

Supplementary Table 1

Topic guide for semi-structured interviews with carers of people with dementia

Topic	Main Questions	Prompts/Probes (not exhaustive)
Difficulties or changes to daily routines	Is life getting 'back to normal' for you yet?	Going out; seeing family/friends; shopping; PwD attending dementia groups AND/OR specific prompt Specific prompts: (Return to normal/reconnecting with world, concerns? Impact of Omicron variant and restrictions, shielding, protecting PwD – COVID risk, Specific prompts: (PwD decline (how?), lost self-confidence? Increased care needs? How? Why not? What would help? AND/OR specific prompts (e.g. Own interests/hobbies/activities prompt, Garden (weather), creative (knitting, woodwork) TV/radio, clubs, cooking
	Are you able to do everything you want to do at the moment	Specific prompts (e.g. burnout caring for PwD /caring in isolation, collective experience?) If coping: what helps you cope? e.g. strong/resilient, keeping busy, learning new skills, talking to friends/family, exercise, pets If not coping: why? What would help you to cope? E.g. Help from family, friends, neighbours, local community, GP, memory service, charity, paid carers, social care, day care, respite, financial support? If last interview was negative, how do you feel you are coping now compared to...? Specific prompts (e.g. not having to go out; more time)
Own coping strategies and/or support found to be helpful	How do you feel you are coping now, at this stage of the pandemic?	Specific prompts (e.g. not seeing family/friends; loss of dementia/carer groups; staying indoors; living situation; health)
	What's the easiest thing to cope with at the moment?	
	What's the hardest thing to cope with at the moment?	
Additional or missing support or information that would be helpful	What information or support do you need now that you aren't getting?	Practical help; emotional support; checking in; advice from a dementia specialist/carers group; financial help Specific prompts (e.g. forgotten/abandoned, didn't get help e.g. wellbeing calls)

		Specific prompts (e.g. How support <u>now</u> compares to pre-pandemic, appropriate, missing?)
	How is your access to healthcare services, such as GP appointments, now?	Specific prompts (e.g. appointments, Face-to-face, alternatives (phone/video call), suitability, get what you need, continuation of care)
Any unexpected benefits or outcomes; and how they might be maintained	Has there been anything positive to come out of the pandemic?	Support from/getting to know neighbours; doing more activities with PwD; more relaxed. If yes, why?
Training or information health or social care professionals or volunteers need to help people with memory difficulties in the COVID-19 situation	If you could give a healthcare professional (e.g. a GP) or someone like a volunteer one piece of advice to best help people with memory problems at this point of the pandemic, what would it be?	Specific prompts (e.g. 'pro-active' service support; practical support; training)

Supplementary Table 2

Summary of the coding framework and development of themes and subthemes

Theme	Subtheme	Origin of framework	Code	Time-point specific sub- code
1. Reassessing 'normal' care		New	A new normal	How life is at interview time point
		CDI/INCLUDE	Attitudes towards the pandemic	
	1.1 Cautious optimism - Getting back out there	New	Going out more or returning to some level of normality	
		CDI/INCLUDE	Receiving some support	Receiving a new source or returned support
		CDI/INCLUDE	Attitudes towards the pandemic	
		CDI/INCLUDE	To risk of getting COVID-19	
		CDI/INCLUDE	To the future (including vaccines and new variants)	
		New	Maintained (beneficial) change in behaviour or routine regarding pandemic	
		CDI/INCLUDE	Benefits of pandemic	
		CDI/INCLUDE	Decline in PwD	Decline between interviews
		1.2 A new normal but no going back	New	Support or care seeking behaviour by PwD
	New		Comparison to being a parent	
	New		Increased amount or variety care provision	
	New		Unable to plan or consider going out	
	New		PwD contented or happy	
	CDI/INCLUDE		Lack of external dementia service support:	Services have not resumed
				Services have permanently closed
				Activity or support no longer suitable for PwD
	CDI/INCLUDE		Challenges as a result of pandemic	
	New	Negative emotional response to caring for PwD		

2. Attitudes and roles of others in supporting cares	2.1 Aiding the caring process	New	Dependent on others	
		CDI/INCLUDE	Benefits of pandemic	
		CDI/INCLUDE	Experience of health providers or care received (Positive)	
		CDI/INCLUDE	Attitudes towards the pandemic: To risk of getting Covid (influence of others and social attitudes - positive)	
	2.2 Barriers to the caring process	CDI/INCLUDE	Need for dementia awareness in wider community or society	
		CDI/INCLUDE	Attitudes towards the pandemic: To risk of getting Covid (influence of others and social attitudes - negative)	
		CDI/INCLUDE	Caring in isolation - limited or lack of informal support -	Informal support stopped or reduced
		CDI/INCLUDE	Experience of health providers or care received (Negative)	
3. Caring under stress		New	Loss of own life or personality	
		New	Support to carers doesn't meet need	
		CDI/INCLUDE	Support required e.g. caregiving assessments, financial	
		New	Pro-active seeking of support or information	
		CDI/INCLUDE	Conflicting pressures	New pressures since previous interview
		CDI/INCLUDE	Own healthcare needs	
		CDI/INCLUDE	Lack of personal time	

Supplementary Table 3

Comparison of carers' experiences at different stages of the pandemic

Carer	Key Experiences from INCLUDE Interview	Key Experiences from Current INCLUDE Interview (Dec 2021-Jan 2022)
	IDEAL-CDI (May-July 2020)	
6	<ul style="list-style-type: none"> • Struggling to provide level of care required to meet PwD needs • Difficulties in relationship, emotionally struggling • Loss of paid carers, respite opportunities e.g. through loss of memory club • Loss of social activities • Easing of restrictions – being reunited with families was welcomed • 'Just checking' services – highly valued 	<ul style="list-style-type: none"> • PwD more dependent • Sleep disruption impacting on health • Struggling to cope, compounded by own health issues not being met • Cautious to protect them both • PwD attending day centre, return to own interest group (choir) • Social 'Bubble' with daughter who offers some respite • Continuation of monthly 'checking in' services from carers' group key worker • Can call admiral nurses if needed. • Key worker checks in monthly but increases frequency if SP is struggling • Think carers are always forgotten
	INCLUDE (Nov-Dec 2020)	
1	<ul style="list-style-type: none"> • Abrupt changes to routine • No external support (All services ceased) • Challenges with internet food shopping • Difficulties keeping PwD occupied • Importance of going out on walks • Need to plan when/where to go • Some welfare calls from dementia charity. • Need joined up, pro-active support, central source of information • Not received any contact from local government • Pandemic information confusing 	<ul style="list-style-type: none"> • Others observe carer not coping as well • 'very little time for non-essentials' • PwD significant decline • Still avoids unnecessary mixing and not going out • Meets up with friends and paid carer offers some respite • Continued with online food shopping – safer and easier • Welfare calls from dementia charity stopped, only call them in crisis • Joined a new Zoom carers group • Need day centre support for PwD • Neighbours and friends more sensitive, increased sense of community
2	<ul style="list-style-type: none"> • Initial problems with food shopping but became confident to do online shopping • Learnt how to cook • Routine altered so used distraction techniques to help cope. • Support from family 	<ul style="list-style-type: none"> • Continued getting food deliveries - getting older and it's helpful • Increased levels of stress • Decline in PwD • Missing interaction with others, meets friends occasionally • Worsening own health needs

- Importance of the garden and walking
- Found it more challenging as pandemic progressed
- Needed Better delivery of information

- 3
- Initial problems with food shopping
 - Increased anxiety around basic needs for PwD
 - Importance of long walks, picnics, garden and nature
 - Keeping in touch with friends via the phone
 - Living in the moment and taking each day at a time
 - Support from dementia carers group
 - Society more friendly
 - Healthcare services became more accessible as pandemic progressed

- 5
- Everything is different – no social activities
 - Deterioration in PwD and more dependent on others
 - More isolated and lonely
 - Friends and family help with shopping, walking dog and domestic work
 - In contact with family using a 'portal' for Zoom
 - Able to continue pottery on Saturdays
 - Rely on family who work in NHS for information
 - Important to keep routine with PwD

- 7
- PwD groups stopped so respite lost
 - Family contact is remote
 - PwD had COVID at start of pandemic - difficulty of trying to communicate PwD symptoms to healthcare professionals

- Carer and PwD attend different groups offering some respite
- Importance of gardens and walks
- Help from cleaner and gardener
- Need financial support

- Returning to pre-pandemic life
- Dementia progression – 'natural progression' but marked
- PwD looked after by paid carers 4 days a week
- Attends various groups including mindfulness but not carer group
- Avoids local news as it can be a source of anxiety
- More funding needed for health and social care
- Believe healthcare services have improved

- Routine has completely changed but for the better. Less pressure now previously their routine was structured around dementia groups. More freedom now to spend time together and do what they want
- Previous activities no longer appropriate for PwD's stage: 'you have to change as dementia changes'
- Dementia progression – lacks motivation
- Own health deteriorated - eye sight and balance
- Lost confidence Company and support of friend very important
- More time for doing things e.g. garden centre, planned holidays
- Daughter a doctor so gives advice
- Visits Psychiatrist every 6 months who is good at explaining conditions
- Finds telephone health appointments not always appropriate
- Neighbours keep their eye on you more and ask how you are
- Realise priorities; 'closer as a family'

- Life ebbing away hard to cope with
- Careful but happy to mix with others. Fully vaccinated so confident to go out
- PwD decline, increased basic care needs

- Creating a routine around physical activity, walking and PwD interests
- Zoom meetings with family and friends
- Formed support bubble with PwD's mum
- Felt more 'reaching out' by groups and dementia charity would have been helpful
- Felt 'left to it'
- Not likely to ask for help but if asked, more likely to disclose his needs
- Returning to carer groups would be of benefit

- 9
- Big change to routine and quality of life
 - Exerted extreme caution by not going out, seeing family in limited way (concerns about passing on the virus to PwD)
 - PwD's activities are very limited, big deterioration in confusion, engagement, abilities
 - Practical help from family (shopping, maintenance)
 - Nurse now coming to see carer for arthritis and checks PwD
 - Keeps busy doing tasks at home e.g. garden, knitting, walking dog
 - PwD tries to read, do pottery & jigsaw but thinks he can't
 - Art group sent things to do
 - Nothing seems to help and carer seems resigned to this
 - Enjoys talking to people but has no respite now
 - Did have calls from dementia charity but that stopped
 - Doesn't use computer
 - Feels 'targeted' as an older person

- Aspects of routine have remained (e.g. Pilates) plus more stimulating activities
- Resumed dementia support groups (changed from YOD focus pre-pandemic to groups with more elderly people)
- Respite resumed – able to go back to golf, good for fitness. Better balance for both
- Zoom groups with family and friends continued
- PwD benefitted from daily routine initially but now enjoys variety
- Lack of proactive contact from external agents

- Coping most of the time but made harder by own health concerns
- Memory café not yet open and unlikely to return
- Dementia progression – loss of structure and routine initially has led to marked decline
- More freedom and mixing more but very conscious and avoids public transport
- PwD goes to art therapy group and day centre, which offers respite
- Good informal support network, closer relationships with family
- Had access to healthcare including face-to-face appointments
- Dementia charity 'could have done more' e.g. wellbeing calls would have helped, and more communication

INCLUDE (Jan-Apr 2021)

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|--|---|
| <p>4</p> <ul style="list-style-type: none">• Challenge of trying to keep PwD's mind active• Lack of social contact especially with family• PwD unable to speak due to FTD so lack of conversation• Challenging as pandemic progressed as no social contact• Exercise helps – gets a 'buzz'• Nurse visits every 6 months but lack of support from time of diagnosis – 'nothing from them is pro-active'• Social services are dismissive• Day centre not suitable as focussed on older clients• Difficulty in accessing incontinence nurse• Rely on relatives who work in healthcare services | <ul style="list-style-type: none">• Continue to protect PwD from COVID throughout pandemic• Decline in PwD with increased caring responsibilities - very few respite opportunities• No communication with people other than through social media and the telephone• Own philosophy 'don't give up, don't give in, don't run away'• Exercise helps – walking and going shopping• Having to seek own support but now has access to care coordinator• Social services – huge delays, remain dismissive• Nurse used to come every 6 months pre-pandemic to assess PwD (dementia review) but stopped• Declined in local charity support since previous staff member left• Good support from pharmacy |
| <p>8</p> <ul style="list-style-type: none">• Concerns over managing care especially given own age• No social contact at home for 4 months and misses own family• Living on 'high level of adrenaline' as waits for 'next difficulty'• Little time for herself and doesn't trust herself to keep going forever without a break• Created good routine in place for care• Deep connection remains as PwD personality not changed• 3 hours per week respite and part of a writing group• Uses Zoom to keep in contact with family• Social services input 'anticipatory' and 'not when crisis arises'; Feels once you pay for your own help and left on own• Good community (e.g. offered to get shopping) | <ul style="list-style-type: none">• Life has become more difficult• Noticeable decline in PwD and is 'mentally he's withdrawing'• Relationship with PwD changed – his decline has affected their cognitive relationship and communication and has increased care needs• Relationships with own family changing – having to try and maintain contact remotely but PwD family have become more supportive• Own memory concerns have emerged in last year• Receiving support from interest groups• Good routine in place now so less sleep deprived• Carers come in several times a week• Feels fortunate to be 'rich in support' – GPs, community, pharmacy, community, friends• Receives monthly care allowance |

- 10**
- 'Been hell', caring 24/7 without respite
 - Shielded PwD during pandemic so feeling exhausted
 - No internet/mobile devices in the house
 - Feels alone and that 'no one really cares', 'nobody cares about the carer'
 - Dementia support group stopped – not sure if/when restarting. No information
 - Respite care unavailable
 - PwD declined, gets frustrated and shouts
 - Paid carer comes in to get wife up/dressed plus 3 hours a week
 - Gardening/ walking dog/ sleep only means of respite
 - Tried art therapy at home (e.g. colouring in) but short-lived
 - Fighting for care with Local Authority
 - Seeks out own information and passes it on to others
 - More funding to dementia charity needed
 - Dementia progression and increased caring responsibilities
 - Dementia club not restarting due to lack of volunteers
 - Can't afford art therapy clubs or dementia groups
 - No computer so can't join online groups
 - Paid carers come in in the mornings and for 3 hours a week
 - Only respite is sleep
 - Routines are key
 - Tries art therapy but PwD 'has to be in the mood'
 - Feels abandoned. 'No-one cares about the carer'
 - Hasn't heard from link worker in a while
 - Unable to access dementia support because he can't afford the privately run clubs and the voluntary clubs have shut down
 - No time to think about his own health
 - Need more support from doctors and free dementia clubs again