

Briefing: Methodology on hours of care provided during lockdown

Alzheimer's Society conducted [an online survey](#) of carers of people with dementia and the impact of lockdown, open between 13 and 31 August 2020. We initially had 1,699 responses. To clean the data, the following filters were applied:

- Q1 – “do you care for someone with dementia who lives in the community”. Excluded “No” responses i.e. only included responses for people who care for someone who lives with dementia in their own home, in the carer's home, or in sheltered housing.
- Q5 – Regional – excluded 3 “prefer not to say” and 39 “others” responses. 8 were in the three nations Alzheimer's Society operates in (ENG/WAL/NI) but the majority (21) were in Scotland, with 10 elsewhere. We could include the other ‘three nations’ answers and the Scottish answers as this is for a UK stat, but it was unfortunately necessary in order to exclude the 10 answers from outside the four nations (USA, Canada, India, Spain, Ireland, and Switzerland).
- Q11 and Q12 - the questions asking “Before 23 March, about how long did you spend each week looking after or helping the person you care for” and “Since 23 March, about how long have you spent each week looking after or helping the person you care for”. Excluded all “Don't knows” and skipped responses. This enables us to compare most accurately between the two sub-sets – it, for example, excludes people who offered a clear answer for only one of the two questions.

This resulted in 953 total respondents. Answer categories were providing care for up to 9 hours (i.e. 1-9 hours); 10-19 hours; 20-34 hours; 35-49 hours; 50-74 hours; 75-99 hours or 100 hours or more. Categories were taken from the *Survey of Adult Carers in England* to ensure comparability and robustness.



Individual average estimate of additional hours of care provided

To develop an estimate for the total hours of care provided, the number of respondents in each category was multiplied by the minimum hours in their answer e.g. the 76 respondents answering 35 to 49 hours was multiplied by 35. This was done to provide a conservative estimate of hours each respondent provided care, and not to risk adding additional hours.

Hours 'bucket'	Low point in range	Before 23 March			After 23 March			Percentage change in responses
		Total Responses	Percent responses	Equivalent Hours	Total Responses	Percent responses	Equivalent Hours	
Up to 9	1	121	12.70%	121	61	6.40%	61	-49.59%
10 to 19	10	127	13.33%	1270	80	8.39%	800	-37.01%
20 to 34	20	116	12.17%	2320	122	12.80%	2440	5.17%
35 to 49	35	75	7.87%	2625	75	7.87%	2625	0.00%
50 to 74	50	67	7.03%	3350	73	7.66%	3650	8.96%
75 to 99	75	62	6.51%	4650	64	6.72%	4800	3.23%
100 or more	100	385	40.40%	38500	478	50.16%	47800	24.16%

The total hours worked by the 953 respondents before 23 March is 52,836 hours – averaged to 55.44 hours per person per week – and after 23 March is 62,176 total hours – averaged to 65.24 hours per person per week. That means an average increase of **9.80 hours** per person per week in the number of hours people of care provided by carers of people with dementia. This is truncated to two decimal places.

UK-wide estimate

To develop further estimates for the total number of hours worked additionally and in total by carers of people with dementia since the lockdown, our estimates were:

- From the MODEM cohort studiesⁱⁱ we estimate 400,000 of the 650,800 people in England in 2015 with dementia live in the community with the remaining in residential care – which gives us a proportion of 61% in the community.
- Our new report from the Care Policy & Evaluation Centre commissioned by Alzheimer's Society on the prevalence of dementiaⁱⁱⁱ estimates there are 907,000 people with dementia in the UK in 2020.
- Applying the 61% ratio to a UK-wide estimate of 907,920 people with dementia, we would reasonably estimate ~553,831 people with dementia living in the community.
- NICE^{iv} estimates there are 0.85 informal primary carers for each person with dementia, so our conservative estimate is that there are around 470,757 informal primary carers of people with dementia who are living in the community. This refers to primary carers, not all who provide care or 'check in' on someone with dementia, but people who are providing sole or primary support, are offering personal care etc.

If we assume that all carers increased their caring responsibilities in the same way as our survey respondents, providing an extra 9.80 hours of care a week then we estimate our 470,757 carers provided c. 26.1 million hours of care a week before lockdown, and since lockdown have provided **an additional c. 4.6 million hours of care a week** to now provide around 30.7 million hours of care weekly.

With lockdown starting on 23 March, it was 20 weeks (and some days) until our survey opened and people started responding. In those 20 weeks we estimate **an additional 92.3 million hours of care was provided**, and a total of 614.2 million hours during the period.

1 week					
Pre lockdown		Additional		Post Lockdown	
55.44	Hours each	9.80	Hours each	65.24	Hours each
470,757	Carers	470,757	Carers	470,757	Carers
26,098,741.5	Total hours	4,613,413.9	Total hours	30,712,155.4	Total hours
20 weeks					
Pre lockdown		Additional		Post Lockdown	
55.44	Hours each	9.80	Hours each	65.24	Hours each
470,757	Carers	470,757	Carers	470,757	Carers
521,974,829.4	Total hours	92,268,277.9	Total hours	614,243,107.3	Total hours

Regional & national estimate

In order to derive a local regional and national estimate for the number of hours of care provided in each region and nation in the UK we turned to the prevalence estimate report. This provides an estimate of the breakdown of the total number of people with dementia in each region of England, and in Wales, Northern Ireland and Scotland. The proportion in each nation/region was then applied to the total number of additional care hours provided during the 20 weeks between lockdown and the survey opening in order to arrive at an approximate number of hours in each nation/region.

This rests on the assumption that the proportion of people with dementia who live in the community and the assumption that the proportion of people with dementia who have a carer are reasonably consistent across regions, at scale.

		Live in community	Carer ratio	Proportion of total	Additional hours of care
		61%	85%		92,268,277.92
North East	39,080	23,839	20,263	4.30%	3,971,544.08
North West	100,320	61,195	52,016	11.05%	10,195,120.32
Yorkshire & Humber	76,130	46,439	39,473	8.39%	7,736,787.38
East Midlands	69,510	42,401	36,041	7.66%	7,064,023.26
West Midlands	84,090	51,295	43,601	9.26%	8,545,730.34
East of England	94,310	57,529	48,900	10.39%	9,584,348.06
South East	134,570	82,088	69,775	14.82%	13,675,810.82
South West	92,510	56,431	47,966	10.19%	9,401,421.26
London	78,700	48,007	40,806	8.67%	7,997,966.20
Scotland	67,900	41,419	35,206	7.48%	6,900,405.40
Wales	48,100	29,341	24,940	5.30%	4,888,210.60
Northern Ireland	22,700	13,847	11,770	2.50%	2,306,910.20
TOTAL	907,920.00	553,831.20	470,756.52	1.00	92,268,277.92

References

- ⁱ NHS Digital (2019) *Personal Social Services Survey of Adult Carers in England 2018-19*, available online at: digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19
- ⁱⁱ Wittenberg, R. et al (2019) 'The costs of dementia in England', *International Journal of Geriatric Psychiatry*, Vol 34, Issue 7, <https://doi.org/10.1002/gps.5113>
- ⁱⁱⁱ Wittenberg, R. et al (2019) *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040*, CPEC Working Paper 5, London: Alzheimer's Society. Available online at: <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers>
- ^{iv} NICE (2006) *Dementia: Costing report – Implementing NICE SCIE guidance in England*, London: NICE. Available online at: <https://www.scie.org.uk/publications/misc/dementia/dementia-costingreport.pdf?res=true> cited in Office of Health Economics (2014) *The Trajectory of Dementia in the UK – Making a Difference*, commissioned by Alzheimer's Research UK. Available online at: <https://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/OHE-report-Full.pdf>