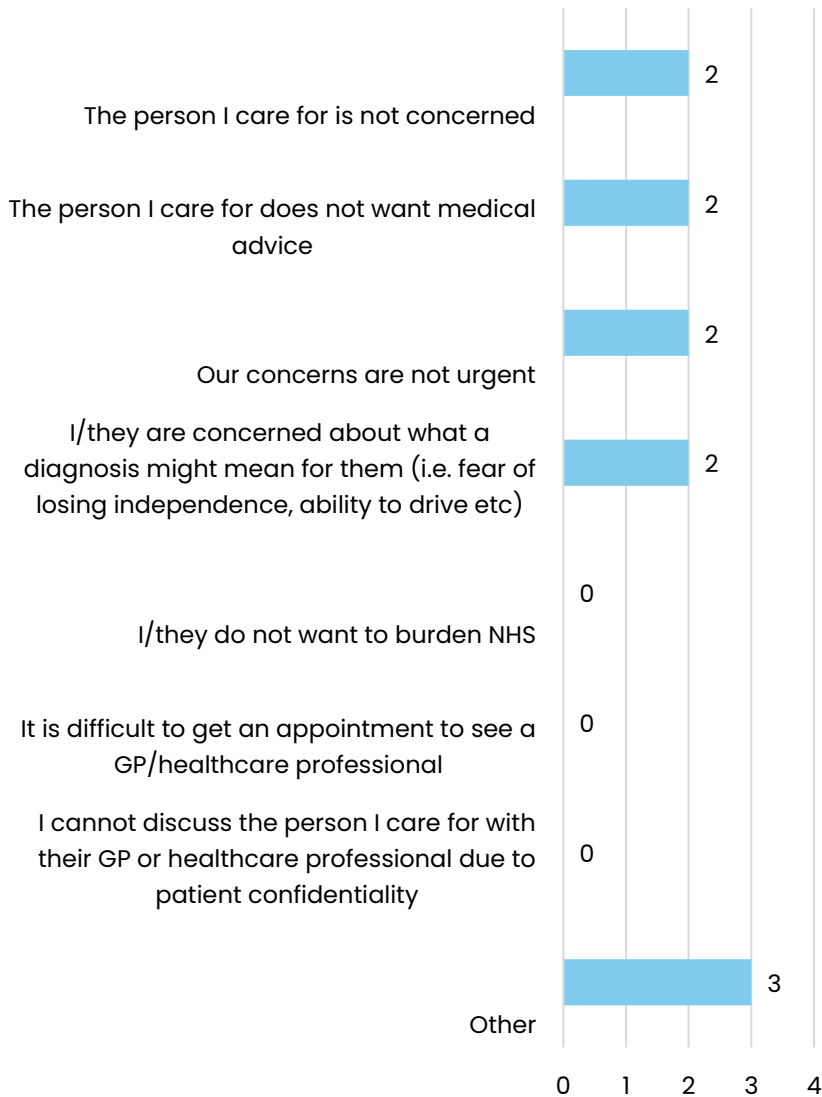


We used chi square tests to explore any differences in diagnosis time depending on participant characteristics. Chi square tests provide p values which give an indication of whether differences in percentages across different groups are statistically significant. P values <0.05 indicate a statistically significant difference between groups. **These are written in pink/bold in the table below.**

Participant characteristics. Number of participants in each group is shown in brackets.	% diagnosed in under 6 months	% diagnosed in 6 months or more	P value
ALL carers (121)	57%	43%	
Integrated care area (ICA) based on participant postcode: <ul style="list-style-type: none"> North & East (45) Central (42) West (29) 	56% 71% 38%	44% 29% 62%	P=0.02
Age of person living with dementia <ul style="list-style-type: none"> Under 65 65 to 74 75 and over 	50% 45% 60%	50% 55% 40%	P=0.20
Carer gender <ul style="list-style-type: none"> Female (92) Male (29) 	62% 41%	38% 59%	P=0.15
Carer relationship with person living with dementia <ul style="list-style-type: none"> Spouse (72) Parent/parent in law (39) 	63% 51%	38% 49%	P=0.52
Carer working situation <ul style="list-style-type: none"> In full or part time work (32) Retired (63) 	44% 59%	56% 41%	P=0.38
Carer financial situation <ul style="list-style-type: none"> No spare income for extras or leisure (20) Spare income for extras or leisure (79) 	55% 56%	45% 55%	P=0.99
Carer location <ul style="list-style-type: none"> Rural Semi-urban Urban 	59% 50% 53%	41% 50% 47%	P=0.68

3. Can you tell us why you or the person you care for have not yet seen a GP or healthcare professional about their memory loss symptoms? Tick all that apply

7 responses:



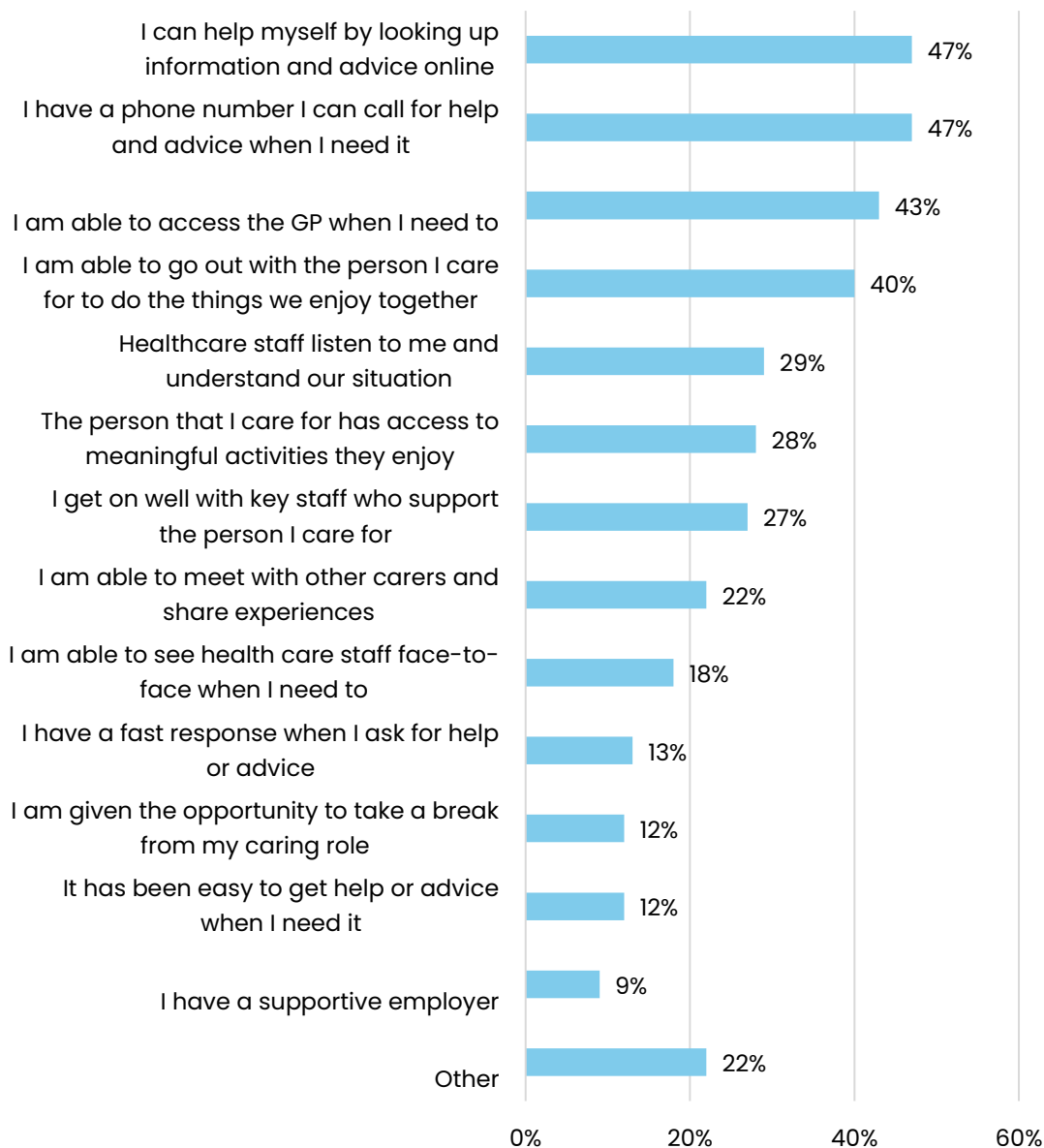
Other: 'don't know how to see GP to get parent assessed'

Your experiences of services and accessing support:

There is a wide range of health, social care and voluntary sector services which support carers and people living with dementia and memory loss in Cornwall. This may include your GP, memory services, specialist nurses, physiotherapy, occupational therapy, carer services and assessments, memory cafes, charities, and local support groups etc. You may have accessed them through your GP surgery, social care services, a hospital, in your own home or community, online or over the phone.

4. What has been helpful or working well for you and for the person you care for?

148 responses:



'Other' included different examples, such as Sensory Trust, Memory cafes and other community activities and privately paid carers. Some carers described the lack of support they have had.

We used chi square tests to explore any differences in responses to questions depending on participant characteristics. We only tested items where there were sufficient numbers for analysis. The tables show the **percentage of each group selecting items that has been helpful or working well**. P values **<0.05** indicate a statistically significant difference and are **written in pink/bold in the tables below**. Differences *close to statistical significance (P between 0.09<0.05)* are in pink italic font. The percentage of all carers selecting each item is included in brackets next to each item. *Percentages for under 65s are difficult to interpret due to small numbers. These are displayed in faded text.

What has been helpful or working well for carers (% of all carers selecting this)	Carer working status			Carer relationship			Age of person living with dementia			
	Full or part time work (42)	Retired (71)	P value	Parent / parent in law (53)	Spouse / partner (80)	P value	*Under 65 (8)	65 to 74 (26)	75 and over (113)	P value
I have a phone number I can call for help and advice when I need it (47%)	29%	58%	P=0.002	30%	60%	P=0.001	50%	50%	45%	P=0.88
I can help myself by looking up information and advice online (47%)	52%	41%	P=0.23	53%	44%	P=0.30	75%	65%	40%	P=0.02
I am able to access the GP when I need to (43%)	<i>33%</i>	<i>51%</i>	<i>P=0.07</i>	36%	48%	P=0.18	38%	42%	42%	P=0.96
I am able to go out with the person I care for to do the things we enjoy together (40%)	43%	41%	P=0.83	36%	45%	P=0.29	75%	<i>46%</i>	<i>35%</i>	<i>P=0.06</i>
Healthcare staff listen to me and understand our situation (29%)	29%	25%	P=0.71	32%	28%	P=0.57	38%	31%	27%	P=0.80
The person that I care for has access to meaningful activities they enjoy (28%)	24%	37%	P=0.16	23%	34%	P=0.17	<i>13%</i>	35%	27%	P=0.46
I get on well with key staff who support the person I care for (27%)	29%	25%	P=0.71	26%	29%	P=0.77	50%	35%	23%	P=0.15
I am able to meet with other carers and share experiences (22%)	10%	31%	P=0.01	11%	30%	P=0.01	25%	27%	20%	P=0.75

The tables show the **percentage of each group selecting items that has been helpful or working well**. P values **<0.05** indicate a statistically significant difference. **These are written in pink/bold in the tables below**. Differences *close to statistical significance (P between 0.09<0.05)* are in pink italic font.

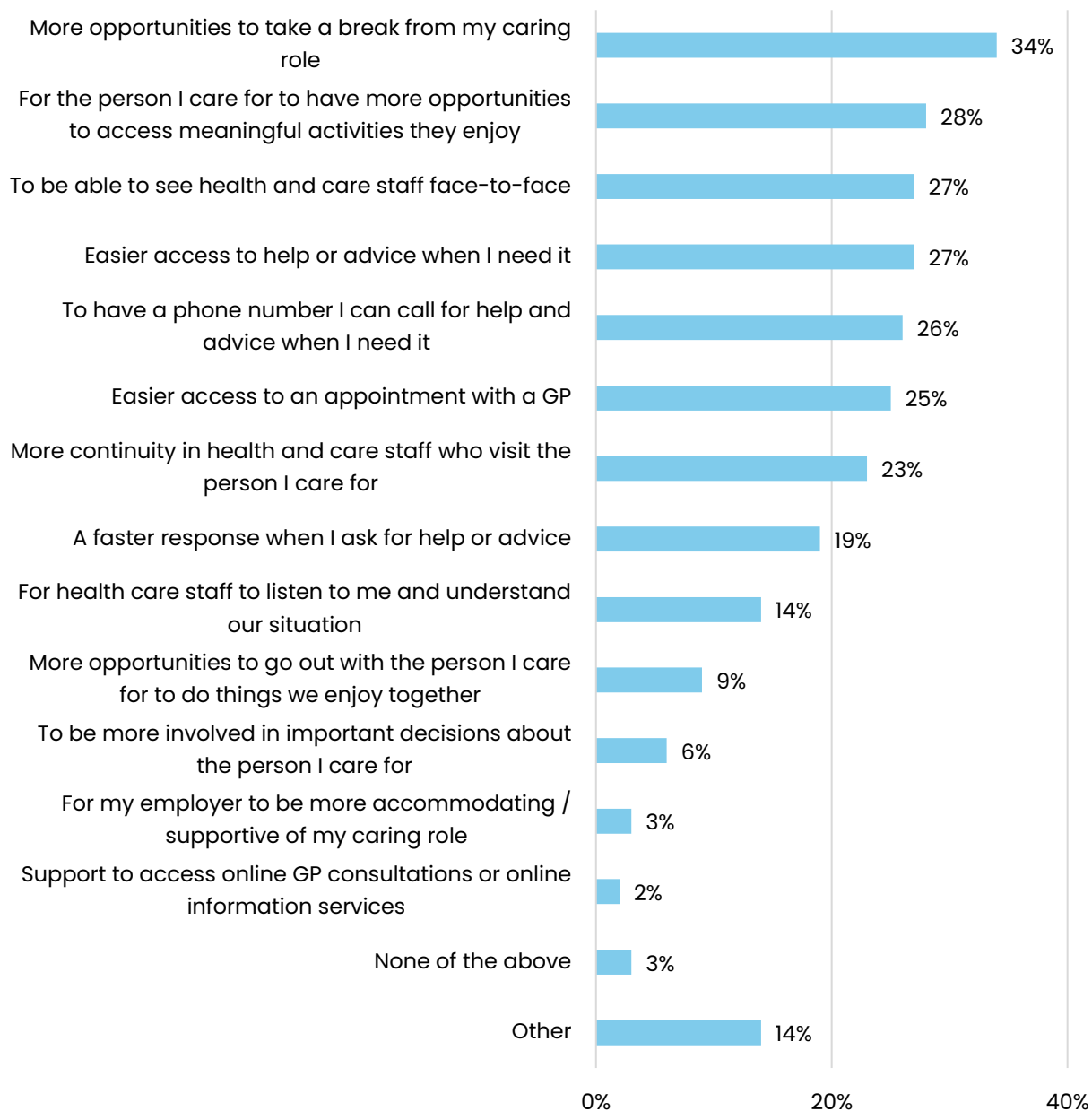
What has been helpful or working well for carers (% of all carers selecting this)	Carer financial situation			Carer gender			Carer activities limited by health condition			
	No spare income (33)	Spare income (90)	P value	Female (116)	Male (32)	P value	No (84)	Yes, limited a little (37)	Yes, limited a lot (18)	P value
I have a phone number I can call for help and advice when I need it (47%)	48%	49%	P=0.97	45%	53%	P=0.40	42%	65%	33%	P=0.03
I can help myself by looking up information and advice online (47%)	42%	51%	P=0.39	50%	34%	P=0.12	50%	46%	50%	P=0.61
I am able to access the GP when I need to (43%)	36%	48%	P=0.26	42%	44%	P=0.88	46%	41%	39%	P=0.75
I am able to go out with the person I care for to do the things we enjoy together (40%)	30%	47%	P=0.10	38%	47%	P=0.36	<i>45%</i>	<i>35%</i>	<i>17%</i>	<i>P=0.07</i>
Healthcare staff listen to me and understand our situation (29%)	27%	34%	P=0.45	32%	19%	P=0.15	32%	24%	39%	P=0.51
The person that I care for has access to meaningful activities they enjoy (28%)	21%	33%	P=0.19	27%	34%	P=0.14	29%	35%	17%	P=0.36
I get on well with key staff who support the person I care for (27%)	21%	30%	P=0.33	27%	28%	P=0.87	27%	27%	33%	P=0.87
I am able to meet with other carers and share experiences (22%)	21%	20%	P=0.88	22%	22%	P=0.95	17%	27%	28%	P=0.32

The tables show the **percentage of each group selecting items that has been helpful or working well**. P values **<0.05** indicate a statistically significant difference. **These are written in pink/bold in the tables below**. Differences *close to statistical significance (P between 0.09<0.05)* are in pink italic font.

What has been helpful or working well for carers (% of all carers selecting this)	Carer age					Carer location				Integrated Care Area			
	25-49 (20)	50-64 (43)	65-79 (64)	80+ (21)	P value	Rural (70)	Semi-urban (49)	Urban (18)	P value	Central (50)	North & East (53)	West (40)	P value
I have a phone number I can call for help and advice when I need it (47%)	20%	40%	58%	52%	P=0.02	51%	55%	44%	P=0.59	46%	53%	40%	P=0.66
I can help myself by looking up information and advice online (47%)	60%	49%	47%	29%	P=0.04	43%	59%	61%	P=0.14	44%	42%	55%	P=0.61
I am able to access the GP when I need to (43%)	30%	40%	47%	48%	P=0.54	46%	45%	39%	P=0.90	46%	42%	40%	P=0.90
I am able to go out with the person I care for to do the things we enjoy together (40%)	25%	44%	41%	43%	P=0.52	34%	45%	44%	P=0.45	50%	40%	28%	P=0.24
Healthcare staff listen to me and understand our situation (29%)	25%	33%	31%	19%	P=0.66	29%	37%	22%	P=0.45	30%	26%	33%	P=0.86
The person that I care for has access to meaningful activities they enjoy (28%)	<i>20%</i>	<i>19%</i>	<i>31%</i>	<i>48%</i>	<i>P=0.08</i>	29%	29%	28%	P=0.99	<i>22%</i>	<i>42%</i>	<i>20%</i>	<i>P=0.09</i>
I get on well with key staff who support the person I care for (27%)	25%	30%	28%	19%	P=0.87	29%	33%	11%	P=0.21	26%	28%	25%	P=0.95
I am able to meet with other carers and share experiences (22%)	5%	14%	30%	33%	P=0.03	24%	22%	17%	P=0.79	20%	34%	10%	P=0.05

5. Which three things would you most like to see improved in relation to services and support you have accessed?

144 responses:



'Other' included suggestions such as a one stop shop for information and advice, better sharing of notes between services, not having to chase up medication, more continuity in health care staff and for health care staff to listen and understand their situation. Two carers said they had all the help they needed.

The tables show the **percentage of each group selecting items they would like to see improved**. We only tested items where there were sufficient numbers for analysis. P values **<0.05** indicate a statistically significant difference. **These are written in pink/bold in the tables below**.

*Percentages for under 65s are difficult to interpret due to small numbers, displayed in faded text.

What carers would most like to see improved (% of all carers selecting this)	Carer working status			Carer relationship			Age of person living with dementia			
	Full or part time work (42)	Retired (71)	P value	Parent / parent in law (53)	Spouse / partner (80)	P value	*Under 65 (8)	65 to 74 (26)	75 and over (113)	P value
More opportunities to take a break from my caring role (34%)	19%	44%	P=0.008	23%	44%	P=0.01	50%	42%	31%	P=0.34
For the person I care for to have more opportunities to access meaningful activities they enjoy (28%)	24%	30%	P=0.51	23%	30%	P=0.35	38%	42%	23%	P=0.04
Easier access to help or advice when I need it (27%)	36%	24%	P=0.27	36%	20%	P=0.04	13%	19%	29%	P=0.38
To be able to see health and care staff face-to-face (27%)	29%	25%	P=0.71	21%	29%	P=0.30	13%	15%	30%	P=0.20
To have a phone number I can call for help and advice when I need it (26%)	24%	24%	P=0.99	34%	21%	P=0.10	0%	23%	28%	P=0.55
Easier access to an appointment with a GP (25%)	19%	25%	P=0.44	25%	28%	P=0.70	25%	27%	24%	P=0.95
More continuity in health and care staff who visit the person I care for (23%)	21%	23%	P=0.90	21%	23%	P=0.81	0%	23%	24%	P=0.72

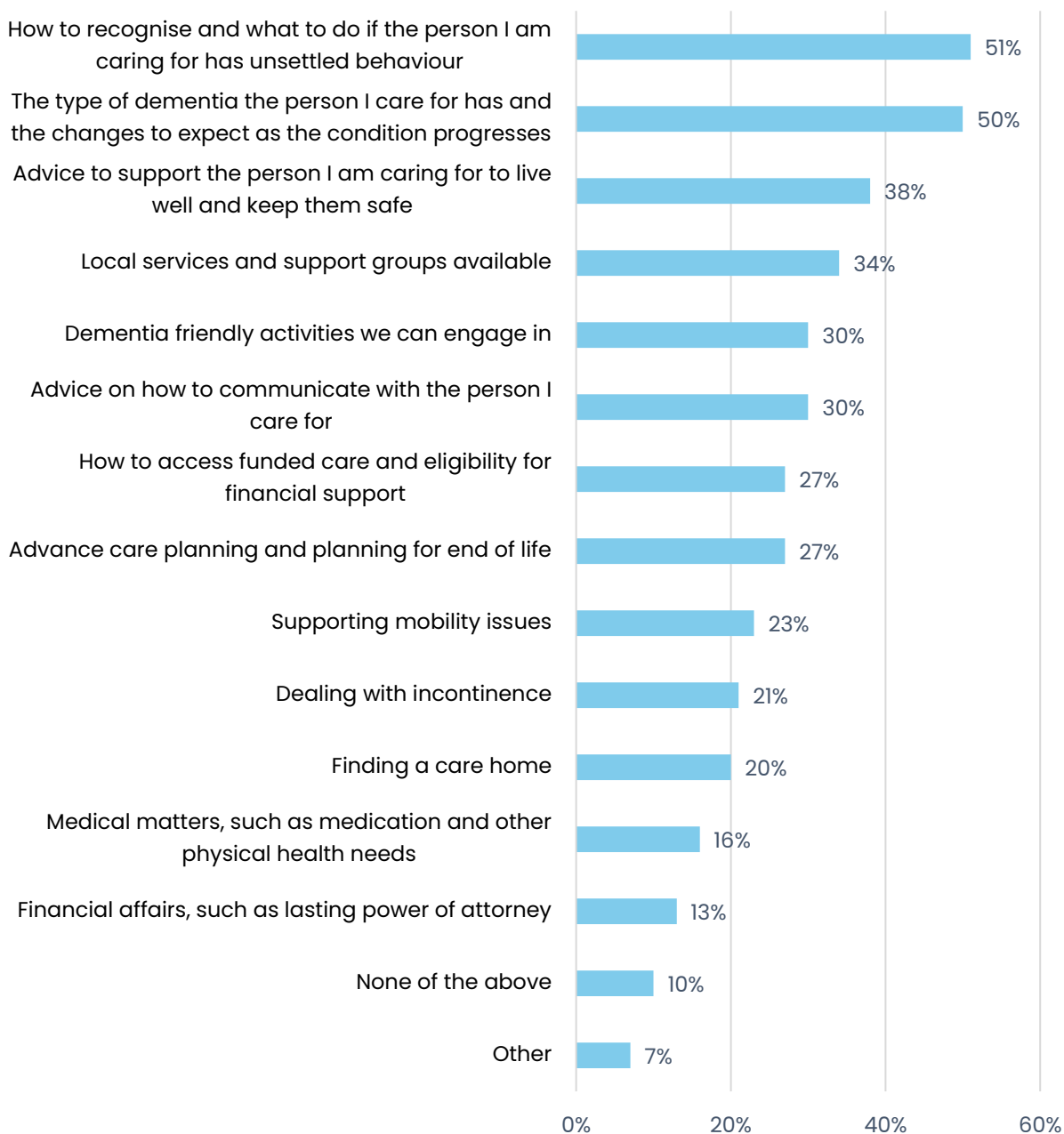
The tables show the **percentage of each group selecting items they would like to see improved**. P values **<0.05** indicate a statistically significant difference. **These are written in pink/bold in the tables below**.

What carers would most like to see improved (% of all carers selecting this)	Carer financial situation			Carer gender			Carer activities limited by health condition			
	No spare income (33)	Spare income (90)	P value	Female (116)	Male (32)	P value	No (84)	Yes, limited a little (37)	Yes, limited a lot (18)	P value
More opportunities to take a break from my caring role (34%)	27%	36%	P=0.39	34%	31%	P=0.73	28%	41%	44%	P=0.33
For the person I care for to have more opportunities to access meaningful activities they enjoy (28%)	27%	23%	P=0.65	28%	25%	P=0.67	26%	35%	28%	P=0.60
Easier access to help or advice when I need it (27%)	27%	22%	P=0.56	27%	25%	P=0.84	27%	22%	28%	P=0.79
To be able to see health and care staff face-to-face (27%)	33%	27%	P=0.45	25%	31%	P=0.48	31%	19%	22%	P=0.35
To have a phone number I can call for help and advice when I need it (26%)	30%	23%	P=0.43	30%	9%	P=0.02	23%	22%	44%	P=0.13
Easier access to an appointment with a GP (25%)	33%	21%	P=0.16	26%	19%	P=0.41	23%	27%	22%	P=0.86
More continuity in health and care staff who visit the person I care for (23%)	27%	20%	P=0.39	21%	28%	P=0.37	20%	30%	17%	P=0.42

The tables show the **percentage of each group selecting items they would like to see improved**. P values **<0.05** indicate a statistically significant difference. **These are written in pink/bold in the tables below**. Differences *close to statistical significance (P between 0.09<0.05)* are in pink italic font.

What carers would most like to see improved (% of all carers selecting this)	Carer age					Carer location				Integrated Care Area			
	25-49 (20)	50-64 (43)	65-79 (64)	80+ (21)	P value	Rural (70)	Semi-urban (49)	Urban (18)	P value	Central (50)	North & East (53)	West (40)	P value
More opportunities to take a break from my caring role (34%)	25%	28%	39%	38%	P=0.51	34%	33%	50%	P=0.39	33%	43%	26%	P=0.37
For the person I care for to have more opportunities to access meaningful activities they enjoy (28%)	30%	28%	25%	33%	P=0.54	24%	31%	39%	P=0.43	33%	26%	18%	P=0.44
Easier access to help or advice when I need it (27%)	25%	35%	23%	19%	P=0.48	30%	18%	28%	P=0.35	35%	21%	26%	P=0.40
To be able to see health and care staff face-to-face (27%)	20%	21%	31%	29%	P=0.59	24%	31%	22%	P=0.68	22%	34%	26%	P=0.53
To have a phone number I can call for help and advice when I need it (26%)	30%	23%	22%	38%	P=0.47	24%	29%	22%	P=0.82	33%	17%	29%	P=0.27
Easier access to an appointment with a GP (25%)	20%	23%	28%	19%	P=0.85	27%	18%	28%	P=0.50	20%	21%	40%	P=0.15
More continuity in health and care staff who visit the person I care for (23%)	20%	21%	23%	24%	P=0.98	20%	25%	28%	P=0.72	20%	21%	24%	P=0.94

6. Is there any additional information and advice that would help you in your caring role? Tick all that apply



'Other' includes information and advice on **arranging respite care** and **accessing a package of care**, as well as **which services are available**.

The tables show the **percentage of each group selecting information and advice items**. P values **<0.05** indicate a statistically significant difference.

These are written in pink/bold in the tables below.

*Percentages for under 65s are difficult to interpret due to small numbers. These are displayed in faded text.

Information and Advice Topics	Carer working status			Carer relationship			Age of person living with dementia			
	Full or part time work (42)	Retired (71)	P value	Parent / parent in law (53)	Spouse / partner (80)	P value	*Under 65 (8)	65 to 74 (26)	75 and over (113)	P value
How to recognise and what to do if the person I am caring for has unsettled behaviour (51%)	57%	54%	P=0.71	55%	49%	P=0.50	63%	54%	51%	P=0.78
The type of dementia the person I care for has and the changes to expect as the condition progresses (50%)	36%	59%	P=0.02	47%	58%	P=0.24	63%	27%	55%	P=0.01
Advice to support the person I am caring for to live well and keep them safe (38%)	50%	35%	P=0.12	42%	36%	P=0.54	63%	38%	31%	P=0.27
Local services and support groups available (34%)	43%	31%	P=0.20	34%	30%	P=0.63	50%	35%	33%	P=0.61
Advice on how to communicate with the person I care for (30%)	40%	32%	P=0.39	36%	29%	P=0.39	25%	65%	30%	P=0.85
Dementia friendly activities we can engage in (30%)	36%	28%	P=0.40	30%	31%	P=0.90	38%	46%	25%	P=0.02
Advance care planning and planning for end of life (27%)	33%	25%	P=0.36	28%	29%	P=0.96	38%	35%	24%	P=0.41
How to access funded care and eligibility for financial support (27%)	31%	24%	P=0.41	32%	24%	P=0.29	38%	19%	28%	P=0.51
Supporting mobility issues (23%)	21%	21%	P=0.97	26%	24%	P=0.73	63%	31%	19%	P=0.17
Dealing with incontinence (21%)	24%	23%	P=0.88	21%	21%	P=0.94	25%	19%	21%	P=0.94
Finding a care home (20%)	19%	23%	P=0.66	25%	16%	P=0.24	13%	23%	20%	P=0.81
Medical matters, such as medication and other physical health needs (16%)	21%	14%	P=0.31	21%	13%	P=0.20	25%	23%	13%	P=0.35
Financial affairs, such as lasting power of attorney (13%)	24%	4%	P=0.002	25%	6%	P=0.002	25%	15%	12%	P=0.5

Information and Advice Topics	Carer financial situation			Carer gender			Carer activities limited by health condition			
	No spare income (33)	Spare income (90)	P value	Female (116)	Male (32)	P value	No (84)	Yes, limited a little (37)	Yes, limited a lot (18)	P value
How to recognise and what to do if the person I am caring for has unsettled behaviour (51%)	64%	51%	P=0.22	51%	53%	P=0.82	55%	46%	56%	P=0.65
The type of dementia the person I care for has and the changes to expect as the condition progresses (50%)	61%	47%	P=0.17	47%	59%	P=0.23	49%	41%	72%	P=0.08
Advice to support the person I am caring for to live well and keep them safe (38%)	39%	36%	P=0.70	35%	47%	P=0.23	43%	22%	44%	P=0.07
Local services and support groups available (34%)	42%	29%	P=0.16	40%	16%	P=0.01	38%	27%	33%	P=0.50
Advice on how to communicate with the person I care for (30%)	33%	32%	P=0.91	31%	28%	P=0.75	37%	16%	33%	P=0.64
Dementia friendly activities we can engage in (30%)	36%	29%	P=0.31	30%	28%	P=0.82	31%	35%	17%	P=0.37
How to access funded care and eligibility for financial support (27%)	30%	23%	P=0.43	27%	28%	P=0.87	26%	19%	39%	P=0.28
Advance care planning and planning for end of life (27%)	27%	27%	P=0.95	25%	34%	P=0.29	33%	14%	33%	P=0.07
Supporting mobility issues (23%)	42%	17%	P=0.003	25%	16%	P=0.26	23%	22%	33%	P=0.59
Dealing with incontinence (21%)	24%	18%	P=0.42	21%	22%	P=0.88	25%	14%	17%	P=0.32
Finding a care home (20%)	27%	18%	P=0.25	21%	19%	P=0.81	25%	11%	17%	P=0.19
Medical matters, such as medication and other physical health needs (16%)	27%	12%	P=0.05	17%	9%	P=0.28	18%	11%	17%	P=0.62
Financial affairs, such as lasting power of attorney (13%)	24%	9%	P=0.02	15%	6%	P=0.21	15%	5%	17%	P=0.28

Information and Advice Topics	Carer age					Carer location				Integrated Care Area			
	25-49 (20)	50-64 (43)	65-79 (64)	80+ (21)	P value	Rural (70)	Semi-urban (49)	Urban (18)	P value	Central (50)	N&E (53)	West (40)	P value
How to recognise and what to do if the person I am caring for has unsettled behaviour (51%)	65%	51%	48%	47%	P=0.61	49%	55%	50%	P=0.78	58%	47%	53%	P=0.75
The type of dementia the person I care for has and the changes to expect as the condition progresses (50%)	55%	40%	53%	57%	P=0.43	46%	53%	50%	0.73	56%	53%	43%	P=0.66
Advice to support the person I am caring for to live well and keep them safe (38%)	40%	42%	40%	33%	P=0.89	34%	41%	33%	0.73	36%	42%	38%	P=0.90
Local services and support groups available (34%)	50%	37%	27%	38%	P=0.24	26%	45%	39%	p=0.09	40%	28%	35%	P=0.60
Dementia friendly activities we can engage in (30%)	50%	21%	30%	29%	P=0.14	29%	29%	44%	P=0.40	32%	25%	30%	P=0.77
Advice on how to communicate with the person I care for (30%)	50%	23%	33%	19%	P=0.11	31%	33%	28%	0.93	36%	32%	23%	P=0.51
How to access funded care and eligibility for financial support (27%)	25%	40%	20%	24%	P=0.17	27%	27%	28%	P=0.99	32%	32%	15%	P=0.22
Advance care planning and planning for end of life (27%)	30%	35%	22%	24%	P=0.45	26%	31%	22%	P=0.74	30%	25%	25%	P=0.84
Supporting mobility issues (23%)	40%	21%	20%	19%	P=0.28	23%	27%	11%	P=0.41	30%	23%	18%	P=0.47
Dealing with incontinence (21%)	30%	19%	17%	21%	P=0.49	16%	27%	22%	P=0.35	28%	25%	10%	P=0.16
Finding a care home (20%)	20%	21%	23%	10%	P=0.59	19%	22%	33%	P=0.40	30%	17%	13%	P=0.15
Medical matters, such as medication and other physical health needs (16%)	15%	23%	11%	14%	P=0.39	17%	20%	6%	P=0.35	8%	21%	20%	P=0.21
Financial affairs, such as lasting power of attorney (13%)	20%	28%	3%	5%	P=0.001	10%	18%	11%	P=0.40	12%	9%	20%	P=0.37

7. What additional support or new service would help you and the person you care for live well with dementia or memory loss?

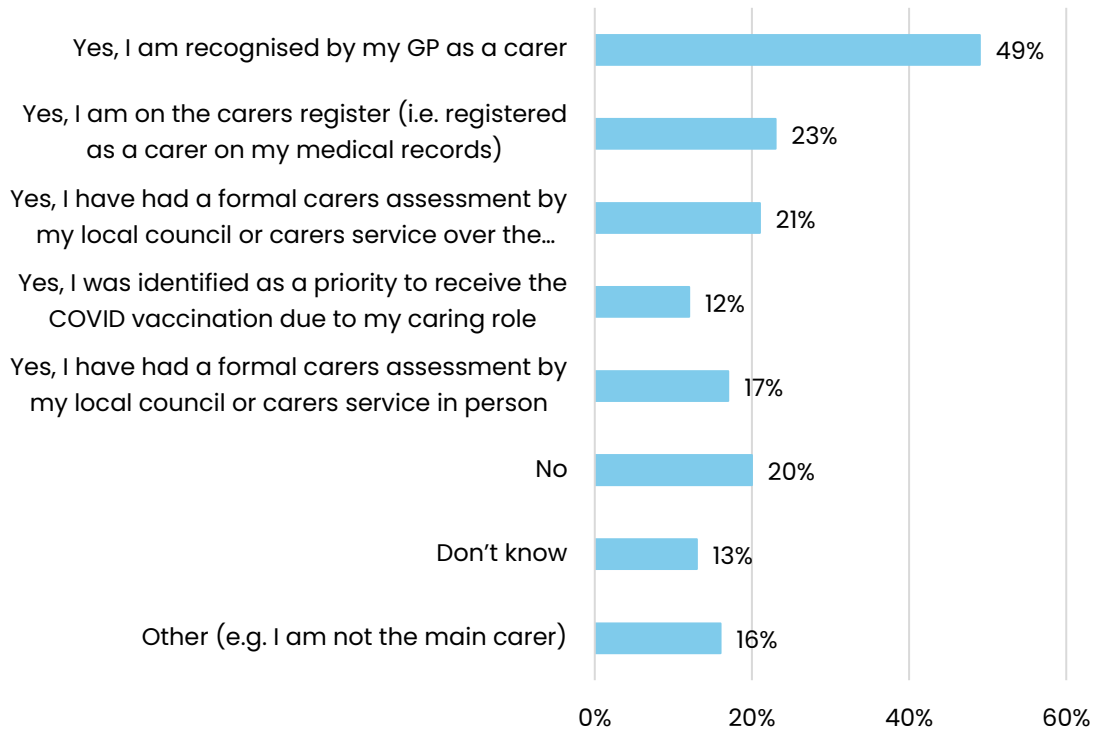
86 people provided free text comments. Many carers described the need for access to respite and day care and more opportunities to take a break. There were also several suggestions to be linked up with other carers for support and advice.

Some examples of comments:

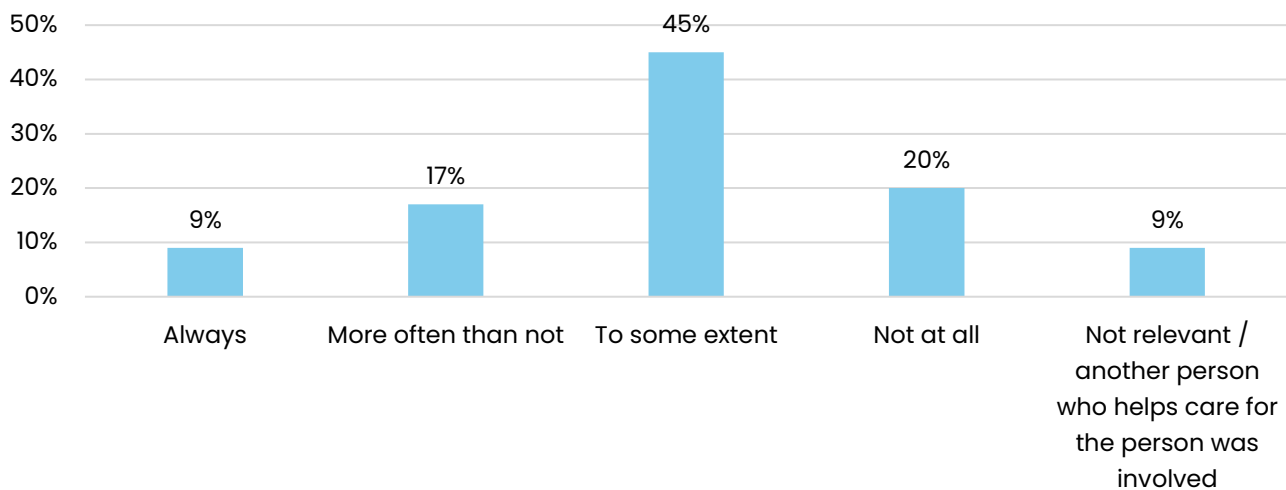
- Access to respite care and day care.
- Opportunities for a break.
- Having a PA we can utilise to support flexibly while I'm at work or need to be somewhere.
- Day care, including weekends, with the option of transport and some overnight stays.
- One health care route to deal with associated illnesses which doesn't rely on absent GP
- Contact with other carers. Groups we could attend.
- Dementia friendly day care with lots of stimulating activities.
- A dedicated IT based brokerage service for respite care for self-funding clients. This could use an integrated IT system which used live data from care and residential homes which self-funders can access.
- Local Online support group. The Sensory Trust provide this but other local services don't seem to.
- Personal contact rather than just computer messages.
- A register of people to call on to enable me to have some respite/me time, the costs, etc.
- Easier access to a GP primarily regarding medication. Not being redirected to nurse practitioners and paramedics who are employed by the GP surgery. Speaking to somebody who is not box ticking or following a flowchart. Having a named individual in the GP surgery who can act as a point of contact.
- Mental wellbeing for me
- To be able to take regular respite breaks
- Being able to meet up with other carers and clients who are at a similar stage for a coffee or walk. However, I do not know how to contact such folks.
- Any support as we have none at present we have just been left to get on with it, the GP doesn't want to know
- Activities/services for younger people with dementia - those I have found are aimed at older people and are not appropriate
- Help to find a gardener and a cleaner to free up more time to spend with the person I care for and also more time for myself.
- Day care available would benefit the Carer and the person being cared for.
- Every day throws new challenges. Just knowing what to expect would be helpful and where to go for advice and help.
- To see health and care staff face to face is almost impossible at times and this needs to be improved.
- More mental stimulation. There is not even a TV in the ward.
- The reinstatement of Memory Matters that my [spouse] had access to via Zoom on a weekly basis.
- Support with financial implications for long term care

- Memory cafe to have separate meeting for carers while partners are in memory cafe. To give carers time to share experiences.
- Being put in touch with other local people managing and caring for similar age group and diagnosis would have been great. Couldn't a 'buddy up' scheme be developed?

8. Do health and social services know about your caring responsibilities and identify you as a carer?



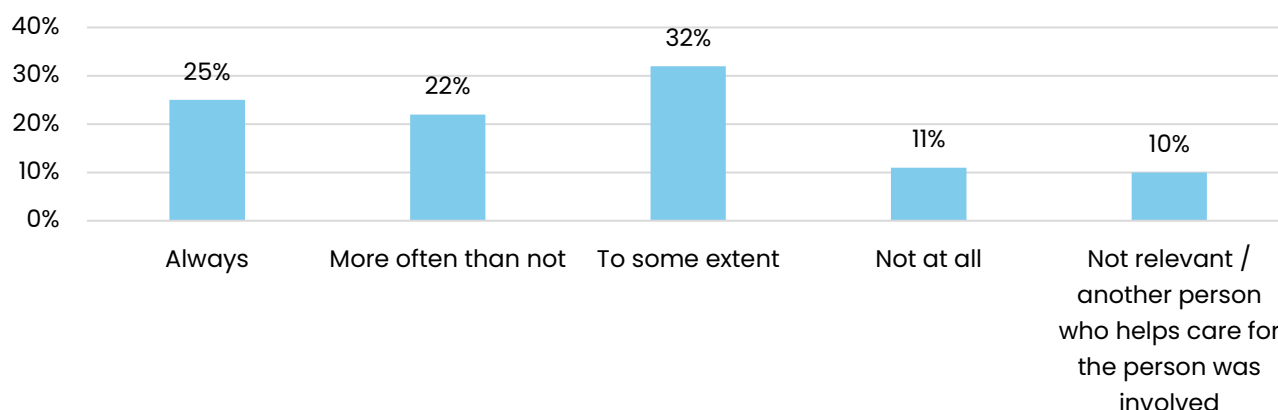
9. When accessing services and support, have you been given the opportunity to discuss what matters most to you and the person you care for, in managing their health and wellbeing?



The table shows the **percentage of each group 'Always' or 'More often than not' OR 'Not at all' or 'to some extent' having the opportunity to discuss what matters most.** P values **<0.05** indicate a statistically significant difference. **These are written in pink/bold in the tables below.**
 *Percentages for under 65s and carers living in urban areas are difficult to interpret due to small numbers. These are displayed in faded text.

Have you been given the opportunity to discuss what matters most?			
Participant characteristics. Number of participants in each group is shown in brackets.	Always or More often than not	Not at all or To some extent	P value
Percentage of all carers (135)	29%	71%	
Integrated care area (ICA) based on participant postcode:			
• North & East (53)	26%	74%	P=0.53
• Central (42)	36%	64%	
• West (35)	26%	74%	
Age of person living with dementia			
• *Under 65 (7)	29%	71%	P=0.90
• 65 to 74 (22)	27%	73%	
• 75 and over (105)	29%	71%	
Age of carer			
• 25 to 49 (16)	19%	81%	P<0.001
• 50 to 64 (40)	25%	75%	
• 65 to 79 (58)	28%	72%	
• 80+ (21)	48%	52%	
Carer gender			
• Female (106)	32%	68%	P=0.12
• Male (29)	17%	83%	
Carer relationship with person living with dementia			
• Spouse (77)	34%	66%	P=0.05
• Parent/parent in law (46)	17%	83%	
Carer working situation			
• In full or part time work (36)	25%	75%	P=0.60
• Retired (67)	30%	70%	
Carer financial situation			
• No spare income for extras or leisure (29)	14%	86%	P=0.02
• Spare income for extras or leisure (82)	38%	62%	
Carer activities limited by a health condition			
• No (74)	29%	71%	P=0.87
• Yes, limited a little (33)	29%	71%	
• Yes, limited a lot (18)	35%	65%	
Carer location			
• Rural (66)	29%	71%	P=0.78
• Semi-urban (46)	28%	72%	
• *Urban (15)	38%	63%	

10. Were you involved as much as you wanted to be in decisions being made about the person you care for and in planning the care and support you/they may need?

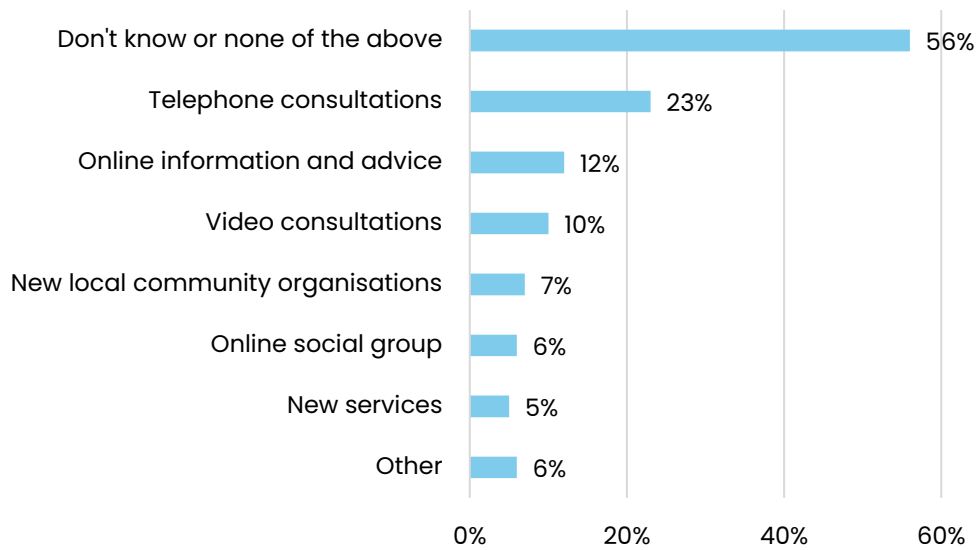


The table shows the **percentage of each group 'Always' or 'More often than not' OR 'Not at all' or 'to some extent' involved as much as you wanted to be in decision being made about the person you care for and in planning the care and support you/they need?** P values **<0.05** indicate a statistically significant difference. **These are written in pink/bold in the tables below.**
 *Percentages for under 65s and carers living in urban areas are difficult to interpret due to small numbers. These are displayed in faded text.

Were you involved as much as you wanted to be in decisions?			
Participant characteristics. Number of participants in each group is shown in brackets.	Always or More often than not	Not at all or To some extent	P value
Percentage of all carers (135)	53%	47%	
Integrated care area (ICA) based on participant postcode:			
• North & East (51)	49%	51%	P=0.76
• Central (42)	52%	48%	
• West (35)	57%	43%	
Age of person living with dementia			
• Under 65 (7)	71%	29%	P=0.02
• 65 to 74 (21)	71%	29%	
• 75 and over (104)	47%	53%	
Age of carer			
• 25 to 49 (17)	59%	41%	P=0.71
• 50 to 64 (39)	46%	54%	
• 65 to 79 (56)	55%	45%	
• 80+ (21)	52%	48%	
Carer gender			
• Female (102)	53%	47%	P=0.90
• Male (31)	52%	48%	

Were you involved as much as you wanted to be in decisions?			
Participant characteristics. Number of participants in each group is shown in brackets.	Always or More often than not	Not at all or To some extent	P value
Percentage of all carers (135)	53%	47%	
Carer relationship with person living with dementia			
• Spouse (77)	55%	45%	P=0.46
• Parent/parent in law (46)	48%	52%	
Carer working situation			
• In full or part time work (36)	56%	44%	P=0.81
• Retired (66)	53%	47%	
Carer financial situation			
• No spare income for extras or leisure (28)	43%	57%	P=0.13
• Spare income for extras or leisure (81)	59%	41%	
Carer activities limited by a health condition			
• No (74)	55%	45%	P=0.32
• Yes, limited a little (33)	61%	39%	
• Yes, limited a lot (18)	39%	61%	
Carer location			
• Rural (62)	53%	47%	P=0.33
• Semi-urban (46)	46%	54%	
• Urban (15)	73%	27%	

11. What positive changes to services and support during the pandemic have helped you and the person you care for, that you would like to see continue?



'Other' free text responses about positive changes to services:

- One person visiting and covering all aspects of support.
- Having access to a district nurse system which supports my partner as housebound.
- To have easy ways of collecting medicines/ local delivery.
- The Memory Cafe.
- The telephone courses offered by Promas.
- During the pandemic the Memory Cafe ran Zoom sessions which helped a lot during lockdown.
- More community organisations to support carers and person they support.
- Somebody visiting at least once a week to take them shopping or just out for an hour.
- The pandemic led to local communities helping those in need and made people more aware of problems people living with dementia and their carers face every day. Carers need support from actually being able to meet with healthcare workers rather than online which is very impersonal.

12. Please use three words to describe your overall experience of dementia and memory loss services and support in Cornwall

121 people provided at least one word; 106 people provided all 3 words

Word	Count	Word	Count	Word	Count
None	19	Challenging	2	Dysfunctional	1
Supportive	17	Hard to access	2	Informative	1
Poor	17	Reactive	2	Non-NHS (voluntary)	1
Helpful	15	Services now available	2	Infrequent	1
Patchy	12	Horrible	2	Not designed for younger people	1
Caring	11	Disappointing	2	Overwhelmed	1
Non existent	11	Dispassionate	2	Patient	1
Disjointed	11	Disinterested	2	Continuity	1
Inadequate	10	Depressing	2	Remote	1
Slow	8	Anxiety	2	Financial support non-existent	1
Good	8	Exhausting	2	Brutal	1
Understanding	7	Try hard	2	Satisfactory	1
Unhelpful	7	Forgotten	2	Funding fragmented	1
Frustrating	6	Long journey	2	Some supportive	1
Inconsistent	6	Repetitive	1	Stressful	1
Lacking	6	Good follow up	1	Local support excellent	1
Stretched	5	GP understanding	1	Strong	1
Underfunded	5	Great	1	Upsetting	1
Mediocre	5	Grim	1	Loss	1
Available	5	Not innovative	1	Traditional	1
Lonely	4	Professional	1	Uncaring	1
Limited	4	Hard	1	Uncommunicative	1
Variable	4	Emerging	1	Difficult	1
Difficult to navigate	3	Hard to get help from GP	1	Mixed	1
Friendly	5	Awkward	1	Adequate	1
Good at first	3	Hope	1	Monochrome	1
Hard to contact	3	Pointless	1	Unsatisfactory	1
Ignored	3	Hopeless	1	More specific diagnosis	1
Hidden	3	Horrendous	1	Interactive	1
Alone	3	Sad	1	Willing	1
Scary	2	Could do better	1	Judgemental	1
Kind	2	Alexandra House	1		
Inaccessible	2	Delayed	1		
Elusive	2	Fair	1		
Confusing	4	Badly managed	1		
Failing	4	Inflexible	1		

13. Please use this space to tell us anything else you wish to share about your experiences of dementia or memory loss

79 people provided further comments. Comments ranged in topic. Several included descriptions of feeling isolated or forgotten and many talked about lack of services, support and advice. Some people described positive experiences of support they had received. **Some examples** are included below:

- Still awaiting a diagnosis 8 months on from raising concern with GP. So, therefore, no access or awareness of services available.
- Had little feedback from professional people in the care I give.
- I feel very isolated. In my area there is a dearth of Memory Cafes. I had to search out one which is a 30 minute drive from our home. I need advice, e.g. on ways to talk to my [spouse]. They have multiple health problems so attending courses or even participating in online events is out of the question as I have to be around 24/7. There must be others like me so support would be much appreciated.
- Apart from the initial diagnosis of dementia which was very poorly done, I have had no contact.
- The Admiral nurse has been the most supportive /helpful person I have come into contact with.
- There needs to be a real overhaul of Social care. More funding for services that would support families at home. More listening. I've met families who have converted houses to bring relatives with dementia closer, without understanding that they need 24 hour care, not a house next door. I have seen families who can't manage the smallest difficulties, simply because they haven't the knowledge or the support.
- I have had to do all the finding out about support in the local community, such as the carers support group, Promas (which I have found to be an excellent resource with brilliant courses for carers) etc. It would be helpful if this information could be displayed in GP surgeries, libraries etc. Our support nurse did have some of this information to give us when we finally saw her several months after my spouses diagnosis, we were due to see them last week ... but this was cancelled.
- The hardest thing was stopping them from driving, they were a danger. Family need to be able to confidentiality say no . I don't think a person with dementia should be allowed to drive. They did not wish to go to memory cafes or any other clubs, since they did not consider it for them. There is nothing that services can do if a person does not consider they need help.

- Initially it was very slow getting anything done (referrals to OT etc..) we waited at least 5 months before anyone contacted us. Now they are involved things have been moving along.
- Good in the main, but can be slow because it is very under funded and information is not always easy or accessible. A lot of info only came about from face to face meeting with other people.
- Generally my experience has been satisfactory however I feel that there are times when the carer is not fully listened to and as a result the carer will then lack the help and support needed. This could lead to frustration and the possible depression of the carer looking after the person they are caring for.
- Definitely need more support and financial support to access help for my [parent]. Help in gaining respite. More face to face help and support. Assessments (more frequently).
- I live in a small village, do not drive and have my own health problems; Services seem to be in the towns I cannot get to.
- I am sorry if I should sound negative, as I am a glass half full person. But I have been left to soldier on alone. I guess if you don't make a fuss you don't get noticed. My [spouse] has deteriorated during the past 2 to 3 years. I am now finding it very challenging and I would really appreciate some HELP!
- The Admiral Nurse used to come to our home. She was very experienced and would listen as well as offering advice.
- During the pandemic we were left with very little care and felt isolated and totally forgotten about it was the worst stage of dementia to be left alone to care for someone. I had to give up my job to care for my relative and had no financial support. It was very frightening and I didn't know where to turn for advice and help. I had tried Adult Social Care and had no response from various emails and telephone calls were not returned.
- Feel like I was left to figure everything out by myself. Adult social care seemed to think throwing money at us for 'care' was the limit of their responsibility. Money is only useful if you can find services/ carers / respite to spend it on. Needed different kinds of help.
- The memory nurse who came to see us was very helpful. Other than that nothing.