

Impact of COVID-19 pandemic on hospital care for people with dementia: Feedback from carers and hospital leads for dementia.

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Appendix A: Hospital leads survey results

Please note that all questions in this survey were optional and, in this report, whole number percentages have been rounded off (0.5 has been rounded up) therefore some total percentages in this report may not add up to 100%.

Responses by Region		N hospitals/total eligible to participate (NAD R4)	
England			
East of England	6/57 (11%)	6/17 (35%)	
London	3/57 (5%)	3/31 (10%)	
Midlands	7/57 (12%)	7/31(23%)	
North East and Yorkshire	9/57 (16%)	9/35 (26%)	
North West	12/57 (21%)	12/25 (48%)	
South East	8/57 (14%)	8/29 928%)	
South West	6/57 (11%)	6/19 (31%)	
Wales			
North Wales	3/57 (5%)	3/3 (100%)	
Mid and West Wales	0/57 (0%)	0/7 (0%)	
South East Wales		1/57 (2%)	1/7 (14%)

How long have you been working in the hospital?	
Less than 6 months	1/57 (2%)
6 months-2 years	5/57 (9%)
2-5 years	10/57 (18%)
More than 5 years	41/57 (72%)

Most patients with identified dementia admitted to general hospitals were aged 75 or older and of white British background. Would you say that this was the case for your hospital?			
Before lockdown		Since Lockdown	
Yes	56/57 (98%)	Yes	50/57 (88%)
No	-	No	2/57 (4%)
Don't know	1/57 (2%)	Don't know	5/57 (9%)
Total reported changed from yes to no	2/57 (4%)		
Total no change	50/57 (88%)		
Total Unknown	5/57 (9%)		

Q1. Have you or members of your team been redeployed from a specialist role?	
Yes, the dementia lead	17/57 (30%)
Yes, other members of the dementia team	24/57 (42%)
Yes, other	9/57 (16%)
Both dementia lead <u>and</u> other members of team	11/57 (19%)
No	21/57 (37%)

Q2. Is specialist support for staff working with people with dementia currently available in your hospital from: (please select all that apply)					
	COVID wards		Non-COVID wards		No support
	Via face to face contact	Via remote contact	Via face to face contact	Via remote contact	
Dementia and delirium team or outreach team	21/57 (37%)	25/57 (44%)	23/57 (40%)	15/57 (26%)	21/57 (37%)
Care of Elderly team or outreach team	25/57 (44%)	7/57 (12%)	19/57 (33%)	8/57 (14%)	31/57 (54%)
Liaison Psychiatry	26/57 (46%)	27/57 (47%)	33/57 (58%)	20/57 (35%)	10/57 (18%)
Other (services that usually provide input) *	5/57 (9%)	4/57 (7%)	5/57 (9%)	3/57 (5%)	49/57 (86%)
Dementia and Delirium and/or COE team (combined)	35/57 (61%)	26/57 (46%)	28/57 (49%)	16/57 (28%)	15/57 (26%)
No specialist support	3/57 (6%)				

*Discharge team (2); Meaningful activity team (1); Social worker (1); Speech therapist (1); Activity Nurse (1)

Hospital leads were asked to comment on positive and negative changes which have occurred as a result of COVID-19. The free text comments were analysed into themes, the breakdown of which can be seen below:

Theme	Positive (n=342)	Negative (n=367)
Communication	137/184 (75%)	47/184 (26%)
Family carer involvement	3/30 (10%)	27/30 (90%)
Patient care	11/50 (22%)	39/50 (78%)
Staffing	39/104 (38%)	65/104 (63%)
Training	9/29 (31%)	20/29 (69%)
Environment	25/85 (29%)	60/85 (71%)
Admission	14/17 (82%)	3/17 (18%)
Discharge	72/144 (50%)	72/144 (50%)
Governance	32/66 (48%)	34/66 (52%)

Communication	Number of comments (n=187)
More/better communication with family/carers including use of technology e.g. tablets, video-calls, e-cards	91/187 (49%)
PPE has a negative impact on communication	29/187 (16%)
Clinics/assessments/referrals/reviews being completed via phone/video call	16/187 (9%)
Joint working/communication between services has improved	12/187 (7%)
General difficulties with communication	11/187 (6%)
Teams to liaise with carers/family members introduced e.g. family support team	10/187 (5%)
Communication between staff and family is not sufficient/not working well	7/187 (4%)
Improving ways to communicate with patients whilst wearing PPE	5/187 (3%)
Other positive communication	3/187 (2%)
Additional comments not coded but relate to theme e.g. suggestions	3/187 (2%)
Patient Care	Number of comments (n=50)
General good care	7/50 (14%)
More/better written documentation and recording of patient needs/personal information e.g. likes, dislikes, "This is me"	4/50 (8%)
Infection control measures make it difficult to provide good quality care	2/50 (4%)
Non-essential contact with specialists reduced	3/50 (6%)
More delirium/prolonged periods of delirium	3/50 (6%)
Lack of visitors to provide support for PWD/PWD experiencing isolation/loneliness/lack of stimulation	15/50 (30%)
General poor care e.g. lack of assessments	10/50 (20%)
Personal information not being recorded or used	6/50 (12%)
Family/carer involvement	Number of comments (n=30)
Restrictions on visiting	20/30 (67%)
Family/carer not allowed to visit	6/30 (20%)
Family/carers can visit	3/30 (10%)
Increased stress/pressure on carers	1/30 (3%)
Staffing	Number of comments (n=105)
Staff redeployed	20/105 (19%)
Less staff available	16/105 (15%)
Staff not experienced working with dementia patients and their needs	14/105 (13%)
Volunteer support reduced/not available at present	12/105 (11%)
More/better access to staff	11/105 (11%)

Positive feedback about staff care	10/105 (10%)
Staff have more time to spend with patients	8/105 (8%)
More/better support from volunteers	5/105 (5%)
Staff have gained experience caring for people with dementia/better awareness	3/105 (3%)
Staff have less time to spend with patients	2/105 (2%)
No specialist staff redeployed	2/105 (2%)
Other negative staffing	1/105 (1%)
Additional comments not coded	1/105 (1%)
Training	Number of comments (n=30)
Training methods changed e.g. virtual training, peer to peer training on wards	10/30 (33%)
Training suspended/cancelled	16/30 (53%)
Highlighted need for more/better dementia training	3/30 (10%)
Additional comments not coded but relate to theme e.g. suggestions	1/30 (3%)
Environment	Number of comments (n=85)
Increase in the number of ward/bed moves	23/85 (27%)
Loss of speciality/dementia friendly wards/Patients placed on wards that are not appropriate for their needs	15/85 (18%)
Event/activities suspended or cancelled	13/85 (15%)
Activities are being used more/more activities resources available	12/85 (14%)
Patients have limited access to space away from their bed due to restrictions on movement	7/85 (8%)
Ward environment improved/quieter as less patients at present	7/85 (8%)
Decrease in the number of ward/bed moves	3/85 (4%)
Other, positive environment	3/85 (4%)
Other, negative environment	2/85 (2%)
Admission	Number of comments (n=85)
Fewer people with dementia admitted	7/17 (41%)
Less inappropriate admissions	5/17 (29%)
More efficient admission process	2/17 (12%)
Improved systems to code and identify patients' needs on admission	2/17 (12%)
People with dementia are not identified/screened on admission	1/17 (6%)
Discharge	Number of comments (n=144)
Faster/more efficient discharge process/reduced LOS/less delayed transfers of care	48/144 (33%)

Changes to discharge procedure have led to an increased LOS/more DTOC/placements only accept PWD if negative for COVID	27/144 (19%)
Concerns that discharge is too fast/unsafe/poor discharge planning	23/144 (16%)
Better access to placements/resources in the community	23/144 (16%)
Lack of social services staff in hospital to assist with discharge/decreased community support	8/144 (6%)
Carer/family member not informed/involved with discharge plans	6/144 (4%)
Limited availability of intermediate care/rehabilitation/memory services	4/144 (3%)
No changes to discharge process	2/144 (1%)
Negative changes to discharge	2/144 (1%)
New team developed to manage discharge	1/144 (1%)
Governance	Number of comments (n=75)
Dementia strategy/planning/projects/services suspended	34/75 (45%)
New/updated dementia strategy/pathways/services	19/75 (25%)
Better awareness about dementia and more engagement at Trust/senior management level	8/75 (11%)
Additional comments not coded	7/75 (9%)
QI work/audits/monitoring (e.g. falls) has continued throughout to improve hospital environment/training/care	3/75 (4%)
No changes to dementia strategy, dementia services/programmes maintained	3/75 (4%)
QI work/audits/monitoring (e.g. falls) has been suspended	1/75 (1%)
Visiting – how this is being implemented	Number of comments (n=60)
EOL patients only	15/60 (25%)
EOL and patients with additional support needs e.g. dementia	14/60 (23%)
Assessed on an individual basis	6/60 (10%)
Visiting supported with appropriate PPE	6/60 (10%)
Visitors encouraged to stay in contact via video calls	5/60 (8%)
Visiting supported by appointment	3/60 (5%)
Dementia patients can have 1 visitor per session	2/60 (3%)
Not consistent approach to visiting	2/60 (3%)
Visitors coming to window to see relative	2/60 (3%)
Visiting supported on Care of the elderly wards	1/60 (2%)
Visitors have to isolate if a patient is COVID+	1/60 (2%)
No visitors allowed	1/60 (2%)

Appendix B: Carer survey results

Please note that all questions in this survey were optional and, in this report, whole number percentages have been rounded off (0.5 has been rounded up) therefore some total percentages in this report may not add up to 100%.

Which of these best describes your relationship to the person you support?	
Family member	23/32 (72%)
Spouse or partner	6/32 (19%)
Professional carer	3/32 (9%)
Are you one of the main carers for the person you look after? E.g. family carer or keyworker	
Yes	30/32 (94%)
No	2/32 (6%)
How do you define your gender?	
Female	28/32 (88%)
Male	4/32 (13%)
Other	-
Prefer not to say	-
What is your age?	
18-24	1/32 (3%)
25-34	3/32 (9%)
35-44	2/32 (6%)
45-54	7/32 (22%)
55-64	11/32 (34%)
65-74	5/32 (16%)
75 and over	2/32 (6%)
Prefer not to say	1/32 (3%)
What is your ethnicity?	
White/white British	28/32 (88%)
Black/black British	1/32 (3%)
Asian/Asian British	1/32 (3%)
Other	1/32 (3%)
Prefer not to say	1/32 (3%)
What country do you live in?	
England	32/32 (100%)
Wales	-
What region do you live in?	
South East	10/32 (31%)
North West	5/32 (16%)
East of England	5/32 (16%)
London	4/32 (13%)
South West	3/32 (9%)
North East and Yorkshire	2/32 (6%)

Midlands	2/32 (6%)
Unspecified	1/32 (3%)

	Yes	Yes combined	No	Other
Was the PWD admitted to hospital?	31/32 (97%)	N/A	1/32 (3%)	N/A
Did the person have symptoms of COVID-19?	6/30 (20%)	N/A	24/30 (80%)	N/A
Did the hospital staff ask you about the needs of the person you look after?	Definitely 7/31 (22%) To some extent 9/31 (28%)	16/32 (50%)	15/31 (47%)	N/A
Visiting Procedures: Were you allowed to visit?	3/30 (10%)	N/A	27/30 (90%)	N/A
Were you given an explanation about visiting the person?	17/30 (57%)	N/A	13/30 (43%)	N/A
Were you given any help to keep in touch with the person?	Definitely 7/31 (23%) To some extent 9/31 (29%)	16/31 (52%)	15/31 (48%)	N/A
Were you kept informed about plans for treatment and discharge?	Definitely 7/31 (23%) To some extent 10/31 (32%)	17/31 (55%)	8/31 (26%)	The person is still in hospital 5/31 (16%) Person died 1/31 (3%)
Was the person able to return to the place they were living before?	Yes immediately – 13/24 (54%) Yes, after a care or rehabilitation placement 6/24 (25%)	19/24 (79%)	3/24 (13%)	Person is still in hospital 2/24 (8%)

Have you been able to access the support you need?	Definitely 5/31 (16%)	13/31 (42%)	8/31 (26%)	I do not require support 10/31 (32%)
	To some extent 8/31 (26%)			

Explanation provided for visiting restriction	
No visitors due to COVID 19	6/17 (35%)
Visiting allowed if wearing PPE	1/17 (6%)
No explanation	6/17 (35%)
Visiting assessed based on individual needs	1/17 (6%)
Allowed in waiting room	1/17 (6%)
Unclear communication about rules	2/17 (12%)

	Positive	Negative
Communication	9/24 (38%)	15/24 (63%)
Patient care	6/31 (19%)	25/31 (81%)
Carer support	5/13 (39%)	8/13 (62%)
Discharge	-	8/8 (100%)
Total	20/76 (26%)	56/76 (74%)

Communication	Number of comments (n=24)
Carers/family can stay in contact with person with dementia including use of technology in hospital has been positive	7/24 (29%)
Communication from staff is poor	6/24 (25%)
No access to phone/staff unable to facilitate phone calls	4/24 (17%)
Phone contact available but not appropriate for PWD	2/24 (8%)
Carer not involved in care including decisions	2/24 (7%)
Team in place to provide regular contact and updates to carers/family	2/24 (8%)
Other negative communication	1/24 (4%)
Patient Care	Number of comments (n=31)
Family/carer had concerns regarding care/treatment of person with dementia	12/31 (39%)
Visiting restrictions had a negative impact on person with dementia	5/31 (16%)
Personal information not being recorded or used	4/31 (13%)
General good care	4/31 (13%)
Family/carer not allowed to visit	3/31 (10%)
Staff were not well informed and didn't understand patient needs	2/31 (7%)
Patient needs/personal information e.g. likes, dislikes, "This is me" was recorded/used	1/31 (3%)
Carer Support	Number of comments (n=13)
Carer felt unsupported/uncared for/lack of services available	4/13 (31%)
Carer/family member removed from hospital	3/13 (23%)
Carer felt supported on discharge/in community	2/13 (15%)
Carer/family member does not require support	2/13 (15%)
Carer felt supported in hospital	1/13 (8%)
Not aware of any support	1/13 (8%)
Discharge	Number of comments (n=8)
Carer/family member not informed of discharge plans	8/8 (100%)

Appendix C: Accessible survey for people with dementia results (returns from one hospital only)

Please note that all questions in this survey were optional and, in this report, whole number percentages have been rounded off (0.5 has been rounded up) therefore some total percentages in this report may not add up to 100%.

Gender	
Female	7/15 (54%)
Male	5/13 (39%)
Did not respond	1/13 (8%)
Age	
65-74	1/13 (8%)
75 and over	11/13 (85%)
Prefer not to say	1/13 (8%)
Have you had to stay overnight in hospital since lockdown?	
Yes	13/13 (100%)
Ethnicity	
White British	13/13 (100%)
Have you had any symptoms of coronavirus?	
No	13/13 (100%)
How was your experience of being in hospital?	
Very good	4/13 (31%)
Quite good	7/13 (54%)
Not very good	2/13 (15%)
Did you think that staff in the hospital understood dementia and how it affects you?	
Yes, all staff understood	1/13 (8%)
Yes, some staff understood	5/13 (39%)
Not many staff understood	5/13 (39%)
No staff understood	2/13 (15%)
Did you feel that staff in hospital listened to you and understood your problems?	
Yes, all of the time	1/13 (8%)
Yes, some of the time	7/13 (54%)
Not much of the time	4/13 (31%)
No	1/13 (8%)
Did staff help you to see or contact your carer or family?	
Yes	9/13 (69%)
No	2/13 (15%)
Don't know	2/13 (15%)

Appendix D: Acknowledgements and project team members

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