



Lockdown Impact on Dementia Care in the Community: Results of a Rapid Survey

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Community care before Covid-19

The vast majority of people with dementia in the UK (about 600,000) live in their own homes, rather than in residential or nursing (long-term) care. Most rely on family or friends and neighbours to support them. These carers help people with dementia to maintain their independence, and they also help the state by delaying admission to long-term care until this is absolutely necessary. Although reliable figures are hard to find, it has been estimated that unpaid carers save taxpayers billions of pounds each year.

People live in the community with every stage of dementia, from mild to advanced degrees of the progressive, incurable disorder, which comes in many forms. These people are mostly known to health services. However, once a dementia diagnosis has been made, the NHS (in England and Wales at least) goes into a minimalist mode, dealing with health-related problems as they arise, effectively taking a self-care approach to dementia. As for local authorities, instead of providing services, they tend to commission providers from the commercial and non-profit sectors to deliver dementia support in the community. Voluntary organisations, charities and commercial providers have developed services to meet the needs of people with dementia and their carers living in the community. There are fees for many of these services such as home care and day care. Local authorities allocate personal budgets to those people with dementia who are unable to pay for the personal care services they need, but most households do not qualify for financial support. Moreover, local authority funding has been declining in recent years due to public sector austerity.

Therefore, diverse non-statutory organisations supply broadly three kinds of provision for people with dementia living in the community: individual care in the home, day care away from the home, and community groups that meet together for a shared purpose. Home care often depends on the client's ability to pay, but it can meet a wide range of needs for support in the community, from diversion and companionship to personal care and live-in support. For those people assessed as being in need of home care to meet their basic needs yet unable to afford it, local authority subsidies may apply through means testing. This funding is also available for day care, however day care is a relatively scarce resource, which means that, even where available, it is often rationed.

Community group provision across the country varies widely. 'Dementia-friendly' activities include cafes or clubs, singing and music making, sports, exercise and other leisure pursuits such as shared reading, participatory arts and gallery visits. Most of these non-clinical types of support are targeted at the individual with dementia together with their carer (dyad); otherwise they generally require people with dementia to be escorted by someone else who will support them to engage with the activity.

All three types of provision; home care, day care and community groups, help to support individuals with dementia with respect to their physical wellbeing, mental health and social inclusion. They also have important functions for carers, relieving them of the physical and emotional stresses of day to day care. Equally important, they afford carers opportunities to access reliable information, advice and peer support. In particular, group activities that bring dyads together play a vital part in helping participants to adjust to the diagnosis and to normalise their experiences. Having fun together can also strengthen the caring relationship.

Lockdown implications

Lockdown to reduce the risk of Covid-19 contagion was introduced in the UK on March 23rd, 2020. People aged over 70 and anyone with a health condition placing them at greater risk were required to remain in their homes, initially for 12 weeks. Most people with dementia are aged over 70. No outings or visitors were allowed except for 'essential care'. Even for younger people, day services and activity groups were suspended indefinitely. It became clear that those people with dementia who had a regular routine of attending day care or community groups faced a radical change,

restricting them to the home and cutting off important sources of stimulation and support.

Survey rationale, design and methods

The Studio, an arts-led day centre for people with dementia, was given a grant by Arts Council England Emergency Response Fund to conduct a survey of dementia carers under lockdown in the UK. This was principally to find out how The Studio might be able to continue to provide helpful interventions remotely, or to adapt to the requirements of a post-Covid society. Therefore we asked what people felt they needed and what media of communication they used. In addition, we were acutely aware of the lifestyle changes that lockdown was imposing on our clients with dementia and the challenges facing carers. We wanted to understand the impact of lockdown restrictions on both members of the dyad, and to document carers' experiences, to enable their voices to be heard. Therefore we asked about their attitudes towards the lockdown experience and invited them to express their views in a free text section at the end of the survey.

A statement promising anonymity and confidentiality prefaced the survey and participants were informed that their completing the survey would imply informed consent to the use of their data. We promised to make the findings available on The Studio website and to send individual reports of the results to participants who requested these. The survey was distributed over 10 weeks between early June and mid-August, 2020; most respondents replied by the end of July. It was sent out online and made available in a printed format. Carers' charities, dementia charities, and co-ordinating bodies like the Dementia Action Alliance were asked to disseminate the survey.

Analysis

Quantitative data were analysed using SPSS 26 (© IBM) to generate frequencies, means and descriptive analyses according to the type of variable. The comments made by respondents in free text were uploaded to NVivo 12 (© QSR International), read and coded into themes drawn from the survey questions. These themes included: virus precautions, home care, day care and community groups. Comments were also coded if they related to the emotions, behaviour or relationships of either the person with dementia or the carer. Cognition of the person with dementia was another theme.

Results

Email distribution proved more effective than postal surveys: 70 people responded online, and 5 paper questionnaires were returned. The sample is therefore biased towards people who use the Internet for communication, which may mean that older carers are under-represented.

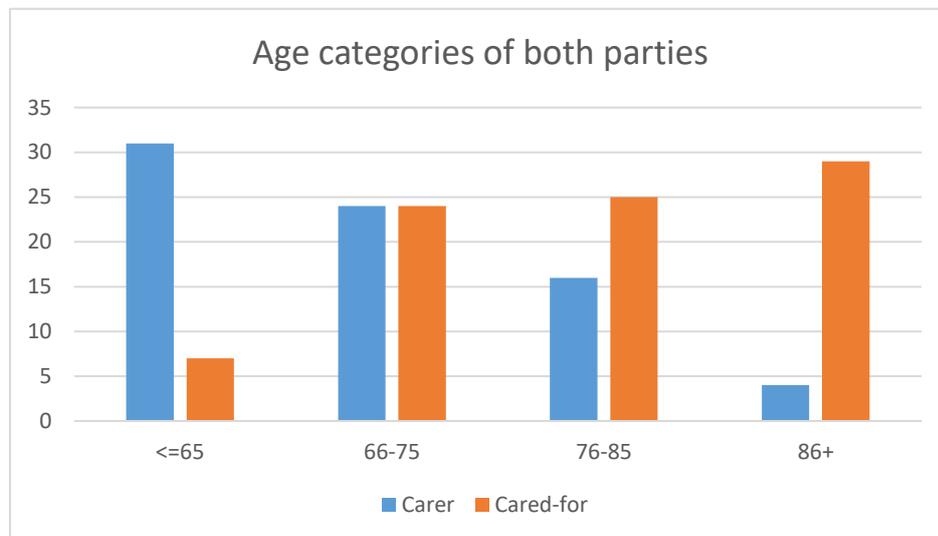
Who responded?

Most of the people who completed the survey were looking after a spouse (48, 64%). Except for one person who was looking after a friend, the rest were looking after a parent or in-law (26, 35%). The ages of the two groups are shown in Diagram 1. Eight of the 26 people looking after a parent or in-law were living under the same roof as their relative. Altogether, 21 carers (28%) were not living with the person for whom they cared. Five people had only taken on the actively-caring role since lockdown, but the rest had been caring beforehand. Twenty carers (27%) were in employment (or on furlough due to Covid) or looking for a job.

In addition to the caring role, four carers were educating their children at home during lockdown while schools were closed. At least 11 respondents also had additional caring responsibilities, including caring for a second relative with dementia, looking after their own young children or regular grand-parenting duties. Most carers were coping on their

own, but 28 (39%) stated that there was someone who shared the caring responsibilities with them.

Diagram 1



The average length of time that the individual with dementia had needed support in the community was 4 years and 4 months (range 1-21 years). This was reflected in the different levels of need. We used the descriptors for the Clinical Dementia Rating Scale¹. The impairment of each individual with dementia was judged by their carer as shown in Table 1.

Table 1: Impairment level of cared-for person

Level of impairment	Number	Percentage
Very mild dementia	7	9%
Mild dementia	28	37%
Moderate dementia	21	28%
Severe dementia	19	25%

Table 1 shows that the majority of carers (53%) were looking after a person with moderate to severe dementia. ‘Moderate’ indicates a need for assistance with most aspects of self-care and ‘severe’ indicates full support. As an indication of the amount of care needed by a person with severe dementia, the following comment was made by one respondent whose father in law lives with herself, her husband and their son:

“I am the lead carer for my father in law and attend to all his physical needs. His dementia is advanced and he is no longer mobile or able to use speech. I feed him all his pureed meals and drinks, do all his personal care and since he is immobile turn him throughout the day and overnight.” (17)

In this and other direct quotations, the number in parentheses is a unique identifier for that respondent.

¹ Hughes CP, Berg L, Danziger WL, Coben, LA, Martin, RL. A new clinical scale for the staging of dementia. Br J Psychiatry 1982; 140:566-572.

What does this population need during lockdown?

The March 2020 lockdown in the UK caused the abrupt closure of support services for people with dementia and their carers. However the impact was different for each group. Table 2 ranks those services which carers judged the people with dementia to lack, alongside those things the carers felt they needed themselves, in descending order of need.

Table 2: Felt needs of carers and people with dementia in lockdown, ranked

Person with dementia N=75		Carer N=75	
Outings	76%	Hairdresser	65%
Social contact	68%	Outings	65%
Hairdresser	65%	Social contact	52%
Chiropody	64%	Someone to talk to	45%
Entertainment	59%	Exercise	44%
Activity	57%	Dentist	41%
Exercise	57%	Optician	39%
Dentist	52%	Entertainment	39%
GP	39%	Activities	29%
Optician	35%	Chiropody	25%
Hearing expert	27%	GP	21%
Religious services	27%	Religious services	20%
Ear wax removal	25%	Other	19%
Physiotherapy	24%	Physiotherapy	16%
Other need	19%	Ear wax removal	15%
Legal advice	5%	Hearing specialist	13%
Someone to talk to	0%	Legal advice	9%

Table 2 reveals some differences between carers' assessment of their own needs and what they consider to be the needs of the people for whom they care. Turning first to primary and community health care, more people with dementia were missing chiropody (64%) than were their carers (25%). Nearly 40% of people with dementia needed a GP consultation, which highlights the likelihood that, for most people with dementia, telephone consultations will be ineffective. A substantial minority of both groups needed a dentist or optician, both services denied to the entire population during the lockdown except in emergencies.

For both carers and people with dementia, outings and social contact ranked in the top three needs. One could take a need for hairdressing as a lockdown 'norm' or a benchmark of universal deprivation; indeed, for carers, hairdressing topped the list of needs. From that point of view, it is noteworthy that people with dementia were even more likely to be judged to need social contact and outings. Unmet needs for hairdressing are unlikely to have lasting effects, but unmet needs for social contact arguably affect cognitive functioning. Once this is reduced, restoring cognition in a person with dementia is difficult if not impossible. A need for outings may signal a desire for both parties to have a break from each other, or the carer's need for brief respite from caring tasks.

People with dementia are rarely able to amuse themselves for long periods of time, most require distractions and deliberate interventions to maintain their engagement. Thus, most people with dementia were also judged to need exercise, activity and entertainment, which may be an indicator of their poor tolerance of the monotony as well as the 'stay home' message of lockdown. Nearly half of carers (45%) needed someone to talk to, but no carer felt that the person they were looking after needed this kind of support.

Household needs

Table 3 shows the percentages of carers who reported unmet needs for practical help with domestic tasks. At the time of lockdown, there was a lot of publicity urging communities to ensure that needs were met for people who were vulnerable with respect to shopping and fetching prescriptions. These household needs were met for the vast majority of people, although the small number reporting unmet needs for shopping, food preparation and fetching prescriptions is somewhat concerning. As time passed and it became clear that providers of cleaning, gardening and odd jobs were unlikely to return quickly, needs of this kind were widely felt in the general population also. The respondents' diversity in terms of carer age and whether or not they lived with the person with dementia needs to be borne in mind in interpreting Table 3.

Table 3: Unmet everyday needs

<i>Thinking about practical needs, please indicate whether any of these apply:</i>	Percentage reporting met or no need (N=75)	Percentage reporting unmet need (N=75)
Home repairs/maintenance	49%	51%
Garden maintenance	47%	43%
House cleaning	67%	33%
Personal care (e.g. bathing, dressing)	76%	24%
Shopping	81%	19%
Preparing meals	83%	17%
Fetching prescriptions	85%	15%

Dementia-specific needs

Dementia is a long-term, progressive degenerative disorder, with a wide range of disabling effects. At some point in the progression of dementia, virtually everyone

affected experiences distressing symptoms such as agitation or depression, and incontinence. At such times, carers need advice, information, support and a rapid response from experts in health care (psychiatry, psychology, occupational therapy, and nursing). However, outside of a crisis, most of the time dementia is managed as a chronic disability. Therapeutic support comes principally through non-clinical services such as home care, day care and community group activities designed for people with dementia. Some people also need generic services such as welfare benefits advice and continence supplies. The availability of all these forms of support provision was not measured in the survey, which simply asked: "*Thinking about the particular needs of carers for people with dementia, if it were possible, would you say that you could use any of the following?*" Responses in rank order of need are shown in Table 4.

Table 4: Felt needs for dementia-specific services

Dementia-specific service	% who 'could use' this (N=75)
Day Care	61%
Meeting other carers	56%
Short break (e.g. a 'sitter' for 2 hours)	53%
Respite break (e.g. 1 week)	48%
Consultation with a dementia specialist	45%
Activities to do together at home	36%
Dementia advice/information	36%
Continence advice/supplies	32%
Telephone counselling/support	25%
Welfare benefits advice	23%
Advance directives for end of life care	21%

In addition, one person was waiting for an assessment for NHS funding for long-term care, and another was waiting for a walking frame that had never been delivered.

Communication sources and IT use

Communication is always important but in the pandemic crisis the rate of information flow accelerated. During lockdown, for example, knowing who was permitted to shop where and when, became vital information. We asked the carers for their main sources of news about the Covid-19 crisis. Table 5 ranks the sources in descending order. National television was the most widely-used information source, followed by the Internet. Local television, friends and family ranked together with national radio and newspapers as the next-preferred sources of Covid-related news. People were less likely to turn for Covid-related information to national official letters, Facebook, or local television and radio. Twitter was seldom used as an information source.

Table 5: Sources of information

Information source about Covid	Carers use
National television	Often
Internet	Sometimes
Local television	Sometimes
Friends and family	Sometimes
National radio	Sometimes
National newspaper	Sometimes
Official letters and flyers	Rarely
Facebook	Rarely
Local radio	Rarely
Local newspaper	Rarely
Twitter	Never

We know that our respondents were likely to be users of digital media because the survey was mostly online. Not surprisingly, survey participants almost all had a computer; 72 (96%) even higher than the number of online responses (70). Fewer had a smartphone, 64 (85%), which avoids the need for (costly) Wifi to access the Internet. We sought to gain some idea of carers' habitual use of communications media by asking people what they had used *in the past week*. Not surprisingly, given the online distribution of the questionnaire, 93% had used a search engine in the past week, 88% had used text messaging, 77% had used a video-conferencing app, 69% had used Facebook, and 29% had used Twitter.

Attitudes and comments

The carers were surveyed at a time when extraordinary measures that restricted their freedom were in place (June-July, 2020), although shops and pubs began to unlock in early July. These strictures were widely accepted to be necessary to protect vulnerable older people and to limit the transmission of Covid-19. Given the circumstances, we wanted to know what the carers thought about the situation and how it impacted on their lives and the lives of the individuals with dementia. Table 6 shows their responses to the following: *Thinking about the 2-3 months since lockdown began, to what extent do you agree or disagree with the following statements?*

Table 6: Carers' attitudes to the lockdown experience

	Disagree	Neither agree nor disagree	Agree
I feel I have coped as well as possible	15%	11%	75%
My care partner's dementia has got noticeably worse	11%	17%	72%
My physical health has got worse	19%	23%	59%
The 'stay home' restrictions imposed to avoid Covid are worth the sacrifice for us	17%	27%	56%
My mental health has got worse	21%	24%	55%
My care partner's physical health has got worse	23%	24%	53%
Our caring situation has been tolerable in the circumstances	28%	24%	48%
I have received the support I need to provide good care	47%	24%	29%

Further comments were made by 59 of the survey respondents. These comments help to interpret the attitudes summarised in Table 6.

Dissatisfaction with support provided

The lockdown came as a shock to many carers and people with dementia, whose lives revolved around a regular routine of social activities and therapeutic groups:

"All the support I had in place for us both was suddenly taken away which was a frightening experience and I felt very isolated". (48)

Few substitutes presented themselves under lockdown, which may explain why nearly half of carers (47%) felt that they had not received the support needed to provide good care.

"All our groups / support ceased immediately and there has been no replacement other than a couple of phone calls. I do not believe enough is available remotely and in an easy to access way." (19)

"We have received support from family and friends only, offers of virtual support are not good for people with dementia, and sole carers do not have time for virtual support, it would have been nice to have a short phone call." (16)

"[Mother in law] does not understand screen communication and cannot engage in it the way she can with real life visitors so attempts with Skype and FaceTime to keep in touch were nightmarish." (14)

These comments reflect the inadequacies of online support and activities via telephone and videoconferencing platforms. While innovative, these proved no immediate substitute for face to face provision. Broadly, dissatisfaction arose from three sources: lockdown rules affecting dementia carers unfairly, and poor organisational responses from health and social services.

Lockdown rules

"The whole shutdown has been devastating, how can 'the rules' be the same for everyone? I have not been afraid of catching the virus, much more afraid of isolation." (11)

Due to its sudden and unforeseen nature, lockdown was imposed with rules against leaving the house for people who were vulnerable through a health condition. The list of conditions that made people vulnerable did not include dementia, despite some confusion about this question. This meant that carers of people with dementia did not qualify automatically for consideration from local volunteer organisers, and were not entitled to priority grocery deliveries. Many shops allowed only one person per household to enter; this meant that carers could not shop with the person with dementia and had to make other arrangements for them.

"Dementia features significantly WRT underlying conditions for Coronavirus deaths, so why are people with Dementia NOT included in the extremely vulnerable list? Not being on that list means you cannot get priority booking slots for food deliveries, so we live with increased risk - we get someone in to sit with my wife ... my shopping increases the risk I might bring home something other than the food shopping!" (58)

When lockdown was eased, on June 10, people living alone and single parents were allowed to join another household in a 'social bubble', infuriating one carer: "... well I wish I was single and could go out whenever I like shop when I like meet friends outside when I like ..." (18). This carer who had struggled alone for ten weeks described her situation as akin to 'being single parent to a toddler'. Although it meant breaking lockdown rules, she went on:

"I have ignored this as it is common sense and I am in a bubble with my son's family who both work from home. My husband is safer going there than trying to socially distance outside the house." (18)

During lockdown, although people with dementia were not barred from going out, anyone with continence issues was deterred by the fact that public conveniences were closed. The re-opening of public conveniences, catering establishments and pubs came about 11 weeks after the start of lockdown. The following comment was made before that change:

"Before lockdown we could take her out and it felt like we had some chance of normality - go for a coffee, meal, something. With no respite we are exhausted, emotionally and mentally." (43)

The restrictions on individual freedom arising from the virus control measures appear to have disproportionately affected carers of people with dementia, who formerly relied on community-based amenities to enable them to continue in this role. The closure of these resources together with the 'stay home' directive of lockdown made the caring task significantly more burdensome.

Social services

It took social services some time to reach an equilibrium after the initial disruption of lockdown. In the circumstances there were carers who felt that they had no safety net:

"Nothing had been put in place by his social worker as to what would happen to him if I, as his sole carer, became ill with coronavirus. The only contact I have had has been from Age UK and the Alzheimer's Society, both rang to check if we needed help. The Adult Social Services have not been in touch except to bill me for services not being used now." (26)

Another carer described getting access to services under lockdown as a battle:

"It has been extremely hard during the last few months, battling with agencies to get support and medication for my mum. The Admiral Nurses have been a godsend. My mum just didn't understand it all and it has been extremely mentally draining for us as carers." (8)

There was also a perceived systemic lack of support for people with young onset dementia (YOD): "Not enough support with YOD at any time not just lockdown." (30)

It appears that social services contact with some carers of clients with dementia resumed after a few weeks of lockdown, and two respondents reported some improvement in this aspect:

"With dementia worsening significantly Social Services have been excellent". (40)

One of them, nevertheless, remained critical of the lack of co-ordination of dementia care, and how the burden falls on carers:

"Now that lockdown is ending, I have had support from local services ... I sometimes feel overwhelmed by the demands of co-ordinating his care. Why is there no consultant specialist in dementia involved?" (67)

The lack of integration between health and social services cannot be attributed to the lockdown measures; it is a longstanding problem that the crisis situation exacerbated.

Health services

Continuity of care for people with dementia and their carers is vital to maintaining their equilibrium in the community with dementia and delaying the need for long-term care. However, in the initial Covid lockdown, getting help from the NHS for non-Covid-related issues proved frustrating for the carers who responded to our survey. In some places community health care appeared to cease altogether:

"Rang the Dr as I was getting no sleep as my wife was continually getting up in the night hallucinating. The Dr said he would arrange for someone from the dementia team to come to see us but nobody ever came." (49)

"We have had no face to face visits from any health care professionals apart from emergency ambulance call out twice." (6)

Some carers were struggling to cope with their own health issues as well as the person with dementia:

"The worst thing is ringing the surgery to be met with people who aren't trained to deal with persons struggling with high anxieties and mental health. Then to be left waiting days for a call back and that they didn't follow through with the all the issues I had stated several times having to repeat myself. Seeing a different doctor every time doesn't help with this either. Explaining your whole life history at each appointment is not what I need. Also different doctors giving tablets and other doctors taking you off them just for another doctor to say they shouldn't have been stopped. It's not much different when I ring for mum. We feel neglected by the surgery and doctors." (28)

Telephone consultations became commonplace during the lockdown, with mixed results:

"We have experienced some confusion WRT what NHS services are open for business - GP appointments have been arranged over the phone, but Memory clinic/consultant appointments are difficult as the Consultant appears reluctant to talk on the phone so I've had to talk to a nurse who relays a message and then gets back to me with advice - I have no idea why a consultant who is no longer seeing patients cannot organise phone calls like my GP?" (58)

"It has been very lonely and exhausting. GP only available by phone and unwilling to help when finally reached." (44)

One carer with a professional background and co-resident family support proved an exception:

"As an ex nurse I was confident of my ability to attend to physical needs ... we were very well organised prior to lock down and the important support of incontinence supplies has continued for which we are very grateful." (17)

Having other people under the same roof in addition to the person with dementia, as well as having home carers coming in, seemed to make the situation better.

Two respondents had experience of hospital admissions for the individual with dementia during this period, when the virus control measures meant that family could not visit.

"The stay in hospital without any carers or relatives for someone with advanced dementia is distressing to both the person and the family. My mum had a DNR put in place without anyone attempting to contact me about it from the hospital. I only found out from her discharge papers!" (6)

Overall, the intensity of the carers' disappointment with the lack of support comes across in the following:

"I have experienced periods of extreme anxiety about the future and how I can face the future of looking after my husband ... We have been badly let down and some of us left to die, or wanting to die. Some of us (at times me) would have welcomed Covid-19." (67)

This is not a majority view, as shown in Table 6, 53% of carers agreed that the stay at home restrictions were 'worth the sacrifice'. Still it appears that one in six carers (17%) disagree with the restrictions; these individuals may be at increased risk of 'carer breakdown'.

Impairments to health and wellbeing

Table 6 indicates that during lockdown the vast majority of individuals with dementia deteriorated with respect to their cognition (72%) as well as their physical health (53%).

"The decline in both cognition and physical health since the beginning of lock down has been shockingly quick." (6)

"My husband has got much worse and I feel I am sinking under the pressure. Most nights when I go to bed I pray not to wake up." (21)

Many carers told us that their own mental health had deteriorated (55%) as did their physical health (59%) under lockdown. Most felt that the need to stay home to avoid the virus had detrimental effects on both them and the person for whom they were caring. However, one respondent found that a more tranquil existence suited his wife:

"My wife has settled well probably due to the regimented days. We have walked regularly and more or less done the same every day. Before we were doing lots of things which now I see ... was too much, as well as travelling. I think now this was unsettling for her. It's routine she needs." (52)

Cognitive decline

Although dementia entails a progressive loss of cognitive capacity and with it declining ability to do everyday things like read, converse and dress oneself, this can be slowed by engaging in physical exercise and maintaining social contact.² Cognitive stimulation is also recommended by NICE guidelines³. Access to sources of these activities was cut off by lockdown with the closure of day centres and community groups. Carers reported disastrous effects on the individual with dementia, with serious consequences for caring:

"My wife was booked in for day-care three to four days a week - this gave her activities and stimulation and me respite - when lockdown occurred - all day care centres were closed to us. Consequently we were left without the said activities and stimulation and respite and my caring workload dramatically increased". (58)

"My wife has PPA, this has got progressively worse over the lockdown period. Both her speech has deteriorated and her behaviour". (19)

² Livingston, G. et al. (July, 2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. The Lancet, Volume 396, Issue 10248, 413 – 446.

³ National Institute for Health and Care Excellence (June, 2018) Dementia: assessment, management and support for people living with dementia and their carers. [NG97] <https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#interventions-to-promote-cognition-independence-and-wellbeing>

"My husband has really missed going to the cinema, our singing group and going shopping and going out on trips and for a meal in Nottingham or locally." (39)

"The most significant losses for me and the person I care for are the closure of the day centre and the cancellation of exercise classes." (68)

With habitual routines, activities and social programmes suspended, carers were sometimes managing highly volatile situations:

"My [mother in law] was meant to be shielding but was furious about the fact people were telling her what she could not do and did not understand that this was meant to be for her own good. At other times she became terrified that she was ill with the mystery virus and we were keeping this knowledge from her and that was why she was not seeing her wider family". (14)

"The mental stress goes unnoticed by the world but it is an extremely real to the person suffering dementia they cannot understand any reasoning so feel the carer is deliberately keeping them in isolation not allowing them to go out or friends etc. ... this happened to my wife." (55)

Accelerated cognitive decline was accompanied by changes in behaviour and increased dependency:

"My mother has noticeably 'aged' these last few months - due to a number of factors including social isolation". (75)

"Lockdown has made my wife more clingy as a result of her activities (day centre, Singing for the Brain and memory cafe) having temporarily closed." (50)

"My husband has missed the company of friends and family and has started wandering within the confines of our property, to see if there's anyone else to talk to. ... We've done a lot more local walks, but he's not been as involved with household matters - and become more repetitive and apathetic." (64)

"It was a struggle to get mum settled every day as she didn't like the silence of nothing and nobody about." (28)

The need to socially distance cut off the people surveyed from contact with activity groups, and also isolated them from seeing family members in person. Grandchildren were sorely missed:

"It was hard not to see the grandkids as they are great for my mental health and mum's dementia." (28)

"Life has been very difficult for both of us during lockdown not being able to see friends and family especially the grandchildren has been hard, and trying to explain to my husband why he cannot hold his new-born grand-daughter, see his grandson play football, go to his weekly club, go out for meals etc. has been very confusing and upsetting for him." (71)

"It's difficult to tell mum that her grandchildren cannot visit for her own safety. It's really hard when she forgets things so quickly and thinks that her friends are still going to the day centre, so why can't she?" (47)

The emotional impact reported by carers with respect to lockdown indicates that their quality of life was markedly impaired by this experience.

"The main problems for me, as carer, are the increase in workload - no cleaner, no meals out (preparing three meals a day every day) and the monotony!" (65)

"Sometimes I feel fine, other times I have felt desperate, sad, angry, resentful, guilty - and lonely because I don't want my family to know how bad I feel." (67)

"Life is completely changed we all become much sadder. ISOLATION is devastating much misunderstood has far reaching consequences." (55)

Limitations and strengths

This opportunistic survey was not widely distributed. Its respondents are not

representative of the whole population of carers for people with dementia. Results are likely to be biased towards carers who regularly use IT, and towards members of the networks known to the author. Therefore, the findings cannot be extrapolated directly to all dementia carers.

Nonetheless, the short timescale for data collection and analysis means that these findings have immediate relevance. The results provide evidence of deterioration in people with dementia that has been caused by lockdown, rather than by the dementia itself, this is called 'excess disability'. Moving testimonies from carers about their lockdown experiences convey the suffering they have undergone, over and above the sacrifices made by the entire population. Careful interpretation of these results indicates recommendations that address many of the issues raised.

Recommendations

Close reading of these findings, in the light of UK dementia policy and best practice in dementia care, indicates a number of recommendations. Four of these recommendations could inform national policy responses to the present crisis and any future lockdowns. Two more describe how front-line services could be better prepared and organised to support dementia carers in similar situations in the future.

National policy

1. Carers and people with dementia need to be treated as a unit in emergency planning because of their interdependence. Whether this is for shopping, visiting care homes or forming social bubbles, the dyad needs to be regarded as a unit.
2. Carers need to be recognised as providers of essential services ('key workers')⁴. They require access to quieter shopping times, priority delivery slots and other entitlements extended to NHS and emergency personnel. This does not only apply to carers of people with dementia.
3. Carers of people with dementia need to be addressed as a group with particular needs when virus control measures are planned and implemented. Clear details of these measures need to be disseminated by national television and other channels of communication most used by carers. Local flyers have little impact.
4. At a national level, consideration needs to be given to providing key services (chiropractic, GP, exercise, audiology, dentistry) to meet the needs of this group in their own homes, because they are vulnerable to excess disability as a consequence of lockdown if left untreated. The relevant professions need to find digital, peripatetic or para-professional ways to treat people with dementia in lockdown.

Local service provision

5. Under conditions of lockdown or other crises, community organisers need to be aware of people with dementia and their living situations. A register of people with dementia and their carers should be maintained by local authorities.
6. Carers of people with dementia, as well as anyone with dementia living alone without an informal carer, need targeted care management support in emergencies. This would seek to prevent dementia-related crises by marshalling resources to meet the needs of the household. This organisational structure requires the following resources in order to operate effectively:
 - Essential support for individuals with dementia should include a personalised activity programme that can be undertaken at home together with relevant materials; a 'crisis activity plan'.
 - Essential support for carers should include sitting services in the home as well as respite, delivered in care homes. Like other essential care, this provision

⁴ On July 9, 2020, dementia campaigners issued an open letter arguing for dementia carers to be granted key worker status. <<https://www.alzheimers.org.uk/news/2020-07-09/open-letter-secretary-state>>, accessed August 16th, 2020.

should be exempt from the lockdown rules regarding social contact.

- Telephone counselling should be offered proactively to carers of people with dementia in a national emergency. Authoritative information and advice about dementia should also be offered proactively, because their needs change in such situations. Welfare benefits advice should be included.
- However, telephone support is not enough. Support for all dementia carers and individuals living alone with dementia should include some face to face monitoring, delivered within the rules for virus control, to assess their situation fully and support them effectively.
- Information and advice on accessing reliable professionals who can meet carers' needs for home or garden maintenance and cleaning, as well as recommended providers of personal care, should be made available and disseminated effectively according to each household's needs.

Conclusion

Society is indebted to dementia carers. Without them, individuals with dementia could face long-term care admission against their will and greater costs of care could fall to the taxpayer. This survey gives dementia carers an opportunity to be heard in relation to lockdown. It shows that there is much more that can be done to support them and the people with dementia they care for. It recommends six strategies for improving dementia care in the community. These recommendations may be useful to anyone aiming to improve provision for people with dementia as well as to organisations seeking to avoid harmful repercussions of future crises or lockdowns. The survey results are therefore applicable to national and local efforts to recover from Covid-19 with regard to the urgent needs of hundreds of thousands of people with dementia and their carers.

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Declaration of interests

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